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Original Paper

Definition of Health 2.0 and Medicine 2.0: A Systematic Review

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Abstract

Background: During the last decade, the Internet has become increasingly popular and is now an important part of our daily life. When new “Web 2.0” technologies are used in health care, the terms “Health 2.0" or "Medicine 2.0” may be used.

Objective: The objective was to identify unique definitions of Health 2.0/Medicine 2.0 and recurrent topics within the definitions.

Methods: A systematic literature review of electronic databases (PubMed, Scopus, CINAHL) and gray literature on the Internet using the search engines Google, Bing, and Yahoo was performed to find unique definitions of Health 2.0/Medicine 2.0. We assessed all literature, extracted unique definitions, and selected recurrent topics by using the constant comparison method.

Results: We found a total of 1937 articles, 533 in scientific databases and 1404 in the gray literature. We selected 46 unique definitions for further analysis and identified 7 main topics.

Conclusions: Health 2.0/Medicine 2.0 are still developing areas. Many articles concerning this subject were found, primarily on the Internet. However, there is still no general consensus regarding the definition of Health 2.0/Medicine 2.0. We hope that this study will contribute to building the concept of Health 2.0/Medicine 2.0 and facilitate discussion and further research.

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KEYWORDS

Health 2.0; Medicine 2.0; eHealth; Patient Empowerment; Professional Empowerment; Web 2.0; telemedicine

Introduction

During the last decade, the Internet has become increasingly popular and now forms an important part of our daily life [1]. In the Netherlands, the Internet is even more popular than traditional media like television, radio, and newspapers [2]. Furthermore, the impact of the Internet and other technological developments on health care is expected to increase [3,4]. Patients are using search engines like Google and Bing to find health related information. In Google, five percent of all searches are health related [5]. Patients can express their feelings on weblogs and online forums [3], and patients and professionals can use the Internet to improve communication and the sharing of information on websites such as Curetogether [6] and the Dutch website, Artsennet [7] for medical professionals. The use of Internet or Web technology in health care is called eHealth [1,8].

In 2004 the term “Web 2.0” was introduced. O’Reilly defined Web 2.0 as “a set of economic, social, and technology trends that collectively form the basis for the next generation of the Internet, a more mature, distinctive medium characterized by user participation, openness, and network effects” [9]. Although there are different definitions, most have several aspects in common. Hansen defined Web 2.0 as “a term which refers to improved communication and collaboration between people via social networking” [10]. According to both definitions, the main difference between Web 1.0 (the first generation of the Internet) and Web 2.0 is interaction [11]. Web 1.0 was mostly unidirectional, whereas Web 2.0 allows the user to add information or content to the Web, thus creating interaction.

This is why the amount of “user-generated content” has increased enormously [12]. Practical examples of user-generated content are online communities where users can participate and share content. Examples are YouTube, Flickr, Facebook, and microblogging such as Twitter. Twitter, for example, improves communication and the sharing of information among health care professionals [13].

According to some critics, Web 2.0 is not a new generation of the Internet because it is still based on old technologies such as HTML, the predominant markup language. Therefore, the term Web 2.0 simply describes renewal or evolution of these older technologies or of the Internet itself [14,15]. Nonetheless, the term Web 2.0 seems to be widely used and accepted. The search engine Google recently found over 85,000,000 results for the search string “Web 2.0 or Web2.0.”

When Web 2.0 technologies are applied in health care, the term Health 2.0 may be used. [16,17]. Other authors use the term Medicine 2.0, which combines medicine and Web 2.0 [18]. There are many examples of Health 2.0/Medicine 2.0, such as the websites Patientslikeme [19] and Hello Health [20]. Recently, the Dutch minister of health awarded a grant to the website MijnZorgNet, which offers 23 virtual networks in which patients and their caregivers communicate. The networks are organized around specific patient categories. Successful examples that preceded the project are a digital in vitro fertilization (IVF) outpatient clinic [21,22] for couples receiving IVF treatment, and the website Parkinson Net [23] for people suffering from Parkinson’s disease. Both initiatives were started to enhance collaborative health care. Expected beneficial aspects of these projects were improved quality and efficiency of care [24]. Another concept that appears in the Health 2.0/Medicine 2.0 literature is “patient empowerment 2.0.” This has been described as “the active participation of the citizen in his or her health and care pathway with the use of information and communication technologies” [25]. It is assumed that Health 2.0/Medicine 2.0 leads to empowerment of the patient, as patients have easier access to health-related information and thereby have better understanding of choices that can be made.

According to Hughes [16], no relevant differences exist between Health 2.0 and Medicine 2.0. Eysenbach [18] agreed but stated, “If anything, Medicine 2.0 is the broader concept and umbrella term which includes consumer-directed ‘medicine’ or Health 2.0.” More and also more specific definitions of Health 2.0 and Medicine 2.0 exist [16,17]. However, these definitions seem to have evolved together with the increased use of the definitions and the different parties involved in Health 2.0 and Medicine 2.0. Ricciardi stated, “Everyone is trying to grasp what Health 2.0 exactly is” [26]. Does Health 2.0 refer to patients or to professionals or both? Does it focus on health care in general, or does it address specific aspects of health care like preventive or curative care, acute or chronic illness? Several authors concluded that there is no authoritative definition of the term yet, and Health 2.0 definitions and translations in practice remain murky and fragmented [27,28].

A clear definition is important for the development of new Health 2.0 or Medicine 2.0 initiatives and also for the comparability of new developments in research. Therefore, the aim of this study was to identify definitions of Health 2.0/Medicine 2.0 and to gain insight into recurrent topics associated with these labels.

Methods

We performed a systematic literature study to find unique definitions of Health 2.0/Medicine 2.0 and identify and recurrent topics discussed in conjunction with these terms.

Search Strategy

First, we searched the following electronic databases: PubMed, Scopus, and CINAHL. For each database, we searched all available years through September 2009. Since there was no relevant MeSH term available for Health 2.0 or Medicine 2.0, we used the following search terms: health 2.0, health2.0, health20, medicine 2.0, medicine2.0, medicine20, Web 2.0, Web2.0, Web20 (Table 1). We scanned the reference lists for relevant articles (the snowball method), contacted individual experts in the field, and inquired after relevant publications.

Second, we searched for gray literature on the Internet using the search engines Google, Bing, Yahoo, Mednar, and Scopus. Mednar and Scopus were used because they focus on scientific literature. Google, Bing, and Yahoo were used because these are the most widely used search engines [29,30]. We used the advanced search option, selected English as the preferred language, and turned the option for regional differences off. Based on earlier research [16], we expected a large number of results. Therefore we added a more specified search string query for Google, Yahoo, Bing, and Scopus (Table 2): “what is health 2.0,” “what is health2.0,” and “what is health20.” For Medicine 2.0 we used: “what is medicine 2.0,” “what is medicine20,” and “what is medicine20.” We studied the first 100 results in Google, Bing, and Yahoo as these search engines display results by relevance using a link analysis system or algorithms [31-33]. All searches in the gray literature were performed in November 2009.

Inclusion Criteria

Subsequently, a combination of three of the authors (TB and LE and LS or SB) independently assessed the retrieved studies and gray literature for inclusion. Sources were included if a definition of Health 2.0 or Medicine 2.0 was identified. Disagreement over inclusion between the reviewers was resolved through discussion.

Data Extraction

TH and LE independently assessed the included studies and gray literature and extracted unique definitions. A predesigned table was used to ensure standardized data extraction. For each definition we noted author, source, and year (Table 3). After completing the table, we used the constant comparison method to explore possible topics of Health 2.0 and Medicine 2.0 [34]. We independently analyzed the definitions and identified recurrent topics by using “coding.” Described by Strauss and Corbin, coding is an analytical process through which concepts are identified and dimensions are discovered in data [35]. The results are displayed in Table 4.

Table 1. Search strategy for scientific literature

Database/ Search Engine:	Search String:	Details	Hits	Relevant[a]	Included[b]
PubMed	“health 2.0” OR “health2.0” OR “health20” OR “medicine 2.0” OR “medicine2.0” OR “medicine20” OR “Web 2.0” OR “Web2.0” OR “Web20”		179	12	7
CINAHL	“health 2.0” OR “health2.0” OR “health20” OR “medicine 2.0” OR “medicine2.0” OR “medicine20” OR “Web 2.0” OR “Web2.0” OR “Web20”		199	4	0
Scopus	(TITLE-ABS-KEY(“health 2.0”) OR TITLE-ABS-KEY(“medicine 2.0”)) OR (TITLE-ABS-KEY(“health2.0”) OR TITLE-ABS-KEY(“medicine2.0”)) OR (TITLE-ABS-KEY(“health20”) OR TITLE-ABS-KEY(“medicine20”))		29	6	5
	(TITLE-ABS-KEY(“Web 2.0”) OR TITLE-ABS-KEY(“Web2.0”) OR TITLE-ABS-KEY(“Web20”)) AND (LIMIT-TO(SUBJAREA, “MEDI”) OR LIMIT-TO(SUBJAREA, “HEAL”) OR LIMIT-TO(SUBJAREA, “NURS”) OR LIMIT-TO(SUBJAREA, “MULT”))	Limited to subcategories: medicine, health professionals, nursing, multidisciplinary	126	3	2
Subtotal			533	25	14
Duplicates					5
Total			533	25	9

[a] Relevant: number of relevant articles based on title, abstract, and keywords

[b] Included: number of included articles based on full article

Table 2. Search strategy for gray literature

Database/ Search Engine	Search String:	Hits	Relevant[a]	Included[b]
Google	“health 2.0” OR “health2.0” OR “health20”	482000	28	13
	“medicine 2.0” OR “medicine2.0” OR “medicine20”	155000	24	16
	“what is health 2.0” OR “what is health 2.0” OR “what is health20”	99	29	25
	“what is medicine 2.0” OR “what is Medicine 2.0” OR “what is medicine 20”	33	14	14
Bing	“health 2.0” OR “health2.0” OR “health20”	328000	4	4
	“medicine 2.0” OR “medicine2.0” OR “medicine20”	62300	8	6
	“what is health 2.0” OR “what is health 2.0” OR “what is health20”	477	26	24
	“what is medicine 2.0” OR “what is medicine 2.0” OR “what is medicine 20”	31	12	11
Yahoo	“health 2.0” OR “health2.0” OR “health20”	466000	17	9
	“medicine 2.0” OR “medicine2.0” OR “medicine20”	45000	19	14
	“what is health 2.0” OR “what is health 2.0” OR “what is health20”	583	21	21
	“what is medicine 2.0” OR “what is medicine 2.0” OR “what is medicine 20”	121	14	12
Mednar	“health 2.0” OR “health2.0” OR “health20”	329	27	10
	“medicine 2.0” OR “medicine2.0” OR “medicine20”	12	13	5
Scopus	TITLE-ABS-KEY(“what is health 2.0”) OR TITLE- ABS-KEY(“what is health2.0”) OR TITLE-ABS-KEY(“what is health20”)	23	3	0
	TITLE-ABS-KEY(“what is medicine 2.0”) OR TITLE- ABS-KEY(“what is medicine2.0”) OR TITLE-ABS-KEY(“what is medicine20”)	0	0	0
Subtotal		1540008	262	184
Duplicates				149
Total				35

[a] Relevant: number of relevant articles based on title, abstract, and keywords in first 100 results

[b] Included: number of included articles based on full article

Results

We scanned a total of 1937 articles, 533 found in scientific databases and 1404 in the gray literature (Tables 1 and 2). We selected 287 articles, 25 peer reviewed articles, and 262 non-scientific articles for further analysis. After selection and removing duplicates, we distinguished 46 unique definitions of Health 2.0 or Medicine 2.0 in 44 articles (Table 3). The length of the definitions varied from 7 to 105 words. We found 42 definitions describing Health 2.0 [3,15-18,25-27,36-69] and two definitions describing Medicine 2.0 [70,71]. Of the 44 articles included, 8 included definitions of both Health 2.0 and Medicine 2.0 [16-18,40,50,52,55,65]. From these 46 definitions, we identified 7 main recurrent topics: patients, Web 2.0/technology, professionals, social networking, change of health care, collaboration, and health information/content (Table 4). In the following paragraphs we describe these recurrent topics from these definitions in more depth.

Patients and Consumers

The first main topic was "patients" or "consumers of health care," which was found in 35 definitions. Of these, 12 included mention of either increased participation or empowerment of patients. The following terms or phrases were identified: increased consumer/patient participation [18,27,49,50,58], patients can actively participate [63], and participatory [42,45], patient empowerment or consumer empowerment [41,49,59,62]. The other 23 mentioned only patient or consumer involvement and not the effects.

Web 2.0/Technology

The second main topic that appeared in 32 definitions from 30 articles was "Web 2.0" or "technology." Terms varied from "Web 2.0" [3,15,17,36,43,44,46,52,55,57,58,60,62,67,70], to "Web 2.0 technology" [18,27,40,41,50,66,68], "technology" [25,39,62-64], "software" [42,51], "Web (based) tools" [69,71], and "ICT (information and communication technology)" [37]. Web 2.0 was seen as the total of available technologies that stakeholders could use for communication and for sharing information. One definition mentioned "mashing" of Web 2.0 concepts and tools [43]. "Mashing" was seen as combining two or more Web 2.0 sources to create a new one. Other definitions indicated that the concept of Health 2.0 originated from a combination of the concepts "health" and "Web 2.0" [17,40].

Professionals

The third topic that was identified concerns "professionals" or "caregivers," and was found in 26 definitions. Of the 46 included definitions, five mentioned increased participation or empowerment of professionals. The following terms were found: "professional empowerment" [49,52,59], "empowerment of the individual" [48], and "empowerment of the user" [3].

Besides patients and professionals, other stakeholders were mentioned. However, they were mentioned less frequently and therefore not included in Table 4 as individual topics. The following stakeholders were mentioned: payers or providers [36,44,52,61], medical and health science students [27,52], biomedical researchers [18,44,49,50,52,71], entrepreneurs [62,65], and government [44]. Other authors were less specific with regard to stakeholders. They included "all stakeholders" [38] or "others" [43,51,57,66].

Social Networking

The fourth topic, the emergence of online communities and social networking, was reflected in 22 definitions. This was described using different terminology. Definitions referred to "online communities" [42,47,48,51,52,58,66], "social communities" [44], "networks" [71], whereas others referred to "online social networks" or "social networking" [18,26,36,43,50,59], "social interaction" [36], "interactive environments" [58], or "intelligent interaction" [63]. Other definitions focused more on technology: the terms used were "social media tools" [60], "social media," or "social software" [38,46,56,59,69].

Two authors mentioned "transparency" or "openness" [18,49]. An additional 2 definitions suggested that "sharing" or "online sharing" of medical information was part of Health 2.0 or Medicine 2.0 [45,65].

Change of Health Care

Fifth, we found that change of health care was described by 15 definitions. According to the definitions, Health 2.0 means change of health care: "a whole new way of involving consumers in the health care system" [64], "next generation of health care services" [67], "new and better health system" [18], "new concept of health care" [52], "all constituent focus on health care value and on improving safety, efficiency and quality of health care" [61], "shaping health care with Web 2.0 tools" [17], and "new wave of innovation" [62]. Change was described differently: "reshaping health care"[17,42], "ever changing" [66], "continually evolving cycle" [49], "evolution of technology and medical industry" [36], "evolution of health care" [41]. Change was also described as "revolutionary" [55], while another author stated, "we should be careful not to assume that a revolution has occurred in health care" [27].

We also found one author who referred to "user generated health care" [25].

Collaboration

The sixth topic, mentioned in 14 definitions, was collaboration. In the Health 2.0 era, patients will actively contribute to their own care process. Collaboration between professionals and patients may improve. Terms varied from "collaboration" [18,36,43,49,51,59,66,69], "collaboratively" [27], "collaborate" [52,71], "collaborative practices" [16], and "collaborate and share knowledge" [70] to "working together" [39].

There were also other aspects described with regard to the relationship among stakeholders. Patients would transform their role in health care [26] and would be on the same level of playing field as other stakeholders [38]. A role change of patients and professionals was also indicated. For example, the following phrase was used: "doctor and patient positioned together" [37]. Patients were described as "active contributors" [55], "active and responsible partners" [25], or "active partners" [42]. Another author mentioned "integration of patients and stakeholders" [45].

Health Information or Content

Seventh and last, there was mention of health information or content in 14 definitions. Terms varied from “information,” “health information,” or “medical information” [27,36,37,42,45,48,53,63,65] to “content” [47], “data” [26,44,71], and “user owned content” [58].

Table 3. Definitions of Health 2.0 and Medicine 2.0

Author, Source, and Whether Found in Scientific Literature[a] or Gray Literature[b]	Year of Publication	Definition
Aller RD et al [36] (Gray)	2007	The term, boiled down to its most basic definition, refers to the evolution of technologies and the medical industry itself to create the next generation of health care for consumers, providers, and payers alike. The term is a take on Web 2.0, which refers to the evolution of the Internet from a tool used essentially for information gathering to one used for collaboration and social interaction.
Bos L et al [25] (Scientific)	2008	Health 2.0 is user generated Health care. What is foreseen is that the self-care information tool of the future will be a combination between the patient's observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.
Bos L et al [37] (Scientific)	2008	Health 2.0 defines the combination of health data and health information with (patient) experience through the use of ICT, enabling the citizen to become an active and responsible partner in his/her own health and care pathway.
Bourre N [38] (Gray)	2009	Social media and conversations related to health care, where all stakeholders are on the same level of the playing field.
Castilla V [39] (Gray)	Unknown	Medicine 2.0 is about realizing the potential of today's technology in health care. Medicine 2.0 is about working together. Medicine 2.0 is about getting closer to colleagues and patients.
Conn J [15] (Scientific)	2007	The health care derivate of the far more ubiquitous "Web 2.0."
Doherty I [27] (Scientific)	2008	Web 2.0 Technologies provide members of the health community–health professionals, health consumers, health carers, and medical and medical and health science students–with new and innovative ways to create, disseminate, and share information both individually and collaboratively. This phenomenon has been termed Health 2.0. There is no authoritative definition of the term yet. Health 2.0 is in its infancy and we should be careful not to assume that a revolution has occurred in health care as a result of these new technologies and their various affordances.
Dolan F [40] (Gray)	2007	Health 2.0 is the application of Web 2.0 technologies in the area of health, while Medicine 2.0 is the use of Web 2.0 technologies in the area of medicine.
Dubay A [41] (Gray)	2007	Health 2.0 is the evolution of health care as a result of consumer empowerment. Its definition ranges from "applied Web 2.0 technology to health care" to "the next generation health care delivery."
Eysenbach G [18] (Scientific)	2008	Medicine 2.0 applications, services, and tools are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual-reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups. Or in broader concept: medicine also stands for a new and better health system, which emphasizes collaboration, participation, apomediation, and openness, as opposed to the traditional, hierarchical, closed structures within health care and medicine. Medicine 2.0 is the broader concept and umbrella term, which includes consumer-directed "medicine" of Health 2.0.
Eytan T [42] (Gray)	2008	Health 2.0 is participatory health care. Enabled by information, software, and community that we collect or create, we the patients can be effective partners in our own health care, and we the people can participate in reshaping the health system itself.
Facebook Health 2.0 Group [43] (Gray)	2007	Health 2.0 is the mashing of Web 2.0 concepts and tools to health care industry, including social networking to promote better collaboration between patients, their caregivers, medical professionals, and others involved in the health care industry.
Flock, B [44] (Gray)	2008	Health 2.0: Expand initial Health care 2.0 concept (Web 2.0 features to health care; ratings, search, social communities, and consumer tools) to include entire Health ecosystem (payers, providers, employers, consumers, life sciences entities, government: anyone who can contribute meaningful data.)
Furst I [45] (Gray)	2008	Health 2.0 is participatory health care characterized by the ability to rapidly share, classify, and summarize individual health information with the goals of improving health care systems, experiences, and outcomes via integration of patients and stakeholders.
Gavgani VZ et al [70] (Scientific)	2008	Medicine 2.0 is the latest approach to ensure better health system and well-being of the humanity, in other words, "health for all," and a healthy community. The development of Medicine 2.0 grossly depends on the application of Web 2.0 sciences.
Goel V [46] (Gray)	Unknown	Health 2.0 is the use of social media and other technologies to improve communication in health care. These platforms may be used to connect patients with patients, doctors with other professionals, or patients with doctors. The Health 2.0 movement is about enhancing communication to improve the focus and results of the health system on the patients it serves.
Goreman J et al [47] (Gray)	2008	Health 2.0: The combination of content and community.

Author, Source, and Whether Found in Scientific Literature[a] or Gray Literature[b]	Year of Publication	Definition
Halper R [48] (Gray)	2007	The empowerment of the individual to have access to detailed objective health care information primarily, though not exclusively, using search engine sites and like-minded communities of patients and physicians.
Hawker M [49] (Gray)	2008	Health 2.0 is a continually evolving cycle of health care innovation enabled by the empowerment of the public, patients, health care providers and suppliers, and researchers through increased collaboration, participation, apomediation, feedback and transparency of value-enabled health care interactions.
Healthcaremanagementblog [50] (Gray)	2008	Health 2.0 aka Medicine 2.0 aka eHealth, can be broadly defined as “applications, services, and tools are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies as well as semantic web and virtual reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups.”
Holt M [51] (Gray)	2007	The use of social software and lightweight tools to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health.
Hughes B [16] (Scientific)	2008	Health 2.0 and Medicine 2.0 were found to be very similar and subsume five major salient topics: (1) the participants involved (doctors, patients, etc); (2) its impact on both traditional and collaborative practices in medicine; (3) its ability to provide personalized health care; (4) its ability to promote ongoing medical education; (5) its associated method- and tool-related issues, such as potential inaccuracy in end user-generated content. Difference Health 2.0 and Medicine 2.0 with eHealth, the key distinctions are made by the collaborative nature of Health 2.0 and Medicine 2.0.
Jessen W [52] (Gray)	2008	Medicine 2.0 is the science of maintaining and/or restoring human health through the study, diagnosis, and treatment of patients utilizing Web 2.0 Internet-based services, including Web-based community sites, blogs, wikis, social bookmarking, folksonomies (tagging) and Really Simple Syndication (RSS), to collaborate, exchange information, and share knowledge. Physicians, nurses, medical students, and health researchers who consume Web media can actively participate in the creation and distribution of content, helping to customize information and technology for their own purposes. Health 2.0, a new concept of health care, also utilizes Web 2.0 Internet-based services but is focused on health care value (meaning outcome/price). Patients, physicians, providers, and payers use competition at the medical condition level over the full cycle of care as a catalyst for improving safety, efficiency, and quality of health care delivery. The goal of both of these movements is the delivery of optimal medical outcomes though individualized care.
Levine C [53] (Gray)	2009	Health 2.0 = a noun that describes user-generated health care content. Spurred by sites like YouTube, Facebook, and Wikipedia, millions are logging on to contribute information and opinions on everything from medications, health professionals, treatment options, side effects, flu pandemics, and best drug practices.
Mesko B [17] (Gray)	2007	Medicine 2.0 = Web 2.0 + medicine (focusing on doctor-patient communication and technologies). Health 2.0 = Web 2.0 + health care (focusing on shaping health care with Web 2.0 tools and concepts).
Maun C [54] (Gray)	2009	Health 2.0 can be broadly defined as interactive applications, services, and tools that are Web-based services for health care consumers, caregivers, patients, and health professionals.
Moturu ST et al [55] (Scientific)	2008	Like the Web 2.0 revolution changed the user from a passive consumer to an active contributor, a similar metamorphosis being termed as Health 2.0 or Medicine 2.0 would extend the role of information seeking users to include dissemination of experiences and acquired knowledge.
Rampy A [56] (Gray)	2008	Health 2.0 = the merging of social media into health care.
Randeree E [3] (Scientific)	2008	Health care 2.0 can be defined as a network of (Web 2.0) applications and services that empower the user and are delivered through the web as a platform.
Ricciardi L [26] (Gray)	2008	Its grassroots push through which patients are using social networks and other tools to generate their own health data and transform their role vis a vis the health care system. Quite honestly, everyone is still trying to figure out exactly what Health 2.0 is.
Richlovsky P [58] (Gray)	2007	Basically, Health 2.0 is a takeoff of Web 2.0, and it alludes to health websites that incorporate Web 2.0 principles of encouraging user-generated and user-owned content, participation, and community-building in rich, interactive environments.
RN Central [57] (Gray)	2008	Health 2.0 embraces the idea of bringing health care into the community of medical professionals, patients, and those in the health care industry together with technology and the Internet to provide the best possible health care environment.

Author, Source, and Whether Found in Scientific Literature[a] or Gray Literature[b]	Year of Publication	Definition
Sarashon-Kahn J [59] (Gray)	2007	Social media on the Internet are empowering, engaging, and educating consumers and providers in health care. This movement, known as Health 2.0, can be defined as: The use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health.
Sharp J [60] (Gray)	2009	Health 2.0 evolved more recently and focuses on Web 2.0 tools, especially social media tools, and their use in health care.
Shreeve S [61] (Gray)	2007	Health 2.0: New concept of health care wherein all the constituents (patients, physicians, providers, and payers) focus on health care value (outcomes/price) and use disruptive innovation as the catalyst for increasing access, decreasing cost, and improving the quality of health care.
Spoetnik L [71] (Gray)	2009	Medicine 2.0 is the use of a specific set of Web tools (blogs podcasts, tagging, search, wikis, etc) by actors in health care, including doctors, patients, and scientists, using principles of open source and generation of content by users and the power of networks in order to personalize health care, collaborate, and promote health education.
Stoakes U [62] (Gray)	2008	Health 2.0: A new wave of innovation in health care as a result of changing trends in technology, consumer empowerment, and growing entrepreneurialism at a time when the health care system is spiraling out of control. These converging trends have created an environment for entrepreneurs, start-up companies, innovative thinkers, health professionals, and consumers to rethink how to solve today’s biggest health care challenges. Health 2.0 is about coming up with new ideas and rethinking what’s possible.
Susheel-Ommen J [3] (Gray)	2007	Health 2.0 derives its definition from the definition of Web 2.0, where the technologies used allowed intelligent interaction between the users and the deployed solutions. Currently available technologies allow users to actively participate and contribute to the information that is front-ended using Web interfaces.
Tenderich A [64] (Gray)	2009	It’s both an explosion in new Web-based personal health technologies and a whole new way of involving consumers in the health care system.
Torrey T [65] (Gray)	2008	Medicine 2.0 or Health 2.0 are terms used to describe the massive Internet-sharing of health and medical information among everyone with interest, from health and medical professionals, to patients, to caregivers, to the businesses (pharmaceutical manufacturers, health insurance) which support them. The two terms, Medicine 2.0 and Health 2.0, are often used interchangeably. However, there is a distinction. Medicine 2.0 usually refers to the science of medicine and the practice of treating or curing patients. Health 2.0 is focused on the business of health in general including the delivery, the quality, the safety, and the cost or efficiency of the people, a practice, or facility.
Venn D [66] (Gray)	2008	Health 2.0 is an emerging concept of health care that uses Web 2.0 technologies to promote collaboration between patients, physicians, health care professionals, and other members of the health community. Its application is ever-changing, and the evidence for its effectiveness is still raw, but there’s a lot of potential for this type of new technology to improve mental health education and mental health care.
Weisbaum W [67] (Gray)	2007	Health 2.0 is the use of movement to harness the technology of Web 2.0 for the delivery of the next generation of health care services.
Williams P [68] (Gray)	Unknown	Health 2.0 is the use of Web technology to deliver consumer-driven health services. It uses the same Web 2.0 technology that drives the successful Internet services such as Ebay, Facebook, Expedia, and Amazon.
Wright-Mark S [69] (Gray)	2008	Health 2.0 is a new concept of health care that employs social software and other Web-based tools to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health care to create a better, more knowledgeable and cost effective environment for better well-being.

[a] Located with search of the following databases: PubMed, Scopus, and CINAHL

[b] Located using the search engines Google, Bing, Yahoo, Mednar, and Scopus

Table 4. Recurrent topics of Health 2.0 and Medicine 2.0

Author and Definition of Health 2.0 (H2) and/or Medicine 2.0 (M2)			Topics						
Author	H2	M2	Patients and Consumers	Web 2.0	Professionals	Social Networking	Change	Collaboration	Health Information or Content
Aller RD et al [36]	*		*	*	*	*	*	*	*
Bos L et al [25]	*		*	*	*				
Bos L et al [37]	*		*	*					*
Bourre N [38]	*					*			
Castilla V [39]	*		*	*				*	*
Conn J [15]	*			*					
Doherty I. [27]	*		*	*	*		*	*	*
Dolan F [40]	*	*		*					
Dubay A [41]	*		*	*			*		
Eysenbach G [18]	*	*	*	*	*	*	*	*	
Eytan T [42]	*		*	*		*	*		*
Facebook Health 2.0 Group [43]	*		*	*	*	*		*	
Flock, B [44]	*		*	*	*	*			*
Furst I [45]	*		*		*				*
Gavgani VZ et al [70]		*	*	*					
Goel V [46]	*		*	*	*	*			
Goreman J et al [47]	*					*			*
Halper R [48]	*		*		*	*			*
Hawker M [49]	*		*		*		*	*	
Health caremanagementblog [50]	*	*	*	*	*	*		*	
Holt M [51]	*		*	*	*	*		*	
Hughes B [16]	*	*	*		*			*	
Jessen W [52]		*		*	*	*		*	
	*		*	*	*		*		
Levine C [53]	*		*						*
Mesko B [17]	*		*	*	*		*		
		*	*	*	*		*		
Maun C [54]	*		*		*				
Moturu ST et al [55]	*	*					*		
Rampy A [50]	*					*			
Randeree E [3]	*		*	*					
Ricciardi L [26]	*		*			*			
Richlovsky P [58]	*			*		*			*
RN Central [57]	*		*	*	*				
Sarashon-Kahn J [59]	*		*		*	*		*	
Sharp J [60]	*			*		*			
Shreeve S [61]	*		*		*		*		

Author and Definition of Health 2.0 (H2) and/or Medicine 2.0 (M2)			Topics						
Author	H2	M2	Patients and Consumers	Web 2.0	Professionals	Social Networking	Change	Collaboration	Health Information or Content
Spoetnik L [71]		*	*	*	*	*		*	*
Stoakes U [62]	*		*	*	*		*		
Susheel-Ommen J [63]	*		*	*		*			*
Tenderich, A [64]	*		*	*			*		
Torrey T [65]	*	*	*		*				*
Venn D [66]	*		*	*	*		*	*	
Weisbaum W [67]	*			*			*		
Williams P [68]	*			*					
Wright-Mark S [69]	*		*	*	*	*		*	

Discussion

This literature search resulted in 46 unique definitions in 44 articles of Health 2.0/Medicine 2.0 in scientific databases and gray literature on the Internet. We distinguished seven recurrent topics: Web 2.0/technology, patients, professionals, social networking, health information/content, collaboration, and change of health care.

This study showed that the use of the terminology differed among the definitions mentioned in literature. The term Health 2.0 was included in 42 definitions, 10 definitions mentioned Medicine 2.0, and 6 definitions described Health 2.0 and Medicine 2.0 as equal. There were 36 definitions that only mentioned the term Health 2.0, and only 4 definitions that described Medicine 2.0. Although some authors indicated that little or no differences existed between the two terms [16,18,27,55], others saw differences, for example that Medicine 2.0 is focused on the relation between professionals and patients whereas Health 2.0 is focused on health care in general [17,52,65]. As most definitions described Health 2.0, this term may be more widely used and accepted than Medicine 2.0.

Overall, we found that the term Web 2.0 was mentioned often: 33 authors used the term directly in the definition, which suggests that they accepted this concept. However, others state that Web 2.0 does not exist at all [72]. Authors' interpretations of the meaning of Web 2.0 influenced their definitions of Health 2.0/Medicine 2.0 profoundly. We generally distinguished two meanings of Web 2.0. The first meaning is that Web 2.0 is a set or "mashing" (ie, a combination) of technological developments [51,58]. The second meaning is that Web 2.0 is a new generation of the Internet where interaction is important, with more user-generated content that empowers people. In this interpretation, technology, or the mashing of different technologies, is only a tool, and Web 2.0 is more than technology. These meanings result in different definitions of Health 2.0/Medicine 2.0. A number of definitions referred to the technological developments embedded in health care, whereas other definitions stated that Health 2.0/Medicine 2.0 is a new generation of health care. We believe Web 2.0 is a facilitator for Health 2.0/Medicine 2.0, but not a necessity. Indeed, patients can still access health related information without Web 2.0; for example, a patient can go to a library and become well-informed without Web 2.0 technology. However, this would be far more difficult than becoming well-informed through the use of Web 2.0 technology. Second, the topic of stakeholders reflects who the main players are in the field of Health 2.0/Medicine 2.0. The two main stakeholders we distinguished were patients or consumers, mentioned in 35 definitions, and professionals or caregivers, mentioned in 26 definitions. Interestingly, other stakeholders such as payers of health care, scientists, students, and entrepreneurs were mentioned less frequently, whereas the government was only mentioned once. This is particularly interesting as the government has great influence on health care and changes in health care. Apparently the government is not yet an active party in the development of Health 2.0/Medicine 2.0.

Also interesting was that most definitions focused on the relation between patients and professionals. With Health 2.0/Medicine 2.0, patients and professionals were seen to collaborate, with patients transforming their role in health care using social networks and access to health information. Moreover, other relationships might also change; for example, the appearance of online communities could change the relationship between health professionals and specific groups of patients. This has been termed collaborative health care [18].

Finally, it is expected that Health 2.0/Medicine 2.0 will lead to change of health care. Expectations concerning the speed of this change ranged from a "gradual shift" [27], an "ever changing" [66] or "continuous interactive process" [49] to "revolution" [55]. However, we advise caution in assuming that a revolution has taken place [27]. It may be that communication, information exchange, and patients' contribution to his or her care has improved or accelerated, but according to Engelen [8], no fundamental changes in health care have yet occurred.

Authors of a Health 2.0/Medicine 2.0 definition generally seemed to approach the definition from their own perspective. For example, patients or patient federations saw patients as the main stakeholder and focused on empowerment of the patient.

That is, definitions may be influenced by different stakeholders' agendas. Therefore, it is important for future Health 2.0/Medicine 2.0 researchers to incorporate all stakeholders and thereby include all possible views and perspectives.

Limitations

Our study has some limitations. First, we found 46 unique definitions, mostly in the gray literature, using the Internet. Only 9 definitions were found in peer-reviewed articles in the scientific literature. This can be explained by the fact that Health 2.0/Medicine 2.0 is a relatively new concept and is still developing. However, it is important to realize there is no evidence-based method available to determine the quality of online content yet. Consequently, proper assessment of the value of the definitions we found was not possible.

Second, it appeared that searches using Google, Bing, and Yahoo showed many results. Although these search engines displayed results by relevance using algorithms and ranking systems, we may have missed unique definitions as we only studied the first 100 results.

Finally, the exact way search engines display results remains unclear. The process can be seen as a black box. As a result, reproduction of searches is far from optimal, as the results literally change every second. Therefore, one might question the suitability of these search engines for scientific research. However, by combining the results of Google, Bing, and Yahoo and using four search queries, we believe we found the majority of all relevant definitions in the gray literature.

Conclusion

Health 2.0/Medicine 2.0 is still a developing concept. Our study identified 46 unique definitions of Health 2.0 and Medicine 2.0 with seven recurrent topics: Web 2.0/technology, patients, professionals, social networking, health information/content, collaboration, and change of health care. There is no general consensus of the definition of Health 2.0/Medicine 2.0 yet. We hope that this study will contribute to building the concept of Health 2.0/Medicine 2.0 and facilitate future discussion and research to achieve a clear conceptual framework.

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Conflicts of Interest

None declared

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Abbreviations

ICT: information and communication technology
IVF: in vitro fertilization

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Orginal Paper

Health Information Technology to Facilitate Communication Involving Health Care Providers, Caregivers, and Pediatric Patients: A Scoping Review

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Abstract

Background: Pediatric patients with health conditions requiring follow-up typically depend on a caregiver to mediate at least part of the necessary two-way communication with health care providers on their behalf. Health information technology (HIT) and its subset, information communication technology (ICT), are increasingly being applied to facilitate communication between health care provider and caregiver in these situations. Awareness of the extent and nature of published research involving HIT interventions used in this way is currently lacking.

Objective: This scoping review was designed to map the health literature about HIT used to facilitate communication involving health care providers and caregivers (who are usually family members) of pediatric patients with health conditions requiring follow-up.

Methods: Terms relating to care delivery, information technology, and pediatrics were combined to search MEDLINE, EMBASE, and CINAHL for the years 1996 to 2008. Eligible studies were selected after three rounds of duplicate screening in which all authors participated. Data regarding patient, caregiver, health care provider, HIT intervention, outcomes studied, and study design were extracted and maintained in a Microsoft Access database. Stage of research was categorized using the UK's Medical Research Council (MRC) framework for developing and evaluating complex interventions. Quantitative and qualitative descriptive summaries are presented.

Results: We included 104 eligible studies (112 articles) conducted in 17 different countries and representing 30 different health conditions. The most common conditions were asthma, type 1 diabetes, special needs, and psychiatric disorder. Most studies (88, 85%) included children 2 to 12 years of age, and 73 (71%) involved home care settings. Health care providers operated in hospital settings in 96 (92%) of the studies. Interventions featured 12 modes of communication (eg, Internet, intranets, telephone, video conferencing, email, short message service [SMS], and manual downloading of information) used to facilitate 15 categories of functions (eg, support, medication management, education, and monitoring). Numerous patient, caregiver, and health care relevant outcomes have been measured. Most outcomes concerned satisfaction, use, usability, feasibility, and resource use, although behavior changes and quality of life were also reported. Most studies (57 studies, 55%) were pilot phase, with a lesser proportion of development phase (24 studies, 23%) and evaluation phase (11 studies, 11%) studies. HIT interventions addressed several recurring themes in this review: establishing continuity of care, addressing time constraints, and bridging geographical barriers.

Conclusions: HIT used in pediatric care involving caregivers has been implemented differently in a range of disease settings, with varying needs influencing the function, form and synchronicity of information transfer. Although some authors have followed a phased approach to development, evaluation and implementation, a greater emphasis on methodological standards such as the MRC guidance for complex interventions would produce more fruitful programs of development and more useful evaluations in the future. This review will be especially helpful to those deciding on areas where further development or research into HIT for this purpose may be warranted.

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KEYWORDS

Infant; child; adolescent; physician patient relations; communication; medical informatics; applications; computers; Internet

Introduction

The US Institute of Medicine (IOM) has produced several important documents that have had substantial influence on US health care. One of these documents, titled *Crossing the Quality Chasm: A New Health System for the 21st Century*, posits that redesign of the health care process by administrators, health professionals, and patients is needed. The report lays out ten rules with which these players should work. The first of these rules is:

> *Patients should receive care whenever they need it and in many forms, not just face-to-face visits. This rule implies that the health care system should be responsive at all times (24 hours a day, every day) and that access to care should be provided over the Internet, by telephone, and by other means in addition to face-to-face visits [1].*

Pediatric patients with health conditions requiring follow-up and their caregivers (unpaid, including family members and school personnel) is probably the group that can most benefit from what the IOM calls the "continuous healing relationship." Children in need of ongoing medical care are typically dependent on a caregiver to mediate at least part of the necessary two-way communication with health care providers. Many of the common chronic diseases in children, such as asthma and type 1 diabetes, can deteriorate rapidly and have serious complications. Parents or other caregivers must rely on observations and intuition to assess when more or different care is needed or if a health care provider's attention must be sought. Information gathering and transmission are vitally important to parents whose children require care and oversight from pediatricians and primary care providers. The needs of all involved in the care of pediatric patients have been supported in various ways by health information technology (HIT). HIT is increasingly being used and studied for its role in information transfer and health care delivery for pediatric patients in community and home care settings, often with involvement of parents and other caregivers.

The Robert Woods Johnson Foundation described HIT as "the use of a variety of electronic methods for managing information about the health and medical care of individuals and groups of patients [2]." Chaudhry and colleagues, in a seminal review of the evidence supporting HIT, showed that HIT can improve the quality and delivery of care although much research remains to be done, especially in specific disciplines and outpatient and home settings [3].

An important subset of HIT includes applications used for communication between people, often patients or caregivers and health care providers. This subset of HIT is sometimes termed “information communication technology” or ICT. ICT is ubiquitous, and its place in daily lives is growing. One major segment of ICT is in health and wellness. Health ICT can be a simple web page or text message to report blood glucose levels. It can also be complex gene analyses to predict future health in newborns, national electronic health records systems, or automatic international outbreak data gathering and reporting mechanisms. ICT function can be data gathering and analyses, monitoring and alerting (eg, breathing monitors in premature infants), diagnosis and treatment at distances (eg, teledermatogy, telesurgery, or telepsychiatry), or communication. In pediatrics, this communication function is especially important in a context where children with health care needs require caregiver mediation for management of their care.

Because the term ICT is rarely used in the HIT literature currently and was not used in any of the studies in this review, we have opted to use the more general term, HIT, in the rest of this paper. We describe ICT as a separate subset of HIT because we feel this term will be adopted more frequently in the future, especially to describe studies such as the ones included in this review.

Awareness of the extent and nature of published research involving such interventions (henceforth HIT) is currently lacking. We conducted a scoping study with the objective of mapping the health literature about HIT used to facilitate communication involving health care providers and caregivers of pediatric patients with health conditions that require follow-up.

The term “scoping study” can refer to a broad range of activities and has so far only been defined imprecisely. Mays and colleagues proposed that, “scoping studies aim to map *rapidly* the key concepts underpinning a research area and the main sources and types of evidence available [4].” This type of study has also been characterized as a form of literature review that differs from systematic reviews because it “tends to address broader topics where many different study designs might be applicable [5].” More recently, Anderson and colleagues developed the concept further by illustrating the different elements or categories of activity that scoping studies could engender. These include literature mapping, conceptual mapping, and policy mapping. According to their categorization, the current study qualifies as a literature map “designed to provide an initial indication of the size and location of the literature relating to a particular topic as a prelude to a comprehensive review of the literature [6].”

Methods

The methods for this scoping review were guided by standard review methods and those described by Arksey and O’Malley [5]. Iterative decisions about data collection, fields for extraction, analysis, and so on, were discussed in meetings attended by the authors and documented in a study log.

Search and Selection

This review was restricted to primary studies of HIT applications used in pediatric care to support communication that involved patients' caregivers and health care providers.

Searches were informed by 6 seed articles [7-12] and other published searches in relevant reviews of HIT [13-15]. The search approach combined terms relating to the concepts of care delivery, information technology, and pediatrics (Multimedia Appendix 1). MEDLINE, EMBASE, and CINAHL databases were searched on January 22, 2008 and again on February 2, 2009 for articles published between 1996 and 2008. The search was limited to studies in English and excluded letters, editorials, and news items.

Inclusion and exclusion criteria for this complex topic were developed and applied iteratively over three rounds of duplicate screening involving all authors (Table 1). In the first round, titles and abstracts were screened inclusively to retain any articles featuring communication, information technology, and pediatrics. In the second round, abstracts and full text of the articles were reviewed to determine whether electronic technology (including telephone) was used to facilitate communication, and whether there was communication of some sort involving caregivers and health care providers. The third screen occurred during data extraction, when each additional criterion was applied iteratively to the retained set of articles. Publications that studied the same intervention in the same set of patients were matched and classified as a single study.

Table 1. Iterative eligibility criteria

	Exclusion Criteria	Inclusion Criteria
First screen	Telephone or email was used for survey or trial recruitment purposes	Electronic health records that allow access by caregivers
	Acute diseases and other conditions not requiring follow-up, including vaccinations	Patient or caregiver use of HIT in settings other than the home, including emergency departments (EDs) or health care provider offices
	HIT used for epidemiological or public health purposes	
	Telemedicine applications where communication was entirely among health care providers	
	Prenatal patients	
Second screen	No communication that involved both caregiver and health care provider	Telephone triage services
	No electronic technology used to communicate	Computer kiosks in health care settings
	Communication while parties were face-to-face	
Third screen	Telephone triage services not explicitly dedicated to chronic diseases or conditions requiring follow-up	Studies of healthy patients, provided the HIT intervention was intended for chronic disease
	Large programs of which telephone was only a small element	

Data Extraction

Microsoft Access was used to develop a form for data extraction. Initial fields and their definitions were developed and recorded in an accompanying guide based on 6 seed articles [7-12] and a sample of 30 abstracts of articles included in the first round of screening. Data regarding the patient, caregiver, health care provider, HIT intervention, outcomes studied, and study design were extracted from the full text (by SG) and maintained in a Microsoft Access database.

To help summarize the heterogeneity in the study types, we used the framework proposed in the UK's Medical Research Council (MRC) guidance for developing and evaluating complex interventions [16]. The majority of studies in this review were of complex interventions, defined by the guidance as those with several interacting components and several possible features that make them complex. According to MRC, these features include:

- Number of and interactions between components within the experimental and control interventions
- Number and difficulty of behaviors required by those delivering or receiving the intervention
- Number of groups or organizational levels targeted by the intervention
- Number and variability of outcomes
- Degree of flexibility or tailoring of the intervention permitted [16]

The MRC framework consists of a continuum of four research phases, which may be non-linear: development, feasibility and piloting, evaluation, and implementation. The guidance stresses the importance of reporting of all stages of research and cautions against focusing too heavily on the evaluation phase while neglecting the others. We categorized each study into one of these phases to give an estimate of how each one is represented in this area of HIT research. Definitions of each phase were developed iteratively to fit the studies we categorized in this review while remaining as consistent with the original MRC definitions as possible (Table 2).

Table 2. Definitions of the research phases adapted from the MRC guideline for complex interventions [16] used to classify studies

Research Phase	Definition
Development phase	Studies in the development phase are those that investigate intervention design-related outcomes (satisfaction, feasibility, usability) before the intervention has reached a deployable state of development. Also included are theoretical and modeling studies or reports limited to describing the technology or user interactions with it.
Piloting phase	Studies in the piloting phase are those that investigate intervention design-related outcomes when it is a question of refining the intervention after it has reached a relatively complete stage of development. User-related outcomes (behavior change, resource use, clinical outcomes, quality of life) are often measured in the same study. Feasibility and pilot studies that feature user-related measures are differentiated from full-scale evaluations (below) if their outcomes are less important (eg, process outcomes), sample size is small, or a less rigorous study design is used. Some studies reported the adaptation of an existing technology (eg, video-conferencing for telemedicine) for a particular disease, using a case study format where patient outcomes are described. Although these studies do not involve a program of development, they were categorized as feasibility and piloting studies because they report user-related outcomes.
Evaluation phase	Studies in the evaluation phase are those that evaluate important user-related outcomes that use one of the more rigorous available study design options and have a large sample size.
Implementation phase	Studies in the implementation phase are those that evaluate user-related outcomes for an intervention that is well established (eg, in use for more than 2 years) or for which a full-scale evaluation has been published. As many implementation efforts are not reported, it was expected that this phase would have low representation.

Analysis

Queries were run in Microsoft Access to summarize the data quantitatively. Also, a qualitative descriptive approach was used to summarize how HIT was used and studied in the four most highly represented disease contexts in our study.

Results

Study Characteristics

We identified 104 studies (112 articles) eligible for inclusion (Figure 1). Represented are 30 different health conditions, with asthma, diabetes, special needs and mental health being the most common. Although 17 countries are represented, the majority of studies were conducted in the United States (Table 3).

Figure 1. Search and screening results

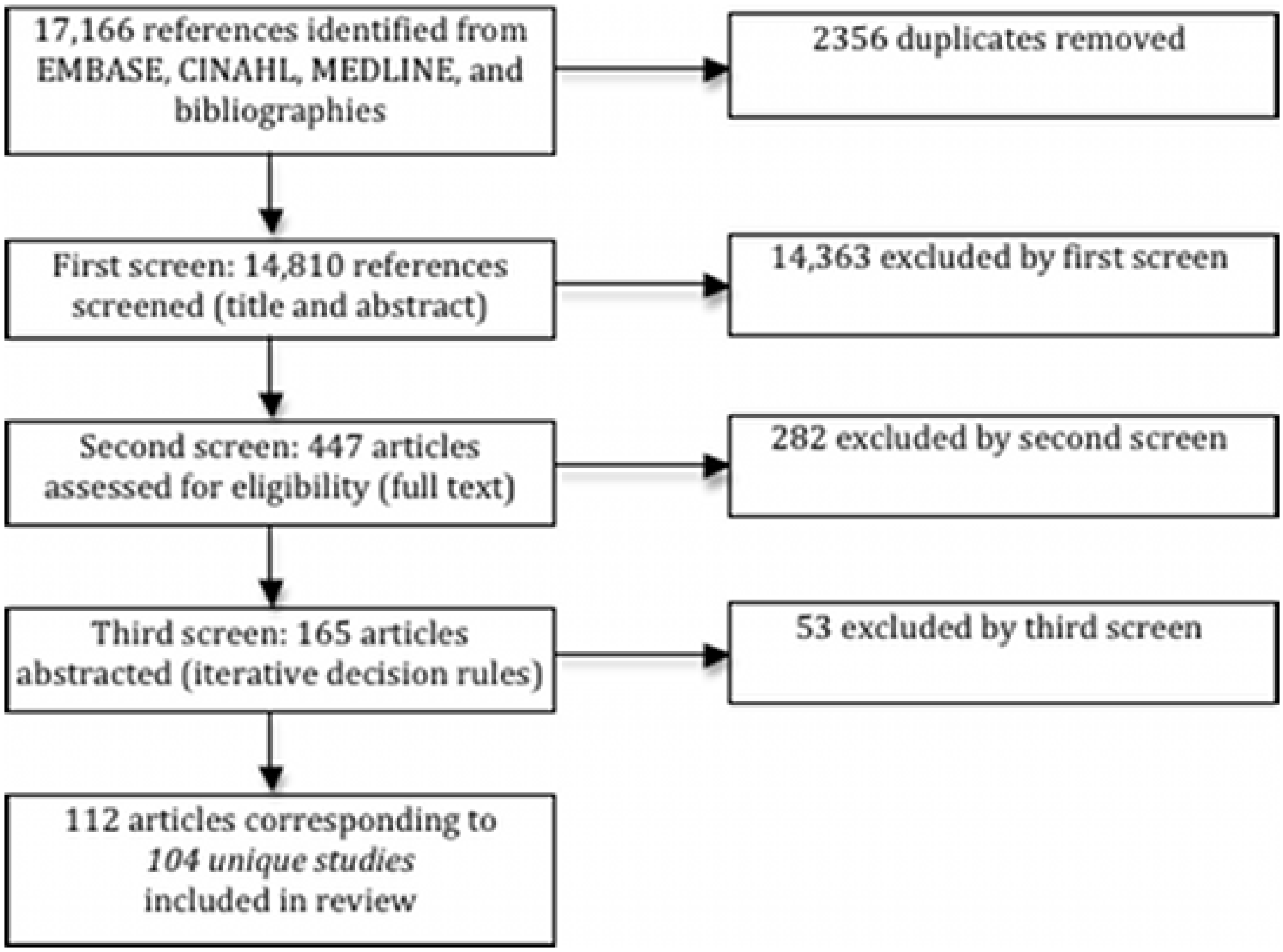

Table 3. Proportional distribution (percent) of studies by disease and country (N = 104)

	Total	United States	Australia	Canada	United Kingdom	Italy	Other[b]
	(n) %	(n) %	(n) %	(n) %	(n) %	(n) %	(n) %
	(104) 100	(53) 51	(15) 14	(12) 12	(6) 6	(4) 4	(14) 13
Asthma [8,9,17-32]	(18) 17	(12) 12	(2) 2	-	-	-	(4) 4
Type 1 diabetes [33-43]	(12) 12	(6) 6	-	-	(1) 1	(1) 1	(4) 4
Special needs [44-55]	(11) 11	(7) 7	(1) 1	-	(1) 1	(1) 1	(1) 1
Psychiatric disorder [56-67]	(10) 10	(4) 4	(1) 1	(2) 2	1	-	-
Various diseases [68-74]	(7) 7	(5) 5	(1) 1	-	-	-	(1) 1
Cancer [75-79]	(5) 5	(2) 2	(3) 3	-	-	-	-
Cardiac disorder [80-84]	(4) 4	-	-	(1) 1	(3) 3	-	-
Sudden infant death syndrome risk [85-88]	(4) 4	(3) 3	-	-	-	-	(1) 1
Burns [89-91]	(3) 3	-	(2) 2	-	-	-	(1) 1
Complex health care needs post-discharge [92-94]	(3) 3	-	-	(3) 3	-	-	-
Speech-language pathology [95-97]	(3) 3	(1) 1	(1) 1	(1) 1	-	-	-
Chronic kidney disease (dialysis) [98,99]	(2) 2	-	-	-	-	(2) 2	-
Cystic fibrosis [100,101]	(2) 2	(1) 1	(1) 1	-	-	-	-
Epilepsy [102,103]	(2) 2	(2) 2	-	-	-	-	-
Traumatic brain injury [10,104-107]	(2) 2	(2) 2	-	-	-	-	-
Very low birth weight [108,109]	(2) 2	(2) 2	-	-	-	-	-
Other[a]	(14) 13	(6) 6	(1) 1	(5) 5	-	-	(2) 2

[a] Diseases that were the topic of only 1 study that met the inclusion criteria: Anorexia nervosa (Canada) [110], endocrine (Australia) [111], feeding disorders (United States) [112], gastroenterological (United States) [113], hemophilia (Canada) [114], HIV (United States) [115], hypertension (Greece) [116], medical and surgical problems (Canada) [117], recurrent pain (Canada) [118], respiratory failure (Japan) [119], rheumatological disease (United States) [7], scoliosis (Canada) [120], sickle cell anemia (United States) [121], vascular infusion (United States) [122].

[b] Countries from which only 1 or 2 studies met the inclusion criteria: Germany (2; SIDS, diabetes), Netherlands (2; asthma), Norway (2; burns, diabetes), France (1; diabetes), Greece (1; hypertension), Ireland (1; special needs), Israel (1; asthma), Japan (1; respiratory failure), Multiple (1; type 1 diabetes), Spain (1; various), Taiwan (1; asthma).

Participants

Of the 104 included studies, 88 (85%) included non-infant children (2 to 12 years of age), while 94 (90%) included children or adolescents (2 to18 years of age). Adults were also included in 5 (5%) of the studies. Caregivers consisted of family members (generally parents) in 102 (98%) of the studies and included school personnel in 7 (7%) of the studies. Characteristics of study patients, providers, and settings are shown in Table 4.

Table 4. Percent of studies with selected participant characteristics (N = 104)

Characteristic	(n) %
Patient ages	
0-24 months	(41) 39
2-6 years	(63) 61
6-12 years	(83) 80
13-18 years	(70) 67
Patient settings	
Home	(74) 71
Community[a]	(11) 11
Clinical	(29) 28
Types of health care provider	
Nurse	(38) 37
Therapist[b]	(25) 24
Primary care physician	(19) 18
Sub-specialist	(65) 63
Health care provider settings	
Public health	(3) 3
Primary care	(10) 10
Hospital[c]	(96) 92
Other	(2) 2

[a] Community settings include school or daycare.

[b] Therapists include psychologists or counselors.

[c] Hospital settings include specialty clinics; other settings include call centers or home care.

Interventions

Interventions featured synchronous (immediate) transfer of data in 44 (42%) of the studies and asynchronous (store-and-forward) transfer in 36 (35%) of the studies, while in 24 (23%) of the studies, the intervention featured both. Communication commonly occurred via the Internet, telephone, videoconference, or email. HIT function was classified into 15 categories centered on support, medication management, diagnosis, education, and monitoring. Shown in Table 5 are these and other characteristics of the interventions featured in the studies.

Table 5. Percent of studies with selected intervention characteristics (N = 104)

Intervention Characteristic	(n) %
Communication modes featured by HIT intervention	
Internet[a]	(34) 33
Intranet[a]	(6) 6
Telephone	(26) 25
Video conference	(46) 44
Email	(22) 21
SMS	(3) 3
Manual download	(13) 13
Types of data delivered by HIT intervention	
Text	(36) 35
Voice	(53) 51
Video or imaging	(50) 48
Multimedia	(18) 17
Binary	(30) 29
Functions served by HIT intervention	
Caregiver psychological support	(34) 33
Patient psychological support	(17) 16
Physiological monitoring	(40) 38
Behavioral surveillance	(16) 15
Diagnosis	(36) 35
Medication management	(49) 47
Physical care management	(18) 17
Patient behavior management	(33) 32
Professional counseling	(33) 32
Medical consultation	(47) 45
Mental health tx (non-counseling)	(15) 14
Education	(41) 39
Referral	(13) 13
Transfer patient data to family	(16) 15
Virtual family visits	(4) 4

[a] Internet and intranet modes generally excluded telephone, video conference, and email.

Outcomes

Of the 104 studies, 72 (69%) measured patient outcomes, 85 (82%) measured caregiver outcomes, 41 (39%) measured provider outcomes, and 58 (56%) measured outcomes at the overall program level. Overall, 86 (83%) of studies measured one of the user outcomes: satisfaction, feasibility, or usability. Of these, 43 (41%) were from the patient perspective, 70 (67%) were from the caregiver perspective, and 34 (33%) were from the provider perspective. Outcomes related to resource use (by patients, caregivers, providers, or the overall program) were measured in 34 (33%) of the studies. Shown in Table 6 are these outcomes broken down by specific outcome categories.

Table 6. Percent of studies measuring selected outcomes (N = 104)

Type of Outcome	Overall (n) %	Patient (n) %	Caregiver (n) %	Health Care Provider (n) %	Program Level (n) %
Broadly applicable outcomes					
Satisfaction	(60) 58	(33) 32	(58) 56	(19) 18	-
Feasibility	(70) 67	(20) 19	(34) 33	(23) 22	(45) 43
Usability	(39) 38	(23) 22	(35) 34	(14) 13	-
Usage	(21) 20	(9) 9	(16) 15	(6) 6	(8) 8
Behavior change	(24) 23	(18) 17	(16) 15	(5) 5	-
Resource use	(26) 25	(18) 17	(8) 8	(5) 5	(12) 12
Patient- and caregiver-specific outcomes					
Knowledge	(10) 10	(9) 9	(10) 10	-	-
Clinical outcomes	(33) 32	(31) 30	(2) 2	-	-
Quality of life	(21) 20	(17) 16	(13) 13	-	-

Study Design

Of all studies, 29 (28%) had a qualitative component. Mixed methods were used in 8 (8%) of the studies. The rest were quantitative studies: 17 (16%) of these were randomized controlled trials; 11 (11%) were non-randomized controlled trials; 61 (59%) were descriptive studies; and 7 (7%) were before-and-after studies. Ninety-seven studies (93%) featured complex interventions according the MRC definition [16], while the remaining 7 (7%) were diagnostic studies that did not fit the MRC framework. Using the MRC framework, 24 studies (23%) were categorized as development phase, 57 (55%) as pilot phase, 11 (11%) as evaluation phase, and 5 (5%) as implementation phase.

Qualitative Themes

HIT interventions were applied to several common problems in the context of pediatric care requiring communication involving caregivers and health care providers: establishing continuity of care, addressing health care provider time constraints, and bridging geographical barriers (Table 7). At least one of these themes was represented in each included study; examples of these are described below for the four most common disease contexts. These sections describe what forms HIT interventions took and how they were studied in each disease.

Table 7. Common themes or problems addressed by HIT interventions

Theme	Description	Example Disease Contexts
Establishing continuity of care	Extending care to patients in the community (home, school) beyond settings where they traditionally access care (eg, hospitals)	Complex health care needs post-discharge from hospital
Addressing time constraints	Increasing efficiency of care or reducing time burden on health care providers	ED decision support for asthma
Bridging geographical barriers	Reducing the need for patient travel or providing access to distant specialists	Burn care to patients in rural Australia

Asthma

Studies that involved pediatric patients with asthma had the highest representation with 17 studies. Parents of pediatric asthma patients may be asked to keep diaries to monitor use of rescue medication and home spirometry tests (measuring lung function in terms of peak expiratory flow). The health care provider traditionally relies on such manually recorded information to guide patient management. In 8 (47%) of these studies, spirometry was electronically monitored, while in 4 (24%), medication use was electronically monitored. Electronic monitoring was used in these cases (together representing 9 [53%] of the asthma studies) to reduce the burden of paper diary keeping and increase the reliability of the data.

Another common function for HIT in the asthma setting is education, the subject of 9 (53%) of these studies. Studies involving patients with asthma generally featured guideline-recommended information including environmental factors, medications (eg, inhaler use), handling of asthma attacks or emergencies, and the patient's individual care plan. Monitoring and education were combined in the same intervention in five studies [8,17,20,25,28]. The common goal of including both functions was to establish continuity of care, an important element of managing chronic diseases and one of three recurring themes addressed by the HIT interventions we report on here (Table 7). In 15 (88%) of the asthma studies, data transfer was asynchronous only, reflecting the unique communication needs in this setting.

A dominant function of HIT in studies involving patients with asthma was to improve medication management (14 studies, 82%), a critical step in optimizing disease control and reducing the likelihood and number of attacks that require medical attention. We found 3 studies that featured computer kiosks used for initial assessments, one in a general practice setting [24] and two others in an ED setting [18,21]. Such use of kiosks was unique to asthma among the 104 included studies. In all cases, the intervention was intended to increase the time-efficiency and comprehensiveness of information transfer to health care providers for decision support purposes. These, and other studies that featured educational functions for HIT, provide examples of efforts to address health care provider time constraints, another of the recurring themes observed in this study (Table 7).

We found 12 (71%) studies that succeeded in measuring clinical outcomes (including lung function, symptom control, and use of rescue therapy). Resource use (usually hospital or ED visits) was also commonly measured (10 studies, 59%). A comparatively high proportion of studies that focused on patients with asthma were evaluation studies (7 studies, 41%). Of these, 3 (18%) were development phase, 6 (35%) were pilot phase, and 2 (12%) were diagnosis studies.

Type 1 Diabetes

We retrieved 12 studies dealing with pediatric patients with type 1 diabetes. Behaviors underlying medication adherence are traditionally important challenges to, and targets of, management [123]. Correspondingly, both behavioral management (7 studies, 58%) and medication management (11 studies, 92%) were predominant functions of HIT interventions among the studies retrieved. Telephone was a comparatively common mode of communication in 4 studies (33%), and data were communicated synchronously in 7 studies (58%).

Physiological monitoring was another common function of HIT interventions in studies involving patients with diabetes (9 studies, 75%). These studies usually involved manual (finger pricks) or continuous (subcutaneous sensor) blood glucose monitoring to provide a feedback mechanism for patients, caregivers, or clinicians to understand the behaviors that lead to hypo- or hyperglycemia. Additionally, continuous recording of blood glucose has been used to detect nighttime hypoglycemic episodes [38]. In two cases [33,34], data from portable insulin pumps were also monitored asynchronously. HIT interventions were used to transfer monitoring data to a caregiver's mobile telephone (via short message service, ie, SMS) in two studies. Blood glucose data could usually be downloaded or uploaded and communicated to health care providers. In these cases, the HIT intervention sometimes also served a decision support function (3 studies, 25%).

Similar to the case with asthma, a goal of interventional strategies for pediatric patients with diabetes is to avoid the need for ED visits to address dangerous elevations in blood glucose. Frequency of ED visits was measured in two studies. Clinical outcomes (including glycosylated hemoglobin A1C, blood glucose, hypoglycemic episodes) were evaluated in 7 studies (58%). Among studies that focused on patients with type 1 diabetes, a comparatively high proportion were pilot studies (8 studies, 67%), while only 2 (17%) were development studies and 2 (17%) were evaluation studies.

In 7 studies (58%), interventions helped establish continuity of care. Diabetes studies also included several examples of HIT used to bridge geographical barriers to health care, another of the themes observed in the studies reported here (Table 7).

Special Needs

The term "special needs" describes the patient populations in 11 of the studies and has been defined as follows:

> *Children with special needs present a complex array of health care requirements that remain throughout their life span. These needs include chronic health disabilities (diabetes, epilepsy, cystic fibrosis), developmental and behavioral disorders (cerebral palsy, spina bifida, attention deficit hyperactivity disorder, mental retardation, autism), and traumatic injuries (traumatic brain injury, spinal cord injury) [45].*

Effective diagnosis, care coordination, and case management for such patients can be complex and require specialist involvement [52].

Unlike studies that involved patients with asthma or type 1 diabetes, in studies that involved pediatric patients with special needs, communication was predominantly synchronous (10 studies, 91%) and videoconferencing was the most common mode of communication (7 studies, 64%). Synchronous communication (telephone or videoconference) between the hospital or specialist clinic and patients' homes was generally used to improve continuity of care.

The most common functions among studies that involved children with special needs were consultation (8 studies, 73%) and diagnosis (7 studies, 64%). Telemedicine videoconferencing replaced in person examination, with virtual consultations reducing sometimes painful trips to the clinic and allowing for diagnosis, referrals, and recommendations on physical care [45-48,52]. Additionally, simultaneous communication among multiple providers, school staff, and the caregiver improved coordination of care with fewer physical trips to multiple clinics [45-48,52]. Such consultations also bridged geographical barriers to care (eg, for patients in rural areas) and increased access to specialists. Similar coordinated communication among multiple health care providers and caregivers was also achieved in a Swedish study in which modes of communication included Internet, email, and SMS [51]. One Italian study featured a portable device for monitoring physiological status and physical activities [53,54].

Studies in this category were mostly development phase (4 studies, 36%) or pilot phase (6 studies, 55%), while there were no evaluation studies and only one implementation study. In addition to patient outcomes, a larger than average proportion of these studies measured caregiver (100% of studies) and health care provider outcomes (9 studies, 83%) including satisfaction, feasibility, usability and usage. Some telemedicine studies conducted economic analyses.

Psychiatric Disorders

A recurring problem described in many of the 10 child psychiatry studies was the shortage of pediatric mental health specialists. Most of the studies featured telemedicine interventions, which have an established history in adult psychiatry and are considered suitable because much of the diagnosis and treatment in this setting is achieved by audiovisual communication [65]. Similar to studies involving children with special needs, the HIT technology used in studies that involved children with psychiatric disorders was predominantly synchronous in 8 studies (80%), with videoconference the principal mode of communication in 7 studies (70%). HIT was applied in 2 (20%) of studies to deliver cognitive behavioral therapy to patients with anxiety disorder [56,57].

Rather than coordinating care involving multiple providers, as is commonly seen with special needs, videoconferencing was used primarily for diagnosis in 7 studies (70%), for mental health therapy in 6 studies (60%), and for medication management in 4 studies (40%). A recurring theme was the use of HIT to bridge geographical barriers and the shortage of child mental health practitioners. Rural patients in the United States, Canada, and Australia represented the main population to receive telemedicine interventions (80% of studies).

Of these studies, 8 (80%) were pilot phase, and 2 (20%) were development phase. The purpose of pilot phase studies was often to evaluate satisfaction (9 studies, 90%) or to determine whether pediatric telepsychiatry was comparable with face-to-face treatment (eg, diagnostic agreement).

Discussion

Principal Results

We have observed how, in the health literature of HIT applications that facilitate communication among caregivers and health care providers, the pediatric diseases that are well represented are those characterized by high prevalence (asthma, type 1 diabetes), acute need caused by geographical barriers or other lack of health care provider access (psychiatric disorders, cardiac disorder, burns), or those requiring continuity of care in home or community settings (type 1 diabetes, special needs, cancer, complex health care needs post-discharge). Efforts to estimate the value of HIT interventions in these cases have included measurement of patient- or caregiver-important outcomes such as quality of life (21 studies, 20%) or clinical outcomes (33 studies, 32%), and evaluations of resource use that often comprise some degree of economic analysis (26 studies, 25%). Few studies, however, were capable of providing definitive evidence (ie, 17 studies, [16%] were RCTs, while only 11 [11%] qualified as evaluation studies). This is to be expected in research involving complex interventions, which is often constrained by methodological limitations and high cost.

Implications

Several uses for scoping reviews as articulated by Anderson and colleagues [6] apply to the current study. Specifically, it has proved valuable "to map and make sense of the extent, range, and nature of research undertaken in a particular area," and "to identify the strengths and weaknesses of the research base." Others may also find this report useful "to identify gaps in research knowledge that need filling" and "to determine the value of undertaking further systematic reviews or empirical research."

We suggest that opportunities exist to improve the utility of future development and evaluation work by focusing energies whenever possible on planning integrated programs of development, evaluation, and implementation as recommended by the MRC guidance for complex interventions [16]. Although the realities of some contexts can make this ideal impracticable, eight examples of researchers using phased approaches (featuring multiple related studies) to development and evaluation of their interventions were found here [8,10,18,21,25,30,65,66,77,78,92-94,102-105,108,109].

For this review, articles were considered to refer to the same study if they investigated the same intervention in the same set of patients. Accordingly, seven of the included studies corresponded to multiple publications. In all but one case, however, there was a lack of cross-reference between publications corresponding to the same study. Moreover, in two studies corresponding to five articles authored by the same study group, the same results were reported in multiple publications without any cross reference. More uniform use of study identifiers, as recommended in the CONSORT statement [124,125], may therefore be warranted to avoid multiple reporting in studies of HIT. Of the 104 studies included in this review, we found that only one [104] referred to CONSORT in its bibliography.

Limitations

Scoping reviews are often characterized by the challenge of searching the literature for complex or ill-defined topics. Thus, unlike systematic reviews that typically have a narrower focus, it may be time-consuming and unrealistic to retrieve and screen all the relevant literature. As our purpose was to merely map the existing health literature on a complex topic and not estimate the effects of HIT interventions, our efforts to identify all eligible studies were limited in some respects. Consistent with our objective, we restricted our search to health databases, leaving out the engineering and computing literature. Also, we considered it unnecessary for our purpose to follow up on all of the many narrative reviews on HIT retrieved by our search. Due to this and the complexity of the topic, our study therefore cannot be considered an exhaustive accounting of the literature in this area. Nevertheless, the searches we designed were broad enough to expect that sensitivity, at least within the health literature, was moderately high. Supportive of this, the bibliographies of included articles yielded only three additional studies not detected by our search. Future reviewers focusing on more limited subsets of the literature than we have surveyed here will be able to employ more exhaustive search methods and may retrieve more articles than reported here.

Conclusions

This study provides a map of the health literature on how HIT is being used and studied to facilitate care of pediatric patients with health conditions requiring follow-up and involving participation of both a caregiver and a health care provider. We have observed how HIT used for this purpose has been implemented differently in a range of disease settings, and how varying needs affect the function, form, and synchronicity of information transfer. Interventions have been repeatedly applied to improve continuity of care, address time constraints faced by health care providers, and bridge geographical barriers. Although a number of authors have followed a phased approach to development, evaluation, and implementation, a greater emphasis on methodological standards such as the MRC guidance for complex interventions would produce more fruitful programs of development and more useful evaluations in the future. This review will be especially helpful to those deciding on areas where further development or research into HIT in pediatric contexts may be warranted.

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Conflicts of Interest

None declared

Mutlimedia Appendix 1

Database searches

[PDF file (Adobe PDF), 86 KB - jmir_v12i2e22_app1.pdf]

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Abbreviations

HIT: health information technology
ICT: information communication technology
IOM: Institute of Medicine
SMS: short message service

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Original Paper

Effectiveness of Web-based Interventions on Patient Empowerment: A Systematic Review and Meta-analysis

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Abstract

Background: Patient empowerment is growing in popularity and application. Due to the increasing possibilities of the Internet and eHealth, many initiatives that are aimed at empowering patients are delivered online.

Objective: Our objective was to evaluate whether Web-based interventions are effective in increasing patient empowerment compared with usual care or face-to-face interventions.

Methods: We performed a systematic review by searching the MEDLINE, EMBASE, and PsycINFO databases from January 1985 to January 2009 for relevant citations. From the 7096 unique citations retrieved from the search strategy, we included 14 randomized controlled trials (RCTs) that met all inclusion criteria. Pairs of review authors assessed the methodological quality of the obtained studies using the Downs and Black checklist. A meta-analysis was performed on studies that measured comparable outcomes. The GRADE approach was used to determine the level of evidence for each outcome.

Results: In comparison with usual care or no care, Web-based interventions had a significant positive effect on empowerment measured with the Diabetes Empowerment Scale (2 studies, standardized mean difference [SMD] = 0.61, 95% confidence interval [CI] 0.29 - 0.94]), on self-efficacy measured with disease-specific self-efficacy scales (9 studies, SMD = 0.23, 95% CI 0.12 - 0.33), and on mastery measured with the Pearlin Mastery Scale (1 study, mean difference [MD] = 2.95, 95% CI 1.66 - 4.24). No effects were found for self-efficacy measured with general self-efficacy scales (3 studies, SMD = 0.05, 95% CI -0.25 to 0.35) or for self-esteem measured with the Rosenberg Self-Esteem Scale (1 study, MD = -0.38, 95% CI -2.45 to 1.69). Furthermore, when comparing Web-based interventions with face-to-face deliveries of the same interventions, no significant (beneficial or harmful) effects were found for mastery (1 study, MD = 1.20, 95% CI -1.73 to 4.13) and self-esteem (1 study, MD = -0.10, 95% CI -0.45 to 0.25).

Conclusions: Web-based interventions showed positive effects on empowerment measured with the Diabetes Empowerment Scale, disease-specific self-efficacy scales and the Pearlin Mastery Scale. Because of the low quality of evidence we found, the results should be interpreted with caution. The clinical relevance of the findings can be questioned because the significant effects we found were, in general, small.

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KEYWORDS

Patient empowerment; Internet; eHealth

Introduction

Patient empowerment refers to the enhanced ability of patients to actively understand and influence their own health status [1]. Patient empowerment focuses on control in individuals' experience of health, disease, and illness, as well as the roles of health care organizations, communities, and the broader health care system [2].

Since its introduction to health care in the 1970s [3], the popularity of the idea of patient empowerment has emerged in the context of several significant societal trends, such as a growth in health care consumerism and, as a result, the need for governments to reduce health care costs [4]. In this case, patient empowerment potentially could be used to justify cost-cutting in which part of the responsibility for care is transferred to individual citizens [5]. Furthermore, increased patient activism and organization has led to more focus on patient empowerment initiatives [6]. Revealingly, and in line with these tendencies, the World Health Organization (WHO) has described patient empowerment as a "prerequisite for health" and "a proactive partnership and patient self-care strategy to improve health outcomes and quality of life among the chronically ill [7]."

During the last decades, the focus on empowerment resulted in many initiatives to increase patient empowerment. In general, strategies to increase patient empowerment have tended to address two aspects of patients' experience of illness: (1) disease management and (2) relationships with health care providers [8]. An increasing number of studies have been conducted in which approaches to increasing patient empowerment have been evaluated. These approaches have varied from patient self-management programs [9-16], to promoting patient involvement in treatment decision-making [17,18], to facilitating the physician-patient interaction [19,20]. Most of these interventions have taken place face-to-face or in facilitator-led group sessions.

Although some face-to-face or group session interventions to increase patient empowerment have been found to be effective, for example, in decreasing depression [21] or in job retention among the chronically ill [22], it is believed that the real opportunities for patient empowerment started with the rise of the Internet and eHealth [23]. In recent years, the number of Internet users has increased considerably, and the Internet is being employed more frequently to locate information on health and health care delivery [24]. The latest studies have shown that, among all Internet users, an estimated 58% consult the Web for health purposes [25]. Because of this increased use of the Internet and its huge potential for delivering patient education and management programs, the Internet may have a revolutionary role in retooling the health care industry [23]. Some scientific evidence already exists on the effectiveness of the Internet to improve health outcomes [26,27], increase specified knowledge [28,29], achieve behavior change [30,31], and increase participation in health care [32]. Therefore, in recent years, a growing number of interventions aimed at patient empowerment are, not surprisingly, delivered online.

In this systematic review, we investigated whether these Web-based interventions were effective in increasing patient empowerment compared with usual care or face-to-face interventions.

Methods

Inclusion Criteria

Types of Studies

Only randomized controlled trials (RCT), quasi-randomized controlled trials, before-and-after studies, and interrupted time series analyses were included.

Types of Participants

Studies in which the intervention was aimed at patients or clients with a medical problem were included. Studies that included children and adolescents less than 18 years of age were excluded to create more homogeneity in the study population.

Types of Intervention

Studies in which the treatment consisted of a Web-based intervention were included. Web-based interventions were defined as all interactive Web applications accessed via the Internet or an intranet. Furthermore, we excluded studies if the intervention did not contain any aspects of health education or intention to change health-related behavior.

Types of Control Intervention

Studies were included only if the control intervention consisted of either usual care or a face-to-face intervention.

Types of Outcome Measures

Studies that measured empowerment or an empowerment-related component were included. Given the absence of a generally accepted definition of empowerment and conflicting views on how to measure empowerment, we decided to initially include concepts that are often linked to empowerment. Examples of these are self-efficacy, mastery, self-control, self-esteem, perceived control, perceived competence, or involvement in the decision-making process [33].

No language restriction was applied.

Search Strategy

Publications were retrieved by a search of the following electronic databases:

- MEDLINE (1985 to January 2009)
- EMBASE (1985 to January 2009)
- PsycINFO (1985 to January 2009)

Detailed search strategies are presented in the Multimedia Appendix. Briefly, we combined two search concepts, the first consisting of the outcome measure (eg, "empowerment" or "self-efficacy") and the second of the intervention (eg, "Internet" or "website"). Various synonyms were used for each concept. We chose a sensitive search strategy so that we would not miss any potentially relevant publications.

Study Identification and Data Abstraction

Citations and brief records identified by the search strategy were downloaded electronically to the bibliographic management package Reference Manager 11 (Thomson Reuters, Carlsbad, CA, USA). The study selection was completed in three steps. In step 1, two reviewers (authors DS and DB) independently screened the titles, keywords, and abstracts of the studies obtained by the search strategy to determine if they met the inclusion criteria. When inclusion or exclusion of a study could not be based on the screening of the title, keywords, and abstract, in step 2, the full article was retrieved and checked for inclusion. This was again, done by two reviewers (authors DS and NE). A consensus meeting with a third reviewer (DB) was arranged to sort out disagreements between reviewers. In step 3, we searched the reference lists of the included studies to find additional publications. Additionally, from all citations that were initially identified by the search strategy, we checked all systematic reviews concerning Web-based interventions and searched in the reference lists of these reviews to find additional publications that met our inclusion criteria.

Two reviewers (DS and NE) extracted the data using a data extraction form that included information on study design, randomization level, population, follow-up period, description of the intervention and control group treatments, and data on relevant outcomes. If certain studies did not report sufficient information on the outcomes, missing data (for example, standard deviations) were calculated according to guidelines in the *Cochrane Reviewers' Handbook* [34]. If it was not possible to calculate missing data, authors of the studies were contacted and additional information on the missing data was requested.

Quality Assessment

We evaluated the quality of individual studies using the Downs and Black quality assessment method, which is a list of 27 criteria to evaluate both randomized and nonrandomized trials [35]. This quality assessment scale (QAS) assesses study reporting, external validity, and internal validity (ie, bias and confounding), and has been ranked in the top six quality assessment scales suitable for use in systematic reviews [36,37]. As has been done in other reviews using the Downs and Black scale [38,39], the tool was modified slightly for use in this review. Specifically, the scoring for question 27 dealing with statistical power was simplified to a choice of awarding either 1 point or 0 points depending on whether there was sufficient power to detect a clinically important effect. The criterion was that to detect a 10% difference, at least 87 subjects had completed follow-up in both the intervention and control groups of the study, assuming power of .90 and alpha of .05. The maximum score for item 5, reporting of principal confounders was 2. Downs and Black score ranges were grouped into the following 4 quality levels: excellent (26 to 28), good (20 to 25), fair (15 to 19), and poor (less than 14).

Two reviewers (DS and DB) independently assessed the quality of the included studies. A consensus method was used to resolve disagreement.

Data Analysis and the GRADE Approach

Analyses of this review were based on the outcome measure, that is, empowerment or an empowerment-related outcome. For studies that were comparable with respect to the control intervention and the outcome, results were pooled using meta-analyses. In these analyses, we included final measurements of continuous data. We were able to do so, because all included studies in this review were RCTs or quasi-RCTs, and no study reported significant baseline differences between the intervention and the control group. Since there were many different scales or instruments used to measure the same outcome, we could not use weighted mean differences and therefore calculated standardized mean differences (SMD). SMDs obtained from the meta-analyses were then reexpressed to a familiar instrument, using a so-called back-translation technique. In this technique, an instrument is selected from a study included in the meta-analysis that is representative of the population and at a low risk of bias, and then the standard deviation of the outcome measure of the control group of this study (the end of study mean) is multiplied by the pooled SMD.

We chose a random-effects meta-analysis because it was considered a more appropriate model to combine the results of the included studies, which were clinically and methodologically diverse [40]. Additionally, publication bias was tested by inspecting the funnel plot on outcomes that were measured in more than 8 studies. A funnel plot is a scatterplot of treatment effect against a measure of study size. An asymmetric funnel indicates a relationship between treatment effect and study size, suggesting a possibility of publication bias. For all analyses Review Manager software (version 5.0) was used [41].

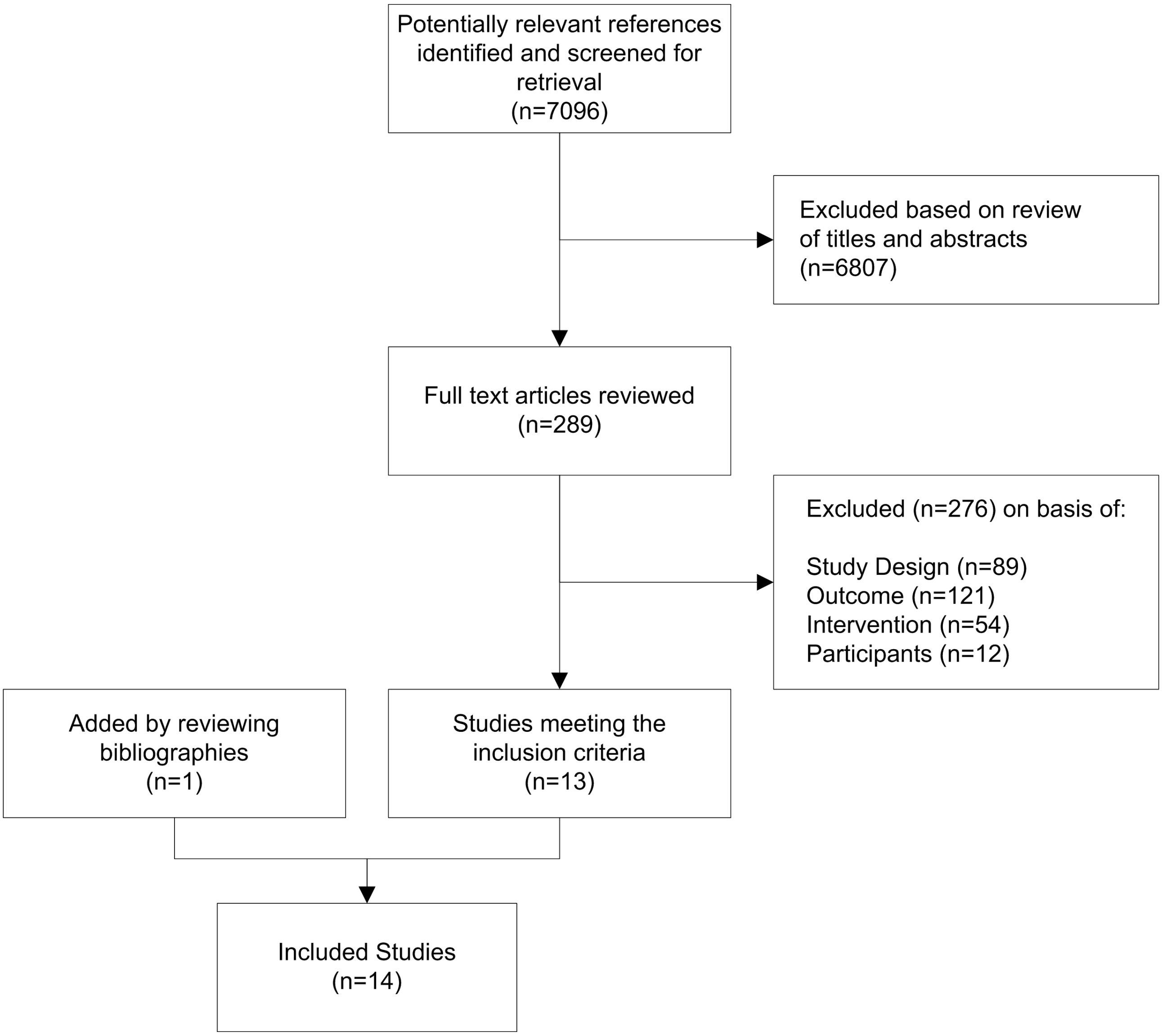
We present the overall quality of the evidence using the GRADE approach as recommended by the *Cochrane Handbook for Systematic Reviews of Interventions* [34] because of its many advantages [42]. That is, for each specific outcome, the quality of the evidence was based on five factors: (1) limitations of the study design or the potential for bias across all studies that measure that particular outcome, (2) consistency of results, (3) directness (generalizability), (4) precision (sufficient data), and (5) the potential for publication bias. The overall quality was considered to be high if multiple RCTs with a low risk of bias provided consistent, generalizable results for the outcome. The quality of evidence was downgraded by one level if one of the factors described above was not met. Likewise, if two or three factors were not met, we downgraded the level of evidence by two or three levels, respectively. Thus, the GRADE approach resulted in four levels of quality of evidence: high, moderate, low, and very low. In the case of only one study measuring an outcome, the data were considered to be "sparse," and subsequently the evidence was labeled as "low quality evidence." If only one study was present for a given comparison, the results are described in the text. GRADEprofiler software (version 3.2) was used [43].

Results

Study Selection

From all databases combined, we identified a total of 7676 titles: 1823 in MEDLINE, 3540 in EMBASE and 2313 in PsychINFO. After exclusion of duplicates, DS and DB reviewed the 7096 titles and abstracts. Figure 1 shows a flow diagram of the reviewed studies.

Figure 1. Study selection



We selected 289 publications for retrieval of full text versions. From these 289 studies, initially 18 publications met our inclusion criteria: these were publications reporting results of 16 RCTs and 2 quasi-RCTs. The main reason for excluding studies was based on the outcome criteria: the majority of the studies did not measure empowerment or an empowerment-related outcome. From the 18 studies that initially met our inclusion criteria, 2 publications of Man et al [44,45] reported on the same study and were handled as one RCT. The publication of Kukafka et al [46] was excluded because standard deviations of the outcome (self-efficacy) were not reported and were not retrieved after contacting the author. The study by Wangberg [47] did not have an appropriate contrast for the website intervention. Instead, this study compared two study groups that both used tailored Internet interventions. After closer examination, the study by Robinson [48] was excluded because it did not meet the patient criteria, and the study by Williams et al [49] was excluded because the intervention in this study was not solely Web-based. The additional reference search resulted in one extra publication [50] that met our inclusion criteria. Because this publication by Warmerdam et al contained a description of a study protocol, we contacted the authors and received relevant unpublished data. With this study included, the total number of studies included in this review was 14 [45,50-62].

Study Characteristics

Table 1 shows the characteristics of the included studies.

Table 1. Characteristics of the included studies

Citation	Population/ Setting (n, % Female)	Duration of Follow-up (% dropout)	Intervention	Comparison Treatment	Outcome Measure(s) (Instrument)	Quality Assessment Score
Cousineau et al 2008 [51]	Online psycho-educational support for infertile women (190, 100%)	4 weeks (3%)	Tailored website containing in vitro fertilization (IVF)-specific cognitive behavioural skill training (CBT) and stress management. Total content: 90 minutes, available over a 4-week period[b,c,e]	Waiting list	Self-efficacy, infertility specific (Infertility Self-Efficacy Scale [51]).	26, Excellent
Gollings et al 2005 [52]	Treatment of body dissatisfaction among women 18 to 30 years old (39, 100%)	8 weeks (18%)	The Set Your Body Free Group Body Image Program: eight therapist-led, online chat sessions (weekly, session duration: 90 minutes), 24/7 discussion board[a]	Face-to-face delivery of the same intervention	Self-esteem (Rosenberg Self-esteem Scale [RSE] [67])	16, Fair
Hill et al 2006 [53]	Increasing psychological health among chronically ill, rural women(12, 100%)	12 weeks (17%)	Women-to-Women (WTW) project: an online web-based educational tool aimed at increasing Web skills, coping with chronic illness, handling family finances, etc[a,b]	No care	(1) Empowerment (adapted Diabetes Empowerment Scale [DES] [63]) (2) General self-efficacy (General Self-Efficacy [GSE] [65]) (3) Self-esteem (RSE [67])	17, Fair
Hirai and Clum 2005 [54]	Internet help for patients with posttraumatic stress disorder (36, 78%)	8 weeks (25%)	Internet-based, interactive cognitive behaviour program (8 weeks) consisting of relaxation training, mastery tests, cognitive restructuring and exposure modules[c]	Waiting list	Self-efficacy, post-traumatic syndrome specific (adapted scale)	15, Fair
Homko et al 2007 [55]	Managing underserved women with gestational diabetes mellitus in a prenatal clinic (63, 100%)	From 4 to 37 weeks, depending on gestation at inclusion (10%)	Web-based disease management interactive telemedicine system. Components: health information and education, patient electronic medical record, and communication with health team[a,b,d]	Paper logbook	Empowerment (DES [63])	18, Fair
Lorig et al 2002 [56]	Internet help for back pain patients (580, 39%)	1 year (27%)	Closed and moderated email discussion group, copy of the Back Pain Helpbook, and a videotape on how to continue active life with back pain[a]	Usual care	Self-efficacy, specific to management of back pain (adapted scale)	20, Good
Lorig et al 2006 [57]	Internet help for patients with chronic diseases (heart or lung disease and type 2 diabetes) (958, 71%)	1 year (19%)	Interactive website (6-week program) based on the book *Living a Healthy Life with Chronic Conditions.* Online workshops with Web moderator, individual exercise programs, cognitive symptom management etc[a,b,c]	Usual care	Self-efficacy, disease management specific (adapted scale)	20, Good
Lorig et al 2008 [58]	Internet-based arthritis self-management program for patients with fibromyalgia (855, 90%)	6 months (25%)	Arthritis Self-Management (6-week) Program: health education, bulletin board discussion, individual tools such as exercise logs, medication diaries, and a tailored exercise program [a,b,c,d,e]	Usual care	Self-efficacy, arthritis specific (adapted scale)	22, Good
Man et al 2006 [44]	Problem-solving skill training for people with acquired brain injury (ABI) (59, 43%)	8 weeks (24%)	Online interactive multimedia presentations on knowledge and concepts required for persons with ABI to function independently [c]	Waiting list	Self-efficacy, ABI specific (adapted scale)	21, Good

Citation	Population/ Setting (n, % Female)	Duration of Follow-up (% dropout)	Intervention	Comparison Treatment	Outcome Measure(s) (Instrument)	Quality Assessment Score
Nguyen et al 2008 [59]	Internet-based dyspnea self-management program for patients with chronic obstructive pulmonary disease (50, 44%)	6 months (22%)	Website containing structured education for dyspnea management strategies, skills training, peer interaction, symptom and exercise monitoring, and exercise consultations (6- month program)[a,b,c,d]	Face-to-face delivery of the same intervention	Mastery, subscale of the Chronic Respiratory Questionnaire (CRQ [59])	20, Good
Ross et al 2004 [60]	Web-based online medical record for patients with congestive heart failure in a speciality clinic (107, 23%)	6 months (22%)	SPPARO web interface, providing patients with a medical record, educational guide and a messaging system[a,b,d]	Usual care	Self-efficacy, patient specific (adapted scale)	23, Good
Tuil et al 2007 [61]	Internet-based personal health record for patients undergoing IVF and intracytoplasmic sperm injection (ICSI) treatment in an academic research environment (244, 50%)	16 weeks (26%)	IVF educational interactive website consisting of general information, a personal medical record with tailored clarifications, and communication (forum, email, chat)[a,b,d,e]	Usual care	(1) General self-efficacy (GES [64]) (2) Self-efficacy, IVF specific (adapted scale)	18, Fair
Warmerdam et al 2009 [50]	Internet treatment for adults with depressive symptoms (263, 71%)	Intervention 1:12 weeks (46%) Intervention 2: 5 weeks (42%)	Intervention 1: Cognitive Behavioral Therapy (12 weeks) based on changing patients' cognitive patterns[c] Intervention 2: Problem-Solving Treatment (5 weeks) aiming at controlling practical problems patients face[c]	Waiting list	Mastery (Pearlin Mastery Scale [66])	23, Good
Zutz et al 2007 [62]	Website for potential participants for hospital-based cardiac rehabilitation programs (15, 20%)	12 weeks (13%)	Website with the ability to interactively monitor heart rate and blood pressure. Plus scheduled one-on-one chat sessions with program nurse case manager, weekly education sessions and monthly ask-an-expert group chat[a,b,d]	Usual care	(1) General Self-efficacy (GSE [65]) (2) Self-efficacy; exercise specific (adapted scale)	15, Fair

Web-based intervention contains:

[a] communication options, such as a forum, chat or (moderated) discussion board

[b] health information to increase knowledge

[c] disease specific self-management modules

[d] e-monitoring, such as a patient medical records or symptom diaries

[e] tailored messages or information

Design of the Included Studies

Of the 14 included studies, 13 were RCTs, while the study that was reported in two publications [44,45] was a quasi-RCT. Most studies compared two study groups: an intervention group in which the treatment was a Web-based intervention and a control group receiving usual care or no care. Exceptions were the studies of Nguyen et al [59] and Gollings et al [52] in which comparisons were made between a Web-based intervention and a face-to-face intervention. Furthermore, the study by Man et al [45] consisted of four intervention arms: a control group, a computer-assisted training program, an online training program, and a therapist-administered training program. For this review, we compared the online training program with the control group. Also, the study by Warmerdam et al [50] included three interventions arms: a Web-based cognitive behavior program, a web-based problem-solving program, and a control group.

The duration of the follow-up measurements varied from 8 weeks [54] up to one year [56,57]. Also, many differences were found in the exact content of the Web-based interventions.

Participants

The number of participants varied from 15 [62] to 958 [57]. Studies differed regarding patient groups. For example, various studies included infertility patients, patients with post-traumatic stress disorder, patients with diabetes, or back pain patients. The mean dropout rate was 23% (SD 11%) after an average follow-up duration of 19 weeks (SD 15 weeks). Participants' compliance with the intervention was not clearly described in many of the included studies.

Outcomes

Empowerment was explicitly measured in only two studies. Both of these used the Diabetes Empowerment Scale (DES) [63]. Although the DES is meant to measure diabetes-related empowerment, the study of Hill et al [53] showed that the DES can be adapted to other diseases. All other included studies (one or more) measured empowerment-related outcomes: 9 studies measured disease-specific self-efficacy, 3 measured general self-efficacy, 2 measured mastery, and 2 measured self-esteem.

Methodological Quality

The quality of the included studies varied. According to the calculated quality assessment score (QAS), none of the studies were rated as being of poor quality, 6 studies were rated fair, 7 were rated good, and 1 was rated excellent. The mean QAS for the included studies was 19.6. Studies scored particularly poor on the following items: patient blinding (11 of 14), blinding of the outcome assessor (12 of 14), failure to adjust for confounding factors in the analysis (11 of 14), bias due to losses of patients to follow-up (9 of 14), and insufficient power to detect outcomes that are clinically important (6 of 14). Furthermore, in 9 of the 14 studies the randomization method and concealment were not described adequately. Because participants in Web-based research are not representative of the whole patient population (in this case through a selection process of only Internet users), the external validity of all studies was rated poor.

Effectiveness of Web-based Interventions (Web-based Interventions versus Usual Care)

Empowerment

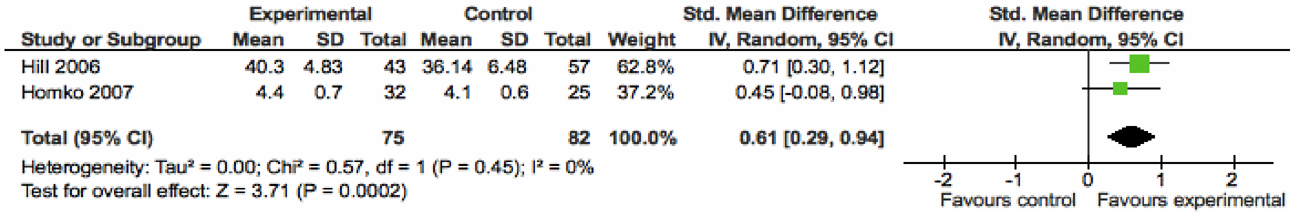
Empowerment was measured in 2 studies with the Diabetes Empowerment Scale (DES). Homko et al [55] examined the effectiveness of an Internet-based telemedicine system that was aimed at self-management of underserved women with diabetes mellitus. Empowerment was assessed at baseline and at 37 weeks of gestation. The control group received paper logbooks, which served as a sham intervention, and in which women could monitor their blood glucose levels. In the study of Hill et al [53], the influence of an online intervention containing self-help support groups and Web-based educational tools on empowerment was examined among chronically ill women.

Because the study of Hill et al included only the 10-item "Setting and Achieving Goals" subscale from the DES, our comparison of the two studies was based on the results of this subscale alone.

Based on the GRADE approach, we downgraded the level of evidence two levels, that is, from high to low, on basis of the studies' limitations and imprecision of the results (Table 2).

Therefore, based on 2 RCTs (combined n = 157) our results, shown in Figure 2, indicate low quality evidence that Web-based interventions had a significant positive effect on empowerment measured with the DES scale. Figure 2 shows that the SMD for these studies was 0.61 (95% CI 0.29 - 0.94). In Figure 2, the green squares indicate the individual study's effect sizes, and the black diamond represents the pooled effect of the combined studies.

Figure 2. Comparison of Web-based interventions versus usual care for the outcome empowerment



Self-efficacy, Disease-specific

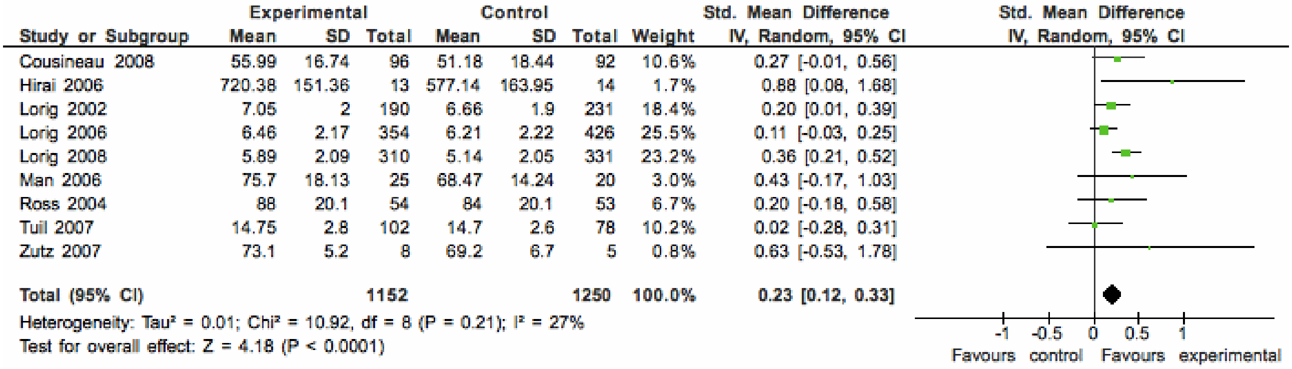
Of the 14 included studies, 9 studies provided sufficient data for calculation of an SMD for disease-specific self-efficacy outcomes. Cousineau et al [51] examined the effects of an online psycho-educational support program for infertile women. In this trial, where 190 females were recruited from US fertility centers, a trend was observed for improvement of self-efficacy levels among the women exposed to the online program compared with the controls (*P* = .07). Hirai et al [54] found that use of an Internet-based self-change program for traumatic event-related fear, distress, and maladaptive coping increased self-efficacy significantly (*P* < .01). In three large and relatively high quality studies (the average Downs and Black score was 21) by Lorig et al [56-58], disease-specific self-efficacy was significantly increased after use of online interventions compared with usual care. These studies contained interventions that dealt with management of heart-lung disease and type 2 diabetes (*P* = .06) [57], arthritis or fibromyalgia (*P* = .01) [58], and back pain (*P* = .02) [56]. Although the duration of the interventions used in these studies was approximately 6 weeks, improvements in self-efficacy remained even after 1 year of follow-up. In a study by Man et al [45], in which people with acquired brain injury (ABI) were able to follow a tele-analogy-based problem-solving program, it was found that after 8 weeks, self-efficacy levels increased more among patients using the program compared with the controls, but this effect was not significant. Ross et al [60] found a trend in improvement of self-efficacy in patients with congestive heart failure who used a Web-based online medical record and educational guide, compared with patients who received usual care (*P* = .08). In a study of Tuil et al [61], patients who had to undergo in vitro fertilization (IVF) were empowered by an interactive website that contained health information, a medical record, and communication possibilities with fellow patients and a physician. No pre/post test differences in IVF-specific self-efficacy were found between the intervention and control group in this study. Finally, a pilot study conducted by Zutz et al [62] found a higher level of exercise-specific self-efficacy after use of an interactive website that was aimed at cardiac rehabilitation. Compared with changes in the control group, this intervention effect was not significant.

According to GRADE guidelines, we downgraded the level of evidence for this outcome by one level from high to moderate based on studies' limitations (see Table 2).

Visual inspection of the funnel plot on this outcome indicated a possibility of publication bias. Figure 4 shows that small studies, as indicated by the high standard errors [SE] (y-axis), with relatively high effect sizes, as indicated by high SMDs (x-axis), were more present in this analysis than small studies with small positive or negative effects. A possible reason for this is that small and effective (pilot) studies are more likely to be published [45,54,62]. We did not, however, downgrade the quality of evidence on basis of the funnel plot because removing these small studies from the analysis did not result in a change of the pooled estimate.

Therefore, there was moderate quality evidence from 9 studies (combined n = 2402) that Web-based interventions had a significant positive effect on self-efficacy measured with disease-specific self-efficacy scales. Figure 3 shows that the SMD of these 9 studies was 0.23 (95% CI 0.12 - 0.33).

Figure 3. Comparison of Web-based versus usual care for the outcome disease-specific self-efficacy

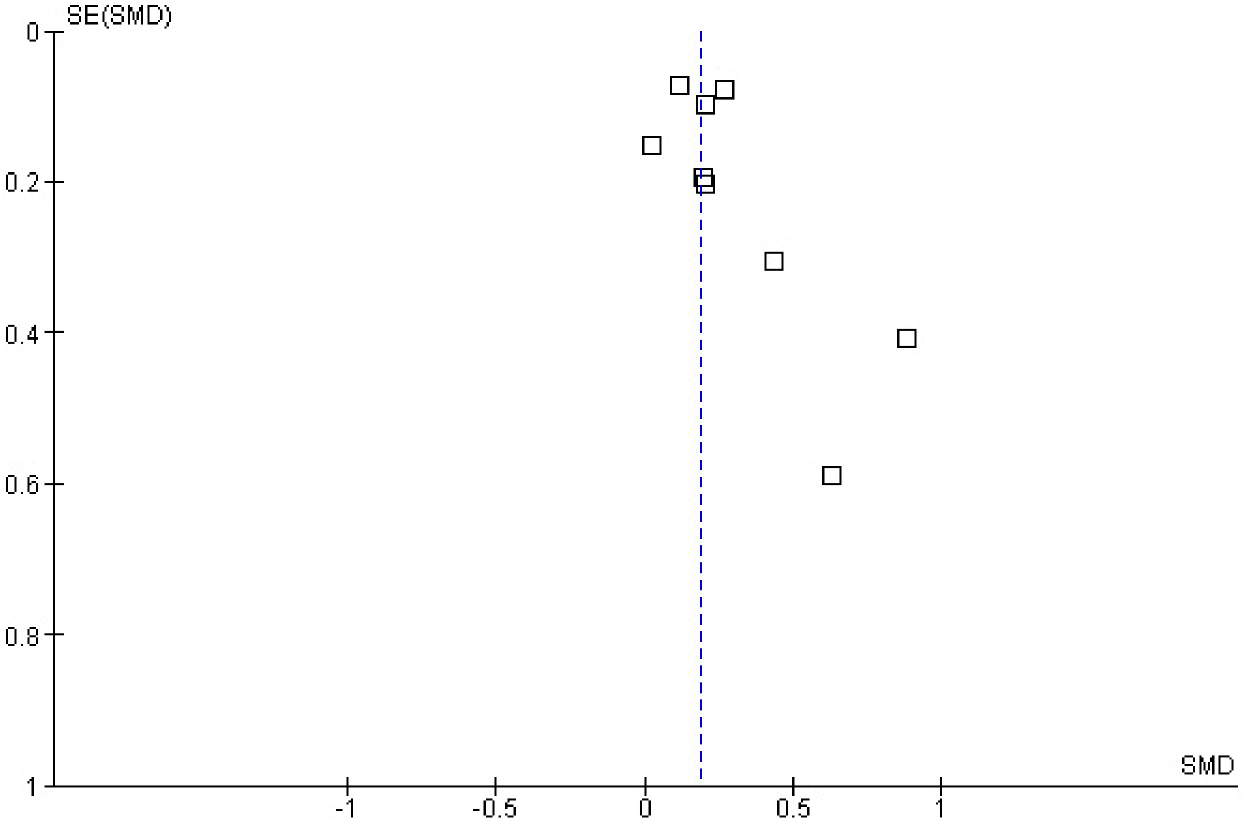


Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Cousineau 2008	55.99	16.74	96	51.18	18.44	92	10.6%	0.27 [-0.01, 0.56]
Hirai 2006	720.38	151.36	13	577.14	163.95	14	1.7%	0.88 [0.08, 1.68]
Lorig 2002	7.05	2	190	6.66	1.9	231	18.4%	0.20 [0.01, 0.39]
Lorig 2006	6.46	2.17	354	6.21	2.22	426	25.5%	0.11 [-0.03, 0.25]
Lorig 2008	5.89	2.09	310	5.14	2.05	331	23.2%	0.36 [0.21, 0.52]
Man 2006	75.7	18.13	25	68.47	14.24	20	3.0%	0.43 [-0.17, 1.03]
Ross 2004	88	20.1	54	84	20.1	53	6.7%	0.20 [-0.18, 0.58]
Tuil 2007	14.75	2.8	102	14.7	2.6	78	10.2%	0.02 [-0.28, 0.31]
Zutz 2007	73.1	5.2	8	69.2	6.7	5	0.8%	0.63 [-0.53, 1.78]
Total (95% CI)			**1152**			**1250**	**100.0%**	**0.23 [0.12, 0.33]**

Heterogeneity: Tau² = 0.01; Chi² = 10.92, df = 8 (P = 0.21); I² = 27%

Test for overall effect: Z = 4.18 (P < 0.0001)

Figure 4. Funnel plot for comparison of Web-based interventions versus usual care for the outcome disease-specific self-efficacy



Self-efficacy, General

In three studies, general self-efficacy was measured using general self-efficacy (GSE) scales [64,65]. In the study of Hill et al [53], no significant effect from the computer-based intervention was found on general self-efficacy. Likewise, in the studies of Tuil et al [61] and Zutz et al [62], the Web-based interventions did not have a significant impact on general self-efficacy levels.

We downgraded the level of evidence by two levels, from high to low, based on limitations in the studies and on basis of imprecision of the results (see Table 2).

Therefore, based on the GRADE approach, there was low quality evidence from 3 studies (combined n = 293) that there was no statistically significant difference between Web-based interventions and usual care in increasing general self-efficacy. The SMD of these 3 studies was 0.05 (95% CI -0.25 to 0.35). (See Figure 5).

Figure 5. Comparison of Web-based versus usual care for the outcome general self-efficacy

Mastery

One study used the Pearlin Mastery Scale [66] to measure the construct mastery, an outcome that is often linked to empowerment. In this RCT by Warmerdam et al [50], two independent Web-based interventions were tested as to their effectiveness to treat adults with depressive symptoms. The first intervention, which lasted 5 weeks, was a problem-solving treatment (PST) based on the idea that by solving people's practical problems their depressive symptoms will improve. The second intervention, which lasted 12 weeks, was a cognitive behavioral therapy (CBT), aimed at changing people's cognitive patterns to decrease symptoms of depression. Pre- and post treatment mastery levels between the intervention groups and a control group on a waiting list were compared. Both interventions were found to have had a significant effect on mastery, when compared with the control group. In our analysis, we combined the effects of the two interventions and compared them to the studies' control group. At 12 weeks follow-up, average mastery levels for both interventions combined was 22.32 (SD 4.17), while the waiting list control group scored 19.37 (SD 3.75). The difference between the control group and the Web-based interventions was significant.

The mean difference [MD] was 2.95 (95% CI 1.66 - 4.24).

Because there was only one study available, according to GRADE there was low quality evidence (one study, n = 263) that Web-based interventions had a significant positive effect on mastery measured with the Pearlin Mastery scale.

Self-esteem

Only one study included a measurement of the construct self-esteem, measured with the Rosenberg Self-esteem (RSE) Scale [67]. In the study of Hill et al [53] no significant effects were found for the intervention on self-esteem. The MD was -0.38 (95% CI -2.45 to 1.69).

For this one study (n = 120), based on the GRADE approach, there was low quality evidence that there was no statistically significant difference between Web-based interventions and usual care in increasing self-esteem.

Summarized in Table 2 are the results of the GRADE approach to judging the quality of the evidence of the studies included in this review. Since all included studies were randomized trials, we started with a high quality of evidence and downgraded, if necessary, on basis of the 5 GRADE domains.

To be able to make clinical interpretations of the reported SMDs described above, we reexpressed the pooled SMDs into MDs, by using the technique of back-translation to a familiar instrument. This technique has been described in more detail elsewhere [43]. Table 3 shows the absolute effects (MDs) on the outcomes for which SMDs were calculated, by using back-translation.

Table 2. Overall judgment of quality of evidence using the GRADE approach

Outcome Measure	N of Studies	Limitations	Inconsistency	Indirectness	Imprecision	Quality of Evidence
Empowerment	2	Serious[a,b,c]	No serious inconsistency	No serious indirectness	Serious[d]	Low[e]
Self-efficacy (specific)	9	Serious[a,b,c]	No serious inconsistency	No serious indirectness	No serious imprecision	Moderate[f]
Self-efficacy (general)	3	Serious[a,b,c]	No serious inconsistency	No serious indirectness	Serious[d]	Low[e]
Mastery	1	-	-	-	-	Low[g]
Self-esteem	1	-	-	-	-	Low[g]

[a] Possibility of a lack of allocation concealment

[b] Lack of blinding

[c] The majority of the studies did not apply intention-to-treat analyses

[d] Pooled effect size upper/lower confidence limit crosses 0.5

[e] Not enough studies available for a funnel plot

[f] Publication bias is likely, but it does not affect the pooled estimate

[g] Low quality of evidence on basis of only 1 study available

Table 3. Back-translation of SMDs into MDs by using a familiar instrument

Outcome Measure	N of Patients	Mean Follow-up Period	Relative Effect	Chosen Instrument for Back-calculation (Range)	Absolute Effect
Empowerment	157	12 weeks	SMD = 0.61 (95% CI 0.29 - 0.94)	DES [63] (1-5)	MD 0.31 (95% CI 0.15 - 0.47)
Self-efficacy (specific)	2402	23 weeks	SMD = 0.23 (95% CI 0.12 - 0.33)	Self-efficacy Scale, as used by Lorig et al [57] (1-10)	MD 0.42 (95% CI 0.22 - 0.6)
Self-efficacy (general)	293	13 weeks	SMD = 0.05 (95% CI -0.25 to 0.35)	General Self-efficacy Scale Schwarzer [64] (1-5)	MD 0.02 (95% CI -0.1 to 0.14)

Web-based Interventions Versus Face-to-face Interventions

Mastery

Nguyen et al [59] compared an Internet-based dyspnea self-management program for chronic obstructive pulmonary disease (COPD) patients with a face-to-face delivery of the same intervention. In this pilot study, 39 COPD patients were randomized into either one of the two intervention groups. At baseline and after a six-month follow-up period, mastery was measured. Results from this study indicated a slight but not significant advantage for the Internet-based delivery compared with the face-to-face intervention (MD = 1.20, 95% CI -1.73 - 4.13).

Because we found only one study (n = 50) in this category, there is low quality evidence that there is no statistically significant difference between Web-based interventions and face-to-face interventions in increasing mastery.

Self-esteem

Gollings et al [52] compared an Internet and face-to-face delivery of a group body image and disordered eating intervention for women. In this 8-week program, participants were able to communicate either online or face-to-face with a therapist that moderated 8 step-by-step group sessions aimed at self-evaluation, managing social pressures and problem solving around weight, and shape and eating issues, for example. Before the intervention and at 8 weeks after the intervention, self-esteem was measured with the RSE in both groups. Although self-esteem improved after both interventions, no significant differences were found between the online and face-to-face delivery (MD = -0.10, 95% CI -0.45 to 0.25).

Again, because we found only one study (n = 39) in this category, there is low quality evidence that there is no statistically significant difference between Web-based interventions and face-to-face interventions in increasing self-esteem (MD = -0.10, 95% CI -0.45 to 0.25).

Discussion

The Internet revolution and growing need for patient empowerment initiatives has resulted in many Web-based empowerment interventions that have been scientifically evaluated. With this systematic review we intended to gain more insight into the effectiveness of these interventions on empowerment or empowerment-related outcomes.

Main Findings

In this systematic review, 13 RCTs and 1 quasi-RCT were included. The included studies were clinically heterogeneous regarding included patients, duration and intensity of the intervention, duration of follow-up, and measured outcomes. Statistical pooling was considered to be appropriate in studies measuring the same outcome and comparing the same treatments (either Web-based vs usual care or Web-based vs face-to-face). This resulted in seven comparisons. Statistical pooling within these comparisons showed that Web-based interventions have a significant positive effect on empowerment measured with the DES (2 studies), self-efficacy measured with disease-specific self-efficacy instruments (9 studies), and mastery measured with the Pearlin Mastery Scale (1 study). No significant effects of Web-based interventions were found on self-efficacy measured with general self-efficacy scales (3 studies) and self-esteem measured with the Rosenberg self-esteem scale (1 study). When comparing Web-based interventions with face-to-face deliveries of the same interventions, no statistically significant effect was found in favor of either one of the two deliveries, when the outcome mastery (1 study) or self-esteem (1 study) was measured. Based on the GRADE approach, we found that the evidence for most of the findings described above is of low quality. This means that high quality future research is likely to have an effect on our confidence in the estimate of the effect. The main reason for the low quality of evidence was that many comparisons contained only one study. In the comparisons with more studies available, limitations in study design (lack of blinding, allocation of treatment, not taking into account loss to follow-up) and imprecision of the results, resulted in downgrading the level of evidence.

Methodological Issues

Although the results of this systematic review indicated that there is some evidence that Web-based interventions are effective in increasing certain empowerment or empowerment-related outcomes, the level of evidence for these effects is rather low, and the results should be interpreted with caution. The basis for the low evidence lies in several methodological issues. First, almost all included studies based their main conclusions on analysis of treatment rather than intention to treat. In this case, results are exposed to a high risk of bias, because characteristics from participants who comply with the treatment may differ from non-participants. This is especially the case in Web-based interventions, where it is known that selection bias is evident, that is, familiarity with the use of computers and the Internet leads to self selection in the use of these technologies [68]. Results of the studies included in this review may thus overrate the effect of the interventions on the patient population as a whole. Moreover, compliance in Web-based research is often found to be low [69], and therefore it seems that Web-based interventions are not suitable for everyone. The issue of low compliance also increases the risk of bias. Other issues that also increase the risk of bias in the studies we found and that should be taken into account involve not adequately describing the randomization method and the lack of patient blinding.

Another concern is the likelihood of publication bias. In the comparison where disease-specific self-efficacy was the outcome, a funnel plot showed some evidence of bias due to publication of smaller and more effective studies or pilot studies [45,54,62]. In the other comparisons and for outcomes represented by only one RCT, many relatively small studies were found, and the choice to publish these studies may have been based on their effectiveness.

Despite these limitations, our meta-analysis included only RCTs or quasi RCTs, which gives our findings a greater robustness than would have been possible if other study designs had been included. Furthermore, by applying the GRADE approach to determine the level of evidence of the effect of an intervention on a set of relevant outcomes, we were able to draw balanced conclusions and give transparency on the basis of how this level of evidence was determined.

A final point involving the methodology of this review is our choice to statistically pool the results of some of the included studies. Even though pooling included studies that measured the same outcome, these studies were clinically heterogeneous with regard to types of patients, duration and intensity of intervention, and duration of follow-up measurements. It has been argued that in the face of this diversity one should not attempt to perform a meta-analysis [70]. We, however, tried to obviate the clinical heterogeneity by pooling studies that measured the same outcome and by choosing a more conservative random-effects model in our meta-analyses. Also, we think that the general question asked by this review, that is, whether Web-based interventions are effective in increasing patient empowerment, could only be answered by including a broad spectrum of studies where Web-based interventions have been used to date for this purpose. As a result of this choice, caution is advised when interpreting this review in that the results may only apply to specific disease or to specific time frames (eg, short-term vs long-term effects).

Other Issues

Self-efficacy

Statistically significant effectiveness of Web-based interventions on disease-specific self-efficacy was found. On the other hand, no effects were found for general self-efficacy. Because general self-efficacy refers to a broad and stable sense of personal competence, it is possible that Web-based interventions aimed at a specific target patient population are too specific to influence a stable personal characteristic (ie, a trait). Therefore, it has been recommended that for the majority of applications, perceived self-efficacy should be conceptualized in a situation-specific manner [71]. In line with this recommendation, a systematic review of Murray et al [72] found that among children suffering from a chronic disease, self-efficacy was more likely to improve after use of Interactive Health Applications compared with no intervention (SMD = 0.24, 95% CI 0.00 - 0.48).

Sustainability of the Effects

From the results of this review, little is known about the sustainability of the effects. In most cases we included data that was measured directly after participants were exposed to the intervention. The effects that are reported, therefore, reflect a direct effect of the intervention. On the other hand, in the studies of Lorig et al [56-58], which measured disease-specific self-efficacy, data was presented only at 6-month or 12-month follow-ups, while the intervention in these studies lasted 6 weeks. Because of the high number of participants included in these studies (total weight in the comparison is 67.1%) there are some signs that the effects of these interventions remain after a longer period of time.

Clinical Relevance

We calculated SMDs in this review. This means that the effect sizes presented do not represent certain improvements on specific instruments. To be able to say something about the magnitude of the effect sizes we found, we used back translations of SMDs to a familiar instrument. The results of these back calculations are shown in Table 3. We should, however, realize that these transformations from SMDs to MDs are somewhat arbitrary and should be interpreted with caution. Nevertheless, we found that the statistically significant improvements in empowerment and empowerment-related outcomes were rather small effects: empowerment measured with the DES increased 6.2% after use of the Web-based interventions and self-efficacy measured with disease-specific self-efficacy scales improved 4.2% compared with usual or no care. What the direct or indirect impacts (on clinical outcomes, for example) of these improvements are remains unknown.

Conclusions

Implications for Clinicians

Based on this review, there is some evidence that the Internet can be an effective method to increase patient empowerment. The results from this review show that Web-based interventions can be effective in increasing empowerment among patients who are, for example, suffering from diabetes, depression, infertility, or arthritis. These findings are in line with the growing literature on the effectiveness of eHealth interventions in general, and on outcomes other than patient empowerment [68,72,73]. Clinicians who are interested in empowering their patients are encouraged to refer their patients to Internet empowerment websites, if available and appealing to the patient.

Implications for Research

The outcome empowerment usually refers to achieving self-efficacy, mastery, and control. Although many researchers underline that these constructs are closely related to the concept empowerment [33], still much is unclear about how empowerment is defined and how it should be measured. For example, recent work from Aujoulat et al [74] added that empowerment also includes a process of accepting relinquishment of control instead of solely gaining control. Either way, much work lies ahead for researchers in defining and conceptualizing the term empowerment. This will enable combining more unambiguous research outcomes and lead to better insight into the conditions under which, and the individuals for whom, Web-based interventions are effective and how effectiveness can be maximized. Furthermore, future Web-based RCTs aimed at patient empowerment should be conducted on large populations, include the intention-to-treat principle in their analysis [69] and, if applicable, use “sham” website interventions to blind participants from treatment in order to increase the quality of evidence in this field of research. In this perspective, to minimize the risk of bias, researchers are encouraged to consult quality assessment lists (such as the Downs and Black list used in this review) prior to conducting a trial.

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Conflicts of Interest

None declared

Authors' Contributions

DS and DB contributed to protocol design, selection of studies, data extraction, statistical analysis, and data interpretation. NE contributed to the selection of studies and data extraction. DS wrote the manuscript, which was commented on by DB, NE, HA, and AB. All authors have seen and approved the final version of this paper.

Multimedia Appendix 1

Medline search strategy

[PDF file (Adobe PDF File), 53 KB - jmir_v12i2e23_app1.pdf]

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Abbreviations

ABI: acquired brain injury
CBT: cognitive behavioral therapy
COPD: chronic obstructive pulmonary disease
CRQ: Chronic Respiratory Questionnaire
DES: Diabetes Empowerment Scale
GSE: General Self-Efficacy Scale
ICSI: intracytoplasmic sperm injection
IVF: in vitro fertilization
MD: mean difference
PST: problem-solving treatment
QAS: quality assessment scale
RCT: randomized controlled trial
RSE: Rosenberg Self-esteem Scale
SMD: standardized mean difference
WTW: Women-to-Women
WHO: World Health Organization

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Review

Clinical Effects of Home Telemonitoring in the Context of Diabetes, Asthma, Heart Failure and Hypertension: A Systematic Review

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Abstract

Background: Home telemonitoring figures among the various solutions that could help attenuate some of the problems associated with aging populations, rates of chronic illness, and shortages of health professionals.

Objective: The primary aim of this study was to further our understanding of the clinical effects associated with home telemonitoring programs in the context of chronic diseases.

Methods: We conducted a systematic review which covered studies published between January 1966 and December 2008. MEDLINE, The Cochrane Library, and the INAHTA (International Network of Agencies for Health Technology Assessment) database were consulted. Our inclusion criteria consisted of: (1) English language publications in peer-reviewed journals or conference proceedings and (2) studies involving patients with diabetes, asthma, heart failure, or hypertension, and presenting results on the clinical effects of home telemonitoring.

Results: In all, 62 empirical studies were analyzed. The results from studies involving patients with diabetes indicated a trend toward patients with home telemonitoring achieving better glycemic control. In most trials in which patients with asthma were enrolled, results showed significant improvements in patients' peak expiratory flows, significant reductions in the symptoms associated with this illness, and improvements in perceived quality of life. Virtually all studies involving patients with hypertension demonstrated the ability of home telemonitoring to reduce systolic and/or diastolic blood pressure. Lastly, due to the equivocal nature of current findings of home telemonitoring involving patients with heart failure, larger trials are still needed to confirm the clinical effects of this technology for these patients.

Conclusions: Although home telemonitoring appears to be a promising approach to patient management, designers of future studies should consider ways to make this technology more effective as well as controlling possible mediating variables.

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KEYWORDS

Home telemonitoring; information technology; chronic illnesses; clinical effects

Introduction

The health systems of many countries are facing serious challenges concerning current and expected demographic trends that may far exceed their financial resources. The United Nations has reported that the world's population will continue to age, reaching 9 billion by 2050, and in the developed countries, the number of people over 60 years of age is expected to almost double, from 245 million in 2005 to 406 million in 2050 [1]. Closely tied to this phenomenon of aging populations are rising rates of chronic illnesses such as heart failure, hypertension, chronic respiratory diseases, and diabetes, some of the factors that are driving the need to review how care is organized and the need to propose new interventions [2]. It is generally recognized that the chronically ill use medical, hospital, and emergency services more often. For instance, the Health Council of Canada has estimated that chronic illnesses are associated with 70% of Canadian hospital stays [3]. Furthermore, a shortage of health professionals has become a problem around the world, which also imposes certain constraints in almost all countries, rich and poor alike. According to World Health Organization estimates, 57 countries are experiencing acute shortages of health professionals [4]. The phenomenon of fewer health professionals suggests that services need to be restricted and priorities need to be set.

Information and communication technologies figure among the solutions that could help attenuate some of the problems associated with aging populations, rates of chronic illness, and shortages of health professionals, and, at the same time, facilitate service reorganization [5]. Greater use of telemedicine, for example, could make it easier to serve remote populations and lessen the impact of the lack of health professionals [6].

Home telemonitoring, the focus of this study, is an application of telemedicine in which physiological and biological data are transferred from the patients' home to the telemonitoring center to monitor patients, interpret the data, and make clinical decisions [7]. Home telemonitoring is a relatively recent approach with growing numbers of applications, not only in many industrialized countries, but also in some developing countries [8]. The underlying goal is to organize this "telecare" approach according to case and care management principles and to substitute home telemonitoring for the integrated and continuous monitoring classically used to monitor patients during an episode of care. In many health care systems around the world, home telemonitoring is an integral part of a broader view of deinstitutionalization and reflects a societal orientation toward maintaining patients in their homes [9].

Paré et al [8] conducted a systematic review of the magnitude of several outcomes associated with home telemonitoring of patients with diabetes, pulmonary conditions (asthma, chronic obstructive pulmonary disease [COPD], and pulmonary transplantation), hypertension, and heart failure. That review provided evidence that confirmed the reliability and accuracy associated with home telemonitoring as an approach to patient management among patients with these diseases. In general, very few errors and technical problems were faced in the projects considered in the review. The earlier systematic review also presented consistent findings related to the effects of home telemonitoring on patients' attitudes and behaviors. It appeared that most patients complied with telemonitoring programs because this approach allowed them to actively participate in the process of care, improved their feelings of security, and led to their empowerment. Of utmost importance, the authors reported some evidence of the positive effects of home telemonitoring on the patients' conditions, especially in the cases of pulmonary conditions and heart failure. Given the importance of improving the medical condition of patients and their well-being with any approach to care, the authors recommended that the goal of future research be to evaluate the clinical effects of home telemonitoring.

In this regard, the primary objective of the present study was to update the systematic review conducted by Paré et al [8] and, most importantly, provide a deeper analysis of the clinical effects associated with home telemonitoring programs. We decided to focus on four chronic conditions: diabetes, asthma, heart failure, and hypertension, given the availability of empirical evidence on these illnesses. The second objective was to identify and discuss the main conditions for success when implementing home telemonitoring programs.

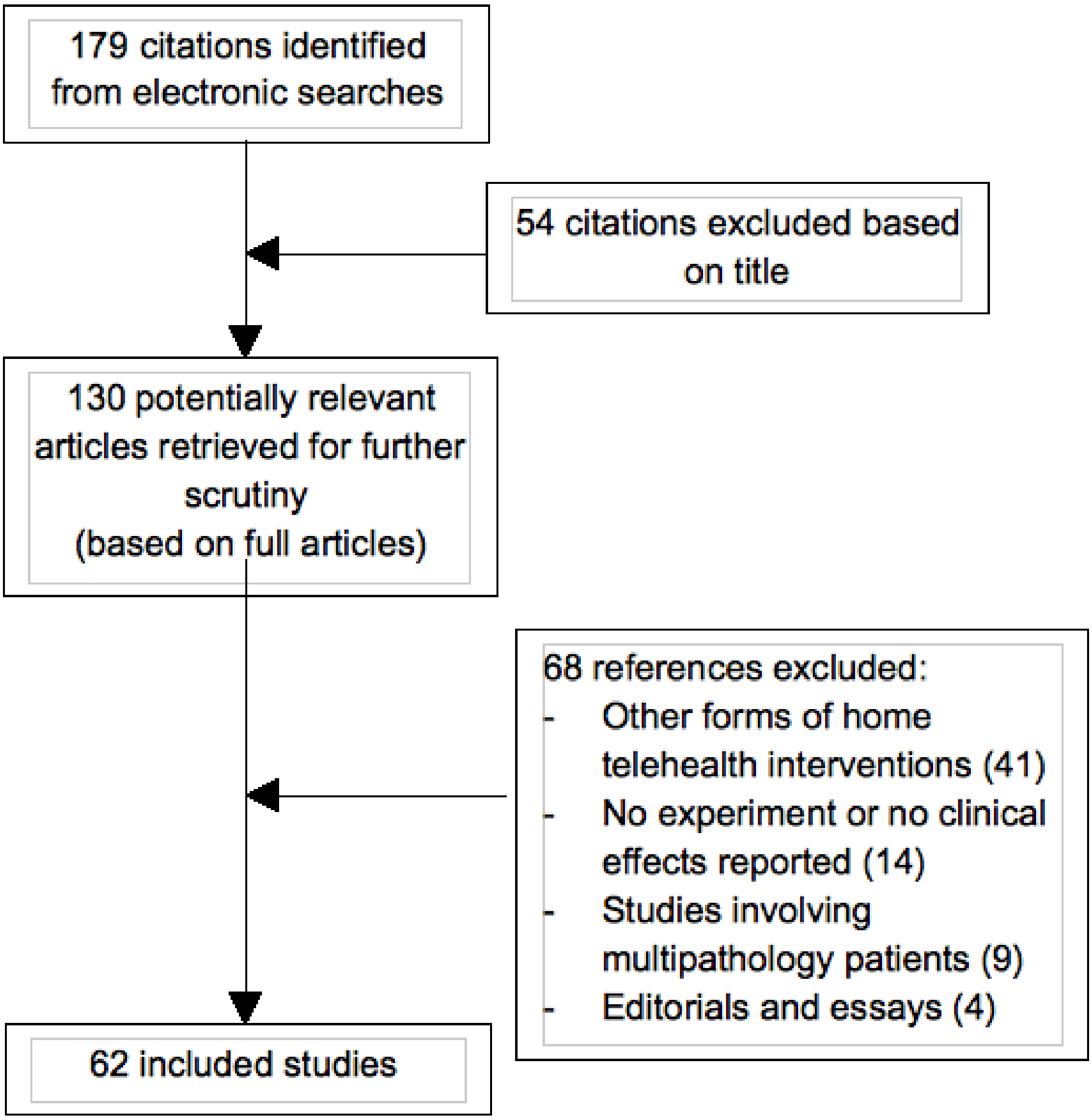
Methods

Our systematic review, which followed the PRISMA guidelines [10], covered studies published from January 1966 through December 2008. The following three databases were consulted: MEDLINE (PubMed interface), The Cochrane Library, and the International Network of Agencies for Health Technology Assessment (INAHTA) database. For the purpose of this study, the inclusion criteria consisted of: (1) English language publications in peer-reviewed journals or conference proceedings, and (2) studies that presented results in terms of clinical effects and involved patients with diabetes, asthma, heart failure, or hypertension.

We conducted the search using four keywords (home telemonitoring, home telecare, telehealth, and telehomecare) in conjunction with each of the following terms: diabetes, asthma, heart failure, and hypertension. The original search resulted in 179 articles after eliminating duplicate studies, systematic reviews, and meta-analyses. From these, 54 articles were deemed not relevant based on title. The remaining 130 articles were reviewed by 2 of the investigators to determine whether they were appropriate for inclusion. In this process, the reviewers relied on the following exclusion criteria: (1) other forms of home telehealth interventions (eg, studies that involved downloading of data during clinic visits or at the end of the study period, studies that included regular telephone calls by care providers, and studies that only considered teleconsultation delivered via video visits); (2) studies that did not involve home telemonitoring experiments and, for instance, focused on a detailed description of the technology deployed; (3) studies examining multipathology groups of patients; and (4) editorials or general essays. Of the 130 articles, 68 were excluded based on these criteria (Multimedia Appendix 1 lists the excluded studies). As a result, the final number of articles included in this review was 62. Figure 1 presents the flow diagram detailing the process of study selection and the characteristics and key findings of the included studies are presented in Multimedia Appendix 2. Importantly, using the same search strategy, studies published after the cutoff date (ie, December 31, 2008) were identified and their findings have been taken into account as complementary material and, as such, are described only in the Discussion section.

To meet our main objective, the first author developed a coding scheme for the articles. The completeness and reliability of the coding table was tested by randomly selecting 8 studies (ie, 13% of the sample) and then having the first 2 authors independently code them. This resulted in a 92% rate of agreement. The differences were reconciled by consensus. Following this pretest, some minor adjustments were made to the coding scheme.

Figure 1. Selection of studies



The studies were analyzed in the following order: those on diabetes (n = 24), asthma (n = 8), heart failure (n = 17), and hypertension (n = 13). The strength of evidence in each study was judged using the classification system drawn by Jovell and Navarro-Rubio [11] in which study design is specified as one of 9 levels in descending order of strength (see Table 1). Each level is further qualified by conditions of scientific rigor for the study. We separated the trials under each chronic disease into three groups and analyzed each group separately. The first group included studies that provided the best evidence, that is, they corresponded to level 2 of the classification system. The second group, corresponding to level 3, included RCTs conducted with small samples (100 or fewer subjects in each arm). Finally, the third group corresponded to levels 4 to 9, representing mainly nonrandomized trials, cohort studies, and descriptive studies.

Table 1. Classification of study design from Jovell and Navarro-Rubio [11]

Level	Type of Study Design
1	Meta-analyses of randomized controlled trials
2	Large-sample randomized controlled trials
3	Small-sample randomized controlled trials
4	Nonrandomized controlled prospective studies
5	Nonrandomized controlled retrospective trials
6	Cohort studies
7	Case-control studies
8	Non-controlled clinical series, descriptive studies, consensus methods
9	Anecdotes or case reports

Results

The data in Table 2 provide a general profile of our sample of 62 studies. The data show that home telemonitoring programs have appeared quite recently. Even though the first study on this subject was published in 1987, most early projects to be described in the literature began to appear in the early 1990s. Studies published between 1991 and 1995 represent 6% of the total sample. The number of published studies then grew in the second half of the decade (1996 to 1999), representing 15% of the sample. The number then increased significantly: more than three quarters of the studies in the sample were published after 2000. The data also show that 45% of the studies were carried out in the United States, approximately a third were conducted in Europe, while 6% were conducted in Asia and in Canada. Finally, almost three quarters of the studies in our sample were RCTs, both small and large.

The following subsections present and illustrate the nature and scope of the clinical effects associated with home telemonitoring programs. As explained above, these effects will be discussed in the specific context of the chronic illnesses included in the present analysis: diabetes, asthma, heart failure, and hypertension. Given the higher level of evidence provided by large RCTs, we highlight these findings in our analysis.

Table 2. Profile of the sample

	Diabetes (n=24)	Asthma (n=8)	Heart Failure (n=17)	Hypertension (n=13)	Full Sample (n=62)
Year of publication					
Prior to 1991	-	-	-	1	1 (2%)
1991-1995	4	-	-	-	4 (6%)
1996-2000	3	1	2	3	9 (15%)
2001-2004	12	4	7	5	28 (45%)
2005-2008	5	3	8	4	20 (32%)
Where the study was conducted					
United States	11	3	8	6	28 (45%)
Europe	10	2	6	3	21 (34%)
Asia	2	1	-	1	4 (6%)
Canada	1	-	2	1	4 (6%)
Elsewhere	-	2	1	2	5 (8%)
Type of publication					
Journal article	24	8	16	13	61 (98%)
Proceeding	-	-	1	-	1 (2%)
Research design					
Large RCT	2	1	5	3	11 (18%)
Small RCT	19	5	8	2	34 (55%)
Nonrandomized study	3	2	4	8	17 (27%)

Diabetes

In the first of two large RCTs in our sample, patients were followed by two general medicine clinics in a single county in California [12]. Veterans with a diagnosis of diabetes mellitus or who had an active prescription for a hypoglycemic agent were identified. Excluded were patients who were more than 75 years of age and patients who had a diagnosed psychotic disorder, a disabling sensory impairment, or a life expectancy of less than 12 months. Patients were randomly assigned to usual care or to receive an intervention that consisted of a series of automated telephone calls designed to identify patients with health and self-care problems and to deliver targeted and tailored self-care education messages. The calls consisted of hierarchically structured messages composed of statements and queries recorded with a human voice. During each assessment, patients were asked to report information about self-monitored blood glucose readings, perceived glycemic control, symptoms of poor glycemic control, foot problems, chest pain, and breathing problems. At the end of each assessment, patients were given the options of listening to a randomly cycling diabetes “health tip” and of participating in an interactive self-care education module focused on diet and weight control. On a weekly basis, the automated system generated reports organized according to the urgency of reported problems, and a nurse used these reports to prioritize patient contacts. During follow-up calls, the nurse not only addressed problems reported during the assessments but also provided more general self-care education. Patients assigned to the usual care control group had no systematic monitoring between clinic visits and received no reminders of upcoming clinic appointments.

Clinical effects were collected at 12 months for 89% of the patients (n = 248). Patients in the intervention group (n = 124) reported better glycemic control (*P* = .01) and fewer diabetic symptoms (*P* < .001) at follow-up than patients in a control group that received usual care. While telemonitored patients had minimally lower HbA1c levels (0.3%, *P* = .1) at follow-up than patients in the control group, the proportion of patients with normal HbA1c levels in the intervention group increased by 9% (17% vs 8%, *P* = .04), while serum glucose levels among these patients decreased by 41 mg/dL compared with baseline (180 vs 221 mg/dL, *P* = .005). Based on these findings, Piette et al [12] concluded that automated calls represented an effective strategy for improving glycemic control and for controlling symptoms among vulnerable patients with diabetes.

In the second large RCT, Shea et al [13] conducted a study comparing home telemonitoring with usual care in 1665 Medicare recipients with diabetes aged 55 years or over and living in federally designated, medically underserved areas of New York State. Excluded were patients with moderate or severe cognitive, visual, or physical impairments or who had severe comorbid disease. Participants randomized to the intervention group (n = 844) received a home telemedicine unit (HTU). The HTU consisted of a Web-enabled computer with a modem connection to an existing telephone line. The HTU provided four major functions: (1) videoconferencing over plain old telephone service (POTS) connections, allowing patients to interact with nurse case managers; (2) remote monitoring of glucose and blood pressure; (3) dial-up Internet service provider access and secure Web-based messaging with nurse case managers; and (4) access to an educational website created for the project by the American Diabetes Association. Patients in the usual care group (n = 821) remained under the care of their primary care providers.

In the intervention group, the study found that, within one year, mean HbA1c had improved from 7.35% to 6.97%. In a subgroup with baseline HbA1c greater than or equal to 7%, HbA1c improved from 8.35% to 7.42% (n = 353). In the usual care group, within one year mean HbA1c had improved from 7.42% to 7.17%. Adjusted net reductions favoring the intervention were as follows: HbA1c, 0.18% (*P* = .01); systolic and diastolic blood pressure, 3.4 mmHg (*P* = .001) and 1.9 mmHg (*P* < .001); and LDL cholesterol, 9.5 mg/dL (*P* <. 001). Based on these results, the telehomecare program improved patients’ glycemic control, blood pressure levels, and total and LDL cholesterol levels after one year of follow-up.

A total of 19 small RCTs examined the effects of home telemonitoring programs on patient outcomes. As indicated in Multimedia Appendix 2, a significant decrease in HbA1c was observed in 10 of these studies for patients in the home telemonitoring groups [14-23]. For instance, Welch et al [20] reported that the mean HbA1c change score for the intervention group (n = 26) was statistically significant at 6 months (*P* = .001) and at 12 months (*P* <. 001), while the usual-care group (n = 26) showed small improvements that were not significant at either 6 or 12 months. These results indicated that the intervention, which focused on blood glucose control and insulin adjustment, was clinically useful in reducing HbA1c. As another example, Lavery et al [17] reported a significant decline in the number of diabetic foot complications in a group using hand-held infrared skin thermometers (*P* =. 01).

These findings were not consistent, however, with the results reported in 9 small RCTs that found that electronic transmission of blood glucose levels was equally as effective as standard or conventional outpatient management [24-32]. For instance, Chase et al [24] did not find significant differences in diabetes complications (eg, hypoglycemia) in their sample of adolescent diabetic patients. They observed that electronic transmission of blood glucose levels and other diabetic data every 2 weeks—in lieu of a clinic visit—resulted in a similar level of glucose control and incidence of acute diabetes complications when compared with current standard care. As another example, Ladyzynski and Wojcicki [32] observed less variability in glycemic control among the patients in the home telecare group. This indicated that the home telecare system helped patients to better comply with their physician’s recommendations to maintain glycemic control. Nevertheless, the mean level of metabolic control and the insulin dose adjustment patterns were very similar in both groups, regardless of a much higher reporting frequency of blood glucose levels in the intervention group.

Finally, three nonrandomized studies [33-35] also reported better glycemic control with home telemonitoring.

Asthma

The data in Table 2 show that our sample included 8 studies associated with asthma, including one large RCT. The RCT was conducted by Rasmussen et al [36] with a sample of 300 Danish adults randomized to three groups: (1)home telemonitoring by Internet (the intervention group), (2)monitoring by a specialist, and (3)monitoring by a general practitioner. After 6 months, the authors found that fewer asthma symptoms were reported by patients in the intervention group than in either the group monitored by specialists (*P* = .002) or the group monitored by a general practitioner (*P* = .001). The intervention group also reported better quality of life compared with the groups monitored by the specialists and the general practitioners (*P* = .03 and *P*= .04, respectively) as well as better pulmonary function (*P* = .002 and *P* = 001, respectively). In summary, this large RCT suggested that a patient's asthma was better controlled when physicians and patients used an interactive tool to monitor asthma over the Internet.

The positive results reported above were confirmed in 4 of the 5 small RCTs that included asthmatic patients [37-40]. For instance, Jan et al [37] assessed the effectiveness of an Internet-based interactive asthma educational and monitoring program. At the end of this 3-month trial, compared with conventional asthma management (n = 76), the Internet group (n = 88) had fewer nighttime symptoms (*P* = .03) and daytime symptoms (*P* = .01); improved peak expiratory flow (PEF) in the morning (*P* =. 02) and at night (*P* = .01); and improved quality of life (*P* = .05). In another example, Guendelman et al [38] observed that the odds of having any limitation in activity during the 90-day trial were significantly lower (*P* = .03) for children randomized to an Internet group (n = 66) than among children in a control group (n = 68). The intervention group was significantly less likely to experience PEF readings that indicated a severe asthma exacerbation or that indicated the child's asthma was not under sufficient control and required additional medication (*P* = .01). Urgent calls to the hospital were also significantly less likely in the intervention group (*P* = .05).

Only one small RCT did not produce significant results. Indeed, Willems et al [41] found nonsignificant differences between the experimental group (n = 55) and the control group (n = 54) in terms of asthma symptoms and quality of life. According to the authors, there were two main reasons for these findings: infrequent data transmission (once a month) and the low to moderate severity of asthma among participants.

Lastly, positive and significant clinical outcomes associated with home telemonitoring were observed in one small nonrandomized trial [42] and in one cohort study [43].

Heart Failure

Most studies concerned with home telemonitoring of heart failure patients have considered either patient outcomes (eg, mortality rates and quality of life) or quality metrics reflecting efficiency in care delivery (eg, hospital readmission rates, emergency room visits, and length of stay) or both. We will begin by highlighting the findings of large RCTs and then present the main trends found in the small RCTs and nonrandomized studies.

In the first large RCT, 280 patients from 16 heart failure centers across the United States were randomly assigned to the intervention group or to the control group. The 138 participants in the intervention group were provided with a home monitoring system and the 142 participants in the control group received standard care [44]. The home monitoring system included an electronic scale placed in the patient's home and an individualized symptom response system, which was linked via a standard phone line. Patients were instructed to weigh themselves and to answer yes/no questions about heart-related symptoms twice daily. Over the course of the 6-month follow-up period, there were 26 (18.4%) deaths in the control group and 11 (8.0%) deaths in the intervention group, representing a 56.2% difference in mortality rates (*P* < .01). However, no significant difference was found between the two groups in terms of time to death or first readmission to hospital (*P* = .16). Further, patients in both groups experienced improvements between quality of life scores obtained at baseline and at the 6-month follow-up. Although none of the differences were statistically significant, the intervention group tended toward improvements in all the quality of life measures. Finally, no significant differences were observed between the intervention and control groups in terms of time to first emergency department visit, total number of emergency department visits, or total number of cardiovascular hospitalizations.

In a second study, conducted by Benatar et al [45], 216 patients with heart failure were randomized to one of two home health care delivery methods for 3 months after discharge from hospital. Care was delivered either through home nurse visits or a nurse telemanagement method. Patients in the nurse telemanagement group (the intervention group) used telephone-linked home monitoring devices to measure their weight, blood pressure, heart rate, and oxygen saturation level. These data were transferred daily to a secure Internet site. When a patient's physiological data exceeded preestablished limits, an alarm would be automatically transmitted to an alphanumeric pager carried by an advanced practice nurse. The results of the study showed that quality of life as measured by the Minnesota Living with Heart Failure Questionnaire was significantly improved for both groups. However, the researchers observed a trend toward greater improvement in quality of life in the nurse telemanagement group compared with the control group. More specifically, the mean score on the quality of life questionnaire fell from 77.9 to 51.6 (lower scores indicate better quality of life) in the intervention group (*P* < .01) compared with a decrease from 77.2 to 57.7 in the control group (*P* < .01). Importantly, patients in the intervention group had fewer hospital readmissions for heart failure (*P* < .001) and shorter lengths of stay in hospital (*P* < .001) compared with the control group.

Third, Cleland et al [46] sought to identify whether patients allocated to a home telemonitoring group (the intervention group) would provide improved outcomes compared with nurse telephone support (control group 1) and usual care (control group 2) for patients with heart failure who were at high risk of hospitalization or death. Patients with a recent admission for heart failure and a left ventricular ejection fraction less than

40% were assigned randomly to the intervention group, control group 1, or control group 2 in a 2:2:1 ratio. The intervention group (n = 106) used automated devices to send self-measurements of weight, blood pressure, heart rate, and heart rhythm twice daily to a cardiac center. Control group 1 consisted of patients for whom specialist nurses were made available by telephone (n = 110). Control group 2 consisted of patients for whom primary care physicians delivered the usual care (n=55). During 8 months of follow-up, higher mortality was observed among the patients assigned to receive usual care than among the patients assigned to receive nurse telephone services or home telemonitoring (*P* = .03). In terms of service utilization measures, the number of readmissions was similar between patients in control group 1 and the telemonitoring group, but for readmitted patients, the mean length of stay was 6 days less for the group with home telemonitoring compared with mean length of stay for readmitted patients in control group 1 (no *P* value reported).

Fourth, the Heart Failure Home Care trial was a multicenter randomized controlled trial of enhanced versus routine heart failure monitoring in Medicare-eligible patients who were women and/or racial minorities [47]. Inclusion criteria included, but were not limited to, Medicare beneficiaries greater than 65 years of age who had been discharged from hospital with a primary or secondary diagnosis of heart failure within 6 months of randomization. A total of 315 patients were randomly assigned to two groups: 160 patients received a home monitoring system and the control group consisted of 155 patients who received standard care. Patients in the intervention group were asked to weigh themselves daily and respond to questions concerning heart failure symptoms. The monitored group transmitted their information to a telemonitoring center. When a patient’s weight exceeded a preestablished limit, a nurse would contact the patient and notify the attending physician. All participants were provided with educational materials and information as to when they should seek medication attention. The compliance rate associated with electronic data transmission of patients’ weights and symptoms of heart failure was very high at 97%. The incidence of the primary outcome, 6-month cardiac mortality, or readmission for heart failure, was not statistically different between the control and intervention groups (*P* = .15). Emergency room visits were common in both groups, and the number of emergency room visits was comparable across groups (*P* = .43). In short, this study was unable to find a benefit from home telemonitoring as compared with the traditional home care model over a 6-month period.

The fifth and last large RCT evaluating the health effects of home telemonitoring of patients with heart failure was conducted by Dansky et al [48] in 10 home care agencies in the same US state. The patient sample consisted of 2 experimental groups and a control group in each of the 10 agencies. The first group allocated to home telemonitoring (experimental group 1) consisted of patients who were each given a terminal to transmit daily their blood pressure, weight, and heart rate to their home care agency. The second home telemonitoring group (experimental group 2) consisted of patients who were given the same type of terminal as the first group in addition to a video camera, which was used 2 or 3 times a week for a remote consultation with a nurse. In all, 284 patients participated in the study as follows: 112 in the control group, 127 in experimental group 1 and 45 in experimental group 2. The outcomes of interest were control of the symptoms associated with heart failure and mortality. Over the 120-day follow-up period, the mortality rate was similar between the control group and experimental group 1 (*P* = .11) and between the control group and experimental group 2 (*P* = .47). However, the reduction in symptoms was more pronounced in the patients in experimental group 1 than in the other two groups, both for symptoms associated with diet (*P* = .04) and those associated with their use of medication (*P* = .001). There was also a tendency for patients in the home telemonitoring groups to have fewer hospitalizations at two points in time, at 60 and 120 days; however, the differences were statistically significant only at 60 days (*P* = .01). Lastly, patients in both home telemonitoring groups had fewer emergency room visits than patients in the control group. At 60 days, approximately 30% of the control group had had an emergency room visit, compared with 24% of experimental group 1 and 18% of experimental group 2 (*P* = .01). The differences were less striking at 120 days, but followed the same pattern.

We found 7 small RCTs and 3 nonrandomized studies in which *P* values were reported [49-58]. We observed that 9 of these studies measured the effects of home telemonitoring on patients’ quality of life or symptoms. All except 2 of these studies [53,56] found an improvement in quality of life or a reduction in symptoms over the course of the intervention in the patients followed by home telemonitoring. The *P* values presented in these studies varied from .002 to .05. However, the two studies in which mortality was the outcome of interest were unable to demonstrate a statistically significant difference in favor of the home telemonitoring group [52-53]. A small RCT [59] and a nonrandomized study [60] did not report *P* values.

In addition to the large RCTs, 3 small RCTs and 2 cohort studies examined the effects of home telemonitoring on health services utilization. All 3 small RCTs [51,52,55] reported no significant differences in the number of readmissions or length of stay between the telemonitoring intervention group and the control group receiving usual care On the other hand, the number of readmissions and the number of days of hospitalizations for chronic heart failure among the participants in both cohort studies [57-58] decreased significantly during the 12-month study period (*P* <. 001).

Hypertension

We found 3 large RCTs that examined populations of patients with hypertension. In the first, Friedman et al [61] evaluated the effects of automated telephone patient monitoring and counselling on patient adherence to antihypertensive medications and on blood pressure control. The randomized trial was conducted in 29 communities in the greater Boston area. The study subjects were 267 patients recruited from community sites who were over 60 years of age, on antihypertensive medication, had a systolic blood pressure (SBP) greater than 160 mmHg and/or a diastolic blood pressure (DBP) greater than 90 mmHg. Patients were excluded if they had a life-threatening illness, did not speak English, did not have a telephone, or were unable to use a telephone. The study compared subjects who received usual medical care (n = 134) with those who used a computer-controlled telephone system in addition to their usual medical care (n = 133) over a period of 6 months. Each week, subjects in the intervention group reported self-measured blood pressures, knowledge of and adherence to antihypertensive medication regimens, and medication side-effects. This information was sent to their physicians. Results indicated that mean antihypertensive medication adherence improved 17.7% in the intervention group and 11.7% in the control group (*P* = .03). Furthermore, mean DBP decreased 5.2 mmHg in the intervention group compared with a mean decrease of 0.8 mmHg in the control group (*P* = .02). Among the intervention group, mean DBP fell more among participants who had improved adherence to their medication regime (*P* = .03).

In the second RCT, Artinian et al [62] tested the hypothesis that individuals who participated in usual care plus blood pressure (BP) telemonitoring (the intervention group) would have a greater reduction in BP from baseline to 12-month follow-up than would individuals who received usual care only (the control group). A two-group, experimental, longitudinal design was used with block-stratified randomization. African Americans with hypertension were recruited through free BP screenings offered in the community. Data were collected at baseline and at 3-, 6-, and 12-month follow-ups. Results indicated that the intervention group (n = 167) had a greater reduction in SBP (13.0 mmHg) than the control group (7.5 mmHg; *P* = .04) from the baseline to the 12-month follow-up. Although the reduction in DBP was greater in the intervention group (6.3 mmHg) compared with the control group (4.1 mmHg), the difference was not statistically significant (*P* = .12).

The third RCT was conducted by Madsen et al [63]. Hypertensive patients recruited by general practitioners participated in the study. Blood pressure of participants in the intervention group (n = 105) was telemonitored from patients' homes. In the control group (n = 118), patients received usual care with office visits to monitor blood pressure. After 6 months, participants filled out the Short-Form-36 Health Survey to assess quality of life. Patients in the telemonitoring group had higher mean scores in the bodily pain domain than patients in the control group, indicating less pain and interference with activities among telemonitored patients (*P* = .03). In both groups, systolic BP decreased significantly from baseline to follow-up. The decrease was -11.9 mmHg in the intervention group and -9.6 mmHg in the control group (mean difference of -2.3, *P* =.23). As a result, the authors concluded that antihypertensive treatment based on telemonitoring of home BP was as effective at reducing BP as usual office BP monitoring.

The two small RCTs in our sample [64-65] confirmed the positive outcomes of home telemonitoring in hypertensive patients. For example, in the study by Rogers et al [63], the intervention group consisting of 60 patients, and the control group consisted of 61 patients. The results indicated that blood pressure fell 2.8 mmHg among the telemonitored patients and rose 1.3 mmHg among usual care patients (*P* = .01 for the difference between the groups). The mean diastolic BP fell 2.0 mmHg in the experimental group but rose 2.1 mmHg among patients in the control group (*P* = .01 for the difference between the groups). Furthermore, mean systolic BP fell 4.9 mmHg in the group with home telemonitoring versus 0.1 mmHg in the group with usual care (*P* = .05).

Finally, 8 nonrandomized studies [66-73] also evaluated the clinical effects of home telemonitoring in hypertensive patients, of which 7 reported *P* values. The results of all of these studies indicated that home telemonitoring appeared to have benefits as shown by the clinical effects that were measured.

Discussion

This section summarizes and discusses our main findings. First, the results from the 24 diabetes studies indicated a trend towards better glycemic control. Positive outcomes were observed in both large RCTs as well as in 13 other studies, including 10 small RCT studies. There were 9 other studies that concluded that home telemonitoring is as effective in glycemic control as the traditional approach to home follow-up. Overall, our findings are consistent with recent systematic reviews and meta-analyses on home telemonitoring for diabetes management, for example, the reviews by Paré et al [8] and Polinesa et al [74]. As shown in Multimedia Appendix 2, most studies included in the present review included patients with insulin-dependent diabetes mellitus (IDDM) and, hence, results might not be generalizable to other types of diabetes. In addition, it was not clear from the results of these 24 studies whether improvement in the clinical condition of patients was the result of the use of the technology itself or because of other factors. For instance, the positive outcomes observed in the study by Shea et al [13] might also be associated with the intensified provider consultation and/or the increased access to educational material. Similarly, Stone et al [75] found that active medication management by a nurse practitioner along with home telemonitoring demonstrated reductions in HbA1c after 3 and 6 months. Future research should therefore assess the relative impact of other potentially mediating variables or conditions on the clinical outcomes observed.

Second, as for asthma, 5 of the 6 RCTs included in this systematic review showed a significant improvement in PEF, a significant reduction in the symptoms associated with this illness, and a large improvement in perceived quality of life. Overall, our findings are aligned with a recent systematic review of home telemonitoring and respiratory conditions [76]. While these results may be encouraging, it is unclear whether the use of technology either promotes the resolution of symptoms, empowers the patient to self-manage their condition, or both. We concur with Smith et al [77] that studies are needed that address how the use of patient monitoring technology leads to self-management.

Third, home telemonitoring also provided for better control of blood pressure than the traditional home follow-up model. The findings from 4 of the 5 RCTs and 7 of the 8 nonrandomized studies of strategies to control blood pressure suggested that home telemonitoring does a better job of improving state of health in hypertension patients than other approaches. It is worth noting that in most cases the studies found a significant drop in blood pressure in the first 3 months of remote monitoring. While our findings are consistent with those reported elsewhere, for example the reviews by Paré et al [8] and Jaana et al [78], very few studies have presented changes in compliance with medication regimens and quality of life associated with home telemonitoring. A recent trial conducted by Parati et al [79] also confirmed the positive outcomes observed in this review. In that study, 329 hypertensive patients were randomized to either usual care on the basis of office blood pressure (the control group, n = 113) or to integrated care on the basis of teletransmitted home blood pressure (n = 216) and were observed over a period of 6 months. Results indicated that the percentage of daytime blood pressure readings that were within the normal range during the study period was higher in the group that teletransmitted their blood pressure readings than in the control group ($P < .05$). However, no significant between-group differences were found in the rate of change in treatment regimens prescribed by the physicians. Quality of life also tended to be higher in the intervention group, but the difference was not statistically significant. As a final remark concerning studies of home monitoring of patients with hypertension, the positive outcomes observed must be interpreted with caution because most trials were nonrandomized and several studies had small sample sizes.

The positive effects reported for diabetes, asthma, and hypertension are mainly associated with the fact that, by its very nature, telemonitoring allows for more frequent follow-up of patients and, as a result, may provide earlier detection of warning signs that a patient's state of health is deteriorating [8]. However, many studies of heart failure have failed to show a reduction in either mortality or hospitalization rates, although a few trials have reported a trend towards shorter lengths of stay in hospital, for example, the studies of Benatar et al [45] and Cleland et al [46]. These findings are consistent with those reported by Paré et al [8] as well as the findings of two recent RCTs. In the Home-HF study [80], 182 patients with a recent hospitalization for heart failure were randomly assigned to daily telemonitoring or to a control group that received a package of intensive, conventional expert care. Although the study did not find significant differences between the two groups in survival (number of days) or in the number of days out of hospital, the results confirmed that home telemonitoring allowed early detection of worsening symptoms ($P < .01$). Similar to previous RCTs, for example the studies by Goldberg et al [44] and Benatar et al [45], the study failed to show an impact on quality of life. In another recent study, the Home or Hospital in Heart Failure trial [81], patients with a hospitalization for heart failure in the previous year were randomly assigned either to usual care (n = 160) or to home telemonitoring (n = 301). Mortality and length of stay were low in both groups and did not differ significantly.

Critical Success Factors

Given the state of knowledge in this area, it becomes pertinent and important to examine the main conditions for a successful home telemonitoring program. These conditions are related to: (1) the patients targeted by the telemonitoring intervention, (2) the technological devices used, and (3) the characteristics of the telemonitoring program and work organization. Meeting the conditions described below may increase the likelihood of positive and statistically significant clinical effects.

First, with respect to the patients targeted by home telemonitoring programs, it needs to be determined whether home telemonitoring is suitable to everyone. On the basis of the studies in our sample, this would not appear to be the case. Several exclusion criteria were used in these studies. Patients were often excluded if they had a moderate or serious cognitive, visual, or physical disability. Also commonly excluded were patients who did not own a phone or who had a life expectancy measured in months rather than years. When determining eligibility criteria, it cannot be denied that some patients appear to benefit more than others. Several studies have suggested that the beneficial effects on state of health are observed mostly among patients whose state of health is considered serious (eg, the studies by Kwon et al [23] and Trappenberg et al [82]); patients who want to play an active role in the management of their illness (eg, the studies by Madsen et al [63], Rickerby and Woodward [83], DelliFraine and Dansky [84], and Hopp et al [85]); and patients who are interested in using this type of technological device (eg, the studies by Vähätalo et al [27], and Madsen et al [63]).

In terms of the technology, the user-friendliness of the device installed in the home and its nonintrusiveness in the lives of patients, particularly for the youngest patients, appear to be important acceptance criteria. Given the fact that the patients with chronic disease who are targeted in home telemonitoring applications do not all have the same level of technological skill, the same level of education, the same professional constraints, or the same lifestyle, and that some may have a slight visual or motor deficit, it would be preferable for application providers to ensure that patients have the technological device best suited to their specific needs. For some, a secure Web link will represent the best solution, whereas for others a cellular phone will be the most appropriate technology. Furthermore, the use of electronic measurement instruments is becoming increasingly common. Such instruments not only simplify data entry and transfer, they also provide more reliable data. As suggested by Dansky et al [48], empirical studies comparing various technologies (eg, Internet-based versus telephone-based) would provide important information for the advancement of chronic illness management.

Finally, certain issues appear to be associated with the tension that is created when telehomecare is added to home care services. The authors of a few studies (eg, studies by Gomez et al [16], Montori et al [21], and Biermann et al [29]) have suggested that the implementation of a telehomecare program requires a review of work organization to ensure a quick response to an alert from the technology as well as of a review of work organization planned around standard interventions. It is therefore important to plan for and then assign one or more nursing resources (depending on the number of patients followed) to monitor the clinical data received every day and take the required actions, as, for example, in the studies by Ahring et al [13] and Knox et al [86]. Moreover, a home telemonitoring application must be designed and implemented with the understanding that it is a complementary intervention and not a solution that replaces primary care [12]. Furthermore, telemonitoring completes and consolidates the health care system by allowing a continuum of care based on patient needs. Many of the telemonitoring programs that produced conclusive clinical results maintained their patient follow-up by telephone or in the hospital, as, for example in the studies by Shae et al [12], Shultz et al [17], and Jan et al [36]. Periodic visits to a medical clinic and home visits by nurses are also maintained, but their frequency may be adjusted based on changes in a patient's state of health. The idea is that the technological device is not a substitute for follow-up of chronically ill patients by a health professional, rather such devices are used as leverage to improve the effectiveness and quality of professionals' work.

Limitations

Despite our use of a thorough search strategy, some empirical studies on home telemonitoring interventions may not have been identified for this review. Specifically, we did not examine the gray literature (unpublished documents and reports) on this topic; we focused instead on data that had been published through the peer-review process. Importantly, a meta-analysis was not possible due to the various data collection methods and outcomes in the reported studies. As well, it was not clear throughout the studies examined herein whether improvement in the clinical condition of patients was the result of the use of the technology itself or of other mechanisms, such as the intensified provider consultation or the greater access to education material. Future research should assess the impact of other potentially mediating variables or conditions on the clinical outcomes observed.

In spite of these limitations, this is the first systematic review to our knowledge that specifically examines the clinical outcomes of home telemonitoring programs across a variety of chronic conditions and addresses the critical success factors associated with such interventions. Insights regarding clinical outcomes of this emerging intervention and possible ways of making it more effective are presented in an organized manner, and future research directions in this area are recommended based on this systematic review.

Conclusion

In the interests of providing appropriate support to the growing offer of home care services for the chronically ill and to maximize the associated benefits, health care organizations and professionals must, in our opinion, incorporate information technologies. Home telemonitoring, which requires the active participation of patients, constitutes a case in point. This mode of intervention allows for closer monitoring of each patient's condition, as well as early detection of warning signs that a patient's health is deteriorating. The findings of empirical studies conducted so far are encouraging. The results of a large majority of studies indicated better glycemic control and improved control of asthma and blood pressure. However, due to the equivocal nature of current findings pertaining to the clinical effects of home telemonitoring in the context of heart failure, larger trials are needed to confirm the benefits of this technology for these patients.

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Conflicts of Interest

None declared

Multimedia Appendix 1

List of excluded studies

[PDF file (Adobe PDF), 90 KB - jmir_v12i2e21_app1.pdf]

Multimedia Appendix 2

List of the 62 included studies

[PDF file (Adobe PDF), 53 KB - jmir_v12i2e21_app2.pdf]

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Abbreviations

BP: blood pressure
COPD: chronic obstructive pulmonary disease
DBP: diastolic blood pressure
HbA1c: hemoglobin A1c
HTU: home telemedicine unit
IDDM: insulin-dependent diabetes mellitus
INAHTA: International Network of Agencies for Health Technology Assessment
PEF: peak expiratory flow
POTS: plain old telephone service
SBP: systolic blood pressure

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Original Paper

Preventing the Obesity Epidemic by Second Generation Tailored Health Communication: An Interdisciplinary Review

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Abstract

Background: The prevention of obesity and health concerns related to obesity are major challenges worldwide. The use of eHealth communication and the tailoring of information delivered via the Internet at the individual level may increase the effectiveness of interventions. Mastering behaviors related to nutrition, physical activity, and weight management are the main issues in preventing obesity, and the need for interdisciplinary knowledge within this area is obvious.

Objective: The objectives were to review the literature on tailored health communication and to present an interdisciplinary analysis of studies on “second” generation tailored interventions aimed at behavior change in nutrition, physical activity, or weight management.

Methods: A literature search was conducted of the main electronic information sources on health communication. Selection criteria were defined, and 23 intervention studies were selected. The content analysis focused on the following: study designs, objectives of behavior change, target groups, sample sizes, study lengths, attrition rates, theories applied, intervention designs, computer-based channels used, statistically significant outcomes from the perspective of tailoring, and possible biases of the studies. However, this was not a structured meta-analysis and cannot be replicated as such.

Results: Of the 23 studies, 21 were randomized controlled trials, and all focused on behavior change: 10 studies focused on behavior change in nutrition, 7 on physical activity, 2 on nutrition and physical activity, and 4 on weight management. The target groups and the number of participants varied: 8 studies included more than 500 participants, and 6 studies included less than 100. Most studies were short; the duration of 20 studies was 6 months or less. The Transtheoretical Model was applied in 14 of the 23 studies, and feedback as a tailoring mechanism was used in addition to an Internet site (or program) in 15 studies and in addition to email in 11 studies. Self-reporting was used in 15 studies, and 14 studies did not have a no-information control group. Tailoring was more effective in nutrition interventions than in physical activity and weight management interventions. The outcomes were mixed or negative in 4 studies of physical activity interventions and in 3 studies of weight management. The use of a no-information control group seemed to have been linked to statistically significant between-group effects in measuring physical activity. This bias effect related to intervention design may explain the differences in the outcomes of the physical activity studies.

Conclusions: Tailoring was shown to have been an effective method in nutrition interventions, but the results for physical activity were mixed, which is in line with previous studies. Nevertheless, the effect of possible biases, such as relying solely on self-reports and on intervention design without a no-information control group, should not be underestimated. Thus, the issue of bias merits more attention in planning interventions and in future meta-analyses.

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KEYWORDS

Health communication; health promotion; intervention studies; tailored interventions; tailoring; computer-based delivery; Internet; health behavior change; obesity; public health

Introduction

Obesity and overweight, which are associated with the metabolic syndrome, type 2 diabetes, and heart disease, are obvious health problems in Western countries and are also increasing in Asia and Africa. Health communication is a key strategy in informing the public about health concerns [1], but conventional approaches are the least effective as they consist of passive dissemination of messages from experts to the public in the hope of motivating people to change their behaviors [2]. As the health information environment has changed dramatically during the past decade, partly due to the rapid diffusion of Internet technology [3,4], eHealth communication provides a new means to prevent obesity from becoming a global epidemic. Through unique features such as mass customization, interactivity, and convenience, eHealth may influence the psychosocial factors of control, motivation, and self-efficacy [2], that is, individuals' expectations about whether they will be able to master a behavior, and if so, how successful they will be [5].

Targeting and Tailoring Health Communication

We claim that eHealth communication as such is not enough for behavior change at the individual level; it also requires targeting and tailoring information. These strategies combine the benefits of interpersonal communication and mass media and are based on the ideas of social marketing [6]. In targeted communication, the aim is to reach particular population subgroups whose members share the same characteristics. In tailored communication, the aim is to reach specific individuals [7] through three mechanisms: personalization, feedback, and adaptation (ie, content matching). These tailoring mechanisms tend to be used in combination (see, for example, [8-11]).

Research indicates that tailored health communication may be more effective than traditional promotion [2,12-14]. Tailored health communication is seen as more satisfying and personally relevant, being read more thoroughly, and discussed with others more often [7,12,13,15]. Tailoring may enhance the motivation for processing health information in at least four ways: (1) by matching content to an individual's information needs and interests, (2) by framing health information in a context that is meaningful to the person, (3) by using design and production elements to gain the individual's attention, and (4) by providing the quality and quantity of information desired and through channels of delivery preferred by the individual, thereby potentially reducing barriers to exposure to interventions [7,16].

The outcomes of tailored health communication can be assessed by studying a specific intervention in which behavioral, physiological, and/or psychological factors are measured at baseline and at the end of the intervention or follow-up, and the results are compared. In addition to determining whether the tailoring element has been effective, the tailored group needs to be compared with the control group, which is a group provided with general information or no information. However, the intervention designs may differ greatly, and the outcomes and effectiveness can be measured and estimated in various ways, complicating evaluation and comparison of the intervention studies reported in the research literature. This justifies examination of specific details, such as the target audience or the length of the intervention period [17], to understand how interventions are built.

Delivery of computer-generated tailored information may differ from print (eg, [18]), telephone [19]), mobile phone (eg, [20]), CD-ROM (eg, [21]) or the Internet (eg, [22]). Computer-tailored but print-delivered interventions, for example, computer-generated printed pamphlets, are deemed the "first" generation, and interventions using interactive media are deemed the "second" generation of tailored health communication [23]. The "third" generation interventions refer to interventions delivered via mobile and remote devices such as mobile phones and handheld computers [24]. In this paper we focus on intervention studies utilizing second generation tailored health communication.

Theories Applied in Second Generation Tailored Health Communication

Improved theoretical understanding in building interventions may enhance their outcomes. The theoretical basis of tailored communications derives from social psychology and communication and persuasion theories and models [25]. The construction of interventions to change beliefs toward behavior may be based on behavior change theories [26] as well as information processing theories. Also, consideration of whether the message content has been tailored for different audiences may help explain its effectiveness or ineffectiveness in changing behavior [26].

Tailored feedback may be based on social psychological theories, for example, the Health Belief Model (HBM) by Rosenstock [27] and Becker [28] or the Transtheoretical Model (TTM) by Prochaska and DiClemente [29]. The HBM predicts that individuals are more likely to act and change their health behavior when at risk and when the perceived benefits of taking action outweigh the perceived costs or barriers. The TTM claims that individuals move through a series of five stages of change in the adoption of healthy behaviors or cessation of unhealthy ones. The TTM is most often used in tailored health interventions [30]. The Precaution Adoption Process Model (PAPM) by Weinstein [31] is another stage-based model. This model describes how a person decides to take action as well as how a person translates that decision into action.

The Elaboration Likelihood Model (ELM) of persuasion by Petty and Cacioppo [32] is based on the assumption that under many circumstances people are active information processors who "think about messages carefully, relate them to other information they have encountered in the past, and consider the messages in the context of their own life experience" [33]. This suggests that people are more likely to process information thoughtfully if they perceive it to be personally relevant. The

ELM also distinguishes between central and peripheral routes to persuasion.

Bandura's [34] Social Cognitive Theory (SCT) permits the assumption that messages can be tailored according to different levels of self-efficacy. The Health Promotion Model (HPM) by Pender [35] is also connected to the SCT. Studies have indicated that using the Internet in tailored SCT interventions have achieved changes in nutrition practices, physical activity, and weight loss, and that the participants have maintained these changes for up to a year [36].

Other theories underlying second generation tailored health communication include the Theory of Reasoned Action (TRA) and the Theory of Planned Behavior (TPB). These theories posit that the most proximal predictor is behavioral intention, or the perceived likelihood of performing behavior [37]. Webb et al [38] suggested that the effectiveness of second generation interventions is associated with more extensive use of theory in general and with the TPB in particular. Another such theory is the Goal Setting Theory (GST). The idea behind the GST is that setting goals specifies the objectives of behavior, directs effort to goal-relevant activities, and increases commitment [39].

Combining demographic and/or behavior concepts with the theoretical frameworks of tailoring has been shown to be efficacious in interventions [37]. We can also claim that careful tailoring on demographic characteristics (eg, gender, race, and age) and feedback provided on the behavior itself may enhance the effectiveness of theoretical tailoring. (See also [40].)

Examples of Meta-analyses of First, Second, and Third Generation Health Interventions

To the best of our knowledge, this paper is among the first interdisciplinary reviews within the context of second generation computer-tailored health interventions. The foci of many meta-analytic reviews of general Internet-based health behavior change interventions have included nutrition, physical activity, and weight management as well as other health behaviors. Meta-analyses of Internet-based physical activity interventions have been conducted by van den Berg et al [41] and Marcus et al [42], for example. A meta-analysis by Wantland et al [43] compared (tailored or nontailored) second generation and other types of health interventions. In this meta-analysis [43], most of the studies revealed improved knowledge and/or improved behavioral outcomes for participants involved in second generation interventions. In another meta-analysis, Norman et al [24] studied eHealth interventions for physical activity and dietary behavior change.

Meta-analytic reviews of first and second generation interventions are provided, for example, by Kroeze et al [30], who scrutinized computer-tailored interventions on physical activity and nutrition education. This group of authors found that 3 of the 11 physical activity studies and 20 of the 26 nutrition studies showed significant effects of the tailored interventions, and the evidence was most consistent for tailored interventions on fat reduction [30]. Neville et al [44], in their analysis of second and third generation interventions, focused on dietary behavioral change and found that 8 of 12 interventions had significant positive effects on dietary behavior [44].

We found only one meta-analysis on second generation tailored interventions related to nutrition, physical activity, and weight management. This review, by Lustria et al [8], screened over 500 studies and selected 30 for the analysis to ascertain how these interventions were implemented and delivered via the Internet and what mechanisms and criteria were used to individualize health messages [8]. The selected interventions spanned four broad areas (nutrition and diet, physical activity, alcoholism, and smoking cessation) and differences in the level of sophistication of message tailoring were identified [8]. Neville et al [45] conducted a systematic review of second and third generation physical activity interventions targeting adults. According to these authors, the evidence of the effectiveness of these interventions was inconclusive.

Aim of the Study

In this paper, we aimed at presenting an interdisciplinary review of the research literature on health communication to prevent obesity and related health problems, such as metabolic syndrome and type 2 diabetes, at the individual level. We assumed that to succeed in preventing these diseases, it is crucial to master behavior related to nutrition, physical activity, and weight management. We reviewed second generation intervention studies conducted in these three areas of activity by examining specific issues related to the selected interventions. We also compared the studies and their outcomes to identify possible differences and reasons for these.

Methods

Search of the Research Literature

The literature searches were performed between January and August 2009. Research literature on health communication and tailoring was sought from the following databases: Pubmed and Ovid (MEDLINE), Science Direct (Elsevier), Google Scholar, Library and Information Science Abstracts (LISA) (CSA), Academic Search Premier (EBSCO), Library, Information Science & Technology Abstracts (LISTA) (EBSCO), Emerald Journals (Emerald), Educational Resources Information Center database (ERIC) (CSA), Scopus, Sociological Abstracts (CSA), Web of Science (ISI), and ABI/Inform (ProQuest). The search terms were: health, health communication, tailor*, Internet, WWW, web, net, online, nutrition, diet*, vegetable/fruit consumption/intake, fat intake, weight, weight management, obesity, overweight and physical activity or exercise. (An asterisk was used to include all terms that began with a particular spelling, such that "diet*" would include dietary and dieting, for example.) The Boolean search queries were based on the following formulations: (tailor* [Title/Abstract/Keywords]) AND (weight OR "weight management" OR obesity OR overweight OR "physical activity" OR exercise OR "fat intake" OR nutrition OR diet* OR "vegetable consumption/intake" OR "fruit consumption/intake" [Title/Abstract/Keywords]) AND (Internet OR WWW OR web OR net OR online [Title/Abstract/Keywords]).

The searches were not limited by publication date, but the availability of articles was taken into account. So-called pearl-fishing, or chaining, strategy was also used by taking a closer look at the articles cited in other articles and at recent articles citing certain older relevant articles. Many of the articles retrieved were published in high quality, peer-reviewed, international journals of psychology, health promotion, health education, nutrition, medicine, nursing and communication.

Inclusion and Exclusion Criteria for the Intervention Studies

In order to find examples of intervention studies for the content analysis, articles were included if they: (1) focused on second generation interventions; (2) focused on health behavior related to nutrition, physical activity, or weight management, alone or in combination; (3) measured or assessed behavioral, psychological, or physiological outcomes; (4) were randomized controlled trials or quasi-experimental designs with pretest and posttest; and (5) were available in full text.

Articles were excluded if they: (1) measured only the feasibility and acceptability of computer-delivered tailored health communication, as for example, the studies by Vandelanotte et al [46], Spittaels et al [47], Comrie et al [48], and Maes et al [49]; (2) focused on diabetes self-management, such as the studies by Glasgow et al [50] and Wangberg [51]; or (3) gave advice in computer kiosk or in an online Internet shopping site, such as the study by Huang et al [52].

Finally, 23 articles that clearly met the criteria were selected for the content analysis [15,21-23,53-72] and were analyzed by categorizing them according to the themes of the research questions formulated as follows:

1. What is the study design and setting?
2. Which objectives are set for the behavior change in the selected intervention studies?
3. Who are the target groups?
4. What are the sample sizes?
5. What are the lengths of the studies (follow-up) and what is their attrition rate?
6. On which theories or theoretical concepts is the background of the intervention studies built?
7. What is the intervention design of the studies?
8. What tailoring mechanisms are used?
9. Which Internet-based channels are used to deliver tailored health information?
10. What are the main outcomes of the interventions from the perspective of tailoring?
11. What kind of biases can be identified in the selected studies?

In this paper we use the term “study” to refer to the intervention and its follow-up examined in the articles selected for analysis.

Results

Study Design, Objectives, Target Groups, Sample Sizes, Lengths of Follow-up, and Attrition Rates

The study design provides the basis for an intervention study. Of the 23 studies selected, 21 were randomized controlled trials. Only 2 studies used quasi-experimental designs, that is, these were nonrandomized controlled trials [53,55]. In the study by Frenn et al [55], participants were assigned to intervention or control group according to their classroom assignment, and in the study by Block et al [53], participants chose their preferred dietary emphasis for a 12-week program. In 20 of the 23 studies, the intervention was performed in a real-life setting, such as at home. Of the 23 studies, 3 were conducted in a controlled situation [23,55,61] in which the participants performed the assessments and received the tailored information or feedback in classrooms or offices.

The objectives of selected interventions may be important factors for preventing metabolic syndrome, obesity, and type 2 diabetes. The analysis showed that these studies may have concentrated on a single facet of health behavior, such as physical activity, or have tried to influence more than one health behavior. For instance, we found that combining fruit and vegetable consumption and fat intake in the same study was quite common [15,53,57]. Of the 23 studies selected, 10 focused on behavior change in nutrition, 7 on change in physical activity, 2 on change in both nutrition and physical activity, and 4 on behavior change related to weight management. Objectives, target groups, sample sizes, lengths of the studies, and attrition rates are summarized in Table 1.

Table 1. Objectives of behavior change, target groups, sample sizes, lengths of follow-up periods, and attrition rates of the selected intervention studies

Author(s) and Year of Publication (n = 23)	Study Focus	Objectives of Behavior Change (Measurement Method)	Target Group	Sample Size	Length of the Study Follow-up in Months	Percent Attrition at Follow-up
Block et al, 2004 [53]	Nutrition	Fruit and vegetable consumption, fat intake, determinants of fruit and vegetable consumption and fat intake (self-report)	Adults	84	3	44
de Vet et al, 2008 [68]	Nutrition	Fruit and vegetable consumption (self-report)	Adults	775	Baseline + 1 week	18
Di Noia et al, 2008 [61]	Nutrition	Fruit and vegetable consumption, determinants of fruit and vegetable consumption (self-report)	Adolescents, minority	549	1	8
Irvine et al, 2004 [57]	Nutrition	Fruit and vegetable consumption, fat intake, determinants of dietary intake (self-report)	Healthy adults	517	2	10
Kroeze et al, 2008 [21]	Nutrition	Fat intake, dietary intake (self-report)	Healthy adults	442	6	13
Luszczynska et al, 2007 [58]	Nutrition	Fruit and vegetable consumption, determinants of fruit and vegetable consumption (self-report)	Healthy adults	285	6	30
Oenema et al, 2001 [23]	Nutrition	Determinants of fruit and vegetable consumption and fat intake (self-report)	Adults	204	Baseline	Immediately posttest
Oenema et al, 2005 [15]	Nutrition	Fruit and vegetable consumption, fat intake, determinants of fruit and vegetable consumption and fat intake (self-report)	Healthy adults	782	1	21
Papadaki and Scott, 2008 [62]	Nutrition	Mediterranean diet score, Fruit and vegetable consumption (self-report) blood lipids (objectively measured)	Women	72	9	27
Park et al, 2008 [63]	Nutrition	Determinants of fruit and vegetable consumption (self-report)	Young adults	160	1	14
Dunton and Robertson, 2008 [54]	Physical activity	Physical activity, determinants of physical activity (self-report)	Women, minority	156	3	29
Hageman et al, 2005 [56]	Physical activity	Physical activity (self report) cardiovascular fitness, % body fat, weight, flexibility (objectively measured)	Older women	31	3	3
Marcus et al, 2007 [59]	Physical activity	Physical activity (self-report), cardiovascular fitness (objectively measured)	Sedentary adults	249	12	12
Napolitano et al, 2003 [60]	Physical activity	Physical activity (self-report)	Sedentary adults	65	3	20
Spittaels et al, 2007 [65]	Physical activity	Physical activity (self-report) weight, blood pressure, % body fat (objectively measured)	Healthy adults	526	6	29
Spittaels et al, 2007 [72]	Physical activity	Physical activity (self-report)	Healthy adults	434	6	34
Wanner et al, 2009 [70]	Physical activity	Physical activity (objectively measured and self-report), determinants of physical activity (self-report)	Adults	1531	13	50
Frenn et al, 2005 [55]	Nutrition and physical activity	Fat intake, physical activity (self-report)	Adolescents, minority	178	1	23
Oenema et al, 2008 [71]	Nutrition and physical activity	Fat intake, physical activity (self-report)	Adults	2159	1	19

Author(s) and Year of Publication (n = 23)	Study Focus	Objectives of Behavior Change (Measurement Method)	Target Group	Sample Size	Length of the Study Follow-up in Months	Percent Attrition at Follow-up
Booth et al, 2008 [22]	Weight management	Weight, waist circumference (objectively measured), dietary intake, physical activity (self-report)	Overweight or obese adults	73	3	27
Rothert et al, 2006 [64]	Weight management	Weight (self-report)	Overweight or obese adults	2862	6	80
Tate et al, 2001 [67]	Weight management	Weight, waist circumference (objectively measured), fat intake, dietary intake (self-report)	Overweight or obese adults	91	6	22
Tate et al, 2006 [66]	Weight management	Weight (objectively measured) dietary intake, fat intake, physical activity (self-report)	Overweight or obese adults	192	6	20

Possible changes in health behavior can be monitored by self-reported indicators or by objective physiological measures conducted in controlled conditions. In 15 of the 23 studies, the measures were only self-reported. Objectively measured factors included weight, physical activity, blood pressure, body fat percentage, blood lipids (eg, cholesterol), waist circumference, flexibility, and cardiorespiratory fitness (eg, maximal oxygen uptake [VO2max]). Of these factors, physical activity and weight were self-reported in 13 of the studies.

The studies selected had many kinds of target groups, whose inclusion criteria were, for example, based on age (eg, adolescents) or gender. The choice of women as a target group was explained as follows: "[W]omen were recruited because they are more likely than men to use the Internet for health information and more likely to be responsible for meal planning and preparation" [62].

Of the 23 studies, 3 concentrated on minority groups. The target groups were economically disadvantaged 11 to 14 year-old urban African-Americans [61], low-income culturally diverse seventh grade students [55], and ethnically diverse women [54]. Risk groups also were chosen as targets: sedentary adults were the focus in 2 studies, overweight or obese individuals were the focus in 4 studies. For example, in 1 study, individuals were included who had a body mass index in the range 27 to 40 kg/m^2 [64]. The selection criteria were also quite strict in some cases. For example, studies may have included only individuals with high BMI and excluded individuals less than 18 years of age, women who were pregnant, or individuals who were taking medication for diabetes [22].

There were large differences in the sample sizes of the studies. Of the 23 included studies, 8 had enrolled more than 500 participants at baseline. On the other hand, in 6 studies the sample sizes were less than 100.

Length of follow-up varied depending on the purpose of the study. Some studies focused on examining short-term effects, such as the immediate impact of Web-based computer-tailored nutrition education on personal awareness and intentions related to intake of fat and fruits and vegetables [23]. Some studies, in turn, tried to ascertain the long-term effects of tailored health communication (eg, 12 months [59] and 13 months [70]). In 20 of the 23 studies, the length of the study or the follow-up period was 6 months or less, and the final measures and observations were made immediately after the participants had received the last intervention contact or some time thereafter. In some of the studies, the attrition rate was decidedly high, but in 18 of 23 studies the attrition rate was under 30%.

Theories Applied, Intervention Design, Tailoring Mechanisms, and Outcomes

In many of the interventions selected, the assessments and information given to participants were based on theories of behavior change or information processing. The TTM and stages of change and the concept of self-efficacy (SE), which is connected to several theories, such as the SCT and HPM, were mentioned most often in the intervention studies selected. The TTM, including the stages of change, was the most commonly mentioned theory, cited in 14 of the 23 studies. Multiple interventions gave participants stage-tailored information (eg, [55,57,61,63,65,68]), and many measured the stage of change at the beginning and monitored any possible improvement (eg, [22,53,54,60,70]). Other theories or models mentioned in the studies were the ELM [15], PAPM [15,23,71], GST [22], TPB [65], TRA [57], and HPM [56]. Some other theoretical concepts were also mentioned, for example, motivation, awareness of risk behavior, goals and intentions. These are not presented here in detail. In 4 studies [59,62,66,67], no theories were mentioned.

Table 2 presents the theories or theoretical concepts applied or mentioned in the studies selected, use of computer for delivering tailored information, intervention design, and statistical values that indicate the significant between-group effects. A positive outcome from the perspective of tailoring, for example, would be a statistically significant increase in self-reported fruit consumption, a bigger decrease in objectively measured weight, or a significant improvement in the stage of change of the intervention group compared with the control group.

Table 2. Objectives of behavior change, theories, intervention designs, and statistically significant outcomes of the tailored intervention groups compared with control groups

Study Authors and Year of Publication (n = 23)	Objectives of Behavior Change	Theories or Theoretical Concepts Mentioned	Intervention and Control Groups	Use of the Computer for Delivering Tailored Health Information	Statistically Significant Outcomes in Favor of Tailored Intervention Group Compared With Control Group[a]
Block et al, 2004 [53]	Nutrition	Transtheoretical Model or Stages of Change (TTM/SC)	1. Tailored fruit and vegetable consumption information 2. Tailored fat information	Email	Change in fruit and vegetable consumption (all evaluation respondents)[d] +0.73 times/day *** Change in consumption of fat sources (all evaluation respondents)[d] -0.39 times/day *** Change in stage of change for fruit and vegetable consumption (all evaluation respondents)[d]*** Change in stage of change for fat (all evaluation respondents)[d]***
de Vet et al, 2008 [68][b]	Nutrition	TTM/SC	1. Tailored precontemplation feedback 2. Tailored contemplation feedback 3. Tailored action feedback	Feedback-letter	-
Di Noia et al, 2008 [61]	Nutrition	TTM/SC, Concept of Self-efficacy (SE)	1. Tailored intervention 2. General intervention	CD-ROM	Change in fruit and vegetable consumption was 38% higher for 1. vs 2., $F_{1,501} = 26.62^{***}$ Change in pro (rather than con) phase of change[d] $F_{1,501} = 5.08^{*}$
Irvine et al, 2004 [57]	Nutrition	TTM/SC, SE, Theory of Reasoned Action (TRA)	1. Tailored intervention 2. Waiting list control	Internet program	Change in fat consumption +0.24 vs +0.19 summary score points $t = 8.44^{**}$ Change in fruit and vegetable consumption +0.36 vs +0.24 summary score points $t = 6.49^{***}$ Change in stage of change to adopt a low fat diet +0.55 vs +0.50 summary score points $t = 7.57^{***}$ Change in self-efficacy to decrease fat $t = 3.87^{***}$

Study Authors and Year of Publication (n = 23)	Objectives of Behavior Change	Theories or Theoretical Concepts Mentioned	Intervention and Control Groups	Use of the Computer for Delivering Tailored Health Information	Statistically Significant Outcomes in Favor of Tailored Intervention Group Compared With Control Group[a]
Kroeze et al, 2008 [21][c]	Nutrition	TTM/SC	1. Tailored CD-ROM-delivered intervention 2. Tailored print-delivered intervention 3. General intervention	CD-ROM	1. vs 3. at 1 month Total fat intake[d] 87.9(35.1) vs 104.2(44.1) g b = -10.93 * Saturated fat intake[d] 32.8(15.2) vs 37.1(16.9) g b = -3.15 * Energy intake[d] 9.1(3.0) vs 10.7(3.4) megajoules b = -1.07 *
Luszczynska et al, 2007 [58]	Nutrition	SE	1. Tailored SE group 2. Tailored SE + action planning group 3. General intervention	Email	Change in fruit and vegetable consumption[d] $F_{2,198} = 6.81$, $\eta^2 = 0.07$ ***
Oenema et al, 2001 [23]	Nutrition	SE, Precaution Adoption Model (PAPM)	1. Tailored intervention 2. General intervention	Internet program	Change in awareness[d] $t_{193} = 3.82$ *** Change in intention to change diet[d] $t_{195} = 3.35$ ***

Study Authors and Year of Publication (n = 23)	Objectives of Behavior Change	Theories or Theoretical Concepts Mentioned	Intervention and Control Groups	Use of the Computer for Delivering Tailored Health Information	Statistically Significant Outcomes in Favor of Tailored Intervention Group Compared With Control Group[a]
Oenema et al, 2005 [15][c]	Nutrition	PAPM, Elaboration Likelihood Model (ELM)	1. Tailored intervention 2. General intervention 3. No-information control	CD-ROM	Change in self-rated fat intake 1. vs 2. -0.13 vs +0.06 score points β = -0.10 [*] 1. vs 3. -0.13 vs +0.07 score points β = -0.10 [**] Change in self-rated vegetables intake 1. vs 2. -0.19 vs -0.07 score points β = 0.14 [**] 1. vs 3. -0.19 vs -0.05 score points β = 0.13 [**] Change in vegetable intake 1.vs 2. +0.1 vs -0.1 servings β = .08 [*] Change in intention to change (fat) 1. vs 2. +0.24 vs 0.00 score points β = -0.09 [*] 1. vs 3. +0.24 vs -0.03 score points β = -0.12 [*] Change in intention to change (vegetables) 1. vs 2. +0.34 vs +0.07 score points β = -0.13 [*] 1. vs 3. +0.34 vs +0.05 score points β = -0.14 [**]
Papadaki and Scott, 2008 [62]	Nutrition	-	1. Tailored intervention 2. General intervention	Email, Internet site	Change in vegetable intake +76.5 vs +27.7 g/d [*] Change in HDL (high-density lipoprotein) cholesterol +0.27 vs +0.07 mmol/l [**] Change in ratio of total:HDL cholesterol -0.47 vs -0.14 [*]
Park et al, 2008 [63][b]	Nutrition	TTM/SC, SE	1. Tailored intervention 2. General intervention	Internet program	-

Study Authors and Year of Publication (n = 23)	Objectives of Behavior Change	Theories or Theoretical Concepts Mentioned	Intervention and Control Groups	Use of the Computer for Delivering Tailored Health Information	Statistically Significant Outcomes in Favor of Tailored Intervention Group Compared With Control Group[a]
Dunton and Robertson, 2008 [54]	Physical activity	TTM/SC	1. Tailored intervention 2. Waiting list control	Email, Internet site	Change in walking +69 vs +32 min/week $\beta = 15.04(SE = 8.35)$ * Change in moderate to vigorous intensity physical activity +23 vs -25 min/week $\beta = 17.02\ (SE = 10.11)$ *
Hageman et al, 2005 [56][c]	Physical activity	SE, Health Promotion Model (HPM)	1. Tailored intervention 2. General intervention	Newsletters	Change in cardiovascular fitness: VO^2 max[d] $F_{1,26} = 4.37$ * Change in body fat %[d] $F_{1,28} = 6.46$ *
Marcus et al, 2007 [59][b]	Physical activity	-	1. Tailored Internet-delivered interventions 2. Tailored print-delivered intervention 3. General intervention	Internet site	-
Napolitano et al, 2003 [60]	Physical activity	TTM/SC	1. Tailored intervention 2. Waiting list control	Email, Internet site	Change in moderate to vigorous intensity physical activity at 1 month +29.5 vs +15.96 min/week $F_{1,54} = 5.79$ * Change in walking at 1 month +30.05 vs -3.78 min/week $F_{1,54} = 12.1$ *** at 3 months +12.46 vs -15.4 min/week $F_{1,48} = 5.2$ *
Spittaels et al, 2007 [65][b]	Physical activity	TTM/SC, Theory of Planned Behavior (TPB)	1. Tailored advice + e-mails 2. Tailored advice 3. General advice	Email, Internet site	-
Spittaels et al, 2007 [72]	Physical activity	TTM/SC SE	1. Tailored advice + nontailored emails 2. Tailored advice 3. Waiting list control	Internet site	1. vs 2. vs 3. Change in active transportation 20 vs +24 vs +11 min/week $F = 5.25$ ** Change in leisure-time physical activity +26 vs +19 vs -4 min/week $F = 3.14$ * Change in weekday sitting time -22 vs -34 vs +4 min/week $F = 3.71$ *
Wanner et al, 2009 [70][b]	Physical activity	TTM/SC SE	1. Tailored intervention 2. General intervention 3. Spontaneous users group	Email, Internet program	-

Study Authors and Year of Publication (n = 23)	Objectives of Behavior Change	Theories or Theoretical Concepts Mentioned	Intervention and Control Groups	Use of the Computer for Delivering Tailored Health Information	Statistically Significant Outcomes in Favor of Tailored Intervention Group Compared With Control Group[a]
Frenn et al, 2005 [55]	Nutrition and physical activity	TTM/SC SE	1. Tailored intervention 2. No-information control	Email, Internet site	Change in moderate to vigorous intensity physical activity +22 vs -46 min $t_{103} = -1.99^{*}$ Change in dietary fat % -0.8 vs +0.1 g $t_{87} = 2.73^{**}$
Oenema et al, 2008 [71]	Nutrition and physical activity	TTM/SC SE PAPM	1. Tailored intervention 2. Waiting list control	Internet site	Change in saturated fat intake -1.61 vs -0.9 fat points $b = -0.76^{**}$ Change in likelihood of meeting physical activity guidelines in the "at risk" group (low physical activity at baseline) +2.53 vs -0.45% odds ratio = 1.34, 95% confidence interval = 1.001-1.80 *
Booth et al, 2008 [22][b]	Weight management	TTM/SC, Goal Setting Theory, (GST)	1. Tailored advice + exercise 2. Exercise only	Email, Internet site	-
Rothert et al, 2006 [64]	Weight management	SE	1. Tailored intervention 2. General intervention	Internet program	Weight loss % 3(0.3) vs 1.2(0.4)% ***
Tate et al, 2001 [67][c]	Weight management	-	1. Tailored intervention 2. General intervention	Email	Weight loss 4.1(4.5) vs 1.6(3.3) kg $t = 2.1^{*}$ Change in waist circumference 6.4(5.5) vs 3.1(4.4)cm **
Tate et al, 2006 [66][c]	Weight management	-	1. Computer-automated tailored counseling 2. Human email counseling 3. No counseling	Email, Internet program	1. vs 3. Weight loss at 3 months 5.3(4.2) vs -2.8(3.5) kg *** Change in fat intake % at 6 months 37.3(6.6) vs 33.1(4.9) % **

[a] Statistical values presented are: mean (SD) (unless otherwise stated), F (F test, analysis of variance), *t* (*t* test), b (unstandardized regression coefficient), β (standardized regression coefficient), and η² (eta-squared, analysis of variance).

[b] Only nonsignificant results were reported.

[c] The effectiveness of the intervention is reported as mixed based on both significant and non-significant results.

[d] Difference between baseline measurements and measurements at follow-up could not be calculated from presented data.

$^{*}P \leq .05$

$^{**}P \leq .01$

$^{***}P \leq .001$

The intervention designs of 13 of the 23 studies included a tailored and a nontailored group, which received general, standard health information or feedback. Participants in the waiting list control groups of the 5 studies in which these were included received health information or feedback after the follow-up period, while 4 studies included a control group that did not receive health information or feedback even after follow-up (these were the no-information control groups, the no-counseling group, and the group receiving exercise only). In some studies, different delivery channels were also compared, for example, the Internet and print [59] or CD-ROM and print delivery [21]. Fourteen of the studies did not include a no-information control group [21,23,53,56,59,61-65,67,68,71].

The tailoring mechanism used in almost all of the studies was feedback. Studies in which participants were given more information were also able to use adaptation by matching the content to personal characteristics and needs. It must be noted that the tailoring mechanism applied was not always specified according to these terms. Personalization was mentioned in 2 studies [58,61].

The most often used channels for providing tailored feedback were Internet site (or Internet program), used in 15 of the 23 studies, and email, used in 11 studies. Moreover, various channels were utilized; for example, both email and Internet site were used in the study by Booth et al [22], while in other studies email and Internet sites were also combined with other media, such as video [55] or a diary and a peer support board [66]. The difference between Internet site and program was not always clear. In Table 2 these terms are used according to the term used in the original article.

In Table 2, only those outcomes are displayed that were statistically significant. Almost all studies, 21 of the 23, measured indicators connected to behavioral or physiological outcomes; the 2 that did not measured only psychosocial factors [23,63]. The majority of the studies (17) ended up with behavioral, physiological, or psychological between-group effects.

It is noteworthy that in 6 studies (2 on nutrition [63,68], 3 on physical activity [59,65,70], and 1 on weight management [22]), tailoring did not increase the effectiveness of the intervention, and consequently the overall outcome, from the perspective of tailoring, can be regarded as negative. By this we mean that some similar positive, neutral, or negative behavioral, physiological, or psychological outcomes were observed in both tailored and nontailored interventions. For example, no differences in self-reported and objectively measured physical activity were observed in either group over 13 months [70]. The results of the statistical analyses indicating nonsignificant outcomes are not presented in detail in Table 2.

Furthermore, it is noteworthy that in some studies the effectiveness of the intervention was reported as mixed from the perspective of tailoring [15,21,56,66,67]. This means that some measured indicators may have been better and others worse when compared with the control group. For example, Kroeze et al [21] reported that after one month both the Internet and print-delivered tailored intervention groups succeeded significantly better than the control group, but at three-month follow-up only the print-delivered tailored intervention group maintained a significant decrease in fat and dietary intake. In the case of weight loss, the same effect was reported by Tate et al [66]. Hageman et al [56], in turn, observed a significant between-group effect on secondary outcomes but not on the primary outcome, namely, physical activity.

Moreover, Tate et al [67] showed that the self-reported and objectively measured results might not always be in line. The tailored intervention group ended up with significantly greater objectively measured weight loss and greater reduction in waist circumference. However, participants in both groups reported changes in diet of similar magnitude despite significantly different magnitudes of weight loss.

Some of the studies attempted to measure psychosocial variables (such as intention, self-efficacy, and attitude toward the importance of diet) affecting the health behavior change or positive movement in the stage of change [15,23,53,57,58,61,63,70], but the variables were not always measured from the control groups or compared with their results. Moreover, it was shown that self-efficacy increased in the control group but decreased in the intervention group, and this was attributed to the fact that the intervention standard newsletters contained more motivational messages than the tailored ones [56]. In some studies, the immediate reaction to the tailored material was also examined. It was noted that the participants of the tailored intervention group reported more intention to change diet, appreciated tailored material more, and found tailored material more personally relevant [23,63-65].

Possible Biases of the Second Generation Intervention Studies

When assessing outcomes, it is important to consider possible biases in the studies. For example, it must be noted that all studies relied on voluntary participants, which causes a self-selection bias. Moreover, the most common biases considered were: self-reporting as the only method of data collection, as in 15 of the 23 studies (see Table 1); lack of a pure no-information control group, as in 14 of the studies (see Table 2); overrepresentation of one sex even though the target group included both sexes, for example, more women than men, as in 10 of the studies [22,53,57-60,63,66,67,70], or more men than women, as in 2 of the studies [65,68].

Furthermore, in 10 of the studies, the participants differed from the national average in terms of their socioeconomic background (eg, education and income) [21,23,54,57,59,61,62,65,66,72], while in 3 of the studies, participants were more physically active than the national average [54,65,70]. In addition, in 3 studies the intervention situation was controlled [23,55,61], and in 2 studies the attrition rate was high [53,64].

In this content analysis, causalities were not investigated further. Thus the outcomes of the interventions from the perspective of tailoring were not examined in relation to the target group or the length of the study.

Discussion

Results and Implications for Research

Of the 23 studies selected, 10 focused on behavior change in nutrition, 7 on physical activity, 2 on nutrition and physical activity, and 4 on weight management. Most of the studies, 21 of 23, were randomized controlled trials. The target groups and the number of participants varied: 8 studies included more than 500 participants while 6 studies included less than 100. Most studies were short, that is, 6 months or less (20/23). Our analysis indicated that the outcomes of the studies were more positive regarding nutrition interventions, and it has been proposed that fruit and vegetable consumption is a relatively easy behavioral change to use as a first step [73]. However, the outcomes were less positive regarding physical activity interventions, as many studies ended up with negative outcomes from the perspective of tailoring (see Table 2). The physical activity measurements were conducted both objectively and by self-report. In 4 physical activity studies, the outcomes were mixed [56] or negative [59,65,70] from the perspective of tailoring. These results are in line with the studies by Neville et al [45] and Kroeze et al [30]. However, it must be noted that through our analysis we identified a bias effect in the intervention designs that may partly explain the differences in the outcomes of the physical activity interventions examined. Physical activity (as well as both physical activity and nutrition) interventions that did not end up with a significant between-group effect on physical activity measurements [56,59,65,70] used a general information control group, whereas those whose outcome was positive from the perspective of tailoring [54,55,60,71,72] had a no-information control group. Moreover, not all weight management interventions measuring physical activity [22,66,67] resulted in a significant effect on that parameter. This seems to be a result that needs more detailed analysis and empirical testing as, to the best of our knowledge, this has not previously been examined in detail.

Michie and Abraham [74] stated that “objective measures of behavior are likely to be the most informative outcomes when evaluating behavior change interventions.” The studies of this analysis used both objective measures and self-report. It must be noted that outcomes of self-report and objective measures of the same type of behavior do not always match, which was the case in two studies [67,70] included in our analysis. In the study by Wanner et al [70], self-reported changes in physical activity levels were not confirmed by objective measures. Tate et al [67] state that this was also the case in other studies. Participation itself may influence the perception of physical activity behavior and thus influence the levels of self-reported physical activity [70]. Moreover, it has been stated that “reported behavior change can also occur in the absence of actual behavior change due to social desirability effects” [74]. Therefore, the use of objective measures of physical activity may be important in determining whether the self-reported changes that are found are real [45].

Theories and models of health behavior change may help in understanding people’s decision-making and attitude changes, and extensive use of theory has been linked to increased intervention efficacy [38]. As in other studies [30], in our content analysis the TTM, including the stages of change, was the most popular theory mentioned. However, it must be noted that the TTM has been criticized, especially when applied for physical activity interventions [75], and has also supported with arguments emphasizing some promising results despite problems confronted in interventions [76].

To assess whether a tailored health behavior change program is effective, a long follow-up time of the intervention may be needed. As noted in other studies, in our analysis, too, 19 of the 23 studies were quite short in length, that is, 6 months or less. Although there is some evidence that even short-term interventions can be effective [8,44], they cannot be used as indicators of maintenance effect. Even though no change in the outcome was in evidence, it must be noted that an individual may feel that the program is personally relevant and this may foster attitudes toward health behavior change. In addition, the health effects of behavior change may also occur after many years. It has been proposed that estimates of health outcomes could be obtained using impact evaluations and epidemiological simulation models as an alternative to actual measurement [77].

The target groups varied widely, and specific minorities and risk groups were also studied. All studies relied on self-selected participants, whose high education level is one of the possible biases we have identified. Whether education level has an effect on attitudes and success in interventions has been under scrutiny. However, in one study, participants with low levels of education were even more positive than those with higher levels of education about how interesting and personally relevant they perceived tailored feedback to be [78]. This could be explained by the process of tailoring, which highlights only such information content that is perceived as the most relevant for the participant [79]. Therefore, tailoring can reduce the disadvantages associated with general health information on the Internet, namely, those related to incorrect information and also to incorrect understanding of the information content. Moreover, at the individual level, tailoring could be based on levels of information literacy, health literacy, and health information literacy (eg, [80] and [81]). These levels have not yet been widely applied in tailored interventions, though, some heuristics for tailoring materials to match the literacy levels have been presented as, for example, by Carstens [82].

It is quite new to apply tailoring in second generation interventions. In the selected interventions, several modes of delivery were used, such as email, Internet site and/or program, computer-delivered feedback letters, newsletters, and CD-ROM. Characteristics such as instantaneous feedback and appeal or engagement are potential advantages that new information and communication technologies (ICT) can provide and that may be of enormous benefit in achieving behavior change [83]. The third generation health communication emerges, and mobile devices are useful platforms for delivering health information. It has been claimed that “these platforms are also incorporating new functions such as sensing, monitoring, geospatial tracking, location based knowledge presentation, and host of other information processes that will potentially enhance the ability for accurate assessment and tailored feedback” [24]. Moreover, mobile devices can help to achieve “kairos,” that is, the opportune moment to persuade, and they can also be used for collecting self-reported data throughout everyday activities [24]. Combining second and third generation media, in this case the use of text messages, with other methods may prove successful, as it has been suggested that use of multiple methods of interaction with participants enhances the effectiveness of interventions [38].

Implications for Practice

On the basis of this content analysis, the critical issues to be considered in planning and implementing a second generation tailored intervention study could be listed as follows: What health behavior change is the objective of the intervention? Does the intervention aim specifically at change in awareness, self-efficacy, motivation, or other factors influencing the behavior change as proposed by health behavior change theories and models? Will the intervention target one or multiple behaviors? What determinants affect the behavior selected and how can they be measured? What is the target group? What determinants of the target group must be taken into account (eg, cultural characteristics, health status, sociodemographic variables, knowledge, attitude, health information literacy)? Which tailoring mechanism is applied, and what is elicited in the assessment? What kind of an intervention design is applied? How is the intervention delivered? What is the length of the intervention? (For more information about the tailoring process, see [10,12,33,84].)

Moreover, biases, as identified in the studies, may have a significant effect on the outcomes of the intervention. Therefore, it is very important to consider how to minimize or even avoid biases. Related questions include: How do we get those at risk to participate in the study? How do we avoid self-selection bias? How can we activate men to participate? Could generating more technology oriented or third generation interventions make a difference in this? How do we get the most representative sample of the population? Should there be both a general information control and a no-information control group in order to achieve more reliable results?

Strengths and Limitations of the Review

The strength of this review is its interdisciplinary approach. The number of selected articles was 23, which is in line with other meta-analyses. The goal of the content analysis was to find a sample of second generation intervention studies meeting the inclusion criteria. However, it must be noted that this is not a structured meta-analysis and cannot be replicated as such. On the other hand, we believe that the wide range of electronic databases searched may have helped us to find some studies that would have been missing in a structured meta-analysis. The number of references found by a literature search in Medline only would have been too high because the term “tailor” is used in many other ways, such as referring to the tailoring of medications or biochemical tests.

It is not easy to conduct a content analysis of intervention studies because methodological approaches, diversity of features, formats, channels for delivery, methods for providing feedback, goals, and ways to measure health behavioral changes differ greatly. Other authors have drawn the same conclusion, such as Lustria et al [8] and Abrams et al [85]. Likewise, researchers are many times forced to omit facts about technical factors or the details of tailoring from the articles, for example. The interventions selected for this content analysis were heterogeneous despite the strictly defined selection criteria. It is therefore demanding to develop generalized conclusions about the effectiveness of tailoring from such studies.

Conclusion

At the individual level, behavior changes in nutrition, physical activity, and weight management can have a major role in preventing obesity, metabolic syndrome, and type 2 diabetes. This supports the individualist interpretation of behavioral strategies, which places emphasis on the responsibility of individuals for their health status and is supported by epidemiological studies.

To the best of our knowledge, this review is among the first to approach tailoring from this specific perspective in which second generation tailored intervention studies conducted in this context were analyzed. The 23 studies selected met the criteria for the content analysis of the specific aspects of the interventions: objectives of behavior change, target groups, sample sizes, lengths, attrition rates, theories applied, intervention designs, computer-based channels used, and the statistically significant outcomes of the interventions from the perspective of tailoring.

This review shows that the use of tailoring could have been effective in second generation interventions aimed at behavior change in nutrition, although the outcomes were mixed for physical activity and weight management. This conclusion is in line with earlier analyses. However, the analysis presented here adds to this knowledge by indicating the influence of biases on the outcomes of the interventions. In our analysis, the intervention design had a distinct effect on the outcomes of physical activity interventions. Thus, we suggest that the issue of bias should be considered more often in planning interventions and also considered in future meta-analyses.

Tailoring of health information is the subject of research in various disciplines. It is one of the tools of persuasive technology, which aims to change attitudes or behaviors through persuasion and social influence [86,87]. An important aspect of interventions is information delivery. To accomplish this we must have an understanding of the information behavior and information practices of the people to whom the information to be delivered is tailored. The discipline of information studies has the potential to fill the gap in the existing knowledge and contribute to theory building within this multidisciplinary research area. This view is supported by the suggestion that information needs should be considered in tailoring [8].

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Conflicts of Interest

None declared

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Abbreviations

ELM: Elaboration Likelihood Model
GST: Goal Setting Theory
HDL: high-density lipoprotein
HPM: Health Promotion Model
ICT: information and communication technologies
PAPM: Precaution Adoption Model
SE: concept of self-efficacy
TPB: Theory of Planned Behavior
TRA: Theory of Reasoned Action
TTM/SC: Transtheoretical Model or stages of change

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Original Paper

Patient and Parent Views on a Web 2.0 Diabetes Portal—the Management Tool, the Generator, and the Gatekeeper: Qualitative Study

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Abstract

Background: The Internet has undergone rapid development, with significant impact on social life and on modes of communication. Modern management of type 1 diabetes requires that patients have access to continuous support and learning opportunities. Although Web 2.0 resources can provide this support, few pediatric clinics offer it as part of routine diabetes care.

Objective: We aimed to explore patients' and parents' attitudes toward a local Web 2.0 portal tailored to young patients with type 1 diabetes and their parents, with social networking tools such as message boards and blogs, locally produced self-care and treatment information, and interactive pedagogic devices. Opportunities and obstacles to the implementation of Web 2.0 applications in clinical practice were sought.

Methods: Participants were 16 mothers, 3 fathers, and 5 young patients (ages 11-18 years; median 14 years) who each wrote an essay on their experience using the portal, irrespective of frequency and/or their success in using it. Two main guiding questions were asked. A qualitative content analysis was conducted of the essays as a whole.

Results: Three main categories of portal users' attitudes were found; we named them "the management tool," "the generator," and "the gatekeeper." One category was related to the management tool functionality of the portal, and a wide range of concrete examples was found regarding useful facts and updates. Being enabled to search when necessary and find reliable information provided by local clinicians was regarded as a great advantage, facilitating a feeling of security and being in control. Finding answers to difficult-to-ask questions, questions portal users did not know they had before, and questions focusing on sensitive areas such as anxiety and fear, was also an important feature. A second category was related to the generator function in that visiting the portal could generate more information than expected, which could lead to increased use. Active message boards and chat rooms were found to have great value for enhancing mediation of third party peer-to-peer information. A certain level of active users from peer families and visible signs of their activity were considered necessary to attract returning users. A third category was related to the gatekeeper function of the password requirement, which created various access problems. This and other unsuccessful experiences caused users to drop the portal. A largely open portal was suggested to enhance use by those associated with the child with diabetes, such as school personnel, relatives, friends and others, and also by young users somewhat unwilling to self-identify with the disease.

Conclusions: Web 2.0 services have great potential for supporting parents and patients with type 1 diabetes by enhancing their information retrieval and disease management. Well-developed services, such as this one, may generate continued use and should, therefore, be carefully maintained and updated by health care professionals who are alert and active on the site with new information and updates. Login procedures should be simple and minimized as much as possible. The education of clinical practitioners regarding the use of Web 2.0 resources needs more attention.

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KEYWORDS

Web 2.0; eHealth; childhood chronic disease; type 1 diabetes; self-care; disease management; patient information; apomediation; networking; social media; learning; health care professionals; children; adolescents; parents

Introduction

The management of diabetes and other chronic diseases is based on the interplay between initiatives and resources on the part of patients, relatives, and health care professionals [1]. Modern pediatric diabetes treatment supports patients in gradually becoming their own treatment experts, and thus the balance in shared responsibilities is shifting over time to patients and their families [2]. This requires families to continue learning and to keep updated regarding treatment, self-care, and scientific findings. In recent decades, many pediatric diabetes practitioners have made efforts to enhance peer-to-peer support and learning with activities such as group education, evening meetings, parent groups, camps for adolescents, mailing list discussion groups, and chat rooms [3-7]. Meanwhile, information technology has undergone rapid development impacting significantly on social life and modes of communication [8]. Technical advances provide a foundation for proactive health systems that use information from multiple sources for support aimed improved health and avoidance of health risks [9]. These networked systems are increasingly connected to the world around them often through the use of portable devices, such as laptops and cell phones. Web 2.0 is an umbrella term describing a range of new collaborative Internet applications [9]. Compared to the earlier Web 1.0, Web 2.0 allows increased user participation in developing and managing content; this has changed the nature and value of the information [10]. This has resulted in dramatic changes in possibilities for informal and self-directed information seeking by individuals, implying that the individual is in command of what information should be sought and why it is important. A continuously greater proportion of online health-related information is created and maintained by apomediation from individuals other than health professionals, such as other patients [9]. Moreover, new criteria are being developed for evaluating the quality of medical advice [11]. Case studies of young people with a chronic health problem have found that young people are enthusiastic about “one stop shopping” sites that target them and their needs. Such sites might include focused chat rooms and message boards, for example [12].

The eHealth resolution WHA58.28, approved in 2005 by the World Health Assembly, stresses the importance of eHealth [13]. The resolution urges member states to make a range of efforts to develop eHealth services for all health sectors and create long-term strategic plans for development and specific implementation, such as reaching communities and vulnerable groups with services appropriate to their needs [13]. There is no doubt that such efforts are relevant for the care of children and adolescents with chronic disease. Interest in searching for health-related information online has been found to be greater among young people with type 1 diabetes and their families than in the general population [14]. Modern treatment of type 1 diabetes includes individualized education, intense multiple-dose treatment regimens, active self-control, and new insulin and insulin delivery technologies [15-17]. Nevertheless, a large proportion of young patients are still at risk for acute and/or long-term complications [18-20]. According to young Swedish patients with diabetes and their parents, improvements are needed regarding patient information and access to services [21]. For adult patients with diabetes, Internet-based interventions may improve access to health services, patient education, and quality of care, and have also been reported to influence these patients’ health care utilization, behavior, attitudes, knowledge, skills, and, to some extent, metabolic control [22-26]. For example, adult patients with diabetes have been perceived online support groups as helpful in improving coping strategies [27]. Interestingly, patients with poor metabolic control, and those with greater use of health care services, higher motivation, and/or less experience with diabetes treatment seem to benefit more than others from the use of electronic communication [28]. Improved quality of life has been reported, but overall, there has been little focus on patient perspectives in clinical studies [28].

However, clinical implementation of Internet-based support systems for young patients with type 1 diabetes seems to be a slow process compared with the rapid technological developments. While young patients frequently connect to various online networks, few of their health professionals are presently familiar with the rapidly emerging social network applications on the Internet. We found few Web 2.0 systems in routine use in pediatric diabetes care that have been developed and evaluated in collaboration with diabetic children and their families, although some studies have suggested potential benefits [7,29-32].

Proactive development of Web 2.0 applications including modern pedagogic devices has received little attention as compared with resources spent on care of late complications of diabetes. The Linkoping Diabit study, which served as a case study in this paper, is a bottom-up project run by practitioners and clinical researchers. Recently, a number of positive attitudes among practitioners involved in the development of the Diabit Web 2.0 portal were reported [33]. The present study highlights views and voices on the portal from a sample of young patients with diabetes and their parents.

The aim of this study was to explore patients’ and parents’ attitudes toward a local Web 2.0 portal tailored to young patients with type 1 diabetes and their parents. Opportunities and obstacles to the implementation of Web 2.0 applications in clinical practice were sought.

Methods

Process of Care

In Sweden, all children and adolescents with diabetes are treated by hospital-based pediatric diabetes teams consisting of nurses and nurse specialists, physicians and dieticians, social workers, and/or clinical psychologists. The practitioners meet the young patients, along with their parents, when hospitalized at onset, and continue to see them as outpatients over many years. The process of care, the treatment policy, and perceived quality of care have been described elsewhere [16,21].

Web 2.0 Portal

During the spring of 2006 the research group and the two participating diabetes teams launched an Internet portal named Diabit for invited patients and parents. This portal contained specific diabetes-related information and social networking functions such as message boards and blogs. The portal had been gradually developed from a previous design model, and a prototype was piloted in 2005 [32-34]. The user-centered design process for the portal and its contents included iterative sessions conducted over a long period of time with groups of patients and parents as well as with the involved diabetes teams.

The content of the portal was designed to be used by children, parents, and their practitioners who belonged to the respective local patient communities of the two hospitals. For younger children, the portal was targeted at their parents, and for children 12 years of age and over, the portal invited both parents and adolescents, based on adolescents' growing responsibility for their treatment along with their increasing maturity and need of autonomy. For the community areas in the portal, there was a set of rules for use based on common sense and national laws, with individual users responsible for the information provided.

The portal also included extensive text pages, education videos and online simulation software, which has been described elsewhere [31]. The practitioners' information was based on scientific evidence and best clinical practice and aimed at creating a trustworthy and reliable source of information. Specific diabetes-related information on 13 main topics, divided into 99 subtopics/web pages had been written by an author group consisting of a nurse, a physician, and a dietician (Figure 1). The text at the bottom of the screen in Figure 1 shows the names of those who wrote and revised the webpage (giving names and affiliations), as well as the date of the last update.

Figure 1. A sample of practitioners' information, entitled "I made a mistake with the insulin!" with advice for specific emergencies.

Jag gjorde fel med insulinet!

Om snabbinsulin gavs istället för basinsulin
Ät mat och följ blodsockret en gång i timmen de närmaste fyra timmarna. Ge även halva dosen basinsulin direkt.

Om basinsulin gavs istället för snabbinsulin
Lägg till en halv dos snabbinsulin och minska ev. till halva dosen vid nästa måltid. Följ blodsockret varannan timme i 6-8 timmar.
Om felet görs vid frukost eller lunch, ge vanliga kvällsdosen basinsulin. Om felet görs vid middag eller senare, ge lägre dos basinsulin på kvällen.

Om rätt insulin gavs dubbelt
Ät motsvarande mer mat och följ blodsockret en gång i timmen de närmaste timmarna. Hur länge beror på insulinsort. Vid direktverkande insulin följ blodsockret varje halvtimme i början.

Skrivet av: Lena Hanberger, sjuksköt, Barnklin, US Linköping
Granskat av: Rosita Ilvered, barnsjuksköt, Britt-Marie Weidby, sjuksköt, Barnklin, Ryhov, Jönköping, Ann-Marie Sandström, barnsjuksköt och Ulf Samuelsson, barnläk, docent, Barnklin, US, Linköping
Senast uppdaterad (2006-03-22)

As a next step, each section was discussed, revised, and cosigned by independent multiprofessional groups from the two hospitals. The portal also provided various services for medical prescription renewal, making appointments, sending questions, viewing questions and answers, contact information, photos of staff, and other general information about the local diabetes teams and their services. In addition, each respective group of professionals comprising the two local diabetes teams summarized important basic information using a personal tone when expressing, "What I may say to newly diagnosed children and their parents."

Study Population and Data Collection

The participants were parents and pediatric patients treated by diabetes teams at two pediatric clinics situated in southeastern Sweden that treat populations in their catchment areas of approximately 200 and 250 patients, respectively, below 19 years of age. During a clinical intervention study from 2006 to 2008, patients aged 12 to 18 years and mothers and fathers of all 510 patients were offered a personal password to the portal. Excluded were 18 families that declined to participate as well as 8 families that had been transferred to other centers. Thus, 484 invitation letters with one reminder were sent in September 2008 by mail (and, when possible, by email) asking recipients about their experiences using the Web portal, Diabit. Recipients could choose to respond either by email or by mail to an independent researcher who was not their practitioner. Of the 24 individuals who responded, 16 were mothers, 3 were fathers, and 5 were young patients aged 11 to 18 years old (median 14 years).

In the letter of invitation, patients and their parents were asked to write an essay about their positive as well as negative experiences using the portal, irrespective of frequency of use and/or success in doing so. Two leading questions were asked, followed by clarifying questions. These were: (1) Tell me about a situation when you succeeded in using Diabit. Has Diabit made managing the disease easier in any way? Are there any advantages in using Diabit? (2) Tell me about a situation when you did not succeed in using Diabit. Has Diabit become an obstacle in some way? Are there any disadvantages in using Diabit.

Nonusers

Of the 24 respondents, 4 reported not having used the portal. The essays of one father and one mother who shared their reasons for nonuse were included, as well as the essay of a nonuser mother reflecting on user experiences of others and perceived needs. One young respondent was excluded who simply stated,

> *I don't have any experience at all with Diabit, I haven't used it at all* [boy]

Thus, the respondents consisted of 23 persons.

Analysis

Considering the explorative aim of the study, the respondents' essays were analyzed as a whole using techniques of conventional qualitative content analysis [35,36]. Qualitative content analysis can be applied to transcribed interviews, texts, narratives, letters, documents, protocols, and media, for example [37].

The analyses were performed by two of the authors (SN and CB), one of whom (CB) maintained a supervisory role throughout the study and was experienced in the methods used for data collection and analysis as well as in nursing and nursing research. The first author (SN) was experienced in clinical research, care of the target group, and the design and elements of the Web portal system.

Before beginning the analyses, both of these authors read all the primary data. As the text material was read, statements with similarities were clustered and summarized into tentative positive and negative categories based on the questions asked. The tentative categories with all respective statements were reviewed in detail. Unclear statements were explored with respect to the original context. Through iterative in-depth discussions, SN and CB recategorized the statements in a stepwise fashion, and a more logical and complete structure gradually emerged. After completion of this process, the material was put aside for six weeks of complete time-out. After this time-out, the complete sentences from the original text material were again reviewed in their original context and condensed into final categories by the same two authors, and final adjustments were made. Thus all the categories were validated through systematic repeated reviews of the material. To confirm and illustrate the categories and subcategories selected, quotations related to the respective categories were selected during the categorization process. The quotes used in the results section were selected to illustrate themes emerging from all respondents' statements.

Thus, the essays were analyzed and categorized by SN, and CB read and scrutinized the texts and the categories as well. For reliability, comparisons were made between SN's and CB's categorizing. Any discrepancies were resolved through discussion; no measure of interrater reliability was used. The risk of bias due to the authors' preconceptions or expectations was prevented as far as possible through the repeated validations of the primary data and the in-depth review sessions.

Ethics

The study was approved by the Research Ethics Committee of the Faculty of Health Sciences at Linköping University, Linköping, Sweden.

Results

Three main categories of attitudes were identified/constructed during the analysis and given the names "the management tool," "the generator," and "the gatekeeper." As shown in Table 1 each main category included a number of subcategories at varying levels of abstraction, and the categories were linked together by the underlying meanings [35].

Table 1. Overview of categories and subcategories

The Management Tool	The Generator	The Gatekeeper
Being enabled to find useful information and services	More than expected	Issues with passwords
Impact of diabetes experience and the disease trajectory	Peer-to-peer communication	Identity and stigmatization issues
Information available whenever needed or "just in time"		
Information perceived as reliable		
Availability of help in spite of limited resources of the local care teams		
Reasons for dropping the portal and suggestions to increase use		

The Management Tool

As is the case when driving a car or running a complicated machine, it is necessary to manage the process of treatment and self-care of a long-term disease. To manage a process, certain tools are usually needed, some of which may be related to adequate and reliable information. With respect to diabetes treatment and self-care, reliable online information tools might be of value, and access to the tools at the time when the information is actually needed may increase their usefulness.

A set of positive attitudes toward the portal was presented by users of different ages and with different durations of diabetes experience. The portal was experienced as a well organized website, where it was easy to find one's way around. Some respondents succeeded in logging onto Diabit every time they tried to do so, and these respondents stated that the portal was a good, reliable place to find current information and facts. Respondents also expressed that Diabit was valuable and that further use would be worthwhile. A parent of a newly diagnosed boy wrote:

> *I've succeeded in using Diabit every time I've tried. I think it's good with very interesting information.* [father]

Young Diabit users wrote:

> *I think the website is good and it's good that there are a lot of facts.* [girl]
>
> *I think Diabit is a good and simple site. It's easy, smooth, cool, and really interesting to log onto Diabit.* [girl]

Being Enabled to Find Useful Information and Services

Being enabled to succeed in a search for specific information seemed to be valuable both in general terms and regarding specific issues. The respondents reported a wide range of individual experiences concerning useful facts and updates on food, carbohydrates, the significance of fat, exercise, glycosylated hemoglobin and blood glucose, locally prescribed devices, the function of glucose meters in very cold weather, and current research in the field of diabetes. Furthermore, respondents also reported that it was helpful to be enabled, when needed, to make online blood glucose diagrams, to find contact information and information about the local staff, information about dealing with errors in insulin doses that had just occurred, and about insulin treatment when afflicted with acute gastroenteritis. Being able to find answers to difficult-to-ask questions, to find answers to questions they did not know they had before, and to find answers to questions focusing on sensitive areas such as anxiety and fear were also described by respondents as important functions of great benefit.

> *As a parent you need to read and hear about the importance of carbohydrates, the importance of fat, and so on, many times...* [mother]
>
> *When my daughter felt mentally unwell last fall, the website was of great help to me since I could find information about anxiety and diabetes.* [mother]
>
> *I think it's important to be able to log onto the site and read it yourself without needing to ask questions that might be difficult to ask.* [mother]

Thus, there appeared to be a great need for general and specific information about diabetes and self-care. Users' success in retrieving problem-based information might facilitate being in control and coping with the disease in daily life.

> *Since there was no diabetes in our family, we were poorly informed about the disease. We've found quite a lot of useful information about diabetes on Diabit, both my husband and me….Thanks to that information and being able to surf around and read about different issues, everything from alcohol to exercise, trips, etc, we've gotten much better control.* [mother]
>
> *There's so much you want to get answers to….Diabetes is a tough disease especially in the teenage years, both for children and adults.* [mother]

Impact of Diabetes Experience and the Disease Trajectory

The actual need may vary according to previous diabetes experience and other factors. The portal appeared to be of particularly great advantage for the more recently diagnosed young patients and their families. Some respondents reported greater use during the period shortly after onset of the disease, and others suggested that the portal was of great interest for those who were newly diagnosed.

> *I think we would have used Diabit a lot if he had gotten his disease now.* [mother]
>
> *Diabit worked well with information about diabetes, especially in the beginning when we were searching for a lot of information.* [mother]

On the other hand, the experience of already being in control and having felt secure with the treatment over a long period of time was one reason for limited use of the portal. Previous good contact with the practitioners, good continuity over time regarding such relationships, sufficient personal experience with living with diabetes, and perceived long-term success regarding treatment were mentioned as factors that might contribute to a low perceived need for repetitive use of the portal.

> *When my son was diagnosed with diabetes, I had had the disease myself since the age of 19, and I therefore already had a lot of knowledge about it…I think the website is well done and informative; it's just that I often have the knowledge and experience needed to solve different problems or plan for different situations, which means that I seldom visit the site…* [mother]
>
> *We logged onto Diabit in the beginning…Because things have gone so well for him, it hasn't felt like there was a need to visit Diabit anymore. It happens less and less. If any questions arise, we might do so, but we're in close contact with the doctor and nurse so maybe we turn first of all to them.* [mother]

Information Available Whenever Needed or "Just in Time"

Being enabled as a parent or young patient to search for facts at the time they are needed, thus to find answers to current questions and to keep updated with the flow of information was regarded as a useful feature and as making life with diabetes easier. Logging onto Diabit from any computer and being able to get tips and advice, that is, getting theoretical information transformed into practical action, was appreciated and considered to be of great value.

> *Diabit makes it easy if you want to find an answer to some question you have. I see only advantages in using Diabit.* [mother]
>
> *I think it's great that there's a search engine you can use if you want answers about diabetes….Everything's gotten easier, I think it's positive….Everything about Diabit is positive, I often log on and check what's there.* [mother]
>
> *Diabit makes it easy for me to quickly find answers to certain questions. I can log on at school if I need to. I haven't failed to log onto Diabit. It's easy to log on.* [girl]

Information Perceived as Reliable

Respondents expressed a feeling of security in knowing that information and facts found on the portal had been checked by the local care teams. Thus, being enabled to find correct, reliable information provided by local practitioners was regarded as very advantageous, making it easier to feel secure and in control.

> *A big advantage with Diabit is that you can feel sure that the information you read there is correct. There's naturally a huge amount of information on the Internet, but you can never be sure that there's a reliable source for everything you read.* [mother]
>
> *I think Diabit has been good since we know the facts and the information have been checked by those who are treating him.* [mother]

Availability of Help in Spite of Limited Resources of the Local Care Teams

Respondents assumed that in light of limited access to the practitioners, the portal could be especially useful when help was needed.

> *…it has been and is hard to get in touch with the diabetes nurse. They're very busy and there's nowhere to email, only voicemail that works poorly. So if you need help I think you have definite problems. Then Diabit is certainly helpful.* [mother]

Reasons for Dropping the Portal and Suggestions to Increase Use

Various unsuccessful user experiences, such as few hits from a specific search or seeing that there had been little activity in the practitioners' news and updates sections of the portal, could create the perception that the practitioners were not "on their toes" (ie, alert to new developments and updating the information on the portal in a timely fashion). This could cause the user to drop the portal.

> *On the other hand it feels like not much "happens" on that website, I mean it's not updated often enough…Of course it depends on the users, but the updates also have to do with other issues.* [mother]

Individual respondents also expressed experiencing that the portal was valuable and that further use would be worthwhile. One respondent suggested using the portal to prepare for clinic visits, such as by filling in a form online with treatment updates and issues that the clinician should be aware of.

> *I have no idea whether or not the website is visited a lot. But it's absolutely worth more visits and more activity…A possible suggestion is that before the visit each individual could write his or her "report" on the Internet, prescriptions that are needed, and questions that might be asked, so that if possible, the diabetes nurse or the doctor can be prepared. Maybe a simple questionnaire?* [father]

Regular use of reminders was suggested to enhance use of the portal in the context of clinical care, and the view was expressed that the technical format of emailed newsletters should be kept simple.

> *A tip for you might be to send a reminder at regular intervals about the website's existence or when there's some news to read. As a user it's a matter of seeing that you benefit from the website, but also that you are in the habit of regularly going out on the site and reading. I really and truly believe that this website has an important function.* [mother]
>
> *Can't you simply send the newsletter and other things as regular text, this way I only get a nice picture and a jumble of meaningless letters. You don't need a lot of fancy formats, the information is what you should get.* [mother]

The Generator

A generator can mean many things and have many functions. One function is to convert one form of energy to another, for example, electric current that can be used for different needs. Visiting the portal may generate more information retrieval than initially planned, which may lead to increased use. In addition to benefits described in the previous categories, the interactive sharing of information mediated by patients and parents themselves seemed to be of particularly important value.

More Than Expected

A successful experience in using the portal could generate positive feelings and contribute to immediately extending use, to a new plan for continued use, and to a new desire to use the portal again. Such unplanned expansions of information retrieval could even include relevant issues about which the user might not yet have formulated any specific questions.

> *...I sought information about something and didn't find anything about just that, but a lot of other useful things…for example, information about those*

> *questions you don't think of asking yourself, since you don't know anything about those things.* [mother]

A young Diabit user wrote:

> *The last time I was out on the Internet I wondered a little about how things were going in research. I thought that I'd log onto Diabit and check. Once I was there, I sat almost an hour and read different texts and even other things. I'm not that "old" yet but have always liked to read and am interested in my diabetes and do as good a job as I can. I thought it was really interesting, and time just flew.* [girl]

Peer-to-peer Communication

Regarding Web 2.0 services, active message boards and chat rooms were considered of great value for enhancing mediation of peer-to-peer information. Parents who had been enabled to share experiences with others online found it advantageous. One respondent with extensive personal experience with diabetes said that peer-to-peer communication between parents was a necessary element for the success of the portal.

> *I thought it was good to be able to read about the experiences of others. We aren't alone in this.* [mother]
>
> *Maybe Diabit can be something good, but that requires parents to give advice to parents.* [mother]

Parents thought that an active message board and chat room would be beneficial, since being able to share experiences with others in "the same situation" was considered positive. A young respondent expressed a clear view on the need for a more functional chat room:

> *I want a better chat room on Diabit; it's hard to understand what to do and how chatting works.* [girl]

Respondents were of the opinion that to attract returning users, it was necessary to have a certain number of active users from peer families and visible signs of their activity on the message boards.

> *I checked the message board a few times when it was new, but it hadn't gotten started much yet.* [mother]
>
> *I hope the forum page really gets going with many users, since it's good to be able to share experiences with others in the same situation.* [mother]

The Gatekeeper

A gatekeeper is someone or something that guards or monitors passage through a gate for some reason, for instance, by restricting or sometimes facilitating a flow of knowledge and information. A gatekeeper may sometimes also deny and, therefore, prevent entrance to some people.

The major theme from reported negative experiences regarding the portal was related to various problems caused by restricted access. Thus it appeared that the effects of technical password procedures had the function of a gatekeeper.

Issues With Passwords

Password procedures, that is, having the key to the gatekeeper, appeared to limit the number of new users as well to limit access to the portal for some returning users. A gatekeeper effect from login procedures was created both by preexisting personal attitudes of users and by incidents of personal mismatch with use of the current login system. Such unsuccessful experiences might have led to discontinued use.

> *I think Diabit is valuable for those who have diabetes. But having to use a password is complicated…* [mother]
>
> *We haven't used Diabit very much; the main reason for that has been that you have to have a password.* [mother]

Procedures for replacing lost passwords could create problems, and standard registration procedures with the option "create your own password" could also do so.

> *The problem I experienced was when a password was needed to log onto the website. I happened to lose my password and had problems getting a new one.* [mother]
>
> *I logged onto the website one time and then tried to change my password. The next time I wanted to visit, neither my new password nor my old password worked. Since then I haven't logged onto the site again.* [girl]

In addition, information about logging onto the website that practitioners gave to newly diagnosed patients was sometimes delayed and even contradictory, with the result that the potential user gave up and dropped the idea of using the portal.

> *…it took a while to get a password for the website.* [mother]

A largely open portal was suggested in order to make access easier for all patients and professionals, not only for practitioners, but also for school personnel. An open portal would facilitate its being used by others related to the child with diabetes, such as relatives and friends.

> *Also good in that you can recommend that school personnel can log onto Diabit and search for information and support concerning how they can handle their support of children with diabetes.* [mother]

Identity and Stigmatization Issues

Users with particularly negative feelings about their disease and/or health care experiences might not be willing to go through the procedure for logging onto a disease-specific portal. Some respondents expressed thoughts about children or adults being forced to participate in something like a disease fellowship. Some ambiguity was expressed concerning this issue; identifying oneself as a person with diabetes was sometimes seen as beneficial and sometimes seen as detrimental.

> *I haven't bothered logging onto Diabit since I'm quite "care-injured" after many years in diabetes care with all that has involved in terms of a lack of integrity, meddling, ignorance, and an inability to see the whole patient.* [mother]

> *…my son has refused to use it at all. He doesn't want to identify himself through his disease at all and thinks it's embarrassing and hard to be on a disease-related website* [mother]

Based on individual experiences, to some respondents, an open portal seemed to be more in accord with the view that there are no secrets about having diabetes and that the disease is no one's fault. The view they expressed was that an open portal might lead to more frequent use by people somewhat unwilling to identify with the disease; that is, if the portal were more open, then the issue of identification would be downplayed.

> *There aren't really any secrets, right? It isn't anyone's fault that you have the disease…* [mother]

> *I have a little trouble with the fact that you have to log onto the website as a whole, and I should think it would be enough if only certain parts required a login. For example, this would make it easier for my son if he got a sudden whim and wanted to have a quick look at the website, and it could also be good for relatives or friends who seek information.* [mother]

Discussion

This study confirms the well-known need for information related to childhood type 1 diabetes [1,21]. Variation exists over the course of the disease and between individuals in the early stages of the disease as well as in individuals' approaches to daily self-care, and a long-term perspective to supporting these individuals and their varying needs is required [2,19,20,28]. At a time when young people are increasingly using computers and cell phones to connect to networks all over the world, health care practitioners and their service providers need to be alert to new developments in health services and health information for young people with diabetes and their parents.

The Management Tool

As previously reported, young patients and their parents value being able to search for specific information when needed [14]. Adolescents and parents have expressed a wide range of specific needs that can be well understood and verified from a clinical perspective [1,5,6]. Findings from the current study as well as earlier studies suggest that enhanced online access to information might contribute to improved coping with the disease and increased control [28].

Regarding previously discussed security and trust issues [11,38], the perceived reliability of the information contained on the portal indicates its advantages for both patients and professionals. Reported positive experiences of finding reliable information may be due to the fact that local practitioners have been responsible for the portal, which contains specific articles written by the practitioners that are signed and personally updated by them (Figure 1). As long as patients and parents feel secure about the information available through the portal, successful management of diabetes is likely to be enhanced. Practitioners, on their part, are able to control the information they provide and refer to it in their practice whenever needed [33].

Although the Web 2.0 portal was found to be of great value in diabetes management for parents and patients, the portal did not appear to be easily handled by involved practitioners. And if users perceive that information is updated too infrequently, or if users are unsuccessful in finding the information they need, use of the service may decline. As has been previously pointed out, more attention needs to be paid to the education of clinical practitioners and others involved in the management of childhood chronic diseases using Web 2.0 resources for parents and patients [33,39,40].

The Generator

Successful use of the portal appeared to generate more information retrieval than planned by the users; some spent more time on the site, and some found more information than expected or found other useful information and returned to the portal more often. Patients' and parents' accumulated experiences from everyday life form a knowledge base from which information can be shared with others [9]. Active message boards and chat rooms are of great value, as has been reported previously by young people with HIV [12]. Parents may inform other parents about a wide range of issues, as can adolescents and children at their own level based on their maturity and autonomy. Younger children may use occasional chatting simply for enjoyment and to identify with others with diabetes, as it may be difficult to find peers with diabetes in their physical neighborhoods. The opportunity for interaction with others distinguishes the Web 2.0 portal in this study from traditional computer-based education efforts related to diabetes or other chronic disease. With evolving Web 2.0 technology, traditional authorities are increasingly being replaced by apomediaries, which are tools or peers that lead to trustworthy information or add credibility to information [9,10].

Thus it appears from the data that the apomediated information and support from peers in a Web 2.0 system is of added and unique value, and that this type of information and support cannot be replaced by practitioners' information per se. In order to attract users and make use of the generator effect, a living site is needed that incorporates social media such as active message boards, chats and blogs, as well as frequent news and updates from practitioners [33]. Some subjects' perceptions of a low level of activity on the portal reflect that initially the portal was open only for selected patients in a clinical study and that practitioners were not used to the new technology. Health care administrators and stakeholders should focus on expanding clinical practitioners' use of interactive Web 2.0 services for improved care and support of people with long-term diseases [33].

The Gatekeeper

A factor that limited spontaneous and active use of the portal was the login requirement for access. Many negative experiences with logging onto the portal were expressed by the respondents, ranging from problems with practitioners' distribution of preprepared passwords to their newly diagnosed patients to the automatic and manual procedures for replacing lost passwords. Indeed, the most commonly reported negative experiences were related to various problems accessing the portal. It appears that the effects of technical password procedures had the function of a gatekeeper, always letting some people in, letting some people in sometimes, and not letting other people in at all. This confirms previous reports that users do not like to use sites that require them to log in [11]. As of today, this potential gatekeeper effect has received little attention in the medical context, and its clinical significance remains largely unknown. It must be stressed that practitioners and system designers developing Web 2.0 systems should pay attention to the risk of creating a digital divide in their use of interventions that require login procedures. Moreover, the risk of selection bias occurring in studies that require a login procedure is obvious.

Based on respondents' perceptions of the usefulness of the portal, further development of the portal seems warranted. Specific suggestions from users especially targeted the gatekeeper effect. Thus a largely open portal was suggested in order to facilitate access for all patients and professionals, including school personnel as well as health practitioners. An open portal would also facilitate use by other persons associated with a child or youth with diabetes, such as relatives, friends, and others. It may be that use by young people with diabetes who are somewhat unwilling to identify with the disease would also be enhanced. Experiences related by respondents indicated that an open portal would be more in tune with the view that there are no secrets about having diabetes, and that the disease is no one's fault. Finally, due to age limits of the pediatric clinics involved and the login required, the portal Diabit during this study targeted selected patients below 19 years of age only. In the future, such resources should target the needs of older adolescents with long-term disease. These young people are in a vulnerable period of establishing their habits and strategies for daily life as an adult living with the disease, and they may also have further experiences to share.

Thus a reasonable approach for practitioners and system designers who develop Web 2.0 systems would be to keep as many functions as possible open, without password requirements, and, when it is necessary to use login procedures, these should be as simple as possible. To enhance openness, participation, and collaboration, we believe that users of the Web 2.0 portal described in the present study should have open access to information supplied by their practitioners and peers, although registration and login may be required to contribute personal comments. Following completion of this study, an open version of the portal was launched.

Limitations of the Study

Because qualitative methods were used to gain a deeper understanding of the respondents' reality, it is not possible in this study to make generalizations in a quantitative manner. A mixed methods methodology would allow gathering of both narrative and numeric data, but that implies asking a different research question [41]. Because self-directed essay writing about a topic gives the respondent opportunities to reflect, the two primary questions asked allowed respondents to reflect on positive experiences as well as negative ones. The majority of the respondents were parents; the views of young patients of different ages were not well represented. Hence transferability of the findings should take into consideration the size and characteristics of the sample. Nevertheless, our findings may be similar to what would be found in other populations [42].

Future Research

Further clinical evaluations from the perspective of young patients' daily life are needed regarding Web 2.0 environments designed to support coping with chronic disease. More information on needs expressed by young people themselves remains to be obtained, including information about the needs of adolescents at a later stage of the disease. Studies are warranted that would also take into account the views of larger samples of young patients and their families. Interactive systems integrating individual feedback and data monitoring designed for patients with diabetes need further development and evaluation, again, taking into account patients perspectives [28]. Moreover, factors of importance for success and failure need to be identified in patients' use of social media for their health issues.

Conclusions

This study suggests that Web 2.0 services have great potential for supporting young patients with type 1 diabetes and their parents, improving their ability to retrieve information, with the goal of enhancing diabetes management. Well-developed Web 2.0 services may contribute to greater use of these services and be more beneficial than initially planned. Such services should be carefully maintained by health care professionals who are "on their toes," that is, alert and active on the site with new information and updates in the field. When designing Web 2.0 services for young patients and their parents, login procedures should be simplified as much as possible. For the management of chronic diseases, Web publishing, social networking, and other Web 2.0 resources seem to be useful from the patient's perspective. Practitioners may need education, support, and guidelines to help them use these strategies optimally in collaboration with their patients.

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Conflicts of Interest

None declared

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Mobile Therapy: Case Study Evaluations of a Cell Phone Application for Emotional Self-Awareness

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Abstract

Background: Emotional awareness and self-regulation are important skills for improving mental health and reducing the risk of cardiovascular disease. Cognitive behavioral therapy can teach these skills but is not widely available.

Objective: This exploratory study examined the potential of mobile phone technologies to broaden access to cognitive behavioral therapy techniques and to provide in-the-moment support.

Methods: We developed a mobile phone application with touch screen scales for mood reporting and therapeutic exercises for cognitive reappraisal (ie, examination of maladaptive interpretations) and physical relaxation. The application was deployed in a one-month field study with eight individuals who had reported significant stress during an employee health assessment. Participants were prompted via their mobile phones to report their moods several times a day on a Mood Map—a translation of the circumplex model of emotion—and a series of single-dimension mood scales. Using the prototype, participants could also activate mobile therapies as needed. During weekly open-ended interviews, participants discussed their use of the device and responded to longitudinal views of their data. Analyses included a thematic review of interview narratives, assessment of mood changes over the course of the study and the diurnal cycle, and interrogation of this mobile data based on stressful incidents reported in interviews.

Results: Five case studies illustrate participants' use of the mobile phone application to increase self-awareness and to cope with stress. One example is a participant who had been coping with longstanding marital conflict. After reflecting on his mood data, particularly a drop in energy each evening, the participant began practicing relaxation therapies on the phone before entering his house, applying cognitive reappraisal techniques to cope with stressful family interactions, and talking more openly with his wife. His mean anger, anxiety and sadness ratings all were lower in the second half of the field study than in the first ($P \leq .01$ for all three scales). Similar changes were observed among other participants as they used the application to negotiate bureaucratic frustrations, work tensions and personal relationships. Participants appeared to understand the mood scales developed for this experience sampling application and responded to them in a way that was generally consistent with self-reflection in weekly interviews. Interview accounts of mood changes, associated with diurnal cycles, personal improvement over the course of the study, and stressful episodes, could be seen in the experience sampling data. Discrepancies between interview and experience-sampling data highlighted the ways that individuals responded to the two forms of inquiry and how they calibrated mood ratings over the course of the study.

Conclusions: Participants quickly grasped the Mood Mapping and therapeutic concepts, and applied them creatively in order to help themselves and empathize with others. Applications developed for mobile phones hold promise for delivering state-of-the-art psychotherapies in a nonstigmatizing fashion to many people who otherwise would not have access to therapy.

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KEYWORDS

Mood phone; experience sampling method; ecological momentary assessment; cognitive behavioral therapy; affect; mood; emotion; mobile phone; self-assessment; Mood Map; cellular phone; psychotherapy; stress; technology; sampling; user centered design

Introduction

Emotional self-awareness is an important skill for personal health [1,2]. Awareness of emotional patterns helps people recognize the situational nature of distress, and over time, to modulate their reactions to stressful events. The ability to monitor and modulate emotional reactions, that is, self-regulation, impacts both mental and physical health [3]. Particularly important for cardiovascular health is emotional resilience, that is, the ability to bounce back quickly from a stressful event [4]. Emotional awareness and self-regulation are becoming recognized as societal issues due to the influence of mood on physical health, interpersonal relationships, civic engagement, and professional effectiveness [5]. Public policy campaigns have called for extending psychotherapy to the large numbers of people who typically do not have access to such services [6,7].

Personal technologies hold promise for helping people learn about their emotional patterns and improve coping in the flow of daily life. Here, we explore mobile phones for extending the well-evidenced practice of cognitive behavior therapy, in which patients learn to modify thought and behavior patterns that contribute to negative emotional states [8]. The appeal of mobile phones as a vehicle for therapy lies in their relatively low cost and lack of stigma, as well as their ability to capture data and offer coaching throughout the day. Experience sampling, a method for prompting in-situ self-report, is well suited for deployment on mobile phones [9]. This technique has been applied previously to understand how a wide range of behaviors and moods vary over time, place, and situations [10]. Prompting at random intervals addresses reporting biases, such as the tendency to recall the most intense and recent emotions [9,11]. Historically, beepers and journals have been the primary tools for experience sampling, but these are cumbersome for long-term use. More recently, Twitter and other microblogging tools accessible through mobile devices, have been allowing many people to sample and share their own behaviors, feelings, and experiences throughout the day.

In this study, we examined the use of a mobile phone application that combined experience sampling of mood with exercises inspired by cognitive behavioral therapy. The intent of the technology was twofold: to gather data trends that could be illuminating to individuals over time and to offer some interventions that could be activated on the spot. This study emerged from a project called Mobile Heart Health, in which mobile therapies were triggered by physiological indications of stress [12]. The physiological sensors, which detected stress according to changes in heart rate variability, were compelling but not easily deployable for extended field trials. Two parts of the Mobile Heart Health system—the experience sampling and the therapies—were tested in the field studies described in this paper. We designed a touch screen Mood Map and several single-dimensional mood scales (Figure 1 and Figure 2) to invite self-reflection and minimize the burden of self-reporting. The Mood Map allowed participants to plot their moods on a two dimensional space, according to their level of physical energy and the valence of their emotional state. This interface was based on the circumplex model, which describes all emotion by these two factors and has been shown to account for 70% of the variance in self-reported affective states [13].

The mobile therapies delivered in our current study were inspired by cognitive therapy interventions. They included visualizations for physical relaxation and cues for cognitive reappraisal. In cognitive reappraisal, patients monitor and correct “attributional biases” in their automatic reactions or interpretations [14]. Biases that have been associated with negative affect include attributing negative events to internal, permanent and global causes, and exaggerating the urgency and morality of situations [15,16]. The reappraisal techniques used to challenge these biases inspired the Mind Scan exercises, one of the mobile therapies described below.

Methods

Participants

Of the ten adults who enrolled in the study, 6 were women and 4 were men. Participants’ ages ranged from 30 to 48 with a mean age of 37 years (SD 5.75). Of these participants, eight completed the study and two discontinued participation due to time constraints. Participants were employees at a large corporation. All had completed a Mayo Clinic Health Risk Assessment in which they indicated a stress level of 3 or above on a 5-point scale. Health coaches showed notices about the study to people they thought might be interested in participating. The notices instructed those who were interested to contact the researcher for more information about the study.

Materials

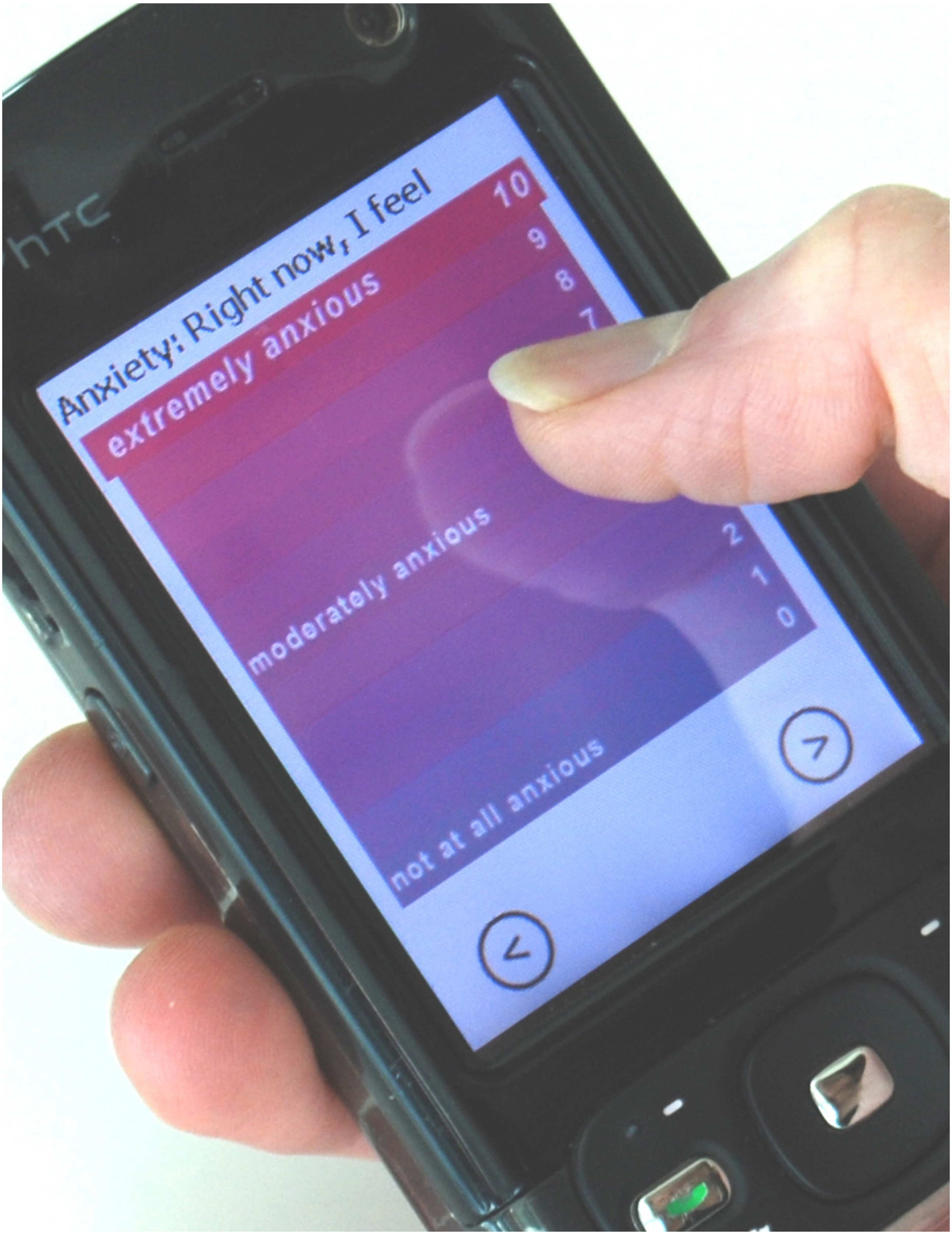
The mood sampling application was run on HTC 3600 mobile phones provided to participants for use during the study. The phones could not be used for phone calls during the study because of complications associated with transferring calling plans. In addition to a phone, each participant was given a charger and a manual that provided detailed instructions and contact information for technical support.

The application consisted of mood reporting scales and mobile therapies. The mood reporting scales included the Mood Map and single-dimension mood scales for happiness, sadness, anxiety, and anger. All scale entries were made via the touch screen. The application logged the time and date of all user interactions.

The Mood Map is a touch-screen translation of the circumplex model of emotion [13], shown in Figure 1. Participants described their mood by indicating its location on a two-dimensional space formed by the horizontal axis of “negative–positive” and the vertical axis of “high–low” energy. The left endpoint of the x-axis, valence, is labeled “negative,” and the right endpoint is labeled “positive.” The bottom end of the y-axis, arousal, is labeled “low energy,” and the top end, “high energy.” When an individual places a fingertip on the appropriate location on the Mood Map, a red dot appears to indicate his or her mood at the time of the experience sampling inquiry. Each axis was intended to capture 15 discrete values, from -7 to +7. An error in data capture limited analysis of the x-axis to a bipolar distinction (ie, whether moods were positive or negative), but the full spectrum of y-axis values, that is, energy ratings, were captured accurately.

Figure 1. Mood Map

Figure 2. Single-dimension mood scale



Single-dimension mood scales for anger, anxiety, happiness, and sadness were used in addition to the Mood Map. These measures of specific emotions complemented the general expression of emotional experience captured by the Mood Map. These mood scales, adapted from a rating scale by Brown [17], were arranged vertically on the screen, with an 11-point range. They were labeled with the specific emotion and were graded in color between the two endpoints. An example, the anxiety scale, is shown in Figure 2. Each scale proceeded from “not at all” (followed by the mood being captured, such as “anxious”) at the bottom of the screen, to "extremely" (again followed by the particular mood) at the top of the screen. The experience sampling application pushed these scales to participants at scheduled times throughout the day.

Participants were prompted for their moods in the morning, evening and throughout the day, using an experience sampling program called MyExperience [18]. The times of morning and evening prompts were determined in the introductory interview, based on each participant's daily habits and schedules. Participants could select prompting intervals ranging from 30 minutes to three hours, but the exact time at which the prompt appeared within this interval varied by several minutes to prevent prepared responses.

To reduce monotony and mindless responses, the prompts alternated between a long and short set of questions. The long query consisted of the Mood Map and all four mood scales: anxiety, anger, happiness and sadness. The short query consisted of the Mood Map and one single dimension mood scale. The single dimension mood scale in the short version depended on the quadrant of the Mood Map response. For example, a Mood Map response in the upper left quadrant (negative mood, high energy) was followed by the anxiety scale, whereas a Mood Map response in the upper right quadrant (positive mood, high energy) was followed by the happiness scale. Participants were instructed to ignore prompts that could disrupt their work or personal communication (eg, a mood query during an important meeting).

Individuals varied considerably in the frequency of their responses: Over the course of the study, the number of mood scale responses ranged from 412 to 828 with a median of 612. Most participants used the application in spurts rather than steadily. On average, participants completed 21 mood scales per day.

Once participants recognized their moods, they could access the "mobile therapies," short translations of cognitive behavioral therapy concepts adapted to the mobile phone (shown in Figure 3, 4, and 5). These could be activated by touching icons on the main screen of the application. The principal mobile therapies included a breathing visualization (Figure 3), a physical relaxation animation called the Body Scan (Figure 4), and a series of cognitive reappraisal exercises called the Mind Scan (Figure 5, described below). The breathing exercise was a blue circle that expanded and contracted slowly to encourage deliberate and slower breathing. The Body Scan included an outline of a human figure with rhetorical questions about where the user might be holding tension, for example, "Are you furrowing your brow?" As the user clicked through the questions, that section of the body outline changed from red to blue.

The Mind Scan was a series of rhetorical questions designed to encourage cognitive reappraisal. The questions addressed cognitive distortions associated with depression, such as attributing negative events to global, stable and internal causes [15]. For example, one Mind Scan screen asked, "Might I be globalizing?" and was accompanied by the example thought, "It's not just that report; it's my whole career." Other distortions, identified by Gorenstein and colleagues [16], related to the perception of annoyances as injustices, translated as, "Might I be making rules out of my pet peeves?" and an exaggerated sense of urgency to resolve an issue, that is, "Might I be exaggerating the urgency of this situation?" Participants could activate the breathing, Body Scan, and Mind Scan features directly or could select "coaching" to access a series of visual prompts for effective handling of interpersonal conflict. All of these exercises could be completed in a minute or less.

Figure 3. Breathing exercise

Figure 4. Body Scan

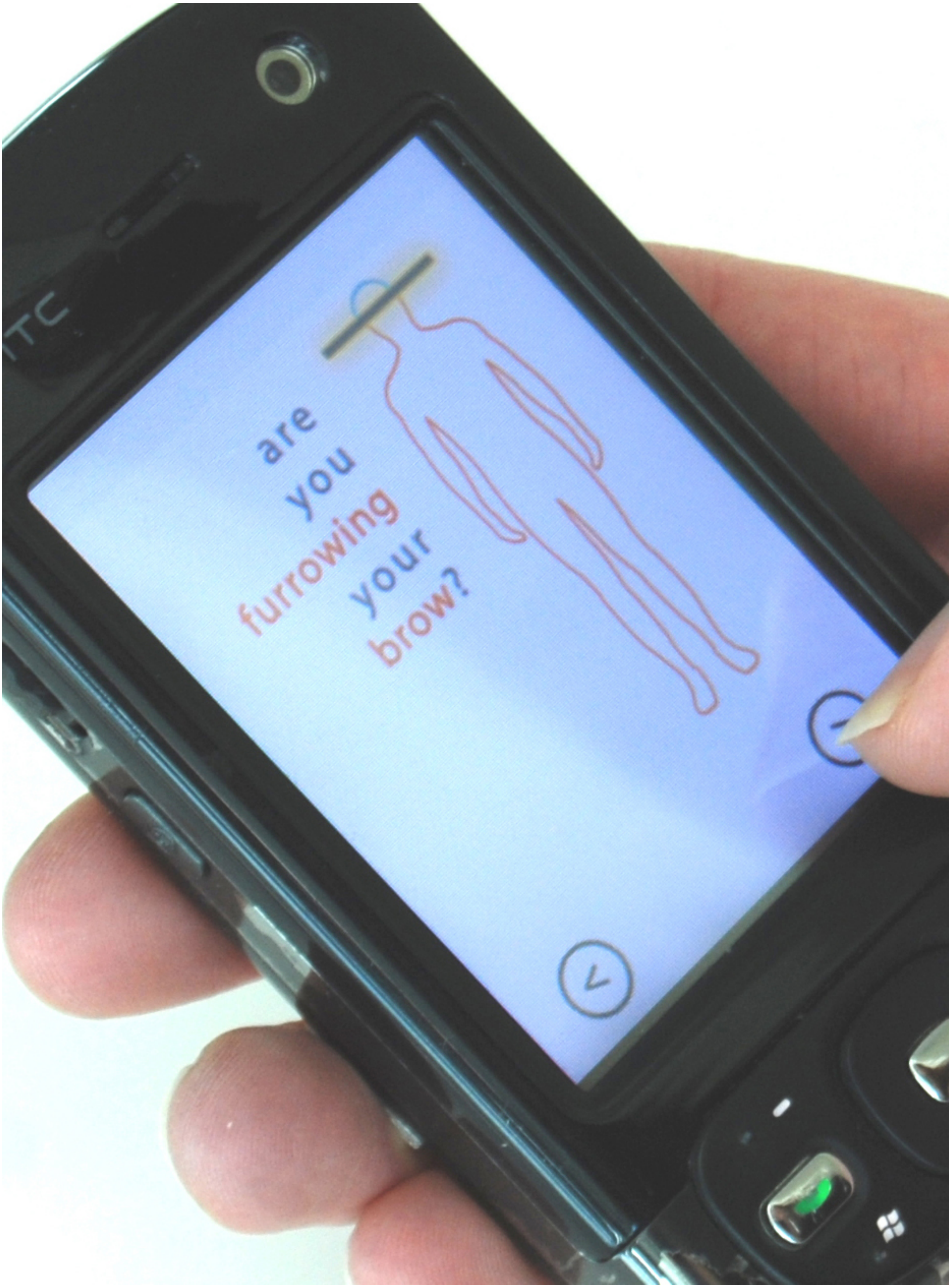


Figure 5. Mind Scan

Procedures

Participants were recruited from a sample of employees who completed a Health Risk Assessment with a health coach. The health risk assessment involved an online survey from the Mayo Clinic that included a question about stress. Those who rated their stress levels as 3 or higher on a scale of 1 to 5 in response to this question were told about the study by the health coach. Potential candidates were given a flyer about the study and told that they could contact the primary researcher for more information.

In a first meeting with the researcher, the application was described and participants were screened for their availability to use the application and participate in four weekly interviews, each approximately one hour in length. Rule-out criteria included extensive travel and current involvement in psychological or psychiatric treatment. These criteria were stated in the consent form, which was read aloud to participants. Training on the phone application, including detailed guidance on Mood Mapping and mobile therapies, occurred in follow-up meetings. Participants were given a phone to use for the study, along with a detailed manual and encouragement to contact researchers with questions.

Four weekly interviews, the last of which was an exit interview, were conducted with each participant by a single researcher, a clinical psychologist. The interviews were open-ended conversations about how participants had used the phone application to reflect on their moods and handle stressful situations, and to identify other ways they had shaped the application to the nuances of their lives. Participants shared reactions to the application and to trends of their experience sampling data, which were shown on a laptop computer. The interviews were structured not as therapy sessions but as discussions about how people could interact with the application in a therapeutic way. Interviews were approximately one hour in length and were recorded and transcribed. In the initial interview, participants described sources of stress and the way stress manifested in their relationships, behaviors and physical experiences. In the exit interview, participants discussed their final week of participation and summarized their experiences with the application.

This study was approved by a board responsible for privacy considerations at the participants' place of employment. Identifiers were removed from the data collected from participants' phones, and data were stored in an encrypted database. Data stored on the phone (numerical responses to scales) were associated with participant numbers but not names. Analysis was conducted after the data were downloaded from participants' phones. The entries made by participants were stored on the phone and not transmitted to anyone outside of weekly downloads. As a result—and as we explained to participants—there was no real-time monitoring of their entries, and no possibility of real-time interventions based on their reports of negative moods. Participants did not receive any financial compensation or organizational recognition for their involvement in the study. Participants were told at the outset that there was no known benefit to participating, and that they could discontinue at any time.

Results

To understand how the phone was used for self-reflection and coping, we analyzed interview narratives and experience sampling data for indications of change in mood patterns. Accounts of mood changes from interviews were used to examine patterns in the experience sampling data during the same time ranges.

We examined changes that were described in interviews as occurring over the course of the one month study; characteristic patterns of change over the diurnal cycle; and changes during specific stressful incidents. These three categories emerged from qualitative analysis of interview data. Agreements and disagreements between experience sampling data and weekly interviews are highlighted in the case studies. A number of participants reported changes over the course of the study in their mood patterns and coping skills, and ascribed these changes to use of the application. These examples illustrate the potential of mobile tools not just for gathering data about mood patterns, but also for querying in a way that invites emotional awareness, self-regulation, and behavioral change. Five case studies are shared.

We examined changes over the one-month study in several ways. We used the Behrens-Fisher *t*-test to compare data from the first half of the study with data from the second half. We also examined standard and robust linear regression of the mood scales against time in the one-month study.The regression results largely corroborated the *t*-test results, but since the linear trends generally are not a good fit to these data, we report only the *t*-test results here.

To study diurnal patterns, we segmented each participant's data into time blocks. This segmentation was guided by the raw data and by mood patterns reported during the interviews. We used a two-way analysis of variance (ANOVA) for joint analysis of diurnal changes and changes over the course of the study. The diurnal time blocks just mentioned formed the first grouping variable for this analysis. Two groupings were explored for the second variable: (1) week number in the study, and (2) first versus second half of the study. This joint analysis of diurnal changes and changes over the course of the study allowed us to study interaction effects between the two. Bonferroni adjustments were made for multiple comparisons in the ANOVA. We adopted a significance level of $P = .05$ for reporting results and report the actual P values for significant test results, except when $P < .001$.

To examine stressful episodes, we segmented the participant's experience sampling data according to the time intervals of incidents reported in interviews. We analyzed whether emotion ratings during time intervals corresponding to reported stressful episodes differed from the emotion ratings outside of those intervals, referred to as the background period. We compared the mood scale levels in the episodes with the background by one-way ANOVA. Names and identifying information of participants have been changed.

Case Studies

Tobias

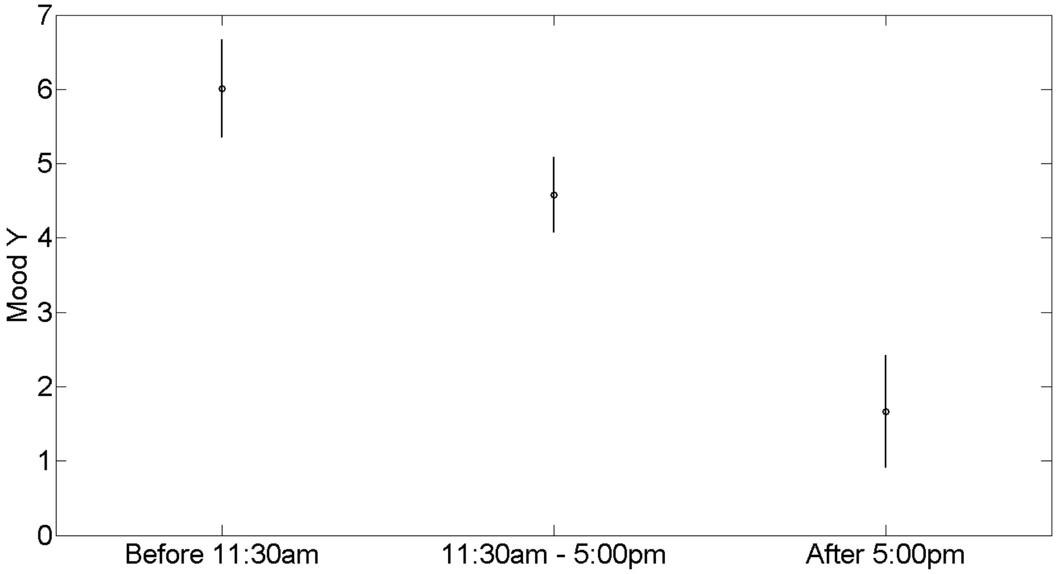
Tobias, a man in his early thirties, enrolled in this study because he was eager to extend his self-improvement from weight loss to stress reduction. During the previous year he had lost close to 60 pounds by following a strict diet and exercise plan. His stress stemmed from conflict with his wife over childcare and household responsibilities.

Tobias described a clear diurnal pattern in his mood. Each day at 5PM, he raced back from work to immediately take over responsibility for the kids, pets, dinner, and general chaos of home life, as his wife, also exhausted, left the house to find time alone. He found the transition jarring and often remained irritated the entire evening.

Echoing this verbal account, Tobias' phone entries show a decrease in energy upon coming home. In fact, his energy, as reflected in the Y values in the Mood Map, decreased continually throughout the day. As shown in Figure 6, his mean energy values were 6.01 before 11:30AM, dropped to 4.58

between 11:30AM and 5:00PM, and further dropped to 1.67 from 5:00PM until his last recording at 10:49PM (two-way ANOVA, *P* < .001).

Figure 6. Progressive drop in Tobias' energy through the day. The circles show the mean values in the diurnal segments indicated on the abscissa. Error bars show the 95% confidence limits on the means. Note that the total Mood Y range available to the user is [-7, +7].



Tobias' mood and communication patterns shifted as the study progressed. He explored some of the mobile therapy concepts, using them to anticipate his negative reactions to coming home and curtail them so that they would not dominate the entire evening. Tobias applied a rhetorical question from the Mind Scan, "Might I be stabilizing?" by telling himself "Just be prepared for the next 15 to 30 minutes…It probably isn't going to be an ideal situation for you, but just get through the 15 to 30 minutes and then, you know, you'll be fine." He practiced this and other short exercises before he walked in the door. Perhaps more importantly, he spoke with his wife about alternative solutions and schedules for sharing responsibilities. He was pleased by the self-awareness and coping abilities he developed during the study.

The improvements in mood and family relations that Tobias described are reflected in his mood entries. There was a lifting of energy (the Y value of the mood scale), and a decrease in negative emotions on the single dimension scales. Figure 7 shows his anger, anxiety, and sadness ratings throughout the study. His mean anger, anxiety, and sadness ratings all were lower in the second half of the study than in the first half. His mean anger ratings decreased from 0.49 during the first half of the study to zero in the second half (*P* = .01, Behrens-Fisher *t*-test). His anxiety ratings decreased from 0.37 to 0.04 (*P* = .006), and his sadness ratings from 0.61 to zero (*P* < .001). His energy ratings (y-axis of Mood Map) increased from 3.28 in the first half of the study to 6.58 in the second half (*P* < .001).

Tobias' pattern of decreased energy in the evenings abated to some degree as the study progressed. His energy continued to decrease throughout the day, but the decrease was less extreme in the second half of the study than in the first half. Two-way ANOVA comparing his energy before and after 4PM and between the first and second half of the study showed a significant interaction (*P* =.005). Specifically, in the first half of the study, Tobias' energy ratings before 4PM averaged 5.09 and after 4PM averaged 2.22. In the second half of the study, his energy ratings before and after 4PM were more nearly equal (3.67 and 3.64, respectively). That is, Tobias showed less fatigue or burnout in the evening hours as the study progressed.

In addition to improved mood, Tobias described greater self-awareness throughout the study. He found the Mood Map useful as a way "to check in with myself." At the beginning of the study, he was disappointed that the system wasn't telling him his mood: "What I was hoping this device was going to be was something that told me how I was feeling, because that's one of the things I struggle with," he said. Later, though, he expressed a comfortable curiosity in his mood patterns, and "more confidence in my feelings."

Figure 7. Anger, anxiety, and sadness mood ratings change across the study for Tobias, who described improved mood and better communication with his wife. Vertical lines mark the half-way point in the study.

Theresa

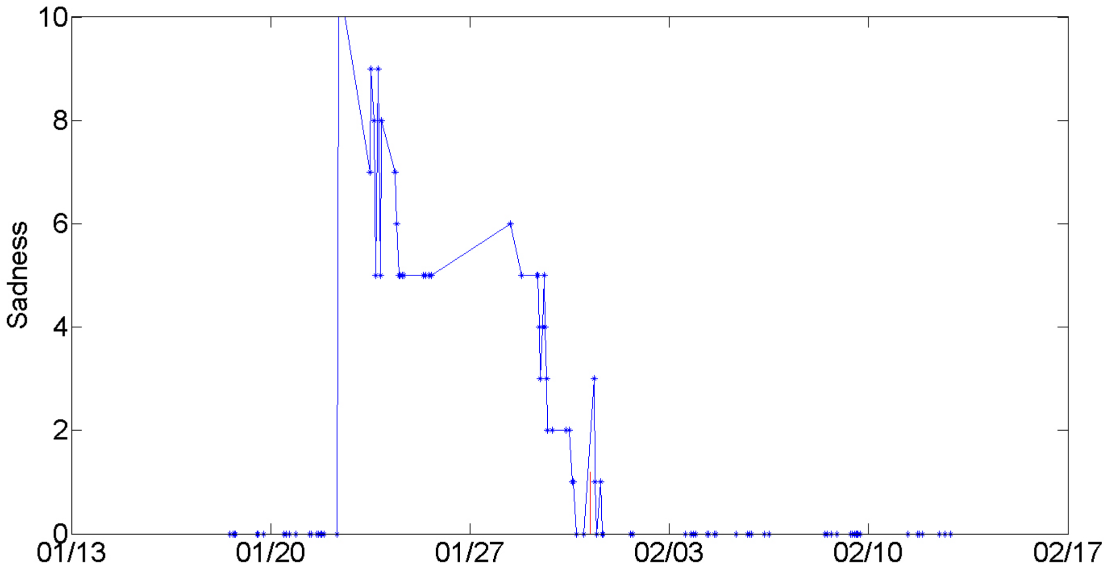
Another participant whose mood improved over the course of the study was Theresa, a woman in her late thirties who had been chronically frustrated at home and in her work as a manager. Her frustration at home related to her niece, who recently had moved in with the participant but never helped with household chores and continually left the lights on when she left the house. At work, Theresa struggled with a technician on her team who failed to take ownership for finishing tasks. In an interview, she characterized her exasperation with both relationships: "It's like [the movie] *Groundhog Day*...it's the same thing...over and over again!"

Eventually, Theresa tried out a collaborative approach that worked well in both situations. At home, she devised a system that finally motivated her niece to turn off the lights: "I was like, 'Okay, maybe we'll have an energy conservation initiative with her, that if she turns off all the lights before she goes to school and turns down her heat, that's a point. And we'll keep points every day.'" And at work, she suggested a "priority list" for managing tasks, and this approach went over well with the technician: "He continued to work on the list, so it was working as expected...and it turns out he loves it!"

She described her satisfaction with her negotiation: "It was this neat experience for me…The conflict was done…and I didn't grow up that way…It goes back to looking—okay, 'What's the priority?' 'What is the true goal?' because we both have the same goal in mind, but we might get there different ways. So, I think that the questions that are on there, you know, helped to get to that, even if I didn't look at them right before the meeting". In these quotes, Theresa not only describes the skills that she developed during the study, but also her internalization of the concepts. She interweaves language and concepts from the mobile therapies, such as "What is the true goal?" with her self-reflection in the interview. She also makes it clear that she applies these concepts even if she isn't looking at the phone.

The satisfaction that Theresa described is reflected in the positive change in her mood ratings recorded on the phone. The energy dimension of her Mood Map ratings rose from a mean 1.14 in the first half of the study to 1.8 in the second half (Behrens-Fisher *t*-test $P = .01$). As shown in Figure 8, her sadness decreased dramatically, from a mean of 3.15 to 0.875 ($P < .001$), the largest cross-study shift in a mood scale we observed among all participants. Surprisingly, this decided drop in sadness was not accompanied by a significant drop in anger. This discrepancy suggests that the label of anger on the specific scale did not resonate with Theresa's frustration, and points to the need to tailor mood queries to an individual's emotional signature, that is, the range and pattern of each person's emotions.

Figure 8. Sadness decreases dramatically in the second half of the study for Theresa, coinciding with her successful negotiation of conflict at home and work.



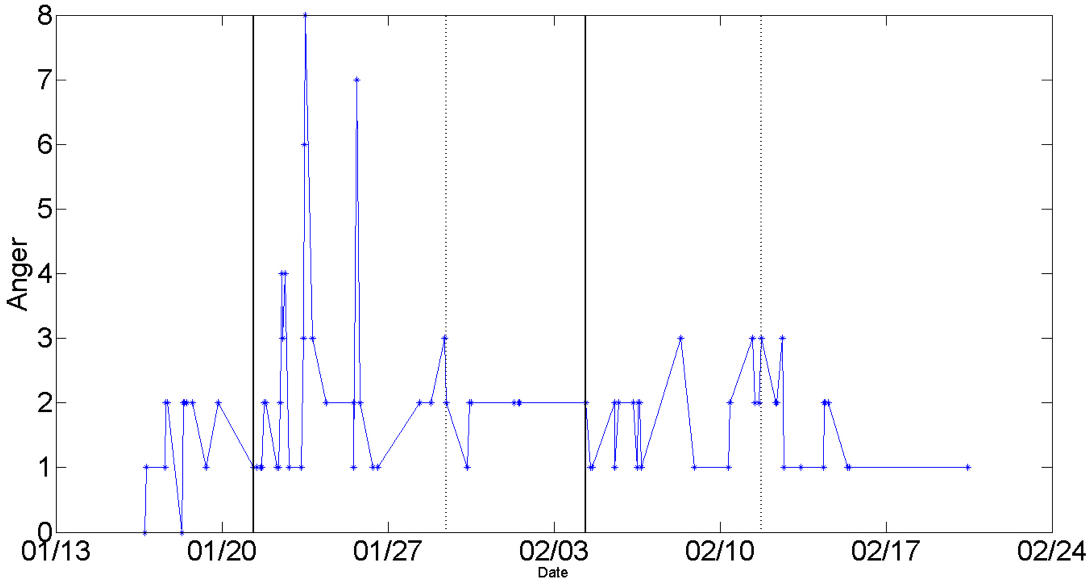
Forest

Personal stressors marked the interview and experience sampling data of Forest, a man in his mid thirties who had recently moved to the United States. He described frequent anger and frustration related to an overarching struggle to establish professional and financial stability.

Here we explore two stressful episodes described in Forest's interviews and experience sampling data. The first stressor, which occurred early in the study, followed his wife's selection of a physician who was not covered by his insurance. He spent days on the phone arguing with insurance companies and with the physician, trying to find a way to please his wife without incurring enormous expense. Although he and his wife eventually agreed on a doctor within the insurance network, he regretted the fruitless frustration he experienced along the way.

Forest's mean anger ratings (but not other emotion ratings) during this episode were significantly higher than the background level (2.41 vs. 1.57, $P = .03$). This difference is reflected in the time series of his anger ratings, shown in Figure 9.

Figure 9. Snapshots of two comparably stressful episodes (1/21 to 1/29 and 2/4 to 2/11) identified by Forest during interviews. The solid and dotted vertical lines mark the beginning and end of the episodes respectively. In the second episode, he applied stress management and conflict resolution techniques and reported less anger.

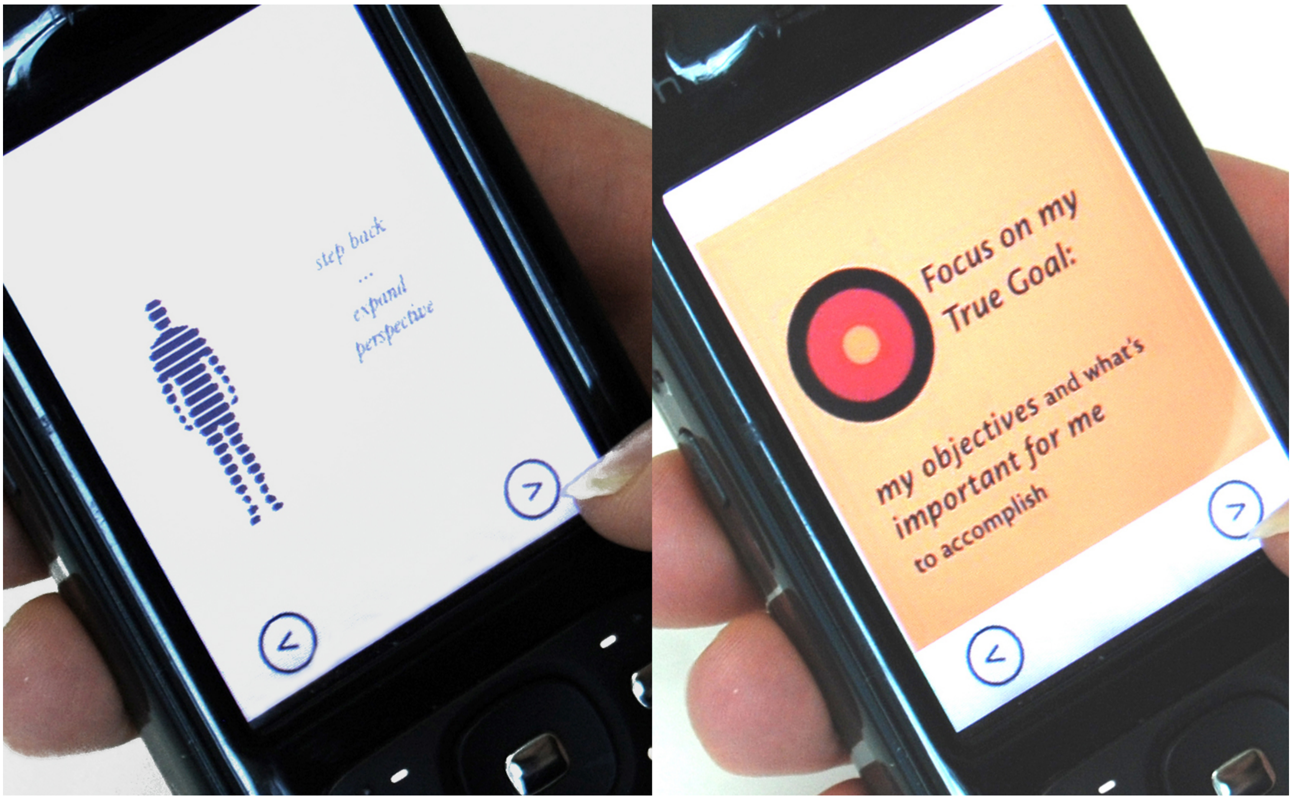


Several weeks later, Forest relayed a similarly stressful series of interactions as he tried to obtain a US passport for his daughter. He was turned away because of missing paper work on his first visit to the consulate, and on each subsequent visit he had to interact with a rude officer.

Although irritated, Forest mentally prepared for each follow-up interaction by repeating to himself some of the mobile therapy concepts about goal orientation and constructive confrontation. In an interview, he relayed his self-talk from the day of the incident, in which he combined text from the mobile therapies shown in Figure 10 (“Step back…expand perspective”) with his own self-reflection (“What is my goal here? So what if I don’t like this guy? Step back, expand perspective.”)

Even though securing the passport required a stressful series of interactions that took up far more time than he had anticipated, Forest felt good about the outcome and the way he handled the interactions. Unlike the first episode, his anger ratings associated with obtaining the passport were not significantly higher than the background level. This episode is reflected in the second segment of the anger time series (dated from 2/4 to 2/11) in Figure 9. The majority of Forest’s mobile therapy usages occurred during these two stressful episodes, suggesting that he reached out to the phone for help in moments of need.

Figure 10. Forest and other participants quickly internalized the mobile therapies.



Octavia

Octavia, a woman in her late thirties with an advanced technical job, described ongoing struggles with anxiety and procrastination. After several reorganizations in her division, she struggled to prioritize tasks and spent much of her day simply reacting to email or addressing small requests. She described the most difficulty focusing and the most anxiety in the morning. In keeping with this interview account, her mood phone entries showed more negativity in the morning hours than in the afternoon. As shown in Figure 11, her anxiety averaged 3.04 before 1:00PM, and dropped to 2.16 after (two-way ANOVA, $P < .001$). Her unhappiness dropped from a mean of 4.27 before 1:00PM to a mean of 3.94 after ($P = .01$).

Figure 11. Octavia's interview accounts of morning procrastination are paralleled in her experience sampling data, which show elevated anxiety before 1:00 PM. The circles show the mean values in the diurnal segments indicated on the abscissa. Error bars show the 95% confidence limits on the means.

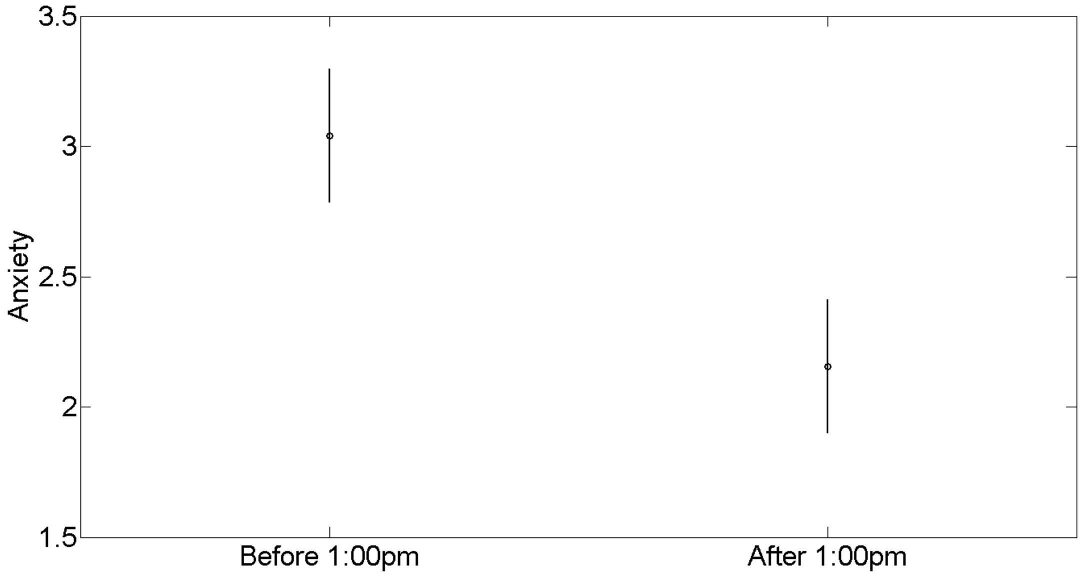


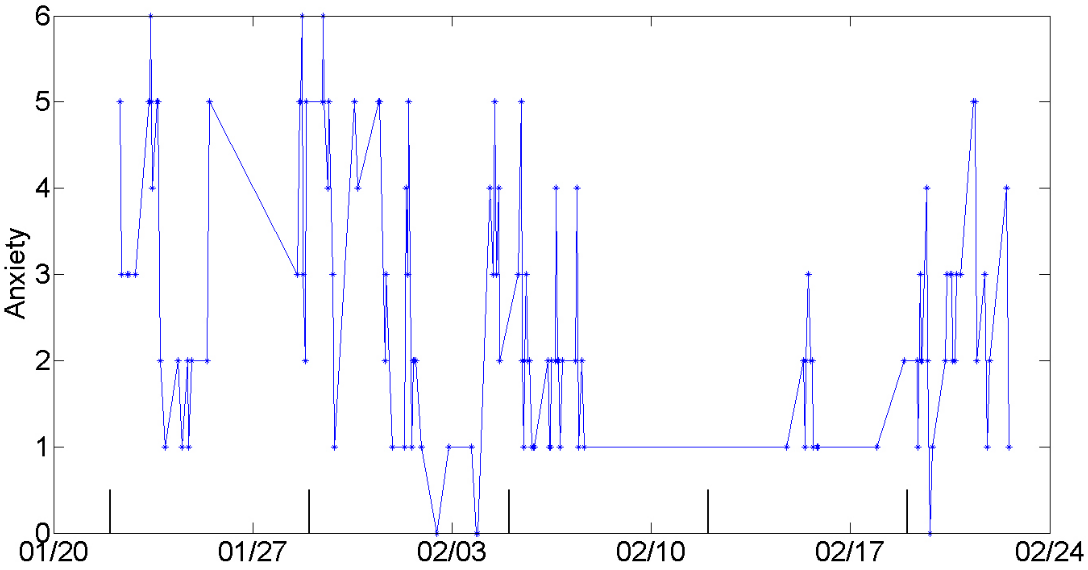
Figure 12. Example Mind Scan prompt that helped Octavia prioritize and stop procrastinating

In her closing interview, Octavia described notably better focus, productivity and clarity in presenting her work to others. She attributed these improvements to the phone application, particularly the prompts about prioritizing (an example prompt is shown in Figure 12):

> *Not a whole lot else has changed other than usage of this (application) and just a refocusing…what it helped me say is, “What is the absolute most important thing I should accomplish?”…knowing there are other things out there that need to happen, that just are not quite as important…I was thinking about the visual…where it says, “Focus on what matters to me.”*

Octavia’s verbal account of increased focus over as the month that she used the phone application was echoed in the experience sampling data: Her mean anxiety dropped from 2.88 to 2.16 from the first to the second half of the study (Behrens-Fisher *t*-test $P = .005$). The drop in anxiety also is evident from the two-way ANOVA, which showed significantly higher anxiety in week one (3.06) than in weeks three or four (1.92 and 1.37, respectively, $P = .001$). The time series of her anxiety ratings, with the weeks demarcated, are shown in Figure 13. Octavia’s sadness and unhappiness also declined through the course of the study; sadness dropped from a mean of 0.49 to 0.08 (Behrens-Fisher *t*-test $P = .001$), and unhappiness dropped from 4.39 to 3.41 ($P < .001$). Her energy ratings on the Mood Map (y-axis) do not reflect the increased energy that she reported, however. As mentioned above, Octavia described improved focus and prioritization over the course of the study. While her anxiety and some other negative moods were lower in the second half of the study, no change in the diurnal pattern of anxiety across the study was revealed by the two-way ANOVA used to simultaneously study diurnal and across-study changes. That is, her anxiety was lower overall by the end of the study, but remained higher in the morning.

Figure 13. This time series visualization shows Octavia's lowered anxiety ratings in weeks three and four of the study, a pattern that matches her interview account of decreased anxiety. The short vertical lines along the x-axis mark the beginning of each week in the study.



Eliza

A more complex trend in moods was exhibited by Eliza, a woman in her mid-forties who juggled a full-time job and close relationships with her two sons, husband and extended family. She managed a tight schedule, running each morning, arriving at work by 7:00 AM, picking up her children after school, and reviewing their homework–all before preparing dinner. Historically, Eliza dealt with anxiety and other negative emotions through constant busyness, but said that this coping style eventually left her exhausted. She worked hard to be positive and supportive at work and at home, and experienced deep regret when she let others down. She also described frequent waves of anxiety that "wipe out the joy" of positive moments with her family.

As the study progressed, Eliza expressed great interest in mapping her moods, describing better self-understanding, clearer communication and improved resolution of conflicts with her husband and eldest son. In light of these reported gains, initially it was surprising to see an increased negative affect in her experience sampling data across the study. Specifically, the mean of her energy ratings on the Mood Map decreased from 2.82 to 1.88 from the first to the second half of the study (Behrens-Fisher *t*-test $P = .007$) and her mean sadness ratings increased from 0.69 to 1.38 ($P = .039$). This change, although surprising in light of her reported increased insight and improved communication, made sense on closer analysis. The trend towards negativity in her experience sampling mirrored statements she made in interviews about learning to acknowledge different emotional states. She described calibrating herself on the Mood Map:

> *I allowed myself more freedom. It's exploratory. I allowed myself more freedom and range of motion in there just to get myself rolling…I thought, "I'm going to explore what it feels like to put it right over here because that's where I think I'm at" …[Before] I need[ed] everybody to be happy. This has allowed me to go, "Oh, it's okay, I'm not always happy either,"…something I've learned from this is, instead of always needing to be in that positive, happy quadrant, accepting that I can be in a negative quadrant, either with energy or with mood, and still be managing myself…that I can be okay even when I'm not in a positive energetic state, and that allows me to say for other people, oh, they can feel that way and still be—I don't have to fix it.*

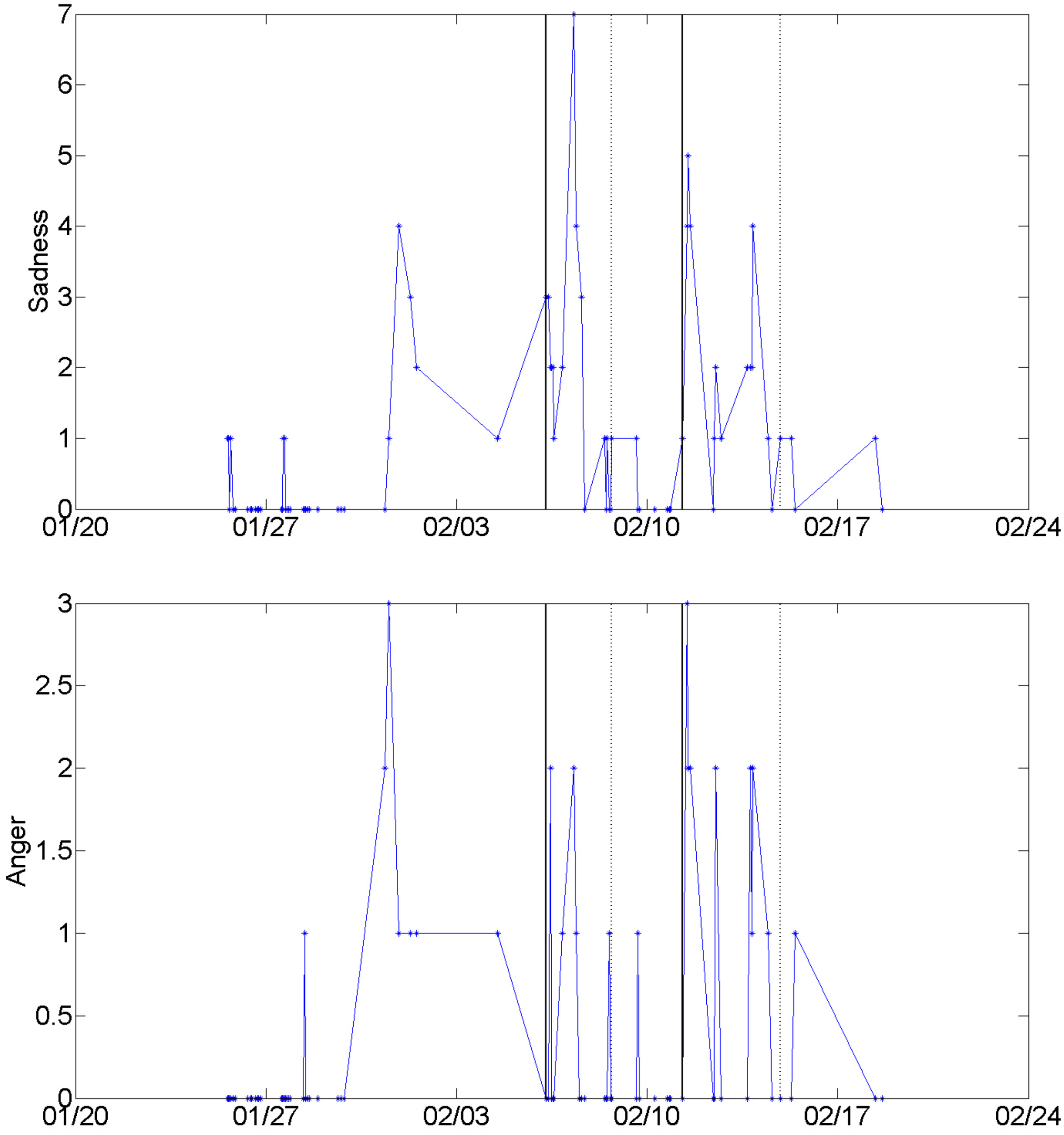
For Eliza and others, it was difficult to disentangle mood changes from changes in self-awareness. That is, the experience sampling data could reflect either increased distress or acknowledgment of previously disavowed negative moods.

Two stressful episodes, both family conflicts, stood out in Eliza's interview narratives and experience sampling data (see Figure 14). The first incident occurred shortly before her birthday. Her mother, after trying unsuccessfully to arrange a birthday dinner for Eliza, sent a card, followed by a phone call and an email, all expressing sorrow that they were not able to see one another. Eliza felt a surge of anger after each message, resenting that her mother had manipulated her into feeling guilt. She explained that the mobile therapies helped her sympathize with her mother's intent and decide to postpone a heated conversation. She also became more comfortable with her decision to decline the dinner invitation and reserve time for herself. Nonetheless, the event took its toll. Eliza described sadness that is mirrored in her experience sampling data: During this episode, her mean ratings for sadness, but no other emotion, rose above the background level (from 0.040 to 1.88, *P* < .001, one-way ANOVA).

The second conflict involved Eliza's ten-year-old son. A call from his teacher about his disruption of a class triggered her anger: "I was definitely in a rage. I was really angry. I was, you know, I was already at my wit's end, and I'd been trying to make the afternoon nice and then, you know, all the chemical elements came together." Shortly after, she regretted lashing out at her son for simply having fun with his friend during class. That afternoon they sat down together, exploring the mobile therapies and scales to process the conflict. Her son started to understand not only his mother's anger, but also his anger at the teacher. During this episode too, Eliza's sadness rose significantly above the background level (0.40) to 1.87 (*P* < .001 one-way ANOVA). In addition, her anger, typically near zero, increased to 0.94 (*P* = .008), and her happiness fell from 5.53 to 4.47 (*P* = .002).

Eliza's phone entries characterize the first event as more disappointing and the second as more infuriating. She used the mobile therapies for anger management and conflict resolution heavily during both episodes; in fact, one half of her usages of these therapies throughout the study fell on the dates of those episodes. For Eliza, negative affect may have been experienced primarily as sadness, but at a certain threshold developed to include anger.

Figure 14. The time series of mood ratings echoes Eliza's interview account of two stressful episodes; both were family conflicts that stretched over multiple days. The first episode (between 2/6 and 2/8) was characterized in mobile entries as sadness; the second (between 2/11 and 2/14) as sadness and anger. A solid vertical line marks the beginning of each episode, and the end of each episode is marked with a dotted vertical line.



Discussion

Emotional awareness and self-regulation are important personal health skills that may be facilitated by mobile technologies. In this exploratory project, we developed and tested a mobile application that enabled users to report their emotional states and access therapeutic exercises based on cognitive behavioral therapy. We examined how people used this application to increase self-awareness in moments of stress, develop insights about their emotional patterns, and practice new strategies for modulating stress reactions.

Interview narratives suggest that study participants applied the mood scales and therapeutic content in ways that helped them initiate meaningful personal change. Examples discussed in the Results section—of a woman who started problem solving in a more collaborative way with her niece and co-worker, a man who became more goal-focused in bureaucratic negotiations,and another who experimented with a new approach to dealing with family stress at the end of his workday—were similar to those shared by other participants. In general, people quickly internalized the mood questions and mobile therapies, applying the concepts whether or not they were physically interacting with the application. Several participants used the concepts from the application to understand and coach other people.

The case studies analyzed self-reflection in weekly interviews in conjunction with experience sampling data. Interview reports of marked patterns (eg, in stress and fatigue) were generally reflected in experience sampling data, with the most striking agreement between the two forms of data appearing in stressful episodes. In these distinct events, participants made clear notations of negative emotions and were far more likely to use mobile therapies than they were at other times. These observations suggest a readiness to use mobile therapies when experiencing intense emotions.

The primary disparity between interviews and experience sampling data was that participants seemed to express more emotional volatility and negativity in the former than in the latter. There are several possible explanations for this disparity. As Kahneman explains in reference to the “peak-end rule,” recall is biased towards intense and recent events [11]. Interviews may have evoked the most dramatic emotional experiences that participants had during the week. Alternatively, people may be more emotionally expressive when interacting with an interviewer than with an application. Some of the disparity appeared to stem from adjusting to the tool over time; for example, one participant who was excited about increased self-awareness reported that she became more comfortable acknowledging negative moods as the study progressed. By highlighting the most emotionally salient events, interviews help in the interpretation of experience sampling data, which includes many data points, equally weighted, over a stretch of time.

This was a preliminary study with limitations that should be addressed in future studies. The first limitation concerns the small sample size used for this initial, qualitative exploration of how people adopt mobile therapies. Our interview approach—repeated, open-ended discussions over the one-month period that participants used the prototype—was influenced by clinical psychology, ethnography, and participatory design. To evaluate the efficacy of such a system, a large controlled study would be required. Second, as noted earlier, a data capture error limited the analysis of the x-axis of the Mood Map to a bipolar distinction between positive and negative responses. Another limitation was the requirement that participants carry an additional phone; future studies should take advantage of application stores, such as those for the iPhone and Android, to test tools on people’s current phones. Ideally the study should continue for a longer period of time to allow accommodation to the mood scales. Finally, evaluating this type of intervention is complicated because it combines therapy and assessment and because people’s use of the tool changes over time.

This study pointed out some key directions for future mobile therapies. The benefits in self-awareness and coping that individuals garnered in this study most likely resulted from a combination of the features on the phone and the reflection offered in weekly interviews. Future systems could combine the assessment, mobile therapies, and feedback that participants experienced in this study. That is, the feedback from interviews could be built into the software and used to customize the mobile therapies. To cultivate self-awareness over daily, weekly, and monthly patterns, the system should ideally present mood trends on the phone immediately after a mood entry. As mentioned above, the system should also invite users to investigate their mood correlates and set goals, activities that were appealing to most of our participants. To help with managing situation-specific stressors, feedback displays could illuminate the contextual triggers and help the user to develop coping strategies. The system could track which therapies were most helpful and provide similar but increasingly sophisticated strategies over time.

In summary, this preliminary study pointed to potential promises of coupling experience sampling tools with mobile therapies to encourage self-awareness and coping in daily life. Future applications should ideally include adaptive learning and query based on an individual’s emotional signature—the range, patterns, and triggers of emotions he or she experiences—and display trends immediately following queries. Mobile therapies should be pushed to the user based on his or her emotional signature, and ideally be integrated with the personal technologies he or she uses for entertainment, calendaring, and communication. We recommend experimental studies to assess the potential benefits of such systems, in addition to larger field deployments to understand how such systems might be adopted in communities. Among other topics that can be examined in qualitative field studies is mood sharing, that is, how people use their Mood Map ratings or media to represent their emotional states, the clusters of people with whom they share mood data, and the contagion effects of mood in social networks.

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Conflicts of Interest

Several authors are employees of Intel Corporation. Intel funded this exploratory research. The investigatory technology described in this paper was a research vehicle and not a commercially available product.

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Original Paper

Sharing Medical Data for Health Research: The Early Personal Health Record Experience

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Abstract

Background: Engaging consumers in sharing information from personally controlled health records (PCHRs) for health research may promote goals of improving care and advancing public health consistent with the federal Health Information Technology for Economic and Clinical Health (HITECH) Act. Understanding consumer willingness to share data is critical to advancing this model.

Objective: The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share.

Methods: A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of *a priori* defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns.

Results: Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89 (59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. Select differences in support for sharing under different conditions were observed across social groups. No gender differences were observed; however differences in age, role, and self-rated health were found. For example, students were more likely than nonstudents to favor an opt-out sharing default (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, P = .03). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% CI 0.91 - 0.96, P < .001). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, P < .001). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, P = .02); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, P < .001). Finally, subjects with fair or poor self-rated health were less likely than those with good to excellent self-rated health to report that willingness to share would increase during a public health emergency (unadjusted OR 0.61, 95% CI 0.38 - 0.97, P = .04).

Conclusions: Strong support for sharing of PCHR information for health research existed among early adopters and focus group participants, with support varying by social group under different conditions and contexts. Allowing users to select their preferred conditions for sharing may be vital to supporting sharing and fostering trust as may be development of safety monitoring mechanisms.

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KEYWORDS

Medical records; personally controlled health records (PCHR); personal health records; data sharing; information altruism; HITECH; public health informatics

Introduction

In the evolving landscape of health information technologies, an opportunity exists to deploy personally controlled health records (PCHR), a special category of personal health record, as a platform for engaging consumers in public health research. The PCHR technology is designed to enable this. The platform model of the PCHR has three key properties [1]. First, data across sites of care are integrated into a repository leveraging the patient's rights to those data. This is achieved in a manner very similar to the way a consumer might use the financial software Quicken (or the newer web application, Mint.com) to aggregate personal financial data across multiple sources. The second property is that the data are under strict personal control. The PCHR users "own" this copy of their medical data and can choose to share it with care providers, family members, or other software applications. The third property is that third party applications may connect to the PCHR central data repository across a standard application programming interface, much as applications from the iPhone apps store can be connected to the iPhone platform. Whether consumers are willing to engage with applications that support sharing their data with public health—which may be an important alternative to extracting patient data *en masse* from electronic health records—is a crucial question.

Broadly diffused personally controlled health records (PCHRs) may serve as uniquely rich consumer-centered environments through which to engage cohorts in consented public health research. This recently articulated vision [1,2] is aligned with the newly enacted Health Information Technology for Economic and Clinical Health (HITECH) Act [3]. HITECH, through a US $24 billion appropriation, aims to "harness the full potential of digital technology to prevent and treat illnesses and to improve health" through providing high quality information to providers for care improvement and through simplifying "collection, aggregation, and analysis of anonymized health information" for public health and safety.

Subscription models for PCHRs, enabling the consumer to add data sources from diverse sites such as clinics, hospitals, pharmacies, and labs, afford the technical means for integrating streams of institutionally tethered health information into a master, patient controlled record that affords views of health and service domains [4,5]. Annotation and possibly even survey features of PCHRs allow for capture of phenomenological, behavioral, and social factors that are not typically included in clinical and administrative information systems [6]. These factors in combination with clinical and biological information may help explain variation in risk, treatment, and outcome for even highly heritable diseases—an area of active research [7-10]. Integration of information that is currently missing from record systems or "siloed" in research datasets and uncoupled from clinical measures may foster improved understanding of health outcomes by supporting assessment of barriers to care, factors related to adherence, patterns of follow-up, follow-through, and adverse events.

At the population level, aggregates of such integrated and longitudinal records in a system that allows investigators to maintain ties to individual record holders may greatly advance opportunities for consented public health research and, importantly, for translation of findings to practice. Conceptual models for engaging cohorts of consumers who make their health information available for research out of altruistic or opportunistic impulses with the possibility of obtaining feedback including through participating in longitudinal research have been proposed [2]. If actualized as practice and adopted by cohorts of consumers, such solutions may contribute greatly toward closing the gap between research and practice, providing opportunity to stage and implement consented interventions along with evaluations of these interventions. Thus, both personalized medicine and public health may benefit from engaging cohorts of information altruists who share their clinical, phenotypic, and even genetic information in a PCHR-enabled model that allows for feedback and follow-up.

To move this model forward, better understanding of attitudes and willingness to engage in public health research is needed. A recent Canadian study assessed attitudes toward consent for sharing personal health information from medical records under different research scenarios and found generally favorable views among chronically ill and general population samples [11], findings that are consistent with large-sample studies conducted in other industrialized nations [12]. However, support for sharing medical record data diminished where suggested uses included commercial, profit, and marketing applications [11,13]. These findings were consistent with those reported from surveys in New Zealand, which found that patients prioritized personal control and strict restrictions on secondary data use as prerequisites for sharing medical record data for research [14]. The emergence of highly active virtual communities of persons affected by chronic or progressive illness, who share their personal health information in hopes of accelerating prevention, treatment, and cure [15,16], is evidence of the perceived value of peer-based sharing models and an indicator of the potential traction of a PCHR-based public health research model. Uncertainty and variability of opinion around appropriate consent mechanisms for use of medical record data in health research characterizes the views of research ethics boards [17-19] and patient populations [20], leaving open questions of fit between extant oversight mechanisms governing health research and the rapidly evolving information technology and research landscape associated with PCHRs [21-23].

Benefits of PCHR-enabled research models may include reductions in cost and turnaround time for the collection and application to practice of research data. Traditional research models that rely on complex methods for outreach, promotion, sampling, and collection of data provide high levels of validity and reliability at what may be prohibitive cost. In an era of resource constraint, it is crucial to develop nimble and cost-efficient approaches for engaging subjects in health research using approaches that may close the gap between researcher and subject.

The purpose of this study was to investigate willingness to share information contained in a PCHR for use in public health monitoring and research. Little is known about individuals' attitudes toward sharing personal health information with public health agencies through this new modality and the ways that different conditions and contexts may affect attitudes among different stakeholder groups. Because deployment and diffusion of PCHRs are rare, there has been limited opportunity to investigate willingness to share health data among individuals with experience of demonstration or live PCHR systems including live systems populated with their medical record data. Understanding willingness to share and the conditions and contexts bearing on that willingness is vital to building usable, not just imagined, systems.

Methods

Overview

Information about attitudes toward sharing information from a PCHR with public health agencies was collected through self-report surveys administered on a PCHR platform and though focus group and one-on-one discussions with community members.

Setting

Research activities were undertaken in an urban area within the northeastern region of the United States.

Study Samples and Data Collection

Questions about willingness to share personal information with public health agencies for monitoring and research and about the conditions and contexts affecting willingness to share were asked of subjects from three participant groups representing varying degrees of exposure to PCHR technology using self-report survey or qualitative interview methods.

Surveys were administered prospectively on the PCHR platform to an early adopter sample of PCHR users affiliated with a local university health center who completed exit surveys after participating in a PCHR-based health promotion demonstration The demonstration exposed them to the live system populated with their own personal health information (PHI) for a nine-month period. During that time they could log in to their PCHR, view their health and medical record information, and review, complete, and save surveys in their PCHR. During the demonstration, users were sent a message informing them that they could provide others with access to their PCHR electronically by using the sharing feature in the system. The survey was administered on the PCHR platform at the demonstration's close and it included fixed-choice and Likert-scaled items asking about health beliefs, behaviors, and attitudes toward sharing from the PCHR for public health research. The exit survey was completed by 151 of 247 (61%) of the demonstration participants. Information about sociodemographic and health characteristics of demonstration participants completing surveys was obtained using standardized self-report measures with fixed choice multi-categorical formats that were included in the surveys, as described elsewhere [24].

Qualitative data were collected using a structured protocol from PCHR usability testers (n = 13) recruited from local area worksites. Subjects were interviewed following a PCHR demonstration session in which they interacted with a live system that was not populated with their own health information.

Qualitative data were also collected through focus groups conducted with community members (n = 17) recruited from an area retiree and health advocacy mailing list. Subjects were interviewed following a demonstration of the PHCR system.

Participants in all three groups were volunteers, spoke English, and provided written informed consent and Health Insurance Portability and Accountability Act (HIPAA) authorization for sharing personal health information when piloting or evaluating live records populated with their personal health information. Research was reviewed and approved by the Children's Hospital Institutional Review Board. The involvement in survey research of participants from the live demonstration was reviewed by the demonstration site local IRB as well.

Analytic Approach

Survey data for the first study group of demonstration evaluation participants were extracted from participants' PCHRs and exported to a SAS file for analysis (SAS version 9.2, SAS Institute Inc, Cary NC, USA). Participants' attitudes toward sharing were characterized using descriptive statistics, and differences in attitude by age, sex, and self-rated health were assessed using chi-square tests of significance, P value < .05, and logistic regression on dichotomized values.

For the second two study groups, narrative data were collected in usability test and focus group discussion sessions. Open-ended responses to structured protocols were audio taped, transcribed, and analyzed for major thematic findings by a trained moderator and observer using previously reported methods [24]. For analysis of all narrative/text data, analysts worked independently with a shared rubric of major thematic codes to describe subject reports. Analysts read all narrative data independently to assign codes to text fragments and develop subsidiary coding schemes. Coding schemes and transcripts were worked iteratively and inductively to refine them and achieve consensus. Findings were reviewed and triangulated across the three assessment samples and activities—i.e., surveys conducted with demonstration evaluation participants, narrative and group interviews conducted with usability testers and community-based focus group participants—to build a comprehensive picture of issues related to attitudes toward sharing, conditions, and contexts. Differences across social groupings/factors including age, sex, social role/employment, and self-reported health status were assessed in analyses of survey data and these factors are commented on where available for analyses of qualitative reports from usability and focus group samples. Major constructs were operationally defined for thematic analysis. “Attitudes toward sharing of personal health information from PCHRs” was defined with respect to willingness and interest in making personal health information available to a health authority for purposes of monitoring, tracking, and needs assessment and preferences for sharing using opt-in or opt-out default designs. “Conditions” affecting sharing of health information from PCHRs for public health research were defined to include issues related to anonymity, privacy, confidentially, exclusive use for research, payment, and research intermediation. “Context” affecting willingness to share PCHR information was defined as the presence of a public health emergency.

We report major findings by thematic area for survey reports with demonstration evaluation participants in conjunction with findings from qualitative analyses, using quotes from focus group and user testing interviews to illustrate findings.

Results

Subject Characteristics

The total number of participants in all three subject groups was 181, and the majority, or 83% (151/181) were engaged in the nine-month demonstration of the live PCHR. Average age varied across the three groups (Table 1) and was youngest in the usability test group (45 years), reflecting an employee and student population, followed by the PCHR evaluation group (54 years) reflecting a community-based health maintenance organization population. Average age was greatest (71 years) among focus group subjects, a group drawn from a retiree and health advocacy mailing list. Females outnumbered males in each of the three groups, and most subjects self-reported that their race was white. Among the demonstration evaluation subjects, 70% (105/151) reported having good or excellent health. Demonstration evaluation subjects also reported high levels of education and moderately high levels of income. Data on income, household status, and education were not available for subjects in the focus group and the usability testing group.

Table 1. Characteristics of study samples by group

Sample group	PHCR Demonstration Evaluation	Focus Group Interviews	Usability Testing
	Number (%)	Number (%)	Number (%)
Total N	151	17	13
Mean age (SD)	54 (18)	71 (14)	45 (15)
Female sex	80 (53)	11 (65)	10 (77)
Lives with family	102 (68)	Not available	Not available
Self-rated health good to excellent	105 (70)	Not available	Not available
Education attained college or higher	136 (90)	Not available	Not available
Current student status	22 (15)	0 (0)	12 (92)
Income less than 100K	63 (42)	Not available	Not available
Race			
White	130 (86)	14 (82)	9 (69)
Asian	13 (9)	0 (0)	3 (23)
American Indian	1 (0.7)	1 (8)	1 (8)
African American	0 (0)	4 (24)	0 (0)

Attitudes Toward Sharing for Health Research and Awareness of Sharing Options

Attitudes toward sharing health information for health research are reported for participants in the PCHR demonstration evaluation group (Table 2) and for usability and focus group participants using illustrative quotes (below). Of the participants in the PCHR demonstration, who were surveyed at the close of the demonstration, 91% (138/151) were agreeable to making their health information available for research (Table 2). Levels of endorsement were equally high for this group across sex, age, social role, and health status groupings.

Table 2. Attitudes of demonstration evaluation subjects toward sharing PCHR data for public health research

Measure	Total No.(%)	Female No. (%)	Male No.(%)	Age ≤ 50 No.(%)	Age > 50 No. (%)	Student No.(%)	Non student No.(%)	Poor Health[e]	Good Health[f]
Agreeable to sharing[d]	138 (91)	71 (89)	67 (94)	51 (91)	87 (92)	21 (95)	117 (91)	13 (93)	125 (91)
Knows can share electronically	61 (40)	31 (39)	30 (42)	23 (41)	38 (40)	13 (59)	48 (37)	6 (43)	55 (40)
Of these, knows can share granularly	43 (71)	22 (71)	21 (70)	16 (70)	27 (71)	11 (85)	32 (67)	4 (67)	39 (71)
Preferred model for sharing									
Sharing should be opt-in	89 (59)	50 (63)	39 (55)	31 (55)	58 (61)	8 (36) [a]	81 (63) [a]	81 (59)	8 (57)
Sharing should be opt-out	54 (36)	27 (34)	27 (38)	22 (39)	32 (34)	12 (55) [a]	42 (33) [a]	5 (36)	49 (36)
Conditions affecting sharing									
Anonymity: *increase* willingness	136 (90)	73 (91)	63 (89)	54 (96)	82 (86)	21 (95)	115 (89)	12 (86)	124 (91)
Privacy not anonymity: *decrease* willingness	107 (71)	59 (74)	48 (68)	44 (79)	63 (66)	21 (95)	111 (86)	2 (14)	17 (12)
Share request came from trusted intermediary: *increase* willingness	96 (64)	46 (58)	50 (70)	29 (52) [a]	67 (71) [a]	11 (50)	85 (66)	9 (64)	87 (64)
Information only used for research: *increase* willingness	106 (70)	56 (70)	50 (70)	41 (73)	65 (68)	17 (77)	89 (69)	11 (79)	95 (69)
Can view audit trail of access and sharing: *increase* willingness	119 (79)	61 (76)	58 (82)	47 (84)	72 (76)	18 (82)	101 (78)	12 (86)	107 (78)
Payment for information: *increase* willingness	44 (29)	28 (35)	16 (23)	29 (52)[c]	15 (16)[c]	16 (73)[c]	28 (22)[c]	3 (21)	41 (30)
Contexts affecting sharing									
Public health emergency: *increase* willingness	125 (83)	63 (79)	62 (87)	42 (75)[a]	83 (87)[a]	11 (50)[c]	114 (88)[c]	8 (57)[a]	117 (85)[a]

[a] $P < .05$

[b] $P < .01$

[c] $P < .001$

[d] Includes very, moderately and somewhat agreeable

[e] Fair to poor self-rated health

[f] Good to excellent self-rated health

Only 61 of the 151 (40%) demonstration evaluation subjects reported knowing that they could provide others with read access to their PCHR and share its content electronically through the system's sharing feature. Of these, 43 (71%) subjects replied that they understood that they could share portions of their record (granular sharing) rather than its entirety. No differences were observed in reported awareness across the various demographic and social groups. However, 54 out of 151 (36%) demonstration evaluation subjects thought sharing for public health research should be opt-out while 89 (59%) favored opt-in. Students were more likely than non-students to favor an opt-out default for sharing (unadjusted odds ration (OR) 2.89, 95% confidence interval [CI] 1.10-7.62, $P = .03$).

Among subjects in the usability testing and focus group samples, no clear preference for an opt-in/opt-out default for research was observed although some voiced an assumption that mandatory participation might eventuate. In either case, need for information and education was stipulated to advance the model:

> *Pretty soon no one's gonna have any choice about it [opt-out or mandatory design] and the best thing you can do is to learn as much as you can and be prepared to maneuver through it so you can expose the least of your things that you can. Because they're gonna… I think this is something that's gonna be mandatory for everyone—you're gonna have to.*
>
> *Should be an opt-out, rather than opt-in. And should have a good educational piece that explains it.*

Participating in public health research was contingent on receipt of an explanation of risks and benefits relating to sharing, including sharing genetic information:

> *I would have to know what is the worst-case scenario and what are the securities in place to prevent that; how likely is it that it will happen; what are the benefits. Knowing that you can opt-out or opt-in at any time. If there's genetic data that has implications for family members, people should have informed consent about potential loss of privacy.*

> *In principle, a fabulous idea. In this political environment, would not share anything! Certainly wouldn't share with government. Opt-in would be ok, but no blanket permission.*

Customization of access controls was described as a condition bearing on willingness to share personal health information from the PCHR and was framed by subjects in terms of content-driven restrictions that apply to topics, sections or domains in the record (ie, granularity) and time-limited restrictions (ie, temporality):

> *Would be willing to share data, as long as…could customize access [granularity]*
>
> *Would be willing to share, as long as there's appropriate privacy. Should be able to select what to leave out. [granularity]*
>
> *Maybe you just get permission for 24 hours [temporality]*
>
> *Do you give them permission…do you have to give them permission every time they go into it or is it forever? [temporality]*
>
> *Which data exactly am I agreeing to share; which identifiers would be connected…how would it be used; is it on a one-time basis or recurrent; what kind of time limit [granularity and temporality]*

Conditions Affecting Engagement in Public Health Information Sharing

Almost all subjects in the demonstration evaluation group, 136 of 151 (90%), reported that guaranteeing conditions of strict anonymity would increase the likelihood they would share their health information for public health research. Findings were the same for focus group and usability test samples,

> *No name, no zip code, nothing.*
>
> *They can't know where you are.*

A large majority of subjects in the demonstration evaluation group, 107 of 151 (71%), reported that guaranteeing privacy but not anonymity of shared health information would decrease their willingness to share. This perception was found in qualitative data also, where subjects in the focus group and usability testing group reported anticipating adverse consequences from disclosure of individually identifiable information:

> *An insurance company can take you off their rolls if they think you have too many illnesses.*
>
> *…employers might not hire you if they think you're sick.*
>
> *[They might] deny you life insurance or something.*

Of demonstration evaluation subjects, 119 of 151 (79%), responded that a system provision for viewing an audit trail of access to health information and a specific summary of shared data would increase their willingness to participate in sharing for public health research. Focus group and usability testing subjects also reported that an audit trail provision would increase trust and willingness to share data:

> *It'd be important to see who's tried to get access to it. Same thing with financial information. Seems like the list is interminable after a while. It's almost impossible to get off that list.*

In qualitative interviews, subjects linked the availability of an audit trail with tight security controls as factors that would increase willingness to share their data, citing encryption of data as an example of such a security condition.

Most of the demonstration evaluation subjects, 106 of 151 (70%), reported that restricting the use of shared data to research would increase their willingness to share their data.

Also among this group, 96 of 151 (64%) reported that receipt of a request to share from a trusted intermediary (examples given to users were Children's Hospital Boston and Harvard Medical School) would increase willingness to share. Persons older than 50 in this group were slightly more likely than younger persons to report that this condition would increase their willingness to share (unadjusted odds ratio [OR] 1.02, 95% confidence interval [CI] 1.00 - 1.04, $P = .04$). Engaging with a trusted intermediary around a request to share was similarly observed to facilitate willingness to share among focus group participants:

> *I don't know. I'd have to know for sure that they are who they say they are. And, how would I find that out?*
>
> *[You might not know] if it was a virus sent from your computer…*
>
> *…if somebody puts out an all-encompassing email, saying "Would you let me look at your records?" how would I know who they are?*
>
> *I think it would be useful. I'd do it. And I agree with [other member] that you'd have to have some way of knowing who you're talking to, some phone number or something, some way to verify that the people are who they say the are.*
>
> *If we knew Elissa, then maybe yes, why not? But without knowing her, just hearing that she's from Harvard—well, Harvard's a pretty big place. I don't know.*
>
> *[Would need to know]…that requester is part of an institution; that the requesters are doctors, not just random individuals.*
>
> *Who would be the gatekeeper of that information? Who would tell that researcher that I had a certain illness?*

A minority of demonstration evaluation subjects, 44 of 151 (29%), reported that payment for health information would increase willingness to share. Persons older than 50 were proportionately less likely to report that payment for health information would increase their willingness to share (unadjusted OR 0.94, 95% CI 0.91 - .96, $P < .001$); conversely, persons describing themselves as students reported that payment for data would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 - 26.87, $P < .001$). For some usability testing group subjects, payment was perceived to increase safety/security of sharing when coupled with a trusted intermediary or requestor:

> *Would feel confident that data was safe if [he] was paid. Wouldn't trust insurance company but would trust Harvard.*

Context of Public Health Emergency and Sharing for Public Health Research

Experience of a public health emergency was reported to increase willingness to share health information by 125 of 151 demonstration evaluation subjects (83%). Similar results were obtained in qualitative interviews among older, primarily retired, focus group participants and among usability testers who were employed and among whom qualified support was evident:

> *I would be more likely to share during an epidemic/outbreak.* [retiree]
>
> *Would be more willing to share during epidemic/outbreak, but willing to share in general anyway.*
>
> *Might be more willing to share in case of epidemic. [conditional on deidentified data]*
>
> *In case of epidemic, before sharing, would want to know: What's the scope of the epidemic; what type?* [employee]

Experiencing a public health emergency was more likely to increase willingness to share among older users in the demonstration evaluation sample (unadjusted OR 1.03, 95% CI 1.01 - 1.05, P = 02). However, subjects in this sample who self-identified as students were proportionately less likely to report that a public health emergency would increase willingness to share data (unadjusted OR 0.13, 95% CI 0.05 - 0.36, P < .001). In this sample, persons with fair or poor self-rated health were less likely than subjects with good or excellent self-rated health to report that their willingness to share would increase during a public health emergency (unadjusted OR 0.61, 95% CI 0.38 - 0.97, P = .04).

Discussion

Principal Results

Across subject groups, regardless of level of exposure to personally controlled health record technology, sex, age, and social role (student or employee), we found high levels of willingness to share personal health information from a PCHR with public health agencies for purposes of disease monitoring, evaluation, and needs assessment. Pragmatism and altruism rather than naïveté seemed to characterize subject preferences and positions. A strong tendency was observed among subjects toward balancing privacy and safety concerns with the possibility of personal or societal gain stemming from public health research. While a greater preference for an opt-in versus opt-out default model was observed, the picture was mixed. Models of blanket information sharing for either default were not favored, and subjects recognized that regardless of the default model, successful approaches toward sharing would be contingent on ensuring clear understanding of risks and benefits associated with their actions. Time and content limitations to sharing were repeatedly suggested as important options for maintaining control over personal information. Other factors conditioning altruistic impulses were guarantees of anonymity, provisions for audit checks on record access and sharing patterns, intermediation from a trusted party, restrictions on use of information for research only and, for some subjects, payment/compensation for data.

Within these affirmative findings, it is notable that despite being sent messages about the feasibility and mechanics of sharing their PCHR electronically, proportionately few subjects, only 61 of 151 (40%) in the live PCHR demonstration understood they could share their record electronically. A substantial minority of these, 18 of 61 (29%), did not understand that they could share their data in a "granular fashion," that is, selectively by topic, domain or section. These findings underscore the need for effective education and training on using this type of system to foster information flows of various types, recognizing that knowledge about sharing and attitudes toward doing so, including through granular controls, are likely to shift as the technology diffuses and opportunities to share increase.

Taken together, our findings suggest that longstanding concerns among technologists, advocates, and policy makers that consumer privacy concerns will undermine PCHR adoption, use, and sharing behaviors may not be born out if the sharing model and system is well-designed, well-executed, and well-explained [25-27]. As observed elsewhere [20], strong impulses toward information altruism auger well for new models of public health research that draw on PCHR data contributed by an engaged citizenry or patient populations.

Limitations

Findings about willingness to share are promising, but it is worth noting that they reflect the views of a regionally sampled, nonrepresentative set of subjects and a specific form of personal health record. Inferences about broad population patterns and generic personal health records cannot be drawn. Findings reflect the attitudes of subjects with some of the earliest substantive experience with PCHRs, specifically with a live system that integrated medical records (redacted of clinician notes) with patient annotations about health-related behaviors, attitudes, and family/household contexts. Future testing with records that represent the full spectrum of clinical information including potentially sensitive information and notes is warranted as the technology continues to develop and diffuse. Additional research is needed to characterize attitudes toward sharing for research that reflects a more comprehensive spectrum of study conditions. It is likely that willingness to share will vary depending on type of data requested (genotypic, phenotypic, care system related, other), time horizon of investigation (cross-sectional vs longitudinal), study design (observational vs interventionist), purpose (discovery, commercial product development, care improvement, as well as surveillance) and by the affiliation and role of investigators (governmental, private, academic, other). All of these factors are important and deserve further study as does the role of incentives and feedback.

Conclusion

Moving public health and medicine from a reactive to proactive stance with regard to detection and response to health problems may require seizing opportunities to engage consumers in health research using new approaches. There are clear advantages to exploring use of PCHRs as a vehicle for collecting health information germane to public health research: (1) the model may temper the one-way pull of data from subjects to investigators and authorities, providing a bridge for feedback and follow-up; (2) flexible cohort models may be facilitated given the dynamic nature of the system and the potential for ongoing ties to subjects; (3) emergency monitoring systems and rapid polling or surveillance of populations can reasonably be envisioned; and (4) linkage of phenotypic, service, and medical-biologic information in support of care improvement and discovery may be feasible. Success in these endeavors will depend on responding to preferences and conditions for fostering trust and maintaining ongoing research engagement. Such conditions include use of appropriate models for education and support of subjects and for obtaining their informed consent—a step that has proven elusive for electronic health record-based research [28]. In the rapidly evolving health information landscape, attention needs to be directed not only to defining preferences and principles for sharing, but also to defining the organizational and institutional mechanisms required for guarantees on safety and oversight.

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Conflicts of Interest

None declared

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Abbreviations

HITECH: Health Information Technology for Economic and Clinical Health
HIPAA: Health Insurance Portability and Accountability Act
PCHR: personally controlled health record

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Original Paper

Sharing Health Data for Better Outcomes on PatientsLikeMe

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Abstract

Background: PatientsLikeMe is an online quantitative personal research platform for patients with life-changing illnesses to share their experience using patient-reported outcomes, find other patients like them matched on demographic and clinical characteristics, and learn from the aggregated data reports of others to improve their outcomes. The goal of the website is to help patients answer the question: “Given my status, what is the best outcome I can hope to achieve, and how do I get there?”

Objective: Using a cross-sectional online survey, we sought to describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes.

Methods: Almost 7,000 members from six PatientsLikeMe communities (amyotrophic lateral sclerosis [ALS], Multiple Sclerosis [MS], Parkinson’s Disease, human immunodeficiency virus [HIV], fibromyalgia, and mood disorders) were sent a survey invitation using an internal survey tool (PatientsLikeMe Lens).

Results: Complete responses were received from 1323 participants (19% of invited members). Between-group demographics varied according to disease community. Users perceived the greatest benefit in learning about a symptom they had experienced; 72% (952 of 1323) rated the site “moderately” or “very helpful.” Patients also found the site helpful for understanding the side effects of their treatments (n = 757, 57%). Nearly half of patients (n = 559, 42%) agreed that the site had helped them find another patient who had helped them understand what it was like to take a specific treatment for their condition. More patients found the site helpful with decisions to start a medication (n = 496, 37%) than to change a medication (n = 359, 27%), change a dosage (n = 336, 25%), or stop a medication (n = 290, 22%). Almost all participants (n = 1,249, 94%) were diagnosed when they joined the site. Most (n = 824, 62%) experienced no change in their confidence in that diagnosis or had an increased level of confidence (n = 456, 34%). Use of the site was associated with increasing levels of comfort in sharing personal health information among those who had initially been uncomfortable. Overall, 12% of patients (n = 151 of 1320) changed their physician as a result of using the site; this figure was doubled in patients with fibromyalgia (21%, n = 33 of 150). Patients reported community-specific benefits: 41% of HIV patients (n = 72 of 177) agreed they had reduced risky behaviors and 22% of mood disorders patients (n = 31 of 141) agreed they needed less inpatient care as a result of using the site. Analysis of the Web access logs showed that participants who used more features of the site (eg, posted in the online forum) perceived greater benefit.

Conclusions: We have established that members of the community reported a range of benefits, and that these may be related to the extent of site use. Third party validation and longitudinal evaluation is an important next step in continuing to evaluate the potential of online data-sharing platforms.

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KEYWORDS

Personal health records; data visualization; personal monitoring; technology; health care; self-help devices; personal tracking; social support; online support group; online health community

Introduction

Managing complex and chronic diseases is a difficult undertaking for patients and clinicians alike. Clinicians are only able to allocate an average of 15 minutes per patient visit [1], frequently use medical jargon that patients do not understand [2], and are also unable to devote enough time to collaborative decision making with their patients [3]. These factors disproportionately affect the socially disadvantaged, such as patients from racial and ethnic minority groups and those with low literacy and low socioeconomic status [4]. For their part, patients do not adhere fully to medical advice [5], miss appointments [6], and use complementary and alternative medicines with little evidence to support these methods [7], often without informing their physician [8]. Although modifying the way clinicians interact with patients can yield some benefits, there is also a corresponding benefit to be gained in educating patients about how to make better use of their health care visits through intensive training programs such as the United Kingdom's "Expert Patient Programme" [9]. However such programs require extensive logistical support and require winning stakeholder "buy-in" from a range of agencies.

The Internet provides a platform to develop efficient, sustainable online resources for patients to research their medical questions, communicate with one another, and support each other, such that patients assume more responsibility for their care and decrease the burden on the health care system. Most American adults (74%) have access to broadband Internet connections, and 61% look online for health information [10], although there are barriers to access for those with a chronic illness [11]. The simplest method for online interaction is email, which even older patients are enthusiastic to use [12]; their physicians, however, are not [13], with estimates of only around 7% of physicians communicating with their patients in this way.

In recent years a number of online communities have been developed by patient organizations, providers, and nonprofit organizations. Such online communities are virtual forums where patients can discuss their health concerns and exchange information. Successful examples of such sites include Braintalk for neurological diseases [14] and Building User Involvement in Motor Neurone Disease (BUILD) for amyotrophic lateral sclerosis (ALS) [15]. While evidence about the impact of participation in online communities on medical outcomes is limited, the psychological benefits and increased quality of patient-physician interactions have been demonstrated [16].

Participation in online communities heightens levels of emotional well-being, perceived control over disease, overall personal empowerment, and level of medical knowledge [17,18]. The psychological outcomes have, in some cases, translated into improvements in medical decision making and positive behavioral change (see Barak et al [18] for a review). Still, concerns remain about potentially detrimental effects of online communities. Providers are concerned about patients diagnosing themselves or finding misinformation online [19]. However, these concerns appear unfounded when examined systematically [16,20], and chronic disease patients themselves are relatively well-informed about the potential limitations of the Internet as a source of information [21].

PatientsLikeMe is a Web-based application where members explicitly choose to share detailed computable data about symptoms, treatments, and health in order to learn from the experience of others and improve their outcomes. These data are presented back to members as individual-level graphical health profiles and aggregated into reports accessible on the site. Members can discuss these data sets either within a group forum or individually through private messages. The resources on the site are designed to help members answer the question: "Given my status, what is the best outcome I can hope to achieve, and how do I get there?" The platform itself has been described previously in detail [22,23,24] and is gaining recognition for its clinical research in areas as diverse as patient-reported outcomes [25], identification and quantification of symptoms in neurological diseases [26], patient education and decision-making [27,28], and patient-lead clinical trials [29]. The site fulfills Fox's definition of a tool helping patients to find a "just-in-time, someone-like-me" peer that can be relied upon to compare options and aid decision making [10].

To date, we have not analyzed the potential psychological and health services outcomes associated with site usage. In this paper, we present an initial study of the potential benefits of sharing health data in the site. We sought to describe the potential benefits of PatientsLikeMe and to understand the effect of our novel functionality on patient-reported outcomes. Specifically, we explored the following research questions: Do members of PatientsLikeMe perceive benefits from participating in this online community? Do they think that they make better treatment decisions? Do they feel they are managing their symptoms better? Do members become more engaged in their health care decisions? Does the site influence health care and outcomes? If so, is this related to site use? Finally, what are members' attitudes toward sharing data on the site?

Methods

We used the PatientsLikeMe survey system (PatientsLikeMe Lens) to construct a core set of questions (Multimedia Appendix 1) which were answered by registered members of PatientsLikeMe.com in the following communities: ALS, multiple sclerosis (MS), Parkinson's disease (PD), human immunodeficiency virus (HIV), mood disorders, and fibromyalgia. The questionnaire included a core set of questions to be answered by all participants, as well a set of community-specific questions. The survey was piloted on members of our rare disease communities (progressive supranuclear palsy, multiple system atrophy, and neuromyelitis optica) to ensure comprehension and ensure that the system functioned correctly, but the sample size was considered too small to draw reliable conclusions from the data (n = 30). Even in this small sample, the full range of responses was used and patients did not report dissatisfaction with completing the survey.

Recruitment

Members of PatientsLikeMe find out about the site through a variety of channels: search, paid advertisements, public relations, press mentions, academic collaborations, word of mouth from patients, and provider referral. Most members (approximately 80%) are based in the United States, with the remainder distributed throughout the world, predominantly in the English-speaking world, although members in some countries use translation software to participate.

Checklist for Reporting Results of Internet E-Surveys

The following information is provided to comply with the Checklist for Reporting Results of Internet E-Surveys [30]. A systematically selected probability sample of members from each community was invited to participate in the survey by electronic private message in March 2009. New private messages triggered an automated email to patients' email accounts (unless they had opted out of being contacted in this way). Sampled patients had their own password-protected login, had previously submitted age and sex data, and had been members of the site for at least 30 days. Patients could only complete the survey once, and we have tools to prevent multiple accounts originating from the same location, including account registration, cookies, and IP tracing. Therefore, we have more confidence in our denominators than might be found using an "open" survey method. The survey was voluntary and completion was not required to continue using the other features of the site. No incentives were offered; question order was not randomized; certain items only appeared conditional on previous responses (ie, were "adaptive") to minimize respondent burden (see Multimedia Appendix 1); and the total number of questions and screens varied by community and participants' responses.

Following initial contact, a reminder message was sent within a week to those who had not yet completed the survey; patients who had only partially completed the survey could reaccess it through the original private message (or reminder message) to complete their survey. Once opened, the survey had a "back" button that allowed participants to change their earlier answers. Only data from completed questionnaires are presented here, with the exception of the analysis between site use and treatment benefit in order to maximize sample size. As an internal research project without external sponsors, and with no anticipated adverse consequences for participation, institutional review board (IRB) approval was not sought for this project. Members of PatientsLikeMe join the site with the expectation that they will be participating in research. The recruitment message (see Multimedia Appendix 1) outlined the purpose of the study, reminded patients that they were under no obligation to participate, that their aggregated results may be published, and that the survey should take about 10 minutes to complete. It was sent from user accounts for authors PW and MM, who could easily have been contacted by potential participants from within the PatientsLikeMe system.

User data was protected in accordance with PatientsLikeMe's internal security standard operating procedures, which include password protection, deidentification of locally held data files, regular automated backup, and physical protection of IT hardware.

Data Analysis

Data analysis was performed using Statistics Package for the Social Sciences, version 18.0 (SPSS Inc, Chicago, IL, USA). Data were assessed for normality to guide the use of parametric or nonparametric statistics. Categorical variables were assessed using chi-square; normally distributed demographic data were analyzed using Student's *t* test or between-groups analysis of variance (ANOVA). Nonparametric between-group differences were tested using the Kruskal-Wallis test. In all cases, tests performed were two-tailed and assumed a cutoff of $P < .05$ for statistical significance.

Table 1. Patient characteristics and response rates by disease

Disease Community	Number of Survey Invitations Sent	Completed	Partially Completed	Opted Out	No Response	Age of Community	Median Duration of Site Use
		n (%)	n (%)	n (%)	n (%)		
MS	1992	347(17%)	14 (1%)	151 (8%)	1480 (74%)	24 months	9 months
PD	997	287 (29%)	45 (5%)	70 (7%)	595 (60%)	24 months	10 months
ALS	988	218 (22%)	41 (4%)	45 (5%)	684 (69%)	40 months	15 months
Fibromyalgia	801	150 (19%)	44 (6%)	39 (5%)	568 (71%)	5 months	2 months
HIV	1088	177 (16%)	58 (5%)	45 (4%)	808 (74%)	18 months	7 months
Mood disorders	999	144 (14%)	37(4%)	46 (5%)	772 (77%)	13 months	6 months
Total	6865	1323 (19%)	239 (4%)	396 (6%)	4907 (72%)	N/A	

Table 2. Demographics of respondents compared to nonrespondents by disease

	Sex			Age		
	Respondent	Nonrespondent		Respondent	Nonrespondent	
Disease Community	Number Male of Total N (% Male)	Number Male of Total N (% Male)	χ^2 (df) *P*	Mean Age (SD)	Mean Age (SD)	*t* test, *P* (95% Confidence Interval [CI] of Age Difference)
MS	65 of 347 (19%)	312 of 1645 (19%)	0.10(1) *P* = .92	46 (9)	43 (11)	3.24, *P* = .001 (0.8 - 3 yrs)
PD	131 of 287 (46%)	404 of 710 (57%)	10.42(1) *P* = .001	60 (10)	58 (11)	2.21, *P* = .03 (0.3 - 3.2 yrs)
ALS	145 of 218 (67%)	445 of 770 (58%)	5.37(1) *P* = .02	54 (11)	53 (12)	0.13, *P* = .9 (-1.6 to 1.8 yrs)
Fibromyalgia	3 of 150 (2%)	37 of 651 (6%)	3.49(1) *P* = .06	45 (12)	45 (12)	0.64, *P* = .52 (-1.4 to 2.8 yrs)
HIV	124 of 177 (70%)	652 of 911 (72%)	0.17(1) *P* = .68	42 (11)	39 (11)	3.28, *P* = .001 (1.2 - 4.8 yrs)
Mood disorders	34 of 144 (24%)	238 of 855 (28%)	1.11(1) *P* = .29	39 (13)	37 (14)	1.9, *P* = .06 (-0.1 to 4.7 yrs)

Results

Participants

The overall response rate was 19% (1323 of 6825) (Table 1). There were significant differences in participation rates between communities ($\chi^2_{15} = 193.78$, $P < .001$), with the highest rate in the Parkinson's disease group (n = 287, 29%) and the lowest in the mood disorders group (n = 144, 14%). Only patients who had been members of the site for more than 30 days were invited to participate; the actual duration of site usage (shown in Table 1) varied by disease; however, because the communities were themselves of differing ages, it is hard to interpret the significance, if any, of such differences.

Within disease groups there were varied patterns of significant differences between respondents and nonrespondents (including those who did not respond at all, those who opted out, and those who did not complete the survey, Table 2. MS respondents were 3 years older than MS nonresponders; PD respondents were more likely to be female and were 2 years older than PD nonresponders; ALS respondents were more likely to be male; fibromyalgia respondents were more likely to be female; HIV respondents were 3 years older than HIV nonrespondents. There were significant differences in sex ratio between diseases ($c^2_5=309.57$, $P < .001$) and in age between disease groups ($F_{5,1317} = 120.06$, $P < .001$). The age differences, though statistically significant are not large, and the between-condition demographic differences are to be expected given the epidemiological profile of each disease.

In the survey invitation (see Multimedia Appendix 1) we suggested that completing the survey should take approximately 10 minutes. During the development of the survey, we added an additional feature to the survey system, which allowed us to estimate the time taken to complete the survey, but this was only available for a limited subset (n = 384). For those participants, the median time to completion was approximately 12 minutes (median 743 seconds, interquartile range 560 seconds). At the end of the survey was an open text response box which stated: "Please use the space below for your final comments, or if you have a suggestion for one thing you would really like to see changed on the site please let us know here." The full set of anonymized responses is presented in Multimedia Appendix 2.

Treatment Decisions

The PatientsLikeMe site has been described previously [22]. Briefly, the site offers a variety of tools to help patients record the treatments they are taking, supported by a drug database to promote accurate data entry. On an individual basis, patients can see a visual display of their treatment history over time on their profiles. Data on treatment brands, dosages, duration on treatment, reasons for stopping, and evaluations of efficacy and side effects are aggregated into "treatment reports." These tools are intended to help educate and inform patients about treatments they are using or considering.

Patients agreed with the statement that using the site had helped them understand the side effects of their treatments. Of the total 1323, 757 (57%) responded the site was moderately or very helpful in this regard (Table 3). Also, 559 patients (42%) agreed that the site had helped them find another patient who had helped them understand what it was like to take a specific treatment for their condition. More patients found the site helpful with decisions to start a medication (n = 496, 37%) than with decisions relating to changing a medication (n = 359, 27%), changing a dosage (n = 336, 25%), or stopping a medication (n = 290, 22%).

Table 3. Reported utility of the site for medication-related issues and symptom management

How helpful has PLM been in…? (Category and Question)	Very Helpful	Moderately Helpful	A Little Helpful	Not at all Helpful	N/A, Never Tried to use for This
	n (%)	n (%)	n (%)	n (%)	n (%)
Treatments					
Understanding possible side effects of a medication for your condition	472 (36%)	285 (22%)	167 (13%)	74 (6%)	324 (25%)
Locating another person who helped you understand what it is like to take a specific medication for your condition	385 (29%)	174 (13%)	164 (12%)	101 (8%)	498 (38%)
Decisions about whether to start using a medication for your condition	266 (20%)	230 (17%)	127 (10%)	131 (10%)	568 (43%)
Decisions to change the medication you use to treat your condition	166 (13%)	193 (14%)	131 (10%)	149 (11%)	683 (52%)
Decisions about whether to change the dose of a medication for your condition	144 (11%)	192 (15%)	127 (10%)	159 (12%)	700 (53%)
Decisions to stop using a medication for your condition	127 (10%)	163 (12%)	128 (10%)	161 (12%)	743 (56%)
Symptoms					
How helpful has PLM been in learning about a symptom or symptoms you experienced?	639 (48%)	313 (24%)	178 (14%)	55 (4%)	136 (10%)
How helpful has recording your symptoms been to help you manage your condition?	476 (36%)	309 (23%)	264 (20%)	108 (8%)	164 (12%)
How helpful have symptom ratings on your profile been in understanding how your treatments are working?	399 (30%)	334 (25%)	279 (21%)	110 (8%)	199 (15%)

Symptom Management

In a similar fashion to the tools available for monitoring treatments and learning from aggregated data, patients can also benefit from symptom tools. Patients were asked to rate their symptoms on a scale of “none,” “mild,” “moderate,” or “severe.” Each community had about 10 “primary symptoms” that were asked of all patients with that condition; users could also opt to add their own “secondary symptoms,” from which duplicates were removed and errors were corrected. Aggregated reports showed which treatments were being used to treat each symptom. Table 3 shows the benefits gained from symptom tools. Relative to the treatment tools, the symptom tools were more widely used by patients; patients found the site particularly helpful in learning about a symptom they had experienced; 952 of the total 1323 members (72%) reported the site was moderately or very helpful. The majority of members found the site helpful to manage symptoms (n = 785, 59%) and understand how their treatments were working (n = 733, 55%).

Association Between Site Use and Treatment/Symptom Management Benefits

To test the hypothesis that the degree of site use (engagement) is associated with benefit, we analyzed the web-logs of participants in the survey to determine how many of the following activities they had engaged in on the site at least once: look at another patient’s profile, open the private message inbox, post in the forum, and start a new topic in the forum. These four activities were turned into a binary 0 or 1 response option and summed to produce an “engagement” score that ranged from 0 to 4. In order to maximize the sample, partially completed surveys were included in this section of the analysis. In Table 4 results from one of the items from Table 3 (“How helpful has PatientsLikeMe been in locating another person who helped you understand what it is like to take a specific medication for your condition”) are compared against the engagement score. There are significant differences between engagement scores for utility (χ^2_8=109.4, $P < .001$), with patients who use the site more often finding more benefit.

Table 4. Relationship between number of site activities and treatment benefit in locating another patient with experience of taking a specific medication

Engagement Score	Very Helpful	A Little or Moderately Helpful	Didn't Try or Not Helpful
	n (%)	n (%)	n (%)
0 activities	49 (16%)	78 (25%)	190 (60%)
1 activity	49 (20%)	60 (24%)	140 (56%)
2 activities	103 (27%)	100 (26%)	179 (47%)
3 activities	64 (31%)	61 (29%)	84 (40%)
4 activities	153 (46%)	87 (26%)	92 (28%)

Medical Management

As a means of communicating with their health care professional (HCP), a patient could print out their patient profile as a "doctor visit sheet" (DVS) that contained a summary of their outcomes, treatments, and symptoms. About a third of patients (388 of 1323, 29%) reported using the DVS during health care visits (see Table 5). Furthermore, 42% of patients (n = 562) reported being either "moderately" or "a lot more" involved in treatment decisions because of what they learned on PatientsLikeMe. A number of questions were asked about the HCP team's view of the patient's use of PatientsLikeMe and 66% (n = 871) reported their HCPs were supportive of their use of PatientsLikeMe. Respondents agreed that the site improved their ability to cope with problems in their life (n = 921, 70% agreed or strongly agreed), that as a result of meeting other patients through the site they felt less self-conscious about their condition (n = 895, 68%), that the site made them feel more in control of their condition (n = 949, 72%) and that it enhanced their quality of life (n = 823, 62%). The majority of respondents, (1,004 or 76%), agreed with the statement: "PatientsLikeMe has helped me understand my own prognosis."

Following anecdotal reports from the forums, we asked patients across our communities to respond to the statement: "As a result of using PatientsLikeMe, I have changed my physician." There were significant between-groupdifferences (χ^2 15 = 42.9, $P <$ .001); overall, 12% (n = 151 of 1320) of patients agreed or strongly agreed, while 88% (n = 1169) of patients disagreed or strongly disagreed. The group that reported the highest rate of changing physician due to PatientsLikeMe use was the fibromyalgia group in which 32 of 150 respondents (21%) strongly agreed or agreed with the statement, followed by the MS group (n = 51 of 344, 15%), the Parkinson's disease group (n = 26 of 287, 9%), the HIV group (n = 15 of 177, 8%), and the mood disorders group (n = 14 of 144, 10%); the ALS group had the lowest rate (n = 13 of 218, 6%).

Table 5. Reported utility of the site for communicating with their health care provider (HCP) using the doctor visit sheet (DVS)

	A Lot	Moderate Amount	A Little	Not at All	Not Applicable, Never Tried to Use Site for This
	n (%)	n (%)	n (%)	n (%)	n (%)
How much do you use the DVS in visits with your HCP team?	91(7%)	136 (10%)	161 (12%)	516 (39%)	417 (32%)
Compared with before PatientsLikeMe (PLM), how much more involved in treatment decisions are you because of what you learned from PLM?	277(21%)	285(22%)	296 (22%)	200 (15%)	263 (20%)
How much easier is it to communicate with your HCP team because of PLM?	281(21%)	300(23%)	284 (22%)	189 (14%)	267 (20%)

Condition-specific Benefits

Patients from each community were asked a number of condition-specific questions in addition to the core survey items; data from patients with HIV (n = 177) and mood disorders (n = 141) are presented here. Of respondents in the HIV group, 71% (n = 125) agreed or strongly agreed that they took more of an interest in their lab values (ie, cluster of differentiation 4 [CD4] and viral load) because of the site; 63% (n = 111) agreed they had better understanding of the consequences of taking a "drug holiday"; 41% (n = 72) agreed they had decreased risky behaviors; 29% (n = 51) agreed it had helped them decide to start taking antiretroviral drugs.

In the mood disorders community, 26% (n = 40) of users agreed or strongly agreed that using the site had reduced thoughts about self harm; 23% (n = 31) agreed they had decided to start therapy or counseling after interacting with others on the site; and 22% (n = 34) agreed they needed less inpatient care as a result of using PatientsLikeMe.

Diagnosis Status and Change in Confidence About the Diagnosis

One concern about online community participation is that patients may self-diagnose and do so incorrectly. Respondents were asked: "Did you have a diagnosis when you first became a PatientsLikeMe member?" The vast majority of respondents (1249 of 1323, 94%) stated they already had a diagnosis at the time of joining. Of the patients who still did not have a diagnosis (n = 72), 12 (17%) stated they were awaiting test results; 2 (3%) had not yet consulted a physician; and 1 (1%) was awaiting a second opinion. There were significant between-group differences for diagnostic confidence ($\chi^2_{20} = 90.37$, $P < .001$). In total, 90% of HIV patients (n = 158 of 176) and 88% of MS users (n = 295 of 336) were "very" or "extremely" confident in their diagnosis, followed by 85% of ALS users (n = 179 of 210), 81% of fibromyalgia patients (n = 117 of 145), 80% of Parkinson's disease users (n = 230 of 286), and 67% of mood users (n = 93 of 139). Patients were asked whether use of the site had changed their level of confidence that they had the correct diagnosis. Most users (n = 824 of 1292, 64%) reported no change in their diagnostic confidence; 35% (n = 456 of 1292) reported that use of the site had improved their confidence; only 1% of respondents (n = 12 of 1292) reported a decrease in confidence.

Sharing Medical Data

Respondents were asked, "When you first joined PatientsLikeMe, how comfortable were you with sharing your health information with other users of the site?" and then, "How comfortable are you today with sharing your health information with other users of the site?" At joining, 1090 of 1294 (84%) of respondents were "comfortable" or "very comfortable," rising to 94% (n = 1212 of 1294) at the time of survey. Between joining and the time of the survey, most respondents remained comfortable sharing health information or became more comfortable, with 69% (n = 889 of 1294) reporting no difference, 27% (n = 354 of 1294) being more positive about sharing, and only 4% (n = 51 of 1294) more negative.

Looking at only those patients who reported being "uncomfortable" or "very uncomfortable" on first joining (16% of users, n = 204), 72% (n = 146 of 204) became more favorable to sharing their health data online since joining; 28% (n = 58 of 204) reported no change; none reported being less comfortable. Comfort levels differed significantly by community on joining ($\chi^2_{15} = 47.52$, $P < .001$); initial discomfort ("uncomfortable" or "very uncomfortable") was highest in patients with mood disorders (n = 26 of 139, 19%) and Parkinson's disease (n = 52, 18%); lowest levels were in the HIV group (n = 24, 14%) and ALS group (n = 28 of 286, 13%). There was no significant between-group difference in changes in comfort level between joining and time of survey (χ^2 30 = 34.94, $P = .25$). At the time of survey, Parkinson's (n = 22 of 286, 8%) and Fibromyalgia patients (n = 12 of 145, 8%) were the groups with the greatest level of discomfort with sharing, followed by patients with mood disorders (n = 10 of 139, 7%), MS (n = 20 of 338, 6%), HIV (n = 9 of 176, 5%) and ALS (n = 9 of 210, 4%).

Discussion

Principal Results

PatientsLikeMe is an ongoing experiment in which patients can gain from sharing and discussing health information online. The site design extends the functionality of traditional qualitative online patient communities to encompass quantitative patient-reported data. Our primary hypothesis was that increased use of the PatientsLikeMe system would lead to greater perceived benefits to patients; our survey suggests that perceived benefits were widespread. Respondents reported learning about symptoms they had been experiencing, improved understanding of how their treatments were working, feeling more involved in treatment decisions, and communicating better with members of their HCP team. As is consistent with findings about members of other online communities [18], members of the PatientsLikeMe site self-reported that the site improved the psychological experience of living with their conditions. Respondents confirmed higher levels of quality of life and perceived control over their condition due to their participation.

Our findings are in line with findings from the recent national consumer survey on health information technology [31], which found that although only about 7% of respondents had ever used a personal health record, those that did reported greater empowerment in managing their health. Reported benefits included feeling that they knew more about their health (56%), feeling like they knew more about the care they were being given by their doctor (52%), and feeling able to ask their doctor questions they would not have asked otherwise (40%).

Treatment Decisions

Research in the general adult population has suggested that many Internet users (up to 60%) use online information to affect a decision on how to treat an illness or condition, and that an increasing number of Internet users (currently 45%) specifically look for information about prescription or over-the-counter drugs [10]. From our sample of chronic and seriously ill patients, the clearest treatment benefits seem to be around improved understanding of side effects.

Exposure to PatientsLikeMe may represent an opportunity to improve upon the deluge of information provided in drug package inserts [32] and the lack of personal experience or practical advice that a HCP can have with the personal impact of side effects. Results from the survey suggest that members of the site were more likely to research a treatment ahead of time or understand possible effects of taking the drug, rather than making changes to an existing treatment regimen. Some patients (about 1 in 5) did use information from the site to help decide to stop a medication; further research could establish what types of medications these were.

Symptom Management

A higher proportion of benefits were identified for improving information about patients' symptoms than for treatments; 59% of users said recording their symptoms on the site had been "helpful" or "very helpful" in managing their condition. Future work could examine whether prospective recording of symptoms is useful in clinical encounters from the provider's point of view.

Association Between Site Use and Treatment Management Benefits

We used our web-logs to analyze the relationship between use of site features and perceived benefit; greater engagement was associated with greater perceived benefit. Specifically, we reported that patients who engaged with the site more were more likely to have identified someone who they could communicate with about a specific treatment. Further analysis (not reported here) suggested that patients who found another patient like them to discuss treatments reported the site was more useful in helping to make treatment decisions such as starting a medication, changing a dose, stopping a medication, or understanding side effects. However, further research will be needed to elucidate the causal chain: is it that engaged users find more benefit, or that patients who have benefitted from the site come back to use more of its features?

Medical Management

Two thirds of patients felt that their HCP team approved of using PatientsLikeMe; further follow-up studies could explore the specific benefits experienced by HCPs. It is our hope that office visits can be more focused and effective because use of the doctor visit sheet takes some of the guesswork out of the interaction, particularly with respect to symptom management. Furthermore, constant access to “expert patients” to ask low-level questions means patients can make more effective use of their HCP’s time. Finally, even being a passive recipient of medical knowledge may have a positive effect on condition-specific health literacy, acknowledged to be a significant predictor of outcomes [33].

Varying by disease, between 6% and 21% of site members changed their physician as a result of using the site. This proportion was highest in the fibromyalgia group, a condition where patients anecdotally struggle to find a clinician who will treat them as a medical patient rather than a psychiatric case, but was also high in the MS group. We speculated that the PatientsLikeMe site offers patients novel opportunities to learn about the medical care and experiences of health interactions that other patients like them experience, and a forum to exchange information about “good” doctors in their local area. Again, anecdotally, there is also a push from patients to encourage newly diagnosed members to seek the care of a specialist in their condition. This finding contrasts with the consumers and health information technology (CHIT) study, which found that users of personal health records said they had become less likely to switch doctors as a result of using a personal health record [31]. Further research is needed to examine this interesting finding.

Condition-specific Benefits

Condition-specific responses provide examples of how the site has helped improve outcomes. For example, medication adherence is a significant problem among patients with HIV for a variety of reasons [34]. The tools provided by the PatientsLikeMe website in the HIV community have helped patients understand their CD4 and viral load test results and the risks inherent in taking a “treatment holiday.” Although the level of participation by members of any given community varies significantly, the HIV community currently stands at over 2700 patients; improved medication compliance among even a fraction of these users could have substantial benefits for those patients, the wider health system, and society as a whole. Encouragingly, 22% of mood disorders group said they needed less inpatient care as a result of using the site, and 26% agreed they think less about self-harm. These findings were not inevitable; there has been some evidence of Internet-related increases in depressive symptoms among patients who are highly engaged in online discussions, speculated to result from rumination or overattention to health problems [35]. Our own site emphasizes data-driven decision making over social functions such as the forum, and future work could look at the effects of participation in the forum as a potential exacerbating factor for some individuals with mood disorders.

Diagnosis Status

In any online community for patients, it is important to establish what proportion are diagnosed patients as opposed to people who are concerned that a symptom (eg, a muscle twitch) might indicate a serious disease such as ALS. The use of the Internet to self-diagnose has been dubbed “cyberchondria,” and in our experience the presence of undiagnosed patients in a community can be a source of irritation to patients coping with a serious medical condition. We were pleased to find that 94% of respondents had a diagnosis at the time of joining the site as this helps to deliver on the value proposition that prospective users will find a “patient like me” within their community; most e-patients (66%) are searching for advice for a specific medical problem rather than a symptom or undiagnosed condition [10].

Sharing Medical Data

In the current study we sought to understand patient attitudes to sharing their health data online. Patients who opt to join the site are, by and large, already comfortable with the notion of sharing their health data when they join. However, patients may have fears about potential risks of sharing their personal health data, such as discrimination by employers, insurance companies, or friends and families, particularly in stigmatized illness such as HIV or mood disorders. There are also a variety of real (and imagined) potential “data intruders” on the Internet with motivations ranging from personal research, genealogy, ancestry, forensic purposes or use in marketing, insurance, or employment decisions [36]. Among respondents in the CHIT study 75% who were not using a PHR reported worry about the privacy of their information as one of the most important reasons for not using PHRs, as compared with 51% of respondents who had concerns about cost, 38% who were concerned with how much time it would take, and 26% who did not like computers or the Internet [31]. Although a realistic possibility to be defended against, only 3% of e-patients have reported that they or someone they know has ever been harmed by following medical advice or health information found on the Internet [10]; this figure might compare favorably with advice from health care providers.

Those patients with the most serious illnesses were most comfortable with sharing, suggesting that patients are making risk/benefit analyses about sharing their health data and taking prognosis into account. Given the high initial rate of comfort with sharing, this is likely to reflect a ceiling effect. Although this finding may suggest that sites such as PatientsLikeMe may widen the “digital divide” between those who choose to share and those who do not, it is worth emphasizing that sharing of data was not a prerequisite to registering on the site or benefitting from the data contributed by others. Even without registering (which required only a valid email address), some

20% of patients opted to share their data publicly with anyone on the Internet, without the need to register their personal details on the site (members were explicitly warned that their results could be indexed by search engines if they set their profile to public). All aggregated treatment and symptom data were also shared publicly as reports. Therefore while the greatest benefits were for those that opted to share, anyone may have gained from the site's database. However, it remains to be seen what the long-term consequences might be of sharing personal health data with the public online.

Limitations

There are a number of limitations inherent in the study design that should be noted. First as a single survey we were not able to compare attitudes or changes in outcomes with any other population or measure change as it occurred over time. Second, the attitudes assessed in this study may not generalize to a broader population. The patients that opted to join the site may already have been highly involved in their care and comfortable with sharing health information. Therefore it was possible that the site was mostly benefitting patients who were among the most empowered of users anyway. Thirdly, there is likely a response bias whereby patients who have benefitted from the site would be most willing to spend their time completing a survey in their spare time; therefore all positive findings should be interpreted conservatively. With respect to responder bias, the age difference between respondents and nonrespondents is typical of surveys of other populations, that is, younger members of the population are less likely to respond. The differences are relatively small and so in our view do not compromise the sample's ability to represent our online community.

Fourth, as with any self-report study, it is not possible to say with certainty that all "patients" were correctly diagnosed with their reported condition, nor whether the survey was completed in the presence of a caregiver. Validation studies using clinical studies are the gold standard in replicating self-report registries [37], but such activities are resource-intensive. Finally there are bound to be social biases in the experimenters (who have built the site and so were hoping for a positive benefit) and in the participants (who, if they have benefitted, would have wanted to express their appreciation). That said, the survey had a large sample size and was subject to many of the same biases that exist in any service evaluation.

Conclusions

Our survey found that a substantial proportion of members of PatientsLikeMe experience benefits from participating in the community. Individually, some system features are relatively underused by patients; we might speculate therefore that much of the benefit identified here comes from peer-peer interaction to aid decision-making [10] as much as from structured data aggregation. Patients reported making more informed treatment decisions as a result of using the site, particularly around managing side effects. Members felt that they were managing their symptoms better and were better able to communicate with peers experiencing the same problems. Patients who used more of the site's features reported greater benefit, but further research is needed to elucidate the mechanism.

A substantial minority of patients (about a third) reported using data from their profile data in visits with their HCPs. Future work could survey HCPs about the utility of the information collected and displayed in order to increase this number. Collaboration with a clinical service in one of the disease areas covered by PatientsLikeMe could examine the impact of data sharing on clinic visits. Approximately 12% of patients reported having changed their physicians; this may reflect a groundswell of dissatisfaction among patients with chronic conditions and represents another important area for follow-up. Some of the condition-specific benefits are extremely important in improving patient outcomes; quality of life is notoriously difficult to improve in chronic conditions and should be investigated systematically and over a longer time period. The condition-specific benefits identified in the mood disorders and HIV groups hold great potential to improve outcomes for patients with those conditions. Future work should ensure third-party validation and replication of these findings, including gathering data from patients who chose not to join the site.

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Conflicts of Interest

The authors are paid employees of PatientsLikeMe and hold stock options in the company. PatientsLikeMe has received research funding from Union Chimique Belge (UCB), Novartis, and Avanir.

Multimedia appendix 1

User survey questionnaire

[PDF file (Adobe PDF), 103 KB - jmir_v12i2e19_app1.pdf]

Multimedia appendix 2

Open text response comments

[XLS file (Microsoft Excel File), 169 KB - jmir_v12i2e19_app2.xls]

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Abbreviations

ALS: amyotrophic lateral sclerosis
ANOVA: analysis of variance
BUILD: building user involvement in motor neurone disease
CD4: cluster of differentiation 4
CHIT: center for health information technology
DVS: doctor visit sheet
HCP: health care professional
HIV: human immunodeficiency virus
IRB: institutional review board
IP: Internet protocol
IRB: institutional review board
MS: multiple sclerosis
PD: Parkinson’s disease
PHR: personal health record
PLM: PatientsLikeMe

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Original Paper

Online Communication Between Doctors and Patients in Europe: Status and Perspectives

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Abstract

Background: Use of the Internet for health purposes is steadily increasing in Europe, while the eHealth market is still a niche. Online communication between doctor and patient is one aspect of eHealth with potentially great impact on the use of health systems, patient-doctor roles and relations and individuals' health. Monitoring and understanding practices, trends, and expectations in this area is important, as it may bring invaluable knowledge to all stakeholders, in the Health 2.0 era.

Objective: Our two main goals were: (1) to investigate use of the Internet and changes in expectations about future use for particular aspects of communication with a known doctor (obtaining a prescription, scheduling an appointment, or asking a particular health question), and (2) to investigate how important the provision of email and Web services to communicate with the physician is when choosing a new doctor for a first time face-to-face appointment. The data come from the second survey of the eHealth Trends study, which addressed trends and perspectives of health-related Internet use in Europe. This study builds on previous work that established levels of generic use of the Internet for self-help activities, ordering medicine or other health products, interacting with a Web doctor/unknown health professional, and communicating with a family doctor or other known health professional.

Methods: A representative sample of citizens from seven European countries was surveyed (n = 7022) in April and May of 2007 through computer-assisted telephone interviews (CATI). Respondents were questioned about their use of the Internet to obtain a prescription, schedule an appointment, or ask a health professional about a particular health question. They were also asked what their expectations were regarding future use of the Internet for health-related matters. In a more pragmatic approach to the subject, they were asked about the perceived importance when choosing a new doctor of the possibility of using email and the Web to communicate with that physician. Logistic regression analysis was used to draw the profiles of users of related eHealth services in Europe among the population in general and in the subgroup of those who use the Internet for health-related matters. Changes from 2005 to 2007 were computed using data from the first eHealth Trends survey (October and November 2005, n = 7934).

Results: In 2007, an estimated 1.8% (95% confidence interval [CI], 1.5 - 2.1) of the population in these countries had used the Internet to request or renew a prescription; 3.2% (95% CI 2.8 - 3.6) had used the Internet to schedule an appointment; and 2.5%

(95% CI 2.2 - 2.9) had used the Internet to ask a particular health question. This represents estimated increases of 0.9% (95% CI 0.5 - 1.3), 1.7% (95% CI 1.2 - 2.2), and 1.4% (95% CI 0.9 - 1.8). An estimated 18.0% (95% CI 17.1 - 18.9) of the populations of these countries expected that in the near future they would have consultations with health professionals online, and 25.4% (95% CI 24.4 - 26.3) expected that in the near future they would be able to schedule an appointment online. Among those using the Internet for health-related purposes, on average more than 4 in 10 people considered the provision of these eHealth services to be important when choosing a new doctor.

Conclusions: Use of the Internet to communicate with a known health professional is still rare in Europe. Legal context, health policy issues, and technical conditions prevailing in different countries might be playing a major role in the situation. Interest in associated eHealth services is high among citizens and likely to increase.

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KEYWORDS

Online physician-patient interaction; email communication; online prescription ordering; scheduling appointments online; eHealth services utilization and trends; Internet; Europe; survey; logistic regression analysis

Introduction

Quality health care depends on successful communication between health professionals and patients [1]. As the use of Web tools becomes more pervasive in health and medicine as represented by the concepts Health 2.0 [2] and Medicine 2.0 [3], and patients become more empowered, all parties need to adjust to a new form of participatory health care. These new environments are likely to promote more personalized health care, increased collaboration, and better health education. Expected outcomes are not only improved health but also more efficiency in the use of scarce resources, improved trust between stakeholders, and greater convenience [3], the essence of quality health care. Prior work suggests that online communication tools such as the Web and email can play important roles in enhancing access to health care and health information, in facilitating clinical management [4], and in increasing the effectiveness of practice administration. Such tools might even play roles in reducing health system expenditure [5] and in increasing overall efficiency [6]. However, a number of barriers and risks have also been identified [7-15]. Evidence from recent fieldwork is mixed, probably because assessment has involved varying methodologies, settings, systems, and perspectives [5,6,13,16-19].

Some studies have indicated that demand for online communication is strong among patients [20,21] and that, among Internet users, willingness to pay for Web portal services does not appear to vary significantly with age [22]. In one study of pediatric primary care, parents were particularly enthusiastic about the possibility of communicating online with their child's physician [23], stating that the ability to communicate online might be a reason to choose a particular pediatrician, even though the majority said they were unwilling to pay for such access [24]. In another study, older patients responded that they would like to use email to communicate with their physicians [25].

Regarding level of actual use, some studies of providers and consumers have found that online correspondence among patients and physicians, both solicited and unsolicited, has increased dramatically, while other studies have found this type of communication to be more limited. In New Zealand, for example, 68% of the 80 general practitioners interviewed in one study had never used email to communicate with their patients, and only 4% had used it regularly [26]. An investigation conducted in the east of Scotland found similar levels of use [27]. On the other hand, a cross-sectional study involving all physicians at the Finnish Student Health Service found that 79% of these physicians use email to communicate with patients [28] the same level reported by other studies of email communication in similar settings [17]. Studies involving the general population have reported much lower but also disparate levels of use. An online survey conducted in the United States in 2006, found that while only up to 4% of adults use or have access to online services for communicating with their physicians, most would like to communicate with their physicians in this way. In fact, the majority stated that the availability of online services would influence their choice of health care provider to some extent [29]. Meanwhile, results from the Health Information National Trends Surveys, HINTS 2003 and HINTS 2005, [30] showed that in 2003, 7% of American Internet users had used email or the Internet to communicate with a physician or a physician's office in the past 12 months, a proportion that had increased significantly to 10% by 2005. In Europe, the World Health Organization (WHO)/European Survey on eHealth Consumer Trends (eHealth Trends) [31] found that the estimated percentage of the population that had approached a family doctor or other known health professional through the Internet, even if only to read their website, had increased from 3.6% in 2005 to 6.9% in 2007, while the percentage of those interacting with a Web doctor or health professional they had never met increased from 8.2% to 11.1% over the same period. Results from a 2007 online survey of Dutch primary care patients with chronic complaints [32], a relevant target group for e-consultations, revealed that 90% had had no prior experience with such a service.

By the time of the second eHealth Trends survey, European countries had established priorities and strategies for eHealth [33]. However, the conditions reported to have been in place in the seven countries that participated in the eHealth Trends survey were very different. In Denmark, several initiatives were in place that aimed at the development of common standards, concepts, and classifications; good integration between electronic health records (EHR) and other health information systems; and the implementation of an Internet-based health care data network. The Danish public national health portal, Sundhed.dk, had been launched in 2003 [34].

In Germany, the two pillars of modernization identified were the establishment of an information and communication technology (ICT) infrastructure and the implementation of a private electronic patient record. The latter, to be introduced in four stages, would allow the provision of administrative data and transmission of electronic prescriptions, among other things [35]. With respect to a legal and regulatory framework, national legislation addressing telemedicine and eHealth service provision was in place. The German Medical Association's professional code of conduct (*Berufsordnung der Ärztekammer*) restricted the exchange of health-related email between doctor and patient to situations where there had been previous face-to-face contact.

In Greece, plans for the period 2006 to 2007 aimed at strengthening standardization and communication infrastructures and preparing the path for national integration by 2015. The plan was to do this through spearheading pilot projects linked to Europe-wide efforts with health insurance cards, e-prescription, and telemedicine [36].

In Latvia, development of telemedicine and provision of health care services online were two of the priorities defined, but by April 2007 the assessment of progress achieved so far was considered irrelevant given that the implementation plan was to have been ready at the end of 2006. As of 2007, there was no legal framework specific for eHealth or telemedicine practice available [37].

In Norway, the implementation of a national eGovernment information portal serving all sectors, including health, that might give access to e-prescription, the implementation of eResept (for electronic communication of prescription information), and the clarification of responsibility, rules, guidelines, and costs in connection with telemedicine consultations were among future activities to be developed. Legislative research started during spring 2006 to determine ways in which existing legislation was hindering progress in eHealth [38].

In Poland, development of electronic communication in health care, telemedicine services, and a central health care portal were some of the strategic targets in the national eHealth roadmap, but by 2007 much seemed to be still at the conceptual phase, and no specific legal framework for eHealth was available [39].

In Portugal, the promotion of telemedicine initiatives and development of e-prescription functionalities were some of the future activities envisaged [40]. There was no legal framework specific for eHealth or telemedicine practice, but online interaction in general involving personal data exchange and diffusion, such as eHealth services, come under very strict legislation that discourages online communication with patients in a clinical setting, especially in private and small practices.

Technical and legal differences in European countries exist together with spreading use of the Internet and email in Europe and the increased potential of these technologies to change the boundaries of communication within medical practice as well as several dimensions of the patient-physician relationship. Therefore, there is an urgent need to investigate how such services are being used, appraised, and valuated by European citizens.

For this paper, we used data of the second eHealth Trends survey that were not analyzed in previous work [31]. We used these data to investigate in the seven participating countries use of the Internet and email to interact with known health professionals for specific online services. First, we report on current levels of use of the Internet to obtain a prescription, schedule an appointment, or to ask a particular health question. We also report on changes in Internet use and expectations about future use that have occurred over the 18 month period following the first eHealth survey administered in 2005 in the seven countries. In addition, we report the importance of the availability of email and Web services for communicating with the physician when choosing a doctor for a first-time face-to-face appointment. Finally, using the results of logistic regression analysis of the data, we draw profiles of the potential consumers of related eHealth services. The discussion focuses on implications for citizens, health care providers, policy makers, and other stakeholders across Europe.

Methods

Participants and Procedures

Residents of Denmark, Germany, Greece, Latvia, Norway, Poland, and Portugal participated in the study. The questionnaire was administered through computer-assisted telephone interviews (CATI). The survey was conducted in April and May 2007 to reach a target of a representative sample of 1000 complete questionnaires in each participating country. Because the 2005 eHealth Trends survey was found to be skewed for some age groups, the 2007 survey used quotas based on census data. Six groups were defined based on age and gender specific to each country, and random digit dialing within strata was used to ensure a randomized representative sample (for more details see [31]). In total, 7022 questionnaires were completed, corresponding to an average response rate of 36% of the 22,867 individuals contacted in the seven countries (for more details see [31]).

Multimedia Appendix 1 shows the frequencies of respondents across age groups by gender and the sociodemographic variables included in the 2007 questionnaire. For comparison, we present the frequencies and percentages of the subjective health status of the European Social Survey (ESS) (September 2006 through March 2007). The eHealth Trends survey used the same question to report subjective health as the ESS, but the ESS used face-to-face interviews at home, with a reported response rate above 60%. The ESS did not cover Greece and Latvia. For the other five countries both studies obtained similar patterns.

Measures

The level of Internet use to obtain a prescription, schedule an appointment, or ask a particular health question was assessed by Question A: “In which connection and for what purpose have you approached your family doctor, specialist, or other health professional(s) via the Internet?” The various nonexclusive possibilities included: “request or renew prescription via email or web," "schedule an appointment," and "ask a particular health question." Expectations about future use were appraised by Question B: "Given that you were provided the possibility, state how likely it is that you will do the following during the next year: (1) have consultations with a health professional online and (2) make, cancel, or change an appointment with your family doctor, specialist, or other health professionals online?" The response categories ranged from 1 ("unlikely") to 5 ("very likely"). The importance attributed by European residents to the provision of email and Web services to communicate with the physician when choosing a new doctor was measured by Question C: "If you were to find a new doctor, state the importance of the following factors for your decision: (1) the possibility of requesting or renewing prescriptions via email or Web, (2) the possibility of scheduling or changing an appointment online, and (3) the possibility of communicating by email." The response categories ranged from 1 ("not important") to 5 ("important").

The focus on factors influencing the choice of a new doctor is relevant to our study. In this way, aspects such as previous experience with a health care provider, either at a clinical or administrative level that might lead to dependence and loyalty, are not considered, and we intended the question to address respondents' perceptions, attitudes, and expectations created through other mechanisms, such as their own experience with online services, knowledge about the experiences of others, or exposure to related information from mass media.

The questionnaire was designed in English and translated to the language or languages of the participant countries by means of a dual focus method, which strives for conceptual correspondence in addition to equivalence in wording and grammar [41].

Data Analysis

Tables 1 to 3 and Multimedia Appendices 2 to 6 provide 95% confidence intervals (CI) derived from Gaussian approximations of the distribution of the sum of strata frequencies or sum of ratios of strata frequencies. *P* values of two-sided tests are not given. For each test, significant test results are reported when the null is not inside the 95% interval. Differences (2007 minus 2005) were computed using poststratified data of the first eHealth Trends survey (October to November 2005) in the analyses (Tables 1 to 3 and Multimedia Appendices 2 to 6). Poststratified weighting of the 2005 distribution was defined by weights based on the 2007 distribution that used six age groups (15-25, 26-35, 36-45, 46-55, 56-65 and 66-80 years) by gender. This was done in order to separate real effects from minor changes introduced by sample construction (for more details see [31]). Binary outcomes of question C were analyzed as dependent variables by logistic regression on demographic, socioeconomic, and health variables. We fitted full models including all independent variables reported in Table 4 and Multimedia Appendix 7. Interaction terms were not fitted. We investigated two different groups: the total sample, which represented the general population, and a subsample of respondents who reported that they had used the Internet for health-related matters in the past. For each factor level, the odds ratio (OR) and 95 % confidence interval of the odds ratio were reported. Factors were tested with type II hypotheses (function Anova, R package: car version 1.2-7) (R Foundation for Statistical Computing, Vienna, Austria). Type-II hypotheses test each term after all others but ignore the term's higher-order relatives. No variables had more than 5% missing data.

All analyses were performed with SPSS version 16.0 (SPSS Inc, Chicago, IL, USA) and R version 2.8.1 (R Foundation for Statistical Computing, Vienna, Austria) [42].

Results

Patterns of Use of the Internet to Communicate With Known Health Professionals

Table 1 shows the prevalence of Internet use in 2007 to request or renew a prescription via email or the Web, schedule an appointment, or ask a particular health question, as well as the changes in the period between the two surveys in the seven European countries (for detailed results for each country, see Multimedia Appendices 2 to 4).

Table 1. Patterns of use of the Internet to communicate with known health professional

	2007		Change From 2005 to 2007	
	General Population	Health-related Internet Users	General Population	Health-related Internet Users
	Frequency Mean % (CI)[a]	Frequency Mean % (CI)[a]	Mean % (CI)[a]	Mean % (CI)[a]
Request or renew prescription	130	130		
	1.8 (1.5 - 2.1)	2.8 (2.4 - 3.3)	*+0.9 (0.5 - 1.3)*	*+1 (0.4 - 1.7)*
Schedule an appointment	226	226		
	3.2 (2.8 - 3.6)	5.4 (4.7 - 6.1)	*+1.7 (1.2 - 2.2)*	*+2.3 (1.2 - 3.3)*
Ask a particular health question	178	178		
	2.5 (2.2 - 2.9)	4.7 (4.0 - 5.4)	*+1.4 (0.9 - 1.8)*	*+2.2 (1.3 - 3.1)*

[a] 95% confidence intervals (CI); differences appear in italics when significantly different from 0 at the 5% level

The highest levels of Internet use were found in Denmark where, in 2007, an estimated 7.4% (95% CI 5.8 - 9.1) of the population reported having approached a family doctor, specialist, or other health professional via email or the Web to request or renew a prescription, 9.9% (95% CI 8.0 - 11.8) to schedule an appointment, and 6.7% (95% CI 5.1 - 8.2) to ask particular health questions. The lowest levels of Internet use in 2007 were found in Portugal, with an estimated use for these purposes of 0%, 0.4% (95% CI 0.1 - 0.7), and 0.7% (95% CI 0.3 - 1.1), respectively. The subgroup of health-related Internet users, who were experienced in looking for information on health matters on the Internet, were more active in using eHealth services than the population in general.

Expectations Regarding Future Use of eHealth Services

Table 2 shows the estimated percentages of European citizens and of European health-related Internet users expecting to have consultations with a health professional online or schedule an appointment with a family doctor, specialist, or other health professional online in the near future in 2007, as well as the mean changes in their expectations from 2005 to 2007 in the seven countries. Detailed results for each country are shown in Multimedia Appendices 5 and 6.

Table 2. Expectations regarding future use of eHealth services

	2007		Change From 2005 to 2007	
	General Population	Health-related Internet Users	General Population	Health-related Internet Users
	Frequency Mean % (CI)[a]	Frequency Mean % (CI)[a]	Mean % (CI)[a]	Mean % (CI)[a]
Have consultations with health professional	1264	876		
	18.0 (17.1 - 18.9)	24.1 (22.7 - 25.5)	*-2.5 (-3.7 to -1.2)*	*-4.9 (-7.1 to -2.7)*
Schedule or change an appointment online	1783	1244		
	25.4 (24.4 - 26.3)	32.5 (31.0 - 34.0)	+0.8 (-0.6 to 2.2)	-0.4 (-2.6 to 1.9)

[a] 95% confidence intervals (CI); differences appear in italics when significantly different from 0 at the 5% level

Among the general population, results showed a decrease in the average percentage of citizens stating they were likely to have consultations with a health professional online and a nonsignificant increase in the average percentage of citizens that believed they were likely to schedule an appointment online in the near future. In the subsample of health-related Internet users, average percentages decreased in the two situations. Denmark stands out as the country where citizens' expectations had increased most since 2005. In 2007, an estimated 26.2% (95% CI 23.5 - 28.8) of Danes stated they were very likely to have consultations with a health professional online in the year following the survey, and an estimated 36.8% (95% CI 33.9 - 39.7) stated they were very likely to schedule or change an appointment online. This corresponds to estimated mean increases of 5.3% (95% CI 1.5 - 9.0) and 7.3% (95% CI 3.3 - 11.3) respectively from 2005 to 2007.

On the other hand in Poland, citizens' expectations had decreased the most since 2005. In 2007, an estimated 25% (95% CI 22.3 - 27.7) of Poles stated they were very likely to have consultations with a health professional online in the year following the survey, representing a decrease of 13.3% (95% CI -17.3 to -9.4) from 2005, and 27.3% (95% CI 24.6 - 30.0) affirmed they were very likely to schedule or change an appointment online, a decrease of 8.7% (95% CI -12.7 to -4.7) since 2005. In 2005, however, Polish citizens' expectations were highest among the European countries studied. In most of the seven countries (as shown in Multimedia Appendices 5 and 6), increases were more pronounced among the general population, while decreases were more pronounced among those using the Internet for health-related purposes. The exception was Latvia, where the average percentage of health-related Internet users expecting to be able to schedule an appointment with a health professional online had increased by 4.9% (95% CI -1.1 to 11.0) from 2005 to 2007.

Importance of eHealth Services When Choosing a New Doctor

Table 3 shows the estimated mean percentages of European citizens and of European health-related Internet users that rated the importance of various eHealth services (using email or the Web) when choosing a new doctor at 4 or 5 (important) on a scale of 5 points in 2005 and 2007 and the mean changes from 2005 to 2007.

Table 3. Importance of eHealth services when choosing a new doctor in 2007 and changes from 2005 to 2007

	2007		Change From 2005 to 2007	
	General Population	Health-related Internet Users	General Population	Health-related Internet Users
	Frequency Mean % (CI)[a]	Frequency Mean % (CI)[a]	Mean % (CI)[a]	Mean % (CI)[a]
The possibility of requesting or renewing prescriptions	1996	1379		
	28.4 (27.4 - 29.4)	37.3 (35.7 - 38.8)	*+2.6 (1.2 - 4.0)*	+1.0 (-1.3 to 3.3)
The possibility of scheduling or changing an appointment	2690	1886		
	38.3 (37.2 - 39.4)	52.0 (50.4 - 53.6)	*+3.2 (1.8 - 4.7)*	+1.3 (-1.1 to 3.7)
The possibility of communicating by email	2644	1858		
	37.7 (36.6 - 38.7)	51.4 (49.8 - 53.1)	*+3.2 (1.7 - 4.7)*	-0.5 (-2.9 to 2.0)
All three services	1237	933		
	17.6 (16.7 - 18.5)	25.2 (23.8 - 26.6)	*+1.3 (0.1 - 2.5)*	+0.2 (-1.9 to 2.2)
At least one service	3702	2482		
	52.7 (51.6 - 53.8)	68.6 (67.1 - 70.1)	*+4.6 (3.0 - 6.1)*	+0.2 (-2.1 to 2.4)

[a] 95% confidence intervals (CI); differences appear in italics when significantly different from 0 at the 5% level

Scheduling or changing an appointment online and communicating with a health professional by email are the most appealing services. In 2007, the former was rated as important by 38.3% (95% CI 37.2 - 39.4) of citizens, corresponding to 2690 individuals and representing a mean change of 3.2% (95% CI 1.8 - 4.7) from 2005. The possibility of communicating by email was valued by a mean percentage of 37.7% (95% CI 36.6 - 38.7) citizens in 2007, corresponding to 2644 individuals and representing a mean change of 3.2% (1.7 - 4.7) from 2005, while the possibility of requesting or renewing prescriptions via email or the Web was quoted as an important factor in their decision by 28.4% (95% CI 27.4 - 29.4) of citizens, corresponding to 1996 individuals and representing a mean change of 2.6% (95% CI 1.2 - 4.0) from 2005. Changes are less significant among health-related Internet users. On average in 2007, half of the population reported that the possibility of having access to at least one eHealth service was important in their decision, while among health-related Internet users the number rises to 7 of every 10 respondents.

Characteristics of Survey Participants who Value eHealth Services When Choosing a New Doctor

Table 4 reports the results of logistic regression analyses that examined relationships between demographic, socioeconomic, and health variables, and the outcomes of the question concerning the importance of eHealth services when choosing a new doctor in the subsample of Internet users for matters related to health or illness. (For detailed results with respect to the general population see Multimedia Appendix 7.)

The estimated odds ratios indicated that those health-related Internet users who appreciated most the possibility of requesting or renewing a prescription via email or the Web when choosing a new doctor were under 25 (OR = 1.97, 95% CI 1.27 - 3.06), had secondary school education (OR = 1.37, 95% CI 1.10 - 1.71) and probably lived in main cities (OR = 1.39, 95% CI 1.08 - 1.78). Among the general population, young, well-educated (OR = 1.68, 95% CI 1.43 - 1.97) working people (OR = 1.27, 95% CI 1.08 - 1.46) no older than 25 (OR = 3.00, 95% CI 2.28 - 3.95) were most interested in this eService. In general, odds ratios for age and education are lower in the subsample, reflecting smaller differences between the groups. In the subsample of health-related Internet users, those valuing most the possibility of scheduling an appointment online were aged 26 to 35 (OR = 2.75, 95% CI 1.81 - 4.19), had no disability or diagnosed illness (OR = 0.67, 95% CI 0.54 - 0.84), and lived in main cities (OR = 1.66, 95% CI 1.30 - 2.11). Multimedia Appendix 7 shows that among the general population young people up to 25 years old (OR = 4.95, 95% CI 3.78 - 6.48) still in education (OR = 1.34, 95% CI 1.07 - 1.68), having some higher education (OR = 1.61, 95% CI 1.38 - 1.87), and living in main cities (OR = 1.30, 95% CI 1.09 - 1.55) were those most frequently interested in the service. The possibility of communicating with a health professional by email seemed particularly appealing to well-educated (OR = 1.93, 95% CI 1.66 - 2.25) working citizens (OR = 1.41, 95% CI 1.22 - 1.62) up to 25 years old (OR = 3.54, 95% CI 2.72 - 4.60). In the restricted sample, we observed significant results for those with secondary education (OR = 1.58, 95% CI 1.28 - 1.96).

Table 4. Characteristics of health-related Internet users who value eHealth services when choosing a new doctor in 2007

	Request or Renew Prescriptions			Schedule or Change Appointments Online			Communicate by email with Health Professionals		
	Odds Ratio	95% CI	*P* value	Odds Ratio	95% CI	*P* value	Odds Ratio	95% CI	*P* value
Gender									
Female	1.08	0.94 - 1.24	.29	1.00	0.88 - 1.14	.99	0.95	0.86 - 1.09	.49
Male	1			1			1		
Age			.005			< .001			.17
15-25	1.97	1.27 - 3.06	.003	2.68	1.73 - 4.16	< .001	1.43	0.95 - 2.16	.09
26-35	1.85	1.21 - 2.81	.004	2.75	1.81 - 4.19	< .001	1.50	1.01 - 2.21	.04
36-45	1.76	1.14 - 2.70	.01	2.58	1.68 - 3.95	< .001	1.53	1.02 - 2.28	.04
46-55	1.36	0.89 - 2.10	.16	2.19	1.43 - 3.35	< .001	1.22	0.82 - 1.81	.33
56-65	1.44	0.93 - 2.21	.10	2.23	1.45 - 3.42	< .001	1.32	0.89 - 1.97	.18
66-80	1			1			1		
Education			.01			.10			< .001
Higher education	1.14	0.93 - 1.40	.21	1.24	1.02 - 1.51	.03	1.34	1.10 - 1.63	.004
A-Level	1.37	1.10 - 1.71	.006	1.22	0.98 - 1.51	.07	1.58	1.28 - 1.96	< .001
below A-Level	1			1			1		
Children at home (< 18)	1.00	0.86 - 1.17	.96	1.06	0.91 - 1.23	.44	1.00	0.86 - 1.16	.99
No children at home	1			1			1		
Place of residence			.03			< .001			.21
City	1.39	1.08 - 1.78	.01	1.66	1.30 - 2.11	< .001	1.22	0.96 - 1.54	.11
Minor city	1.20	0.93 - 1.54	.17	1.37	1.07 - 1.75	.01	1.23	0.97 - 1.57	.09
Village	1.14	0.88 - 1.48	.33	1.45	1.13 - 1.86	.004	1.31	1.02 - 1.68	.04
Rural/remote location	1			1			1		
Work situation			.31			.22			.24
Student	0.84	0.63 - 1.12	.23	1.10	0.83 - 1.45	.52	1.14	0.86 - 1.50	.37
Working	1.02	0.83 - 1.25	.85	1.19	0.98 - 1.45	.08	1.19	0.97 - 1.44	.09
Not working	1			1			1		
With diagnosed illness	0.85	0.68 - 1.07	.16	0.67	0.54 - 0.84	< .001	0.82	0.66 - 1.01	.07
No	1			1			1		
Relative with diagnosed illness	0.90	0.76 - 1.05	.17	0.86	0.74 - 1.00	.05	0.94	0.80 - 1.09	.39
No	1			1			1		
Subjective health status			.11			.62			.55
Good	0.84	0.56 - 1.26	.40	0.94	0.63 - 1.40	.76	0.84	0.57 - 1.24	.39
Fair	1.01	0.67 - 1.52	.97	1.02	0.68 - 1.53	.91	0.80	0.54 - 1.20	.28
Bad	1			1			1		

Discussion

Use of the Internet to communicate with a known health professional is still rare in Europe, but interest in using it is high and likely to increase. Denmark is the only country in which consistent increases were found in all the variables under analysis in the 18 months between the two surveys.

Patterns of Internet Use to Communicate With Known Health Professionals

As expected, the estimated level of use of the Internet to request or renew prescriptions via email or the Web, schedule an appointment, or ask a known health professional a particular health question is still very low in the seven countries. Although not directly comparable, these results are in line with other reports of the use of these means to communicate with a doctor or a doctor’s practice in the United States [30]. One question remains: were the reasons for such low use the same in the two settings? In Europe, technologies that enable electronic storage of administrative patient data and of medical patient data seem to be available [43], at least in countries like Denmark, Norway, the United Kingdom, Sweden, the Netherlands, and Germany, although in Germany these technologies are not as available as in the other countries. However, use of email to communicate with patients may be in contravention of health authority policy. Benchmarking studies have confirmed that using the Internet or electronic health networks to email patients about health or even administrative issues is very rare (around 3%) in general practitioners’ practices throughout Europe [43], Denmark (at about 60%) being a clear exception.

In the United States, as early as 2001, the Institute of Medicine asserted that “patients should receive care whenever they need it and in many forms, not just face-to-face visits” and that “access to care should be provided over the Internet, by telephone, and by other means [44].” Meanwhile, the level of adoption of other health information technology by the health sector is still low and will likely remain slow unless significant financial incentives are made available [45,46]. Reported experiences with Web messaging have been promoted and financially supported by some health plans in the United States [5]. Many aspects of electronic communication related to reimbursement, legal issues, trust, and security remain unclear and need to be addressed.

The change in use during the 18 months between the two eHealth Trends surveys in Europe is statistically significant, even though certainly not impressive. However, the real relevance of this change must be analyzed in the light of the legal and regulatory environment prevailing in Europe and the policies governing health care delivery in the participating countries, as well as the technological achievements in each country. Despite the stated intentions [47], so far little seems to have changed in most of the countries studied. In Greece, for example, the legal framework for e-prescription and reimbursement is still incomplete.

According to a federal government report issued in Germany in April 2009 [48], the electronic health card is being piloted there, and electronic prescription has not been implemented so far. While email is available for interaction with most practitioners in Germany, it is not normally used for consultation but for administrative requests only, while the directive from the German Medical Association regarding email communication between doctor and patient remains [49].

In Poland, there are still no specific policies or legal regulations that could encourage online or even telephone medical consultations. Currently, basic online eHealth services are rare and there are few services offering online interaction with general practitioners. In 2004 the Ministry of Health issued an internal document called “Poland: eHealth Strategy for 2004-2006,” which stated that strategies for eHealth are part of the broader effort focused on development of the information society in Poland [47]. This might be the reason why the number of Poles expecting to use eHealth services in the year following the survey was the highest among the European countries studied in the 2005 survey. However, in spite of many promises and assurances from the government, the situation has not changed during the last 2 years and it still lacks regulation. Such regulations could solve the legal problems associated with eHealth consultations, enabling eHealth services to be officially implemented and reimbursed. On the other hand, attempts to implement and develop a registry of health services based on the use of electronic health insurance cards have been underway for the last ten years [47], but there is still no common and functional EHR system. These situations are probably part of the explanation for such a large decrease in citizens’ expectations in Poland in the 18 months between the two surveys.

In Norway, direct communication between patients and health professionals is limited to making appointments. It is illegal in Norway to communicate about personal health matters (ie, providing personally identifiable information) via email unless a special encrypted service is used. So far, only a minority of general practitioners’ (GP) offices in Norway offer this service.

In Portugal, the implementation of a national EHR system is currently under public discussion, while specific legislation for eHealth is still missing.

Expectations Regarding Future Use of eHealth Services

Overall, the citizens of the seven countries surveyed seemed to have had low expectations regarding the likelihood of having consultations with health professionals or being able to schedule appointments online in the period from 2005 to 2007. A study conducted in the United Kingdom in 2003 [50] concluded at the time that “patients simply doubted whether it was possible for the National Health Service and technology to cope with patients ordering prescriptions, emailing GPs, and booking appointments online.” Therefore, further work is needed to assess how our results should be interpreted, whether as a sign of doubt regarding the capacity of health systems and technology to handle such demands, as a reaction to the current level of provision, or as a barometer of the need and intention to use. Meanwhile, it is almost impossible not to question the extent to which the delay in implementation of the “information society” in many European countries is lowering the expectations of their citizens and cooling down enthusiasm for these new services. This may be the reason why the decrease in expectations concerning the use of eHealth services in the near future is higher among those experienced in using the Internet for health-related matters.

Importance of eHealth Services When Choosing a New Doctor

Nevertheless, the percentage of citizens that considered the availability of such eHealth services to be important when choosing a new doctor increased significantly by around 3% from 2005 to 2007. On average, in 2007, more than one third of the overall population seemed to be interested in the possibility of renewing a prescription, scheduling an appointment, or asking their doctors health questions online. This suggests that an attractive market for health organizations using the Internet as part of their business models is developing in Europe. Further research is needed to find out if European citizens would be willing to pay for access to such services, as has been reported in studies conducted in the United States [22].

A pilot study conducted in Poland and Greece showed that three out of four Greek patients (73.2%), once they felt comfortable with telemedicine (28% of the general population), were willing to pay €10 for each online consultation. The percentage of Polish respondents comfortable with telemedicine (35.5%) that were willing to pay for remote medical consultation was found to be somewhat lower (58.3%) but still significant. Among the general population in Poland and in Greece, 1 in 5 respondents said they were willing to pay €10 for a medical online consultation [51].

The situation in Denmark was shown to be remarkable compared with that in the other countries and deserves special mention. Not only was use of the Internet for renewing prescriptions, scheduling appointments, and asking health professionals about health questions reported to be higher, but Danes stood out as having had the highest expectations regarding the possibility of using particular eHealth services in the near future.

Five major factors seem to facilitate a positive environment for eHealth services: regulation/legal framework; reimbursement schemes; security and trust/infrastructure; the eHealth portal; and maturity in Internet adoption and usage.

In Denmark, the collective agreement (CA) between the General Practitioners Association and Danish Regions, via The Regions Salary and Fee Committee (RLTN), specifically addressed and set the terms for electronic communication in general practitioner practices. The CA stated that electronic communication (appointment booking, repeat prescription, and email consultation) must be offered to clinic patients by no later than January 1, 2009, although it was possible to apply for dispensation of the rule. Email consultation must be of a simple, concrete, and nonurgent nature without the need for further information. Lab results can also be offered via email after agreement with the patient. Email consultations are to be reimbursed by a fixed fee. Appointment booking and repeat prescriptions are considered a general service and are not reimbursed.

Security requirements have been established in Denmark. For a patient, there are two ways of sending an email to the doctor: through the eHealth portal sundhed.dk [52], which requires a digital signature, or through the doctor’s own website, which requires logging in. In both cases the email is written on a Web interface where it is Secure Sockets Layer (SSL) encrypted. It is actually converted to an EDIFACT, so it goes directly into the doctor’s information system. The patient receives an ordinary email announcing that there is now a reply to the email from the doctor, and the patient can then log in again either through sundhed.dk or the doctor’s own website to read the message.

Sundhed.dk [52] is the official Danish eHealth portal for the public Danish health care services (*sundhed* means “health” in Danish) that have been brought together on the Internet by the portal. This makes it possible for patients, their families, and health care professionals to access information and to communicate with each other. Use is registered and logged for security. Access to the restricted area (based on proof of employment) is possible for all health care professionals (eg, general practitioners, specialist doctors, dentists, physiotherapists, psychologists, and chiropractors) and organizations (eg, hospitals, pharmacies, and municipalities). Organizations such as municipalities can register for the digital signature as a single unit and assign staff approved by the authorities to it.

Regulatory and technical conditions are echoed by the maturity of the Danish in Internet adaptation and usage [31]. Many daily activities both private and work-related normally take place on the Internet, including public administration. Therefore, using it to communicate with the health care sector is a natural consequence. Secondly, thanks to sundhed.dk, Danes are now familiar with health services and information available online. A survey on the use of electronic services in general practitioner clinics published in December 2007 [53] also clearly showed the same pattern, reporting an increase of more than 75% from 2006 to 2007. However, in the public health care sector, development of electronic patient health record systems has been slow due to the level of decentralized decision-making regarding ICT investment. Pressure for interoperability and the structural reform taking place have either delayed or put many ICT projects in eHealth on hold [54].

Characteristics of Survey Participants Who Value eHealth Services When Choosing a New Doctor

From the results of logistic regression analysis, we know that, at least for now, the most prevailing characteristics of European citizens for whom availability of eHealth services are important in their decision when choosing a new doctor are age and having completed higher education. This profile changes slightly for those interested in the possibility of scheduling or changing an appointment online to include being a student and living in a main city, while for those interested in communicating by email with the physician, the profile includes being employed. Many reasons may be invoked to explain these findings. For example, younger people may feel more at ease with technology and have a natural predisposition to test new solutions, and people with higher education are likely to have more access to technology. The shortage of time experienced by most professionals may also explain their desire to communicate with their physicians by email.

For the subsample of health-related Internet users, the most interesting findings are the difference in the impact of age on each dependent variable and the interest shown by those having completed secondary school education. That is, the possibility of requesting or renewing prescriptions via email or the Web was attractive to young people up to 25 years old, the possibility of scheduling or changing an appointment online appealed most to those in the 26 to 35 age group, and the possibility of communicating by email--probably a more engaging and demanding activity in terms of responsibility, appealed most to those between 36 and 45 years old. Regarding level of education, we found that among those with access to the Internet, citizens with secondary school education seemed more eager for eHealth services than those with higher education. This finding probably reflects the greater difficulty people with lower levels of education have in reconciling work and visits to the doctor and their lower economic power to pay for health care. This interesting line of research deserves more thorough study in the future. Place of residence also had an influence on these profiles, with those living in big cities giving more value to the possibility of requesting or renewing prescriptions via email or the Web and the possibility of scheduling or changing an appointment online, while there was an indication that communicating by email with the doctor was more appealing to those living in villages. It seems that those who may have easier access to health care appreciate the Internet for simplifying administrative tasks, while those for whom personal contact with health professionals is more difficult because of the distance are more likely to appreciate email communication.

As we could not find any other reported studies of use of the same eHealth services, benchmarking of our results can be done only to a limited extent. Compared with our findings, a study conducted in 2005 [30] showed that online American women were more likely than men to have communicated with a health care provider through the Internet; education was not associated with online patient-provider communication in the multivariate model, age was not a predictor of behaviour, and use of online patient-provider communication was higher among Internet users experiencing health problems or with significant medical histories. A Dutch study of nonusers of e-consultations [32] showed that the elderly, less-educated individuals, chronic medication users, and frequent GP visitors were more motivated to use the service. Several studies have found that online women were more likely than men to search for health information [31,55,56]. However, besides differences at the demographic level, we did not find evidence of higher interest in the eHealth services we studied among those feeling in poor health, those suffering from a disability or long-term illness, or those associated with someone close who is disabled or suffering from long-term illness. In fact, having no disability was found to be a predictor of interest in the possibility of scheduling appointments online.

Study Contributions and Limitations

The study reported here is novel both in its aim and dimension.

To our knowledge, by the time of the second survey, no reports were available in the literature regarding the extent to which attempts being made by governments in Europe to implement eHealth services were reaching the population at large. Nor was it known the extent to which citizens and even health providers were conscious of what was technically or legally feasible. In fact, recent work confirms that this is still the case in other settings [19]. Therefore, this work represents a timely assessment of conditions being experienced by citizens in the seven countries and of how they perceived and internalized what they knew about efforts being made.

Results are based on representative samples of the populations in seven European countries. In these countries there has been a lack of empirical evidence regarding citizens' attitudes and expectations towards online interaction with known health professionals and the present levels of use of specific eHealth services. However, the surveys did not cover all European countries. In addition, the possibility of generalizing the results may be hindered by the survey response rate.

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Conflicts of Interest

None declared

Multimedia Appendix 1

Frequencies of age groups by gender and of sociodemographic variables per country, in 2007

[JPEG file (JPEG Image), 160 KB - jmir_v12i2e20_app1.JPG]

Multimedia Appendix 2

Observed frequency and percentage of citizens who have requested or renewed prescription via email or web in 2007 in each country and changes from 2005 to 2007

[JPEG file (JPEG Image), 60 KB - jmir_v12i2e20_app2.JPG]

Multimedia Appendix 3

Observed frequency and percentage of citizens who have scheduled an appointment via the Internet in 2007 in each country and changes from 2005 to 2007

[JPEG file (JPEG Image), 61 KB - jmir_v12i2e20_app3.JPG]

Multimedia Appendix 4

Observed frequency and percentage of citizens who have asked a particular health question to their family doctor, specialist or other health professional via the Internet in 2007 in each country and changes from 2005 to 2007

[JPEG file (JPEG Image), 66 KB - jmir_v12i2e20_app4.JPG]

Multimedia Appendix 5

Observed frequency and percentage of citizens expecting to have consultations with health professional online in the year following the survey in 2007 in each country and changes from 2005 to 2007

[JPEG file (JPEG Image), 70 KB - jmir_v12i2e20_app5.JPG]

Multimedia Appendix 6

Observed frequency and percentage of citizens expecting to schedule an appointment online in the year following the survey in 2007 in each country and changes from 2005 to 2007

[JPEG file (JPEG Image), 67 KB - jmir_v12i2e20_app6.JPG]

Multimedia Appendix 7

Characteristics of European citizens prizing eHealth services when choosing a new doctor in 2007

[JPEG file (JPEG Image), 107 KB - jmir_v12i2e20_app7.JPG]

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Abbreviations

CATI: Computer-Assisted Telephone Interviews
EHR: Electronic Health Records
ESS: European Social Survey
ICT: Information and Communication Technology
HINTS: Health Information National Trends Survey
SSL: Secure Sockets Layer

WHO: World Health Organization

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Original Paper

Effects of a Financial Incentive on Health Researchers' Response to an Online Survey: a Randomized Controlled Trial

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Abstract

Background: Nonresponse to questionnaires can affect the validity of surveys and introduce bias. Offering financial incentives can increase response rates to postal questionnaires, but the effect of financial incentives on response rates to online surveys is less clear.

Objective: As part of a survey, we aimed to test whether knowledge of a financial incentive would increase the response rate to an online questionnaire.

Methods: A randomized controlled trial of 485 UK-based principal investigators of publicly funded health services and population health research. Participants were contacted by email and invited to complete an online questionnaire via an embedded URL. Participants were randomly allocated to groups with either “knowledge of” or “no knowledge of” a financial incentive (£10 Amazon gift voucher) to be provided on completion of the survey. At the end of the study, gift vouchers were given to all participants who completed the questionnaire regardless of initial randomization status. Four reminder emails (sent from the same email address as the initial invitation) were sent out to nonrespondents at one, two, three, and four weeks; a fifth postal reminder was also undertaken. The primary outcome measure for the trial was the response rate one week after the second reminder. Response rate was also measured at the end of weeks one, two, three, four, and five, and after a postal reminder was sent.

Results: In total, 243 (50%) questionnaires were returned (232 completed, 11 in which participation was declined). One week after the second reminder, the response rate in the “knowledge” group was 27% (66/244) versus 20% (49/241) in the “no knowledge” group ($\chi^2_1 = 3.0$, $P = .08$). The odds ratio for responding among those with knowledge of an incentive was 1.45 (95% confidence interval [CI] 0.95 - 2.21). At the third reminder, participants in the “no knowledge” group were informed about the incentive, ending the randomized element of the study. However we continued to follow up all participants, and from reminder three onwards, no significant differences were observed in the response rates of the two groups.

Conclusions: Knowledge of a financial incentive did not significantly increase the response rate to an online questionnaire. Future surveys should consider including a randomized element to further test the utility of offering incentives of other types and amounts to participate in online questionnaires.

Trial Registration: ISRCTN59912797; http://www.controlled-trials.com/ISRCTN59912797 (Archived by WebCite at http://www.webcitation.org/5iPPLbT7s)

(J Med Internet Res 2010;12(2):e13) doi:10.2196/jmir.1251

KEYWORDS

Questionnaires; Electronic Mail; Randomized Controlled Trial; Reminder Systems; reward

Introduction

Nonresponse to questionnaires can affect the validity of surveys and introduce bias.

The offer of financial incentives has been a widely used method to increase response rates to postal questionnaires. A Cochrane systematic review of 481 randomized controlled trials (RCTs) evaluating 110 different ways of increasing response rates to postal questionnaires in a wide range of populations found that odds of response can be doubled through the use of monetary incentives [1]. Other factors shown to increase the odds of response included a topic of interest, pre notification, follow-up contact, unconditional incentives, shorter questionnaires, provision of a second copy of the questionnaire at follow-up, mention of an obligation to respond, and university sponsorship [1].

However, this evidence base relates to postal questionnaires, and although a number of systematic reviews [1,2] and meta-analyses [3] have been conducted, the available evidence base relating to use of incentives in electronic questionnaires is less substantive. The Cochrane review included 32 RCTs that evaluated 27 different ways of increasing response rates to electronic questionnaires in a wide range of populations [1]. Although the one included RCT that evaluated monetary incentives found no significant effect, a further six RCTs found that use of other financial incentives (such as Amazon gift vouchers) doubled the odds of response. Limited evidence from social and market research also suggests that the offer of some form of monetary or financial incentive can increase the odds of a person responding and completing a web survey [3].

Theoretical frameworks have been used to explain the potential influence of incentives on response rates. Social exchange theory [4] proposes that the actions of individuals are influenced by the balance between the rewards they expect to obtain and the costs they perceive may occur as a consequence; this exchange paradigm has become a key concept in marketing [5]. A systematic review of the design and conduct of questionnaire surveys suggests that making exchange theory operational (in order to maximize response)involves minimizing the physical, mental, emotional, and economic costs of response, maximizing the tangible and intangible rewards for response, and establishing trust that those rewards will be delivered [6]. In contrast, Leverage-saliency theory [7] proposes that a potential participant's decision to respond to a survey is influenced by the importance placed on key factors such as interest in the topic, [8] available time; the credibility of the research source, and the benefits (tangible or otherwise) the individual perceives will result from participation. The theory postulates that potential participants with a strong interest in the topic are more likely to respond; incentives can act as leverage for those potential participants for whom influencing factors (such as topic of interest) are deemed less important.

Our study was undertaken as part of a survey to assess what steps researchers in the fields of health service and population health within the United Kingdom are taking to disseminate the findings of their research. Addressing deficiencies in the dissemination and transfer of research-based knowledge into routine clinical practice is high on the policy agenda both in the United Kingdom [9-11] and internationally [12]. Research dissemination and knowledge transfer is also highly relevant to the United Kingdom applied health research community. The main funder, the National Institute for Health Research (NIHR), is seeking to maximize the impact of its £800 million investment in applied health research [13]. The NIHR has expectations that researchers will work to ensure that research is made available, can be used to support decision making, and will ultimately improve the quality and delivery of health care.

The population of interest for this survey is university-based and has high levels of Internet and email access. In addition, the major public funders of public health and health services research in the United Kingdom operate electronic online submission processes and use email as the principal mode of communication with grant holders and applicants. Given this, we decided to adopt a Web-based survey approach as it represented the most efficient and low cost mode of delivery.

However, there is some evidence that Web-based surveys can result in lower response rates (around 10%) compared with other survey modes [2,14,15]. Because of this, we decided to offer an incentive (gift vouchers from the online retailer Amazon) to participants to respond. Although a variety of incentives to increase response rates have been tested in a wide range of professional populations (including nine previous studies involving faculty members at universities [1]), to our knowledge there is no evidence based on a randomized trial relating to our specific population of interest. In addition, the Cochrane review included three randomized evaluations of Amazon gift vouchers that showed mixed effects [1]. Given this, we decided to test—using a randomized controlled trial nested within a survey—whether knowledge of a financial incentive would increase the response rate to the online questionnaire.

Methods

Recruitment

In July 2008, after obtaining ethical approval for the study from the University of York IRISS Ethics Committee, we contacted 10 UK programs and agencies that fund health services and public health research. The agencies were invited to provide (secure and encrypted) email contact details for UK-based principal investigators of health services and public health research completed in the last five years (2003-2008). Five agencies (the Scottish Chief Scientist Office, Economic and Social Research Council, Medical Research Council, NIHR Health Technology Assessment Programme and Wellcome Trust) responded and provided details. Principal investigator details for one non responding agency (NIHR Service Delivery and Organisation Programme) were publicly available and were obtained from their website. Two agencies (British Heart Foundation and Joseph Rowntree Foundation) indicated that they fund very little public health and health services research and so were excluded from the survey. The Department of Health Policy Research Programme and Cancer Research UK responded stating that they were unable to provide details of principal investigators.

We identified 743 principal investigators from the six funding agencies. Duplicates were removed from the list resulting in a total survey sample of 536 potential participants. Email addresses for identified principal investigators were then checked and compiled.

Study design and randomisation

Potential participants were randomized to receive either “knowledge of” or “no knowledge of” a financial incentive—in this instance gift vouchers (from the online retailer Amazon) to the value of £10. Amazon gift vouchers (distributed via the Amazon email gift certificate facility) were sent to all participants who completed the questionnaire regardless of the study group to which they were randomized.

Random allocation of participants using computer-generated numbers was undertaken independently by a statistician at the Medical Research Council (MRC) General Practice Research Framework.

Administration

On October 13, 2008, both groups were contacted by email (Textbox 1). Participants were told the purpose of the study and invited to complete an online questionnaire via an embedded URL. The online questionnaire was hosted on the SurveyMonkey website [16] and was based on an instrument previously used to assess the practices of intramural MRC Research Units in an earlier phase of the project. The questionnaire comprised a combination of 36 open and closed questions that could be completed in 20 to 30 minutes. The questionnaire was piloted prior to use.

Textbox 1. Email invitation to knowledge group

Subject: MRC PHSRN survey invite

Dear Colleague,

Disseminating the Findings of Health Services and Public Health Research

We are writing to invite you to take part in a survey.

This survey aims to find out what steps public health and health services researchers working across the United Kingdom are taking to disseminate the findings of their research.

The survey is part of a three-year project funded by the MRC Population Health Sciences Research Network (Ref: PHSRN 11). The project aims to identify ways by which the uptake of publicly funded public health and health services research can be enhanced.

We very much hope that you will agree to participate and complete the questionnaire.

The questionnaire contains 36 questions and can be completed in 20-30 minutes.

Respondents who complete the full questionnaire will receive a £10 Amazon gift voucher.

Any information provided will be treated in the strictest confidence and presented on a nonattributed basis.

Click here to go to the questionnaire. http://tinyurl.com/5olpfq

Please do not circulate to other colleagues

Thank you for your cooperation.

Best wishes

Paul Wilson

On behalf of:

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The email sent to the participants in the “knowledge” group stated that those who completed the online questionnaire would receive a £10 Amazon gift voucher. The study design specified that four reminder emails (sent from the same email address as the initial invitation) would be sent out to nonrespondents at one, two, three, and four weeks following the initial invitation; a fifth postal reminder would be sent to nonrespondents if the response rate was considered to be low. Participants who completed the online questionnaire were deemed to have given their consent. Questionnaires not returned by December 31, 2008, were deemed to be nonresponses.

As this RCT was nested within a larger survey, the primary concern was to maximize response rates. Given this, it was determined thatif the difference in the response rate between the two groups was such that it was likely to adversely affect the main aims of the survey, then knowledge of the incentive would be provided to the “no knowledge” group, but not before the third reminder. At the third reminder, we provided “knowledge of” the incentive to the “no knowledge” group to limit any adverse effects on total response to the survey.

A combination of IP address and questionnaire responses were used to identify multiple responses from a single participant [17]. Where multiple responses from a single participant occurred, the most recently completed questionnaire was retained for analysis. Noninvited responses from individuals not part of the study sample were excluded from the analysis.

Analysis

The primary outcome measure for the trial was rate of response one week after the second reminder. Rate of response was also measured at the end of weeks one, two, three, four, and five, and after the postal reminder. Data were entered and analysed in SPSS version 15.0 (SPSS Inc, Chicago, IL, USA). We compared the response rates in each group using the chi-square statistic.

Results

Of the 536 identified email addresses, 51 were undeliverable resulting in a sample of 485. A total 243 (50%) questionnaires were returned (232 completed; 11 in which participation was declined). Figure 1 illustrates the flow of responses to the study.

As a measure of completion [17], 100% of the 232 participants who completed questionnaires answered the questions on the first page, and 95% (220/232) answered the final question. Excluded from the analyses were 4 questionnaires completed by noninvited individuals. Multiple responses were submitted by 2 participants; the most recently submitted questionnaire was included in the analyses in each case.

Table 1 shows the cumulative response rate over time by group. Figure 2 shows the cumulative percentage response over time, again by group. The primary outcome measure for the trial was rate of response one week after the second reminder. The cumulative response rate in the ”knowledge” group was 27% (66/244) versus 20% (49/241) in the “no knowledge” group. This difference was not statistically significant (χ^2_1=3.0, *P*=.08). The odds ratio for those with knowledge of an incentive that responded was 1.45 (95% confidence interval [CI] 0.95 - 2.21).

Figure 1. Flow chart of “knowledge of” versus “no knowledge of” financial incentive

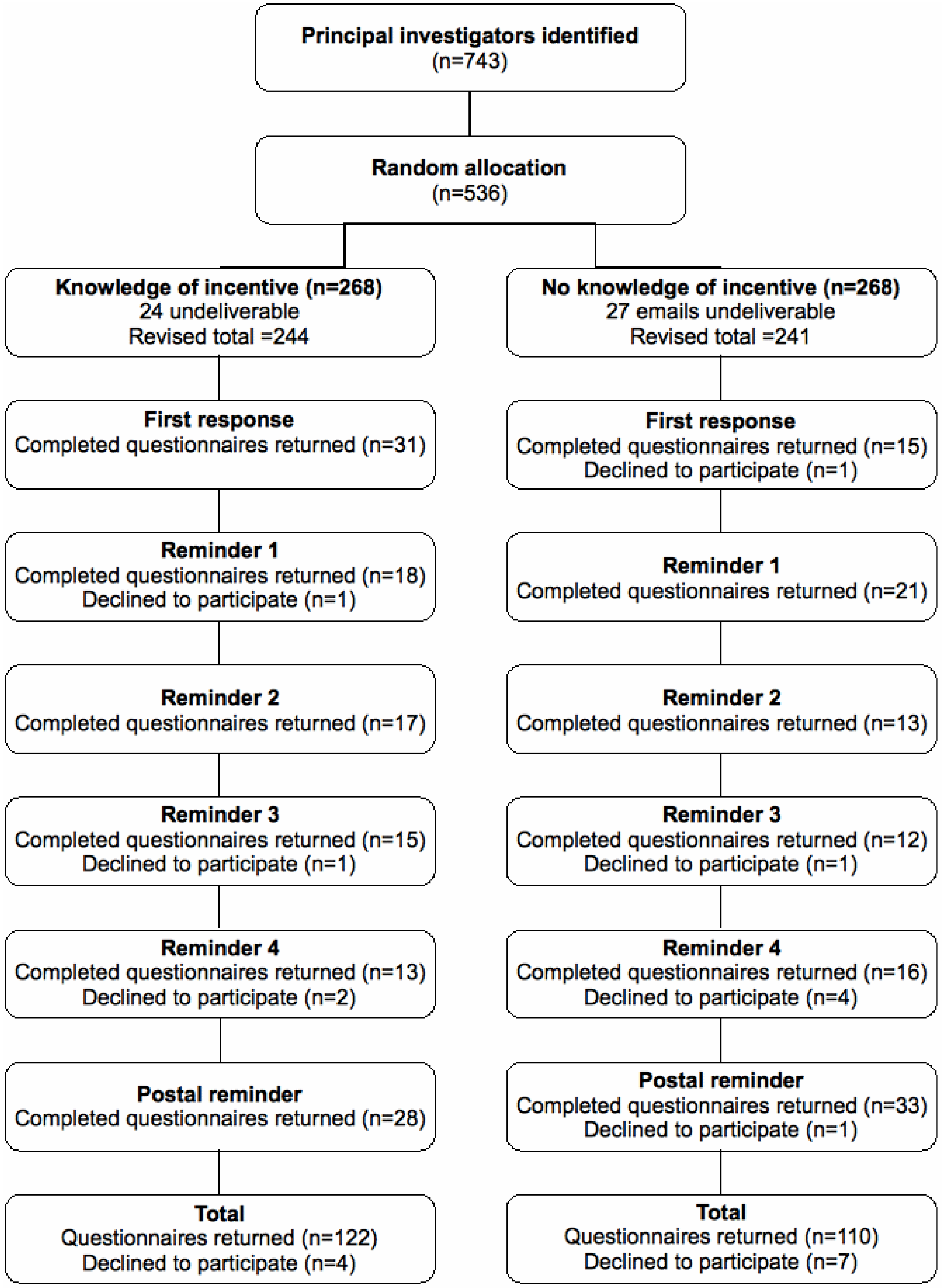
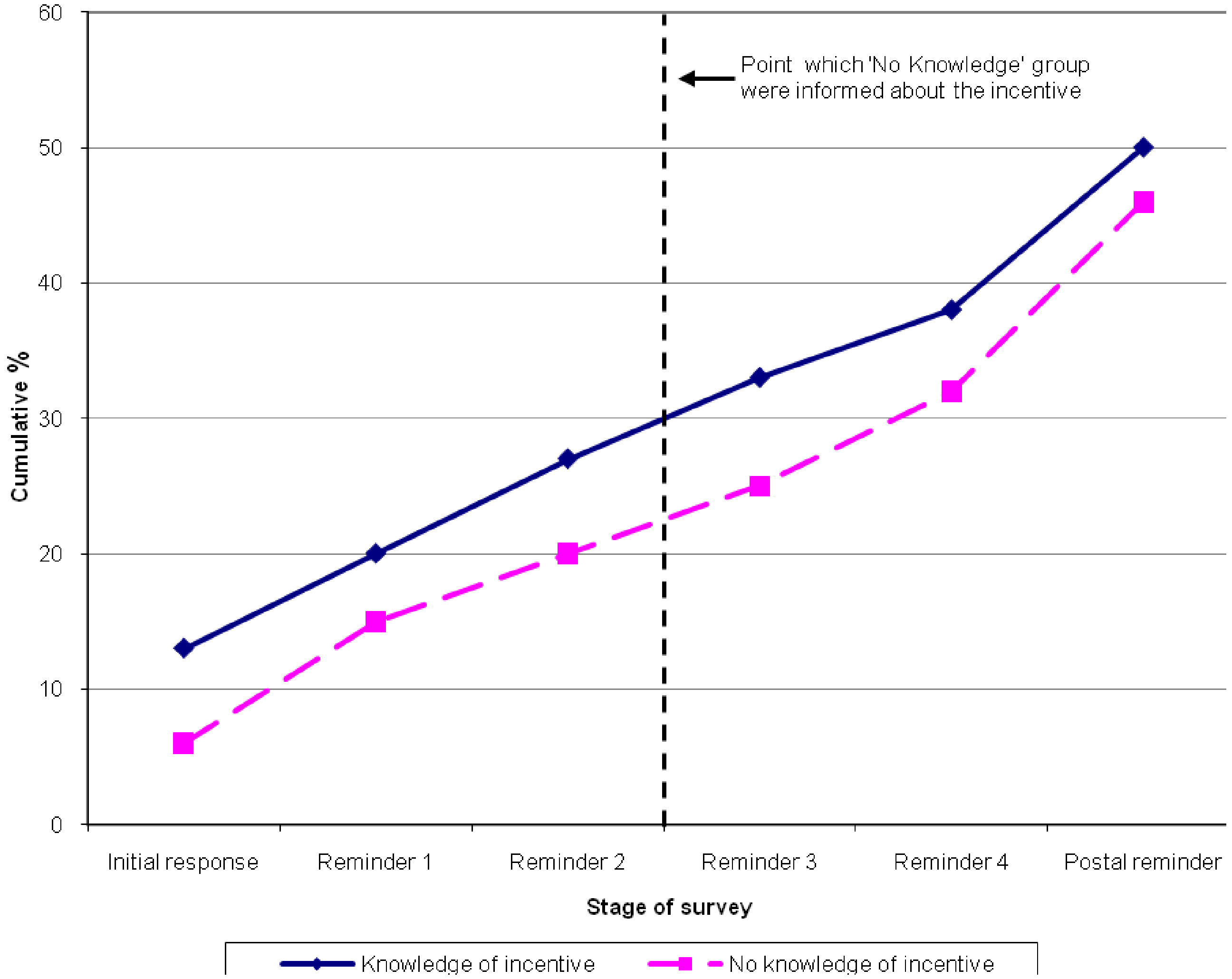


Table 1. Cumulative response over time by group

	Knowledge Group (n = 244)	No Knowledge Group[a] (n = 241)	χ^2 Significance
First response	31 (13%)	15 (6%)	*P*=.01
Reminder 1	49 (20%)	36 (15%)	*P*=.13
Reminder 2	66 (27%)	49 (20%)	*P*=.08
Reminder 3	81 (33%)	61 (25%)	*P*=.06
Reminder 4	94 (38%)	77 (32%)	*P*=.13
Postal Reminder	122 (50%)	110 (46%)	*P*=.33

[a] No knowledge group informed about incentive from reminder 3 onwards

Figure 2. Cumulative response (%) over time by group



At the third reminder, participants in the “no knowledge” group were informed about the incentive, ending the randomized trial nested within the survey. As this was a survey, we continued to follow up all respondents, and for transparency purposes, Table 1 presents further data on the cumulative response rates. No significant differences were observed in response rates between the two groups from reminder 3 onwards.

Discussion

Statement of principal findings

Knowledge of a financial incentive did not significantly improve the response rate to this online questionnaire. However, one week after the second reminder—the point before the “no knowledge” group were informed about the incentive—a difference of 7% was apparent.

Comparison with other studies

In terms of overall response, our rate of 50% compares favourably with those reported for other Web surveys. For example, in a review of comparisons of Web survey versus other survey modes, only 6 of 45 Web surveys managed to obtain a response rate higher than 50% [14]. In a second meta-analysis, which reported an 11% difference in response rates in favor of postal over Web modes, only 10 of 39 comparisons obtained a Web survey response rate higher than 50% [15]. Previous randomized evaluations of our choice of incentive (an Amazon gift voucher) [1] have shown mixed effects in different populations and settings. However, of three previous studies similar to ours included in the Cochrane review, researchers compared the effects of: a $5 cash incentive versus a $5 gift voucher [19]; no incentive versus entry into a lottery for $50, $100, $150, or $200 gift vouchers [20]; and unconditional $15 or $25 gift vouchers versus $15 or $25 gift vouchers conditional on completion of the survey [21].

Strengths and limitations of study

In developing our survey, we adhered to recommendations for the design of email questionnaires [18]. These included deriving an appropriate sample, using an embedded URL, using incentives, and sending the request for information from a recognized academic source. One recommendation beyond our control was that the research be perceived to be relevant to the population surveyed. As stated above, there is renewed emphasis on increasing the uptake and transfer of publicly funded research into policy and practice, and those responding indicated that dissemination of the results of research was highly relevant to their work. However, we had no way of knowing beforehand whether the topic or goal would be deemed relevant or of interest by those we surveyed.

In our study, we utilized a 36-item questionnaire and stated that it would take participants up to 30 minutes to complete. Shorter postal questionnaires are associated with increased response rates [1]. It may be that the perceived return (£10) for time invested in completing the 36 items was deemed inadequate compensation by some participants, especially if considered in relation to their incomes as professional researchers. We do not know whether an increase in the financial incentive relative to participant income would have made any difference in this instance. Another consideration relates to the nature of the incentive offered. Receipt of the gift voucher was dependent on the participant completing the questionnaire. There is evidence that response rates can be higher when an incentive is given up front unconditionally rather than given conditional on completion [1]. The use of unconditional versus conditional incentives merits further investigation.

In this study, members of the population of interest have high levels of Internet and email access. Yet, around a fifth of all returned completed questionnaires were paper copies that had been mailed out as part of the postal reminder. This decision to adopt a mixed mode approach in the event of a low response rate appears sensible in light of feedback from two of the respondents. They indicated that they found it hard to find the time to respond to Web surveys, and as they were often out of the office, it was easier to complete a survey that used a paper-and-pen format. Although we recognize that our experience relates to a very specific population and suggest some caution in generalizing these findings to other populations, designers of future Web surveys may wish to consider using this mixed mode approach.

This randomized study was undertaken as part of a wider survey to assess what steps public health and health services researchers working across the United Kingdom are taking to disseminate the findings of their research. This nesting approach offered a cheap and efficient method of adding to our knowledge of the utility of different survey modes. However, undertaking such an approach was not without potential challenges. Normally in randomized studies, one would compare an intervention against standard practice when the outcome is unknown. But in this instance our primary concern was to maximize response rates to the wider survey. In doing so it was possible we limited the duration of the intervention making it difficult to determine what the true effect of the incentive would have been over a longer time period. Future web surveys should consider nesting a randomized element to further test the utility of incentives but should also consider whether the time frame for response is adequate to determine the true effect.

Conclusions

Our trial can help researchers planning future Web-based surveys. It would appear that immediate responses within two weeks of initial contact to a Web-based survey might be improved by the offer of a small financial incentive. Hence, we would recommend small financial incentives to those researchers requiring quick responses to Web-based questionnaires. However our findings suggest that this effect may dissipate over time. Researchers should consider that even in specific populations with high levels of access to the Internet, there might be advantages in using mixed methods (ie, use of both web and paper questionnaires) in terms of participant preferences and in increasing response rates.

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Conflicts of Interest

None declared

Authors' Contributions

All authors contributed to the conception, design and analysis of the study. All authors were involved in the writing of the first and subsequent versions of the paper. The views expressed in this paper are those of the authors alone.

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Original Paper

An International Comparison of Web-based Reporting About Health Care Quality: Content Analysis

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Abstract

Background: On more and more websites, consumers are provided with public reports about health care. This move toward provision of more comparative information has resulted in different information types being published that often contain contradictory information.

Objective: The objective was to assess the current state of the art in the presentation of online comparative health care information and to compare how the integration of different information types is dealt with on websites. The content analysis was performed in order to provide website managers and Internet researchers with a resource of knowledge about presentation formats being applied internationally.

Methods: A Web search was used to identify websites that contained comparative health care information. The websites were systematically examined to assess how three different types of information (provider characteristics and services, performance indicators, and health care user experience) were presented to consumers. Furthermore, a short survey was disseminated to the reviewed websites to assess how the presentation formats were selected.

Results: We reviewed 42 websites from the following countries: Australia, Canada, Denmark, Germany, Ireland, the Netherlands, Norway, the United Kingdom, the United States, and Sweden. We found the most common ways to integrate different information types were the two extreme options: no integration at all (on 36% of the websites) and high levels of integration in single tables on 41% of the websites). Nearly 70% of the websites offered drill down paths to more detailed information. Diverse presentation approaches were used to display comparative health care information on the Internet. Numbers were used on the majority of websites (88%) to display comparative information.

Conclusions: Currently, approaches to the presentation of comparative health care information do not seem to be systematically selected. It seems important, however, that website managers become aware of the complexities inherent in comparative information when they release information on the Web. Important complexities to pay attention to are the use of numbers, the display of contradictory information, and the extent of variation among attributes and attribute levels. As for the integration of different information types, it remains unclear which presentation approaches are preferable. Our study provides a good starting point for Internet research to further address the question of how different types of information can be more effectively presented to consumers.

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KEYWORDS

Consumer health information; information display; decision making; Internet; international comparison; content analysis

Introduction

Public reporting of comparative health care information has become increasingly important in several countries. Comparative health care information is information by which consumers can make explicit comparisons between the performances of health care providers or health plans in order to make an informed choice. In the United States and the United Kingdom, efforts to make this kind of information publicly available have been ongoing for about fifteen years. The aims are to increase public accountability and to support consumer choice in health care and indirectly to improve the quality of health services. Health care policy in the Netherlands currently focuses on transparency as well: health care consumers are encouraged to make use of public comparative information about health care services and quality [1,2]. Dutch consumers have been provided with public reports of health care information in newspapers and magazines since the late 1990s. In addition, comparative health care information has been published on the Internet in the Netherlands for the past few years.

The number of websites containing comparative health care reports is rapidly growing worldwide. This number will continue to rise given the increased tendency of many health care systems to become publicly accountable and to use market-based approaches. In addition, existing websites likely will offer more types of information as well as information about different health care sectors in order to support health care consumers' decision making. When we look at various websites, no standard approaches for presenting information seem to emerge. Carlisle [3] examined ten American websites and concluded that “each is unique in presentation of grades and how the grades are tabulated.” However, based on laboratory studies on human decision making, it is known that information presentation formats influence consumers' responses [4,5]. Therefore, it is necessary to reflect on and learn from the presentation approaches used in different countries within the rapidly growing movement of public health care reporting.

In fact, presentation formats of comparative health care information have been steadily gaining attention. Poor information presentation is frequently cited in the literature as one reason that this kind of information is rarely used by consumers [6-8]. Despite several years of international experience, there is little evidence that health care reports support consumer decision making [9-11]. Many researchers have suggested that the information presented is too complex for consumers and is not adjusted to consumers' cognitive processing and decision making strategies. In a recent review, Fung and colleagues [8] concluded that “[d]espite its theoretical appeal, making public reporting work requires successfully addressing several challenges, most notably designing and implementing a reporting system appropriate for its purpose.”

One of the difficulties that consumers may face is the large amount of information on Web pages, which is often overwhelming [12]. It is known that consumers can only process a few “chunks” of information simultaneously [13] and are easily overloaded by information [14,15]. Consumers' attitudes toward the amount of information on websites are somewhat mixed: higher numbers of features on websites have been associated with both positive [16,17] and negative [18] attitudes. In this context, the number of different types of information and the structure in which these are presented are important [19].

With respect to public comparative health care information, van Loon and Tolboom [20] defined three different information types. The first type is information about the characteristics and services provided by individual health care providers and health care facilities. This is factual information about providers' names, addresses, and the geographic region in which health care is provided as well as information about the type of provider (eg, academic or non-academic hospital), provider specialty, available facilities, provider's religion, costs of services, and waiting times. The second information type is information about quality of health care based on performance indicators, usually derived from existing provider registrations (ie, administrative records) or registrations required by governments and established for public reporting purposes. These concern medical and health care performance information based on relatively factual information relating to a particular health facility such as the number of patients with pressure wounds or the number of operations of a particular type. The third information type is quality information based on health care user experience. Like the second information type, this information type concerns health care performance. However, in this case, the data are derived from patient surveys. For example, patients or clients are surveyed about their experiences with the treatment in the hospital or about their satisfaction with the food or privacy in the nursing home. Within each of the three types of information, several subtypes can be distinguished as well, such as general quality indicators and more specific underlying aspects of care.

Using different information types and various indicators to make a decision is known to be a difficult cognitive process [5,21]. Moreover, as the amount of information on a Web page increases, a simple information structure combined with high usability is, almost inevitably, not attainable. Apart from the fact that more information types will increase the amount of comparative information, presenting different information types can be complex in itself. For example, it is a complex task for consumers to make a choice when a health care provider performs well on one specific quality aspect but badly on another. It can become even more complex when indicators stemming from different information types are contradictory although they concern the same aspects of care. This can be the case when quality information is drawn from both hospitals' administrative records and patient surveys. A hospital's registration may indicate, for example, that patients have the opportunity to participate in the decision for a particular type of anesthetic. This would be reflected by the score “yes” on the quality indicator “patient participation in choice of anesthetic.” Despite this, results of a patient survey may show that patients reported negative experiences concerning participation in decision making. For example, if patients at a particular hospital were more negative compared with patients at other hospitals, the first hospital's performance would be given a lower rating. The question is how consumers are supposed to deal with these kinds of complexities. We know that consumers may respond differently to information depending on its complexity [22-24]. For example, the number of contradictions in the information increases information complexity, which can affect decision making accuracy [24].

An additional difficulty might emerge when different information types are presented by different information displays, such as numbers versus stars. It is unknown whether inconsistent information displays further hamper consumers' ability to process comparative health care information.

Information display, such as words, numbers and symbols, may be another source of difficulty for consumers. In an early review of McCormack and colleagues [25], concerned largely with offline comparative health care information, the dominant presentation approaches consisted of combinations of text and graphics or text and percentages in a table format. The use of numbers may lead to confusing and overwhelming information display. Consumers may not have an emotional or affective understanding of numbers and the information may therefore be less "evaluable," a term coined by Hibbard to refer to the ease or precision with which the values of the attributes across alternatives create an affective (good/bad) feeling [21,27]. Hibbard and colleagues demonstrated that visual display in the form of stars facilitated consumers' comprehension and use of comparative health care information [26,27]. Previous research has also shown that the readability of text is important for consumers [28,29], and that health information on the Internet is often beyond consumers' reading ability [30,31].

In short, the large amount and variety of information as well as how the information is presented are important issues pertaining to the publication of comparative health care information. Indeed, these issues have been cited in the literature since the early days of offline and online public reporting [3,25]. In the past decade, the number of different information types has increased, largely due to emerging information technology. Apart from a few reviews of information types presented and presentation formats used [3,19,25], no comprehensive reviews have been conducted recently. More importantly, since more countries are adopting a public reporting system for health care information, it is of interest to document which strategies are applied in countries outside the United States to present different types of health care information. If we want to understand the decision maker's current health care information environment and be able to simplify it, an up-to-date overview of what consumers are actually confronted with is needed.

The aim of the present paper was to describe how different types of information are presented on websites containing public comparative health care information. Our primary concern was the structure used to integrate different information types. We further reviewed the drill down paths offered on websites and how information was displayed. Drill down paths are paths that provide options to get more detailed information that may also be used to structure the total amount of available information. Information display can make information more valuable to consumers. Our intention was not to review all of the websites that exist worldwide but rather to provide an overview of the state of the art that can be used as a resource of knowledge for website managers and Internet researchers. Our research question was: "How are different types of Web-based comparative health care information presented worldwide?"

Methods

Search Strategy

This study was conducted from July to September 2008. Two key Dutch publications on public reporting of health care were used as a starting point to search for websites providing health care information to the public [32,33]. These studies only included countries in which both performance indicators and public reporting have been incorporated in the health care system. We then performed a search using the Web search engine Google for particular terms and their translations in English, German, French, Spanish, Italian, Dutch, Norwegian, Swedish, Danish, and Finnish. The terms chosen were: quality, quality indicators, health care, compare, choose, information, patients, consumers, satisfaction, health plans, hospitals, nursing homes, home care, and mental health care. We included only websites that contained comparative information, that is, information by which consumers can make explicit comparisons between health care providers or health plans. For websites where information for health care providers was presented separately, we reviewed only the comparative information. We chose to do this because, as stated previously, comparative information is intended to facilitate consumer choice in health care.

Analyses

We visited the selected websites and assessed the presentation approaches that were used. The following aspects were systematically considered: (1) the health care sector(s) for which information was presented; (2) the types of information presented; (3) the degree of integration of different information types; (4) the drill down paths provided; and (5) the information displays used.

For types of information, we followed the classification system of Van Loon and Tolboom [20] for public health care information: "A" indicated factual information based on provider characteristics and services; "B" indicated quality information based on performance indicators; and "C" indicated quality information based on health care user experience. The degree to which different information types were displayed in an integrated way was also assessed. In the absence of a ready taxonomy of classifying presentation formats, we classified information integration as: "0" to mean no integration, that is, different information types on different pages; "1" to mean limited integration, that is, different types of information on one page, but no integration in a single table; "2" to mean a medium amount of integration, that is, different information types on one page but clearly separated from each other; and "3" to mean a high level of integration, that is, different information types were presented in a single table. Drill down paths were assessed qualitatively according to the different approaches on the websites; we used no particular classification system. Finally, we reviewed the display of information and focused on the use of words, numbers, bar graphs, and different types of symbols. All analyses and coding activities were performed by two of the authors (OD and YH) independently. They discussed their findings and searched for agreement.

Besides reviewing the website content, we disseminated a short survey to each website included in this study. This survey contained open and closed questions about which types of information the website presented and how the presentation formats were chosen. The survey was either directly mailed to the website (in case a direct contact address was found on the website) or delivered indirectly by contacting the website through a request form. Respondents could return the completed survey to the researchers by email or by post.

Results

Search Results

In total, we found 42 websites in 10 different countries that presented comparative health care information. Table 1 gives a short description of each website. Most websites we identified were in the United States, although we also found a range of websites in the United Kingdom, Germany, and the Netherlands. The aim of most reporting systems was to inform consumers about health care performance and to support consumers' choices. A few websites were not explicitly designed for consumers, but because these websites were intended to increase public accountability and were accessible for consumers, we included them in the current study.

Table 1. Brief descriptions of reviewed websites

Country and Website[a]	URL (Archived WebCite URL)[b]	Description
Australia		
1. Your Hospitals	http://www.health.vic.gov.au/yourhospitals (http://www.webcitation.org/5clVd3AEQ)	Initiative of the Consumer Participation and Information Program. The aim is to provide information to patients, caregivers, and health care professionals. The information is generated by the Department of Health, its funded agencies, and special interest groups.
Canada		
2. Hospital Report	http://www.hospitalreport.ca (http://www.webcitation.org/5clVfMnoX)	Initiative of the HHRC (Hospital Report Research Collaborative). The aims are to increase public accountability and to improve quality of care.
Denmark		
3. Sundhed	http://www.sundhed.dk (http://www.webcitation.org/5clVsUhI3)	Initiative of the Danish Ministry of Health. The reporting system 'Sundhedkvalitet' is managed by the National Board of Health. The aim is to support consumers in their health care choices.
Germany		
4. Weisse Liste	http://www.weisse-liste.de (http://www.webcitation.org/5clW384wA)	Initiative of the Bertelsmann Stiftung in collaboration with patient associations and scientific partners. The aims are to empower consumers and to support them in their health care choices.
5. Klinik Führer Rhein-Ruhr	http://www.kliniken-rhein-ruhr.de (http://www.webcitation.org/5clW4zeOf)	Initiative of the Initiativkreis Ruhrgebiet Verwaltungs-GmbH (a collaborative of hospitals) in collaboration with scientific partners. The aim is to support consumers in their health care choices. The information is generated from the hospitals and from patient surveys.
6. Klinikführer Rheinland	http://www.klinikfuehrer-rheinland.de (http://www.webcitation.org/5clWCp5WX)	Initiative of the Krankenhauszweckverband Köln, Bonn, und Region (KHVZ) (a collaborative of hospitals). The aim is to support consumers in their health care choices. The information is generated from the hospitals by the KHVZ.
7. Hamburger Krankenhaus-spiegel	http://www.hamburger-krankenhausspiegel.de (http://www.webcitation.org/5clWR10vD)	Initiative of 25 hospitals in collaboration with other partners. The aim is to support consumers in their health care choices, and to stimulate providers' quality improvement initiatives. The information is generated from the hospitals by independent audit parties.
8.Klinikbe-wertungen	http://www.klinikbewertungen.de (http://www.webcitation.org/5clWVbRiG)	Initiative of MedizInfo, which is an Internetportal about health and health care. The aim is to provide an independent online forum about consumers' experiences in order to help consumers in their health care choices. A second aim is to stimulate providers' quality improvement initiatives. The information is generated from consumers' reports on the forum.
Ireland		
9. Health Information and Quality Authority	http://www.hiqa.ie (http://www.webcitation.org/5clZNb8km)	Initiative of the Health Information and Quality Authority (part of the government's health reform program). The aims are to monitor quality of care on a set of standards and to stimulate improvement initiatives. A third aim is to help consumers in their health care choices.

Country and Website[a]	URL (Archived WebCite URL)[b]	Description
The Netherlands		
10. kiesBeter	http://www.kiesBeter.nl (http://www.webcitation.org/5clT0whdn)	Initiative of the Ministry of Health and managed by the National Institute for Public Health and the Environment (RIVM) in collaboration with patient associations, health care providers, and scientific partners. The aim is to provide an independent portal for all questions from the public about health and health care. One particular aim is to support consumers in their health care choices.
11. Independer Gezondheids-zorg	http://www.independer.nl (http://www.webcitation.org/5clU1lwM3)	Initiative of Independer.nl in collaboration with other parties. The aim is to increase transparency and to support consumers in their health care choices. The information is generated by the external parties, Mediquest and Zorgweb.
12. Zorgkiezer	http://www.zorgkiezer.nl (http://www.webcitation.org/5clU6C5MZ)	Initiative of DGN Publishers (Internet company) in collaboration with health care providers and health insurance companies. The aim is to help consumers and health care professionals in their choices. The information is generated by the website editors.
13. Zorgbelang	http://www.zorgbelang-nederland.nl (http://www.webcitation.org/5clUFSXlV)	Initiative of Zorgbelang Nederland (association of local organizations advocating health care consumers' interests) in collaboration with patient associations and other parties. The aim is to provide the public with information about health care.
14. Agis Zorggids	http://www.agisweb.nl (http://www.webcitation.org/5clUPVzGY)	Initiative of health insurer Agis. The aim is to inform the insured about their options in health care (concerning contracted providers) and to provide public accountability for the activities of Agis. The information is generated by external parties.
15. Menzis behandelwijzer	http://www.menzis.nl (http://www.webcitation.org/5clUWhkfA)	Initiative of health insurer Menzis. The aim is to support the insured in their health care choices (concerning contracted providers). The information is generated by the health purchase department and by external parties.
16. VGZ Zorggids - Vergelijk en kies	http://www.vgz.nl (http://www.webcitation.org/5clUcadC0)	Initiative of health insurer VGZ. The aim is to support the insured in their health care choices (concerning contracted providers). The information is generated by external parties.
17. CZ Ziekenhuisvergelijker	http://www.cz.nl (http://www.webcitation.org/5clUhnHi0)	Initiative of health insurer CZ. The aim is to support the insured in their health care choices (concerning contracted providers). The information is generated by external parties.
18. AD Ziekenhuisvergelijker	http://www.ad.nl/ziekenhuistop100 (http://www.webcitation.org/5clUkUGcj)	Initiative of the daily paper Algemeen Dagblad (AD), in collaboration with health care professionals and medical associations. The aim is to inform the public about hospital performances. The information is generated by the paper: hospitals are asked to provide the information.
19. Elsevier Beste Ziekenhuizen	http://www.elsevier.nl/artimg/200709/besteziekenhuizen.pdf (http://www.webcitation.org/5clUqCXSH)	Initiative of the weekly magazine, Elsevier, in collaboration with health care professionals, managers, and researchers. The aim is to inform the public about hospital performance concerning current questions in health care.
20. Vaatpatient	http://www.vaatpatient.nl (http://www.webcitation.org/5clUrNSEI)	Initiative of the Vereniging van Vaatpatienten (VVVP) (vascular disease patient association). The aim is to support patients in their health care choices. The information is generated by external parties. The VVVP provides quality marks based on the information.
Norway		
21. Fritt Sykehusvalg Norge	http://www.frittsykehusvalg.no (http://www.webcitation.org/5clV91h05)	Initiative of the Norwegian Ministry of Health in collaboration with patient advisors. The aim is to empower consumers and to support consumers and health care professionals in their choices. In addition, the aim is to stimulate competition and quality improvement.
United Kingdom		

Country and Website[a]	URL (Archived WebCite URL)[b]	Description
22. Dr. Foster	http://www.drfoster.co.uk (http://www.webcitation.org/5clV0liGA)	Private initiative in collaboration with the Information Centre for Health and Social Care, health service organizations, and local authorities. The aims are to inform consumers and health care professionals about the options in health care, and to support consumers in their health care choices. In addition, the aim is to stimulate quality improvement initiatives. The information is generated from a number of external sources.
23. NHS choices	http://www.nhsdirect.nhs.uk (http://www.webcitation.org/5clVBVDFE)	Initiative of the NHS (National Health Services), in collaboration with the National Library for Health, the Information Centre for Health and Social Care, the Health care Commission and other parties. The aim is to support consumers in their decisions about health and health care.
24. Human Fertilisation and Embryology Authority, clinics guide	http://www.hfea.gov.uk (http://www.webcitation.org/5clVXndpE)	Initiative of the Human Fertilisation and Embryology Authority (HFEA). The aims are to inform consumers about the options in health care and to support them in their health care choices. The information is generated by the HFEA and provided by the clinics.
25. British Association of Aesthetic Plastic Surgeons	http://www.baaps.org.uk (http://www.webcitation.org/5clVJK6mK)	Initiative of the British Association of Aesthetic Plastic Surgeons. The aims are to inform the public about the practice and quality of plastic surgery and to support consumers in their health care choices.
26. Private Healthcare UK	http://www.privatehealth.co.uk (http://www.webcitation.org/5clVKQVND)	Initiative of Intuition Communication Ltd (a commercial organization). The aims are to inform consumers about options in private health care and to support them in their health care choices.
United States		
27. Hospital Compare	http://www.hospitalcompare.hhs.gov (http://www.webcitation.org/5clZSIjyU)	Initiative of the US Department of Health and Human Services (HHS). Hospital Compare is a collaboration of the Centers for Medicare and Medicaid Services (CMS), the Department of Health and Human Services, and members of the Hospital Quality Alliance (HQA). The aim is to support consumers in their health care choices. The information is provided by the health care providers.
28. The Leapfrog Group	http://www.leapfroggroup.org (http://www.webcitation.org/5clZVjgKj)	Initiative of the Leapfrog Group (a collaboration of employers). The aim is to stimulate transparency and access to information in order to support health purchasers and consumers in their choices. In addition, the aim is to stimulate quality improvement initiatives. The information is provided by the health care providers.
29. The Patient Advocate	http://www.opa.ca.gov/report_card (http://www.webcitation.org/5clZX6PqW)	Initiative of the Office of the Patient Advocate (OPA) in collaboration with the Department of Managed Health Care. The aim is to inform health care consumers about their rights and about the options in health care (patient empowerment). In addition, aims are to stimulate health care transparency and to support health care purchasers and consumers in their choices. The information is generated from a number of external sources.
30. Nursing Home Compare	http://www.medicare.gov/NHcompare (http://www.webcitation.org/5clZpsiiX)	Initiative of Medicare. The aims are to inform the public about nursing home options in Medicare and to support consumers in their choices. The information is generated by external parties and/or provided by the nursing homes.
31. Home Health care Compare	http://www.medicare.gov/HHcompare (http://www.webcitation.org/5clZlSuKF)	Initiative of Medicare. The aims are to inform the public about home health care options in Medicare and to support consumers in their choices. The information is generated by external parties and/or provided by the home health care providers.

Country and Website[a]	URL (Archived WebCite URL)[b]	Description
32. Dialysis Facility Compare	http://www.medicare.gov/dialysis (http://www.webcitation.org/5clZvYdSV)	Initiative of Medicare. The aims are to inform the public about chronic kidney disease and dialysis, about dialysis facility options in Medicare, and to support consumers in their choices. The information is generated by external parties and/or provided by the facilities.
33. Medicare Options Compare	http://www.medicare.gov/MPPF (http://www.webcitation.org/5cla2KXFv)	Initiative of Medicare. The aims are to inform the public about health plans options in Medicare and to support consumers in their choices. The information is generated by external parties and / or provided by the plans.
34. U Compare Healthcare	http://www.ucomparehealthcare.com (http://www.webcitation.org/5cla68Ljp)	Initiative of About, Inc (part of the New York Times Company). The aim is to support consumers in their health care choices. The information is generated from a number of external federal sources
35. California Nursing Home Search	http://www.calnhs.org (http://www.webcitation.org/5claA0qhi)	Initiative of the California Health care Foundation in collaboration with the Department of Social and Behavioral Sciences of the University of California. The aim is to inform the public about the options in health care. The information is generated from a number of external state and federal sources.
36. NCQA	http://www.ncqa.org (http://www.webcitation.org/5claG27UP)	Initiative of the National Committee for Quality Assurance (NCQA). The aim is to stimulate transparency and quality improvement initiatives. In addition, the aim is to support consumers in their health care decisions. The information (based on a set of standardized measures) is generated by the NCQA.
37. US News Health	http://health.usnews.com/sections/health (http://www.webcitation.org/5claM7ca0)	Initiative of the US News magazine (which also includes a weekly digital magazine). The aim is to inform the public about performance of hospitals (America's best hospitals) and about health plans (America's best health plans). The information is generated by the magazine's editors.
38. AHD.com	http://www.ahd.com (http://www.webcitation.org/5claNNKMz)	Initiative of the American Hospital Directory, Inc. (a private company). The aim is to inform subscribers about performances of hospitals. The information is generated by the company and extracted form a number of external sources.
39. Health Care Choices	http://www.healthcarechoices.com (http://www.webcitation.org/5claTftLr)	Initiative of Health Care Choices (HCC) which is a not-for-profit corporation. The aims are to inform the public about the health care system and to support health care purchasers and consumers in their choices.
40. Quality Check	http://www.qualitycheck.org (http://www.webcitation.org/5claYPkbV)	Initiative of the Joint Commission on Accreditation of Health care Organizations (JCAHQ), which is a non-for-profit organization. The aim is to support consumers in their health care choices. The information is provided by the health care providers to the Joint Commission.
41. PHC4	http://www.phc4.org (http://www.webcitation.org/5ndQxiDQX)	Initiative of the Pennsylvania's Health Care Cost Containment Council. The aim is to increase transparency and competition between health care providers. The information is generated from hospitals and health plans by the Council.
Sweden		
42. Aldre-guiden	http://www.socialstyrelsen.se/aldreguiden (http://www.webcitation.org/5cladHprj)	Initiative of Socialstyrelsen (a governmental organization of the Ministry of Health). The aims are to inform consumers about the options in elderly care and to support their choices. In addition, the aim is to stimulate quality improvement initiatives. The information is provided by local authorities.

[a] Description based on website content in September 2008.

[b] Because website content and presentation formats change over time, the URLs have been archived: the URLs within brackets can be used to view the information on the home page.

Most websites contained, in one way or another, both summary and more detailed information. Summary information was usually presented in tabular formats using rows to display providers and columns to display attributes (see Figure 1). Tables with a display configured differently (ie, providers in columns and attributes in rows) were also common but this configuration was not typically used in summary tables. However, tables configured in this way were frequently found to present more detailed comparative information pertaining to the specific providers selected. Although some summary tables presented many different attributes, in most cases only a limited number of attributes (about 3 to 7) was displayed. In some summary tables, the main attributes were divided into subattributes. Another frequently used method was to allow the consumer to determine the amount of information to be presented in a table.

Figure 1. Example of a typical tabular format displaying providers in rows and attributes in columns

Accreditation Ratings

NCQA Accreditation ratings summarize overall plan performance on a number of standards and measures. Plans with a higher NCQA Accreditation status can be generally expected to provide better care and service than plans with lower accreditation statuses. **Plans with PPO Accreditation can receive a maximum of 3 stars in each category; plans with MCO or Health Plan Accreditation can receive a maximum of 4 stars in each category.** View more information about Accreditation ratings.

Plan Name ?	Plan Type ?	Accredited Product ?	Accreditation Type ?	Access and Service ?	Qualified Providers ?	Staying Healthy ?	Getting Better ?	Living with Illness ?	Overall Accreditation Status ?
Aetna Health Inc. (New Jersey) - Northern New Jersey	Medicare	HMO	MCO Accreditation	★★★★	★★★★	★★☆☆	★★★★	★★★☆	Excellent
Aetna Health Inc. (New Jersey) - Southern New Jersey	Medicare	HMO	MCO Accreditation	★★★★	★★★★	★★☆☆	★★★★	★★★☆	Excellent
Aetna Life Insurance Company	Medicare	PPO	PPO Accreditation	★★★	★★★	Does Not Apply	Does Not Apply	Does Not Apply	Full
AmeriHealth HMO, Inc. - New Jersey	Medicare	HMO/POS Combined	MCO Accreditation	★★★★	★★★★	★★★☆	★★☆☆	★★★★	Excellent
Oxford Health Plans of New Jersey	Medicare	HMO	MCO Accreditation	★★★☆	★★★☆	☆☆☆☆	★★☆☆	★★☆☆	Commendable

Updated as of 10/31/2008

Information Characteristics

Table 2 provides an overview of the information characteristics on the reviewed websites.

Table 2. Reviewed websites and their information characteristics

Website[a]	Health Care Sector	Types of Information[b]	Classification of Integration Format[c]	Drill Down Paths	Information Display	Rationale for Presentation Formats[d]
1. Your Hospitals	Hospitals	B, C	2	No drill down paths, reports downloaded as PDF files	Words; numbers	-
2. Hospital Report	Hospitals	B, C	0	No drill down paths, reports downloaded as PDF files	Numbers	-
3. Sundhed	Hospitals	A, B, C	0 (separate pages for different types of information); 2 (different types in one table by consumer choice)	Drill down paths to same information per provider	Numbers; stars (5); capitals	-
4. Weisse Liste	Hospitals (will include nursing homes and rehabilitation facilities in near future)	A, B, C	1	Drill down paths to more specific information per hospital	Words; numbers; horizontal bars; round icons (favorites)	D, E, F
5. Klinik Führer Rhein-Ruhr	Hospitals	A, B, C	3	Drill down paths to more specific information per hospital	Words; numbers; thermometers	-
6. Klinikführer Rheinland	Hospitals	A, B	3	Drill down paths to more specific information per hospital	Words; numbers; traffic lights (3 colors); horizontal bars	D, E, F
7. Hamburger Kranken-haus-spiegel	Hospitals	A, B	0	No drill down paths	Numbers; horizontal bars	-
8.Klinikbewertungen	Hospitals	A, C (anecdotal information)	3	Drill down paths to specific evaluations of patients	Numbers; stars (6); words	-
9. Health Information and Quality	Hospitals	B	-	No drill down paths, reports downloaded as PDF files	Words in different colors (= symbols)	-
10. kiesBeter	Hospitals, nursing homes, home care, outpatient mental health care, care for the handicapped, primary care, palliative care, health plans	A, B, C	0 and 2 (depending on health care sector); 3 (summary information)	Drill down paths to more detailed information	Words; numbers; capital letters; stars (3); stars (5); horizontal bars (1)	D, E, F
11. Independer Gezondheids-zorg	Hospitals, home care, primary care, physiotherapy, health plans	A, B, C	3	Drill down paths to more specific information per provider	Words, numbers, stars (4), stars (5), round icons (colored), coins, horizontal bars	D, E, G
12. Zorgkiezer	Hospitals, health plans	A, B	3	Drill down paths to more specific information per provider	Words, numbers, stars (5), checkmarks	-
13. Zorgbelang	Nursing homes, home care, care for the handicapped, outpatient mental health care	A (links to websites with B and C)	-	No drill down paths	Words	-

Website[a]	Health Care Sector	Types of Information[b]	Classification of Integration Format[c]	Drill Down Paths	Information Display	Rationale for Presentation Formats[d]
14. Agis Zorggids	Contracted hospitals	A ,C	0	No drill down paths	Words, round icons (3)	E, F
15. Menzis behandelwijzer	Contracted hospitals	A, B, C	3	No drill down paths	Words, numbers, stars (4), round icons (with certain degree of filling), plus icons (3)	F, G
16. VGZ Zorggids - Vergelijk en kies	Contracted hospitals and other providers	A, B, C	3	No drill down paths	Words, numbers, squares (4)	-
17. CZ Ziekenhuisvergelijker	Contracted hospitals	A, B, C	1	No drill down paths	Words, numbers, stars (4), stars (5)	-
18. AD Ziekenhuisvergelijker	Hospitals	B, C	2	Drill down paths to more specific information per provider	Words, numbers	-
19. Elsevier Beste Ziekenhuizen	Hospitals	A, B	3	No drill down paths, reports downloaded as PDF files	Round icons (5, colored), horizontal bars	-
20. Vaatpatient	Hospitals	A, B	2	Drill down paths to more specific information per provider	Numbers, checkmarks	-
21. Fritt Sykehusvalg Norge	Hospitals	A, B, C	1	Drill down paths to somewhat more detailed quality information	Numbers, words, symbols (-, +, 0)	-
22. Dr. Foster	Hospitals, specialized clinics, complementary practitioners	A, B	1 (with exception of distance)	Drill down paths to more specific information per hospital; selection options to obtain more detailed information	Words,numbers, horizontal bars, stars (5), squares (3)	-
23. NHS choices	Hospitals	A, B, C	3 (summary information); 1 (detailed information)	Drill down paths to more detailed information; drill down paths to more specific information per provider	Words, numbers, round icons with words, stars (3), horizontal bars, squares (5)	-
24. Human Fertilisation and Embryology Authority, clinics guide	Specialized clinics	A, B	0	No drill down paths	Words, numbers, horizontal bars, triangles (1)	-
25. British Association of Aesthetic Plastic Surgeons	Plastic surgeons	A, B	2	Drill down paths to more specific information per provider	Words, numbers, stars (1)	-
26. Private Healthcare UK	Hospitals, doctors, GP's, nursing homes, cosmetic surgery, dental care, health plans	A, B, C (anecdotal information)	1	Drill down paths to more specific information per provider	Words, numbers, ribbons (1)	D
27. Hospital Compare	Hospitals	A, B, C	3 (summary information); 2 (after selection of hospitals)	Drill down paths to hospital location on map	Words, numbers, horizontal bars (1)	-

Website[a]	Health Care Sector	Types of Information[b]	Classification of Integration Format[c]	Drill Down Paths	Information Display	Rationale for Presentation Formats[d]
28. The Leapfrog Group	Hospitals	B	-	Drill down paths to more specific information per provider	Vertical bars (4), horizontal bars (1)	-
29. The Patient Advocate	Medical groups, hospitals, health plans	B, C	3 (summary information); 0 (detailed information)	Drill down paths to more detailed information	numbers, stars (4), horizontal bars (1), round icons with words and colors (5)	-
30. Nursing Home Compare	Nursing homes	A, B	0 (summary information); 2 (detailed information)	Drill down paths to more specific information per provider; drill down paths to provider location on map; drill down paths to visual display in bar graphs	Words, numbers, cubes in bar (4), horizontal bars	-
31. Home Health care Compare	Home care	A, B	0 (summary information); 2 (detailed information)	Drill down paths to visual display in bar graphs	Words, numbers, checkmarks, horizontal bars	-
32. Dialysis Facility Compare	Specialized centra	A, B	0 (summary information); 1 (detailed information)	Drill down paths to more specific information per provider; drill down paths to more detailed quality information; drill down paths to provider location on map	Words, numbers, horizontal bars, checkmarks	-
33. Medicare Options Compare	Health plans	A, B, C	0 (summary information); 3 (detailed information)	Drill down paths to more specific information per health plan	Words, numbers, stars (5)	-
34. U Compare Healthcare	Doctors, hospitals, nursing homes, health plans, mammography centers; fertility clinics	A, B	1	Drill down paths to more specific information per provider	Words, numbers, vertical bars (1), plus icons (1), checkmarks	-
35. California Nursing Home Search	Nursing homes, home care, hospices	A, B	3 (summary information); 1 (detailed information)	Drill down paths to more specific information per provider	Words, numbers, stars (3)	D
36. NCQA	Doctors, health plans	A, B, C	3 (summary and detailed information)	Drill down paths to more detailed quality information; drill down paths to more specific information per provider	Words, numbers, stars (4), horizontal bars, certification symbols (1)	-
37. US News Health	Hospitals, health plans	B, C	0 (hospitals); 3 (health plans)	Drill down paths to more detailed information; drill down paths to more specific information per provider	Words, numbers, round colored icons (5), stars (5)	-
38. AHD.com	Hospitals	A, (B and C only when for members)	0 (summary and detailed information)	Drill down paths to more specific information per provider	Words, numbers, colored parts	-
39. Health Care Choices	Hospitals (and doctors for pay)	A, links to B	-	No drill down paths	Words, numbers	-

Website[a]	Health Care Sector	Types of Information[b]	Classification of Integration Format[c]	Drill Down Paths	Information Display	Rationale for Presentation Formats[d]
40. Quality Check	Hospitals, nursing homes, home care, outpatient mental health care	A, B	1 (summary information); 0 (detailed information)	Drill down paths to more specific information per provider; drill down paths to more detailed information	Words, numbers, checkmarks, certification symbols (1), round icons (3)	-
41. PHC4	Hospitals, health plans	A, B, C	3 (hospitals); 0 (health plans)	No drill down paths, reports downloaded as PDF files	Numbers, round icons (3)	F
42. Aldreguiden	Care for the elderly	B	-	Drill down paths to more detailed quality information	Numbers, vertical bars	D, E, F

[a] Description based on website content in September 2008. Website content and presentation formats change over time. Therefore, the URLs have been archived (see Table 1).

[b] This classification is based on Van Loon and Tolboom [20]: A = Factual information based on provider characteristics and services; B = Quality information based on performance indicators; C = Quality information based on health care user experience

[c] 0 = no integration of different types of information (different types of information on different pages); 1 = limited integration of different types of information (different types of information can be selected and viewed on one page, but no integration in one table on one page); 2 = quite amount of integration of different types of information (different types on one page, but clearly separated from each other); 3 = high level of integration of different types of information (different types of information presented in one table, with or without action of the consumer).

[d] D = test(s) of different formats; E = existing scientific knowledge; F = expert opinion; G = other rationale

Health Care Sectors

On 32 of the 42 websites (76%), information about hospitals was presented. Although in recent years more information has become available in other health care sectors, such as nursing homes and home care (found on 10 websites; 24%), and health plans (found on 10 websites; 24%), hospital information clearly had the largest share on the Internet. Information about health plans was found mainly on US websites. Reporting systems containing information on several health care sectors were found mainly on websites from the United Kingdom and the United States.

Types of Information

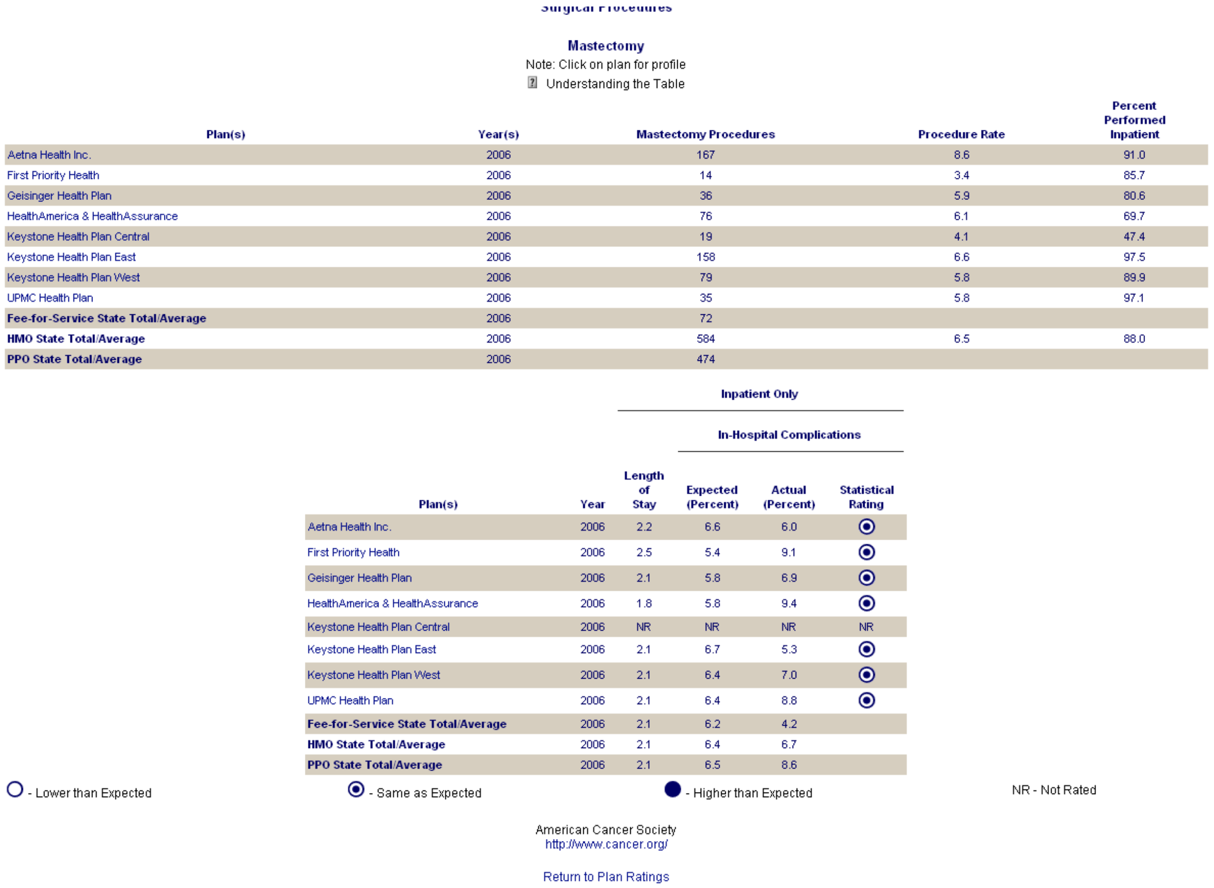
The most common type of information found on the reviewed websites was quality information based on performance indicators (found on 37 websites; 88%). Information on health care providers' characteristics and services was also common (found on 34 websites; 81%); this information was usually presented for each provider separately. In these cases, we did not further evaluate the information. Quality information based on health care users' experiences was found on a little more than half (found on 22 websites; 52%) of the reviewed websites.

Integration of Different Information Types

The degree of integration of different information types was most often classified as type 0 (no integration of different types of information; different types of information on different pages). This type of information integration was found on 15 websites (36%). Type 3 (high level of integration of different information types; different types of information presented in one table) was found on 17 websites (41%). The two integration structures falling in between these extremes were less often found: type 1 on 10 websites (24%) and type 2 on 9 websites (21%), respectively. Concerning type 1 and type 2 integration, many different options were used to separate the information types. For example, separate tab pages, menu bars, white spaces, bold headlines, and colors to distinguish between different information types were displayed. In some cases, different information displays were used at the same time.

Examples of all four classifications are shown in Figures 2 to 5. Figure 2 is an example of type 0 integration (no integration of different types of comparative information). The example is from the PHC4 website in the United States. In this example, information on health care user experience is displayed, but information based on performance indicators can be found elsewhere on the website. Figure 3 is an example of type 1 integration (limited integration of different types of comparative information). The example is from the Fritt Sykehusvalg website in Norway. In this example, different information types can be selected on the displayed tab pages, but are not displayed in a single table simultaneously. Figure 4 is an example of type 2 integration (a medium amount of integration of different types of comparative information). This example is from the kiesBeter website in the Netherlands. Different information types on one page are presented in separate blocks. Figure 5 is an example of type 3 integration (high integration of different types of comparative information). This example is from the Kliniken Rhein Ruhr website in Germany. Different information types are integrated in a single table.

Figure 2. Example of type 0 integration (no integration of different types of comparative information)



Surgical Procedures

Mastectomy

Note: Click on plan for profile

Understanding the Table

Plan(s)	Year(s)	Mastectomy Procedures	Procedure Rate	Percent Performed Inpatient
Aetna Health Inc.	2006	167	8.6	91.0
First Priority Health	2006	14	3.4	85.7
Geisinger Health Plan	2006	36	5.9	80.6
HealthAmerica & HealthAssurance	2006	76	6.1	69.7
Keystone Health Plan Central	2006	19	4.1	47.4
Keystone Health Plan East	2006	158	6.6	97.5
Keystone Health Plan West	2006	79	5.8	89.9
UPMC Health Plan	2006	35	5.8	97.1
Fee-for-Service State Total/Average	2006	72		
HMO State Total/Average	2006	584	6.5	88.0
PPO State Total/Average	2006	474		

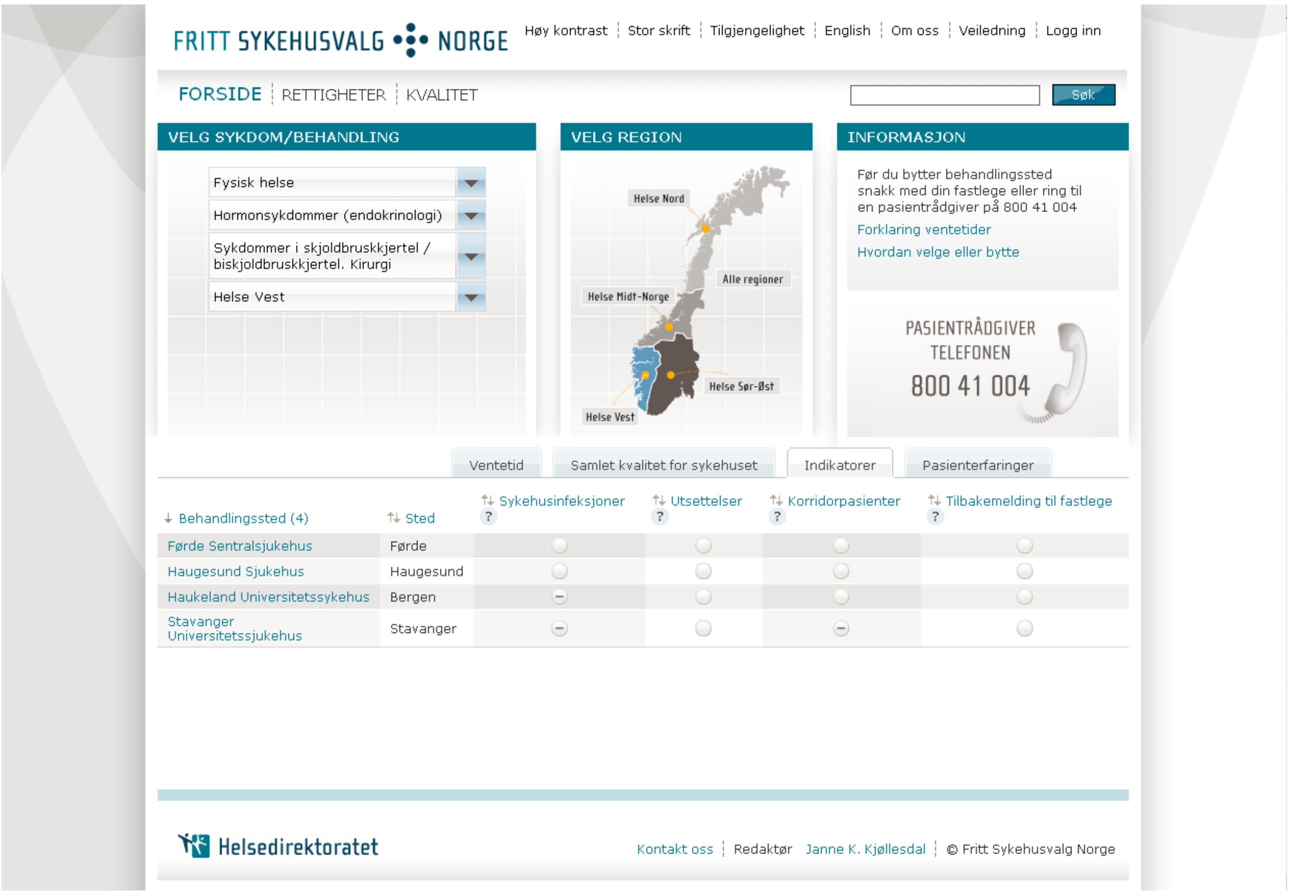
		Inpatient Only			
			In-Hospital Complications		
Plan(s)	Year	Length of Stay	Expected (Percent)	Actual (Percent)	Statistical Rating
Aetna Health Inc.	2006	2.2	6.6	6.0	⦿
First Priority Health	2006	2.5	5.4	9.1	⦿
Geisinger Health Plan	2006	2.1	5.8	6.9	⦿
HealthAmerica & HealthAssurance	2006	1.8	5.8	9.4	⦿
Keystone Health Plan Central	2006	NR	NR	NR	NR
Keystone Health Plan East	2006	2.1	6.7	5.3	⦿
Keystone Health Plan West	2006	2.1	6.4	7.0	⦿
UPMC Health Plan	2006	2.1	6.4	8.8	⦿
Fee-for-Service State Total/Average	2006	2.1	6.2	4.2	
HMO State Total/Average	2006	2.1	6.4	6.7	
PPO State Total/Average	2006	2.1	6.5	8.6	

○ - Lower than Expected ⦿ - Same as Expected ● - Higher than Expected NR - Not Rated

American Cancer Society
http://www.cancer.org/

Return to Plan Ratings

Figure 3. Example of type 1 integration (limited integration of different types of comparative information)



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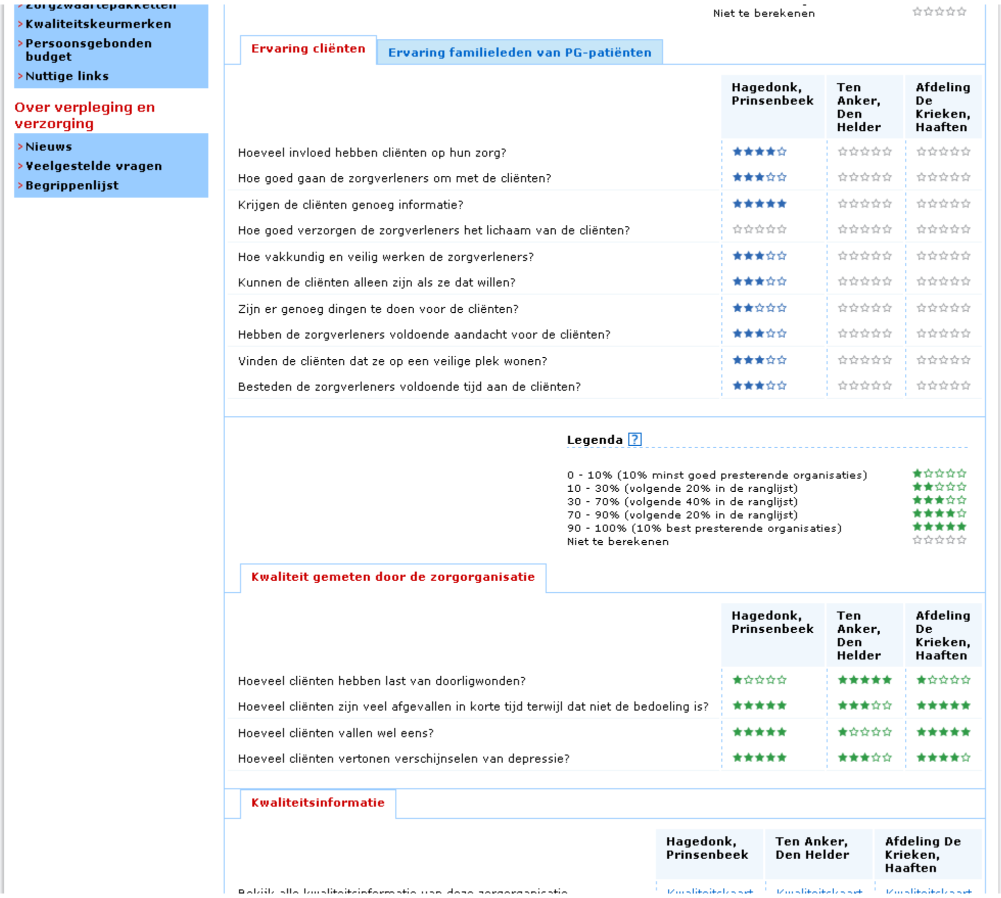
↓ Behandlingssted (4)	⇅ Sted	⇅ Sykehusinfeksjoner ?	⇅ Utsettelser ?	⇅ Korridorpasienter ?	⇅ Tilbakemelding til fastlege ?
Førde Sentralsjukehus	Førde	○	○	○	○
Haugesund Sjukehus	Haugesund	○	○	○	○
Haukeland Universitetssykehus	Bergen	⊖	○	○	○
Stavanger Universitetssjukehus	Stavanger	⊖	○	⊖	○

Figure 4. Example of type 2 integration (medium amount of integration of different types of comparative information)



Niet te berekenen ☆☆☆☆☆

Ervaring cliënten | Ervaring familieleden van PG-patiënten

	Hagedonk, Prinsenbeek	Ten Anker, Den Helder	Afdeling De Krieken, Haaften
Hoeveel invloed hebben cliënten op hun zorg?	★★★★☆	☆☆☆☆☆	☆☆☆☆☆
Hoe goed gaan de zorgverleners om met de cliënten?	★★★☆☆	☆☆☆☆☆	☆☆☆☆☆
Krijgen de cliënten genoeg informatie?	★★★★★	☆☆☆☆☆	☆☆☆☆☆
Hoe goed verzorgen de zorgverleners het lichaam van de cliënten?	☆☆☆☆☆	☆☆☆☆☆	☆☆☆☆☆
Hoe vakkundig en veilig werken de zorgverleners?	★★★☆☆	☆☆☆☆☆	☆☆☆☆☆
Kunnen de cliënten alleen zijn als ze dat willen?	★★★☆☆	☆☆☆☆☆	☆☆☆☆☆
Zijn er genoeg dingen te doen voor de cliënten?	★★☆☆☆	☆☆☆☆☆	☆☆☆☆☆
Hebben de zorgverleners voldoende aandacht voor de cliënten?	★★★☆☆	☆☆☆☆☆	☆☆☆☆☆
Vinden de cliënten dat ze op een veilige plek wonen?	★★★☆☆	☆☆☆☆☆	☆☆☆☆☆
Besteden de zorgverleners voldoende tijd aan de cliënten?	★★★☆☆	☆☆☆☆☆	☆☆☆☆☆

Legenda ?

0 - 10% (10% minst goed presterende organisaties)	★☆☆☆☆
10 - 30% (volgende 20% in de ranglijst)	★★☆☆☆
30 - 70% (volgende 40% in de ranglijst)	★★★☆☆
70 - 90% (volgende 20% in de ranglijst)	★★★★☆
90 - 100% (10% best presterende organisaties)	★★★★★
Niet te berekenen	☆☆☆☆☆

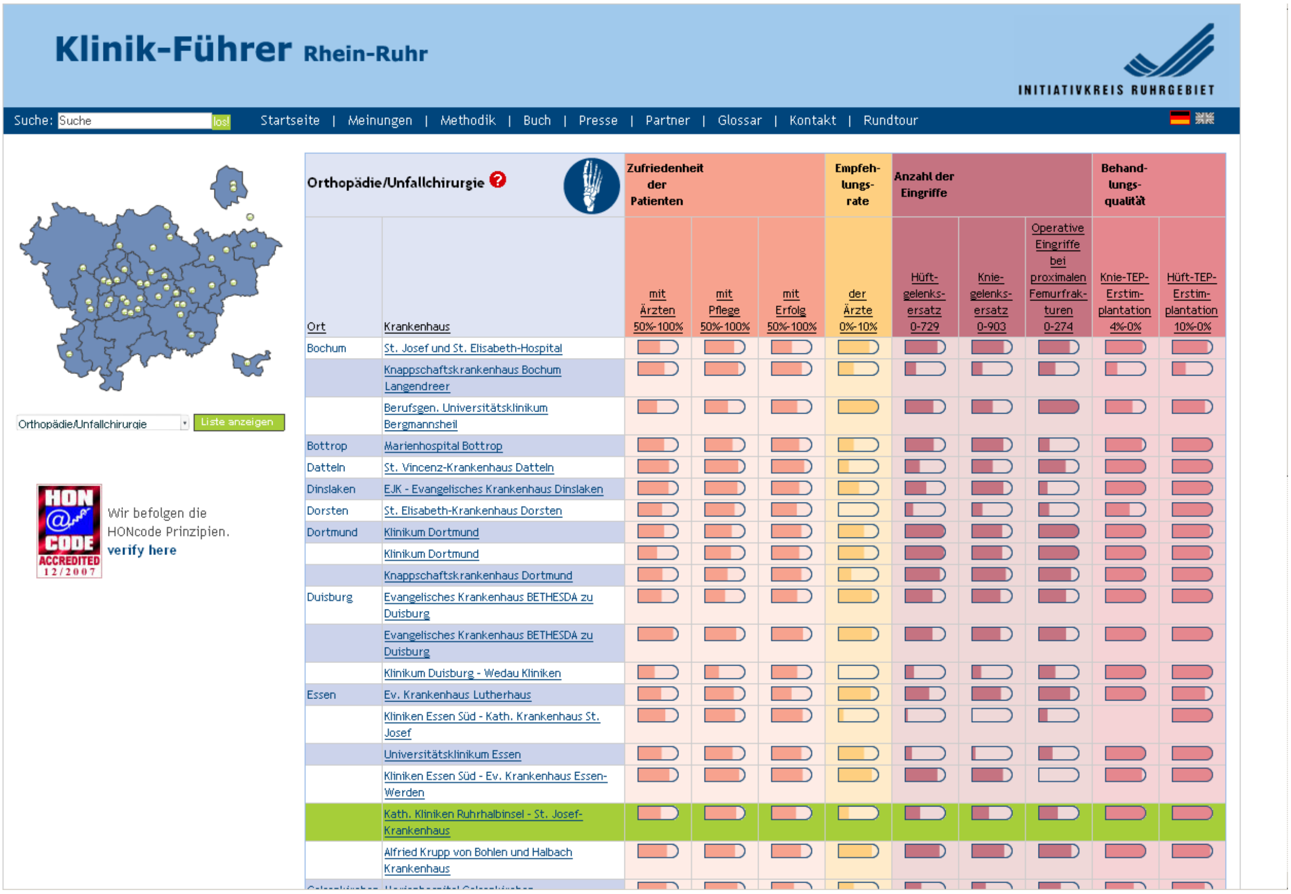
Kwaliteit gemeten door de zorgorganisatie

	Hagedonk, Prinsenbeek	Ten Anker, Den Helder	Afdeling De Krieken, Haaften
Hoeveel cliënten hebben last van doorligwonden?	★☆☆☆☆	★★★★★	★☆☆☆☆
Hoeveel cliënten zijn veel afgevallen in korte tijd terwijl dat niet de bedoeling is?	★★★★★	★★★☆☆	★★★★★
Hoeveel cliënten vallen wel eens?	★★★★★	★☆☆☆☆	★★★★★
Hoeveel cliënten vertonen verschijnselen van depressie?	★★★★★	★★★☆☆	★★★★☆

Kwaliteitsinformatie

	Hagedonk, Prinsenbeek	Ten Anker, Den Helder	Afdeling De Krieken, Haaften

Figure 5. Example of type 3 integration (high integration of different types of comparative information)



Orthopädie/Unfallchirurgie ?

		Zufriedenheit der Patienten			Empfehlungsrate	Anzahl der Eingriffe			Behandlungsqualität	
Ort	Krankenhaus	mit Ärzten 50%-100%	mit Pflege 50%-100%	mit Erfolg 50%-100%	der Ärzte 0%-10%	Hüftgelenksersatz 0-729	Kniegelenksersatz 0-903	Operative Eingriffe bei proximalen Femurfrakturen 0-274	Knie-TEP-Erstimplantation 4%-0%	Hüft-TEP-Erstimplantation 10%-0%
Bochum	St. Josef und St. Elisabeth-Hospital									
	Knappschaftskrankenhaus Bochum Langendreer									
	Berufsgen. Universitätsklinikum Bergmannsheil									
Bottrop	Marienhospital Bottrop									
Datteln	St. Vincenz-Krankenhaus Datteln									
Dinslaken	EJK - Evangelisches Krankenhaus Dinslaken									
Dorsten	St. Elisabeth-Krankenhaus Dorsten									
Dortmund	Klinikum Dortmund									
	Klinikum Dortmund									
	Knappschaftskrankenhaus Dortmund									
Duisburg	Evangelisches Krankenhaus BETHESDA zu Duisburg									
	Evangelisches Krankenhaus BETHESDA zu Duisburg									
	Klinikum Duisburg - Wedau Kliniken									
Essen	Ev. Krankenhaus Lutherhaus									
	Kliniken Essen Süd - Kath. Krankenhaus St. Josef									
	Universitätsklinikum Essen									
	Kliniken Essen Süd - Ev. Krankenhaus Essen-Werden									
	Kath. Kliniken Ruhrhalbinsel - St. Josef-Krankenhaus									
	Alfried Krupp von Bohlen und Halbach Krankenhaus									

Drill Down Paths

A considerable number of websites (29; 69%) provided drill down paths to more specific information. The most common types of drill down paths were paths to more specific information per provider (on 21 websites; 50%) and paths to more detailed (underlying) information (on 11 websites; 26%). The information per provider to which a Web page was linked usually consisted of very specific information listed on a single Web page. Concerning more detailed comparative information, the degree to which more specific information was provided differed across websites. Figure 6 shows an example of more detailed information available after drilling down. The example is from the website US News Health. In this example, more detailed information can be found by clicking on “more detail.”

Information Display

To display comparative health care information, numbers (37; 88%) and words (32; 76%) were most commonly used. Most often, information about provider characteristics and services was presented by using words and numbers only. Graphical formats and symbols were frequently applied as well, usually to present quality information. The most frequently applied symbols were stars (on 15 websites; 36%; see Figures 1 and 4) and round icons (on 10 websites; 24%; see Figure 2). The numbers of stars, round icons and other symbols differed both across and within websites: five, four, and three symbols were most frequently found. Furthermore, it was quite common (on 18 websites; 43%) to use bar charts to present quality information.

Rationale for Presentation Formats

In total, 10 of the 42 websites (24%) returned a completed survey. Of these 10, the most common rationales for the presentation formats used were expert opinion and tests with consumers and/or other stakeholders (both found on 7 websites; 70% of the responding websites) (see Table 2).

Figure 6. Example of drill down path to more detailed information

Discussion

Principal Results

We reviewed 42 websites providing public comparative health care information and analyzed the presentation approaches of different information types. The general conclusion is that a wide variety of presentation approaches are used on Web-based reporting systems, in particular with respect to the integration of different information types and the information display. The two extreme options to integrate different information types were most often found: providing no integrated information at all and presenting a high level of integration in a single table. Between these two extremes, different options to either separate or integrate the information types were applied. Although different presentation formats were found, some standard elements emerged as well. On most websites, for example, tabular formats were used that presented providers in rows and indicators in columns. The majority of information was provided hierarchically, with options to get an overall sense of performance provided first, and options to get more detailed information provided subsequently. This format seemed necessary to manage the total amount of available information.

Study Limitations

Our study was intended to provide an impression of existing presentation approaches of comparative health care information. Clearly, not all aspects related to information presentation have been systematically reviewed. Although it is beyond the scope of the current study, it is important to keep in mind that the quality of the information itself has not been assessed. Websites may vary on the quality of the information collected and presented. We believe, however, that the current study results provide insight into the state of the art concerning the presentation of comparative health care information in the late 2000s. Our study might be limited by the fact that the search strategies were performed solely by native speakers of Dutch. The number of websites per country might be biased toward including more Dutch websites. And, in general, the number of websites found per country may be partly influenced by each author’s mastery of the different languages included in the search. We only captured Western websites, and the results should therefore be interpreted as only representative of Western websites. Another limitation is the fact that the response rate of the survey was very low. Because of this low response rate, we had limited insight into how information was tested and what consumers’ reactions were. From the returned surveys, it appeared that consulting experts and tests with consumers were important methods to select presentation formats. It is unknown whether these methods are representative of those used for development of the other websites included in the study.

Conclusions

Regarding the usefulness of comparative information for consumers, several results related to the reviewed presentation formats are worth discussing further.

First, the standard use of tabular formats to structure the information is important. On the investigated websites, the use of rows for providers and columns for attributes was the typical format for displaying summary information, whereas the opposite display format was used for more detailed information (after selection or drill down paths). It would be relevant to determine whether it makes a difference for consumers to see either providers or attributes in rows. It is known that consumers use both holistic processing (providers first) and dimensional processing (attributes first) with a slight preference for the latter [34]. Swait and Adamowicz [23] argued that the more complex information is, the simpler the heuristics that are used, which results in readers focusing more on alternatives (providers) than on attributes. From these findings we conclude that it is not the direction of the information display that is particularly important, but rather the information complexity in the table. Given the fact that most consumers will probably view only summary information, these tables should thus contain graspable numbers of providers and attributes. Otherwise, consumers will not concentrate on the attribute information even though this is the information that has been provided to support their decisions.

A second important aspect to consider is the variety of information display options found on websites. Words as well as numbers were frequently used to present comparative information. It is striking that numbers were displayed on so many websites although it is known that consumers have difficulty evaluating them [21]. As recently demonstrated by Peters and colleagues [35], numbers do not have evaluative meaning to consumers. On a large number of the websites, however, information was presented using symbols. Hibbard and colleagues [21,27] argued that visual cues such as stars increase the evaluability of information, because these cues help consumers sort providers into categories of better and worse. Furthermore, symbols might more easily attract attention compared with numbers and words, similar to pictorial information [36,37]. Pictures seem to promote a more holistic and integrative strategy to process information than do words [38]. However, when there is text-symbol incongruity, symbols may decrease message comprehension, especially among consumers having low literacy [39]. In an experiment by So and Smith [24], symbols (smiley faces) added to tabular information did not facilitate consumers’ decision accuracy. Future research on comparative health care information should include similar experiments and examine the impact of symbols. The use of stars,which were frequently found on the reviewed websites, may be an effective presentation format of comparative health care information. More research is needed to confirm this.

Third, attention should be focused on the integrated presentation of different information types. To our knowledge, there are no studies that examined the effects of integration levels of different information types. Hence, we cannot make scientifically based inferences about how the different degrees of integration found on the websites included either support or impede consumer decision making. Compared with the 1996 review of McCormack et al [25], who analyzed the content of comparative health care information, it is important that more “objective” performance indicators are dominant in the current review (included in 88% of the reviewed websites). In the findings of McCormack et al, such performance indicators were included in 10 out of 24 (24%) reporting systems, all in combination with health care user experience data. Despite the lack of evidence for consumer reactions, some arguments about the advantages and disadvantages of integrating information types can be made. One important benefit of a high level of integration is that all information can be viewed in an overview at the same time. This may contribute to a sense of clarity and to better coping with a large amount of information. A drawback is that such an overview cannot take up too much space on Web pages, and that the chance that a page will contain contradictory information increases. In addition, more specific information will be lost or difficult to find for consumers, and the flexibility to apply different search strategies diminishes. The opposite of no or very limited integration can, however, also bring about negative consequences. For example, consumers may not see a large part of the information at all or may fail to notice important information elements. In addition, consumers may need to undertake many steps in the process of viewing information, although it is known that consumers prefer to see information on one Web page [40]. An approach advocated by Harris-Kojetin et al [19] is to help consumers to think about their own priorities in the major dimensions of health care. This approach using self-selection menus could be applied to assess whether consumers are more focused on technical outcomes of health care or more focused on aspects related to trust in health care. The fact that these two health care consumer profiles can be distinguished among different patient groups [41] may be used as argument for low levels of integration of different information types. However, the approach of self-testing consumer preferences assumes that consumers have stable preferences, although we know that consumers often construct these preferences while viewing information [42]. All in all, the issue of integrating different information types remains an important topic for further discussion and, importantly, for future research on health care information. In our opinion, a certain level of integration is necessary to prevent consumers overlooking important information or getting stuck in too many decision steps.

A fourth topic for further discussion is the role of contradictory information, which appears to be inherent in comparative health care information. As stated, a higher integration of different information types increases the chance that contradictory information must be processed. It is usually assumed that conflicting information increases task complexity. Psychological theories such as cognitive dissonance theory [43] suggest that when people meet aspects of their decision environment that are incompatible with each other, they attempt to reestablish consistency by transforming some of the incompatible elements. The activities associated with this restoring process are known to demand elaboration [44], and will probably lead to distress as well. Individuals tend to avoid conflict or to avoid choosing at all when choices become more complex [14,45-48]. In addition, there is a higher chance individuals will use simpler choice heuristics [23]. At this time, it remains unclear how to deal with the issue of contradictory information. It is important that future studies search for comprehensible presentation formats that facilitate correct processing of contradictory information. Meanwhile, website managers should be careful not to present information that includes many contradictory elements.

Finally, we want to address the large amount of information we found on websites. It is known that today's consumers are often overloaded with information. Different effects of information overload have been described in the literature. Importantly, a large amount of information can lead to low quality of consumers' choices [14] and to less purchasing [49]. Lurie [50] showed that the amount of information that needs to be processed not only depends on the number of alternatives and attributes in a choice set, but also on the number of attribute levels and the distribution of attribute levels across alternatives. To control the amount of information on websites, it seems necessary to provide only limited numbers of providers and attributes to consumers, as was already suggested concerning information complexity. When a large variety of attribute levels are shown, Web designers and research staff should note the increasing complexity and search for alternative options to display information. Drill down paths can be used to layer information and to comprehensibly provide a large amount of information, as was done on many websites reviewed in this study. Furthermore, it may be necessary to inform consumers on the home page about the amount of information that can be viewed on the website. Consumers will then be better prepared and perhaps less discouraged when they attempt to access the information. Future research should focus on the amount of information that consumers are able and willing to process.

With the current descriptive study, we have shed some light on the decision environment of health care consumers in a period of market-based, consumer choice-driven health care sectors. We believe that more transparency about the effectiveness of the chosen formats on websites is greatly needed; currently it is largely unclear which rationales are used to select them. Evidence-based quality criteria for presentation approaches should be formulated, and future research can assess how different websites meet these criteria. Moreover, research is needed on other aspects of the decision environment, such as consumers' considerations and motivations to achieve a (good) decision and their decision strategies. Consumers highly motivated to search for good performance might be less distressed by complex information presentation than people who do not care to actively choose health care in any case. More generally, the design of websites should be linked to theoretical models of consumer decision making and communication technology. In our opinion, it is a challenge for Internet research to create more manageable comparative health care information that is actually used by consumers. Current presentation approaches on websites do not seem to be systematically selected. Website managers should not just release data on the web, but instead should become aware of the many complexities inherent in the comparative information they are providing.

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Conflicts of Interest

Ylva van den Hengel and Jeanne van Loon work for the National Institute for Public Health and the Environment (RIVM), which manages the Dutch website kiesBeter (www.kiesBeter.nl), one of the websites reviewed in this paper.

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Original Paper

Supporting Informed Decision Making Online in 20 Minutes: An Observational Web-log Study of a PSA Test Decision Aid

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Abstract

Background: Web-based decision aids are known to have an effect on knowledge, attitude, and behavior; important components of informed decision making. We know what decision aids achieve in randomized controlled trials (RCTs), but we still know very little about how they are used and how this relates to the informed decision making outcome measures.

Objective: To examine men's use of an online decision aid for prostate cancer screening using website transaction log files (web-logs), and to examine associations between usage and components of informed decision making.

Methods: We conducted an observational web-log analysis of users of an online decision aid, Prosdex. Men between 50 and 75 years of age were recruited for an associated RCT from 26 general practices across South Wales, United Kingdom. Men allocated to one arm of the RCT were included in the current study. Time and usage data were derived from website log files. Components of informed decision making were measured by an online questionnaire.

Results: Available for analysis were 82 web-logs. Overall, there was large variation in the use of Prosdex. The mean total time spent on the site was 20 minutes. The mean number of pages accessed was 32 (SD 21) out of a possible 60 pages. Significant associations were found between increased usage and increased knowledge (Spearman rank correlation [ρ] = 0.69, $P < .01$), between increased usage and less favorable attitude towards PSA testing (ρ = -0.52, $P < .01$), and between increased usage and reduced intention to undergo PSA testing (ρ = -0.44, $P < .01$). A bimodal distribution identified two types of user: low access and high access users.

Conclusions: Increased usage of Prosdex leads to more informed decision making, the key aim of the UK Prostate Cancer Risk Management Programme. However, developers realistically have roughly 20 minutes to provide useful information that will support informed decision making when the patient uses a web-based interface. Future decision aids need to be developed with this limitation in mind. We recommend that web-log analysis should be an integral part of online decision aid development and analysis.

Trial Registration: ISRCTN48473735; http://www.controlled-trials.com/ISRCTN48473735 (Archived by WebCite at http://www.webcitation.org/5pqeF89tS)

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KEYWORDS

decision aid; informed decision making; internet; prostate cancer; prostate specific antigen (PSA) test; user tracking; web-log; website transaction log file

Introduction

Enabling patients to make informed decisions is the new benchmark for high quality care as recently highlighted by the NHS (National Health Service) Constitution document in which the patient's right to choice and information were emphasized [1]. Decision aids have been developed to support patient participation in health care decisions [2]. Although decision aids are rapidly establishing themselves as the ideal medium for supporting informed decision making, we know very little about the best way to develop these interventions [3,4].

Decision aids are designed to facilitate informed decision making, which is characterized by improved knowledge and attitudes that are congruent with subsequent behaviors [5]. Since their introduction to clinical practice, research on decision aids has developed rapidly over the last fifteen years. Most research has focused on the effect of using decision aids on certain outcomes in a variety of clinical settings. Evaluations of decision aids, summarized in a Cochrane review [2], have shown that they increase knowledge and are more likely to lead to informed values-based decisions than routine care. We also know that users of decision aids tend to make conservative decisions or postpone interventions, especially when faced with surgical procedures: a trend which has significant implications for health service resource use [6,7].

Decision aids are therefore powerful tools that have the potential to influence patients' health care decisions and use of services. Given their prominence in health care and policy making, clinicians and developers are realizing the need for a greater understanding of how decision aids are developed and used. If decision aids have the potential to influence patients' decisions, then we need to know how we can optimize their design, particularly for diverse groups of users. We also need to know if usage of decision aids is sufficiently high to justify the expense involved in developing increasingly sophisticated decision support tools for patients.

Until recently, the formats of decision aids (eg, leaflets and videos) did not allow researchers to analyze patterns of use, particularly if the decision aid was used by the patient when alone. The migration of decision aids to the Internet, however, has offered the potential of analyzing use of decision aids in greater detail by using website transaction log files (web-logs). Within the context of website interface design, web-log analysis has long been realized as an important tool for examining website usability and usage [8-10]. Although researchers in other contexts have realized the practical use of web-logs for improving website interface design, developers of web-based decision aids have failed to recognize this potential. An early indication of the potential to use web-logs in the health care context was given by Molenaar [11], who examined the association between decision aid usage and several patient characteristics.

We believe, however, that far greater research opportunities are offered by analyzing patients' usage of decision aids using web-logs. First, we can examine associations between usage and key outcomes that decision aids are known to affect, including the components of informed decision making. In the current study, we hypothesized that increased usage of the decision aid would be associated with informed decision making. Secondly, we can explore the usage data to inform the future design of web-based decision aids. Based on the field-testing of Prosdex in its development stage [12], we hypothesized that the users would not represent a homogeneous group, and that they would use the decision aid differently from one another.

Prosdex [13] is one of the first web-based decision aids developed to help men decide whether or not to have the prostate-specific antigen (PSA) test for prostate cancer. The decision is difficult due to the inaccuracy of the test and the fact that the natural history and management of prostate cancer is poorly understood. Controversy surrounding the test has increased recently with the publication of contrasting data: a European randomized controlled trial (RCT) showed that PSA screening reduced mortality by 20% [14], while results of a trial in the United States indicated no difference in mortality after 7 to 10 years follow-up [15]. Prosdex was subsequently developed with the mandate of promoting informed decision making, the strategic aim of the UK Prostate Cancer Risk Management Programme (PCRMP) [16]. We aimed to observe participants' use of Prosdex using web-log data to identify patterns of use and to explore associations between usage and informed decision making.

Method

Design

We conducted an observational study of users of a web-based PSA test decision aid (Prosdex*)*. Observations were performed on the web-log data generated by Web server software when participants accessed Prosdex. After viewing Prosdex, participants were also required to complete an online questionnaire.

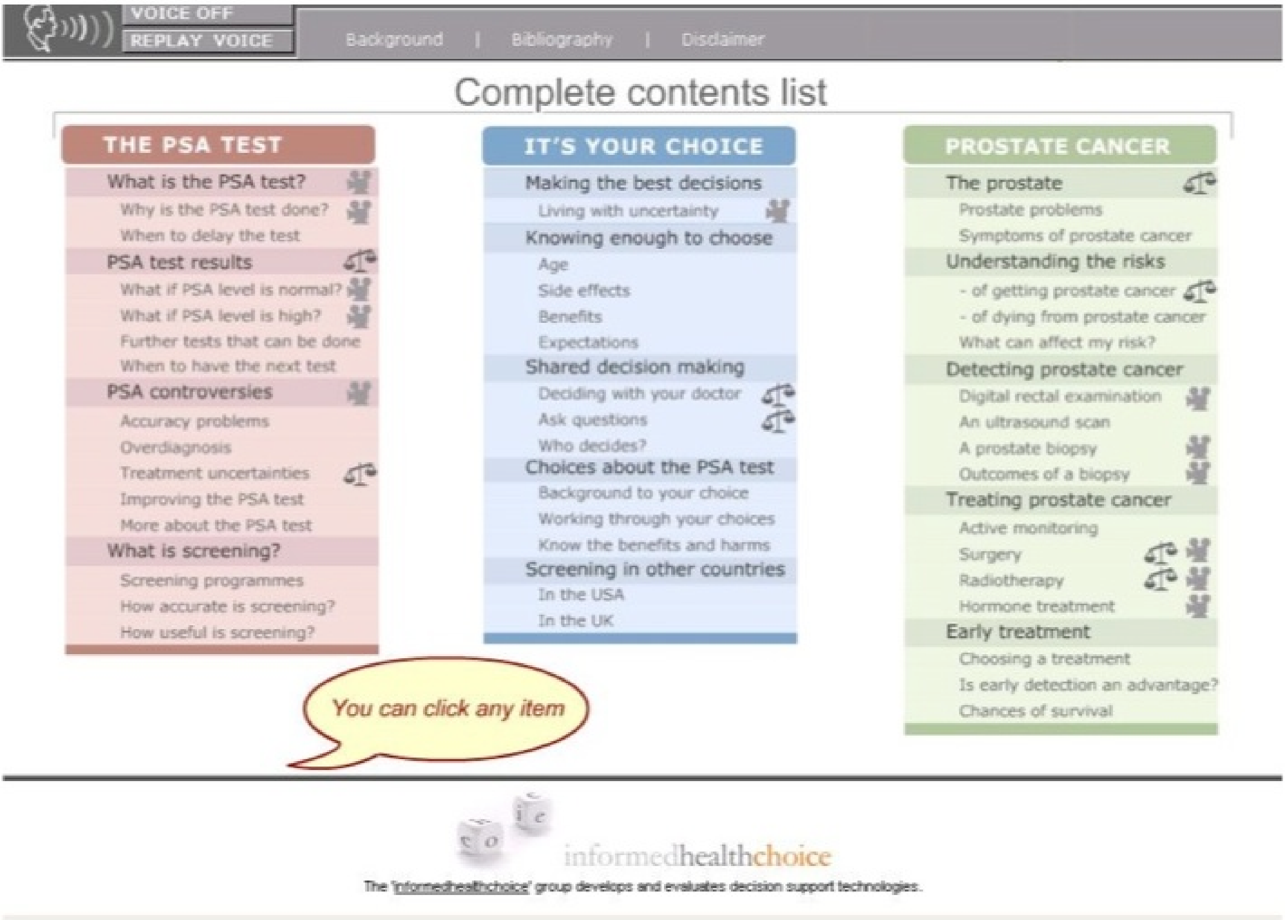
Participants and Setting

The study took place in the context of a randomized controlled trial of Prosdex [17], and participants were those men allocated to the intervention group asked to view Prosdex. Participants were recruited via their general practitioners in South Wales, United Kingdom, and were included if they were 50 to 75 years of age and had access to the Internet. They were excluded if they had previously had a PSA test or prostate cancer, had insufficient understanding of English, or were identified by their general practitioner as having learning disabilities, significant mental illness, serious ill health, or terminal illness. For full details of the study protocol see Evans et al [17].

Intervention

Participants were asked to access and view an online study version of Prosdex without supervision in their own home or in a setting of their choice. After viewing the website, participants were automatically redirected to an online questionnaire that included questions to assess informed decision making (described below) and asked participants to select from predefined categories their age, ethnicity, marital status, and educational level.

Figure 1. A screenshot of the Prosdex main contents list



Complete contents list

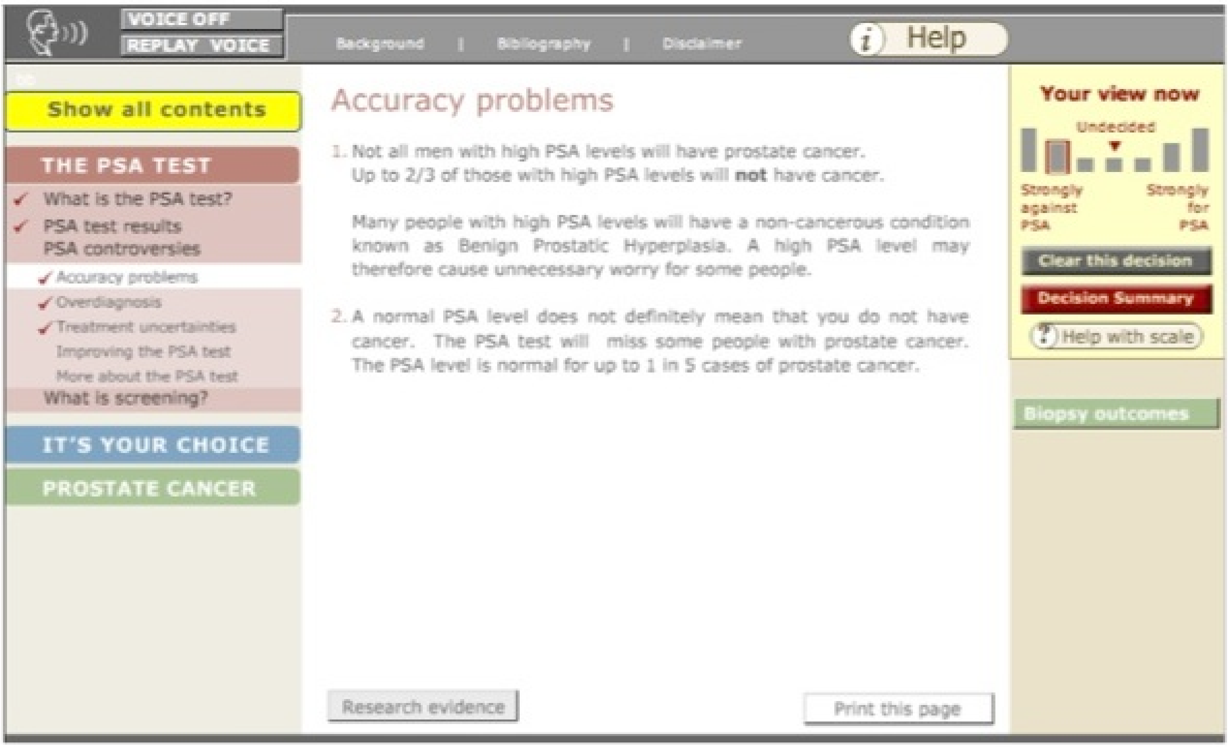
THE PSA TEST
- What is the PSA test?
  - Why is the PSA test done?
  - When to delay the test
- PSA test results
  - What if PSA level is normal?
  - What if PSA level is high?
  - Further tests that can be done
  - When to have the next test
- PSA controversies
  - Accuracy problems
  - Overdiagnosis
  - Treatment uncertainties
  - Improving the PSA test
  - More about the PSA test
- What is screening?
  - Screening programmes
  - How accurate is screening?
  - How useful is screening?

IT'S YOUR CHOICE
- Making the best decisions
  - Living with uncertainty
- Knowing enough to choose
  - Age
  - Side effects
  - Benefits
  - Expectations
- Shared decision making
  - Deciding with your doctor
  - Ask questions
  - Who decides?
- Choices about the PSA test
  - Background to your choice
  - Working through your choices
  - Know the benefits and harms
- Screening in other countries
  - In the USA
  - In the UK

PROSTATE CANCER
- The prostate
  - Prostate problems
  - Symptoms of prostate cancer
- Understanding the risks
  - - of getting prostate cancer
  - - of dying from prostate cancer
  - What can affect my risk?
- Detecting prostate cancer
  - Digital rectal examination
  - An ultrasound scan
  - A prostate biopsy
  - Outcomes of a biopsy
- Treating prostate cancer
  - Active monitoring
  - Surgery
  - Radiotherapy
  - Hormone treatment
- Early treatment
  - Choosing a treatment
  - Is early detection an advantage?
  - Chances of survival

The 'informedhealthchoice' group develops and evaluates decision support technologies.

Figure 2. A screenshot of a page on Prosdex showing the decision stacker (right) and the navigation bar (left)



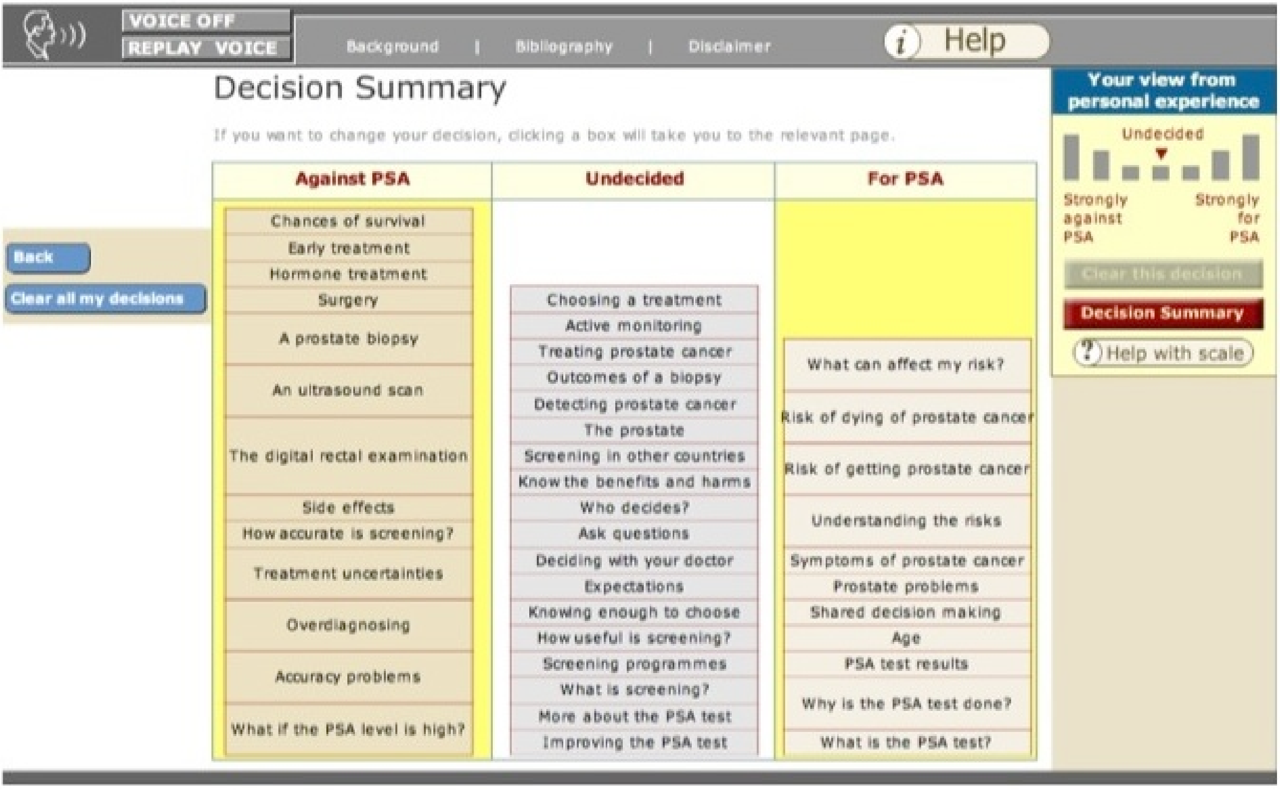
Accuracy problems

1. Not all men with high PSA levels will have prostate cancer. Up to 2/3 of those with high PSA levels will **not** have cancer.

Many people with high PSA levels will have a non-cancerous condition known as Benign Prostatic Hyperplasia. A high PSA level may therefore cause unnecessary worry for some people.

2. A normal PSA level does not definitely mean that you do not have cancer. The PSA test will miss some people with prostate cancer. The PSA level is normal for up to 1 in 5 cases of prostate cancer.

Figure 3. A screenshot of the decision summary in use



Decision Summary

If you want to change your decision, clicking a box will take you to the relevant page.

Against PSA	Undecided	For PSA
Chances of survival	Choosing a treatment	What can affect my risk?
Early treatment	Active monitoring	Risk of dying of prostate cancer
Hormone treatment	Treating prostate cancer	Risk of getting prostate cancer
Surgery	Outcomes of a biopsy	Understanding the risks
A prostate biopsy	Detecting prostate cancer	Symptoms of prostate cancer
An ultrasound scan	The prostate	Prostate problems
The digital rectal examination	Screening in other countries	Shared decision making
Side effects	Know the benefits and harms	Age
How accurate is screening?	Who decides?	PSA test results
Treatment uncertainties	Ask questions	Why is the PSA test done?
Overdiagnosing	Deciding with your doctor	What is the PSA test?
Accuracy problems	Expectations	
What if the PSA level is high?	Knowing enough to choose	
	How useful is screening?	
	Screening programmes	
	What is screening?	
	More about the PSA test	
	Improving the PSA test	

Prosdex is divided into three key modules: "The PSA Test," "It's your Choice," and "Prostate Cancer" (Figure 1). Each module is further divided into sections and individual pages containing relevant information. Users navigate through the pages of the website using the navigation bar on the left-hand side of the screen (Figure 2). The website is an open learning environment, that is, users do not follow a fixed sequence through the site and are free to select the pages that are of interest to them. Users are also able to move freely between the different modules. When a page has been viewed, a tick appears in the navigation bar (see Figure 2). Each page contains links to other pages of related interest. The website is composed of text (accompanied by an optional audio track), images, video clips, and animations. Prosdex also contains a “decision stacker” (Figure 2) and “decision summary” (Figure 3). These features allow users to track and view their evolving decision status. The decision stacker is a five-point rating scale that allows user to rate whether they are for or against PSA testing at that point based on the information viewed in that section of the website. The ratings are recorded in the decision summary that users can view and print at anytime. Users are able to print each page by clicking a link at the bottom of the page.

Outcomes

The key outcomes derived from the web-logs were:

- Total time spent on site
- Total number of main content pages accessed on site
- Time spent viewing each module (“The PSA Test,”' “It’s your Choice,” “Prostate Cancer”)
- Time spent viewing each section (eg, “What is the PSA test?” and “PSA test results”
- Time spent viewing each page (eg, “Why is the PSA test done?”)
- Number of pages accessed in each module and section and actual pages accessed
- Total number of interactive elements used (ie, videos and animations)
- Whether the participant tracked their decision using the “Decision Stacker”
- Whether the participant used the integrated print function

The 3 components of informed decision making assessed were: (1) knowledge of PSA testing and prostate cancer-related issues; (2) attitudes toward testing; (3) behavior, for which a proxy measure was the declared intention to have the PSA test.

Measurement of Outcomes

Prior to the web-logs being collected, the Prosdex website was coded so that each page/file request had a unique code. By doing this, we were able to determine from the web-logs the pages that had been viewed and which multimedia elements had been accessed by each participant.

The web-log files were generated by web-server software that tracked users’ interaction with the server. When a participant clicked the mouse button to view a particular page or interactive component of the website (eg, video), the browser sent a request to the web-server for a specific page or file. This created a log entry in a transfer log file, also known as a web-log. For each participant, a web-log was generated that contained detailed information about each request the server received from that participant’s web browser. Web-logs generated for Prosdex included information regarding the Internet Protocol address, time/date of each visit, the names of the pages/files requested, and the time difference in seconds between two consecutive page/file requests.

The component outcomes of informed decision making were measured in an online questionnaire that participants completed immediately after viewing Prosdex. Knowledge and attitude were assessed using sets of previously validated questions for PSA testing [18], and intention to undergo PSA testing was assessed using a single question which was answered on a Likert scale ranging from 1 meaning “definitely not” to 5 meaning “definitely will.”

The study received ethical approval from South East Wales Research Ethics Committee, 06/WSE04/13 (REC reference number). All participants gave informed consent before taking part in the trial after the nature and possible consequences of the study were explained.

Analysis

Frequency distributions were made to assess participants’ use of the site (eg, total number of pages selected and total time spent on each page). Data were examined for outliers. To assess whether there were distinct subgroups of users characterized by the number of pages accessed, we examined the frequency distribution and the Q-Q (Quantile - Quantile) plot.

Correlations between the number of pages accessed and informed decision making outcomes (knowledge, attitude, intention) were assessed at the individual level using Spearman’s rho. For comparisons across subgroups, *t* tests and Mann-Whitney tests were employed. Significance level of alpha = .05 was chosen for all tests, and all statistical analyses were performed using SPSS version 12 (SPSS Inc, Chicago, IL, USA).

Results

Participant Sample

There were 129 participants (all men) allocated to the Prosdex intervention group in the associated RCT [17]. Of these, 82 successfully viewed Prosdex and had web-logs available for analysis. Web-logs were not available for 47 participants: 30 of the 47 did not attempt to access the site, and 17 attempted to access the site but then encountered software problems (eg, were unable to install Flash media player).

For 8 of the 82 men who successfully viewed Prosdex, we found an excessive amount of time spent viewing particular pages, indicating that these men had likely left the computer on for long periods of time with no interaction (in one case this was 11 days). Viewing times for these participants distorted the mean amount of time spent on each page, section, module, as well as the site as a whole, and were therefore excluded from descriptive analyses relating to time.

Of the 82 men whose web-logs indicated that they had successfully viewed Prosdex, 73 completed the online questionnaire and provided complete outcome data. Data for these 73 men were included in correlation analyses. The 17 men who attempted to access the Prosdex site but were unsuccessful (therefore providing no web-log data) had, however, completed the online questionnaire and provided complete outcome data. These men were compared with the 73 men who successfully accessed the site and who had complete outcome data.

Participants’ Characteristics

Table 1 presents participant characteristics of the sample. Most men were between 50 and 59 years of age, married or living as married, and white. In addition, 36 out of 82 (44%) had a graduate or postgraduate qualification.

Table 1. Participants' characteristics (n = 82)

Characteristic	Percent (Number)
Age group	
50-59	61 (50)
60-69	22 (18)
70 or over	6 (5)
Unknown	11 (9)
Highest level of education	
No formal qualifications	11 (9)
School leaver age 16 (formal qualification)	20 (16)
School leaver age 18 (formal qualification)	8 (7)
Clerical or commercial qualification	6 (5)
Graduate or post-graduate qualification	44 (36)
Unknown	11 (9)
Marital status	
Married or cohabiting	81 (66)
Single or never married	2 (2)
Divorced or separated	6 (5)
Unknown	11 (9)
Ethnicity	
White	88 (72)
Mixed race	1 (1)
Unknown	11 (9)

Prosdex Use

Table 2 presents a summary of the outcomes relating to participants' use of Prosdex and the 3 modules: "The PSA Test," "It's Your Choice," and "Prostate Cancer." Table 3 presents a summary of the outcomes relating to participants' use of the interactive features, including videos and animations.

Table 2. A summary of participants' use of Prosdex: mean time (seconds); mean number of pages viewed; percentage of available pages viewed and percentage of videos/animations viewed among men in the low, intermediate, and high access groups

Module/Section	Time		Access		Percent of Available Pages Viewed Among Men in Each Group		
	Mean (SD)[a] Time in Seconds Spent in Module/ Section	Range	Total Number of Pages in Module/ Section	Mean Number (SD)[b] of Pages Viewed	Low Access (n = 37)	Intermediate Access (n = 18)	High Access (n = 27)
PROSDEX site	1191 (914)	75-3672	60	32 (21)	19	60	94
The PSA Test	412 (329)	0-1385	19	11 (6)	37	58	91
Introduction	8 (19)	0-99	1	0.5 (0.5)	24	28	37
What is the PSA test?	91 (66)	0-310	3	2 (1)	67	85	94
PSA test results	132 (129)	0-772	5	3 (2)	45	68	92
PSA controversies	103 (118)	0-420	6	3 (2)	28	44	93
What is screening?	76 (87)	0-327	4	2 (2)	22	56	97
It's Your Choice	218 (263)	0-996	19	9 (8)	5	51	97
Introduction	13 (15)	0-77	1	1 (0.5)	54	83	93
Making the best decisions	18 (49)	0 -394	2	1 (1)	4	58	94
Knowing enough to choose	65 (85)	0-302	5	2 (2)	1	70	99
Shared decision making	49 (70)	0-285	4	2 (2)	3	42	98
Choices about the PSA test	44 (70)	0-341	4	2 (2)	2	32	99
Screening in other countries	29 (42)	0-212	3	1 (1)	5	39	94
Prostate Cancer	428 (449)	0-1824	22	12 (9)	15	70	94
Introduction	15 (14)	0-63	1	1 (0.5)	43	100	96
The prostate	70 (68)	0-231	3	2 (1)	20	70	95
Understanding the risks	60 (82)	0-503	4	2 (2)	12	76	100
Detecting prostate cancer	114 (169)	0-733	5	3 (2)	17	63	91
Treating prostate cancer	115 (180)	0-883	5	2 (2)	10	68	90
Early treatment	50 (59)	0-228	4	2 (2)	12	65	94

[a] based on 74 participants (8 outliers excluded)

[b] based on 82 participants (8 outliers did not sufficiently distort usage data)

Table 3. A summary of participants' use of video clips and animations on Prosdex among men in the low, intermediate, and high access group

Module/Section	Number of Videos (Animations) in Each Module/ Section	Percent of Available Videos (Animations) Viewed Among Men in Each Group		
		Low access (n = 37)	Intermediate Access (n = 18)	High Access (n = 27)
PROSDEX site	25 (8)	0.5 (2)	8 (16)	8 (21)
The PSA Test	9 (2)	1 (5)	3 (14)	2 (30)
It's Your Choice	1 (2)	0 (0)	0 (6)	4 (13)
Prostate Cancer	14 (4)	0 (1)	12 (22)	12 (21)

Participants (n = 74, outliers excluded) spent a mean of 20 (SD 15) minutes on Prosdex. The shortest time spent on Prosdex was 1 minute and the longest time was 61 minutes. Participants spent a mean of 7 (SD 5) minutes on the "The PSA Test" module, a mean of 4 (SD 4) minutes on the "It's your Choice" module, and a mean of 7 (SD 7) minutes on the "Prostate Cancer" module. The longest time spent on each module was 23 minutes, 17 minutes, and 30 minutes respectively. The relatively large standard deviations obtained highlight the large variability in the time that men spent on the modules.

The participants (n = 82) viewed a mean number of 32 (SD 21) out of a possible 60 main content pages on the Prosdex site with only seven men (8.5%) viewing all 60. A mean of 11 (SD 6) pages out of 19 were viewed from the "PSA Test" module. Eight men (10%) viewed all 19 pages while four men (5%) did not view any pages from this module. A mean number of nine (SD 8) pages out of 19 was viewed from the "It's your Choice" module, with 17 men (20%) viewing all 19 pages, and 16 men (20%) not accessing any pages. A mean number of 12 (SD 9) pages out of 22 was viewed from the "Prostate Cancer" module. All 22 pages were viewed by 19 men (23%) while 13 men (16%) did not view any pages from this module. Overall, men spent longer and viewed more pages in the "PSA Test" and "Prostate Cancer" modules than they did in the "It's Your Choice" module.

The interactive features of the site included videos and animations. The mean number of videos viewed was 1 out of 25, and the mean number of animations viewed was 1 out of 8. Of the 82 men, 64 (78%) did not view any video clips, and 44 (54%) did not view any animations. Of the 82 men, 37 (45%) used the "decision stacker," designed to facilitate involvement in the decision making process. The majority of these men only used the stacker once, and therefore, usage was minimal. Only 3 men out of 82 (4%) used the integrated print functionality, printing only one item of information each.

Analysis to Identify Subgroups of Users

By examining the frequency distribution and Q-Q (quantile-quantile) plot of the number of pages accessed, we identified a bimodal distribution. The frequency distribution of number of pages accessed suggested two modes, at ≤ 40% and ≥ 80% of the pages, with a relative dearth of intermediate values. Therefore, we defined three groups in terms of the number of pages participants accessed: low access was defined as 0 to 40% (ie, 0 to 24 pages), intermediate access as 41 to 79% (ie, 25 to 47 pages), and high access as 80 to 100% (ie, 48 to 60 pages).

Table 2 highlights the difference in overall Prosdex usage between the three groups and also demonstrates that the difference in usage was fairly consistent throughout each module and section of the website. Men in the low access group viewed a mean of 37% (7 out of 19 pages) of the "PSA Test" module, 5% (1 out of 19 pages) of the "It's Your Choice" module, and 15% (3 out of 22 pages) of the "Prostate Cancer" module. On the other hand, men in the high access group viewed, on average, over 90% of the available pages in each module: 17 out of 19 pages of the "PSA Test" module, 18 out of 19 pages of the "It's Your Choice" module, and 21 out of 22 pages of the "Prostate Cancer" module. Table 3 shows that the use of videos and animations was low in all three groups, although the high access group viewed a greater percentage of available videos and animations than the low access group.

Correlations Between Usage and Components of Informed Decision Making

Correlations between usage (measured by number of pages accessed) and the measures of informed decision making were assessed (Spearman rank correlation [ρ], two-tailed). Focusing on number of pages as an indicator of usage allowed for the inclusion of participants with outliers on time data. There was a significant positive correlation between the total number of pages viewed and the overall knowledge score ($\rho = 0.69$, $P < .001$). In other words, the more pages a user accessed, the higher their knowledge score.

A negative correlation was found between the total number of pages viewed and attitude to screening ($\rho = -0.52$, $P < .001$). That is, the more pages the user accessed, the less favorable their attitude to the PSA test became. A negative correlation was also found between total number of pages viewed and intention to take the PSA test ($\rho = -0.44$, $P < .001$). In other words, the more pages the user accessed, the less likely their intention was to have the test.

Comparisons Between Groups

Significant differences were demonstrated in knowledge scores, attitudes towards the test, and intention to have the test between men who accessed less than 40% of the website and men who accessed 80 to 100%. Specifically, *t* test results demonstrated that those in the high access group (80 to 100%) had significantly higher knowledge scores ($t_{56} = 6.35$, $P < .001$), and significantly less favorable attitude towards the PSA test ($t_{48} = -4.51$, $P < .001$). There was also a significant and inverse effect of number of pages viewed on intention to have the test when comparing the high access and low access groups (Mann-Whitney U = 211, $n_1 = 31$, $n_2 = 26$, $P < .001$, two-tailed).

On comparing participants with successful and unsuccessful access to Prosdex, there were significant differences. Specifically, *t* tests demonstrated that those who were successful had significantly higher knowledge scores ($t_{36} = 4.59$ $P < .001$) and significantly less favorable attitudes towards the PSA test ($t_{43} = -2.44$ $P = .02$). There was no significant difference between the groups on intention to have the PSA test (Mann-Whitney U = 585.5, $n_1 = 73$, $n_2 = 17$, $P = .71$, two-tailed)

Discussion

Summary of Findings

This web-log analysis of men using an online decision aid demonstrates a strong correlation between increased usage and increased knowledge, a less favorable attitude to the PSA test, and a congruent reduction in intention to take the test. We have found a significant dose-response relationship whereby informed decision making increases with increased usage of the website.

We found that men who used Prosdex spent a mean time of 20 minutes viewing the website before quitting. Therefore, while increased access is preferable due to the significant dose-response relationship, developers realistically have roughly 20 minutes in which to support an informed decision online. However, it is possible that users would spend even less time viewing such a site outside of the research context, so this time frame may be further limited. As predicted, we also found that men who used Prosdex did not comprise a homogeneous group, and access was not characterized along a continuum. Instead, the bimodal distribution of the data highlighted two distinct groups of users, characterized as low access and high access. The key findings of this study have important consequences for the future design of decision aids, as discussed at the end of the paper.

Strengths and Weaknesses

This is the first study to analyze the web-logs of an online decision aid collected during an online study. We not only successfully identified patterns of usage, but also demonstrated correlations with outcome measures obtained from an associated randomized controlled trial. Specifically, we were able to identify associations between actual usage of a decision aid and components of informed decision making. If decision aids are designed to facilitate informed decision making, it is important that we understand the type of usage that leads to this.

Using a novel method of analyzing website log files, we have identified research limitations that require improvement. First, web-logs were unavailable for 47 of the men; 30 men did not attempt to access the site. This is a relatively high nonparticipation rate that could have an impact on the overall findings. There was evidence of software problems as 17 of the 47 participants were unsuccessful in their attempt to log in to the site. Future web-based research should ensure that software support is made available to users to minimize participant dropout associated with software downloads. The second weakness related to interpretation of the time data and the assumptions made from the web-logs. Although a long time spent on a particular page could indicate that the user took time to read it, it might also mean that the user left the computer and returned later. Given that the web-logs were collected in the home context, where it is likely that there are more interruptions, it is possible that the time data may be overestimated. Therefore, we cannot be sure that time spent on the site meant that the user was viewing the page for that time.

We recommend that interpretations of web-log data should be based primarily on the number of pages viewed rather than time spent. These two measures are highly correlated, but the former is more stable and robust. The correlations between usage and the outcome measures must also be interpreted with caution. While the dose-response correlations suggest that increased usage leads to more informed decision making, it might be the case, for example, that men with more doubts and less positive attitudes toward the test prior to viewing Prosdex were more likely to spend longer viewing the site.

Comparison with Existing Literature

Molenaar's [11] research on an interactive CD-Rom for breast cancer also used computer transaction log data for observational analysis, but they conducted an observational study where researchers were monitoring access. The mean time users spent viewing the decision aids was much longer with users spending over 1 hour viewing the information on the CD-Rom. In comparison, we found that participants' spent a mean of 20 minutes viewing Prosdex. Unlike our study, participants were asked to view Molenaar's decision aid in the presence of a nurse, which potentially encouraged participants to spend longer viewing the information than they would under natural conditions. As such, we believe the 20-minute time frame observed in our study is a more realistic and ecologically valid representation of use, and decision aid tools should be designed with this in mind.

However, we should note that the differences in time spent might also be a function of the population sampled. First, there is some evidence to suggest that women are generally more motivated to be involved in decisions about their health [19]. Second, PSA testing remains controversial as the test is limited by its sensitivity and specificity, and there is uncertainty relating to the natural history and management of prostate cancer. As such, there is often no imminent time frame in which a man would need to make a decision about whether or not to have the PSA test, unlike the decision a woman might be required to make between breast-conserving therapy and mastectomy, as was addressed by Molenaar [11]. It is therefore important to examine the use of decision aids for screening procedures that are more accurate and for disease treatment options where the natural history and management of the condition are better understood.

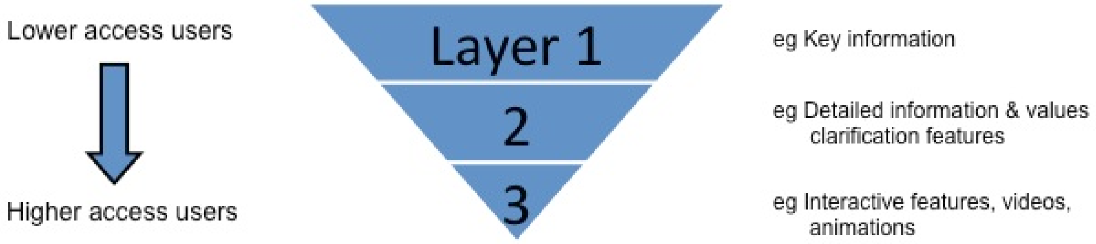
The study has expanded on existing research [11] by examining correlations between usage and outcome measures. This allowed us to examine patterns of usage that lead to informed decision making, which is what decision aids are designed to facilitate. We also examined patterns of usage, which we propose should inform the future design of decision aids. Previous studies have yet to address this functional use of web-log data.

Conclusions and Implications for Research and Practice

There is evidence that Prosdex promotes informed decision making in men, and we highlight factors that should inform the future design of decision aids. First, for the population using Prosdex, 20 minutes seems to be a critical time window in which we can realistically expect information to be accessed. This finding is significant as there has been a recent trend towards developing more sophisticated decision aids that take longer to use, which could be seen as over engineering. We demonstrated, however, that participants did not use the interactive features, and that the window of opportunity for information transfer to support decision making is narrow. Second, users of decision aids are not a homogenous population: there are different types of users characterized by their level of interaction with the decision aid. Therefore, developers need to design tools that sufficiently support and facilitate informed decision making among the different types of users, and should move away from designing one intervention for all.

We caution against the simple response of developing shorter decision aids, with possibly two versions for high and low users. A more valid response, in our opinion, would be to move away from the traditional linear design of decision aids toward designing tools with a stratum approach (Figure 4), that is, decision aids with several layers.

Figure 4. A diagram representing the stratum approach to developing decision aids



The top layer would present users with the key messages and allow them to access the most important and relevant information with little navigation. This layer would be aimed at the low access group. It would ensure they receive the information they need to make an informed decision in a short time period. For those who wish to dig deeper, the more complex features (eg, interactive elements) and detailed information would be accessible. By adopting this stratum approach, developers could address the needs of different types of users and deliver the relevant and most important information within the relatively limited timeframe. We believe that developers who conduct further research and decision aid development along these lines will be able to support informed decision making for the greatest number of people. Additionally, the “golden” 20-minute time limit, found in the current study, could provide a useful heuristic for other developers. However, we recommend that web-log analysis be an integral part of the development process for online decision aids as well as a tool for posthoc analysis, so that developers can establish the “critical window” that is relevant to their own situation.

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Conflicts of Interest

None declared

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Abbreviations

NHS: National Health Service
PCRMP: Prostate Cancer Risk Management Programme
PSA: prostate specific antigen
Q-Q plot: Quantile – Quantile plot
RCT: randomized controlled trial
Web-log: website transaction log file

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Original Paper

Clinician Search Behaviors May Be Influenced by Search Engine Design

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Abstract

Background: Searching the Web for documents using information retrieval systems plays an important part in clinicians' practice of evidence-based medicine. While much research focuses on the design of methods to retrieve documents, there has been little examination of the way different search engine capabilities influence clinician search behaviors.

Objectives: Previous studies have shown that use of task-based search engines allows for faster searches with no loss of decision accuracy compared with resource-based engines. We hypothesized that changes in search behaviors may explain these differences.

Methods: In all, 75 clinicians (44 doctors and 31 clinical nurse consultants) were randomized to use either a resource-based or a task-based version of a clinical information retrieval system to answer questions about 8 clinical scenarios in a controlled setting in a university computer laboratory. Clinicians using the resource-based system could select 1 of 6 resources, such as PubMed; clinicians using the task-based system could select 1 of 6 clinical tasks, such as diagnosis. Clinicians in both systems could reformulate search queries. System logs unobtrusively capturing clinicians' interactions with the systems were coded and analyzed for clinicians' search actions and query reformulation strategies.

Results: The most frequent search action of clinicians using the resource-based system was to explore a new resource with the same query, that is, these clinicians exhibited a "breadth-first" search behaviour. Of 1398 search actions, clinicians using the resource-based system conducted 401 (28.7%, 95% confidence interval [CI] 26.37-31.11) in this way. In contrast, the majority of clinicians using the task-based system exhibited a "depth-first" search behavior in which they reformulated query keywords while keeping to the same task profiles. Of 585 search actions conducted by clinicians using the task-based system, 379 (64.8%, 95% CI 60.83-68.55) were conducted in this way.

Conclusions: This study provides evidence that different search engine designs are associated with different user search behaviors.

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KEYWORDS

Clinician; search behavior; information retrieval; Internet

Introduction

Searching for information on the Web to support decision making is now an important part of clinician practice [1]. While much research focuses on the design of retrieval algorithms to identify potentially relevant documents, there has been little examination of the way that different search engine capabilities influence search behavior. Yet, to develop information retrieval systems that actively support decision making, it is necessary to understand the complex process of how people search for and review information when making decisions [2] and to design search user interfaces appropriate for these needs.

Recent studies of clinical search strategies have concentrated on methods of optimizing queries sent to information retrieval systems that enhance the performance of the retrieval. Hoogendam and colleagues conducted a prospective observational study of how physicians at a hospital used PubMed to search for information during their daily clinical activities [3]. They found that the likelihood of physicians viewing article abstracts returned from PubMed increased as the number of terms contained in a search query increased. Haase and colleagues investigated the optimal performance for different search engines in retrieving clinical practice guidelines by combining different search query terms [4]. Our own prior analysis of information searching by clinicians used a Bayesian belief revision framework to retrospectively model how documents might influence decisions during and after a search session [5]; the analysis demonstrated that clinicians can experience cognitive biases while searching for online information to answer clinical questions [6].

Few studies have looked at how clinicians reformulate queries and select sources to retrieve information during a search session to answer clinical questions. In previous studies, we have shown that a task-based search engine design allows for faster clinical decision making (ie, “decision velocity”) compared with purely resource-based engines at no cost in correctness of answers [7]. Similar results with respect to search times have been noted by others for the use of topic-specific “infobuttons” [8]. In the current study, we sought to understand the basis for these performance variations, by testing whether differences in search engine interface design are associated with any differences in user search behaviors.

Methods

Participants and Study Design

In all, 75 clinicians (44 doctors and 31 clinical nurse consultants) practicing in the state of New South Wales, Australia, were recruited to use an online information retrieval system to answer questions on 8 clinical scenarios within 80 minutes in a controlled setting in a university computer laboratory (Table 1) [9]. Participants had an average of 17 years of clinical experience, with the majority having rated their computer skills as good to excellent and having reported use of an online information retrieval system once per week or more.

Participants were randomly allocated to use either a resource-based or a task-based version of an online information retrieval system to answer the 8 questions. All participants were given a brief written orientation tutorial regarding their allocated system. Questions were presented in random order. Each participant was asked to use the allocated system to locate documentary evidence to help answer each question. Participants were asked to work through the questions as they would in a real clinical setting and not spend more than 10 minutes on any one question.

Table 1. Clinical questions presented to participants [9]

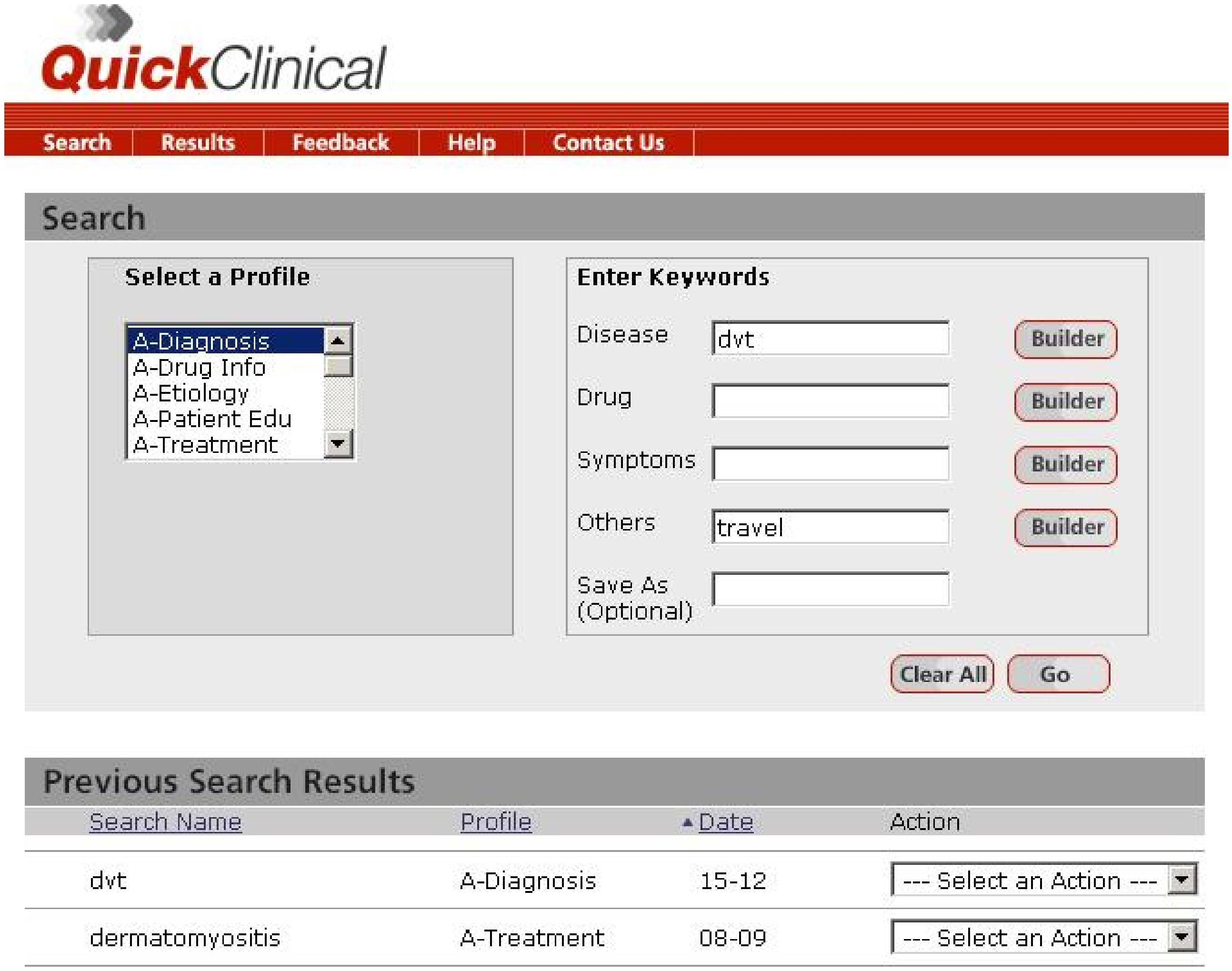
Question	Expected Correct Answer
Does current evidence support the insertion of tympanostomy tubes in a child with normal hearing?	No, not indicated
What is the best delivery device for inhaled medication for a child during moderate asthma attack?	Spacer (holding chamber)
Is there evidence for the use of nicotine replacement therapy after myocardial infarction?	No, use is contraindicated
Is there evidence for increased breast and cervical cancer risk after in vitro fertilization (IVF) treatment?	No evidence of increased risk
Is there evidence for increased risk of sudden infant death syndrome (SIDS) in siblings of baby who died of SIDS?	Yes, there is an increased risk
What is (are) the anaerobic organism(s) associated with osteomyelitis in diabetes?	*Peptrostreptococcus, Bacteroides*
Does existing evidence demonstrate that glucosamine has a disease-modifying role in osteoarthritis?	Conflicting evidence
Should epinephrine be given with the antivenom to prevent anaphylaxis?	Conflicting evidence

Resource-based System Versus Task-based System

The search systems used by participants were essentially identical in that both systems allowed users to first select a profile (ie, search filter) to delimit their search and then to enter keywords to specify the focus of their search. The resource-based system first required clinicians to select a profile by specifying one of six online resources. These included PubMed, MIMS (a pharmaceutical database), Therapeutic Guidelines (an Australian synthesized evidence source focusing on guidelines for therapy), the Merck Manual, Harrison’s Principles of Internal Medicine, and HealthInsite (a government-funded consumer-oriented health database). Of the six resources, five presented evidence in a predigested, summarized form with references available for follow-up.

The task-based system first required the clinicians to select a profile by selecting one of six clinical tasks: diagnosis, drug information, etiology, patient education, treatment, and other (Figure 1). Four keyword categories were available for both systems: disease, drug, symptom, and other. Clinicians could enter keywords under one or more of these categories. Quick Clinical (University of New South Wales, Sydney, Australia), the task-based information retrieval system, utilized meta-search filters to simultaneously search across a set of disparate information sources [10]. This task-based system has been demonstrated to be effective and efficient in searching and delivering information in various technical, laboratory, and longitudinal evaluation studies [9-14].

Figure 1. Screenshot showing Quick Clinical, the task-based query user interface



Disease: dvt

Drug:

Symptoms:

Others: travel

Save As (Optional):

Previous Search Results

Search Name	Profile	▲Date	Action
dvt	A-Diagnosis	15-12	--- Select an Action ---
dermatomyositis	A-Treatment	08-09	--- Select an Action ---

Coding of Search Actions

System logs unobtrusively capturing participants' interactions with the systems were coded and analyzed for their search actions and query reformulation strategies. For each clinical scenario question, participants were able to reformulate queries and conduct a sequence of searches as they explored information to assist in answering the question. We first coded these query reformulations by the change in profile selection (task or resource) between consecutive searches in a session as “new profile,” “same profile,” or “previously used profile.” We next coded the keyword changes, as indicating a syntactic and/or a semantic reformulation [14]. Examples of syntactic reformulations include changing the following: the use of capitalization, the order of words, the conjunctions used between words, word spacing, or the typographic of the words (ie, variants of the base form of the word) used in the query (Table 2). Semantic reformulations include adding, removing, or replacing keywords.

Table 2. Examples of syntactic query reformulation

Syntactic Query Reformulation	Explanation
Change capitalization	Change capitalization of the words in a query, for example, change “IVF” to “ivf”
Change word order	Change the way words are ordered in a query, for example, “asthma diagnosis” to “diagnosis asthma”
Change conjunction	Remove, add, replace, or reorder conjunctive terms used in a query, such as “AND,” “OR,” or ”NOT”
Change spacing	Split, group, or merge words in a query by using punctuation symbols, for example, by using quotation marks to group words together to form a term or by transforming keywords, such as “heart-attack” to “heart attack”
Change typographic	Change stems, plurals, or spelling variations of words, for example, changing “run” to “running,” “apple” to “apples,” or “behavior” to “behaviour”

Quantitative Analyses

Chi-square analyses and the test for difference between proportions were conducted to detect statistically significant differences in profile and query search actions between clinicians using the resource-based and task-based systems.

Results

Of 75 clinicians, 39 were randomly allocated to use of the resource-based system and 36 to use of the task-based system. Two resource-based scenarios were not completed, giving a total of 310 (ie, 39×8−2) search sessions, 1708 searches, and 1455 document accesses using the resource-based system. The task-based system generated 288 (ie, 36×8) search sessions, 873 searches, and 1136 document accesses.

Next Action in a Search Sequence

Chi-square analyses conducted of data presented in Table 3, Table 4, and Table 5 showed statistically significant differences in the next action in a search sequence between the resource-based and task-based systems. These significant differences included (1) selecting the next profile in a search sequence ($\chi^2_2 = 103.45$, $P < .001$) (Table 3), (2) reformulating keywords ($\chi^2_3 = 59.37$, $P < .001$) (Table 4), and (3) both selecting the next profile and reformulating keywords ($\chi^2_{11} = 165.33$, $P < .001$) (Table 5).

Table 3. Comparison of next profile actions between resource-based and task-based systems

Search System	Next Profile Action N (%) (95% CI)		
	Same Profile	Previous Profile	New Profile
Resource-based (n=1398)	557 (39.8%) (37.31 to 42.43)	202 (14.4%) (12.70 to 16.39)	639 (45.7%) (43.11 to 48.33)
Task-based (n=585)	379 (64.8%) (60.83 to 68.55)	55 (9.4%) (7.29-12.04)	151 (25.8%) (22.43-29.51)

Table 4. Comparison of next query reformulation actions between resource-based and task-based system users

Search System	Next Query Reformulation Action N (%) (95% CI)			
	No Change	Syntactic Change[a]	Semantic Change[b]	Syntactic and Semantic Changes
Resource-based (n=1398)	588 (42.1%) (39.50-44.67)	294 (21.0%) (18.97-23.24)	326 (23.3%) (21.18-25.61)	190 (13.6%) (11.89-15.49)
Task-based (n=585)	144 (24.6%) (21.30-28.26)	137 (23.4%) (20.17-27.02)	179 (30.6%) (27.00-34.45)	125 (21.4%) (18.24-24.87)

[a] Syntactic change refers to changes in capitalization, typographic, ordering of words, spacing of words, and adding or removing conjunctions in a query.

[b] Semantic change refers to adding, removing, or replacing words in a query.

The test for difference between proportions revealed that clinicians using the resource-based system were 19.5% more likely to select a new profile and apply no changes to keywords (Z =11.43, $P < .001$), and 5.9% more likely to select a profile that was previously visited and apply no changes to keywords (Z = 5.80, $P < .001$) (Table 5). Also, clinicians using the task-based system were 7.8% more likely to keep the same profile in a sequence of search actions (Z = –5.28, $P < .001$), 7.5% to keep the same profile and apply both syntactic and semantic changes to the query (Z = –4.69, $P < .001$), and 6.5% to keep the same profile and apply semantic changes to the query (Z = –3.37, $P < .001$) (Table 5). Further, task-based clinicians seldom accessed a profile that had been previously visited (9.4%, 95% CI 7.29-12.04) (Table 3).

Table 5. Comparison of profile and query reformulation actions between resource-based and task-based systems

Next Profile Action + Next Query Reformulation Action	Resource-based (n=1398) N (%) (95% CI)	Task-based (n=585) N (%) (95% CI)	Z	*P*
Same profile + no change	67 (4.8%) (3.79-6.04)	74 (12.6%) (10.20-15.59)	–5.28	<.001
Same profile + syntactic changes only	193 (13.8%) (12.10-15.71)	99 (16.9%) (14.10-20.18)	–1.73	.08
Same profile + semantic changes only	203 (14.5%) (12.77-16.46)	123 (21.0%) (17.92-24.51)	–3.37	<.001
Same profile + syntactic and semantic	94 (6.7%) (5.53-8.16)	83 (14.2%) (11.59-17.25)	–4.69	<.001
Previous profile + no change	120 (8.6%) (7.23-10.17)	16 (2.7%) (1.69-4.40)	5.80	<.001
Previous profile + syntactic changes only	18 (1.3%) (0.82-2.03)	10 (1.7%) (0.93-3.12)	–0.69	.49
Previous profile + semantic changes only	36 (2.6%) (1.87-3.54)	17 (2.9%) (1.82-4.60)	–0.41	.68
Previous profile + syntactic and semantic	28 (2.0%) (1.39-2.88)	12 (2.1%) (1.18-3.55)	–0.07	.94
New profile + no change	401 (28.7%) (26.37-31.11)	54 (9.2%) (7.14-11.85)	11.43	<.001
New profile + syntactic changes only	83 (5.9%) (4.81-7.30)	28 (4.8%) (3.33-6.83)	1.06	.29
New profile + semantic changes only	87 (6.2%) (5.07-7.61)	39 (6.7%) (4.91-8.98)	–0.36	.72
New profile + syntactic and semantic	68 (4.9%) (3.85-6.12)	30 (5.1%) (3.62-7.23)	–0.24	.81

Search Actions During a Session

We examined search behaviors at the beginning, middle, and end of a search sequence. At the beginning of a search sequence, query reformulation was the most frequent choice for both systems (Table 6). In the middle of a session, clinicians using the resource-based system were 26.6% more likely to change profile only (Z = 10.21, *P* < .001) (Table 6), and clinicians using the task-based system were 20.7% more likely to reformulate query only (Z = –6.06, *P* < .001) (Table 6). At the end of a sequence, clinicians using the resource-based system were 26.7% more likely to change profile only (Z = 6.50, *P* < .001) (Table 6), and clinicians using the task-based system were 14.9% more likely to reformulate query only (Z = –2.75, *P* = .006) (Table 6).

Table 6. Search action between resource-based and task-based systems during a session

Search Action	Resource-based N (%) (95% CI)	Task-based N (%) (95% CI)	Z	*P*
First	(n=263)	(n=189)		
No change	9 (3.4%) (1.81-6.37)	31 (16.4%) (11.80-22.34)	–4.45	<.001
Change query only	115 (43.7%) (37.86-49.77)	100 (52.9%) (45.81-59.90)	–1.93	.05
Change profile only	82 (31.2%) (25.89-37.01)	24 (12.7%) (8.68-18.20)	4.93	<.001
Change query and profile	57 (21.7%) (17.12-27.04)	34 (18.0%) (13.17-24.09)	0.98	.33
Middle	(n=913)	(n=267)		
No change	47 (5.1%) (3.89-6.78)	32 (12.0%) (8.62-16.43)	–3.23	.001
Change query only	303 (33.2%) (30.21to 36.31)	144 (53.9%) (47.94-59.81)	–6.06	<.001
Change profile only	359 (39.3%) (36.20-42.53)	34 (12.7%) (9.26-17.27)	10.21	<.001
Change query and profile	204 (22.3%) (19.76-25.16)	57 (21.3%) (16.86-26.65)	0.35	.73
Last	(n=222)	(n=129)		
No change	11 (5.0%) (2.79-8.65)	11 (8.5%) (4.83-14.62)	–1.25	.21
Change query only	72 (32.4%) (26.62-38.84)	61 (47.3%) (38.87-55.86)	–2.75	.006
Change profile only	80 (36.0%) (30.01-42.54)	12 (9.3%) (5.40-15.56)	6.50	<.001
Change query and profile	59 (26.6%) (21.20-32.75)	45 (34.9%) (27.20-43.44)	–1.62	.11

Consecutive Search Actions

Table 7 displays comparisons of the frequencies of use of consecutive pairs of actions anywhere within a sequence between the two systems. For clinicians using the resource-based system, the pair “change profile only” followed by “change profile only” was 18.6% more likely (Z = 13.88, *P* < .001) (Table 7). Among clinicians using the task-system, the pair “change query only” followed by “change query only” was used 17.8% more frequently compared with clinicians using the resource-based system (Z = –6.95, *P* < .001) (Table 7).

Table 7. Consecutive search actions in a session between resource-based and task-based systems

Current Search Action	Next Search Action	Resource-based (n=1135)[a] N (%) (95% CI)	Task-based (n=396)[b] N (%) (95% CI)	Z	*P*
No change	No change	10 (0.9%) (0.48-1.61)	7 (1.8%) (0.86-3.60)	–1.23	.22
	Change query only	17 (1.5%) (0.94-2.39)	28 (7.1%) (4.94-10.03)	–4.17	<.001
	Change profile only	20 (1.8%) (1.14-2.71)	6 (1.5%) (0.70-3.27)	0.34	.73
	Change query and profile	8 (0.7%) (0.36-1.38)	16 (4.0%) (2.50-6.46)	–3.27	.001
Change query only	No change	16 (1.4%) (0.87-2.28)	26 (6.6%) (4.52-9.45)	–3.99	.001
	Change query only	157 (13.8%) (11.95-15.96)	125 (31.6%) (27.18-36.30)	–6.95	<.001
	Change profile only	122 (10.7%) (9.08-12.69)	21 (5.3%) (3.49-7.97)	3.75	<.001
	Change query and profile	107 (9.4%) (7.86-11.27)	42 (10.6%) (7.94-14.03)	–0.66	.51
Change profile only	No change	21 (1.9%) (1.21-2.81)	5 (1.3%) (0.54-2.92)	0.85	.40
	Change query only	103 (9.1%) (7.54-10.89)	24 (6.1%) (4.11-8.86)	2.05	.04
	Change profile only	228 (20.1%) (17.86-22.52)	6 (1.5%) (0.70-3.27)	13.88	<.001
	Change query and profile	74 (6.5%) (5.23-8.11)	15 (3.8%) (2.31-6.15)	2.26	.02
Change query and profile	No change	11 (1.0%) (0.54-1.73)	5 (1.3%) (0.54-2.92)	–0.46	.65
	Change query only	98 (8.6%) (7.14-10.41)	28 (7.1%) (4.94-10.03)	1.02	.31
	Change profile only	69 (6.1%) (4.83-7.62)	13 (3.3%) (1.93-5.53)	2.45	.01
	Change query and profile	74 (6.5%) (5.23-8.11)	29 (7.3%) (5.15 to 10.32)	–0.54	.59

[a] 263 searches were excluded because the next search action was stop searching.

[b] 189 searches were excluded because the next search action was stop searching.

Discussion

Clinicians using the resource-based system appeared to favor a “breadth-first” search strategy, exploring different resources with the same keywords in the query before searching in a specific resource with query reformulations. Clinicians using the task-based system were provided with results from multiple resources in each search and so appeared to favor a “depth-first” search strategy, searching in the same task profile exhaustively with different keyword reformulations in the query before moving to other profiles.

We have previously shown that changes in search engine design and interface were associated with changes in clinical decision velocity, number of search actions undertaken, and ultimate decision outcome [7]. To understand the basis for such differences, we have now looked at the type of actions undertaken by users of two different systems and the sequences of these actions. While it was the intention of the experiment to detect changes in search behavior, our present analysis extends the analytic framework of the original experiments and may thus suffer from being a post hoc explanation of the observed differences. This limitation may readily be addressed by further experiments specifically designed to test for changes in search strategy.

Further study is needed to understand how clinicians assess the results of a search and formulate the next step in their strategy. We have discussed elsewhere that the process of searching can be thought of as a conversation [15] where individuals ask questions of knowledgeable agents (eg, information retrieval systems or people) to help find answers to their questions. Thinking of the interaction with a search engine as a conversation between a human with a question and a search engine with capabilities to help find an answer may help us understand the human behaviors observed in this study.

According to Grice’s conversational maxims [15], (which were originally created to describe the “rules” for effective human conversations), an answer to a question may be inappropriate for a number of reasons. The respondent may be poorly qualified to answer the question (eg, the respondent may be an inappropriate, out of date, or otherwise misleading information source); may misunderstand the question (eg, the query may not be well expressed in terms understandable by the resource); or may reply with unhelpful or irrelevant information (eg, because of poor relevance metrics of the search algorithm). We can speculate that the search actions taken by clinicians are in response to judgments they make about the progress of their “conversation” with the information retrieval system.

One can hypothesize, when clinicians are faced with a choice of several resources with no clear indication of which is the best, they scan multiple resources to gauge the "competence" of each before committing to a detailed conversation with the resource they feel best qualified to help. In contrast, clinicians with a task-based system are simultaneously receiving answers from multiple resources and so should be able to quickly form a view of the overall capabilities of the group of resources being simultaneously searched. Not faced with concerns about the competence of the system they are interacting with, clinicians focus on improving the dialogue with the system. This is done by finding different ways to ask the same question or by changing the question focus if there has been a “misunderstanding.” As a result, this could explain why users of task-based systems conduct fewer searches and consult fewer documents [7], that is, these users may not need to credential the resources they are interacting with in the same way that users of resource-based systems appear to do.

Overall, given the clear differences in the styles of user-system dialogue demonstrated in this study, and the impact of such behavior on the clinical utility of information retrieval systems, discovering ways of optimizing the dialogue between knowledge sources and users seems a productive line of further enquiry.

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Conflicts of Interest

Quick Clinical (QC) was developed by researchers at the Centre for Health Informatics at the University of New South Wales, and the university and some of the authors could benefit from commercial exploitation of QC or its technologies.

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Abbreviations

IVF: in vitro fertilization
SIDS: sudden infant death syndrome

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Original Paper

Perspectives of Family Physicians on Computer-assisted Health-risk Assessments

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Abstract

Background: The firsthand experience of physicians using computer-assisted health-risk assessment is salient for designing practical eHealth solutions.

Objective: The aim of this study was to enhance understanding about computer-assisted health-risk assessments from physicians' perspectives after completion of a trial at a Canadian, urban, multi-doctor, hospital-affiliated family practice clinic.

Methods: A qualitative approach of face-to-face, in-depth, semi-structured interviews was used. All interviews were audio recorded and field notes taken. Analytic induction and constant comparative techniques were used for coding and analyses. Interpretation was facilitated by peer audit and insights gained from the social exchange theoretical perspective.

Results: Ten physicians (seven female and three male) participated in the interviews. Three overarching themes emerged in relation to computer-assisted health-risk assessments: (1) perceived benefits, (2) perceived concerns or challenges, and (3) feasibility. Physicians unanimously acknowledged the potential of computer-assisted health-risk assessments to open dialogue on psychosocial health risks. They also appreciated the general facilitative roles of the tool, such as improving time-efficiency by asking questions on health risks prior to the consultation and triggering patients' self-reflections on the risks. However, in the context of ongoing physician-patient relationships, physicians expressed concerns about the impact of the computer-assisted health-risk assessment tool on visit time, patient readiness to talk about psychosocial issues when the purpose of the visit was different, and the suitability of such risk assessment for all visits to detect new risk information. In terms of feasibility, physicians displayed general acceptance of the risk assessment tool but considered it most feasible for periodic health exams and follow-up visits based on their perceived concerns or challenges and the resources needed to implement such programs. These included clinic level (staff training, space, confidentiality) and organizational level (time, commitment and finances) support.

Conclusions: Participants perceived computer-assisted health-risk assessment as a useful tool in family practice, particularly for identifying psychosocial issues. Physicians displayed a general acceptance of the computer tool and indicated its greater feasibility for periodic health exams and follow-up visits than all visits. Future physician training on psychosocial issues should address physicians' concerns by emphasizing the varying forms of "clinical success" for the management of chronic psychosocial issues. Future research is needed to examine the best ways to implement this program in diverse clinical settings and patient populations.

Trial Registration: ClinicalTrials.gov NCT00385034; http://clinicaltrials.gov/ct2/show/NCT00385034 (Archived by WebCite at http://www.webcitation.org/5pV8AGRgt)

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KEYWORDS

Computer; health; risk assessment; screening; psychosocial; primary care

Introduction

In today's era of eHealth technologies, interactive computer applications are transforming medical practice and empowering health consumers [1,2]. Some of these applications focus on patients to provide them with information, social support, and training in coping skills (eg, Internet kiosks and networking websites), while others focus on clinicians to improve the consistency and quality of care they provide (eg, handheld digital devices with decision-trees on differential diagnosis and treatments). However, the utility of eHealth tools is not limited to use only by patients or providers The recent wave of eHealth innovations attempts to connect patients and clinicians, benefiting both simultaneously. One such example is the computer-assisted health-risk assessment (HRA) where patients complete a computer survey before seeing their clinician. The interactive program then prints an individualized risk report for the clinician and a recommendation sheet for the patient just before the medical consultation. The intention of such computer-assisted health-risk assessment is to facilitate face-to-face consultation with the provider and not to substitute for patient self-care. Computer-assisted health-risk assessments have many advantages including increasing time efficiency, response accuracy, and providing tailored questioning with skip patterns (eg, not asking how many cigarettes one smokes if a respondent is nonsmoker) [3,4]. Further, studies have demonstrated patients' positive attitudes toward its use [5].

Recently, Rhodes et al [6-8] and the authors [9] studied the effectiveness of a multi-risk computer-assisted HRA tool. In these studies, the interactive computer survey was completed by patients using touch-screen technology and included questions on psychosocial risks (alcohol, tobacco and street drug use, sexual health, conflict in relationships, and depression), road and home safety, cardiovascular risks, and sociodemographics. The recommendation sheet for patients provided them with simple language health suggestions and contact numbers of relevant community services. The one-page risk report for physicians indicated the patient's positive responses to the health-risk questions and the community services to which the patient could be referred for the reported risks. These studies, which were randomized trials [6-9], were conduced in an emergency department [6-8] and in family practice [9] settings. The results suggested that computer-assisted HRA improved patient disclosure and physician detection of the risk of partner violence and compromised mental health. For example, in the study conducted in an urban emergency department, the rates of provider detection of partner violence were 14% in the patient group that had completed a computerized screening questionnaire versus 8% in the usual care group (*P*= .07) [8]. In the family practice setting, provider detection of partner violence occurred in 18% of the computer-screened patient group compared with 9% of the usual care group (adjusted relative risk, 2.0; 95% confidence interval [CI] 0.9 - 4.1) [9]. In the same study, provider detection of compromised mental health occurred in 36% of the patients in the computer-screened group compared with 25% of the usual care group (adjusted relative risk, 1.5; 95% CI 1.0 - 2.2).

Thus, computer-assisted health risk assessments provide a positive and salient change in clinical practice because both partner violence and compromised mental health issues remain under detected in routine medical visits [10-17] despite their seriousness and high prevalence [18,19]. Wider incorporation of computer-assisted HRA could facilitate the orientation of health services toward a comprehensive concept of health and well-being. However, the "real life" success of any intervention is contingent upon its acceptance by users and its contextual feasibility.

The aim of this study was to enhance understanding of the attitudes of family physicians toward a computer-assisted HRA after they had used this tool in a randomized controlled trial conducted by the authors [9]. The study site was a multi disciplinary family practice clinic affiliated with a teaching hospital in the inner city of Toronto.

Methods

Study Design

We used a qualitative research approach to develop in-depth understanding about perspectives of physicians [20,21]. Face-to-face, semistructured, in-depth interviews were conducted with family physicians to elicit their perceptions of and experiences with the computer-assisted HRA. As all potential participants worked at the same clinic, individual interviews were preferred over focus groups. This resulted in scheduling of the interviews at times convenient to each participant and ensured participants' confidentiality [22,23]. Physicians were eligible to participate if they had seen at least five patients who had participated in the randomized trial. This purposeful sampling allowed information-richness in relation to the studied phenomenon [24,25]. For an exploratory study with a homogeneous sample, five to eight participants are generally considered sufficient [26,27]. We considered our sample homogeneous because all participants were physicians working at the same clinic, and all had used the computer-assisted health-risk assessment tool. The study procedures were approved by the ethics review boards of the University of Toronto and the hospital with which the family practice clinic where the study took place was affiliated.

Participants

Ten eligible physicians (seven females and three males) participated in the interviews which were conducted between October and November of 2005. The average age of participants was 46 years (range 32-64 years). Participants had been in practice for 16 years on average (range 1-30 years) and reported practicing 30 to 50 hours per week. At the trial site, physicians' weekly number of hours ranged from 16 to 40. Eight of the physicians reported seeing female patients at 50% or more of visits.

Data Collection

All interviews were conducted by the first author at a place and time convenient to the physician.

Participant physicians provided written consent and completed a one-page demographic questionnaire before the interview. No monetary incentives were offered. The interviewer used the principle of "ask, wait, and probe" and a semistructured interview guide with open-ended questions [23]. All interviews were audio recorded and field notes were taken.

The interview guide was constructed jointly by the research team and clinical collaborators (a family physician, a nurse, and a social worker) from the study site. This was informed by our literature review on the modes of inquiry for psychosocial health risks [28-33]. We identified dual barriers for the face-to-face encounter of physicians and patients. Patient barriers included feelings of embarrassment, fear of physician's rejection or reaction, concerns about confidentiality, and lack of physician's direct inquiry [34-36]. Physician barriers included discomfort, fear of patient's negative reactions, lack of time, priority of the acute problem, and lack of familiarity with resources [10-13]. At the same time, computer-assisted HRA was identified as having potential to address many of these barriers on the patient (eg, desire of "direct questioning" by provider in a nonjudgemental manner) and provider side (eg, time efficiency, referral information, and anonymity). This informed the development of topic areas and probes for the interview guide (eg, sensitivity of certain health risks and visit time).

The use of open-ended questions and probes in the guide allowed defining the research area without restraining the expressions of participants [22,23]. The guide was revised after the first two interviews and included four key questions: (1) What do you think of your experience with the computer-assisted HRA? (2) How would you describe its potential across various risks and visits? (3) Would you recommend such computer-assisted HRA in a family practice setting? and (4) What factors are important for its implementation in a family practice setting?

Data Management and Analysis

The interviews with the physicians were taped, transcribed verbatim, and from the transcriptions, Word files were prepared. The techniques of analytic induction and constant comparison were used to code and analyze the transcripts [37]. Analytic induction, originating from Znaniecki's work [38], entails the development of concepts and testing of propositions from the data by a systematic examination of the similarities between various social phenomena (eg, acceptance or rejection) and processes (eg, agent-agent and agent-structure relations) while emphasizing the research context and negative cases that challenge an emerging finding and thus lead to analytical refinement [39,40]. Also, the analytical method of constant comparison, derived from the grounded theory approach [41], was used within and between interviews [42]. Informant statements were compared for thematic and/or conceptual similarities within and between interviews (eg, What do these quotes have in common? What is unique?)

Coding involved collating and analyzing all of the transcribed data related to the emerging themes and concepts informed by our literature review. An initial coding scheme was developed jointly by the research team after all members had read the collected information [43,44]. This initial coding scheme was then applied to the text data by assigning symbols to represent each category. The sorted and coded data was then read and read again by the first and last author to refine the analysis and to control researcher bias [37]. For rigor, attention was directed to the range and diversity of experiences, meanings, and perceptions along with a search for disconfirming evidence. For example: What does this tell about how participants developed their perspectives? How do these relate to each other? How are emerging relationships confirmed or disconfirmed within data?

All participating physicians emphasized the on going nature of their relationship with patients. This prefaced both positive and negative perceptions of physicians with respect to the computer-assisted HRA tool. For interpretation of this two-sided aspect of the tool, we used the lens of social exchange theory [45,46]. This theory has been applied at both micro and macro levels to explore the provider-patient relationship [47-49]. According to this theory, health services are provided through an exchange process in the physician-patient relationship. Patients need the physician's knowledge and competence to restore or maintain their health. Physicians need patients for income, new patient referrals, and the less tangible rewards of compliance, praise, and appreciation. Patients' relative dependency on physicians is influenced by the degree of their trust in physicians while increasing trust in return enhances the social responsibility of physicians. Limited successes in social exchanges give rise to negative emotions (eg, self-depreciation, guilt, anger, or discomfort with others), which act as internal stimuli to avoid recurrence of these emotions. Therefore, a tool which can change the nature of social exchange between physician and patient and/or physician and institution, such as computer-assisted HRA, can be perceived as helpful or not helpful depending on how it influences the exchange and provokes negative or positive emotions. The inclusion of the theoretical lens (ie, social exchange theory in this study) at the time of interpretation augments rigor and trustworthiness of the findings [50]. We also incorporated the technique of peer audit by sharing our findings with the site collaborators whose feedback refined our interpretation, adding credibility [37,50].

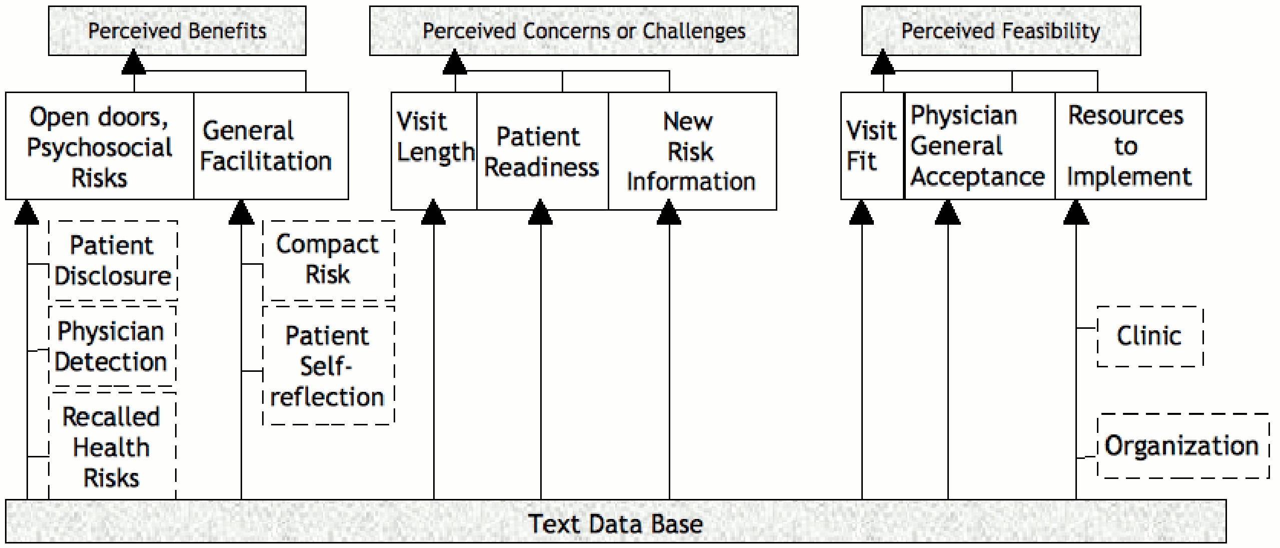
Results

Three overarching themes (Figure 1) emerged in relation to computer-assisted HRA. These were: (1) perceived benefits with subthemes of opening doors for psychosocial risks and general facilitation; (2) perceived concerns or challenges with subthemes of new risk information, patient readiness, and visit length; and (3) feasibility with subthemes of general acceptance, visit fit, and resources. For each theme, we present dominant views as well as provocative dissenting views, where applicable. Representative quotations from the data exemplifying each theme and subtheme are presented in Tables 1 to 3.

Theme 1: Perceived Benefits

Benefits of the computer-assisted HRA emerged as a dominant theme across all physician interviews and included two subthemes. The tool was unanimously perceived to open dialogue on psychosocial health risks. The HRA or screening was also perceived to serve a general facilitative role in providing patient care in a busy clinic environment. We discuss each subtheme and its subcategories (also see Table 1).

Figure 1. Physician in-depth interviews: themes, subthemes, and subcategories



Subtheme: Opening Doors for Psychosocial Risks

All physicians agreed with the potential of the computer-assisted HRA for “opening doors” for discussion on socially sensitive health risks. Physicians’ comprehensive discussions on this sub-theme included three subcategories: types of risks recalled, mechanism of patient disclosure, and mechanism of physician detection.

Physicians recalled having discussions on multiple socially sensitive issues due to the computer generated risk reports. These included risks of partner abuse, depression, safe sex practices, use of street drugs, and alcohol overuse. Physicians discussed the various mechanisms in which the computer-assisted HRA possibly improved patient disclosure and physician detection of the psychosocial risks. They attributed enhanced patient disclosure to the tool characteristics in that it asked specific questions, gave permission to talk, and provided an anonymous and unrushed mode of disclosure. One physician drew a metaphoric similarity between the computer-assisted HRA and a brochure on domestic assault as message conveyers about the readiness of family physicians to address the issue. Physicians attributed their detection of new psychosocial risks to the comprehensiveness of the computer survey while acknowledging they often miss these risks. Some physicians commented that the computer-printed report helped them to initiate conversations on socially sensitive risks in a straightforward manner.

Table 1. Physician perceived benefits of the computer-assisted HRA

Subtheme and Subcategories	Representative Quotations
Opening doors for psychosocial risks	
Recalled health risks	I think screening around issues like mood, depression, and abuse, I think it could be really, really good for that. (Interview # 2, page 4)
Patient disclosure	Often it gives permission that patients might not even answer it correctly initially, but it might open up dialogue in the future. (Interview # 8, page 5)
	When things are a little bit anonymous, I think that people, if they're a bit shy or reticent, will come out with more, particularly if the interview is rushed. I think that's a problem here. (Interview # 7, page 2)
Patient disclosure	Patients don't necessarily think they're medical. I've had a patient who was raped who said to me, "I wasn't sure if I should tell you about this because I wasn't sure if it was a medical problem. Do you deal with this?" And you know, obviously that's a message you want to get out there, is that yes, we do deal with this... So, absolutely any information is good! And I think the reason she did that is that I had a message on the wall about domestic violence. (Interview # 4, page 3)
Physician detection	It allows you to be more comprehensive; or at the very least, allows you to identify things that sometimes in a physical setting or in an appointment, you don't have time to get to. (Interview # 2, page 4)
	Um, well I guess it just gives a starting point to the discussion that you know, "you said here that you used marijuana in the past" and just sort of acknowledging it and then, "how much are you using?" It's just sort of a good starting point. And asking them what they thought of the survey. Was there anything that they learned from the survey? And then they might bring it up. (Interview # 10, page 2)
General facilitation	
Compact risk report	Because it was very compact. So, you got a lot of information right in front of you, without obviously having to ask about all of it. So, you could hone in on the things that needed to be dealt with and that was nice. (Interview # 7, page 2)
Patient self reflection	[When completing computer survey] in the privacy of their own room or waiting room or whatever, they could sit and think about it. And they could change their minds. There is that sort of time for reflection. (Interview # 4, page 5)
	In some instances it made patients aware of problems that they weren't—that were sort of at the back of their minds, that they weren't really aware of. (Interview # 7, page 1)

Subtheme: General Facilitation

Physicians also discussed the general facilitative roles of the computer HRA, particularly its compact time-efficient nature and patients' self-reflections.

Physicians found the one-page risk summary generated from the more comprehensive review especially useful and, in their words, "compact." The one-page summary was said to have saved the physician time to screen for health risks.

Many physicians remarked that the computer survey seemed to enhance patients' self-reflection by asking about several health risks in a private and unrushed manner. They linked patients' heightened self appraisal to their improved risk recognition. Further, most of the physicians described patient reactions as positive, using expressions such as "showed interest," "felt comfortable," "felt more cared for," "analyzed reports [with me]," "wished to be in the computer group," "happy," and "seemed to [have] had benefit from it."

Theme 2: Perceived Concerns or Challenges

Physicians discussed some concerns or challenges in relation to the computer-assisted HRA. Three subthemes emerged: scope of new risk information, patient readiness, and length of visit. Participants expressed both positive and negative stances (Table 2).

Table 2. Physician perceived concerns/challenges of the computer-assisted HRA

Subtheme and Divergent Views	Representative Quotations
New risk information	
Positive stance	Um, it was interesting and in terms of sometimes bringing up topics that wouldn’t have normally come up. Because sometimes that happens in family medicine that you know your patients so well that you don’t necessarily go over the same old ground every visit. And so it would actually bring these things up in a timely manner. (Interview # 4, page 1)
Negative stance	I didn’t have any problem with it. It didn’t really give me any new information that I didn’t already know about my patients...Now it would be very different in a department like emergency where they don’t have that ongoing relationship. Or for a busy physician who perhaps doesn’t talk about psychosocial issues. (Interview # 8, page 1)
Patient readiness	
Positive stance	Some of the things were actually quite, um, quite different in terms of why the patient came in, in terms of what the survey picked up. And so a lot of the time we would acknowledge it and then ask the patient, you know, “did you want to focus on this, or focus on the primary reason” they came in. (Interview # 6, page 1)
Negative stance	To do it when somebody comes in for a sore throat, or blood pressure…I don’t know that that would be the best timing. Mind you, the best timing is, when the patient is ready. (Interview # 9, page 2)
Visit length	
Positive stance	[When] they were in here to discuss their high blood pressure and their diabetes, and there’re no other issues around what we’ve been [given]—the computer survey generated—I did not push it at that point…You’d ask about it, but then say, well maybe you should come back about that. That’s what you’d have to do. Because if they’re in and out and there are five people waiting, it’s not good. I’d probably put it in my notes…to discuss. (Interview # 7, page 4)
Negative stance	There were all these issues that were brought to light, but most of them were over…it did lead to more time with the patient of course…a lot of them were over diagnosis. (Interview # 10, page 1)

Subtheme: New Risk Information

In the randomized controlled trial, eligible patients were recruited without differentiating the purpose of their visit (new patients were not recruited). Some physicians felt that computer-assisted HRA had limited use in generating new risk information for most of their patients because they had seen them for several years and knew their risk profile. In contrast, some physicians shared their surprised detections. One physician was critical of the notion of “knowing the patient” in family practice and emphasized the potential of the patient risk profile to change overtime. This physician remarked, “It would actually bring these things up in a more timely manner.”

Subtheme: Patient Readiness

A few physicians expressed concern about the readiness of patients to discuss the risks which may have been identified by the computer assessment when they were unrelated to the main reason for their visit to the clinic. For example, they remarked that patients coming for acute health problems, such as high fever, may not feel comfortable discussing the computer-reported psychosocial issues.

However, other physicians emphasized the various ways to manage patient hesitation. They discussed the possibilities of noting the patient-reported risks in the chart, offering follow-up visits, or inquiring about a patient’s wish to talk about the reported risk in that particular visit. Comments from these physicians reflected a positive stance as they considered the potential benefits of computer-generated risk reports across many types of visits in the context of ongoing care in family practice.

Subtheme: Visit Length

Contact time with the physician during the health care visits of the trial patients varied from brief (eg, acute care visit) to lengthy (eg, periodic health exam). A few physicians expressed concern about the increase in length of the visit due to the additional task of reviewing the computer generated risk report.

In contrast, other physicians described managing the time pressure by offering follow-up visits or viewed the task of risk review as a professional obligation even if it meant increases in the consultation time. They explained using the option of a follow-up visit in order to avoid “taking time away” from other waiting patients, mirroring the individual- versus collective-responsibility dilemma, discussed below.

Theme 3: Feasibility

The overall feasibility of the computer-assisted HRA in a family practice setting emerged in physician discussions. Three subthemes characterized concerns about feasibility: general acceptance of the tool; the tool’s fit with the visit; and availability of clinical and organizational resources for its implementation (Table 3).

Subtheme: General Acceptance

Physicians accepted the patient administered computer-assisted HRA with varying intensity. Two of the ten participant physicians (20% of sample) were highly enthusiastic about computer-assisted HRA and perceived it as useful for all types of visits. Six of the participant physicians (60% of sample) had moderate acceptance and wished to have more details about the tool’s utility and the results of the trial in which they participated. Two physicians (20% of sample) expressed a conditional acceptance of the tool provided the results are prescreened by a nurse before the physician sees the patients because of the perceived onus on physician time. This pattern is consistent with the “innovation adoption curve” of Roger’s theory of diffusion of innovation [51]. This curve estimates the proportion of adopters as innovators/early adopters (17%), early/late majority (68%), and laggards (16%). Thus, 20% of the participants who were very enthusiastic seem to fit the innovator/early adopter group while 60% with moderate acceptance fit the late majority group of the Roger’s theory.

Table 3. Physician perceived feasibility of the computer-assisted HRA

Subtheme and Subcategories	Representative Quotations
Visit fit	I would say in the annual health exam...Otherwise we’re going to find that the patient’s coming in for something else and we only have fifteen minutes. We don’t have time to deal with it. (Interview # 8, page 6) The right time is when the patient is ready to do it. So, it could be a follow-up visit. It could be a physical. (Interview # 9, page 2)
General acceptance	Oh, absolutely. I think it’s a great idea. I think it’s really good [enthusiastic]. (Interview # 7, page 5) As far as I am concerned, if something like this is to be used as part of the screen, it’s perfectly fine [moderate]. (Interview # 1, page 3)
Resources to Implement	
Clinic (patient flow)	Not interrupting patient flow that much...[l]ike if they know before physical, you have ten minutes allotted for this screen, so come ten minutes early. (Interview # 2, page 3) You’d have to have some allied health professional to do that [explain to patients]. (Interview # 4, page 6)
Clinic (space privacy)	We’re so short on space, I don’t know where we would…and I don’t know that it would be fair for those patients to fill out a survey while they’re in the waiting room. They have to have a private place to do that. (Interview # 9, page 6)
Clinic (information privacy)	How do you house that information? How do you keep that information confidential? What do you do with the information? And how that flows?...it’s something really quite sophisticated...our clinic is a little bit archaic in terms of its record keeping...the only thing, to try to fuse them both together. (Interview # 6, page 3)
Organization (time and money)	Time, time, and time (light laugh). So, I mean the administration of something of this nature. There is a cost involved. (Interview # 1, page 4)
Organization (amalgamation of policies and needs)	Things like addictions in this area are very common. Um, mental health is up there, quite high, in terms of depression, anxiety, abuse. You know, so anything related to the sort of top ten diagnoses. I’m part of the quality steering committee, we look at quality issues in terms of immunizations, pap tests, mammograms, cholesterol screening…so, uh, I guess from an organizational standpoint, it would be nice [to set priorities according to the local needs]. (Interview # 3, page 3)

Subtheme: Visit Fit

When asked about the tool’s potential, all of the physicians considered it most appropriate for the periodic health exam and/or for follow-up visits in a family practice context. However, the reasons for this recommendation varied. Many commented on the need for a fit between the preventive focus of the HRA tool and the main reason of the visit in order to overcome the issues of time constraints and/or patient readiness. Two physicians considered the tool useful across all visits but recommended its use be limited, at least in this early phase of the initiative, to periodic examinations or follow-up visits due to logistical concerns (discussed below). Two physicians also expressed interest in the HRA tool for first-time visits due to its comprehensive and time-efficient nature.

Subtheme: Resources to Implement

When asked about the future implementation of computer-assisted HRA, physicians discussed resources needed at the clinic and organizational levels. At the clinic level, physicians emphasized mobilizing or strengthening the resources to manage patient flow and provide private space and confidentiality to patients. For an appropriate flow of patients, physicians focused on time-efficiency and information-flow by proposing the early arrival of patients and the training of allied health staff to monitor the tool’s administration. Physicians perceived that provision of a private space for patients to complete the computer survey was important due to the sensitivity of risks included in the survey. Likewise, some physicians emphasized the need to ensure patient confidentiality. One physician acknowledged the HRA tool could be a technological challenge for “archaic” practices where computer technology has not yet been introduced

At the organizational level, many physicians emphasized time and money as necessary resources to implement computer-assisted HRA. As a solution, some proposed a model of comprehensive primary care services such as family health teams as feasible sites for implementation of the HRA tool because of the available resources within such settings. Some physicians discussed the need to amalgamate clinical guidelines, organizational priorities, and/or a local risk profile of patients to prioritize the inclusion of health risks in the computer HRA programs.

Discussion

To our knowledge, this is the first in-depth study of physicians’ perceptions and experiences with a computer-assisted HRA program for psychosocial health risks. Participants unanimously acknowledged the potential of the computer for assessing socially sensitive psychosocial health risks. They showed general acceptance of this mode of health-risk assessment and evaluated its utility rigorously in the context of an ongoing physician-patient relationship. Participants viewed the use of computer-assisted HRA as most feasible for periodic health exams and/or follow-up visits in a family practice setting, based on perceived benefits, concerns or challenges, and logistics.

Perceived Benefits

Perceived benefits of the computer-assisted HRA for psychosocial health risks emerged as a dominant, crosscutting theme. Physicians felt the tool improved patient disclosure and physician detection of psychosocial health risks, consistent with recent effectiveness studies [6-9]. Participants also discussed possible underlying mechanisms of this positive aspect. Physicians attributed improved patient disclosure to the tool's specific inquiry about these risks and its anonymity in conjunction with the patients' time for self-reflection. In other words, physicians felt that patients were empowered to disclose and discuss their socially sensitive risks with a higher level of comfort and confidence. This is in accordance with existing research on modes of inquiry [28-31] and "activated patients" [52-55], who receive pre-visit interventions (eg, education about their health risks) to become knowledgeable and willing to discuss their risk status. These activated patients become effective "prompts" for the medical providers, leading to the provision of health preventive and promoting care in medical visits. We have also conducted qualitative interviews with the participant patients to understand their enablement and empowerment; this work is in progress.

In our study, physicians attributed their enhanced detection of patients' psychosocial risks to the consistency and comprehensiveness in risk screening provided by the tool. These findings imply that computer-assisted HRA enhanced the patient-centeredness of the physician-patient interaction [56], an area that needs further exploration. In brief, future use of the tool in a family practice setting could benefit a large number of patients seeking care for multiple health reasons.

Perceived Concerns and Challenges

Some concerns or challenges also emerged in relation to the newness of the risk information generated by the computer program, patient readiness to discuss the reported risks, and the increase in visit time. Few physicians discussed the dilemma of providing adequate care to one versus many patients within limited time. Some physicians proactively managed these challenges by assessing a patient's willingness to discuss the risks, taking notes, and/or setting up follow-up visits. Indeed, strategic management of the perceived barriers is possible in future applications of the tool. For example, physicians should receive comprehensive training on the varying forms of "clinical success" for the management of chronic psychosocial issues so that they don't feel frustrated when dealing with these complex cases in the time constrains of a medical visit. The training program should emphasize various stages of patient-readiness to take an action [57,58] along with motivational interviewing techniques [59,60] and the physician's gatekeeper role of making referrals to other services. Management of psychosocial issues often requires diverse health and social resources [61,62], and physicians need not be the sole providers of care. Also, multidisciplinary models of care and the incentive of billing codes for counseling hold potential to address physicians' time concerns.

Computer Mediated Visits

Physicians perceived the success of computer mediated patient interactions in light of the perceived benefits and concerns or challenges of this type of interaction. Interactions were perceived as successful when patients shared health risk information (they disclosed and were ready to talk) and when the information was new to the physicians and led to the provision of care, provided time was available. The interactions were perceived as partially successful when patients disclosed but were not ready to talk, and/or physicians did not have enough time to adequately deal with the reported risks. Based on Lawler's social exchange theory and related research [63,64], exchanges with low success generate negative emotions, such as frustration leading to low self-efficacy. These internal stimuli in turn lead to motivations to avoid recurrence of negative feelings, consistent with the social cognitive theory [65,66]. Accordingly, physicians in our study sought to reduce the likelihood of partially successful exchanges. Because of the preventive focus of computer-assisted HRA, physicians recommended the use of this tool for periodic health exams and/or follow-up visits where time and patient-readiness were not seen as undermining factors. Also, prevention is a built-in focus of periodic health exams. It seems that system level supportive mechanisms are needed to enhance physicians' confidence in their ability to manage psychosocial health risks [67].

Resources to Implement

Physicians discussed the need for clinic and organization-related resources to implement the use of computer-assisted HRA in the future. At the practice level, physicians emphasized the management of patient flow through early appointments and staff training. Patient privacy and confidentiality were viewed as important for completion of the computer surveys, but lack of space and technological skills were considered logistical limitations. These findings provide practical insights for future initiatives on computer-assisted HRA in a family practice setting and have theoretical implications for advancing understanding about diffusion of innovations [51,68]. At the organization level, physicians pointed toward the need for greater financial support or mitigation of time investment. Indeed, institutional prioritization is salient for health-promotion and disease-prevention orientation in medical settings [69]. Health care service institutions could incorporate effective computer-assisted HRA tools as part of their quality initiatives because of their potential to detect socially-sensitive health risks (eg, poor mental health, partner violence, or substance abuse) in a timely and efficient manner. This could be especially beneficial in assisting vulnerable populations who are exposed to higher risks of psychosocial issues. Thus, from the population health perspective, system level adoption of such programs could play an important role in addressing health inequities.

Participant physicians also wished for the merging of clinical practice guidelines, institutional goals, and local patient needs in the identification of health risks for assessment or screening.

This reflects not only physicians' multiple roles at various levels of health care (individual, institutional, public health) but their desire to have coherence within policies. Lack of consistency in policies across health sectors is often reported as a barrier to timely screening practices [70]. There is a need to actively involve clinicians, public health experts, health care administrators, and policy makers to establish locally tailored coherent screening guidelines.

Future direction for implementation should draw from the tenets of diffusion of innovation theory [51]. For example, early efforts could focus on settings with characteristics of enthusiastic "early adopters" who use the data on an innovation to make their own careful adoption decisions. Their success then creates a domino effect where a larger majority adopts the innovation at a pace quicker than the average.

The emerging eHealth tools can contribute to new models of care by linking clinic care and self care. For example, computer-assisted HRA (augmenting clinic care) could be offered in conjunction with "virtual clinics" and "e-messaging" to patients, supporting self care [71-73]. This evolving area holds potential to improve timely access to health care with fewer errors, leading to patient empowerment and cost savings.

Limitations

Some limitations in the design of our study warrant caution for the interpretation of the results. Participant physicians who volunteered in a randomized controlled trial of the computer-assisted HRA practiced at an inner-city, hospital-affiliated, academic family practice clinic. The views of these physicians may not represent the views of physicians practicing at different sites. The qualitative nature of the study may limit the applicability of results to wider clinical settings. We used several strategies for rigor and trustworthiness (as described in the methods section), such as a jointly agreed upon initial coding-scheme and a theoretical lens along with peer audit for the interpretation. This increases our confidence in the transferability of findings. The data were collected in 2005, but we don't anticipate much change in the studied population. Perhaps patients today are more likely to be acquainted with computer-assisted tools in medical settings or electronic health records than they were five years ago.

Conclusion

Participant physicians perceived computer-assisted HRA as a useful tool in family practice, particularly for the detection and discussion of psychosocial health risks. Physicians displayed a general acceptance of the computer HRA tool and indicated its greater feasibility for periodic health exams and/or follow-up visits than for all visits. Physician training on psychosocial issues should address physicians' concerns about patient readiness and visit time by emphasizing the varying forms of "clinical success" for the management of chronic and complex psychosocial issues. Future research is needed to examine the best ways to implement this program in diverse clinical settings and patient populations. From a public health perspective, computer-based HRA in a family practice could mean timely psychosocial risk identification and access to care for many people.

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Conflicts of Interest

None declared

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Original Paper

Dirt Cheap and Without Prescription: How Susceptible are Young US Consumers to Purchasing Drugs From Rogue Internet Pharmacies?

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Abstract

Background: Websites of many rogue sellers of medications are accessible through links in email spam messages or via web search engines. This study examined how well students enrolled in a U.S. higher education institution could identify clearly unsafe pharmacies.

Objective: The aim is to estimate these health consumers´ vulnerability to fraud by illegitimate Internet pharmacies.

Methods: Two Internet pharmacy websites, created specifically for this study, displayed multiple untrustworthy features modeled after five actual Internet drug sellers which the authors considered to be potentially dangerous to consumers. The websites had none of the safe pharmacy signs and nearly all of the danger signs specified in the Food and Drug Administration´s (FDA´s) guide to consumers. Participants were told that a neighborhood pharmacy charged US$165 for a one-month supply of Beozine, a bogus drug to ensure no pre-existing knowledge. After checking its price at two Internet pharmacies—$37.99 in pharmacy A and $57.60 in pharmacy B—the respondents were asked to indicate if each seller was a good place to buy the drug. Responses came from 1,914 undergraduate students who completed an online eHealth literacy assessment in 2005-2008. Participation rate was 78%.

Results: In response to "On a scale from 0-10, how good is this pharmacy as a place for buying Beozine?" many respondents gave favorable ratings. Specifically, 50% of students who reviewed pharmacy A and 37% of students who reviewed pharmacy B chose a rating above the scale midpoint. When explaining a low drug cost, these raters related it to low operation costs, ad revenue, pressure to lower costs due to comparison shopping, and/or high sales volume. Those who said that pharmacy A or B was "a very bad place" for purchasing the drug (25%), as defined by a score of 1 or less, related low drug cost to lack of regulation, low drug quality, and/or customer information sales. About 16% of students thought that people should be advised to buy cheaper drugs at pharmacies such as these but the majority (62%) suggested that people should be warned against buying drugs from such internet sellers. Over 22% of respondents would recommend pharmacy A to friends and family (10% pharmacy B). One-third of participants supplied online health information to others for decision-making purposes. After controlling for the effects of education, health major, and age, these respondents had significantly worse judgment of Internet pharmacies than those who did not act as information suppliers.

Conclusions: At least a quarter of students, including those in health programs, cannot see multiple signs of danger displayed by rogue Internet pharmacies. Many more are likely to be misled by online sellers that use professional design, veil untrustworthy features, and mimic reputable websites. Online health information consumers would benefit from education initiatives that (1) communicate why it can be dangerous to buy medications online and that (2) develop their information evaluation skills. This study highlights the importance of regulating rogue Internet pharmacies and curbing the danger they pose to consumers.

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KEYWORDS

skill assessment,; health literacy; eHealth; health information skills; Internet pharmacies; counterfeit pharmaceuticals; cyberdrugs; cyberpharmacies

Introduction

In 2007, US adults spent out-of-pocket US $47.6 billion to buy pharmaceutical drugs and an additional US $14.8 billion out-of-pocket to purchase nonvitamin, nonmineral natural products [1]. Even in better economic times, some US patients could not afford pharmaceuticals and resorted to skipping medications, reducing doses, or leaving prescriptions unfilled [2]. A recent downturn in the US economy may have worsened cost-related medication nonadherence, especially among the poorest and the sickest.

Pressed to choose between buying expensive medications and spending on other basic needs, some health consumers go online to search for bargains. They find websites that boast low prices and advertise their readiness to dispense prescription drugs without a valid prescription. Because many of these websites are rogue, consumers are at risk for taking medications that are inappropriate for their health condition and that interact with other drugs they take. In addition, they may be sold unapproved, contaminated, impure, or fake drugs.

As conservatively estimated by the Center for Medicine in the Public Interest, the sales of counterfeit medicines will grow twice as fast as the sales of legitimate pharmaceuticals (13% as compared to 7.5%, annually, 2004 to 2010) [3]. The Internet is a global distribution channel for these fake medicines, but little is known about the extent to which consumers are able to buy medicines online safely. Are consumers evaluating pharmacy websites and paying attention to signs of low credibility, unsupported claims, and violations of privacy? If an illegitimate pharmacy offers prescription medications at a deep discount, how likely are consumers to buy these products? This exploratory study examined the ability of students enrolled in US higher education academic programs to determine the legitimacy of Internet pharmacies. If even college-educated individuals and those with specialized training in health-related sciences are enticed by low price tags and unsubstantiated claims offered by rogue online sellers of prescription drugs, then risks of purchasing drugs online could be even greater for America's most vulnerable, such as less educated patients without prescription drug coverage whose failing health necessitates the use of multiple expensive drugs.

Creation of pharmacy websites coincided with the growth of the number of Internet users. Today, the majority of American adults are using the Internet. In 2008, 74% of adults were Internet users [4]. The rate of Internet use is even higher among younger, more educated individuals and those with higher incomes. Two of the most popular uses of the Internet are to find medical information and access health care research and findings. Although these numbers may be somewhat inflated due to social desirability bias [4], reports have suggested that 83% of American adults who use the Internet (or 61% of adults in the United States) seek health information online [5], and that many of these individuals rely on the Internet as their main source of health information [6]. Studies suggest that consumers use search engines to find health information but do not precisely specify their keywords or limit their searches in any way [7]. Only 15% of individuals seeking health information say they "always" check the sources and date, while an additional 10% stated they do so "most of the time [7]." This may indicate that 85 million Americans get health information without knowing the quality or legitimacy of the information provided [7].

With the increased commerce on the Internet comes increased risk for users. The average user accesses unregulated sites without the necessary skills to discern if these are trustworthy websites or dangerous ones [8]. Therefore, individuals learn about their health conditions from the Internet without knowing if the source is reputable or questionable. Internet users often underestimate the effort and competence required to review and search for trustworthy and credible health information. An uneducated search can lead to a greater risk of making health decisions on the basis of incomplete, out-of-date, or untrustworthy information, and the risk can exponentially increase for individuals with poor overall health literacy and poor eHealth literacy in particular [9].

While searching for health information online, consumers are offered advice about prescription medications, exposed to drug advertisements, and given links to websites that sell medications. Access, convenience, and privacy are potential benefits of Internet pharmacies for the consumer. Internet pharmacies increase access to drugs for those that are disabled or otherwise homebound. They also provide individuals with the convenience of 24-hour shopping, a huge selection of available drugs, and privacy for those who do not wish to discuss their medical conditions with pharmacists [10]. Some proponents of Internet pharmacies claim that paper prescriptions are often poorly written with illegible handwriting, wrong dosages, and inappropriate medications [10]. Proponents further claim that e-prescribing can often avoid these errors and save millions of dollars of health care costs [11].

There are also many concerns and risks associated with Internet pharmacies, most importantly, those related to using the Internet as a means of bypassing the usual regulatory systems [10]. In fact, Bessell and colleagues [12] found that even with tighter standards in many countries, consumers are still at risk for problems when buying nonprescription drugs from Internet pharmacies since balanced information about the medications may not be presented. Those who shop in Internet pharmacies—virtual patients—never meet the doctors or pharmacists who distribute their medications. A buyer can go to an Internet pharmacy online, select a particular prescription, and fill out a questionnaire. This questionnaire might be sent to a physician for approval, but this is not always required. As Besell and others found [12], drug interactions were not detected by the majority of e-pharmacy staff. The prescription is often filled in a location that is completely different from the location of the Internet pharmacy [13].

Many individuals may not have the ability to know what they are getting when they buy drugs online. Consumers are potentially receiving more counterfeit drugs due to large Internet sales (projected at US $75 billion by 2010) [14]. Internet pharmacies can also be seen as a last resort for individuals who are desperate for a cure to serious medical conditions and may be particularly susceptible to false claims [10]. Electronic records of dispensed medications, such as a national register or a personal record, will not be complete unless they include seller information that can be checked to identify rogue pharmacies [15].

Another major issue with Internet pharmacies is the potential for the buyer to purchase illegal substances. In addition to many legitimate Internet pharmacies that prescribe in accordance with local and federal laws, a great number of online operations offer controlled substances without regard for the prevailing national law [9]. In the United States, psychoactive drugs rank second only to marijuana as drugs of abuse, if tobacco and alcohol are discounted [9], while amphetamine-type stimulants are the second most widely used drugs in the world [16]. The Internet plays a significant role in global misuse of these stimulants, permitting uncontrolled dispensing by online pharmacies and providing information on techniques for illicit manufacture [16].

Although the US government has developed regulations and policies to protect its consumers from illegitimate Internet pharmacies, there are many implementation challenges. The biggest challenge stems from trying to regulate US pharmacies that are in offshore locations [17]. Another challenge is the current license status of the prescribing physician in a state other than where the patient receiving the prescription drug resides [17]. Additionally, in those online pharmacies where no physician is involved, patients cease to be patients and instead become consumers able to buy prescription medications (and possibly controlled substances) from anonymous providers offering no ongoing treatment relationship or responsibility for the drugs dispensed [8]. In these situations, regulatory concerns and the patient's health and safety are not often the priority. If complications do arise from these medications, however, individuals return to the traditional medical systems to manage overdoses, addictions, and adverse drug effects and interactions [8] with providers that do not have adequate knowledge of the patient's condition or status.

There are federal efforts underway to protect American citizens who utilize online pharmacies. According to the Food and Drug Administration (FDA), the distribution of controlled substances or dangerous pharmaceuticals without a valid prescription is illegal, and officials have had concerns about the safety of obtaining prescription drugs over the Internet for many years [10]. Their concerns center on the many individuals who may not have the ability to recognize that their purchases may be fraudulent. The FDA warns that drugs purchased over the Internet may be counterfeit or contaminated, the wrong drug, outdated drugs, or incorrect dosages, not to mention the possible ill effects of impure or unknown ingredients found in drugs manufactured in substandard conditions [18]. Web-based prescription monitoring programs help curb drug abuse and are spreading across the US. These programs aim to stop patients from doctor shopping, prescription forgery, and reckless prescribing of controlled substances [11]. At least 33 states have enacted Prescription Drug Monitoring Programs, and many others are considering them [11]. These programs have not been extended to all Internet pharmacies, especially those that are based outside of the US.

Additionally, the FDA encourages that prescription drugs and treatment regimens should be made with the advice of licensed health care providers who have access to the patient's current health status and medical history. Under many of the recent laws, patients must be physically examined by a licensed health care practitioner the first time drugs are prescribed to determine if the drug is appropriate for treatment [10]. When the patient is using an Internet pharmacy, the health care provider is often not involved and cannot perform a physical examination. Therefore, the patient is self-diagnosing. This process also allows a consumer to misrepresent their medical information. Self-diagnosing, information misrepresentation, and lack of involvement of providers have implications for the medical system and doctor-patient relationship. The added burdens are inappropriate self-treatment, use of counterfeit or inaccurately labeled drugs, and adverse interactions with other medications, all of which may delay or complicate proper treatment. Doctor-patient relationship may suffer when patients request inappropriate treatments and misinterpret denials as cost cutting [19]. Another reason for relationship deterioration is physicians' dismissal of questions that patients ask after searching for health information online [20].

Under the federal Food, Drug and Cosmetic Act, the FDA has the legal authority to take action against the importation, sale, or distribution of adulterated or misbranded drugs; the importation, sale, or distribution of approved new drugs; illegal promotion of a drug; the sale or dispensing of a prescription drug without a valid prescription; and counterfeit drugs [10,17]. When the Internet is used for an illegal sale, the FDA, working with the Department of Justice, must establish the same elements of a case, develop the same charges, and take the same actions as it would if another medium, such as a storefront or a clinic, had been used. The FDA has investigated and referred cases for criminal prosecution and initiated civil enforcement actions against online drug sellers [10].

In July 1999, the FDA adopted and implemented the Internet Drug Sales Action Plan to expand and improve the activities of the agency in addressing unlawful sales of drugs over the Internet [10]. The plan includes engaging the public by informing them about safe ways to purchase pharmaceutical products over the Internet; verifying the legitimacy of Internet sites dispensing pharmaceuticals; cooperating internationally with foreign governments; and customizing and expanding enforcement activity by establishing priorities, improving data acquisition, and coordinating case assessment [17]. Since 2000, the FDA has issued numerous cyber letters to online sellers suspected in illegal drug trade and in "promoting dietary supplement products with claims to diagnose, mitigate, treat, cure, or prevent a specific disease or class of diseases [21]."

Additionally, the National Association of Boards of Pharmacy (NABP) has developed a Verified Internet Pharmacy Practice Sites accreditation program and a website to help consumers identify Internet pharmacies that are out of compliance with state and federal laws or do not meet patient safety and pharmacy practice standards (http://www.nabp.net). Still, Palumbo et al [14] have stated that Congress needs to be more involved in curbing illegitimate online pharmacies. At this time, the US government has limited control over foreign Internet pharmacies. The FDA efforts include requesting other foreign governments to take action against the seller of the product, asking US Customs and Border Protection to stop the imported drug at a US port of entry [10], or sending warning letters to online sellers [21].

International cooperation is underway to combat online sales of illegal and counterfeit medicines. Coordinated by INTERPOL and the World Health Organization's (WHO) International Medical Products Anti-Counterfeiting Taskforce, an Internet monitoring operation called Pangea II, focused on key elements of online drug sellers' businesses—the Internet service provider, payment, and delivery. This five-day operation (November 16-20, 2009) involved 24 countries and "revealed 751 websites engaged in illegal activity, including offering controlled or prescription only drugs, 72 of which have now been taken down [22]." The first operation Pangea took place in 2008. It lasted one day and involved 8 countries [23]. Global press coverage of both operations was used to raise consumer awareness about counterfeit medicines.

While it is useful to take down established websites by illegal pharmacies, the online sellers often employ direct-to-consumer advertisement strategies, such as email spam messages with Web links to ephemeral websites. These websites are hard to track due to their transient nature. Gernburd and Jadad studied health spam offers and found that about half of online sellers of health products deactivated their spam links within a week of message delivery and three-quarters deactivated them after one month [24]. The oversight and regulation of ephemeral "cybersellers" who market directly to consumers would require continuous monitoring of email traffic. That is an enormous challenge because most email traffic is spam and because in any given month between 10% and 30% of spam messages fall into the category of health-related spam (higher spikes are possible if rogue sellers see an opportunity to capitalize on a global health issue or piggyback on press coverage, as was the case with H1N1) [24-26].

Given the global nature of the Internet and the challenge of regulating activities that cross national borders, federal efforts may be insufficient to protect US residents who purchase drugs online. Consumer education is likely to play an important role. An example of consumer education is an FDA consumer update titled "The possible Dangers of Buying Medicines Over the Internet [27]." It instructs consumers to look for the following signs of trustworthy pharmacies: a US location, a pharmacy license by the state board of pharmacy, complete contact information (patients can talk to a licensed pharmacist), and a requirement of a prescription from a licensed health care provider for any prescription medicine. The FDA update also lists the following signs that help detect rogue, unsafe pharmacies: no phone contact with pharmacy staff, medicines that are priced much lower than the average market price, an illegal practice of requiring no prescription, and poor protection of consumers' personal information.

This study was designed to gain understanding of how individuals evaluate the websites of two Internet pharmacies that were specifically designed to show many of the unsafe signs and no signs of trustworthiness, as specified by the FDA consumer education materials.

The purpose of the study was to examine health consumers' vulnerability to fraud by rogue Internet pharmacies. Since little is known about consumers' judgment of online pharmacy features, in particular those of illegitimate sellers of prescription medications, this exploratory study is based upon secondary data from a convenience sample—a large group of university students who completed the Research Readiness Self-Assessment (RRSA). A health version of RRSA, an online interactive application, was designed to help information seekers to become effective, independent users of health information from digital (electronic) sources [28]. The assessment was used to obtain objective measures of competencies related to finding and evaluating health information. The evaluation module of the assessment included several questions about online pharmacies. Specifically, the assessment takers were asked to review two pharmacy websites, designed specifically for the purposes of the assessment. The features of these websites were common to websites of illegitimate online pharmacies. Responses by about 2000 individuals who completed the assessment between September 2005 and March 2008 were used to examine the degree to which college-educated information seekers are able to determine the trustworthiness of online pharmacies. The outcomes of this study can provide important insights for policy makers, authorities involved in regulating pharmacy operations, and consumer educators.

Methods

Research Design

Since September 2005, a cross-sectional online assessment titled Research Readiness Self-Assessment, Health Version (RRSA-Health) was administered to students, most of whom were enrolled in introductory health courses at a large Midwestern university. The study was approved by an institutional review board (IRB). The interactive online assessment contained questions about Internet pharmacies specifically designed for this study that showed multiple signs of low credibility.

Focus Population

The findings of this study can be generalized to a population of healthy young adults who are in their early 20s and enrolled in college programs. These individuals have the requisite computer skills related to using email, navigating websites, and conducting basic searchers in popular search engines. Individuals in this age group are among the most active users of the Internet, who are likely to do information searchers for themselves and others, for example, less computer literate family members.

Procedures

RRSA and its Administration

The RRSA is an online assessment of eHealth literacy skills, specifically, those related to finding and evaluating health information from digital sources. It is a combination of an e-survey and an e-test with detailed performance feedback and suggested resources for skill improvement. To complete the RRSA, participants needed basic computer skills that are now acquired at the high school level. The purpose, development, and administration of the RRSA were described in an earlier study by Ivanitskaya et al [28]. Since that publication, RRSA-Health was expanded to include new questions that measured the evaluation of health information, such as questions about a medical doctor's credentials and the credibility of two Internet pharmacies that advertise drug prescription services based on an online questionnaire rather than a physical exam by a doctor. To assess how students would evaluate these online pharmacies, six new items were developed, as well as seven additional items that asked students to explain low drug costs. The addition of new questions lengthened the average completion time from 26 to 37 minutes.

The link to an assessment was given via an email and posted on a course website. In addition, instructors who taught face-to-face courses advertised the RRSA in class. A password was required to register for and then to participate in the assessment. The participants were informed that their participation was voluntary, that the assessment takes about 35 minutes to complete, and that their aggregate data may be used for research purposes. The primary investigator's email address was provided, and the purpose of the study was explained. Access to online respondent data was restricted through a password, an identification of a unique IP address, and a 60-minute time limit.

Development of Rogue Pharmacies and Measures

The two pharmacies featured in the assessment had a large number of untrustworthy features (see Table 1) and no signs of trustworthiness listed in the recent FDA update [18]. Students accessed the two websites by clicking on links provided in the RRSA questions. The pharmacy websites were kept on a local server. Their pages could be navigated by clicking on buttons labeled "home," "contact," "search," "about us," "FAQ," and "disclaimer."

Table 1. Features of online pharmacies used in this study

Feature	Pharmacy A (URL extension: .net)	Pharmacy B (URL extension: .com)
Advertising claims (as they appeared in the source)	"Beozine—US $37.99—now available in a gel!" "No prescription required! Our staff can prescribe medications based on a detailed questionnaire. We would review the information you submit and respond within one hour! Order prescription medications without leaving home! Low low prices!!!! Next-day delivery. World-wide delivery. Easy and secure ordering. FREE medical review with prescription from real doctor. We proudly serve customers who know how to find a good price."	"Beozine retails for US $200, we sell for $59.50!" "Get medications without the hassle, embarrassment, and cost of the doctor's office and pharmacy. Everything is done online and confidentially. 1000s of low cost pharmaceuticals, wholesale pricing, prescription updates, worldwide shipping, private online ordering, and discreet packaging. No need to meet your doctor if your prescription expired. Discount generic drugs, save over 70%. Our competitors can't match our prices! INTEGRITY IS TRULY EVERYTHING!!!!!"
Prescription process	Fill out and submit an online questionnaire. No prescription is required.	Submit a valid prescription by FAX or email (with a scanned prescription attached) or request an updated prescription.
Contact options	Pharmacy's physical address (outside the US), online contact form, and email address.	Pharmacy's physical address (outside the US), toll-free FAX, online contact form, and email address.
Information requested from customers	Name, date of birth, email address, mailing address, detailed insurance information, specific medical problems, all past surgeries, conditions treated with each surgery, all medications they plan to take, and all current medical conditions.	All over-the-counter and prescription medications they are currently taking, the length of time for each, and medications they plan to take in the near future.
Promises and disclaimers	"Any information provided by our customers is never shared, sold, or released to any third party outside of our network of doctors, who need to view the information in order to write and fill a prescription and our network of partners." Customers must agree with a responsibility statement: "All questions asked of me during the medication request have been answered truthfully and completely."	"By requesting this medication the requestor confirms the release of pharmacy and all of its employees and contractors, including doctors, from ANY and ALL liability whatsoever associated or connected with the request for and use of medication. The statements have not been evaluated by the FDA. No advice or product listed here is intended to diagnose, treat, cure, or prevent any disease."
Statements to reassure customers	"Our organization is committed to meeting and exceeding current regulations. We utilize licensed doctors. Our pharmacies are licensed to ship medication worldwide and employ licensed pharmacists to provide you with the highest standards of pharmaceutical care." "Online consultations are the latest concept in health care."	"Rest assured you are receiving the same medication as you would at your neighborhood pharmacy." "As a marketing group primarily involved in membership-based ordering service promotion, we established relationships with the largest pharmaceutical wholesalers. We don't sell any type of medications, we are here just to help members get cheap medications."
Customer testimonials, examples	No testimonials.	"I tried your pharmacy after I read a testimony of a customer who got a new prescription in 15 minutes. I am so happy I did not have to go see an expensive doctor..."

Designed for the health version of the RRSA, the two pharmacies were closely patterned after five actual Internet pharmacies that the first author accessed in 2005 by searching for the phrase "no prescription required" in Yahoo and Google. Researchers who recently studied characteristics of Internet pharmacies reported that 96 of 118 drug sellers did not require a medical prescription [29]. The two websites were designed to show that the pharmacies were located outside of the US. Just like the original sellers, these pharmacies could be contacted by FAX, via email, or by submitting a comment typed into an online textbox. No phone numbers were given to contact a live person. Posted on their websites were misleading statements ("we don't sell any type of medication, we are just here to help members get cheap medications"), suspicious disclaimers ("by requesting this medication the requestor confirms the release of pharmacy and all if its employees and contractors, including doctors, from ANY and ALL liability whatsoever associated or connected with the request for and use of medications"), and unsupported claims ("rest assured that you are receiving the same medication as you would at your neighborhood pharmacy"). Also of concern was the large amount of personal information requested from customers. As promised by pharmacy A, "any information provided by our customers is never shared, sold, or released to any third party outside of our network of doctors, who need to view the information in order to write and fill a prescription and our network of partners." Although crafted as a reassuring statement, the undefined "network of partners" may include nearly anyone. Both websites requested consumers' personal information and provided no phone number to contact their staff. Similar to the original websites on which the two pharmacies were modeled, the online text contained grammatical mistakes and typographical errors. Previous studies demonstrated that surface credibility, defined as attractive design or professional appearance, plays an important role in building consumer's confidence in the website [30,31]. The two pharmacy websites used in this study were designed to display below average surface credibility. Therefore, it is unlikely that many study participants were impressed by the design or appearance of the websites.

Among the measured variables were students' evaluations of the two pharmacies. The students were presented with a scenario: "You have been prescribed the drug Beozine. Your out-of-pocket cost at your neighborhood pharmacy is $165 for a one-month supply of this drug. While searching for cheaper options, you found two online pharmacies. Suppose you have a credit card and do not mind using it online. Click on the line to indicate how good pharmacy [name linked to pharmacy's website] is as a place to buy a drug called Beozine, which costs $165 at your neighborhood pharmacy." The students were then instructed to rate each pharmacy using an electronic visual analog scale (eVAS), designed as an online slider. The slider had 400 possible points located on a "click or drag" scale that ranged from 0 (very bad) to 10 (very good). As a proxy measure of their intent to use the two pharmacies, students were asked to agree or disagree with the following statements, "I would recommend [Pharmacy name] to my friends or family," "people should be advised to buy cheaper drugs in such online pharmacies as these," and "people should be warned against buying cheaper drugs in such online pharmacies as these."

To assess students' interpretations of low drug costs, they were asked to check the most plausible explanation for a lower cost of Beozine in Pharmacy B. Eight choices, such as "few regulations" or "high sales volume," were listed and explained.

Other measured variables were demographics (gender and age) and education (health major, yes or no, and the number of college credits earned to date). Self-reported health was measured using an eVAS where 0 = very poor and 10 = excellent. An Internet-related belief, "The quality of health information found through Web search engines, such as Google or Yahoo, is usually higher than health information in libraries," was also measured with an eVAS with end points marked 0 = strongly disagree and 10 = strongly agree. Finally, there was a measure of health-related Internet behavior, that is, whether an individual had used information from general Internet searches for health decision making for themselves or to help others.

Results

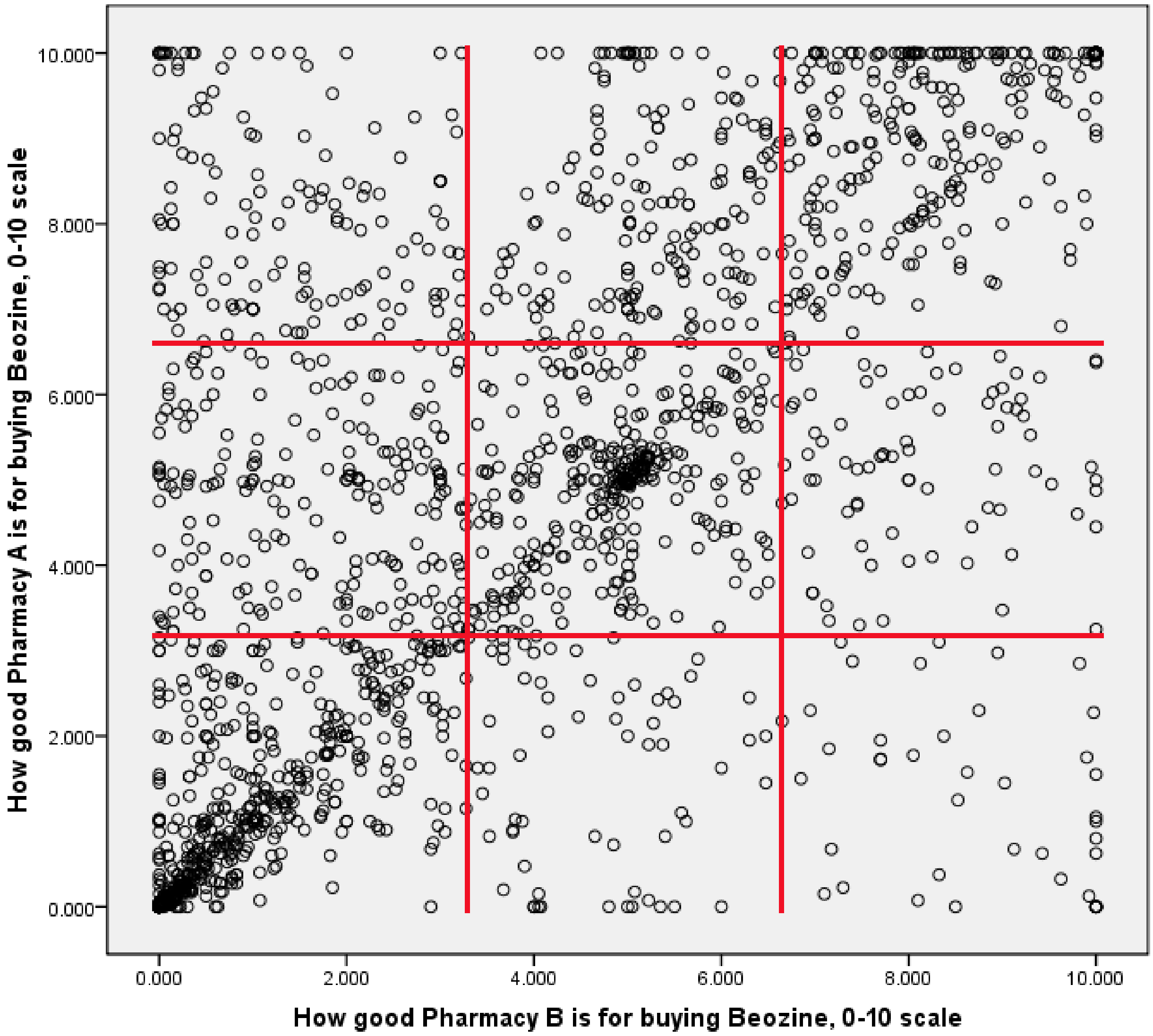
Study Participants

Between September 2005 and March 2008, 2096 students completed the RRSA as an optional educational activity. The participation rate was 78%.The participants were drawn from the population of undergraduate and graduate students enrolled in health-related courses offered by a Midwestern university. Although the study participants came from a variety of graduate and undergraduate programs in health-related sciences, the vast majority of students (75%) were enrolled in an undergraduate healthy lifestyles course. Data from 1914 study participants who took more than 15 minutes to complete the RRSA were used for analyses; 172 records (less than 1%) were excluded due to a short time taken to complete the assessment. Approximately 73% of students were female, 77% were younger than 22 years old, and 44% had selected a health-related field of study as their main academic concentration. Most students (90%) were completing a four-year undergraduate degree, the remainder had earned their bachelor's or master's degrees.

Evaluation of Rogue Pharmacies

In Figure 1, each of the 1914 respondents is designated as a dot, the placement of which is based on how this respondent rated Pharmacy A and Pharmacy B. There was a lot of variation in how the respondents rated pharmacies. Figuratively speaking, respondents' ratings were "all over the map." A visible diagonal line indicates that ratings of Pharmacy A and Pharmacy B were correlated (Pearson's $r = 0.61$, $P < .001$, one-tailed). Students in the top right corner of the graph (15% of all respondents) thought that both pharmacies were great places to buy the drug, whereas students in the bottom left corner were more cautious in their evaluations. The top left triangle has more dots than the bottom right triangle, which means that Pharmacy A was evaluated more favorably than Pharmacy B. Indeed, the median rating for Pharmacy A was 4.95 (mean 4.72, SD 3.23) and the median for Pharmacy B was 3.55 (mean 3.82, SD 3.04).

Figure 1. Scatter plot of respondents’ ratings of Pharmacies A and B (n = 1914)



In Figure 1, red lines divide the scatter plot into nine quadrants based on bottom one-third, middle one-third, and top one-third of the ratings (out of 10) of each pharmacy. Percent of respondents in each cell is presented in Table 2. Only 31% of respondents gave low ratings to both pharmacies.

Of interest is the conditional probability of B=b | A = a, as shown in Table 3. Respondents who rated Pharmacy A low (bottom one-third) would likely rate Pharmacy B low: Probability (B=low|A=low) = .838.

Table 4 shows distributions for study participants’ ratings of the Internet pharmacies. A relatively small number of participants (between 17% and 25%) had highly negative judgments of the two pharmacies as sources for obtaining the drug. About half of the participants (49.8%) provided a positive evaluation of A and over one-third (37.3%) of study participants rated Pharmacy B favorably, as indicated by ratings of five or higher. Students’ perceptions of Internet pharmacies varied greatly, as indicated by a wide range of responses and high standard deviations.

Table 2. Joint and marginal probabilities for respondents’ ratings of online pharmacies (n = 1914)

		Pharmacy B			Total
	Rating range	0 to 3.3	3.3 to 6.7	6.7 to 10	
Pharmacy A	0 to 3.3	31.0%	3.8%	2.2%	37.0%
	3.3 to 6.7	10.4%	17.5%	4.1%	32.0%
	6.7 to 10	7.4%	8.9%	14.7%	31.0%
Total		48.9%	30.1%	21.0%	100.0%

Table 3. Conditional probabilities for respondents' ratings of online pharmacies (n = 1914)

		Pharmacy B			Total
	Rating Range	0 to 3.3	3.3 to 6.7	6.7 to 10	
Pharmacy A	0 to 3.3	83.8%	10.3%	5.9%	100.0%
	3.3 to 6.7	32.5%	54.6%	12.9%	100.0%
	6.7 to 10	23.9%	28.7%	47.4%	100.0%

Table 4. Distributions for respondents' ratings of online pharmacies (n = 1914)

Rating[a]	Cumulative Percent of Respondents	
	Pharmacy A	Pharmacy B
0 up to 1.0	17.7	25.0
1.0 up to 2.0	25.7	35.4
2.0 up to 3.0	32.7	44.7
3.0 up to 4.0	41.0	52.4
4.0 up to 5.0	50.2	62.7
5.0 up to 6.0	63.5	73.8
6.0 up to 7.0	70.3	80.7
7.0 up to 8.0	78.3	86.8
8.0 up to 9.0	86.1	93.5
9.0 up to 10.0	100.0	100.0

[a] Ratings were made on a 0 to 10 electronic visual analog scale with a .025 increment and end points marked as "0 = Very bad" and "10 = Very good."

Over 22% of respondents indicated that they would recommend Pharmacy A to friends and family, as compared to 10% of respondents who would recommend Pharmacy B. While 16% of respondents reported that people should be advised to buy cheaper drugs at these Internet pharmacies, the majority of respondents (62%) suggested that people should be warned against buying drugs at Pharmacy A and Pharmacy B.

Table 5 shows reasons commonly chosen by the study participants to explain why Pharmacy B sells Beozine much cheaper than a local neighborhood pharmacy. Both pharmacies offered drugs at a lower price than a neighborhood pharmacy. To keep the assessment completion time under 40 minutes, participants were asked to explain a cheaper price at only one pharmacy, which displayed a greater number of features that put into question its legitimacy. The majority of participants explained cheaper prices by a lack of regulatory standards with which the pharmacy must comply, followed by the fact that Internet pharmacies' operational costs are lower than operational costs of traditional, neighborhood pharmacies. Other commonly chosen reasons were potentially lower quality of drugs, supplementary revenues from advertising, customer pressures (comparison shopping), higher sales volume, and supplementary revenues from selling information about customers.

Table 5. Respondents' explanations for low cost of Beozine sold by Pharmacy B

Reasons	Percent of Respondents[a]
Negative reasons	
Few regulations: pharmacy B may follow fewer operational guidelines or service standards than neighborhood pharmacies	60.0
Low quality of drugs: pharmacy B may not meet the standards of drug quality that neighborhood pharmacies must meet	47.5
Selling customer information: revenue from information sold to others may be used to lower prices in Pharmacy B	30.0
Neutral reasons	
Low operation costs: it may cost less to operate Pharmacy B (eg, because customers type their own information)	56.7
Advertising: revenue from online ads may be used to lower prices in Pharmacy B	37.1
Comparison shopping: the customers of Pharmacy B may compare prices, demand free shipping, discounts, coupons or other incentives	34.6
High sales volume: more people may buy drugs online than in neighborhood pharmacies, which lowers prices in Pharmacy B	30.3
None of the above	7.5

[a] n = 1914. The sum of percentages exceeds 100% because the respondents could choose more than one reason.

To better understand these responses, reasons for low drug cost were sorted into three categories: (1) negative reasons that have the potential to cause harm to pharmacy customers, (2) neutral reasons, and (3) none of the above. When explaining low cost of Beozine at Pharmacy B, 59% of respondents checked a mix of neutral and negative reasons, 19% of respondents checked only neutral reasons, 14% of respondents checked only negative reasons, and the remaining 8% of respondents checked a "none of the above" option. The more negative reasons a respondent checked, the more likely he or she was to negatively judge Pharmacy B as a place to buy Beozine ($F_{3,1910} = 66.3$, $P < .001$). The number of neutral reasons checked also had a significant relationship with pharmacy ratings but in the opposite direction. Those who checked several neutral reasons for cheap prices were more likely to assign higher ratings to Pharmacy B than those who checked few or no neutral reasons ($F_{4,1909} = 23.4$, $P < .001$).

Next, as a proxy measure of critical judgment, a pharmacy evaluation index was calculated as a mean of five factor scores: (1) ability to recognize negative reasons for low costs of Beozine at Pharmacy B; (2) willingness to recommend Pharmacy A to friends and family; (3) willingness to recommend Pharmacy B to friends and family; (4) rating of Pharmacy A as a place to purchase Beozine; and (5) rating of Pharmacy B as a place to purchase Beozine. The index ranged from 0 to 1 where 0 was "very bad judgment" and 1 was "very good judgment." Each factor score was scaled from 0 to 1 and, if needed, recoded so that higher scores consistently demonstrated better judgment of pharmacies. For example, factors 4 and 5—ratings of pharmacies—were originally scaled 0 to 10 where 10 meant "good place to buy the drug." Any rating between 0 and .999 was recoded as one and any rating between 1 and 10 was recoded as zero. Scaled 0 to 1 with a rating of one representing better judgment, factors 4 and 5 were prepared for inclusion in the pharmacy evaluation index.

Independent-samples *t* tests were conducted to evaluate if individuals who use Internet information for making health decisions demonstrate better critical judgment skills, as indicated by the pharmacy evaluation index. The results were counter to expectations. Study participants who made health decisions using information they found by searching Google or another Internet search engine (n = 762) had a lower mean (SD) score on a pharmacy evaluation index than individuals who did not make such decisions (n = 1,152): 0.61 (0.23) versus 0.65 (0.21). Similarly, individuals who helped another person (eg, a relative or a friend) to make a health decision based on the information they located in Google or another Internet search engine (n = 604) had a lower mean (SD) judgment score of online pharmacies than individuals who did not help others to make such decisions (n = 1310): 0.61 (0.24) versus 0.65 (0.21). Both *t*tests were significant, $t_{1912} = 3.62$, $P < .001$ and $t_{1912} = 3.75$, $P < .001$, respectively. The effect size was small; Cohen's d was .18 for both comparisons.

Predictors of the pharmacy evaluation index were examined using a hierarchical regression analysis. The predictors were demographics (gender and age), education (health major, yes or no, and the number of college credits earned to date), self-reported health, Internet-related beliefs ("The quality of health information found through Web search engines, such as Google or Yahoo, is usually higher than health information in libraries") and Internet behaviors (applying health information found by searching general search engines to health decisions). As can be seen in Table 6, Model 1 took into account demographics, education, and self-reported health. Nearly 5% of the variance in the dependent variable was accounted for by education credits, age, health major, and self-reported health. All of these variables, except self-reported health, were significantly and positively related to the pharmacy evaluation index. Gender was not a significant predictor of pharmacy judgment. Model 2 included the same predictors as Model 1 plus Internet-related beliefs and behaviors. It accounted for a significant yet small (8%) amount of the variance in the pharmacy evaluation index. After controlling for Model 1 predictors, whether an individual used information from general Internet searches for health decision making (for self or to help others) was a significant negative predictor, as well as a belief in the high quality of Internet health information. Together, these variables explained 3% of additional variance in the pharmacy evaluation index. The practical significance of this finding is limited by a small effect size.

Table 6. Summary of hierarchical regression analysis for variables predicting a pharmacy evaluation index (n = 1914)

Variable	Model 1			Model 2		
	B[a]	SE[b]B	Beta[c]	B[a]	SE[b]B	Beta[c]
Age	0.01	0.00	0.09[d]	0.01	0.00	0.10[d]
Gender	0.02	0.01	0.03	0.01	0.01	0.02
College credits earned	0.04	0.01	0.09[d]	0.03	0.01	0.07[d]
Health major	0.02	0.00	0.13[d]	0.01	0.00	0.10[d]
Self-reported health	-0.01	0.00	-0.08[d]	-0.01	0.00	-0.08[d]
Belief in the high quality of Internet health information				-0.03	0.01	-0.06[d]
Made health decisions[e]				-0.02	0.00	-0.17[d]
R^2		.05			.08	
F change for R^2		19.56[d]			34.66[d]	

[a] Unstandardized regression coefficient (uses units unique to each variable)

[b] Standard error of B

[c] Standardized regression coefficient (uses the same units for all variables in the equation)

[d] Significant at the .01 level

[e] Whether an individual used information from general Internet searches for health decision making, for self, or to help others

Discussion

The findings of this study indicate that university students are not making appropriate judgments about health information that is provided on the Internet. The two Internet pharmacies used in this study had multiple untrustworthy features that were borrowed from five actual pharmacy websites that the authors considered to be potentially dangerous to consumers. Yet, almost one-half of the study population rated the Pharmacy A site favorably, while over one-third rated Pharmacy B in a favorable manner. It is interesting to note that some of the participants who gave these rogue pharmacies positive evaluations would not recommend them to family and friends. In fact, 62% of the study population would warn family and friends against using them. Even so, about one quarter of respondents would recommend Pharmacy A to friends and family. An alarming number of college-enrolled respondents (16%) thought that people should be advised to buy cheaper drugs at such Internet pharmacies.

When asked about why Beozine was cheaper at an Internet pharmacy versus the local pharmacy, the respondents checked several explanations. First, 60% of respondents believed that cheaper drugs were due to less regulatory restrictions, as compared to local pharmacies. Perhaps these respondents noticed that Pharmacies A and B were located outside of the US and took this as an indicator, perhaps in conjunction with other untrustworthy features, that these pharmacies might not be compliant with the US laws. An alternative explanation would be that the respondents did not believe that Internet pharmacies could be regulated as well as storefront pharmacies. Future research should continue to monitor the level of consumer awareness of pharmacy standards and accreditation. Do consumers know that all US Internet pharmacies must comply with the same regulations and face the same penalties for non-compliance as storefront pharmacies or clinics [10]? Do they know to look for a Verified Internet Pharmacy Practice Sites (VIPPS) logo that indicates that the pharmacy was accredited by the National Association of Boards of Pharmacy?

Only 30% of the respondents stated the lower drug costs might be due to the Internet pharmacies selling their information to other companies, despite the fact that both pharmacies asked for large amounts of personal customer information. In addition to these information requests, a large number of other features communicated potential danger, such as misleading statements, suspicious disclaimers, unsupported claims, requests for personal information, typographical errors, and no way to contact a live person by phone. But these plentiful signs of danger, absence of credibility markers, and very low drug prices did not arouse consumer suspicion in at least one-third of young people who participated in this study.

Individuals who linked low drug costs to signs of danger (few regulations, low quality of drugs and selling customer information) had more negative evaluations of the Internet pharmacies than those who cited neutral reasons. The actual rogue pharmacy websites we accessed offered their customers multiple neutral reasons, saying that their low prices were a result of high sales volumes, low operation costs, and consumer pressure due to comparison shopping. About 30% of study participants thought that the drugs could be cheaper online due to volume sold. As warned by Palumbo [13], increased sales volumes may not result in lowered drug costs but may result in more counterfeit drugs in the future.

We also examined if those who used Internet information to make health decisions had better judgment skills. It was not the case. In fact, individuals who used general search engines had worse evaluation skills than students who reported more traditional methods for making health decisions. Additionally, it was found that those helping others make informed health decisions using the Internet information had worse judgment than those who did not. In other words, people with worse judgment (controlling for all other variables) are the ones most likely to use information to help others. Perhaps these individuals are more eager to use any information versus quality information. Not very skilled in evaluating the Internet pharmacies, these individuals may then recommend buying drugs to others. This was an interesting finding that was not hypothesized a priori and had a small effect size.

In this study, the evaluation of Internet information was positively correlated with students' age, number of earned college credits, and a health-related major. Therefore, it would be expected that older individuals with more college education should be able to make better judgments about the health information provided online. As compared with younger people, older consumers of information would have had more experience with a wide variety of media—interpersonal communication, TV, radio, print, etc—and might have learned to be cautious. Their folk wisdom that people should not believe everything they see, hear, or read may transfer from old media to new media, even for those with limited Internet experience. It is also likely that any higher education, and especially education in health sciences, serves to improve electronic health literacy skills, such as the skills involved in determining the credibility of health websites. On the other hand, individuals with low literacy and those with less formal education are expected to be susceptible to making a purchase from a rogue Internet pharmacy.

Motivated by high profits from illegal drug sales, creators of rogue Internet pharmacies are likely to employ new, sophisticated ways to lure consumers to their products. For example, when the popular press was covering the price advantage of Canadian pharmacies, a large number of Internet pharmacies, including those not based in Canada, exploited the opportunity to gain consumer trust by presenting themselves as Canadian pharmacies [32]. From this study, it can be determined that many college-educated young people cannot see the signs of danger displayed by rogue Internet pharmacies, and those that have skills and competencies may not use them when viewing Internet pharmacy information. An even greater number of individuals are likely to be misled by seller websites that show fewer signs of untrustworthiness and greater surface credibility—marked by professional Web design, a polished appearance, or attractive graphics—than the websites used in this study.

Suggestions for future study include designing research that can directly test the relationships noted here to find out if these results can be replicated in other settings and populations. Since these findings were not predicted or hypothesized, but found in post-hoc analyses, additional research is warranted to purposefully test these relationships. The RRSA had only a few pharmacy questions that explored a limited number of issues in the population of college students. A more sophisticated design could help to explain some of the presented findings. Using this as a preliminary study, it can be stated that better educated consumers have higher electronic information literacy and better health-related decision making. Another interesting direction for future study is to examine the relationship between consumer attitudes about the enforcement of intellectual property laws and their willingness to buy from rogue Internet pharmacies. How many consumers see small online sellers as a viable alternative to traditional drug distribution channels? Do online shoppers believe that traditional drug distribution channels are tightly controlled by large drug companies that overprice their patented drugs?

It is suggested that a two-tiered approach be utilized for consumers that would include both educational programs and regulatory efforts. Health care professionals, including health educators, need to develop consumer education programs and communication campaigns that explain the variable quality of Web-based health information and that build information evaluation skills and otherwise promote digital media literacy. This study highlighted the importance of making consumers aware of the concerns with medications purchased online and with Internet pharmacies and the importance of explaining to consumers the reasons for very low drug costs and the dangers of self-diagnosis. Further, consumer education is needed about the medications themselves, as Internet pharmacies are often not providing adequate information or education [12]. Because health educators and consumer educators have relatively easy access to young Internet users, these users can be included in pilot tests of new programs developed to educate these individuals about illegitimate pharmacies and to build their health information literacy skills.

From a governmental perspective, the federal system cannot lose sight of the dangers of Internet pharmacies. Although much progress has been made in regard to regulating US Internet pharmacies, there is still much work to be done in regulating foreign pharmacies and curbing the danger they pose to consumers. With improved regulation, international collaboration, and consumer education, there will be an increased assurance of safety for those wishing to utilize Internet pharmacies.

In sum, our findings suggest that at least a quarter of consumers would consider using rogue sellers of medications similar to the ones we used in this study. Many more consumers are likely to be misled by rogue Internet pharmacies that (1) use website designs that appear more professional, (2) better veil their untrustworthy features, and (3) mimic reputable websites to a greater extent than the Internet pharmacies used in this study.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Website of Pharmacy A and Website of Pharmacy B

[PDF file (Adobe PDF), 273 KB - jmir_v12i2e11_app1.pdf]

Multimedia Appendix 2

Video (different formats) that demonstrates interactive web-based questions about Pharmacies A and B and navigation of their websites

[FLA file (Adobe Flash), 668 KB - jmir_v12i2e11_app2.swf] [AVI file (AVI movie), 5200 KB -] [MP4 file (MPEG-4 movie), 1200 KB -]

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Abbreviations

eVAS: electronic visual analog scale
FDA: The US Food and Drug Administration
RRSA: Research Readiness Self-Assessment
VIPPS: Verified Internet Pharmacy Practice Sites

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Letter

The Touro 12-Step: A Systematic Guide to Optimizing Survey Research with Online Discussion Boards

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Abstract

The Internet, in particular discussion boards, can provide a unique opportunity for recruiting participants in online research surveys. Despite its outreach potential, there are significant barriers which can limit its success. Trust, participation, and visibility issues can all hinder the recruitment process; the Touro 12-Step was developed to address these potential hurdles. By following this step-by-step approach, researchers will be able to minimize these pitfalls and maximize their recruitment potential via online discussion boards.

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KEYWORDS

Anabolic Steroids; Internet Research

A Proposed Process for Posting Surveys in Discussion Boards

The Internet, particularly online discussion boards, can be a useful and low cost instrument in recruiting participants for online surveys and data collection [1,2]. Online discussion boards often provide quick access to hundreds or even thousands of participants with similar interests within a relatively short period of time [1]. Furthermore, discussion board users generally encompass diverse geographical (often worldwide) and demographic segments of the study population universe and can be useful in facilitating and streamlining the recruitment process [3,4]. Multiple studies and a review by Krantz and Dalal have shown that web-based data collection and traditional methods (e.g. paper and pencil) result in equivalent conclusions, demonstrating the validity and reliability of online data collection for research [5,6,7,8].

Despite the tremendous potential, recruitment of subjects via online discussion boards may not be an easy task [9,10]. A study by Koo and Skinner describes the struggles in obtaining subjects from online discussion boards including: 1) Survey postings being immediately removed by a board administrator; 2) Messages and survey links being mistaken for “spam,” and 3) Having poor visibility on the discussion forums within a few days of the initial post [9]. As a result, the authors expressed disappointment in the small number of subjects recruited for a study. Presented here are insights and strategies to address these issues. These insights were gained from experience developing a systematic approach to successfully recruit study participants via online discussion boards.

A clinical research team at Touro University-CA College of Pharmacy in Vallejo, CA utilized various bodybuilding, weightlifting, fitness, and anabolic steroid discussion forums to recruit subjects to participate in an online research survey (Touro University-CA IRB# P-0308). Since many of the discussion boards approached require registration to gain access, an informed consent page was created to deal with potential privacy issues, to assure confidentiality and anonymity, and to provide additional information regarding the study [11]. Clearly stated on the informed consent page were the disclosures that no individually identifiable data would be collected, that internet provider (IP) addresses would not be logged, and that all data transfer would be encrypted. After consenting to take part in the study, the strength-trained subject was allowed to start the 99-item survey which queried specific information related to exercise trends, medication utilization, behavior/psychiatric traits, and demographic variables.

Between February and June 2009, the survey was posted on over 50 different discussion boards with varying success. Encountered initially were several limitations resulting in low survey attempt and completion rates. These limitations included: 1) Postings and survey link being quickly removed by website administrators; 2) Lack of initial trust from discussion board members; 3) Lack of enthusiasm by members for participation in a survey with no apparent reward; and 4) Losing visibility of the thread and survey link when it was no longer on the first page of the discussion board forums. After encountering these hurdles during the early phases of enrollment, a systematic step-by-step (12-step) process was developed to improve the popularity and visibility of the survey link on respective sites. This 12-step approach led to a marked increase in survey attempts and completion rates. Using this 12-step method, the link was successfully posted on over 30 individual sites, resulting in over 2,250 survey attempts generated worldwide with over 1,500 individuals (518 admitted anabolic steroid users) completing the survey during a relatively short four-month window (February-June, 2009).

The Touro 12-Step Process

1. Use an internet search engine (e.g. Google.com) to search for websites that have discussion boards which suit your study's topic (e.g. "bodybuilding forums," "weightlifting forums," "steroid discussion boards").
2. When an appropriate website discussion board is found, determine if the discussion board has an adequate number of members/views/activity.
3. Sign up as a member of that discussion board (create a user name and password).
4. Look for a discussion section that is most appropriate to introduce the survey (e.g. "Bodybuilders," "Powerlifting," "Anabolic Steroid Discussion," "Female Bodybuilders").
5. Create a simple yet accurate title for the thread (e.g. "Exercise Study" or "Steroid Survey").
6. Post an introduction thread that explains the research objectives and facilitates feedback/questions from the discussion board users. Include the actual name and credentials of the researcher involved, but avoid using the prefix "Dr." as this may appear less personable. It should be emphasized: *Do not include the research survey link in the first post.* Website moderators and members often do not trust a researcher who is a first-time poster and may even perceive that individual as an outsider or an "intruder," potentially altering the discussion board environment [11]. At best, the thread may be removed—and there is a likely chance that your username and IP address will be permanently banned from the website. It is important to develop a rapport with the website members and administrators before attempting to post the survey link.
7. Subscribe to the created thread so that instant e-mail notification can be received anytime a website member posts a response. Timely responses (ideally within 12-24 hours) are valuable as this demonstrates to other website members the seriousness and willingness to address their concerns.
8. Only post the survey link when support of the discussion board members and moderators has been clearly established. This will increase the chances of having a high participation rate and prevent the survey link from being prematurely removed.
9. Create an active and ongoing discussion. Asking board members questions and soliciting feedback will create enthusiasm about the research topic and survey.
10. As days and weeks transpire, answering posts from members provides two benefits: a) continuing to increase interest in the survey and b) "bumping" or moving the survey thread back to the top of the discussion board (improving visibility of the thread).
11. Be courteous. Thank participants when they make a post stating that they have completed the survey (e.g. "Thanks for supporting our survey!"). Website members appreciate the politeness and just as importantly, the "thank you" post will bring the thread back to the top of the discussion board forum (again improving visibility).
12. Don't go overboard. If there has been no activity or replies on the thread, wait at least 5-10 days before reposting (more frequent attempts to promote the survey may become an annoyance to discussion board members). Some sites may be fine with "bumping" or promoting survey participation more frequently, so pay attention and acquire a feel for the particular forum group. Try to provide value when reposting to move the thread back to the top (e.g. post progress on survey participation or provide an update on reaching the survey recruitment goal). This is especially useful towards the end of data collection to create a strong, final push.

Using the internet, especially online discussion boards, to collect survey data can be very powerful and a cost-efficient tool to promote your research survey. Over 1.5 billion individuals, roughly 23.8% of the world's population, utilize the internet on a regular basis [12]. To help maximize its recruiting potential, it is imperative to recognize and address potential challenges. Keys to success are to find website forums that suit the research needs, to develop a rapport with website members and moderators, to post the survey link at an appropriate time, and to strategically increase the survey link visibility through reposting and responding to website members. Finally, when the results have been compiled and are finally ready to be reported for publication, it is recommended to follow the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) guidelines to ensure quality and thoroughness [13]. By utilizing the Touro 12-Step, researchers may be able to increase recruiting potential with online discussion boards.

Conflicts of Interest

None Declared.

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