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Guest Editorial

Reconciling the Patient's Role in the Improvement of Health Outcomes: Medical Informatics' Newest Frontier

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In this issue of the Journal of Medical Internet Research, the reader is presented with two important studies that focus on the challenges of integrating patient participation and partnership in medical informatics. Both studies address the enormous potential of information technology to effect change in health by influencing patient behavior.

The study by Ross et al is a randomized controlled trial of SPPARO (System Providing Patients Access to Records Online), a patient-accessible electronic patient records (EPR) system implemented at the University of Colorado, measuring its impact on health outcomes and patient satisfaction [1]. SPPARO is one of a handful of organizational EPR patient-access projects with a substantial body of peer-reviewed literature easily available for study. SPPARO shares a common identity paradox with these other systems in that it portends to be patient-centered while employing physician-centered design and evaluation frameworks [2]. It is therefore not surprising that, in their study, patient access has little measurable impact on patient-specific health outcomes.

The SPPARO study also serves to illustrate two key dilemmas facing clinical informatics researchers. In defining the unit of analysis, is "access" the antecedent for change in outcomes, or is it more appropriate to look for some kind of behavioral change, like technology acceptance or actual system utilization [3]? Furthermore, in the short time frame which characterize most studies, how realistic is it to expect the substantial, meaningful changes in patient health behavior that could conceivably promote changes in health outcomes [4]?

The second study by Kim and Johnson observes the contributory role of format on the subsequent accuracy of data entry by patients in personal health records (PHR), and vividly illustrates the most important challenge facing developers: how to make the PHR useful for patients [5]. The interfaces reviewed in this paper are presented with little knowledge of the research behind them. As readers, we never really know if these products faced rigorous usability testing or if they were constructed with knowledge or awareness of health literacy. In fact, it appears as if the interfaces were most likely written in physician language. Does a patient's thinking about disease proceed along the same trajectory as a clinician's thinking without substantial training? Or, should a PHR ideally be constructed from the ground up, emphasizing the patient's perception of illness and disease [6]?

In conclusion, medical informatics research must continuously develop the capacity to demonstrate that information technology can effect positive change for patients [7]. These two studies illustrate the importance of availing ourselves of the knowledge gained in other related fields, and applying it to the challenges of our own field. For example, we should familiarize ourselves with validated models for evaluation that have appeared in the social science, behavioral psychology, and information systems literatures in the last several decades, and adapting them to research questions around the relationship between patient behavior, technology use, and health. As we are presently in an age of shrinking healthcare resources and expanding health expectations, the medical informatics academic community has the responsibility to public health decision-makers, healthcare providers, and patients to expeditiously provide high quality evidence for the value of information technology to improve health [8,9].

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Original Paper

Do the Leading Children's Hospitals have Quality Web Sites? A Description of Children's Hospital Web Sites

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Abstract

Background: Although leading children's hospitals are recognized as preeminent in the provision of health care to children, the quality of their Web sites has not been described.

Objective: To describe technical characteristics of the Web sites of leading children's hospitals.

Methods: This is a cross-sectional descriptive infodemiology study. Two reviewers independently reviewed and analyzed the Web sites of 26 nationally prominent children's hospitals in June 2003, using objective criteria based on accessibility (based on age and language), attribution, completeness, credibility, currency, disclosure, readability, and other technical elements.

Results: One-third of Web sites included content for children and adolescents. Twenty-four (92%) of the Web sites had health and disease-specific information. One-third contained only English, while two-thirds included other languages. All 26 Web sites included a disclaimer, although none had a requirement to read the disclaimer before accessing health and disease specific information. Twenty-four (92%) had search options. Although most (85%) listed a copyright date, only 10% listed the date last updated.

Conclusions: This is the first study to examine the Web sites of leading children's hospitals. Although the Web sites were designed for children's hospitals, only a few sites included content for children and adolescents. Primary care physicians who refer patients to these sites should be aware that many have limited content for children, and should assess them for other limitations, such as inconsistent documentation of disclaimers or failure to show the date of the last Web site update. These Web sites are a potentially useful source of patient information. However, as the public increasingly looks to the Internet for health information, children's hospitals need to keep up with increasingly high standards and demands of health-care consumers.

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KEYWORDS

World Wide Web; Internet; children's hospitals; hospitals; pediatric; health information; quality; quality indicators; health care

Introduction

Although leading children's hospitals are recognized as preeminent in the provision of health care to children, the quality of their Web sites has not been described. Providers may be interested in referring parents and patients to the Internet for pediatric information and may look to the leading children's hospitals as a source. In this paper we seek to describe technical and content characteristics of the Web sites of leading children's hospitals.

The World Wide Web is becoming a popular source of health information for patients [1]. A general rule for selecting an online source for health information is to "find a Web site that has a person, institution or organization in which you already have confidence" [2].

The public and medical providers recognize leading, tertiary care, teaching hospitals as credible sources of information [3]. Many of these institutions include children's hospitals. Because the leading children's hospitals in the United States are commonly held in high regard, a parent or patient might expect that they would also be reasonable sources of online health information. Our findings suggest that such academic Web sites may disappoint [4].

It is not clear if the best children's hospitals that provide high quality care also have Web sites that provide high quality access and content. Although numerous systems for rating the quality of health information on the Internet have been developed [5-8], to our knowledge, there has been no reported evaluation specifically assessing the Web sites of the leading children's hospitals. The criteria used in this study to assess quality involved the domains of accessibility, attribution, credibility, currency, and disclosure, and other Web site elements. The purpose of this paper is to describe the technical characteristics of these Web sites, in terms of quality and content, for the leading children's hospitals.

Our research questions are the following: Do children's hospitals that are considered to provide high quality care also have Web sites that provide high quality access and content? What are the technical characteristics of the Web sites of the leading children's hospitals?

Methods

We conducted a cross-sectional descriptive infodemiology analysis of the Web sites of the prominent children's hospitals in the United States. We selected 26 children's hospitals based on the 2002 *United States News and World Report* and the 2002 *Child* magazine rankings of the leading children's hospitals.

Sample Selection

Although there are many methods for selecting leading medical institutions and children's hospitals, medical providers and the public are influenced by the *United States News and World Report* ranking of "America's Best Hospitals" [9-11]. Another rating system, specific to pediatric hospitals, is published in *Child* magazine. For this study, we selected all 23 hospitals listed as leading children's hospitals from *US News and World Report* and all 10 leading pediatric hospitals from *Child* magazine. Together, these represent 26 distinct Web sites. The Internet addresses of these hospitals were published in the *US News* and *World Report* online. However, as these Web sites were not always specifically referring to the pediatric hospital, but rather to the parent medical center, reviewers searched for the correct address on the parent medical center's site, or by entering the hospital name into Google if a hospital was listed only in *Child* magazine (Table 1).

The *US News and World Report* list has been published and updated every year since 1990, and is the longest running annual ranking of hospital quality [10]. The list also represents a common source for parents when finding medical information on the Internet [11]. *US News and World Report* ranks hospitals in pediatrics based on reputation [12]. The "America's Best Hospitals" methodology was devised in 1993 by the National Opinion Research Center at the University of Chicago [13].

Child magazine has also published a list of leading children's hospitals that are full members of the National Association of Children's Hospitals and Related Institutions. *Child* first selects hospitals that received a score of at least 93 (91 in some circumstances) by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). These hospitals then complete a survey developed by *Child* advisory board members to identify the leading 10 children's hospitals [14].

Although these selected institutions are acknowledged as leaders, their Web sites are not necessarily the most popular (eg, as defined by the number of backlinks or a ranking in search engines such as Google). Our selection method assumes that people who are familiar with the non-Web reputations of these institutions may directly look up these institutions' Web sites, but they may not think critically about whether the sites are as reputable as the institutions themselves.

Two of the researchers (TK, MDC) independently reviewed each Web site using a set of objective criteria pre-determined by the authors. These included criteria in the domains of accessibility, attribution, credibility, currency, and disclosure, and other Web site elements. Specifically, we determined the presence or absence of the following: child-focused content and links for children, bilingual or multilingual content, health or disease specific information, references for medical information, posting of a "last update" and copyright date, an internal search engine, disclaimer and requirement to read it, option to make purchases or donations, and advertisements. For Web sites that included disease-specific information, we selected a basic text passage about asthma, and determined the readability using the Flesch-Kincaid Grade Level method, a commonly used computerized software program for scoring readability that is embedded in Microsoft Word [15].

Eysenbach et al have described five different types of criteria to evaluate the quality of a Web site [16]. These include technical characteristics, readability, design, accuracy, and completeness. To evaluate the Web sites, we included technical characteristics, readability, and completeness criteria. We did not include criteria based on Web site design, since previous studies have reported kappa scores of only 0.08 and 0.23 [16]. In addition, design criteria might not be valid for an analysis of these Web sites, since the pages might be designed for children. Since not all the Web sites offered disease-specific information, we did not include criteria for accuracy.

Data were abstracted from June 1, 2003 to June 30, 2003. Differences in classification were resolved by another reviewer (KLW or BR). We calculated kappa statistics for the dichotomous categories to describe the agreement in the initial classification of each of the characteristics. Simple counts and descriptive statistics are presented to describe the frequency of these characteristics on each hospital's Web site.

The hospital rankings from *US News and World Report* (n=23 hospitals) and from *Child* magazine (n=10 hospitals) are listed in Table 1, along with their Internet addresses. Combined, the two lists included a total of 26 hospitals. Seven hospitals

appeared on both lists. All 26 leading hospitals in the initial sample had Web sites specific to pediatrics or to the children's hospital.

Table 1. Leading Hospital Web Sites Included in Analysis

Hospital	Web Site Address as Listed By US News*	Pediatric or Children's Hospital Web Site Address*
Children's Hospital Boston	childrenshospital.org	Same
Children's Hospital of Philadelphia	chop.edu	Same
Johns Hopkins Hospital	hopkinsmedicine.org	Hopkinschildrens.org
Children's Hospital, Denver	tchden.org	Same, also thechildrenshospital.org
Children's Hospital of NY Presbyterian	nyp.org	childrensnyp.org
Children's Hospital of Pittsburgh	chp.edu	Same
University Hospitals of Cleveland	uhhs.com	rainbowbabies.org
Texas Children's Hospital, Houston	txchildrens.org	Same
Children's Hospital Medical Center, Cincinnati	cincinnatichildrens.org	Same
Children's Memorial Hospital, Chicago	childrensmemorial.org	Same
Children's Hospital, Los Angeles	childrenshospitalla.org	Same
University of California, San Francisco Medical Center	ucsfhealth.org	ucsfhealth.org/childrens/index.html
UCLA (Mattel Children's Center)	healthcare.ucla.edu	peds.ucla.edu
Massachusetts General Hospital	mgh.harvard.edu	massgeneral.org/mghfc/
Lucile Packard Children's Hospital (Stanford)	stanfordhospital.org	lpch.org
Mayo Clinic	mayo.edu	mayo.edu/pediatrics-rst/
Children's National Medical Center, DC	dcchildrens.com	Same
Children's Hospital and Medical Center, Seattle	seattlechildrens.org	Same
Duke University Medical Center	dukehealth.org	dukehealth.org/health_services/childrens_health.asp
Miami Children's Hospital	mch.org	Same
Yale-New Haven Hospital	ynhh.org	ynhh.org/ynhch/ynhch.html
University of Michigan Hospitals	med.umich.edu	med.umich.edu/mott
St. Christopher's Hospital, Philadelphia	stchristophershospital.com	Same
St Louis Children's Hospital	n/a	stlouischildrens.org
Children's Mercy Hospital, Kansas City	n/a	childrens-mercy.org
Primary Children's Medical Center, Salt Lake City	n/a	ihc.com/xp/ihc/primary

* all addresses in this table have URLs (Uniform Resource Locators) prefixed with http//:www(HyperText Transfer Protocol; World Wide Web). n/a = not applicable, ie, the hospital was only listed in *Child* magazine, which did not list the URL

Characteristics of the Web sites are listed in Table 2. All 26 Web sites included a disclaimer and/or privacy policy and/or terms of use. Twenty-four (92%) of the Web sites contained health and disease-specific information. None of the sites required the user to log in before reading health and disease-specific information. None of the sites included a requirement to read a disclaimer before accessing their health and disease-specific information. Twenty-four (92%) of the Web sites had search options.

We measured accessibility of the Web sites for children, based on whether or not the Web site included information for children or recommended links. Although the Web sites were designed for children's hospitals, only one-third included content for children and adolescents. Accessibility was also examined with regard to multilingual content. One-third of the Web sites contained only English, while two-thirds included other languages.

In terms of completeness, 92% provided health or disease-specific information. Two-thirds (65%) provided additional or recommended Web sites. With respect to technical features, 92% of the sites allowed the user the option of searching the site.

All the sites offered a disclaimer and/or privacy policy. Although most Web sites (85%) listed a copyright date, fewer than 10% (2 hospitals) listed the date of the last Web site update.

All Web sites provided information about making a donation to the hospital; however, only one site (4%) had advertisements for organizations or companies other than the hospital itself [4].

Kappa statistic calculations revealed that the agreement between the two reviewers exceeded expected agreement for all variables assessed. Kappa ranged from 0.24 to 1.00.

Table 2. Characteristics of Web Sites for the Leading Children's Hospitals

Domain:	Does the Web site have	n (%)	K*
Accessibility (children)	content for children (educational or non-educational games)?	10 (38.5)	0.53
Accessibility (children)	recommended links for children?	9 (34.6)	0.49
Accessibility (teens)	recommended links or content for teens?	10 (38.5)	0.65
Accessibility (language)	English language only (no other languages)?	9 (34.6)	0.24
Attribution, Completeness	recommended links or resources for more information?	17 (65.4)	0.35
Completeness	Health or disease specific info?	24 (92.3)	0.34
Credibility, Conflict of Interest	purchase or donation option?	26 (100)	1.00
Credibility, Conflict of interest	advertisements other than for hospital itself?	1 (3.9)	0.47
Currency	copyright date on main (home) page?	22 (84.6)	0.90
Currency	has date last updated on main (home) page?	2(7.7)	0.34
Disclosure	disclaimer, privacy policy, or terms of use?	26 (100)	1.00
Disclosure, Accessibility	requirement to read disclaimer prior to accessing health information?	0 (0)	n/a
Disclosure, Accessibility	requirement to log in prior to accessing health information?	0 (0)	n/a
Readability	8th grade or lower readability for disease specific info (asthma)?	8 of 21 (38.1)	n/a
Technical Features	search option?	24 (92.3)	1.00
Technical Features	option to email child or join an online community?	14 (53.8)	0.45

* Kappa score, reflecting the agreement between the two raters. 1.0 represents perfect agreement.

Discussion

Main findings

This is the first study to examine the Web sites of the leading children's hospitals. Although all the commonly recognized leading children's hospitals have their own Web sites, style and content vary. Many of the Web sites lacked information for children. We also found that access to many sites was limited by the reading level and the language(s) in which the information was offered. In addition, although many had disease-specific information, the currency of such information was not described.

Given increasing use of the Internet as a source for health information by parents and patients [1], we expected that most of the Web sites for the leading children's hospitals would include pediatric health information, especially educational content intended specifically for children. However, this study shows that although the Web sites created by hospitals are dedicated to children, only one-third have information specifically for such an audience. Internet users with children (ie, parents), and pediatric providers who refer children to these sites for educational content would be disappointed by most of the sites.

In addition to being a useful and trusted source of patient information, these sites can easily guide and potentially link the parent or patient to information about a specialist at the hospital. As a result, children's hospitals are in a unique position to provide disease-specific information on the Internet, and theoretically may be more useful to health-care consumers than government sites (eg, Centers for Disease Control and Prevention or the National Institutes of Health) or private organization sites (eg, the American Lung Association), which traditionally do not contain links to providers or centers for care. By recommending high quality Web sites, pediatricians and other providers can assist parents and patients in becoming more involved in their own care and in learning about their health [17].

However, providing disease-specific information requires that such information be updated regularly. One reason leading children's hospitals might be considered "top" is because they remain current, on the cutting edge of medical research and technology. Because Web sites can easily be updated, users probably assume that information on the Internet is up-to-date [8].

Yet as the results of this study show, fewer than 10% of the Web sites of the leading children's hospitals assessed in this study posted the date the site was last updated on their home pages. It is not clear to the Web site audience how current the information is. Out-of-date information can contribute to inaccurate patient information. For example, McClung reviewed Internet sources regarding the treatment of childhood diarrhea and found that only 20% of sites, including those of traditional medical institutions, had information consistent with the most recent American Academy of Pediatrics guidelines for the management of acute diarrhea [18]. Web sites should post the date of the most recent update.

Given ethical concerns and legal regulations about Internet usage as it relates to health-care services [19-22], it was expected that all sites would include a disclaimer, privacy policy, and/or terms of usage. Yet, while some sites prompted the user to "read this disclaimer first," none required that the user read or view the disclaimer in order to gain access to the information on the Web site. Disclaimers and terms of use contain important cautions regarding the limitations of the information on a Web site, stating, for example, that it does not substitute for a physician visit or that the Web site is intended only for physician use. It has yet to be determined whether users actually read disclaimers if not compelled to do so. If they do not read the disclaimer, Web site visitors may misuse the information and could put themselves at risk by not seeking care from a health professional. While a prior evaluation of reported cases of harm associated with the use of Internet-based health information yielded just a few reported cases of harm, this finding could be due to a true low risk, underreporting, or bias [23]. Yet, a one-time prompt on the Web site would be a reasonable way to promote reading of the disclaimer without placing an undue burden on the user.

Accessibility of the Web site was also measured in terms of language. The children's hospitals we surveyed were from different parts of the country, with different populations to serve. Although we only considered Web sites from the leading children's hospitals in the United States where English is the primary language, two-thirds of the Web sites did include languages other than English. This is a commendable effort on the part of the hospitals to reach out to their non-English-speaking patients. The differences in language availability may reflect the differences in the population of patients served by each hospital.

Limitations

There are several limitations to this study. Although most of the Web sites in this study contain health and disease-specific information, we did not evaluate the accuracy of this information. Not all sites contained disease-specific information, and some of the sites had disease-specific content that did not differ from content on other sites, as it was purchased from a third party. Nonetheless, future investigation of disease-specific content would be necessary to evaluate on this criterion.

In addition, the low kappa scores for certain variables in this study may relate to Web site design. Because we were evaluating Web sites as opposed to specific Web pages, the range in kappas may reflect the differences in the ability to find the specific information among the different Web pages at one hospital Web site.

Another limitation of this study is that, although we evaluated the Web sites whose target audience is public, this was not a natural experiment using actual consumers of Internet-based pediatric health information. Further research can clarify how parents, for example, use the Internet for health information.

There are many criteria upon which a Web site can be evaluated. Our study did not ask whether sites had "contact us" information, which would attest to the accountability of the site. In addition, information on Web team composition would assist the user in learning who specifically authored the site. Although we did not include all the possible domains upon which a Web site can be evaluated, we chose several that are relevant to the pediatric community as well as those that are commonly employed in literature reports of Web site evaluation [5-8].

Conclusion

This is the first study to examine the Web sites of the leading children's hospitals. Surprisingly, only one-third had links or content for either children or adolescents. All had disclaimers but none required users to read the disclaimer. Almost all of the Web sites contained health and disease-specific information, and many had multilingual information on their sites. The Web sites of the leading children's hospitals are a potentially useful source of patient information for primary care physicians to offer to their patients. However, this study indicates that the current Web sites of children's hospitals have several limitations.

This study suggests methods to improve Web sites for children's hospitals. Specifically, those responsible for such Web sites could provide educational content for children or provide quality links, as well as improve the readability levels of their content. In terms of technical features, Web sites should describe and maintain the currency of the information on their sites, and maintain appropriate disclaimers with adequate prompting of users to read such disclaimers. Finally, based on the population that the children's hospital serves, the Web site should provide reasonable multilingual options.

For providers interested in referring parents and patients to the Internet for pediatric information, this study demonstrates variability with respect to the leading children's hospital Web sites. These sites could be potential sources of additional information and patient education; however, providers should examine the extent that the Web sites they recommend meet the above quality criteria. As the public increasingly looks to the Internet for more health information, children's hospitals need to keep up with the increasing standards and demands of health-care consumers.

Conflicts of Interest

The authors are either employed by or students at two of the children's hospitals discussed in the current study.

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Viewpoint

Setting the Public Agenda for Online Health Search: A White Paper and Action Agenda

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Abstract

Background: Searches for health information are among the most common reasons that consumers use the Internet. Both consumers and quality experts have raised concerns about the quality of information on the Web and the ability of consumers to find accurate information that meets their needs.

Objective: To produce a national stakeholder-driven agenda for research, technical improvements, and education that will improve the results of consumer searches for health information on the Internet.

Methods: URAC, a national accreditation organization, and Consumer WebWatch (CWW), a project of Consumers Union (a consumer advocacy organization), conducted a review of factors influencing the results of online health searches. The organizations convened two stakeholder groups of consumers, quality experts, search engine experts, researchers, health-care providers, informatics specialists, and others. Meeting participants reviewed existing information and developed recommendations for improving the results of online consumer searches for health information. Participants were not asked to vote on or endorse the recommendations. Our working definition of a quality Web site was one that contained accurate, reliable, and complete information.

Results: The Internet has greatly improved access to health information for consumers. There is great variation in how consumers seek information via the Internet, and in how successful they are in searching for health information. Further, there is variation among Web sites, both in quality and accessibility. Many Web site features affect the capability of search engines to find and index them.

Conclusions: Research is needed to define quality elements of Web sites that could be retrieved by search engines and understand how to meet the needs of different types of searchers. Technological research should seek to develop more sophisticated approaches for tagging information, and to develop searches that "learn" from consumer behavior. Finally, education initiatives are needed to help consumers search more effectively and to help them critically evaluate the information they find.

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KEYWORDS

eHealth; Internet; information management; health services research; quality of health care; consumer participation; patient education

Introduction

Searches for health information are among the most common reasons that consumers use the Internet. The Pew Internet & American Life Project (Pew) reported in 2003 that 80% of Americans with Internet access have used the Web to get health or medical information [1]. The Internet has transformed the ability of consumers to find health information and to connect with other individuals with similar interests. The Internet has been recognized as an important source of health information by the federal government, which established a series of goals relating to access and quality of information on the Internet in the Healthy People 2010 action plan [2].

Health information on the Internet can dramatically improve consumers' health-care and lifestyle choices. However, increased access to Web-based information has also raised concerns about the quality of information consumers are using, and the impact of this information [3]. Disparities in access to information have also become apparent. These factors suggest the need to better understand how consumers find health information on the Web, how to evaluate the quality of information retrieved, and how to help consumers to critically evaluate and manage information. These factors suggest the need to better understand how consumers find health information on the Web, how they evaluate the quality of information retrieved, and how to they could be helped to critically evaluate and manage information.

Research on health Web sites raised concerns about the quality of information on the Web [4]. A 2001 study by RAND for the California Healthcare Foundation showed that information on health Web sites is often incomplete or out of date [5]. This might be of little concern if consumers routinely consulted health-care professionals about the information. However, Pew found that 69% of consumers did not discuss the information they found with a doctor or nurse.

Many people use search engines to find the information they use to help make personal health decisions. Search engines and the Internet have vastly improved access to health information for many consumers. However, search processes and results vary considerably among search engines, and are not transparent to consumers. The criteria used to identify and rank health-related Web sites vary among search engines, and often is not apparent to consumers. Search results may be affected by the structure of content on health Web sites, consumer search terminology, and the use of paid placements by the search engine.

In short, research on health searches suggests that the process by which consumers locate health information on the Internet, and the evaluations they make regarding which Web sites to review are important variables in the quality of information they ultimately view and use. Improved understanding of factors influencing online searches will facilitate technical and educational approaches for maximizing quality and benefit of health searches.

Methods

In 2003, URAC and Consumer WebWatch (CWW), a project of Consumers Union, carried out a project funded by the Robert Wood Johnson Foundation to examine factors influencing the results of online health searches and to develop an agenda for future research and development that would improve the results of health searches. We reviewed published literature and industry reports, and convened two stakeholder groups consisting of consumers, quality experts, search engine experts, researchers, health-care providers, informatics specialists and others.

Literature Review Method

Our literature review was not exhaustive: its purpose was to provide a baseline understanding of consumer, Web site, quality measurement, and search engine factors that influence the results of searches for health information. We conducted a search of key terms in the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline, PubMed, Expanded Academic ASAP, Lexis-Nexis, Proquest, Ingenta, and related databases in health care, information science, and computer science. The initial searches took place in early 2003, but citations were added as they were identified.

Where initial searches revealed poor topic coverage, associated reference lists, books and other media that were considered to inform the topic were included. The following search terms were included: Web-based, Web site, information quality, Web search, consumer health, eHealth, health information, search engine, information retrieval, information seeking. We also examined bibliographies of articles retrieved by electronic searches and solicited recommendations from members of the project advisory committee. We discontinued searching in specific topic areas when project staff believed we had adequately described current understanding of key issue areas.

Methods for Convening Stakeholder Meetings

An open announcement about the project and recommendations from industry leaders helped identify interested stakeholders, and participants were selected by URAC and CWW with guidance from a project advisory committee. Not everyone invited was available to attend. We attempted to achieve a balance of different stakeholders at each meeting. Meetings were held in California and Washington, DC to facilitate participation.

The purpose of each stakeholder meeting was to review existing knowledge about results of consumer searches for health information, and to develop recommendations for additional research, technical improvements, and educational approaches needed to improve the results of online consumer searches for health information. Participants reviewed the summary recommendations presented in this article after the meeting and had the opportunity to comment, but were not asked to vote on or endorse the recommendations.

For the purposes of this project, we assumed that most searchers would prefer information that is accurate and reliable. These attributes are also components of effective health communication [2]. This was our working definition for quality Web sites. The perception of other elements that might be used to define quality, such as the site's reading level and comprehensiveness, will vary depending on the user and the user's needs at a given time.

Results

Results of Literature Review

How Consumers Use the Internet to Locate Health Information

An April 2003 report from the Pew Internet & American Life (Pew) report provided an overview of the US Internet consumer population [6]. The study found that Internet access has grown across-the-board, but that demographic gaps remain. A variety of factors continue to separate Internet users from non-users. Internet users tend to be younger and more affluent, and are

more likely to be employed, white, well-educated, and to be suburban or urban residents.

Pew noted that consumers often overestimate their knowledge of the Internet and their ability to locate information. A 2002 analysis by Houston et al using Pew data noted a need to educate patients about searching for health information online and for tools to help them identify high quality information [7]. They also found that chronically ill Internet users were often relatively new to the Internet, but noted that they were more likely than those in good health to discuss findings with their physicians.

Consumer Search Strategies

A 2002 Pew Internet & American Life Project poll found that the typical health-information seeker usually starts searching for medical information at a general search site, not a medical site. Eighty-one percent of online health seekers start at a search engine or use the search function of a general portal such as the Yahoo home page, MSN, or AOL. Consumers visit two to five sites during an average visit and typically spend at least thirty minutes on a search [8].

Several studies have investigated behaviors consumers exhibit in retrieving and health information on the Internet and in assessing its quality. Eysenbach and Köhler, examining Web searchers in Germany, found that although search technique was often suboptimal, Internet users found the health information they were looking for relatively quickly [9]. A search optimization firm, iProspect, reports that users generally use the same search engine for all types of search requests. Users look at up to three pages of search results to determine relevance, and abandon a search if they do not find appropriate results in the first three pages. Users usually modify their query after abandoning an initial search, and may at that point change search engines [10]. These findings illustrate the importance of search engines to the process of retrieving health information. They imply a business rationale for search engines to ensure that health searchers locate what they want, since they may otherwise lose search traffic.

Comprehension, Literacy, and Access Issues

Searches are heavily influenced by the search terms used, even when the terms used are considered to be synonyms. Use of lay terminology for a health subject can result in unrelated or misleading information [11]. Berland et al concluded that accessing health information using search engines and simple search terms was not efficient because Web sites are inconsistent in their provision of key information, and because high reading levels are required to comprehend Web-based health information [4]. Also, the relevance of information located was often of limited value, which may have been due to terminology used in the original search phrase. Non-English speakers face challenges finding and reviewing information on the Internet. One Internet accessibility study for people with disabilities found that there are significant access barriers. Governmental and educational health-information Web sites were more accessible than other categories, such as Web portals and community sites [12].

Physician Responses to Internet Information

A study of physician views on online information found that physicians increasingly encounter patients who have conducted health searches. Use of the Internet by patients does appear to affect treatment processes: for example, many physicians reported having changed the treatment protocols they had initially planned as a result of consumer requests. Although most physicians believe the information their patients find is accurate, many believe that having to discuss this information with their patients decreases their efficiency and challenges their authority. Some are also concerned that the information may be inaccurate. The study concluded that quality of information on the Internet is critical, as it does influence both patient requests and physician treatment choices [13]. In an effort to steer patients to credible Web sites, some health-care organizations have begun to suggest ("prescribe") credible Web sites to their patients in the course of their consultations [14].

Consumer Evaluation of Web Site Credibility

Experts and consumers use different criteria for evaluating the quality of Web sites. Eysenbach found that consumers assessing the credibility of a Web site primarily looked for the source, a professional design, a scientific or official touch, language, and ease of use. Study participants never checked any "about us" sections of Web sites, disclaimers, or disclosure statements. Very few participants noticed and remembered which Web sites visited [9]. A Consumer WebWatch (CWW) study of consumers reported findings similar to Eysenbach's: once people get to a site, they do not use rigorous criteria to assess the site's credibility. For example, they almost never referred to a site's privacy policy. The average consumer paid far more attention to the superficial aspects of a site, such as visual cues, than to its content. Nearly half of all consumers in the CWW study assessed the credibility of sites based in part on the appeal of the overall visual design, including layout, typography, font size, and color schemes. In comparison, a parallel group of health and finance experts were far less concerned about the surface aspects of these industry-specific types of sites and more concerned about the breadth, depth, and quality of a site's information [15].

How Web Sites Influence Availability of Quality Health Information

Techniques for Conveying Information about Web Site Content

The structure of a Web site influences how information can be retrieved from the site by a search engine, as well as the usability of the site for consumers. Coding and structure of Web sites can facilitate retrieval by search engines or can pose a barrier to information retrieval. Coded information on a Web site is processed through the search engine algorithm, and determines whether and how the site is ranked in search returns. The same tags and codes that can be used to highlight information on a legitimate Web site may also be used by "spoofers" who try to lure traffic onto the site.

In general, Web sites can support retrieval of information on their pages by using metadata, metatags and keywords to guide search crawlers to important content. These codes provide a

means for relaying information directly to the search engine. Keywords are recognized indicators of specific services or products that can be used to increase specificity of searches and help Web sites attract "qualified" traffic. One strategy for enhancing search rankings of quality Web sites is to code certain types of information for consistent retrieval by the search engine. Efforts are under way to implement metadata codes to support a "semantic Web." The semantic Web uses code to establish relationships between words to enable search engines to effectively understand intent, rather than simply identifying the presence of a search term [16].

Quality Indicators for Web Site Content

Eysenbach et al found wide-ranging differences in studies of the quality of health Web sites. There are significant variations in study methods and rigor, quality criteria, study population, and topic chosen. Operational definitions of quality are often inconsistent. As a result, the conclusions on quality of health-related Web sites vary widely. Eysenbach found that the most frequently used quality criteria include accuracy, completeness, readability, design, disclosures, and references provided [16].

Griffiths and Christensen evaluated the quality of Web-based information on treatment of depression to identify potential indicators of content quality, and to establish whether accountability criteria are indicators of quality [17]. They found that although the sites examined contained useful information, their overall quality was poor. Sites typically did not cite scientific evidence in support of their conclusions.

Researchers have also studied the correlation between popularity of Web sites and quality of content. Meric et al found that more popular breast cancer-related Web sites were more likely than less popular ones to contain information on ongoing clinical trials, results of trials, and opportunities for psychosocial adjustment. These characteristics were also associated with a higher number of links. More popular sites were more likely to provide updates on other breast cancer research, information on legislation and advocacy, and a message board service. Measures of quality such as display of authorship, attribution or references, currency of information, and disclosure did not differ between popular and less popular sites [18]. In similar findings, Kunst et al found that while there is a correlation between credibility features and accuracy of information, the association is relatively weak [19].

These findings suggest that additional research is needed to identify indicators of content quality, and to correlate consumer preferences to quality indicators. Sites that include content correlated with popularity may best meet the public's desire for health information. Current search algorithms may not be in agreement with quality clinical indicators and performance measures currently used throughout the health-care industry.

Codes of Conduct

A wide range of tools has been developed to assist site developers to produce good quality sites and for consumers to assess the quality of sites. Adherence to accepted codes could theoretically be used as a factor in searches. Ratings instruments include codes of conduct, quality labels, user guides, filters, and third party certification. The value of these tools is unclear: studies have demonstrated that consumers do not routinely seek out information on certifications or adherence to voluntary codes. However, it is assumed by many that such codes benefit consumers indirectly by influencing Web site behaviors and practices. For example, most standards require sites to implement privacy protections and disclosure of site information as consumer protections. No research has been done on the effect of compliance to a code of conduct on Web sites.

A number of organizations have developed quality criteria for health-related Web sites, some with verification and some completely voluntary. Voluntary, self-certifying standards have been developed by the eHealth Code of Ethics of the Internet Health Coalition [20], the American Medical Association [21] and the Health On the Net (HON) Foundation [22]. URAC has developed a health Web site accreditation program that involves independent verification of compliance with its standards. URAC accreditation includes review of the Web site by an external auditor [23].

Web Site Rating Instruments

Web site ratings could be potentially be used to inform searchers and search engines as well, if ratings could be clearly correlated to quality. Two common approaches to rating Web sites include expert ratings, and user (consumer) ratings. Gagliardi and Jadad conducted two evaluations of Web site rating tools, published in 1998 and 2002 respectively [24,25]. They concluded that ratings instruments tend to proliferate and disappear, and that few have been validated for direct correlation between standards and quality. Few provide details on how they were developed, or provide instructions for use, or information about the inter-observer reliability and construct validity of the measurements.

Kim et al reviewed published criteria for evaluating health-related information on the Web, and identified areas of criteria-based consensus [26]. They identified 29 published rating tools and journal articles that had explicit criteria for assessing health-related Web sites. The most frequently cited criteria were those dealing with content, design and aesthetics of site, disclosure of authors, sponsors or developers, currency of information (includes frequency of update, freshness, maintenance of site), authority of source, ease of use, and accessibility and availability.

A number of tools are available to guide users in evaluating information on the Web. Interactive user guidance systems can be used to assess characteristics of Web sites. Tools such as DISCERN and QUICK allow Web site users to assess Web site credibility by responding to a series of questions [27]. Other organizations such as the National Library of Medicine, which operates MEDLINEplus, and the Medical Library Association, have developed guidelines and tips for consumers to evaluate health Web site content [28]. The European Union sponsored a collaborative project called MedCERTAIN to develop a rating system to enable consumers and professionals to rate quality information on the Web. The MedCERTAIN project evolved in a project called MedCIRCLE, which has developed a metadata coding language to mark quality indicators on health Web sites [29].

Discussion

Search Engines and Mediators of Health Information

Electronic and Human Mediation

Search engines serve an essential function in enabling users to find relevant information on the Internet. Recognizing the challenges of sorting the enormous amount of information on the Internet, many organizations are augmenting or mediating the results of electronic searches. Mediation can be either electronic or human-augmented techniques for reviewing information and making a pre-selected set of information available to consumers. One challenge to search engines and human mediators is making access to personalized information as effortless as possible, as consumers rarely use even the advanced search features currently available to them [30].

How Search Engines Work

Search engines and Web directories play a central role in facilitating access to health information. Web directories are organized Web site listings put together by human reviewers. Search engine listings are put together by automated systems and lack a navigable structure. Directories usually concentrate on indexing Web sites, while search engines typically index individual Web pages. Consumer searches for keywords will result in a valid match only if the keyword appears in the Web site's description. Hybrid models of search engines and directories are common.

Search Engine Indexing and Retrieval Methods

Virtually all commercial search engines rely on large powerful databases that utilize automated search agents called robots ("bots"), crawlers, or spiders. Search agents crawl the Web continuously to index information on Web sites. Crawlers capture metadata, page titles and textual content, and add them to the search engine's index or main database. The search engine's algorithm compares indexed data to the user term to process a search. Search engine algorithms are quite complex and scientific. They make frequent use of complementary directories aimed at optimizing and positioning Web sites in the right categories. Search algorithms are closely guarded as proprietary corporate information [31].

Current metrics for evaluating search engines include initial page retrieval capacity and the ability to revisit Web sites to update information. Currency of information, as demonstrated by elimination of non-working links to Web sites is also a performance metric. These criteria are features of business performance, not necessarily the content relevance or quality of the sites returned by a search.

Content and format of Web sites determine how they are indexed by search engines. Some search engines use keyword location, frequency, phrasing, and density as indexing and ranking factors. Type and number of links associated with a Web site are common indexing factors. Web sites also use tags to identify certain types of information. Search engine databases include only Web sites that have been registered with or indexed by the search engine-hence the importance of Web site developers making their sites accessible to automated agents, or becoming known to directory developers.

Ranking and Ratings

Ranking of sites in the final display of search results is of great importance to Web sites, users, and search engines. Ranking effectively drives the likelihood of particular sites being recognized and visited because, as noted, consumers rarely look at more than three pages of results. A poorly designed or executed search may produce an unwieldy list of Web site results that is difficult to navigate. Alternatively, searches that are too narrowly drawn may omit important sites.

Paid preference and placement by search engines also affects which sites are retrieved in a given search [32]. A study by CWW demonstrated that consumers experience considerable confusion about paid listings, and may not distinguish them from other returned listings [33]. The Federal Trade Commission has also expressed concern about how paid placement is disclosed to consumers, and has warned search engines to clearly distinguish advertising from search returns. Search engines may operate their own paid placement programs or obtain search results from third parties, who in turn operate paid placement programs.

Mediated Searches

Mediated searches may be as simple as having a librarian assist with a search, or they may be based on much more complex algorithms. Participants in the URAC/CWW stakeholder group noted that medical and general librarians play an important role in helping large segments of the population retrieve online information and learn effective search strategies. More complex mediated search strategies employ both human mediation and electronic queries to interface with users and focus a search.

Many search engines offer filters that allow users to exclude unwanted search results, most typically pornographic sites. Users, including libraries, can also install blocking software to prevent unauthorized use. However, this electronic mediation may unintentionally block desired health information and create an access barrier. For example, because pornography-blocking software and filters cannot perfectly distinguish between pornographic and non-pornographic Web sites, such products may block access to legitimate health-information sites, particularly those related to sexuality [34].

Gateways employ filters, either electronic or human, to accept or reject types of sites of information based on preset criteria. Gateways are used to organize information on the Internet through selection of resources based on quality and relevance of information to a particular audience. Internet resources are reviewed, classified, and stored with descriptive information. In the US, healthfinder.gov®, is a widely used gateway to selected consumer health and human services information resources provided by US government agencies and other organizations serving the public interest [35].

Participants in the stakeholder meetings noted that domain name extensions such as .com or .org could be used as a distinguishing feature of Web sites for the purpose of focusing search efforts. The World Health Organization is considering the feasibility

of requesting a "dot health (.health)" extension for a pre-selected set of trusted Web sites [36]. In informal proposals describing the .health domain name, the extension is proposed for health information, services and organizations under a framework promoting minimum standards of conduct. Oversight of Web sites would be delegated to independent verifying organizations. The advantage to sites for adhering to standards of content quality would be more ready identification of sites by search engines as a result of the .health domain name.

Stakeholder Discussion of Literature Review

Research Needs to Address Consumer Evaluation of Web Quality

There is great variation in how consumers seek information via the Internet, and in how successful they are in searching for health information. Since there is significant consumer-level variation in how consumers search for health information, search algorithms that support variation and still return expected results will meet consumer needs most effectively. Additional research is needed on information needs of different consumer segments and how to effectively educate differing consumer segments to improve the results of their health searches. Research is needed on how to efficiently validate the quality of Web sites and communicate this information to consumers.

Research Needs for Web Site Quality Indicators

There is a need for tools to enhance recognition of quality Web sites by consumers and search engines. Such tools may be implemented by Web sites themselves, for example through increasingly sophisticated coding to highlight quality indicators. The MedCERTAIN project has been created precisely to address this issue, and has developed the HIDDEL vocabulary to mark features of Web sites [29]. Technical tools can be used to direct consumers more effectively to relevant, high quality information. In addition, since there are currently multiple tools for either self-evaluation or third party evaluation of Web sites, future research should be undertaken to validate these tools.

As noted, gateways filter information to increase its relevance to consumers and provide expert assessment regarding validity of sources is available. It may also be useful to develop more sophisticated search models for providing useful and relevant information to consumers via customization approaches. Such approaches could potentially be embedded in search algorithms. In addition, more research is needed on the impact of Internet-based health information on outcomes. The benefits and risks of health information, both from a health outcome and a system outcome (quality, cost), are poorly understood and should be examined further.

Research Needs for Search Factors Influencing Search Results

Search engines are increasingly important as a tool for locating and organizing information from the vast Internet resource. The volume of information on the Web is so significant that consumers may need different types of mediators, such as search engines or librarians, to help manage the volume of information. Human assistance is also helpful to counteract electronic spoofing and to help consumers overcome limitations in their search strategies.

To effectively improve health searches, more information is needed about search algorithms and how quality factors are identified in the algorithms. Search engines are also developing technology to search for synonyms, which may enhance health searches conducted by laypersons. It may also be helpful for search engines to develop methods to distinguish health related searches from other types of searches, rather than using a simple word match. Search technology to intuit consumer needs more effectively and learn from repeated searches could help search engines steer consumers to quality results. New technologies may ultimately be more effective than electronic filtering, requiring consumers to apply filters, or modifying their search strategies.

With technology advances, search engines may be able to identify quality proxies that could improve page rankings of high-quality Web sites. Search engines could, for example, give higher ranking to "official sites" for diseases. They could also piggyback onto credibility assessments provided by groups such as healthfinder.gov, or give higher ranking to sites listed in directories from trusted independent sources. Ultimately, adoption of technological solutions depends on the ability of researchers to understand the relationship between electronic proxies for quality and actual quality of content.

Discussion of Stakeholder Recommendations for Next Steps

The URAC and CWW expert panels discussed consumer, Web site, and search engine factors that influence the outcomes of health searches. In the course of discussion, they developed a number of recommendations for future research and development (Textbox 1). Their recommendations fell into several categories: needs for health services research, consumer and provider education, technological improvements, and development of tools and information to improve the results of health searches. For some recommendations, the evidence base for implementation is strong; for others, not. Implementation of some recommendations will be enhanced by creation of a national research agenda for health information and targeted funding to study and improve consumers' ability to locate and retrieve quality health information on the Internet. Other recommendations could be embraced at any time by researchers, educators or technology organizations as a business need becomes increasingly evident.

Textbox 1. Recommendations of the Group

Leadership for Health Search Improvement

- Organizations concerned about the quality and accessibility of health information online should continue to collaborate to promote "health search literacy."
- Collaborators should convene a leadership summit on health search literacy to discuss feasibility and implementation of many of the recommendations herein.
- Collaborating organizations should
- work with funding organizations to develop a comprehensive long-term research agenda to improve health searches and increase access to quality health information;
- develop enhanced research methodologies to evaluate the quality, impact, and effectiveness of online health information.

Consumer-directed Tools

- Create tools to support consumer health-information needs, including preset, prescreened health bookmarks and more guidance on how to reach health gateways and portals containing trusted health content.
- Develop and circulate a public domain brochure on health search strategies that could be branded and distributed by physicians, employers, health plans, and others to educate consumers.
- Develop public domain interactive, validated search strategy content pages that could be branded and used by health Web sites.

Research Needs

- Identify the search needs and capabilities of diverse populations of searchers, including culturally diverse users and searchers with health needs of differing intensity and severity.
- Develop more understanding about how consumers interpret online health information, assess its credibility, and make health-related decisions.
- Research the relationship between consumer search strategies and consumer expectations for results to determine effective approaches for conveying information on the Internet.
- Research factors affecting physician assessments of Web-based information and how quality content affects physician recommendations to patients about online health-information resources.
- Assess the relationship between expert accreditation, quality seals, ratings and content quality, as well as the impact of such endorsements on both consumer behavior and Web site behavior.
- Research the correlation between Web site traffic volume and consumer satisfaction, particularly for health Web sites where there is variation in dimensions of quality such as accuracy, comprehensiveness, ease of navigation, and reading level.
- Evaluate content quality of Web sites in different domains, (eg, .gov, .edu, .com, and .org) to identify similarities and differences related to quality within and across categories of Internet domain names
- Evaluate the impact of Internet-based health information on health outcomes: utilization, behavior change, knowledge, burden of illness and disease, or other measures.
- Research the relative effect of each component of a search algorithm (word frequency and placement, links, etc) for finding health information.
- Validate elements of some search algorithms, such as link frequency, as indicators of value/quality.
- Conduct periodic studies to monitor changes in accuracy and quality of content over time, including updating findings from the California HealthCare Foundation /RAND study [5].

Education Agenda

- Develop models for offering health search education at teachable moments and in diverse consumer settings.
- Promote dissemination of existing educational tools and resources to assist consumers in evaluating health information on the Web more effectively.
- Develop user-appropriate tools and approaches to assist Internet users with special needs. High priority user groups may include disability, low literacy, and non-English speaking groups.
- Urge provider organizations to educate provider members on the value of offering Internet information and interactive learning recommendations as part of the therapeutic intervention.
- Educate health Web site developers on how to make information easy to find and how to meet the content-level of their intended users.
- Urge education organizations, in collaboration with health organizations, to develop a school-based or publicly available health search curriculum.

Technology Improvement Agenda

- Continue to develop interactive features on search engines and sites to customize and personalize health searches.
- Develop more functionality for search engines to enhance selected health queries by offering additional relevant information.
- Develop technological markers or indicators that could be uniformly applied by Web site developers to indicate accuracy and comprehensiveness of health Web sites.
- Develop codes to indicate when information on a Web site supercedes previous information.
- Develop collaborations between health quality and search engines experts to develop codes for validated quality proxies.
- Develop search technology similar to that used in the commercial sector to direct consumers to related, relevant information based on both searching and viewing behaviors.
- Enhance personalized searches by building search engine capability to "learn" from repeated searches and user behavior.

Expanding the Market for Quality

- Develop a health equivalent of "BizRate" or "eBay" surveys that can be used by consumers to evaluate Web sites after viewing. Existing models for such a survey could be adapted and disseminated.
- Sponsor a competition for individuals or organizations to design a search algorithm that returns the most credible health results as evaluated by experts. Design a separate contest for the most effective business plan to make the business case for building quality factors into health searches.

Conclusion

The Internet has opened a vast library of information to consumers of health information and made that information more accessible than ever before. This represents a significant step forward for consumers. However, the volume of information and the variable quality of information has created new interpretive challenges. Now, one great challenge is helping consumers find the information they want that is also accurate, reliable, and presented in an accessible format. Searches for health information rely on a complex interplay of search algorithms, Web site content and coding, and consumer behaviors. The recommendations presented here address each of those factors with ideas for further research as well as more immediate recommendations for action. This agenda is a start at maximizing the potential of the Internet to deliver high-quality health information for diverse users.

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Conflicts of Interest

Many participants in the stakeholder meeting have an commercial interest in health Web sites and search-related businesses, and were invited to the meeting expressly to represent the views of such organizations. Implementation of some of the recommendations may benefit one or more of the stakeholders. The authors accept responsibility for any bias that may be reflected in presentation of the information. Two of the authors (Greenberg, D'Andrea) are staff members of URAC, a national accreditation organization. URAC has developed standards for health Web sites, and the authors further disclose that the standards are referenced in this report.

Appendix 1

URAC/CWW Stakeholder Summit Participants (titles as they were at time of the summit)

Lois C Ambash, PhD, MA, MS, President, Metaforix Incorporated; David R Baker, Senior Publishing Advisor (Internet), ODPHP Office of Public Health and Science; Cynthia Baur, PhD, Health Communication and e-Health-Advisor, DHHS ODPHP; Beau Brendler, Director, Consumer WebWatch.org, Consumers Union; Patrick E Cochran, PhD, CSD, Periodic Paralysis Association; Stephen J Downs, SM, Senior Program Officer, The Robert Wood Johnson Foundation; Mary P Doyle, MD, Associate Medical Director, Anthem Blue Cross & Blue Shield; Joan H Dzenowagis, PhD Project Manager, Health InterNetwork, World Health Organization; Kathleen C Eckett, MHA, RN, CPHQ, Director, Quality Management, Group Health Incorporated; Tom Eng, MD, President, EvaluMetrix LLC & eHealth Institute; Ray Fabius, MD Global Medical Leader, General Electric; Steven Figman, Director, eBusiness Strategy, Johnson & Johnson-Ortho Biotech; Susannah Fox, Director of Research, Pew Internet & American Life Project; Alan Greene, MD, President of High Ethics, founder www.drgreene.com; Jennifer Haslip, Director of Communications,

National Health Council;; Nancy Hitzschke, Project Manager, BlueWeb and Plan Education, Blue Cross Blue Shield Association; Leslie Hsu, Chair, healthfinder.gov Steering Committee, DHHS ODPHP; Ann Mond Johnson, President, Subimo, LLC; Kevin Kujawa, CIO, American Specialty Health; Adria Kyne, Manager, Search Engine Marketing, Catalyst on-line; Devin A Jopp, Chief Information Officer; Health Insurance Association of America; Eve-Marie Lacroix, MS, Chief Information Officer, Public Services Division; National Library of Medicine; Daniel J Lorence, PhD, JD, Pennsylvania State University, School of Information Sciences and Technology; Sarah Loughran, MBA, MHSA, Senior Vice President, Health Grades, Inc; Scott McWilliams, Chief Technology Officer, VitalSeek / Today Communications, Inc.,; Janice M Morton, MD, Schering-Plough, Internet Strategy; Linda Neuhauser, DrPh, Clinical Professor, School of Public Health University of California; Hana Paek, Research Associate, Health Improvement Institute; Andrew Robinson, Executive Director, Patient2Patient; Michael Patrick Rutter, BA, Senior Project Manager, Harvard Medical School Harvard Health Publications; Ronni Sandroff, Director of Health Information / Health Editor, Consumer Reports, Consumer Reports on Health; Skye Schulte, MS, MPH Content Editor / Marketing Liason, HealthGate Data; Joshua Seidman, PhD, Executive Director, Center for Information Therapy; Al Shar, Vice President, Information Technology, Robert Wood Johnson Foundation; Gail Shearer, Director of Health Policy Analysis, Consumers Union; Michele Spatz, MS, Director, Planetree Health Resource Center; Mark Spranca, PhD, Director, Center for Healthcare and the Internet, RAND; Beverly Thomas, JD, Senior Attorney, Federal Trade Commission; James "JT" Thome, Vice President, Business Operations, WebMD

URAC Staff

Guy D'Andrea, Senior Vice President, URAC; Lisa A Gallagher, Senior Vice President, Information & Technology Accreditation, URAC; Liza Greenberg, RN, MPH, Vice President, Research and Quality Initiatives; Ryan F Lawton, MS, Director, Information & Technology Accreditation, URAC

Multimedia Appendix

Powerpoint Presentation from URAC about the Project [PowerPoint file, 655 KB - jmir_v6i2e18_app2.ppt]

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Abbreviations

CWW: Consumer Web Watch

RAND: Research and Development Corporation
URAC: Utilization Review Accreditation Commission

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Original Paper

Health Attitudes, Health Cognitions, and Health Behaviors among Internet Health Information Seekers: Population-Based Survey

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Abstract

Background: Using a functional theory of media use, this paper examines the process of health-information seeking in different domains of Internet use.

Objective: Based on an analysis of the 1999 HealthStyles data, this study was designed to demonstrate that people who gather information on the Internet are more health-oriented than non-users of Internet health information.

Methods: The Porter Novelli HealthStyles database, collected annually since 1995, is based on the results of nationally representative postal mail surveys. In 1999, 2636 respondents provided usable data for the HealthStyles database. Independent sample t-tests and logistic regression analyses were conducted.

Results: The results showed that individuals who searched for health information on the Internet were indeed more likely to be health-oriented than those who did not. Consumers who sought out medical information on the Internet reported higher levels of health-information orientation and healthy activities, as well as stronger health beliefs than those who did not search for medical news on the Internet. It was observed that those who reported searching for information about drugs and medications on the Internet held stronger health beliefs than the non-searchers. Comparison of individuals who reported seeking out information about specific diseases on the Internet with individuals who did not showed those who sought out disease-specific information on the Internet to be more health-oriented. Finally, consumers who sought out healthy lifestyle information on the Internet were more health conscious and more health-information oriented than those who did not. They were also more likely to hold stronger health-oriented beliefs and to engage in healthy activities.

Conclusions: The results support the functional theory of Internet use. Internet searchers who used the Internet for a wide range of health purposes were typically more health oriented than non-searchers.

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KEYWORDS

Internet; health beliefs; health consciousness; consumers; information seeking; functional approach

Introduction

The exponential growth in health-care consumerism and limitless consumer access to health information have propelled a surge in scholarship on eHealth [1]. In the last few years, the Internet has become central to the process of health-based consumer decision-making, resulting in a tremendous growth in expert debates about the Internet's impact on the health-care consumer [2]. Although the extant health literature supports the existence of systematic motivational differences in health orientations, consumer use of the Internet has not yet been interrogated in the context of health motivation [3,4,5]. This article examines the idea that the motivational differences in health orientation drive consumer search for health information on the Internet [6,7]. Based on a functional approach to Internet use, the article argues that the health-oriented consumer is more likely to seek out a variety of health-based information on the Internet than people who are not health-oriented [8,9].

The functional approach to media use posits that people use a given medium for many different reasons [10]. The function served by a particular medium emerges from the communicative needs of the audience [11]. Communication behavior, in the functional realm, is goal-directed, and individuals select and use communication channels to satisfy felt needs [12]. This article examines consumer behavior in the following information functions of the Internet: (a) gathering medical news, (b) looking for information about medical services, (c) searching for information about drugs and medications, (d) gathering disease-specific information, (e) searching for information about healthy lifestyle, and (f) looking for discussion groups. It uses the HealthStyles data to examine the differences in demographic, attitudinal, and cognitive variables between individuals on the basis of the different Internet sources of health information that they consider to be most credible.

Methods

Data

The Porter Novelli HealthStyles database, collected annually since 1995, is based on the results of three postal mail surveys. The initial survey, the DDB Needham Lifestyles survey (commissioned by DDB Needham Worldwide), is sent to a stratified random sample of approximately 5000 US adults in April of each year. The sample is generated from a panel of 500,000 cooperating households that represent a range of sociodemographic characteristics. Approximately 3400 responses were obtained for the 1999 Lifestyles survey, representing a response rate of 68%. The second survey is a supplemental mailing of the Lifestyles survey to adjust the representation of particular households in the database. In 1999, the supplemental mailing was sent to 210 low-income households and 210 minority households to compensate for their lower return rates. The third survey, HealthStyles, is sent to respondents who complete either the initial or supplemental Lifestyles survey. Respondents to each of the surveys are sent small gifts for their participation (such as a 20-minute calling card) and are entered into a cash prize drawing. In 1999, 2636 (74%) respondents provided usable data for the Healthstyles survey. The entire sample is weighted on age, sex, race/ethnicity, income, and household size to reflect the US Census population. The demographic comparison of the sample with the 2000 Census data is provided in Table 1.

Table 1. HealthStyles 1999 data comparison with 2000 Census data (medians or %)

Category		1999 HealthStyles Data	2000 Census Data
Mean Age		42	35
Gender	Men	48%	49%
	Women	52%	51%
Race	White	74.6%	77%
	Black	11.6%	12.3%
	Other	13.8%	10.7%

Measures

Health-information Functions

To measure the different online health-information functions engaged in by the consumer, the following guideline was provided: "When looking for information on the Internet, which topics do you mainly look for?" Categories included (a) medical news, (b) medical services, (c) drugs and medications, (d) specific diseases, (e) how to stay healthy, and (f) discussion groups on health. Responses were measured in a dichotomous Yes/No format.

Health Consciousness

Health consciousness was measured by five items on a 1 to 5 scale with 1 representing "strongly disagree," and 5 representing "strongly agree." When subjected to a principal axis factor analysis, a single factor was produced with an Eigenvalue of 2.36 and explaining 47.24% of the variance (see Table 2). The Cronbach alpha for the scale was .72.

Table 2. Principal axis analysis of health consciousness attitude

Items	Loading	α
I do everything I can to stay healthy.	.76	
Living life in best possible health is very important to me.	.74	
I actively try to prevent disease and illness.	.73	
Eating right, exercising, and taking preventive measures will keep me healthy for life.	.62	
My health depends on how well I take care of myself.	.57	
		.72

Health-information Orientation

Eight items were used to measure health-information orientation on a 1 to 5 scale. A principal axis factor analysis produced a single factor with an Eigenvalue of 4.18 (see Table 3). Factor loadings ranged from .55 to .80 and the factor explained 52.24% of the variance. Cronbach alpha for the aggregated scale was .87.

Table 3. Principal axis analysis of health-information orientation

Items	Loading	α
It's important to me to be informed about health issues.	.82	
I need to know about health issues so I can keep myself and my family healthy.	.80	
Before making a decision about my health, I find out everything I can about the issue.	.73	
I really enjoy learning about health issues.	.73	
To be and stay healthy it's critical to be informed about health issues.	.71	
When I take medicine, I try to get as much information as possible about its benefits and side effects.	.68	
I make a point to read and watch stories about health.	.68	
The amount of health information available today makes it easier for me to take care of my health.	.62	
		.87

Health-oriented Beliefs

The respondents were provided the following instruction: "please rate each of the following health behaviors on a scale of 1 to 5 depending on how important you think that behavior is for your overall health." Items included "eating a diet that is low in fat," "eating lots of fruits, vegetables, and grains," drinking plenty of water every day," "taking vitamins and mineral supplements regularly," "exercising regularly," "not smoking cigarettes," "not drinking alcohol or drinking in moderation," and "maintaining a healthy body weight." Cronbach alpha for the aggregated scale was .82.

Healthy Activities

Healthy activities were measured by eight items. The respondents were provided the following instruction: "please place an X for each of these behaviors that you currently perform to maintain your health." Items included "eating a diet that is low in fat," "eating lots of fruits, vegetables, and grains," drinking plenty of water every day," "taking vitamins and mineral supplements regularly," "exercising regularly," "not smoking cigarettes," "not drinking alcohol or drinking in moderation," and "maintaining a healthy body weight." Responses were measured on a dichotomous Yes/No format, and the activities were summed up to constitute the healthy activities variable. It is important to note that the scale used to measure health activities is different from the scales used to measure health consciousness, health-information orientation and health-oriented beliefs.

Data Analyses

The data were entered into Statistical Package for the Social Sciences (SPSS 10.0). Correlation analysis, t-tests and a binary logistic regression were run to analyze the data. Six information seeking functions were identified: (a) medical news, (b) medical services, (c) drugs and medications, (d) specific disease, (e) healthy lifestyle, and (f) discussion group. For each information-seeking function, a t-test was conducted in each of the four areas: health consciousness, health-information orientation, health beliefs, and health activities.

Results

Correlation analysis demonstrated that the independent variables were positively correlated with one another at the p<.001 level (see Table 4).To analyze the relationship between Internet functions and health-oriented variables, independent sample t-tests were conducted. Given that four t-tests (attitudes, information orientation, beliefs, and activities) were conducted for each information function on the Internet, Bonferroni correction was used to adjust the alpha level by the number of tests. The adjusted alpha for each of the hypotheses was .05/4 = .0125.

Table 4. Correlation among health consciousness, health-information orientation, health beliefs, and health activities

Variables				
Health Consciousness	1.00			
Health-information Orientation	.62*	1.00		
Health Beliefs	.46*	..45*	1.00	
Health Activities	.32*	.27*	.46*	1.00

* $p < .001$

Internet Health-information Use

The results presented in Table 5 show that individuals who searched for health information on the Internet were indeed more likely to be health conscious and health-information oriented, hold strong health beliefs, and engage in healthy activities than individuals who did not search for health information on the Internet.

Table 5. Comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of Internet health-information use

Health-oriented Variables	Internet Health Information		t	α^2
	Searcher (n = 979)	Non-searcher (n = 1657)		
Health Consciousness	3.95 (SD = .64)	3.95 (SD = .66)	.05	.003
Health-information Orientation	3.80 (SD = .68)	3.61 (SD = .75)	6.24*	.008
Health-oriented Beliefs	4.23 (SD = .57)	4.08 (SD = .74)	5.14*	.004
Healthy Activities	4.19 (SD = 2.34)	3.66 (SD = 2.50)	5.41*	.009

* $p < .001$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Medical News Seeking

Table 6 presents the comparison between individuals who sought out medical news on the Internet with individuals who did not use the Internet to look for medical news. The results show that consumers who sought out medical information on the Internet reported higher levels of health-information orientation and healthy activity, and stronger health beliefs than those respondents who did not search for medical news on the Internet. However, no significant differences were observed between searchers and non-searchers for medical news on the Internet in the realm of health consciousness.

Table 6. Comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of medical news use

Health-oriented Variables	Medical News		t	α^2
	Searcher (n = 345)	Non-searcher (n = 2291)		
Health Consciousness	4.00 (SD = .69)	3.94 (SD = .65)	1.52	.001
Health-information Orientation	3.91 (SD = .69)	3.65 (SD = .73)	6.24*	.013
Health-oriented Beliefs	4.26 (SD = .58)	4.11 (SD = .69)	3.60*	.005
Healthy Activities	4.37 (SD = 2.28)	3.78 (SD = 2.47)	4.16*	.007

* $p < .001$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Medical Service Information

In the domain of searching for medical service information on the Internet, the t-tests demonstrated no significant differences between searchers and non-searchers in the realms of health consciousness, health-oriented beliefs, and healthy activities. A significant difference was found only in the realm of health-information orientation, with searchers being more likely to be health-information oriented than non-searchers.

Table 7. Comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of medical services

Health-oriented Variables	Medical Services		t	α^2
	Searcher (n = 105)	Non-searcher (n = 2531)		
Health Consciousness	3.82 (SD = .79)	3.96 (SD = .65)	1.99	.001
Health-information Orientation	3.96 (SD = .73)	3.67 (SD = .73)	3.88*	.006
Health-oriented Beliefs	4.24 (SD = .55)	4.13 (SD = .69)	1.62	.001
Healthy Activities	4.33 (SD = 2.34)	3.83 (SD = 2.46)	2.00	.001

* $p < .010$
$p < .001$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Drug and Medication Information

In the realm of consumer information search for information about drugs and medications on the Internet, it was observed that searchers held stronger health beliefs than the non-searchers (see Table 8). Searchers were also more likely to be health-information oriented and engage in healthy activities than non-searchers. However, no significant differences were observed between searchers and non-searchers in the realm of health consciousness.

Table 8. Comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of seeking information about drugs and medications

Health-oriented Variables	Drugs and Medications		t	α^2
	Searcher (n = 382)	Non-searcher (n = 2254)		
Health Consciousness	3.96 (SD = .67)	3.95 (SD = .65)	.45	.000
Health-information Orientation	3.93 (SD = .66)	3.64 (SD = .73)	7.27*	.017
Health-oriented Beliefs	4.25 (SD = .58)	4.11 (SD = .70)	3.51*	.004
Healthy Activities	4.26 (SD = 2.34)	3.79 (SD = 2.47)	3.51*	.007

* $p < .001$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Disease-specific Information

Table 9 compares individuals who reported seeking out information about specific diseases on the Internet with individuals who did not seek out disease-specific information on the Internet. Differences were observed in the realms of health-information orientation, health beliefs, and healthy activities, with those who sought out disease-specific information on the Internet being more health-oriented than those who did not. However, no significant differences were observed between disease-specific health-information seekers and non-seekers in the domain of health consciousness.

Table 9. Comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of seeking information about specific diseases

Health-oriented Variables	Specific Diseases		t	α^2
	Searcher (n = 619)	Non-searcher (n = 2017)		
Health Consciousness	3.97 (SD = .61)	3.94 (SD = .67)	.95	.003
Health-information Orientation	3.84 (SD = .66)	3.64 (SD = .74)	6.23*	.013
Health-oriented Beliefs	4.23 (SD = .55)	4.10 (SD = .72)	4.07*	.005
Healthy Activities	4.27 (SD = 2.27)	3.73 (SD = 2.50)	4.77*	.007

* $p < .001$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Healthy Lifestyle Information

Consumers who sought out healthy lifestyle information on the Internet were more health conscious and more health-information oriented than those other consumers who did not seek out health information (see Table 10). They were also more likely to hold stronger health-oriented beliefs and to engage in healthy activities.

Table 10. comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of seeking healthy lifestyle information

Health-oriented Variables	Staying Healthy		t	α^2
	Searcher (n = 272)	Non-searcher (n = 2364)		
Health Consciousness	4.09 (SD = .61)	3.93 (SD = .66)	3.62*	.003
Health-information Orientation	3.99 (SD = .61)	3.65 (SD = .73)	7.45*	.018
Health-oriented Beliefs	4.36 (SD = .48)	4.11 (SD = .70)	5.64*	.010
Healthy Activities	4.71 (SD = 2.22)	3.75 (SD = 2.46)	6.09*	.012

* $p < .001$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Health-based Discussion Groups

Individuals who sought out health-based discussion groups on the Internet were more likely to be health-information oriented than individuals who did not seek out discussion groups on the Internet (see Table 11). No significant differences were observed in the realms of health consciousness, health beliefs, and healthy activities.

Table 11. Comparison of health consciousness, health-information orientation, health beliefs, and health activities in the context of seeking discussion groups

Health-oriented Variables	Discussion Groups		t	α^2
	Searcher (n = 37)	Non-searcher (n = 2599)		
Health Consciousness	4.16 (SD = .57)	3.95 (SD = .66)	1.95	.001
Health-information Orientation	4.02 (SD = .72)	3.67 (SD = .73)	2.83*	.002
Health-oriented Beliefs	4.25 (SD = .64)	4.13 (SD = .68)	.10	.000
Healthy Activities	4.61 (SD = 2.45)	3.84 (SD = 2.45)	1.89	.001

* $p < .005$; Bonferroni correction was conducted and significance level was set at .05/4 = .0125.

Health-oriented Variables and Internet Functions

Finally, to account for the correlation among the different health-oriented variables, six logistic regression analyses were conducted (see Table 12). The health-oriented variable that consistently demonstrated the strongest relationship with the different Internet information functions was health-information orientation.

Table 12. The relationship between health-oriented variables and Internet functions

	Medical News		Medical Services		Drugs and Medications		Specific Disease		Healthy Lifestyle		Discussion Group	
	B	P	B	P	B	P	B	P	B	P	B	p
Hlth Csnss	-.46	<.001	-1.3	<.001	-.74	<.001	-.45	<.001	-.27	.06	.21	.59
Hlth Beliefs	.08	.50	.11	.58	.09	.44	.09	.32	.25	.08	-.27	.41
Hlth Inf. Orntn	.70	.001	1.21	<.001	.97	<.001	.62	<.001	.72	<.001	.47	.17
Hlth Actvts	.07	.01	.09	.07	.05	.06	.07	.004	.10	.003	.12	.18
Nagelkerke R^2	.044		.074		.07		.045		.065		.024	

Discussion

The results provided support for the functional approach to Internet consumption in the health context. Motivation emerged as a critical factor in driving consumption of media types. Demonstrating a match between motivation and content choice, health-orientation was positively correlated with information seeking on the Internet. The results suggest that the underlying motivation in a specific issue is likely to draw the consumer to use media (such as the Internet) to gather information about the specific issue. This match between content-based motivation and Internet content use is likely to be strong because of the user-driven nature of the Internet.

Consumers who sought out medical news on the Internet were more health conscious and health-information oriented, held stronger health beliefs, and were more likely to engage in healthy activities. In the domain of Internet use for gathering information about medical services, the only realm where systematic differences were observed between searchers and non-searchers was health-information orientation. Once again, this result makes sense in the context of the functional approach to the Internet. Searching the Internet for medical services information is a reflection of health-information orientation. Given the finding that the health-information-oriented consumer uses the Internet for procuring information about medical services, service providers should use the medium to reach out to health-oriented individuals.

Consumers who seek out information about drugs and medications on the Internet are also more health-information oriented. They hold stronger health beliefs and are more likely to engage in healthy activities. Pharmaceutical companies and providers of treatment options could effectively harness the ability of the Internet to reach the health-active group. The message, however, must be cogently constructed, and strong arguments must be provided because searchers are actively engaged in their health decisions. It is also important to present complete health information given the active orientation of the group. The search for disease-specific information was positively correlated with health orientation. Also, the search for information about a health lifestyle was positively associated with health consciousness, health-information orientation, health beliefs, and healthy activities. Developers of new health solutions should target this health-active group given its strong involvement with health information. Finally, individuals who sought out discussion groups on the Internet were more health-information oriented, although no other differences were observed.

The t-tests, and subsequently the regression analysis, pointed out that the strongest effect across the different Internet health-information functions is in health-information orientation. This is perhaps a result of the fact that health-information orientation is most closely aligned with specific health-information-seeking functions on the Internet. The negative relationship of health consciousness to the Internet information-seeking functions is attributable to the multicollinearity. This is proven by the results of the

independent t-tests that demonstrated either no relationship or positive relationship between health-conscious attitude and Internet information-seeking function.

One of the limitations of the study was its use of self-reported measures. Self-reported indicators of health consciousness, health beliefs, health-information orientation, and healthy activities raise questions about validity. The "topics of health information" variable was treated as a dichotomous variable measured in a Yes/No format; therefore, it did not provide information about the degree of consumer use of the different health topics. The items "eating right, exercising, and taking preventive measures" and "eating lots of fruits, vegetables, and grains" were triple-barreled. The mailback panel used in the study suffers from problems of attrition and panel bias. Also, the effect sizes were typically small. Finally, the use of an American sample that is predominantly white limits the generalizability of the study results. Future research needs to extrapolate the research findings to other cultural domains.

Conflicts of Interest

None declared.

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Original Paper

First evaluation of the NHS Direct Online Clinical Enquiry Service: A Nurse-led Web Chat Triage Service for the Public

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Abstract

Background: NHS Direct is a telephone triage service used by the UK public to contact a nurse for any kind of health problem. NHS Direct Online (NHSDO) extends NHS Direct, allowing the telephone to be replaced by the Internet, and introducing new opportunities for informing patients about their health. One NHSDO service under development is the Clinical Enquiry Service (CES), which uses Web chat as the communication medium.

Objective: To identify the opportunities and possible risks of such a service by exploring its safety, feasibility, and patient perceptions about using Web chat to contact a nurse.

Methods: During a six-day pilot performed in an inner-city general practice in Coventry, non-urgent patients attending their GP were asked to test the service. After filling out three Web forms, patients used a simple Web chat application to communicate with trained NHS Direct triage nurses, who responded with appropriate triage advice. All patients were seen by their GP immediately after using the Web chat service. Safety was explored by comparing the nurse triage end point with the GP's recommended end point. In order to check the feasibility of the service, we measured the duration of the chat session. Patient perceptions were measured before and after using the service through a modified Telemedicine Perception Questionnaire (TMPQ) instrument. All patients were observed by a researcher who captured any comments and, if necessary, to assisted with the process.

Results: A total of 25 patients (mean age 48 years; 57% female) agreed to participate in the study. An exact match between the nurse and the GP end point was found in 45% (10/22) of cases. In two cases, the CES nurse proposed a less urgent end point than the GP. The median duration of Web chat sessions was 30 minutes, twice the median for NHS Direct telephone calls for 360 patients with similar presenting problems. There was a significant improvement in patients' perception of CES after using the service (mean pre-test TMPQ score 44/60, post-test 49/60; p=0.008 (2-tailed)). Patients volunteered several potential advantages of CES, such as the ability to re-read the answers from the nurse. Patients consider CES a useful addition to regular care, but not a replacement for it.

Conclusions: Based on this pilot, we can conclude that CES was sufficiently safe to continue piloting, but in order to make further judgments about safety, more tests with urgent cases should be performed. The Web chat sessions as conducted were too long and therefore too expensive to be sustainable in the NHS. However, the positive reaction from patients and the potential of CES for specific patient groups (the deaf, shy, or socially isolated) encourage us to continue with piloting such innovative communication methods with the public.

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KEYWORDS

E-health; telemedicine; Web chat; triage; NHS Direct Online

Introduction

NHS Direct is a national service founded in 1998 by the UK National Health Service (NHS) to provide a nurse-led 24-hour help and advice service over the telephone. NHS Direct is a free service (only the local telephone call costs) for the public [1] currently receiving approximately 7.5 million calls a year in England and Wales [2,3]. In 2000, the UK Government introduced a plan for future investment and reform within the NHS [4]. At the heart of these changes was the desire to provide a health service built around patients' needs, including the need for knowledge and information. Modern means of communication, such as the Internet, have introduced new ways for accessing health services and information. As in other, especially Western, countries the number of Internet users in UK is growing rapidly. NHS Direct decided to extend its services to the Internet, introducing NHS Direct Online in 1999 [5]. The Web site offers information about illness, keeping healthy, and how to access local health services. One of the functions of this Web site is an e-mail online enquiry service that offers more detailed information on health issues, but does not accept enquiries from patients about specific symptoms. Although this restriction is clearly stated on the Web site, nearly a quarter of all online enquiries are about symptoms [6]. This highlighted the need for a more personalized, clinical problem-based service.

With this in mind, NHS Direct Online developed a prototype Clinical Enquiry Service (CES) offering a secure, confidential one-to-one Web-based consultation with a nurse. It was thought that such a service might also provide access to health information and advice for clients whose needs are not currently met by the telephone NHS Direct service because of accessibility problems, e.g. the socially isolated or those with hearing or speech limitations.

There are various Web sites offering chat room services for specific patient groups, such as cancer patients [7] or schizophrenia patients [8]. A number of Web sites have scheduled chat sessions where patients can ask questions directly of a specialized physician in the field. However, there are no services offering a one-to-one chat service with a medical professional.The pilot study described here was set up to identify the challenges and implications of such a Web-based chat service. The aim of this pilot study was to explore for CES the three most important aspects of any eHealth service or application: its safety, its feasibility, and patient perceptions of it.

Methods

Procedure and Participants

The six-day pilot was performed in an inner-city general practice in Coventry (England), an industrial city. Non-urgent patients (ie, those telephoning the practice who did not request an appointment that day) were asked to participate in the study. There were no other inclusion criteria for the patients and their level of computer literacy was not a factor. When patients arrived in the waiting room, a researcher gave them a short explanation of the study and they were invited to participate and sign a consent form. The CES Web chat session took place soon after in an examination room. A researcher was present to assist the patient only if he or she needed assistance to proceed with the CES consultation, and to observe the patient's behavior and reactions. The patients could remain anonymous during the Web chat, but, for a more personal approach, provided a first name for the nurse to use. The first step in the chat was to exclude any urgent conditions by querying the patient about the presence of chest pain, shortness of breath, etc.

Five NHS Direct-trained nurses based in Southampton were further trained in the use of Web chat. These nurses used the same NHS Clinical Assessment System (NHS CAS), a triage decision support system generating questions and advice based on patient answers, used in the telephone NHS Direct service. The CES Web chat application could not be implemented on the same computer as CAS, so the nurses had to use two computers during each Web chat session.

The possible triage endpoints generated by CAS, which correspond to the advice that NHS Direct nurses give patients, were:

- call 999 for an urgent ambulance
- visit the accident and emergency department as soon as possible
- visit the accident and emergency department within 4 hours
- contact your GP within 4, 12, or 36 hours or within 2 weeks
- home care.

Immediately after participating in the CES Web chat session, all patients were seen by a GP at the same practice. The patients were instructed not to discuss the Web chat or the suggested end point with this doctor. A system manager was present at the practice to solve technical problems if they arose.

The Web Chat Application

A Web chat application service was leased from Instant Service USA and was made accessible only to the nurses and patients participating in the pilot. The interface to the service was tailored to our needs. Prior to each Web chat session, patients filled out several online forms about their general health. The Web chat was between patient and nurse, and the discussion was not shared with anyone else. A log file of each session was stored on a secure server.

Evaluation of Safety

One of the most important aspects of any innovation in health care is its safety. Prior to developing any telemedicine or eHealth service, it is important to decide exactly who the intended users are. It is equally important to decide who should not use the service (eg, very sick patients), and to test the service's ability to detect these patients to ensure its safe operation. In addition, we should check whether the service may harm eligible users included in the pilot study. In this pilot study, the safety of the Web chat was evaluated on two levels: the ability of the NHS CAS-assisted nurse to detect urgent cases, and agreement between the CES endpoint and the GP endpoint. After every consultation, and with the benefit of a full consultation, the GP recorded the advice he or she would have given to the patient if the patient had phoned the GP that day before attending, using

the same list of possible endpoints as the Web chat nurse. For each patient, we compared the endpoint allocated by the GP with the endpoint allocated by the nurse at the end of the CES session. To validate the GP end point, the GPs also provided a list of interventions performed on all patients collected from the patient records, and patient outcomes after a 3-month follow-up.

Evaluation of Feasibility

The evaluation of feasibility needs to include a check that that the resources required are likely to be available and that the technology has adequate coverage and some promise of cost-effectiveness. One of the common problems of telemedicine or eHealth applications is that they often involve not only expensive technology (video-conferencing tools, digital cameras, fast Internet connections), but also significant time, training, and changes in work practice for health-care professionals (8)]. We explored the general feasibility of CES by focusing on the range of potential CES users, the resources needed to run the service, and the quality of interpersonal communication. For all patients, age, gender, and self-reported computer literacy were recorded. In order to calculate the duration of the Web chat and its components, the intervals between specific defined events occurring during a CES session were logged into a file.

We compared the total duration of the Web chat session with the median duration of NHS Direct telephone consultations for patients calling with the same symptom. For each presenting symptom, the median call duration of a random sample of 30 cases with the same symptoms was calculated by NHS Direct.

Since communication using Web chat consists only of exchange of typed text, we explored whether this was enough to establish a sufficient level of rapport between the nurse and patient. Patients were interviewed about this, and the log files were used to retrieve any nurse questions for which the patient response indicated a need for clarification or rephrasing.

Evaluation of Patient Perceptions

Patient perceptions about a variety of issues were checked using three instruments. The Telemedicine Perception Questionnaire (TMPQ) [9], a validated questionnaire designed by the University of Minnesota, was used to measure the change in patient perception of CES after using it. The questionnaire was adapted to our study with permission by slight rephrasing (changing "home telecare" into "CES" or "Web chat") or excluding some questions (eg, those about costs). The users scored each item twice: before and after using CES, with each score ranging from 1 (strongly disagree) to 5 (strongly agree). The highest possible score with our modified TMPQ was 60. Some items (*italic* in Table 3) were negatively worded, so scores for these items were transformed (eg, a score of 5 was transformed into 1) during the analysis, so that higher scores always represent positive patient attitudes toward CES. A paired sample t-test was used to check for differences between the pre- and post- test scores. We also used a second, researcher-administrated, instrument containing 23 open and closed questions to capture patient comments and experiences with CES. Finally, all patients were observed by a researcher to study their behaviour and log revealing comments spontaneously made by the patients during the Web chat.

Data analysis was performed using SPSS 10.1.

Results

Safety

The nurses were instructed to ask several questions in order to exclude any possibility of an urgent problem. However, the patient could have shown signs of urgency without the nurse responding to them. The log file analysis showed that the nurse responded to every patient comment or question. This was partially enforced by the Web chat application, as the nurse could see when the patient was typing, which prevented the nurse and patient typing at the same time.

The GP consultation resulted in 13 patients receiving advice only, 13 a prescription, three investigations, two referrals and one a medical certificate. Eight patients received multiple interventions. More than half (57%) the patients did not go back to their GP for the problem, and 30% (7/23) returned only once during the three-month follow-up period. Three patients (13%) returned more times (three, four, and eight times) to their GP for the following problems: urinary frequency, chest pain after taking medicine for acid indigestion, and carcinoma of the prostate.

Table 1. Agreement between CES and GP endpoints

GP endpoint					Total	Match
	Contact GP within 12 hours	Contact GP within 36 hours	Contact GP within 2 weeks	Self-care		
Contact GP within 12 hours	4	1	5	0	10	40%
Contact GP within 36 hours	1	1	3	1	6	17%
Contact GP within 2 weeks	0	1	4	0	5	80%
Self care	0	0	0	1	1	100%
Total	5	3	12	2	22*	46%

* One patient did not finish the Web chat session due to lack of time.

We found an exact match between the CES endpoint and the endpoint defined by the GP in 45% (10/22) of patients (Kappa (K)=0.25; 95% confidence interval 0.37 to 0.45, which is low) [10]. Where there was a difference in endpoints, in most cases the CES nurse suggested a more urgent follow-up than the GP (45%; 10/22). With only two patients did the CES nurse propose

a less urgent consultation (shown as bold in Table 1). These two patients attended their GP for acute lumbar back pain and tiredness.

Feasibility

During the pilot, 25 patients agreed to participate. Two patients were excluded from further analysis as they were members of the practice staff. More than half (57%, 13/23) of the patients were female. Patients varied in age (range 19-80, mean 48 years), educational background, and occupation. Although 78% (18/23) of patients considered themselves computer literate, only 64% (14/22) reported good typing abilities. Not all patients were experienced PC users, but 87% (20/23) found it easy to describe their symptoms on the Web, and 96% (22/23) stated that CES offered sufficient rapport with the nurse. No patient asked for a clarification of any of the questions asked by the nurse.

The Web chat connection with the nurse was disconnected four times in 25 consultations, but each time was easily re-established.

The median duration of the Web chat sessions was 30 minutes [25th percentile 23, 75th percentile 36 minutes]. This was more than twice as long as for a similar group of patients using the telephone NHS Direct services (Table 2). There was a positive correlation between patient age and total duration of Web chat (r_s=0.44, p=0.04 (2-tailed)).

Almost all patients (96%, 21/22) were happy about the time that the Web chat took to complete. One patient disconnected himself after 10 minutes as the Web chat took longer than he expected and a technical problem occurred.

Table 2. Comparison of session duration for CES and the telephone NHS Direct service

CES problem	CAS code	NHS Direct duration	CES duration	Difference*
Painful left elbow	arm injury	0:13:27	0:31:39	0:18:12
Acute lumbar back pain	back pain	0:12:09	0:22:51	0:10:42
Back pain			0:40:32	0:28:23
Acute lumbar back pain			0:28:56	0:16:47
Lumpy area in both breasts	breast lump	0:10:54	0:29:39	0:18:45
Chest pain after taking medicine for acid indigestion	chest pain	0:11:49	0:46:04	0:34:15
Prolonged cough	cough	0:15:22	0:49:04	0:33:42
Chronic cough			0:23:48	0:08:26
Cough and chest infection			0:29:01	0:13:39
Impacted ear wax	ear problems	0:12:27	0:32:49	0:20:22
Lethargy/tiredness	fatigue	0:13:30	0:17:33	0:04:03
Knee pain	knee pain/swelling	0:11:50	0:19:53	0:08:03
Recovery advice after knee cartilage operation			0:39:25	0:27:35
Whiplash after car accident	neck injury	0:12:03	0:35:26	0:23:23
Contact dermatitis on hands	rash	0:14:59	0:40:02	0:25:03
Itchy face and neck			0:34:53	0:19:54
Dry and discolored nails			0:17:43	0:02:44
Intertriginous rash			0:22:59	0:08:00
Tonsillitis	sore throat	0:14:56	0:31:39	0:16:43
Frequent urinating	urine frequency	0:14:50	0:25:24	0:10:34
Review of polymyalgia/frequent urinating			0:29:23	0:14:33
Waterworks problems/review of post- operative ovarian cyst.			0:33:08	0:18:18
Overall (medians)		**00:12:57**	**00:30:39**	**00:17:29**

* Session duration is in minutes. Comparison is of cases with similar clinical problem (median of 30 randomly selected cases).

Turning to the components of the CES consultation, the first part of each session was exclusion of any urgent conditions and this took a median of 9 minutes [25th percentile 6, 75th percentile 11 minutes]. This process also included answering several questions on a Web form prior to the Web chat. The median duration of discussion about the patient's current problem was 18 minutes [25th percentile 9, 75th percentile 25 minutes].

Patient Perceptions

The highest mean score (3.9) in the TMPQ pre-test was for patients' estimate of the ability of nurses to obtain a good understanding of their health problem over the Internet; the lowest was 3.2 for concern about the lack of face-to-face contact. The most positive opinion following experience with CES was for CES as an addition to regular care (4.3). A paired sample t-test was performed with 20 cases, as one pre-test answer and two post-test answers were missing. The analysis showed significantly higher mean post-test scores compared to pre-test scores (mean pre score 44/60, mean post 49/60, paired sample t-test: p=0.008 (2-tailed), score difference 5, (95%CI 7.4-1.3)). It is unlikely that the missing data would significantly alter the mean score for these items. Patient perceptions improved for all items after using the CES Web chat (Table 3), but this improvement was significant for only two items, about CES becoming a standard way of health assessment in the future and CES making it easier to contact NHS Direct.

Table 3. Adapted TMPQ with mean scores for pre- and post-test for 20 patients *

Question	Pre-mean	Post-mean	Mean difference	2-tailed p-value
A nurse can get a good understanding of my health problem over the Internet.	3.9	4	0.1	0.9
I am concerned that the NHS Direct Online Clinical Enquiry Service (CES) is a threat to my privacy.	3.7	4.1	0.4	0.16
The use of a personal computer seems difficult or unreliable to me.	3.8	4.2	0.4	0.23
I can be as satisfied talking to a nurse over the Internet as talking in person.	3.5	4	0.5	0.15
The NHS Direct Online CES can improve my understanding of my health.	3.8	4.2	0.4	0.09
I am concerned that there is no face-to-face conversation during the use of the NHS Direct Online CES.	3.2	3.7	0.5	0.14
The NHS Direct Online CES is a convenient form of health assessment for me.	3.8	4.2	0.4	0.11
The NHS Direct Online CES will save me time.	3.8	3.9	0.1	0.82
The NHS Direct Online CES will be a standard way of health assessment in the future.	**3.7**	**4.2**	**0.5**	**0.014**
The NHS Direct Online CES can be an addition to the regular care I receive.	4	4.3	0.3	0.08
A nurse cannot assess me as well over the Internet as in person.	3.3	3.7	0.4	0.2
The NHS Direct Online CES makes it easier for me to contact NHS Direct.	**3.7**	**4.2**	**0.5**	**0.004**
Overall mean score	**3.7**	**4**	**0.3**	**0.008**

* Significant changes are in bold. Italicized items are negatively worded items for which the responses were re-coded.

The total TMPQ score per individual patient decreased after using CES for four patients (ranging from 7 to 1 points less than in pre-test, mean fall 3.8) and increased for 15 patients (ranging from 1 to 18 points more than in pre-test, mean rise 6.8). One patient did not change her opinion about CES after using it. No correlation was found between patient age or gender and perception about CES measured using TMPQ.

Discussion

The results of this pilot suggest that the CES nurse-led Web chat service might be safe as a triage system for non-urgent patients. This safety aspect is supported by the fact that CES nurses suggested a more urgent follow-up than the GP for the same symptoms in almost half of the cases. However, patients who participated in this pilot study were not typical users of CES, as they had already made a decision to visit their GP. Although a general practice as study setting is a safe and practical environment for the first pilot study, further studies should be performed in a home or workplace setting where the service would actually be used by the public. CES was designed to for members of the public who are hard to reach by other means of communication. In this first pilot, we did not present the service to this group of users.

Exclusion of urgent patients is one of the important functionalities of CES. Because we did not include urgent patients in our study, we are not able to judge whether CES would be a safe and reliable service in a real life situation.

As all communication between the nurse and patient is based on typed text, signs of emotion and empathy are hard to communicate. Therefore, it is possible that some answers given by patients, and some questions asked by nurses, might be interpreted differently than expected. Another threat of such indirect communication is the possibility that patients might give untrue information (eg, incorrect details of their age, sex, severity of symptoms, or geographical location) that cannot be checked by the nurse.

Patients with a wide range of age, gender, and computer experience were able to explain their symptoms using Web chat and to establish an adequate level of communication with the CES nurse. The Web chat of older patients lasted longer than that of younger patients. It is difficult to determine for which age this difference is significant as we had small samples from each age group. This difference might be due to the patients' speed of typing. Since we did not succeed in finding a similar study exploring one-to-one Web chat between a patient and health professional, we compared the duration of CES triage

with the duration of telephone triage. In general, CES Web chat took twice as much of the nurse's time as NHS Direct telephone triage and this was considered unacceptable from the financial point of view. However, we believe that this problem is partly due to an inefficient information management system (eg, CAS and CES were running on two different computers) and time-consuming procedures, such as exclusion of emergency conditions by the nurse. Most patients did not have problems with the duration of a CES session.

Although CES would be too expensive as a service open to any UK patient in the same way as NHS Direct, it might be helpful for certain groups of patients, such as those who wish to discuss private problems (eg, sexually transmitted diseases, HIV, psychological problems, addiction) [11- 13], especially where they can be overheard, such as at work or at home, and for people with speech problems (eg, those who are deaf, shy, have dysphasia or other types of speech difficulties).

The TMPQ is a validated instrument, but it underwent some adjustments before using in the pilot and was not re-validated. In further studies, this adapted questionnaire should be re-validated. Nevertheless, patients were positive about the potential of a Web chat version of NHS Direct and became even more positive after trying out the service, independent of their age and gender. After using CES, some patients stated that this service will become a standard way of health assessment in the future. However, as NHS Direct Online intended, most patients considered CES an addition to regular care, not a replacement for it. Privacy issues did not seem to be a problem for the patients included in our study. A significant improvement in patient perception was found about the ease of using CES to contact NHS Direct. The patients were more positive about the service after having tried it out. The technology became less "scary" after using the service, and patients started to recognize the advantage of CES over the telephone service. Several patients volunteered novel benefits of the Web chat medium over the telephone NHS Direct service, such as the ability to re-read the nurse's answers and having more time to think about her questions before responding. An 80-year old patient described these advantages as follows:

...When you go to a doctor, you forget things because you're a little bit nervous. You forget what you've said, to say what you wanted to say and what has been said by the doctor. Using this service you have more time to think and ask anything you want, you can see what you and the nurse said, that is much better...

Conclusions

This study was performed to explore whether the pilot CES service was sufficiently safe, feasible, and acceptable to patients to justify a larger study. We can conclude that CES was sufficiently safe in the pilot phase, but in order to make further judgments about safety, more testing with urgent cases should be performed. At this stage, further development on the CES service has been postponed because of the long duration of conversation between the patient and nurse, and other NHS Direct Online priorities. The pilot resulted in several recommendations about how to improve the software and decrease the communication time. Communicating with patients through the Internet should first be further explored in more closed, controlled settings, such as GP practices or health centres, before this service is offered to the public at large. However, it is likely that commercial companies will develop and offer such services before scientific studies are performed. Therefore, we believe that early pilots such as ours, exploring safety, feasibility, and acceptability, are important to predict the risks and benefits of eHealth applications such as CES.

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Conflicts of Interest

AM Tarpey and G Murray were employed by NHS Direct Online during the design and evaluation of NHS CES.

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Abbreviations

NHS: National Health Service
NHSDO: National Health Service Direct Online
CAS: Clinical Assessment System
CES: Clinical Enquiry Service
NHSCAS: National Health Service Clinical Assessment System
SPSS: Statistical Package for the Social Sciences
TMPQ: Telemedicine Perception Questionnaire

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Original Paper

Improvement of the Educational Process by Computer-based Visualization of Procedures: Randomized Controlled Trial

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Abstract

Background: Before any invasive procedure, physicians have a legal obligation to inform patients. Traditionally, this involves a discussion with a physician, supplemented by written leaflet information directed at the specific procedure.

Objective: Comparison of the use and effectiveness of computer-based visualization opposed to standardized conversation for providing patients with information of forthcoming procedures (coronary catheters or endoscopy procedures).

Methods: Prospective, randomized trial with 56 participants allocated in two different groups: Visualization Group (standardized information supported by a tool for displaying two-dimensional pictures to explain medical facts as well as informative leaflet) or Control Group (standardized information and informative leaflet only). Detailed information was given about the indication, the probable complications and the details of the forthcoming procedures (coronary catheters or endoscopy procedures). All participants had to reach a Karnofsky Score of 70 points and be able to understand German or English. Main outcome measures were patient's satisfaction with physician-patient conversation, patient's acquired knowledge and duration of the intervention as described above.

Results: Patients of the Visualization Group were more satisfied with the conversation and had higher knowledge scores after the conversation. A Mann-Whitney-U-Test between the two groups showed that these differences in satisfaction (P<0.001) and knowledge (P=<0.006) were statistically significant. Length of time needed for the conversation was slightly higher in the Visualization Group, but this difference was not statistically significant (25 versus 23 min; *P*= 0.441). No differences could be found due to differing age or educational level in the results of the Visualization and the Control Group.

Conclusions: Using computerized visualization increased the satisfaction and knowledge of the patients. The presentation of the visualized information in the Visualization Group did not demand significantly more time than the standard conversation in the Control Group.

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KEYWORDS

Computer-based visualization; evaluation of visualization; patient empowerment; technology assessment

Introduction

Background

During the last decade we have observed an increasing demand for better integration of patients in clinical and ambulatory health care [1]. Well-informed patients are better able to support their health and to use health services in a sensible way, thus contributing to their treatment outcome. Patients need more possibilities to keep themselves informed about medical benefits and the quality of medical care [2,3].

The information has to present the available evidence in a form that is acceptable and useful [4].

Since the beginnings of human communication, learning and comprehension have always been supported graphically. In education, pictures often clarify difficult facts better than written language. In anatomy, for example, drawings by Netter explain the human body [5].

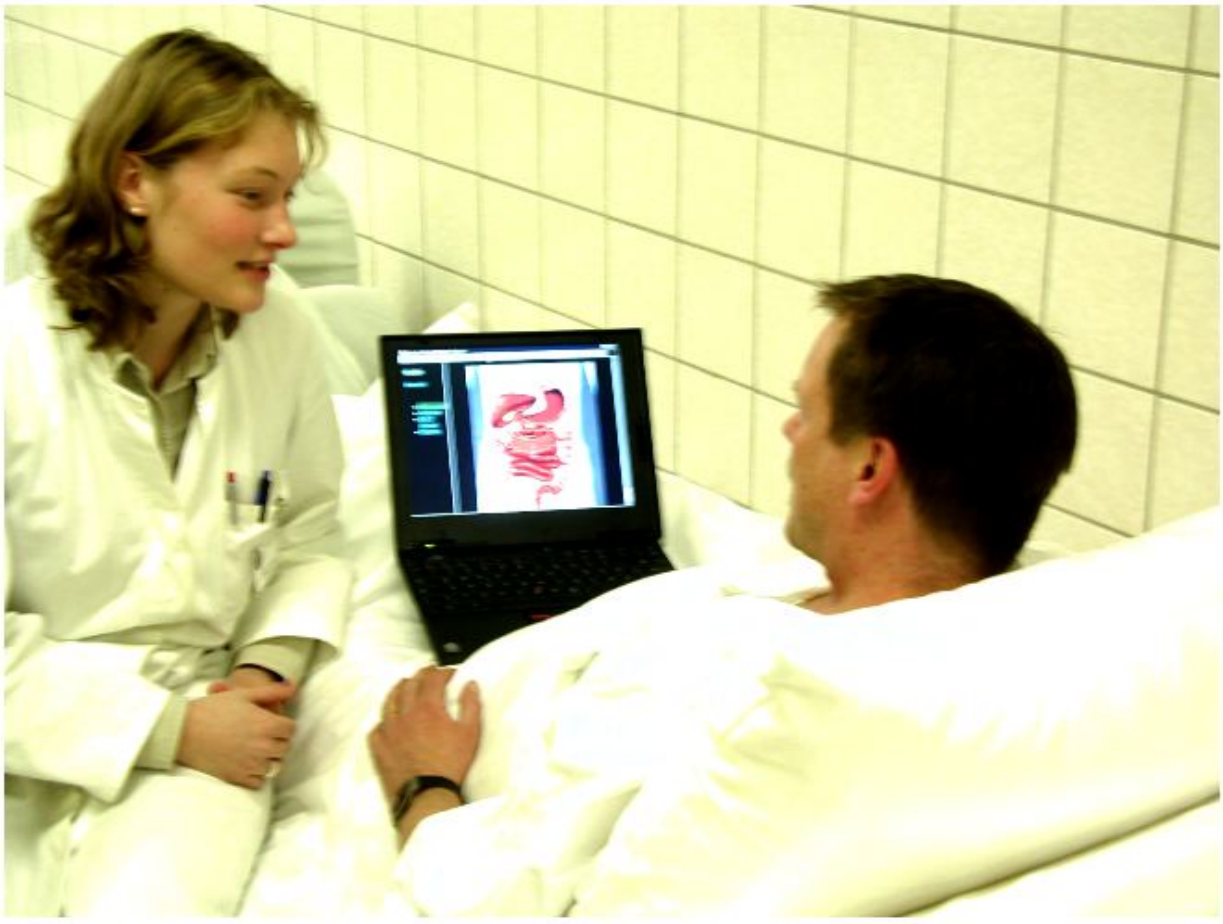
Patient Information Systems

Educational materials designed to deliver information and support a more active participation of patients in health care decisions can be effective tools for empowering patients [6]. Shaw et al found that in patients having colonoscopies,computer-assisted instruction (CAI) provided better comprehension and greater satisfaction with computer-assisted education than standard education [7]. Another randomized and controlled trial aimed to determine the impact of an interactive diagnosis-specific video program for informing patients about possible treatments on outcomes and surgical choices. The tested program facilitated decision-making and helped to ensure informed conversation [8]. As a result, standardized templates and systems of informative and visual material are increasingly used to inform patients [4,9]. A distinction has to be made between passive and active (interactive) systems [10,11]. The conventional paper-based patient information brochure is a typical example of a passive system [12]; others are web-based (WWW) information tools, which are gaining more and more importance [13].

Patient Information Systems Used by Physicians

Most multimedia tools and information brochures serve as a source of information for patients lacking a professional adviser. It has been reported that in too many cases the information contained in patient information leaflets is inaccurate or misleading [4]. The issues of a possible time-pressure of the advisor, the variety of differential diagnoses, and the problems with language barriers and social circumstances raise the question of how the physician is to render comprehensible information to the patient [1,14]. Coulter reported that physicians who are concerned that more empowerment for patients means greater burdens on their time should consider ways of sharing the load. She pointed out that information material and educational packages are available to help in this task [15]. Through using an active system-like our tested system "Dr Topf's patient information system"-the physician can control the tool and only show selected pictures to the patients (Figure 1). This system is designed to be used in cooperation with the patient and is expected to lead to better communication and relationship between doctor and patient.

Figure 1. Mobile computer at patient bedside

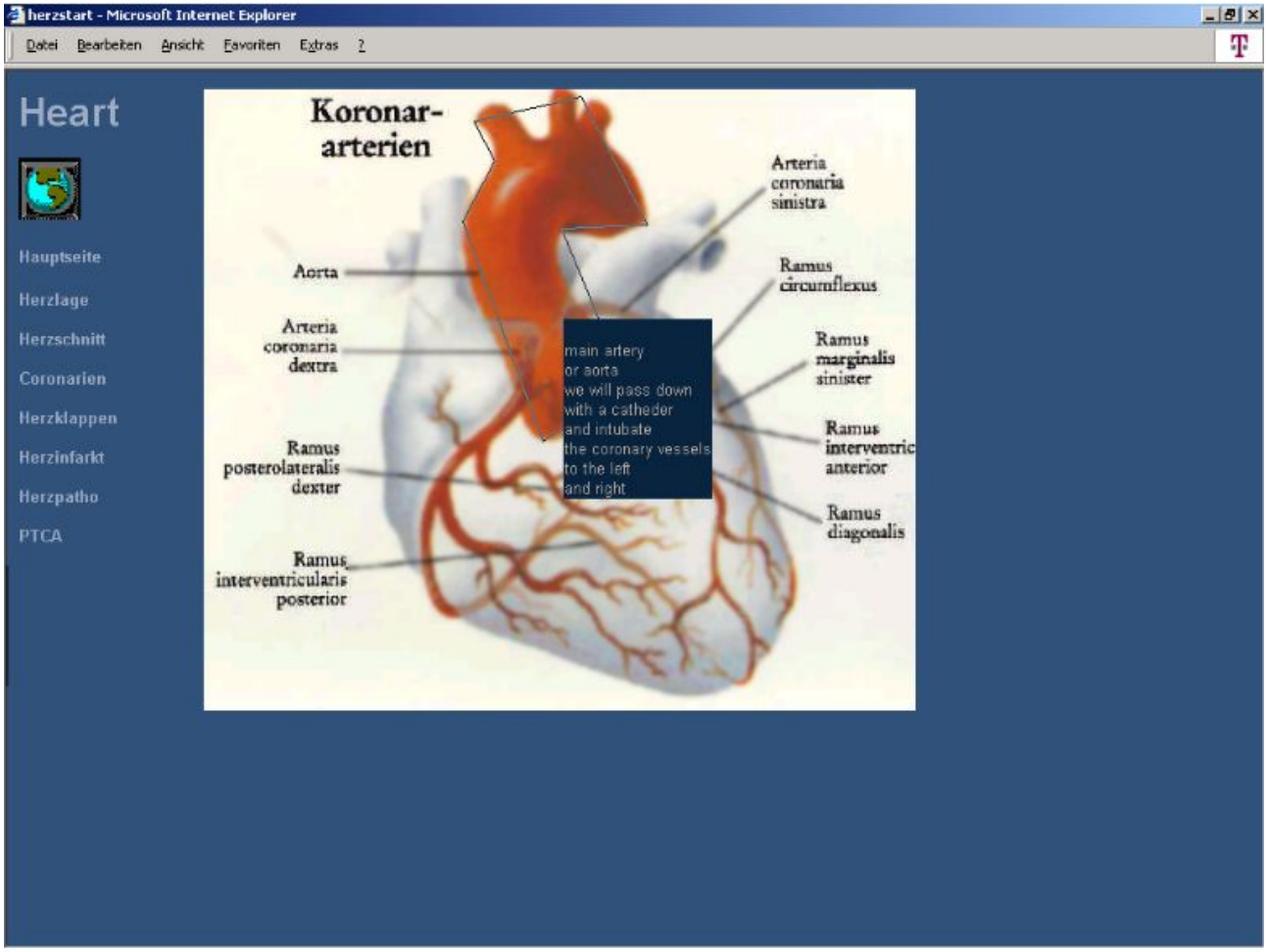


Materials and Methods

"Dr Topf's Patient Information System"

Dr Topf's patient information system makes use of the graphical presentation of medical content during the conversation between the physician and the patient to give the patient a quick and extensive understanding of the medical facts [16]. The system has been developed in cooperation with a scientific institute of general practitioners in Heidelberg in order to explain medical facts with the help of two-dimensional pictures [10]. The browser-based information tool contains a collection of pictures used in cardiology and gastroenterology, and has been primary tested in pilot studies in which 28 patients were informed about their symptoms and the forthcoming procedures [17]. By pointing on different items in these pictures, a short explanation is displayed (Figure 2). The evaluation used standardized questionnaires.

Figure 2. Screenshot Dr Topf



Protocol

Study Population

Participants included 56 patients of a cardiology ward and a gastroenterology ward. The patients were examined over a period of 5 months (Figure 3). Participants needed a Karnofsky Performance Status of 70 points minimum [18] to ensure that they were in the necessary state of health for finishing follow-up. According to this index, they should be able to care for themselves, be neither disabled nor have any serious visual defect, and be literate. Sufficient knowledge of the German or English language was also a criterion of inclusion (55 German, 1 English). In an explanatory document patients were informed that the study would not have any negative effects for them and the law for data protection would be strictly observed.

Sample Size

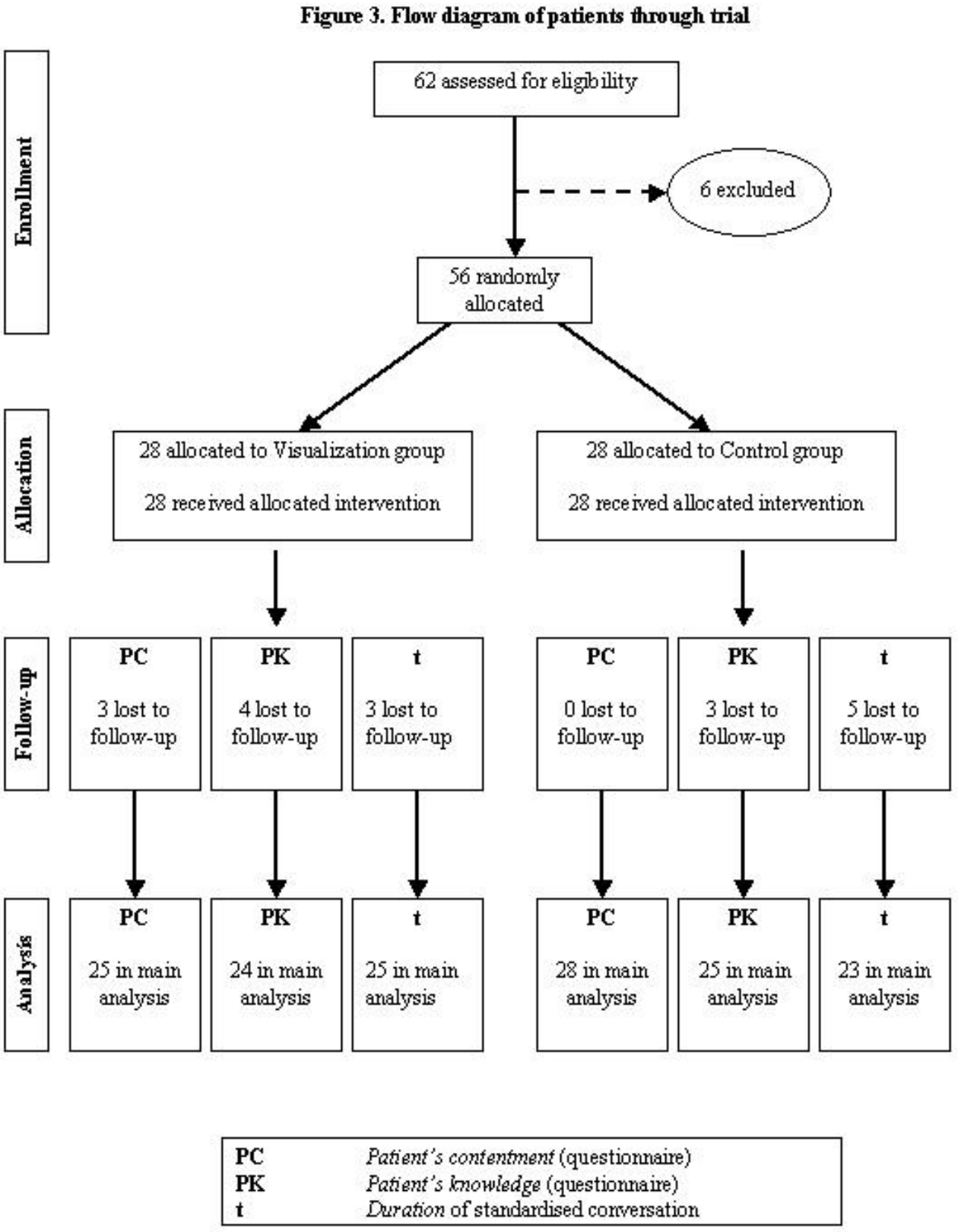
The sample size calculation was determined by the measured effects of our pilot study. As a result of the pilot study, satisfaction and knowledge of the patient obtained effect sizes between 0.65 and 0.71. For a parametric test comparing two independent groups with an assumed power of 0.8 and a level of significance (alpha = 0.05), 26 patients were perceived as an ideal number for each study group [19]. To compensate a loss due to nonevaluable patients, the study was designed to enroll 28 patients per group. The nonparametric test was not adjusted because the collected data did not follow any evident distribution.

Assignment and Randomization

For the allocation of the patients to one of the study groups, every physician received eight sealed envelopes. The inscription

on the envelopes only indicated the name of the physician and the kind of procedure (cardiology or gastroenterology). Four of the envelopes contained method A (standardized information supported by computer-based picture material), the other four contained method B (standardized conversation). The proportion of four patients per intervention group was equally divided into cardiology and gastroenterology procedures. To prevent the case of double information, all physicians were told that one of their envelopes had been given to another physician. This implied that the ratio of method A to method B could have changed from 4:4 to 5:3 or 3:5. As a consequence the physician would remain blinded from his first to his last patient. In the course of this study no change of the ratio was needed, so a balance of 4:4 for each physician was guaranteed.

Figure 3. Flow diagram of patients through trial



Intervention

After signing a written declaration of consent, patients were randomly assigned to one of two groups via the random envelopes as previously described . The intervention group received standardized information supported by picture material (i.e. a sample of five pictures maximum was presented on a sub-notebook at patient bedside). The computerized presentation

was limited to 5 minutes. Physicians who were taking part in the study had been trained to handle the information tool before the trial began.

A second group was informed by means of standardized conversation by a physician. This group was referred to as the "Control Group" because this procedure is the most common way of informing patient in Germany. Participants of both groups received the same informative brochure [12].

Seven physicians (4 senior house officers, 2 residents, 1 junior house officer) had to inform four patients of each group. Before providing information to the patient, they had to report to the study supervisor whether a patient met the criteria of inclusion.

The physicians gave every participant detailed information about the indication, the probable complications, and the details of the forthcoming procedures (i.e. about anatomy, pathology, complication ratio, possible side effects, postinterventional behavior, and alternative interventions). The following procedures were taken into consideration:

Cardiology procedures:

- Right-cardiac catheter
- Left-cardiac catheter and coronary catheter
- Percutaneous transluminal coronary angioplasty (PTCA)
- Electrophysiologic catheter of the right heart

Endoscopy procedures:

- Endoscopic retrograde cholangiopancreatography (ERCP)
- Gastroscopy
- Colonoscopy

A list with all necessary contents regarding each procedure was given to the physicians.

Consequently, they had to give every participant detailed information about the purpose of the procedure (pathological changes such as ulcers, varicose veins, sources of bleeding, polyps, or tumors), alternative ways to the procedure (e.g., x-ray, surgery), the probable complications and their treatment (e.g., punctured or injured colon wall requiring immediate surgery; bleeding, which can be treated by injection of drugs; allergic reactions), and the appropriate postsedation behavior (bed rest, no food or liquids for at least 1 hour after the examination).

The procedure was carried out one day after providing the information to the patient.

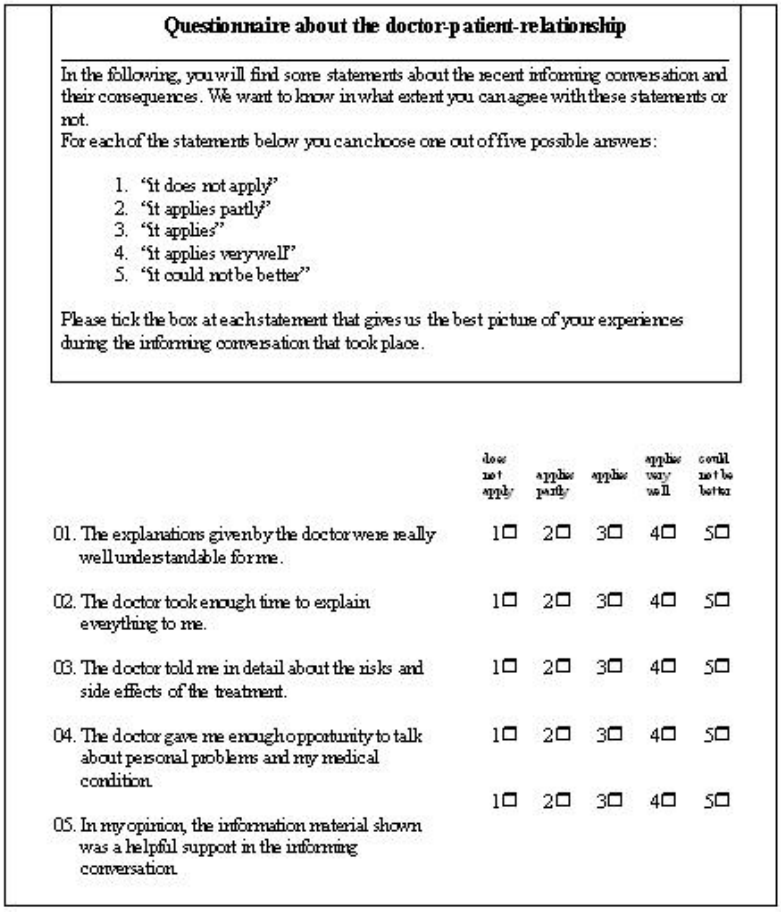
Outcomes Measured

After the intervention, every physician completed an anonymous numbered protocol to determine the time spent on the conversation, the time used for visualization, the method of intervention, the kind of procedure, and any important questions asked by the patient.

Shortly after the conversation the patient was asked to personally assess the quality of the physician-patient conversation via a patient satisfaction questionnaire (Figure 4). Five possible answers ranging from "it does not apply" (one point) to "it could not be better" (five points) were arranged on an ordinal scale. A total score of 5 to 25 points could be reached. Higher scores indicate greater satisfaction (see Table 2).

The evidence of the visualized approach was evaluated using a formalized questionnaire (standard of knowledge). Ten multiple choice questions taken from assessment papers for medical students and adapted to patient knowledge level were used to assess the method of patient education. For every query the patient had to choose either a correct or a wrong statement of five probable statements. A total score of 10 points could be reached. Higher scores indicate greater knowledge (Table 2). The questionnaires had to be answered within three days after the intervention.

Figure 4. Patient satisfaction questionnaire



Questionnaire about the doctor-patient-relationship

In the following, you will find some statements about the recent informing conversation and their consequences. We want to know in what extent you can agree with these statements or not.
For each of the statements below you can choose one out of five possible answers:

1. "it does not apply"
2. "it applies partly"
3. "it applies"
4. "it applies very well"
5. "it could not be better"

Please tick the box at each statement that gives us the best picture of your experiences during the informing conversation that took place.

	does not apply	applies partly	applies	applies very well	could not be better
01. The explanations given by the doctor were really well understandable for me.	1☐	2☐	3☐	4☐	5☐
02. The doctor took enough time to explain everything to me.	1☐	2☐	3☐	4☐	5☐
03. The doctor told me in detail about the risks and side effects of the treatment.	1☐	2☐	3☐	4☐	5☐
04. The doctor gave me enough opportunity to talk about personal problems and my medical condition.	1☐	2☐	3☐	4☐	5☐
05. In my opinion, the information material shown was a helpful support in the informing conversation.	1☐	2☐	3☐	4☐	5☐

Statistical Analysis

Scale reliability was calculated for patient's satisfaction as internal consistency (Cronbach's alpha coefficient) for the total sample population. Baseline data was collected before randomization. To check whether the assessment criteria correlated with the patient's educational level, age, and the time allocated to the conversation, a Mann-Whitney U test or *t*- test for unrelated groups using the SAS System®, version 8.2 was performed [20].

The Mann-Whitney U test was used for the comparison of patients' satisfaction and knowledge in both groups.

Masking

Allocations were sealed in opaque numbered envelopes that were opened by the physician after instruction by the independent study supervisor who generated the allocation sequence. Questionnaires had been handed out to the patients by an independent observer who was not informed about which group each patient was in. The statisticians had no contact with study participants and received only unblinded data.

Results

Participants Flow and Follow-Up

Between June and October 2002, a total of 62 patients were identified as potential participants. Of the remaining 60 patients who met the criteria of inclusion, 56 received the allocated intervention (see Figure 4). One patient received English information because of minor knowledge of the German language. Three patients dropped out because of moving to other department, 3 other patients did not meet the criteria of inclusion as acute distress (2 patients) and anxiety (1 patient). Eighty-eight percent completed the multiple choice questionnaire and 95% returned the patient satisfaction questionnaire. The reasons given for not completing follow-up (patient's satisfaction and knowledge) were not specific and included inconvenience (2 patients), lack of interest (2 patients), acute depression (2 patients), and moving to another department (4 patients).

The length of time needed for the conversation was analyzed for 86% interventions (see Table 2). No patients exceeded the limited time for visualization (5 minutes maximum).

Baseline Characteristics

As the performed *t*-test showed, no major differences were seen between the characteristics of the 56 patients of the Visualization Group and the Control Group. Furthermore, no significant difference resulted from professional qualification.

The study subjects ranged in age from 22 to 91 years. The average age was approximately 57.5 (SD 13.8) years (Table 1).

Table 1. Sociodemographic data of the Visualization- and Control Group

Variable	Visualization Group *(n=28)*	Control Group *(n=28)*	*P**
Age (years)			0.498
Mean age ± SD†	55.7 ± 10,35	58.2 ± 11.6	
Gender			0.717
Female	11	8	
Male	17	20	
Professional qualification			0.666
N.A.†	3	1	
Apprenticeship	9	18	
Craftsman/technical school	6	2	
Technical college/university	3	3	
No graduation	7	4	

* The group differences were calculated using *t* test (age), Mann-Whitney-U-Test (professional qualification) and χ^2 test (gender) at the 5% level of significance.

† SD = standard deviation; N.A. = not announced

Table 2. Outcome measures of the Visualization- and Control Group

	Visualization Group *(n=28)*			Control Group *(n=28)*			
Variable	*n*	*M (CI)*	*SD*	*n*	*M (CI)§*	*SD§*	*P**
Patient satisfaction questionnaire‡	25	21.2 (19.2 to 23.8)	4,8	28	15.8 (14.1 to 17.5)	4,5	<0.001
Item no. 5		4.1 (3.50 to 4.69)	1.44		2.9 (2.46 to 3.34)	1.13	
Knowledge questionnaire†	24	7.21 (6.5 to 7.9)	1,6	25	5.04 (3.3 to 6.2)	2,8	0.006
Knowledge questionnaire†	24	7.21 (6.5 to 7.9)	1,6	25	5.04 (3.3 to 6.2)	2,8	0.006
Knowledge questionnaire†	24	7.21 (6.5 to 7.9)	1,6	25	5.04 (3.3 to 6.2)	2,8	0.006
Overall time *(min)*	25	10.16 (8.55 to 11.24)	3,0	23	9.23 (7.19 to 11.28)	4,8	0.441
Time for visualization *(min)*		3.54 (3.41 to 4.40)	1.2				

* The group differences were calculated using *t* test (overall time) and Mann-Whitney-U-Test (patient satisfaction - and knowledge questionnaire) at the 5% level of significance.

‡ possible range 5 - 25 points

† possible range 0 - 10 points

§ M = mean score; CI = 95% confidence interval, SD = standard deviation

Primary Outcomes

Cronbach's alpha coefficient for the internal consistency of the patient satisfaction questionnaire was 0.94 and can be considered good (Figure 4). An evaluation of the satisfaction questionnaire showed a difference of 5.4 points between the Control and Visualization Groups (95% confidence interval [CI] = [2.9 to 7.9]). Concerning the evaluation of the informative material, emphasis should be given to the fact that patients of the Control Group only awarded 2.9 points compared to 4.1 points awarded by the Visualization Group (95% - CI = [0.95 to 1.45]).

In the total knowledge score, the patients of the Visualization Group reached 2.2 points more than the patients of the Control Group (95%-CI = [0.9 to 3.43]) (see Table 2).

No major differences were seen between the length of time needed for the conversation of the analyzed 48 patients of the Visualization and Control Groups (average time, *P*= 0.441) (see Table 2).

Qualitative Data

Textbox 1 shows some of the spontaneous comments from physicians.

Textbox 1. Quotes from physicians after the conversation

"I do not feel that a presentation of the images takes up significantly more of my time. However, as a consequence, the patient wants to learn more about his disease from the physician."

"The laptop computer did not attract the attention of the patient too much. I had the impression that the patient quickly picked up the physiological-pathological information and was able to ask further specific questions."

"Letting the physician operate the program seems more effective to me than having the patient look at such images by himself."

Discussion

In this prospective, randomized trial, we hypothesized that computer-based visualization would support a conversation for providing patients with information about forthcoming procedures. The patient's satisfaction with the conversation revealed higher satisfaction scores. In spite of the high reliability score of the internal consistency (0.94), sufficient variance in the scale of the patient satisfaction questionnaire was found. As a main focus, the impact of the computer-based visualization tool was directly addressed by our questionnaire, which showed a difference of 1.2 points. This means a difference from "it applies" (3 points) to "it applies very well" (4 points).This observation is consistent with other reported results [7,21].

The time needed for the conversation between physician and patient when supported by visualization was one of the most important points of interest. Some physicians pointed out that the supplement of visualization did not take more time compared to the standardized conversation (see Table 2). Although they needed more time for instruction with the computer-based information, overall time possibly could be reduced because patients could work with the computer-based information mostly by themselves. Additionally, one physician stated that these patients seemed to have less questions than the patients in the Control Group.

While in the present study the software ran on a laptop computer and was brought to the patients' bedside, the information, which is implementated in HTML, could alternatively be distributed to patients via the internet prior to hospitalization. In the future, patients undergoing elective procedures could be empowered at home or in the general practitioner's office before hospitalization. In this study our main focus was on the examination of patient empowerment by physicians assisted with computer-based visualization for already hospitalized patients.

By the increase of knowledge in the Visualization Group, it could be assumed that visualization effectively supports the educational process. Although other studies have evaluated patient satisfaction with computer-assisted instruction, few have evaluated patient knowledge before forthcoming procedures [7]. In this study patients informed by support of visualization scored significantly higher on the knowledge scale than patients from the Control Group (Table 2). The question of whether patients really get a better understanding of the medical content by being informed with support of visualization certainly depends on their previous knowledge and their intellect. A standardized questionnaire about intellect was not performed because of limited time (other examinations of the patient before forthcoming procedure), but there was no significant difference in regard to professional qualification.

Another concern frequently voiced by physicians during the pilot phase of testing was that the visualization could raise patients' anxiety. In this study none of the patients mentioned or expressed concerns in any other way that would support this hypothesis.

After our pilot study we decided to continue the study with several physicians and one independent observer to minimize the Hawthorne-Effect [22]. In contrast to our initial assumption that the computer could be an obstacle for the interaction between patient and physician, we observed the opposite effect: intrigued by visualization, patients asked more questions about the forthcoming procedures (see Box 1). Accordingly, the computer helped to improve the communication between patient and physician and reduce some of the differences in knowledge, especially for patients with little knowledge of medicine. This suggests that active patient information systems such as "Dr Topf´s patient information system" have a significant role in promoting shared decision-making. By assisting patients in clarifying and expressing their values and preferences even when their physicians have different values and preferences, such visualization is a step toward a better relationship between patient and physician.

Our findings show that computer-based visualizations like "Dr Topf´s patient information system" have desirable effects on the patient's satisfaction and knowledge. Research into improving health care by visualization of medical content should be intensified. Following the line of argumentation of Faden and Beauchamp [23] and the principles of the "informed consent" of patients, we showed the feasibility of computer-based visualization within the same time, compared to the paper-based standard, with our patients achieving higher levels of satisfaction and knowledge.

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Contributors: ME, the principal investigator, participated in the research design, collected the data, undertook the preliminary analysis of the results, and was primarily responsible for writing the paper. HBB identified the need for a trial and designed the trial; coordinated the project, guided the collection, analysis, and interpretation of data, and helped write the paper. NK participated in the design of the trial and contributed to the writing of the paper. BW undertook the data analysis and contributed to the interpretation of the results. KM advised on the design of the trial and assisted in the interpretation of findings. WH conducted the project. AH provided many helpful suggestions during study design development and preparation of the manuscript. ME will act as guarantor for the study.

Conflicts of Interest

None declared.

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Original Paper

Providing a Web-based Online Medical Record with Electronic Communication Capabilities to Patients With Congestive Heart Failure: Randomized Trial

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Abstract

Background: It is possible to provide patients with secure access to their medical records using the Internet. Such access may assist patients in the self-management of chronic diseases such as heart failure.

Objective: To assess how a patient-accessible online medical record affects patient care and clinic operations. The SPPARO (System Providing Access to Records Online) software consisted of a web-based electronic medical record, an educational guide, and a messaging system enabling electronic communication between the patient and staff.

Methods: A randomized controlled trial was conducted in a specialty practice for patients with heart failure. Surveys assessing doctor-patient communication, adherence, and health status were conducted at baseline, 6 months, and 1 year. Use of the system, message volume, utilization of clinical services, and mortality were monitored.

Results: One hundred and seven patients were enrolled (54 intervention and 53 controls). At 12 months, the intervention group was not found to be superior in self-efficacy (KCCQ self-efficacy score 91 vs. 85, p=0.08), but was superior in general adherence (MOS compliance score 85 vs. 78, p=0.01). A trend was observed for better satisfaction with doctor-patient communication. The intervention group had more emergency department visits (20 vs. 8, p=0.03), but these visits were not temporally related to use of the online medical record. There were no adverse effects from use of the system.

Conclusions: Providing patients with congestive heart failure access to an online medical record was feasible and improved adherence. An effect on health status could not be demonstrated in this pilot study.

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KEYWORDS

Heart Failure; Congestive; Patient Participation; Patient Advocacy; Patient Compliance; Internet; Randomized Controlled Trial; Electronic Communication; Electronic Health Record

Introduction

Even before electronic medical records became available, there was interest in encouraging patients to review their medical records [1]. In doing so, researchers sought to educate, engage, and empower patients. At the same time, researchers recognized that the medical record contains technical language and raw data that was never intended for the layman, so the medical record might also worry or confuse patients [2]. Clinical trials that gave medical patients access to their written records showed modest benefits (such as improved doctor-patient communication) with minimal risk of harm [3- 6]. These studies were limited, however, by small sample sizes, lack of randomized controls, short duration of exposure to the medical record, and use of non-standardized instruments for assessment of outcomes.

With the advent of electronically stored medical records and of the Internet, it has become technically feasible to provide patients access to their records online. In comparison to a written medical record kept in centralized storage, an Internet-accessible medical record may be particularly helpful for patients. Patients can review an online medical record repeatedly at their convenience, in the context of other resources that may assist them in comprehending it. Demonstration projects have shown that patients can be provided access to online medical records without compromising privacy and security. Furthermore, access to these records is appreciated by patients and causes little disruption to clinical operations [7- 9]. Controlled trials of this intervention, however, have not yet been reported.

The aim of our study was to assess the effects of a patient-accessible online medical record in a rigorously controlled fashion. Our version, System Providing Patients Access to Records Online (SPPARO), provides access to clinical notes and test results, and also provides a method of sending electronic messages to the clinic staff. We sought to determine whether access to SPPARO would improve patient satisfaction, adherence, and health status. We also studied whether providing access to SPPARO would affect the clinical workload. In addition, to assess the reach of the intervention, we obtained information from the patients who were offered SPPARO, but declined to use it.

We chose to intervene in a specialty clinic for heart failure in order to study a set of patients who shared a common medical condition and were likely to benefit from reading their medical records. Because patients with heart failure often require frequent visits and complicated medical regimens, we anticipated that access to medical records would be particularly helpful for these patients, by clarifying their doctors' assessments and instructions. We hypothesized that access to the medical record would improve their self-efficacy, adherence, and satisfaction, and might improve their health status as well.

Methods

Setting

We conducted the clinical trial in a specialty clinic for patients with heart failure at University of Colorado Hospital in Denver, Colorado. The majority of patients in the practice have New York Heart Association Class II or Class III symptoms of heart failure. Patients in this practice are cared for by a team of physicians. They therefore receive clinical notes from a variety of physicians over the course of their treatment.

The Colorado Multiple Institutional Review Board approved the study design. Security systems, including the use of passwords, firewalls, and encryption were used to prevent unauthorized access to the medical record. All participating patients signed an informed consent that included information on how to protect the privacy of the medical record. All physicians in the practice gave informed consent for their clinical notes to be shared during the study period, as well as reports of laboratory, radiology, and procedure results.

Recruitment of Study Participants

Patients were eligible for the study if they were followed in the practice, spoke English, and were 18 years of age or older. They needed to have used a Web browser before, although they did not need to have access to the Internet at home. Physicians, nurses, physician assistants, and nurse practitioners were excluded, since their sophistication in interpreting information from the medical record would not reflect the typical user of the system.

In August 2001, a recruitment letter explaining the study was sent to eligible patients. From September 2001 through December 2001, our research assistant approached patients in the waiting room of the practice, asking them if they would be interested in reading their medical records online in the context of a study that would provide this by random assignment.

After enrollment of participants in the primary study was completed, we then surveyed the patients who had declined to participate ("decliners"). After an initial solicitation by mail, patients who had not enrolled were solicited to complete written questionnaires in the clinic's waiting room from April 2002 through September 2002.

Randomization

After completing the informed consent, patients who were interested in enrolling in the primary study were provided with an enrollment form and the initial questionnaire. When patients completed the initial questionnaire they were blinded to their enrollment status.

As the questionnaires were received, patients were consecutively assigned identification numbers that were linked to either the intervention group or the control group according to a predefined computer-generated randomization scheme developed by a statistical consultant. Randomization was restricted so that equal numbers of patients were assigned to the intervention and the control groups in blocks of 10.

Intervention

Participants in the intervention group were given a user identification and password to SPPARO (System Providing Access to Records Online). These participants also received a written user guide to the system. Patients in the control group continued to receive standard care in the practice. They were offered use of SPPARO after the study was completed as an incentive to participate.

SPPARO provides a secure Web interface to three components: the medical record, an educational guide, and a messaging system (see Multimedia Appendix). Security was provided through Secure Socket Layer 128 bit encryption for all transactions beginning with login. SPPARO retrieves data from the hospital's clinical data repository (3M Lifetime Data Repository, St. Paul, MN), which is kept behind a firewall. The medical record consists of clinical notes, laboratory reports, and test results (including reports of radiographs and echocardiograms). The clinical notes were dictated by physicians and transcribed after every office visit. All clinical notes from the physicians in the heart failure practice from the start of the study period onward were available. The educational guide is

an online version of the printed materials that all patients in the heart failure practice receive at their first visit. The messaging system allowed patients to exchange secure messages with the nursing staff in the practice.

The physicians and practice staff were not told which patients were enrolled into the study. They could become aware of a patient's enrollment status, however, if a patient directly mentioned using it, or if a patient sent an electronic message using SPPARO.

During the study, periodic messages were sent by the research staff to all participants. Participants were informed about upcoming surveys, and were encouraged to contact the research assistant if they had a change of address of telephone number. In addition, patients in the intervention group were reminded to call the research assistant if they had problems using SPPARO.

Data Collection

Use of SPPARO/Electronic Messaging

Throughout the study period we tracked the dates that participants used SPPARO and what components were used. The unit of analysis was a "patient hit day," which was defined as a day that a particular participant used a component of SPPARO. Thus, if a single participant used a component of SPPARO multiple times on a given day, this counted as a single "patient hit day" for that component.

We tracked messages sent to the practice through the SPPARO system and categorized them based on content. We also tracked phone messages from participants through review of the written medical record and through logs kept by the nursing staff.

Questionnaires

For the primary study, participants completed written questionnaires at baseline, 6 months, and 12 months. The 6-month and 12-month questionnaires were mailed.

The baseline questionnaire assessed sociodemographic characteristics. All questionnaires included assessments of health status, patient satisfaction, and self-reported compliance. We used previously validated survey instruments when available. Health status was assessed using the Kansas City Cardiomyopathy Questionnaire (KCCQ) [10]. Patient satisfaction with doctor-patient communication was assessed using the Art of Medicine Questionnaire (HealthCare Research, Inc., Denver, CO, USA) [11]. Questions were modified to reflect the care provided by the panel of doctors, rather than the care of a specific doctor or a specific clinical encounter. A 5-point categorical response scale was used in place of a 9-point semantic differential scale. Adherence to medications was assessed using the questions derived from Morisky [12], and general adherence to medical regimens was assessed from the General Adherence Scale from the Medical Outcomes Study (MOS) [13].

The written questionnaire for the "decliners" assessed sociodemographic characteristics. Health status was assessed using a modification of the KCCQ symptom score. Most of these questionnaires were completed in the clinic's waiting room.

Mortality and Utilization of Health Services

Information on mortality came from chart review, the nursing staff, and telephone and mail contact with the homes of patients who had not returned follow-up questionnaires. Information on emergency department visits and hospitalizations at the University of Colorado Hospital came from chart review. The nursing staff from the practice also kept a weekly log of the time they spent answering messages sent through the SPPARO messaging system.

Outcome Measures and Sample Size

The primary endpoint of the study was a change in the self-efficacy domain of the Kansas City Cardiomyopathy Questionnaire. Like the other domains of the KCCQ, this domain generated a scaled score from 0-100. We chose a change of 7.7 to be the minimal clinically significant difference in this measure, based on a validation study of the KCCQ, which found that the mean difference in self-efficacy score during and 3 months after hospitalization for congestive heart failure was 15.4 points [10]. We set our criterion of clinical significance to be half this difference. Based on the validation study's standard deviation of change of 18.5 , we derived a target enrollment of 100 patients per group, which would provide 80% power to detect a difference of 7.7 points on the KCCQ self-efficacy domain at the $p<0.05$ significance level, using a two-sided test.

We did not set *a priori* thresholds of clinical significance for the other outcome measures. However, a change of 5 points on KCCQ scale scores, either as a group mean or as an intra-individual change, is considered clinically important (Rumsfeld J, Masoudi F, personal communication). For patient satisfaction, a difference of 0.25 points in the mean 9-point summary score from the Art Of Medicine survey, equivalent to a change of 0.14 points in our 5-point Likert scale, was previously considered to be a minimally significant difference [11]. For adherence, although the Morisky score and the MOS General Adherence score have been shown to be valid measures of adherence [12] and have been associated with clinical measures of disease activity and control [14,15], no minimal threshold of clinical significance has been established.

Statistical Analysis

Baseline comparisons were made between the intervention and control groups and between participants and decliners using t-tests and Chi-square tests. For insurance status, patients were considered to be in a "safety net" program if they had no insurance, were enrolled in a state assistance program for needy patients, or were enrolled in Medicaid.

Utilization of health services (number of hospitalizations, emergency department visits, clinic visits, and messages sent to the clinic) was analyzed in several ways because of the skewed nature of the data:

1. The proportion of patients who utilized a service was compared using Chi-square and Fisher's exact test.
2. The mean number of utilizations per patient was compared using the Wilcoxon Rank-Sum test. The number of

messages sent per patient was also transformed using square root, and means were compared using t-test.

3. Mean monthly message volume was compared using paired t-tests.

For scored questionnaire items, we used a repeated measures analysis for incomplete data to test whether the groups diverged from baseline to the 6-month and 12-month questionnaires. (A mixed model analysis was performed using PROC MIXED from the SAS statistical package, version 8.1, SAS Institute, Cary, NC, USA). The repeated measures model for incomplete data used observations prior to dropout to adjust the 6-month and 12-month means for each outcome measure, under the assumption that data were missing at random. The adjustment made to the 6-month and 12-month outcome measures was based on (1) the previously observed values of the outcome measure in the censored subjects, and (2) the strength of the association between previously observed values and the 6-month and 12-month measures in the uncensored subjects. This implicitly assumed that the associations observed among the baseline, 6-month, and 12-month measures in the uncensored subjects would have been observed in the censored subjects [16].

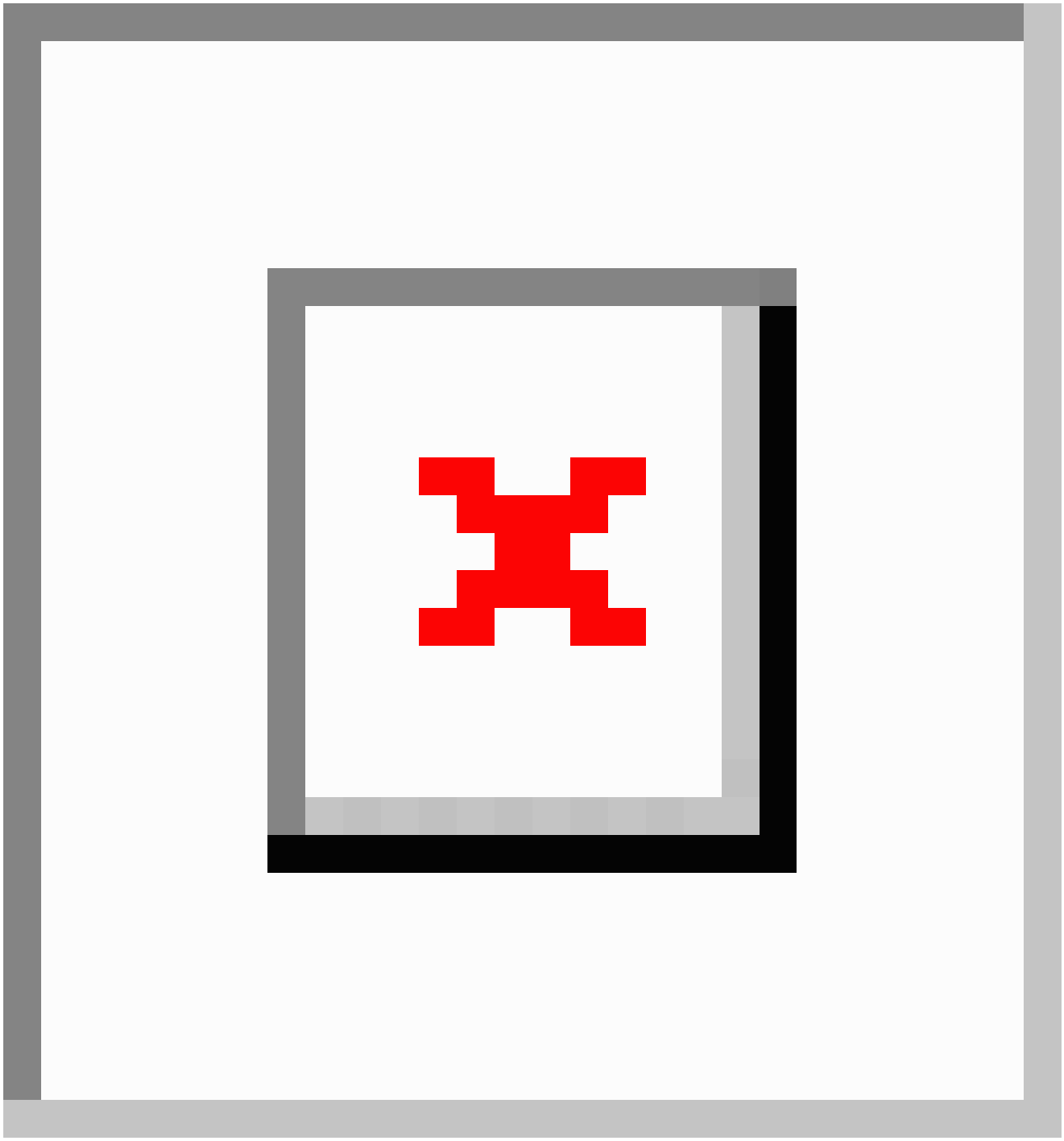
Results

Enrollment, Retention, and Demographics

Out of 394 patients in the practice panel, we enrolled a total of 107 participants (27%), 54 in the intervention group and 53 in the control group. We capped enrollment from the heart failure practice in December 2001, when we reached a point of maximal recruitment from the waiting room of the practice. Unfortunately, this point was reached before we were able to achieve our target enrollment.

Figure 1 illustrates the flow of participants through the study. The pool of eligible patients was derived from the practice census at the beginning of the study and subsequent records of patients who had appointments during the enrollment period. Two interested patients were excluded because they were health professionals (one physician's assistant and one nurse practitioner). Approximately 10 patients were not approached for enrollment because they did not speak English. Of the patients enrolled, 78.5% remained at 6 months and 76% remained at 12 months.

Figure 1. Flow of Participants Through The Study



After recruitment was completed, we identified a pool of 288 patients who were cared for by the practice during the recruitment period but did not enroll in the primary study. Of these, 144 (50%) completed the "decliners" survey.

Table 1 summarizes the characteristics of the intervention, control, and decliner groups. At baseline, the intervention and control groups did not differ in their socioeconomic characteristics, or in their health status as assessed by the KCCQ symptom score. Although we did not use the New York Heart Association (NYHA) heart failure classification, our "participants" (the combination of the intervention and the control groups) had a mean KCCQ symptom score of 65, similar to the mean score for patients with NYHA Class II symptoms in the KCCQ validation study [10].

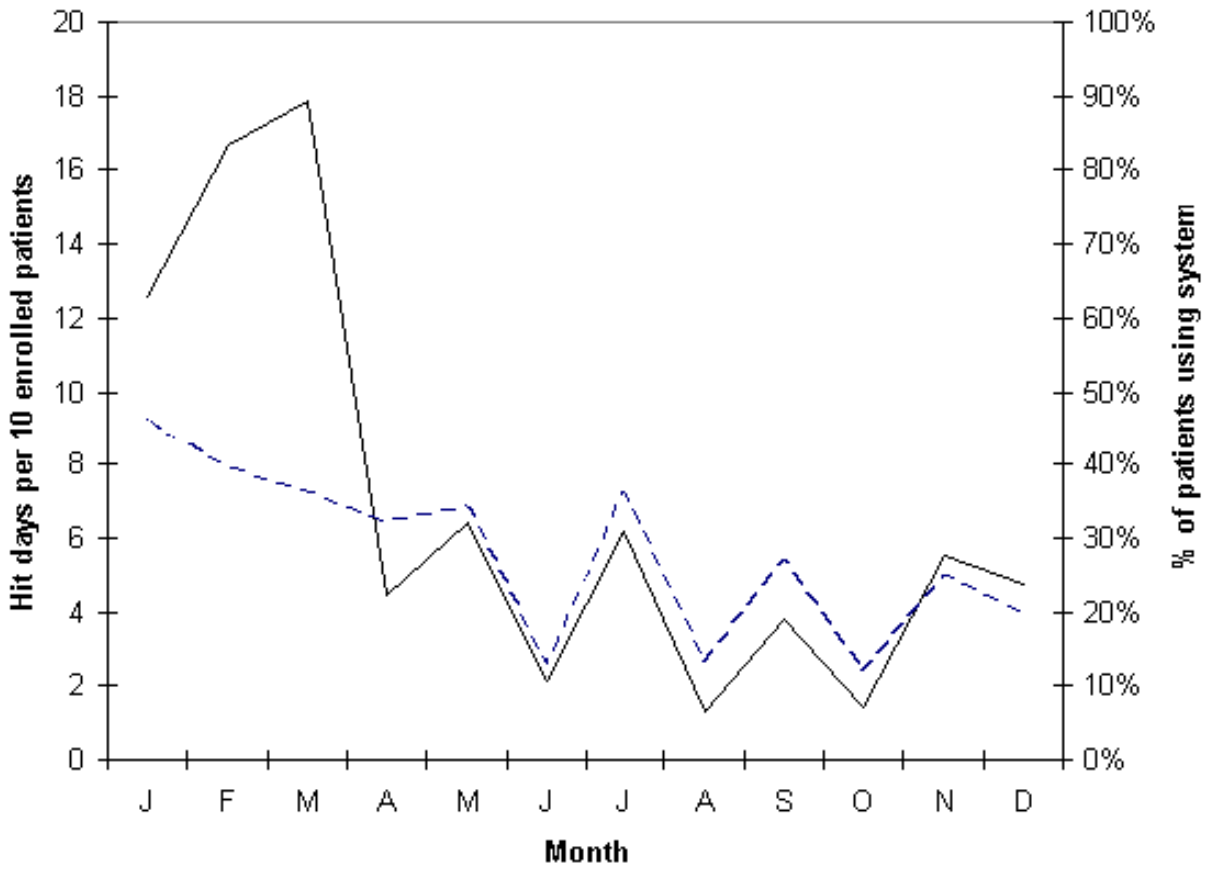
Table 1. Baseline Demographic Characteristics *

Variable	Participants (n = 107)		Decliners (n=144)	Participants vs. Decliners p-value
	Intervention Group (n = 54)	Control Group (n = 53)		
Mean age (years)	57	55	58	0.12
Male	80%	74%	64%	0.19
Self-Efficacy (from KCCQ)†	86	83	83	0.56
Symptom Score (modified KCCQ)†	69	60	61	0.15
College graduate	53%	44%	26%	< 0.001
White, non-Hispanic	92%	88%	75%	< 0.01
Household income < $45,000/year	56%	50%	76%	< 0.001
Safety-net insurance program	19%	19%	37%	< 0.01
Previous experience using the Internet	100%	100%	48%	< 0.001
Access to home computer	96%	94%	56%	< 0.001

* Participants and decliners are compared using t-test for continuous variables, and chi-squared for dichotomous variables.

† KCCQ = Kansas City Cardiomyopathy Questionnaire

Figure 2. Monthly Use of SPARRO Over Study Period



Decliners did not differ from participants in their age and gender distribution, their health status, or their self-efficacy. Compared with participants, however, decliners had lower incomes, and a lower percentage were white or of non-Hispanic race/ethnicity. Furthermore, fewer had standard medical insurance, or a college education. Although they were less likely than participants to have experience with the Internet, roughly half of the decliners

nonetheless did have access to a computer and experience with the Internet.

Use of SPPARO/Electronic Messaging

The number of patients using SPPARO and the number of patient hit days are presented in Figure 2. Use of SPPARO was highest in the first 3 months after enrollment, then leveled off. After the first 3 months, an average of 24% of the enrolled patients used SPPARO in a given month. During this time interval, frequency of use of SPPARO averaged 0.4 hit-days per enrolled patient per month. This was approximately 1 hit-day per clinic visit.

Solid line indicates hit days per 10 intervention patients per month. Dashed line indicates the percentage of the intervention patients that used SPPARO (System Providing Patients Access to Records Online) each month. Monthly website activity is normalized to account for attrition over the course of the study.

Figure 3. Cumulative Use of SPARRO Over the 12-Month Study Period

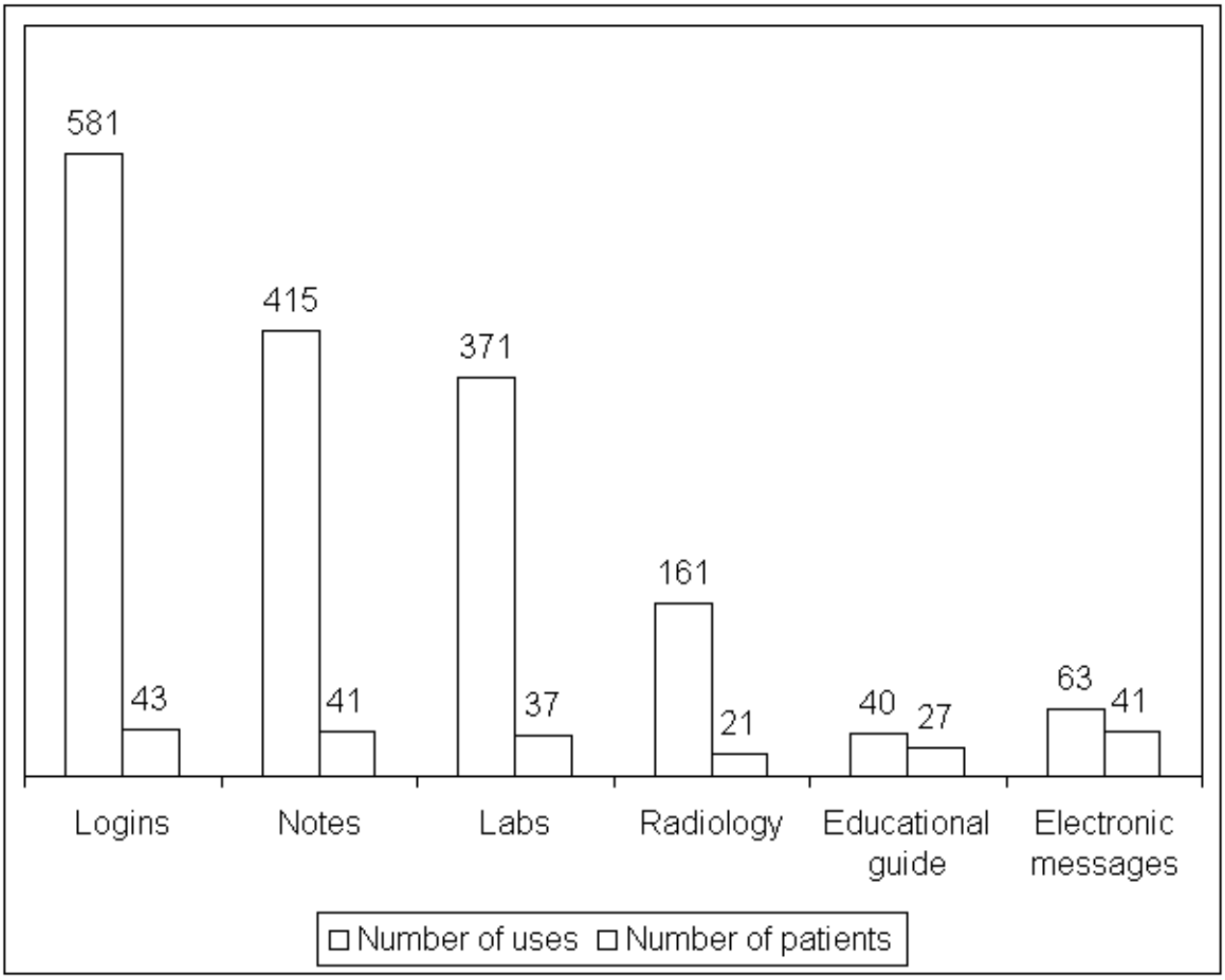
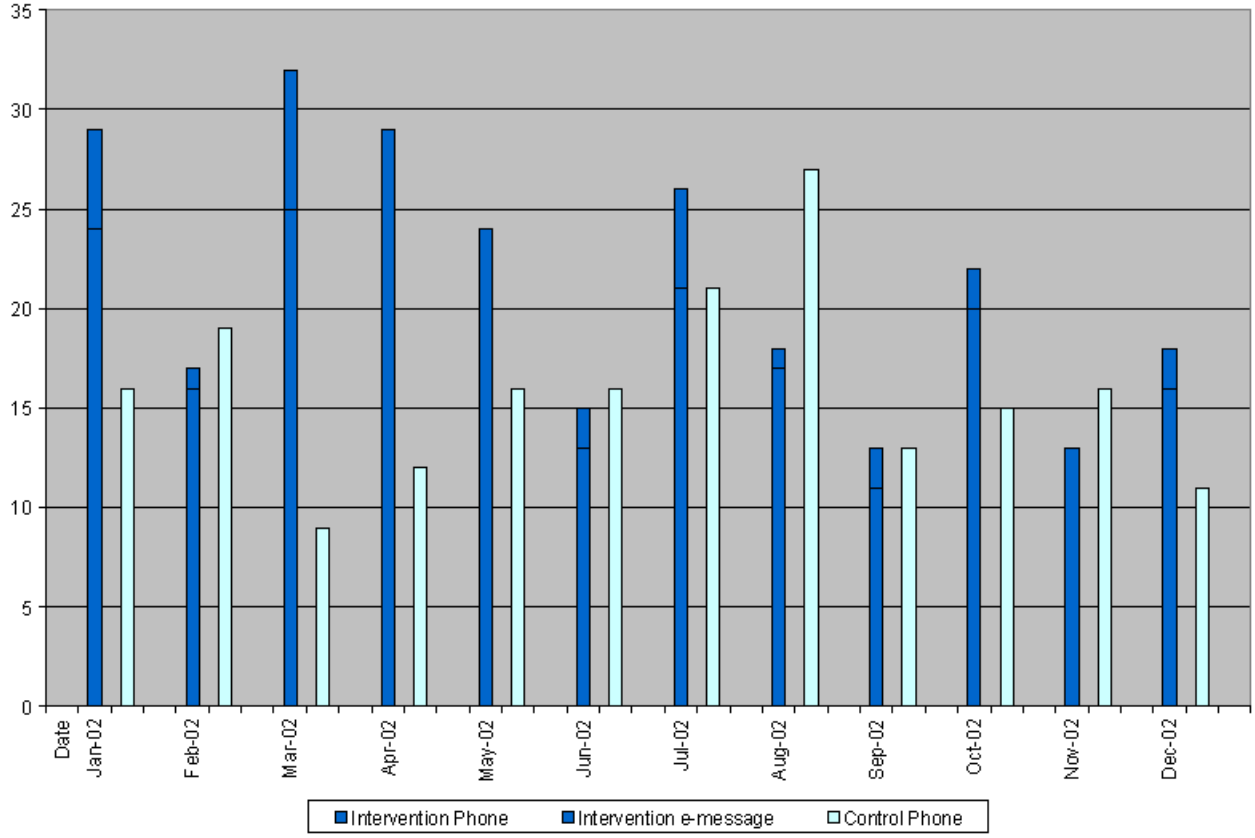


Figure 4. Monthly Message Volume



Cumulative use of SPPARO over the study period is shown in Figure 3. Subjects most commonly reviewed clinical notes and laboratory results, and did so repeatedly. Fewer subjects reviewed radiology results, but those who did also reviewed them repeatedly. The educational guide was reviewed least frequently, and was generally reviewed only once.

The electronic messaging function in SPPARO appeared to supplement, rather than replace, telephone messages. The intervention group sent more messages to the practice (350 total: 287 phone calls and 63 electronic messages) than the control group (267 phone calls) over the course of the study. The number of total messages (phone + electronic messages in the intervention group, phone messages in the control group) sent per month are compared graphically in Figure 4. The number of total messages sent per month did not show a statistically significant difference (p=0.70). The number of messages sent per patient did demonstrate a statistically significant difference when analyzed by square root transformation (p=0.02). The difference was more pronounced during the first 6 months of the intervention (150 messages in the intervention group vs. 88 in the control group, p=0.05) than the second 6 months (109 messages vs. 103, p=0.66). The main categories of messages overall were to schedule appointments (20% of total messages), to refill medications (15%), to ask questions about medications (14%), to get test results (12%), to report feeling ill (8%), and to get assistance interpreting test results (3%). In none of the individual categories was there a statistically significant difference in call volume between the intervention and the control group.

Nurses spent a total of 304 minutes answering computer messages over the course of the 12 months, a mean of 5.6 minutes per subject per year. In interviews, the physicians and nursing staff did not feel that providing SPPARO to the intervention group resulted in a perceptible change in their workload.

Self-Efficacy, Health Status, Adherence, and Patient Satisfaction

Repeated measures of self-efficacy, health status, adherence, and patient satisfaction are presented in Table 2. For our primary outcome, the self-efficacy domain of the KCCQ, there was a trend towards an improvement in the intervention group, but the improvement of 6 points did not reach the threshold value of 7.7 that we had set as a standard for this outcome. (Based on actual enrollment, the study had a power of 73% to detect a difference of 7.7, and 80% power to detect a difference of 8.8, with a two-sided alpha of 0.05). For the other measures of health status from the KCCQ, there were trends towards improvement in a many domains, but no statistically significant improvements were demonstrated when adjusted for multiple comparisons.

General adherence to medical advice showed significant improvement in the intervention group compared with the control group. Adherence to medications showed a similar trend but did not reach statistical significance.

Patient satisfaction with doctor patient-communication demonstrated a trend towards improvement in two areas: how well patients felt their problems were understood, and how well doctors explained information. While significant results were

found for these two items individually, the findings did not reach statistical significance when adjusted for multiple comparisons. There was no significant improvement in the other patient satisfaction domains.

Mortality and Utilization of Health Services

Table 3 compares mortality, hospitalizations, Emergency Department visits, and practice visits for the intervention and control groups. Although the number of patients who visited the emergency department did not differ significantly, there was a significant increase in the number of overall emergency department visits in the intervention group (20 visits) relative to the controls (eight visits). Of the emergency department visits in the intervention group, only four occurred within 7 days of using SPPARO.

Proportions of patients in the two groups are compared using Chi-squared and Fishers' Exact Test. The number of utilizations in the two groups is compared by comparing the number of utilizations per patient using the Wilcoxon rank-sum test.

Table 2. Changes In Adherence, Health Status, And Patient Satisfaction Over Time

Measure	Baseline	6 months		12 months		p-value
		Intervention - Control	Difference (CI)	Intervention - Control	Difference (CI)	
Health Status (KCCQ Domains), scored from 0 to 100						
Self-efficacy	85	88 - 84	+4 (-3, 9)	91 - 85	+ 6 (-1, 11)	0.08
Symptom stability	49	45 - 49	-4 (-15, 6)	63 - 46	+17 (4, 29)	<0.01†
Symptoms	63	61 - 65	-4 (-11, 3)	64 - 65	0 (-8, 8)	0.96
Quality of life	56	64 - 59	+5 (-5, 13)	64 - 62	+2 (-7, 11)	0.63
Functional status	66	63 - 69	-6 (-12, 0)	67 - 70	-3 (-11, 3)	0.31
Clinical summary	64	62 - 66	-4 (-10, 2)	69 - 66	-3 (-10, 4)	0.38
Physical limitations	66	63 - 70	-7 (-13, -1)	69 - 73	-4 (-12, 3)	0.26
Adherence						
Medication Adherence (scored from 0 to 4)	3.4	3.5 - 3.4	+0.1 (-0.2, 0.4)	3.6 - 3.4	+0.2 (-0.1, 0.6)	0.15
General Adherence (scored from 0 to 100)	82	81 - 78	+2.3 (-3.7, 8.3)	85 - 78	+6.4 (1.8, 10.9)	0.01*
Patient Satisfaction, scored from 1 to 5						
Overall, how well do the heart doctors understand your problems?	4.5	4.4 - 4.4	0 (-0.3, 0.2)	4.6 - 4.2	+0.4 (0.1, 0.6)	0.02§
Overall, how well do the heart doctors explain to you what they are doing and why?	4.2	4.5 - 4.1	+0.4 (0.1, 0.7)	4.5 - 4.1	+0.4 (0.1, 0.7)	0.02§
Overall, how well do the heart doctors speak to you using words that are easy for you to understand?	4.2	4.2 - 4.3	-0.1 (-0.4, 0.1)	4.1 - 4.3	-0.2 (-0.5, 0.1)	0.15
Overall, how well do the heart doctors listen to your concerns and questions?	4.5	4.6 - 4.3	+0.3 (0.02, 0.5)	4.5 - 4.3	+0.2 (-0.1, 0.5)	0.26
Overall, how much confidence do you have in the ability or competence of the heart doctors?	4.5	4.6 - 4.4	+0.2 (-0.1, 0.4)	4.5 - 4.5	0 (-0.2, 0.3)	0.80
Overall, how satisfied are you with the service that you received from the heart doctors?	4.5	4.5 - 4.5	0 (-0.2, 0.3)	4.6 - 4.4	+0.2 (-0.2, 0.5)	0.07‡

* p = 0.02 when adjusted for multiple comparisons

† p = 0.06 when adjusted for multiple comparisons

§ p = 0.13 when adjusted for multiple comparisons

‡ p = 0.30 when adjusted for multiple comparisons

The changes in outcome measures in the intervention group at each time interval are compared to the corresponding changes in the control group. Statistical analysis uses a repeated measures approach, with a mixed model to account for censored patients.

Table 3. Mortality, Hospitalizations, Emergency Department Visits, and Clinic Visits During Study Year 2002

	Intervention Group	Control Group	p-value
Deaths	6 (11%)	6 (11%)	1.00
Hospitalizations			
Number of patients	11 (20%)	12 (23%)	0.81
Number of hospitalizations	22	21	1.00
Emergency Room			
Number of patients	11 (20%)	7 (13%)	0.44
Number of visits	20	8	0.03
Heart Failure Practice			
Number of patients	50 (93%)	49 (92%)	1.00
Number of visits	324	325	0.66

Adverse Effects

There were no reports of adverse effects resulting from use of SPPARO. In only one case did access to SPPARO result in a patient complaint. That patient did not agree with a statement regarding his alcohol consumption. He requested that an amendment be placed in the clinical notes, and his concerns were documented.

Discussion

Principal Findings

Overall, this randomized controlled trial demonstrated that an Internet-accessible medical record can be provided to chronically ill patients without disrupting clinical practice, and may offer modest benefits. Although we did not demonstrate a significant effect on our primary outcome, self-efficacy, there was an improvement in general adherence to medical advice, and there were trends towards improvement in patient satisfaction with doctor-patient communication. Both adherence and doctor-patient communication are important issues in the management of complex chronic diseases such as heart failure. Although we did not demonstrate improvements in overall health status in this study, the study was not powered to exclude the possibility of such improvements.

Two other statistically significant findings are of dubious clinical significance. Although the intervention group demonstrated a dramatic improvement in symptom stability between 6 and 12 months, it seems implausible that this measure, which is based on a single item in the survey, represents an important clinical outcome when the other KCCQ domains remained unchanged. Likewise, although emergency department utilization was significantly higher in the intervention group, the intervention group did not differ from the control group in hospitalizations or mortality. It seems implausible that use of SPPARO would be the cause of increased emergency department visits without a temporal relationship between the events, or a more consistent increase in use of health services overall.

Including the electronic messaging system did result in a significant increase in the number of messages sent to the practice, particularly in the first 6 months of use. Neither the nurses nor the physicians perceived an increase in workload.

Comparisons to Other Studies

Our results were generally consistent with previous studies of patient-accessible medical records [1]. Several of these studies have also demonstrated improvements in adherence [17,18] and satisfaction with doctor-patient communication [19,20] . Most studies also did not find that patient-accessible medical records increased subjective workload [4-6,19], although a randomized trial of hospitalized patients demonstrated increased time spent answering patient questions [3]. With regard to the use of SPPARO over time, we found that use of the system was initially high, and then leveled off. This pattern has been seen in other patient-centered information technology programs, such as D-Net [21]. To some degree, this may have represented greater efficiency in use of the system, as patients learned that information was not updated unless they had a clinical encounter or laboratory study, and as they learned how long it took for transcribed notes and laboratory reports to appear. There may also have been an initial novelty effect that waned over time. With regard to electronic messaging, we found that electronic messaging did not substitute for phone communication, which is similar to the study by Katz [22].

Strengths and Weaknesses

In comparison to previous studies, this study is notable for its rigorous design. By obtaining a participant pool of only those who were interested in online patient-accessible medical records, and randomly assigning exposure status within that pool, we were able to minimize selection bias and maximize internal validity. Nonrandomized studies of interventions using information technology may be particularly prone to selection bias. In our own study, there were clear socioeconomic differences between the participants and the decliners, although their age, gender composition, and health status were not significantly different. Selecting patients with a homogeneous, serious disease process also facilitated the study of outcome measures such as mortality, symptoms, and quality of life (albeit at some cost to the study's generalizability.) The primary weakness of the study was its small sample size, which limited

its power to detect effects of the intervention, particularly after the attrition in the first 6 months.

Implications

Overall, this trial suggests that a patient-accessible electronic medical record can be implemented with the potential for a modest benefit in adherence and minimal impact on clinic operations. Although the majority of patients were not interested in online medical records, the fact that fully one-quarter of the patients in the practice were interested demonstrates that this intervention can appeal to a substantial number of patients, demonstrating its "reach" [23]. However, results may vary in more heterogeneous practices (such as primary care practices). Patients with more acute illnesses, or less severe chronic illnesses, may only access an online medical record sporadically, so the effects of the intervention may be less robust. Providing access to clinical notes that address mental health issues may also be more problematic [24- 26] .

The overall impression from studies of patient-accessible medical records is that they can improve certain aspects of care, but they are unlikely to substantially improve health status. This probably reflects the inherent limitations of interventions that focus on information alone: a better-informed patient is not necessarily a healthier patient [27]. Future directions in patient-accessible electronic medical records will likely involve integrating educational strategies with behavioral strategies, so the medical record will be presented to patients in formats that are more comprehensible, more useful, and more likely to empower patients to care for themselves.

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Conflicts of Interest

None declared.

Multimedia Appendix

[PowerPoint file, 592 KB - jmir_v6i2e12_app1.ppt]

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Abbreviations

KCCQ: Kansas City Cardiomyopathy Questionnaire
MOS: Medical Outcomes Study
NYHA: New York Heart Association
SPPARO: System Providing Patients Access to Records Online

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Original Paper

Web Content Accessibility of Consumer Health Information Web Sites for People with Disabilities: A Cross Sectional Evaluation

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Abstract

Background: The World Wide Web (WWW) has become an increasingly essential resource for health information consumers. The ability to obtain accurate medical information online quickly, conveniently and privately provides health consumers with the opportunity to make informed decisions and participate actively in their personal care. Little is known, however, about whether the content of this online health information is equally accessible to people with disabilities who must rely on special devices or technologies to process online information due to their visual, hearing, mobility, or cognitive limitations.

Objective: To construct a framework for an automated Web accessibility evaluation; to evaluate the state of accessibility of consumer health information Web sites; and to investigate the possible relationships between accessibility and other features of the Web sites, including function, popularity and importance.

Methods: We carried out a cross-sectional study of the state of accessibility of health information Web sites to people with disabilities. We selected 108 consumer health information Web sites from the directory service of a Web search engine. A measurement framework was constructed to automatically measure the level of Web Accessibility Barriers (WAB) of Web sites following Web accessibility specifications. We investigated whether there was a difference between WAB scores across various functional categories of the Web sites, and also evaluated the correlation between the WAB and Alexa traffic rank and Google Page Rank of the Web sites.

Results: We found that none of the Web sites we looked at are completely accessible to people with disabilities, i.e., there were no sites that had no violation of Web accessibility rules. However, governmental and educational health information Web sites do exhibit better Web accessibility than the other categories of Web sites ($P < 0.001$). We also found that the correlation between the WAB score and the popularity of a Web site is statistically significant ($r = 0.28$, $P < 0.05$), although there is no correlation between the WAB score and the importance of the Web sites ($r = 0.15$, $P = 0.111$).

Conclusions: Evaluation of health information Web sites shows that no Web site scrupulously abides by Web accessibility specifications, even for entities mandated under relevant laws and regulations. Government and education Web sites show better performance than Web sites among other categories. Accessibility of a Web site may have a positive impact on its popularity in general. However, the Web accessibility of a Web site may not have a significant relationship with its importance on the Web.

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KEYWORDS

People With Disabilities; World Wide Web; Internet; Health Services Accessibility

Introduction

The World Wide Web (WWW) has become an increasingly essential resource for health information consumers. One recent study estimated that 73 million US residents searched for health information online during the year 2002 [1]. The investigators estimated that seventy-odd percent of the online population search for health-related information for their decision-making [1]. Eysenbach and Kohler [2] estimated that approximately 4.5% of all search queries submitted to Web search engines are health related, which is equivalent to a global minimum of 6.75

million health-related searches on the Web every day. With the advances of computer and Internet technology, the distribution of the online population is becoming representative of the general population in terms of demographic and socioeconomic status [3].

The ability to obtain accurate medical information online quickly, conveniently, and privately provides health consumers with the opportunity to make informed decisions and participate actively in their personal care [4]. Little is known, however, about whether this online information is equally accessible to people with disabilities who must rely on special devices or technologies to process online information due to their visual, hearing, mobility, or cognitive limitations.

The latest report on Internet use from the National Telecommunication and Information Administration (NTIA) demonstrated that people of all ages, races, and ethnicities, including people with disabilities, are moving more and more of their activities online [3]. A recent investigation on Internet use by people with disabilities reported that people without disabilities are four times more likely (38.1%) to use the Internet than are people with disabilities (9.9%) [5]. Similar patterns remain even when factors, such as income, gender and educational attainment, are taken into account [5]. The large disparity in Internet usage may be attributable to problems with the accessibility of Web content [5]. Nielsen (2001) reported that the usability of the Web is about three times better for users without disabilities than it is for users with disabilities [6].

For people with disabilities, the Web is very often the only source of information that they may access without having to depend unduly on others. Equivalent Internet access to health information will open a door to people with disabilities by offering them exciting possibilities for independent living and community participation [7]. People with disabilities can find a wealth of information on the Internet that addresses many issues of special concern to them, including chronic disease information and rehabilitation and assistive technology services [8]. According to a recent report, people with disabilities tend to seek health related information online more frequently than the able-bodied population [9]. Nevertheless, for health information Web sites to be of real use to people with disabilities, they must first be accessible to them. Health information Web sites are a classic example of the "inverse information law": access to appropriate information is particularly difficult for those who need it most [4].

Background and Prior Work

Web content accessibility helps people with disabilities access Web pages directly or use assistive technologies. Many people with disabilities have to rely on specialized software or hardware to access the Web. For example, people who are visually impaired have to install a software package called a screen reader to read all the content on the Web page aloud to them. Some people who are blind also use a talking browser like IBM Home Page Reader to access the Web page aurally. Some people who are blind prefer a hardware-level solution like the computer-controlled Braille embosser to help them perceive content of the Web page haptically. Regardless of the solution favored by the users with disabilities, if the content of the Web page is not available to their remaining sensory channel, then the page is not accessible to them.

The Web inadvertently has become increasingly inaccessible to people with disabilities as it adopts numerous emerging multimedia technologies. The Web at its beginning was designed for sharing and accessing documents across different computer systems and platforms. These documents are primarily text-based and mostly accessible to assistive technology, such as screen readers. With the introduction of appealing multimedia content, however, the Web is becoming an information medium that is not accessible to or not easily interpreted by assistive technology. Graphics, animations, and even video/audio clips, now commonly appear on the Web. The absence of alternative information about multimedia content makes them less accessible to people with disabilities than those with multimodal access to the multimedia content. The rapid expansion of e-commerce also makes the Web even more complicated and less accessible for people with disabilities. As Herbert A. Simon [10] once stated, "What information consumes is rather obvious: it consumes the attention of its recipients. Hence a wealth of information creates a poverty of attention, and a need to allocate that attention efficiently among the overabundance of information sources that might consume it." Web page developers believe that multimedia content could lure more visitors to the Web site and make them stay longer. However, they may overlook or ignore the accessibility for people with disabilities to that multimedia content because its primary purpose is to draw attention from potential consumers, the majority of whom are not people with disabilities.

Realizing this dilemma, the World Wide Web Consortium (W3C), the international organization that oversees the standardization and operation of the Web, announced the establishment of the Web Accessibility Initiative (WAI) on April 7, 1997 [11]. Supported by all W3C members, including such heavyweight stakeholders as Microsoft and IBM, the WAI plays a central role in promoting and correcting the functionality of the Web for people with disabilities. The first major responsibility of the WAI was to formalize guidelines for Web content developers and designers. WAI introduced Web Content Accessibility Guidelines (WCAG) to the public as a draft in 1998, and developed it into a full recommendation in 1999 [12]. WAI expanded the guidelines to be applicable in the design of user agents (e.g., Web browsers or assistive technology agents like the screen reader JAWS for Windows), authoring tools (e.g., Microsoft FrontPage or Macromedia Dreamweaver) and related techniques, and a practical checklist [13,14].

There are two basic themes reflected in the WCAG: ensuring graceful transformation of Web pages, and making content understandable and navigable. By providing Web pages that transform gracefully, people with disabilities or users with device limitations will be able to access them without constraints. Keys to graceful transformation include separating structure from presentation, providing text equivalents to non-textual elements, creating documents that work even if the user cannot see and/or hear, and creating device-neutral documents. When the content is understandable and navigable, end users can utilize the page in a more effective, efficient and satisfactory manner. Keys for making content understandable

and navigable include providing a navigating context and orienting information, providing a clear navigation mechanism, and ensuring succinct content descriptions.

Another initiative in the development of accessibility standards is Section 508, conducted by the US Access Board [15]. The Access Board issued standards for accessible information technology under the Reauthorized Rehabilitation Act. These amendments strengthen Section 508 of the Rehabilitation Act of 1973. It mandates that when federal agencies develop, procure, maintain, or use electronic and information technology, they shall ensure that the electronic and information technology will allow federal employees with disabilities access to and use of the same information and data as that accessed and used by federal employees who are not individuals with disabilities, unless an undue burden would be imposed on the agency. Section 508 also mandates that agencies ensure equal access to individuals with disabilities who are members of the public seeking information on data that are comparable to that provided to those who are not individuals with disabilities, unless undue burden would be imposed on the agency. Section 508 clearly defines the accessibility for people with disabilities for federal government Web sites. Section 508 took effect on February 20, 2001.

Many software packages have been developed and commercialized to help Web developers evaluate the accessibility of their Web sites to people with disabilities [16]. These packages can scan Web pages, list computer detectable violations of Web accessibility standards, and give warnings for suspicious HTML snippets. Some tools integrate themselves into Web site developing or quality control programs to assist Web developers in quickly eliminating the inaccessible parts. Bobby, one of the earliest and most well known packages for checking Web accessibility, was used in our study.

Researchers from different disciplines have evaluated Web accessibility and usability of Web sites in various domains. The Journal *Library Hi Tech* published two special issues dedicated to Web content accessibility of Web-based information resources for people with disabilities [17,18]. Axel Schmetzke [19] maintains a Web accessibility survey site that aspires to be a clearinghouse for studies involving the collection of accessibility data pertaining to Web sites and online resources in education. The site listed many Web accessibility evaluation studies on libraries and higher education Web sites. Another related effort is the Web Usability Index (WUI), a free Web usability statistics database provided by UsableNet [20]. It employs an automatic Web usability evaluation tool for testing Web accessibility and obtains daily statistics of Web usability of sample Web sites from the Internet. According to WUI, only about 43% of current Web sites provide excellent or good Web usability design.

Although the Web is considered a powerful force for reshaping the healthcare infrastructure, the accessibility of Web content to people with disabilities is not a primary consideration for most designers of Web sites providing health related information [21]. Very few research studies have been conducted on the accessibility of health information Web sites for people with disabilities. Research studies on the accessibility of health information Web sites are, for the most part, about the find-ability and search-ability of Internet Web sites by online search engines or about the availability of information technology for the people who need it 22-26]. Previous guidelines related to the quality of health information Web sites failed to emphasize the accessibility of Web sites by people with disabilities [27] until the National Cancer Institute (NCI) published research-based guidelines addressing Web usability [28]. Chapter 3 of the NCI report is specifically dedicated to the issue of Web accessibility for persons with disabilities although the rest of the guidelines can also benefit general Web users.

The only study known to us that covers health information Web sites was the study conducted by Joel Davis in 2002 [29]. Davis explored the extent to which Internet-based health information is accessible to visually impaired individuals who rely on automated screen readers. Davis selected 500 individual Web sites representing 50 common illnesses and conditions for evaluation. The study found that accessibility is currently very low-only 19% of the examined sites' home pages were accessible. It also found that the reason for the inaccessibility of the Web pages was noncompliance with the recommended design and coding changes.

Our study will be different from other studies in several ways: first, the study will check the degree of accessibility not only of home pages (main pages) of health information Web sites, but also of other Web pages within certain levels below the home pages. Second, the majority of other studies report the state of accessibility in terms of the absolute number of violations of accessibility checkpoints. Although absolute numbers of violations of Web content accessibility provide useful information about the state of accessibility, it is not straightforward for direct comparison of general accessibility between Web sites, and it does not include the complexity of the webpage into the evaluation. Third, we will investigate the relationship between Web accessibility and other features of a Web site including function, popularity and importance.

Research Questions

The overall objective of the study was to evaluate the accessibility of consumer health information Web sites for people with disabilities. We were interested in the following specific research questions:

1. What is the current level of accessibility for consumer health information Web sites?
   We were interested in using automated computer programs to evaluate the current state of content accessibility of Web sites providing health information to consumers. The checkpoints used in the program were derived from Web accessibility specifications -- WCAG 1.0 and Section 508.
2. What is the relationship between Web accessibility and the functional category of the Web site?
   We were interested in determining the distribution of the level of accessibility among these Web sites after we categorized them into functional groups. We expected government and education Web sites to provide information that is more accessible to consumers than other types of Web sites because of the existing specifications and initiatives.

3. What is the relationship between Web accessibility and the popularity of the Web site?
   The hypothesis for this research question is that there is a positive correlation between the degree of Web accessibility and the popularity of the Web sites. The variable representing popularity of a Web site was determined by its visiting traffic.
4. What is the relationship between Web accessibility and the importance of the Web site?

We wanted to investigate whether there is any correlation between the level of Web accessibility and the importance of the Web site. We expected to find that more important Web sites would be more accessible to people with disabilities. The variable representing the importance of a Web site was determined by the page importance ranking data provided by a Web search engine.

Materials and Methods

Design

The study is a cross-sectional study concentrating on the degree of accessibility of Web sites providing consumer health information. We used established Web accessibility specifications as the sources for constructing the measurement framework. Additionally, we investigated the relationship between Web accessibility and other features including function, popularity, and importance.

Materials

An individual Web site providing consumer health information is the unit of analysis in the study. Because the exact number and distribution of Web sites are not pre-determinable due to the tremendous size and rapid growth of the Web, probability based sampling methods, such as random or stratified sampling, are not applicable in the study. An alternative sampling approach widely adopted by researchers conducting studies on Web sites is to use search engines or online Web site directories.

We acquired a list of consumer health information Web sites from the directory service of the Google search engine (See Appendix A). Google's directory service obtained data from the Open Directory Project, the largest, most comprehensive human-edited directory of the Web [30]. We included all Web sites under the subdirectory "Health/Resources/Consumer" as our candidate Web sites for evaluation. These are health information Web sites for the public, and their content are not necessarily specific to issues related to disability. We excluded ones that had their content changed to non-health related areas or were continuously unavailable during our study period after we reviewed the home page of each Web site.

After selecting the sample Web sites, we needed to establish a limit to the scope of the Web pages to be included within each site. Because WCAG only applies to Web pages, other content formats such as PDF (Portable Digital Format) files were not considered. However, server side scripting such as Active Server Page (ASP), or JavaServer Page (JSP) is able to dynamically produce HTML-based code at the client side, therefore we took these types of pages into consideration. Second, we needed to determine the number of Web pages from each Web site to be included in the analysis. Due to the large number of Web pages in some Web sites, it was not feasible to include all the pages into the study. We selected only the first two layers from the home page within a domain of a Web site in our sample. We hypothesized that the first two layers would be the most visited and would reflect the overall accessibility of the Web site for the study. The other reason for choosing only the first two layers was that Bobby version 4.01 has the ability to only process a limited number of pages on a given Web site because it consumes a large amount of computer memory during the analysis. When we selected three layers from the home page, Bobby encountered an "out of memory" error when analyzing large Web sites using a Pentium 2.4Ghz desktop computer with 1Gb memory.

Measurements

Web Content Accessibility

One of the objectives of the study is to construct a measurement framework to assess the accessibility of consumer health information Web sites. As we discussed in the background section, two major specifications served as the normative guidelines for Web content accessibility design. The first-the W3C Web Content Accessibility Guideline 1.0 (WCAG)-is a stable international specification developed through a voluntary industry consensus. The US Access Board published the second specification-Electronic and Information Technology Accessibility Standards-in December 2000, pursuant to the US rulemaking process as required by Section 508 of the Rehabilitation Act Amendments of 1998 [31]. Both specifications offer checklists or rules that Web developers should follow with regard to content accessibility for people with disabilities. These two specifications largely overlap; only three of the checkpoints defined in Section 508 are not mentioned in the WCAG guideline 1.0. WCAG is more comprehensive than Section 508 on checkpoints of Web content accessibility, and it provides a priority level to each checkpoint to reflect severity of violations. Therefore, WCAG was used as the foundation for the accessibility metrics we developed.

The number of violations of each checkpoint is a component of our scoring method called the Web Accessibility Barrier (WAB) score. For example, a Web page with fewer accessibility checkpoint violations, e.g., providing an alternative description for an image object, would be considered to present fewer barriers for people with disabilities and will have a lower WAB score.

Because we are interested in automated evaluation of the degree of accessibility of a Web site, the subset of Web accessibility checkpoints demanding manual checking are not included in the calculation of the WAB score. For example, compliance to the rule "If you use color to convey information, make sure the information is also represented another way," cannot be verified until a manual check is done. For a list of Web accessibility rules that need to be manually checked, please see the WAI references [32].

WCAG attaches a three-point priority level to each checkpoint from its impact on Web accessibility. Priority 1 checkpoints mandate the largest level of compliance while Priority 3

checkpoints are optional for Web content developers. In weighting the calculation of the WAB score, we used the priority level in reverse order. The weighting factor for Priority 1 violations is 3, for Priority 2 violations is 2, and for Priority 3 violations is 1.

Using only the number of violations of Web accessibility checkpoints, however, may bias the results of the measurement. For example, a Web page with five "image without alternative text" violations may have 500 image objects embedded in the page and the Web page with one "image without alternative text" violation may have only one image object in the page. The developer of the first page may have already paid a great deal of attention to and put great effort into complying with the Web accessibility specifications while the developer of the second page may be completely unaware of accessibility. Therefore, the number of true violations of a checkpoint must be normalized against the number of potential violations of the checkpoint. In the last example, true violations are the image objects without alternative text, and the potential violations include all image objects on the page. Whenever a Web developer puts an image element into a Web page, he increases the potential that there could be a violation of the "alternative text" checkpoint. Table 1 explains the selection of potential violations from HTML code. The average WAB score of all Web pages within a Web site will be the WAB score of the Web site.

Figure 1 summarizes the calculation of the WAB score of a Web site as a formula. A higher score means there are more accessibility barriers on the site, while a lower score indicates fewer barriers. A score of zero denotes that the Web site does not violate any Web accessibility guidelines and should have no automatically detectable accessibility barriers to people with disabilities.

Figure 1. Formula for Calculating the Web Accessibility Barrier (WAB) Score

$$WAB\ Score = \frac{\sum_{p}\sum_{v}\left(\frac{n_v}{N_v}\right)(W_v)}{N_p}$$

p: Total number of pages within a website

v: Total number of violations on a Web page

n_v: Number of actual violations

N_v: Number of potential violations

W_v: Weight of violaitons in inverse proportion to WCAG priority level

N_p: Total number of webpage checked

We employed several program tools to examine the true and potential violations of the Web pages. Bobby is a checking program that can examine a Web page and report violations of Web accessibility checkpoints [33]. It is the most widely used accessibility checking software package and has been around longest. Bobby was originally developed by the Center for Applied Special Technology [34], and is now maintained and distributed by Watchfire Corporation [35].

Bobby desktop version 4.0.1 was used in this study. The desktop version can check compliance with WCAG of an entire Web site or only certain layers from the main page of the Web site. The version 4.0.1 can check non-compliance issues with both WAI and Section 508 checkpoints. After checking a Web site, Bobby generates a report in eXtensible Markup Language (XML) format that can be further processed to extract data about true violations.

Bobby implements 91 distinct testing rules, each of which maps onto a specific WCAG checkpoint. The Bobby tests are classified into a number of different "checking" categories, as follows: (1) Full: Bobby automatically checks this rule and decides whether there is an error. (2) Partial: Bobby automatically performs some checking of the rule, but cannot decide the existence of violations. Instead, the line number is used as a warning to the testers. (3) Partial Once: Similar to the Partial category, but the warning is not specific to an individual line. (4) Ask Once: Bobby does not have a mechanism to check the rule, so the rule is presented as a reminder to the testers.

For all categories other than Full, a human tester must manually evaluate the Web site further to determine the WCAG compliance, which is not viable for a large scale Web site study like this one. We used only the 25 rules that Bobby implements with Full checking capacity for our evaluation. Even for the rules with "Full" checking capacity, we still could not determine the quality of the compliance with WCAG. For example, the Web page developer could simply put the file name of the image into the "alt" attribute of the <IMG> element to avoid a flag from Bobby. The quality of such compliance is much less acceptable than providing detailed description in the "ALT" attribute.

The data of corresponding potential violations for each checkpoint can be extracted using a Web crawler program, which is an automated program that follows hyperlinks to visit Web pages. We developed a lightweight Java-based Web crawler program to access Web pages at remote Web sites and determine the number of potential violations of Web accessibility checkpoints. We did not use the built-in Web crawler in Bobby because it cannot be customized to check potential violations of checkpoints in a Web page. We also made use of the "homemade" crawler as the basis for future development of tools for Web accessibility evaluation. For a list of rules for extracting data of potential violations, please see Table 1. Since the crawler embedded in Bobby and the "homemade" Web crawler may retrieve an unmatched number of pages for the different capacities of both crawlers, we only used the Web pages retrieved by both programs in the study.

Table 1. Checkpoints and the Determinant of the Number of Potential Violations

WAI Priority	Checkpoint	Determining the number of potential violations
1	Provide alternative text for all images.	All <img> elements
1	Provide alternative text for each APPLET.	All <applet> elements
1	Provide alternative content for each OBJECT.	All <object> elements
1	Provide alternative text for all image-type buttons in forms.	All <input type="image" …> elements
1	Provide alternative text for all image map hot-spots (AREAs).	All <area> elements
1	Each FRAME must reference an HTML file.	All <frame> elements
1	Give each frame a title.	All <frame> element
2	Use a public text identifier in a DOCTYPE statement.	1*
2	Use relative sizing and positioning (% values) rather than absolute (pixels).	All <table>, <th>, <td>, and <frame> elements
2	Nest headings properly.	All heading elements
2	Provide a NOFRAMES section when using FRAMEs.	All <frameset> element
2	Avoid blinking text created with the BLINK element.	Same as the number of true violations#
2	Avoid scrolling text created with the MARQUEE element.	Same as the number of true violations#
2	Do not cause a page to refresh automatically.	1*
2	Do not cause a page to redirect to a new URL.	1*
2	Make sure event handlers do not require use of a mouse.	Number of event handler for both keyboard and mouse
2	Explicitly associate form controls and their labels with the LABEL element.	Number of form elements such as <input>, <select>, and <textarea>
2	Create link phrases that make sense when read out of context.	Number of <a> elements
2	Do not use the same link phrase more than once when the links point to different URLs.	Number of <a> elements
2	Include a document TITLE.	1*
3	Client-side image map contains a link not presented elsewhere on the page.	Number of <area> elements
3	Identify the language of the text.	1*
3	Provide a summary for tables.	Number of <table> elements
3	Include default, place-holding characters in edit boxes and text areas.	Number of <input type = "text">, <text area>, and <select> elements
3	Separate adjacent links with more than white space.	Number of links

* This feature is determined at the entire page level. Therefore, we assign 1 to the number of potential violations.

The number of potential violations of this feature was not able to be determined. Therefore, we used the same number of the true violations as the number of potential violations. The frequency of the violations is simply 0 or 1 according to the formula of Web Accessibility Barrier (WAB) score.

Function of the Web Sites

We measured three variables-function, popularity and importance-as other features of the Web sites. We classified the candidate Web sites based on their functions. We used a taxonomy that classifies the Web sites into six functional categories: e-commerce, corporate, portal, community, government, and education. We derived the taxonomy from a similar one from the Web Usability Index database [20]. An e-commerce Web site conducts online transactions of health related products or services. A Corporate Web site represents a health care service corporation online. A Portal Web site

provides entrance to various health related information resources. A Community Web site hosts online activities for patients or health information seekers. Government and education Web sites have the postfix ".gov" and ".edu", respectively in their domain names. Table 2 lists example Web sites from each category.

Table 2. Example Web Sites of Each Functional Category

Category	Definition	Examples
Portal	Web site provides entrance to various health related information resources	Web MD (http://www.webmd.com)
Government	Web site has the postfix ".gov" in the domain name	Health Finder from U.S. Department of Health and Human Services (http://www.healthfinder.gov)
Corporate	Web site represents a health care service corporation online	Mayo Clinic (http://www.mayoclinic.com)
E-commerce	Web site conducts online transaction of health related products or services.	Health Windows (http://www.healthwindows.com)
Community	Web site hosts online activities for patients or health information seekers.	Health Forum (http://www.healthforum.com)
Education	Web site that has the postfix ".edu" in the domain name	HealthLink from medical college of Wisconsin (http://healthlink.mcw.edu)

Two evaluators individually assigned each Web site to one of the aforementioned categories. In case of a disagreement about the assignment, both evaluators discussed it until reaching a consensus. Each Web site fell into only one of the categories. Government (.gov) and education (.edu) Web sites had precedence over other function categories. For example, HealthFinder.gov is a government Web site, but its function is also to provide health information as a portal. We assigned it to the government instead of portal category. The reason for the precedence is that we were especially interested in the degree of Web accessibility of these two functional categories because of the existing specifications and initiatives.

Popularity of the Web Sites

We used daily traffic-ranking data of each Web site that was provided by the search engine Alexa as the measurement variable for the popularity of the Web sites [36]. Alexa calculates statistics about the traffic patterns of a Web site after aggregating visit data from all users who install Alexa's toolbar in their Web browsers during a three-month period. Because the Alexa toolbar is currently only available for Microsoft Windows and Internet Explorer, the accuracy of the traffic ranking of the Web site is limited. However, it may reflect the popularity of the Web site on the Web to a certain extent. We retrieved the ranking data of the entire candidate Web sites from Alexa on February 25, 2003.

Importance of the Web Sites

We measured the degree of importance using the PageRank score of each Web site available from the Google search engine. The PageRank score relies on the uniquely hypertext nature of the Web by using its vast link structure as an indicator of an individual page's value. In essence, Google interprets a link from page A to page B as a vote by page A for page B. Therefore, the PageRank score of a page can be viewed as an indicator of the importance of the page. But Google looks at more than the absolute volume of votes, or links that a page receives; it also analyzes the page that makes the vote. Votes cast by pages that are themselves "important" weigh more heavily and help to make other pages "important." [37] Because Google does not provide PageRank in a numerical value from its searching interface, we had to rank the sites according to an implicit PageRank score and use the ranking number as the value of the variable of importance. We retrieved the ranking of importance of all candidate Web sites from Google on February 26, 2003.

Data Analysis

All statistical analyses were performed with alpha value at 0.05 and power at 0.80. Descriptive statistics (means and standard deviation) were calculated for each variable considered in the study. Univariate statistics of the WAB scores were calculated at the level of each category. Then a one-way ANalysis Of VAriance (ANOVA) test was applied to the WAB scores at the level of the Web site's functional category. If the ANOVA test indicated a large difference in the WAB scores among different categories, the post hoc Bonferroni test of the WAB scores between different categories was conducted. The alpha level was adjusted for multiple comparisons in the Bonferroni test.

Google ranked Web sites with a sub-category from highest to lowest PageRank value. Therefore, we used the ranking sequence as the value of Web page importance for nonparametric Spearman correlation. Nonparametric Spearman correlation statistics were also conducted to measure the level of correlation between the WAB scores and the popularity of the Web sites. All statistical analyses were conducted using the SPSS 11.0 software package.

Results

Descriptive Statistics

The Google subdirectory "Health/Consumer/Resources" lists 122 Web sites, 14 of which were excluded because their content are no longer healthcare related or they were not active during the study period. The assessing program retrieved 7,109 Web pages from the remaining 108 sites. Means and standard deviations of WAB scores for the remaining 108 Web sites were calculated. The average WAB score was 9.31 with standard

deviation of 6.29. None of the 108 Web sites was absolutely accessible (WAB score = 0). The National Institutes of Health (NIH) Combined Health Information Database (CHID) Web site (http://chid.nih.gov/) achieved the lowest WAB score, i.e., it had the fewest accessibility barriers, of the sites tested (0.97), while a community Web site (http://www.discussyourhealth.com/) received the highest WAB score (24.99). The five most frequently violated WCAG checkpoints of all webpages were: "identify language of the text" (77.0%), "use a public text identifier in a DOCTYPE statement" (65.6%), "provide a summary for tables" (61.6%), "use relative sizing and positioning (% values) rather than absolute (pixels)" (60.0%), and "provide alternative text for all images" (52.2%).

WAB and Categories

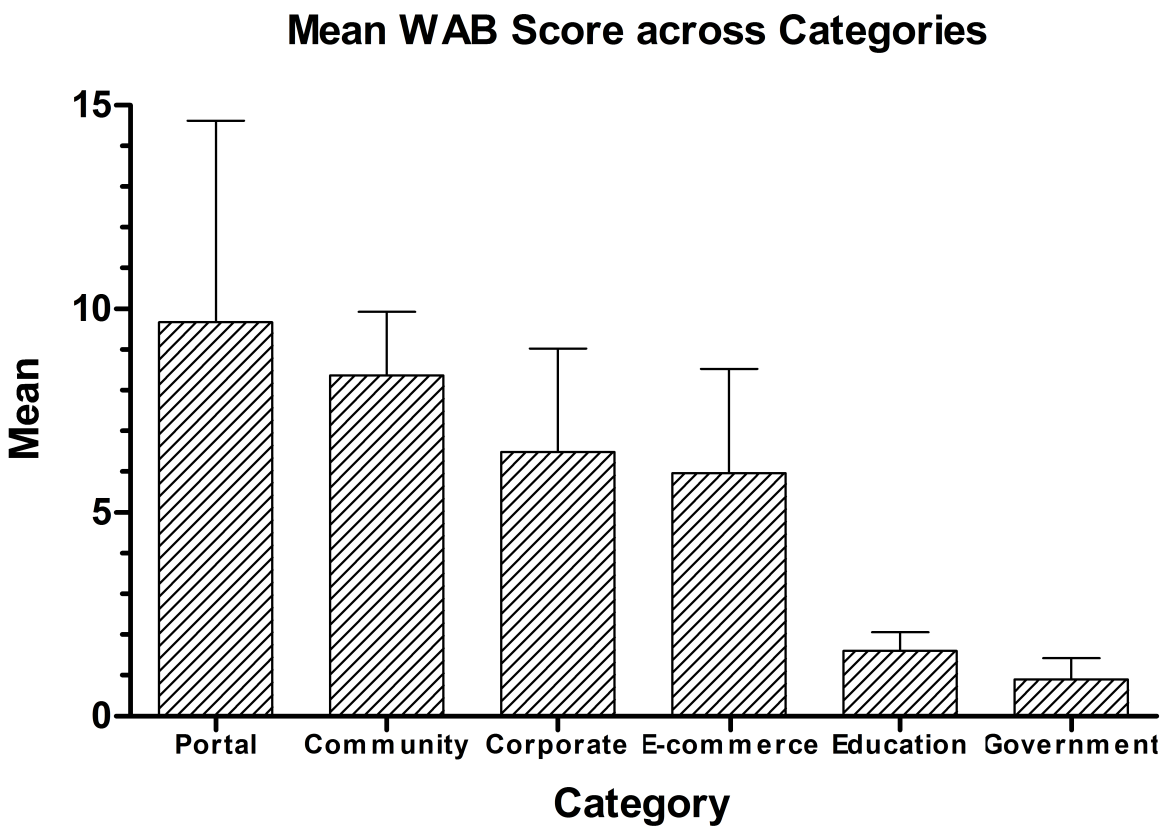
Among the six functional categories of Web sites, government Web sites were most accessible and had the lowest WAB scores, and portal Web sites were least accessible to people with disabilities, indicated by higher WAB scores (Table 3).

Table 3. Means and Standard Deviations of the Web Accessibility Barrier (WAB) Scores Across Functional Categories

Category	Mean	Number of Web sites (n)	Standard Deviation
Portal	13.17	30	6.16
Government	1.42	6	0.39
Corporate	9.03	25	3.94
E-commerce	8.53	8	3.39
Community	9.92	29	6.8
Education	2.06	10	1.16
Total	9.31	108	6.29

The average scores of Web accessibility were calculated for each of the Web categories and the results indicate possible clustering among the six categories, as shown in Figure 2.

Figure 2. Means of the Web Accessibility Barrier (WAB) Score of Each Category. Height of Each Bar Represents Mean WAB Score. The Horizontal Tick Above Each Bar Represents Standard Deviation of WAB Score



Statistically significant differences among the category groups were found using the ANOVA test on the WAB scores ($F = 9.705$, $P < 0.001$). In addition, the post hoc Bonferroni test found that the mean WAB scores of governmental and educational

Web sites were significantly different from the rest of the categories (P < 0.001). There is no statistically significant difference between any two categories within each of the two clusters.

WAB Score vs. Popularity and Importance

Furthermore, the Spearman correlation test indicates a statistically significant, though modest, correlation between the WAB score and the Alexa traffic ranking (r= 0.28, P < 0.01). No statistically significant correlation between the WAB score and the PageRank of Web sites was found (r= 0.15, P = 0.111) using the Spearman correlation test (Table 4). The correlation between the Alexa's traffic ranking and Google's PageRank was statistically significant (r= 0.32, P < 0.01) using the Spearman correlation test.

Table 4. Spearman Correlation Coefficients Between the Web Accessibility Barrier (WAB) Score, Alexa Ranking and Google's Pagerank

	WAB score	Alexa ranking	PageRank
WAB score	1.00	0.28*	0.15
Alexa ranking	0.28*	1.00	0.32*
PageRank	0.15	0.32*	1.00

* Correlation is significant at the 0.01 level (2-tailed). The complete results data set is included as a data supplement with this article.

Discussion

Awareness of accessibility issues is increasing among developers of Web sites due to law enforcement, public initiative, and prospective commercial incentives [21]. Even though many evaluation tools are now available to developers intending to improve the accessibility of their Web sites, the status of Web accessibility, especially among health information Web sites, is largely unknown. Compliance with the specifications of Web content accessibility is necessary to narrow the digital divide between the information affluent and digitally underserved people, in this case, those with disabilities. Ours is the first study to address the issue. It provides a relatively comprehensive evaluation of the Web accessibility of consumer health information Web sites, and proposes a metric evaluation for measuring the accessibility of a Web site, taking into account both accessibility violations and the complexity of the Web site presented as potential violations of accessibility checkpoints. This approach provides a more accurate and impartial measurement about the level of accessibility barriers than using only the absolute number of violations as has been employed by most other evaluations. Additionally, the study investigates the relationship between the level of accessibility and the function, importance and popularity of a Web site.

Current Level of Web Accessibility Across Consumer Health Information Web Sites

No consumer health information Web sites satisfied all of the Web accessibility requirements, which may be attributed to Web site developers knowing little about accessibility standards, the lack of effective and efficient evaluation and repair tools, and the pressure to update information on the Web site quickly. Web accessibility, if ever considered, is often an afterthought once Web content design is finished. This implies that program tools that produce efficient, effective post-hoc repairs of Web content accessibility violations, or an accessible proxy server that transforms and filters inaccessible online content for people with disabilities may be more accepted by both the developers and Web site visitors.

Web Accessibility and Functions of the Web Sites

Of the sites providing health information, government sites followed by education sites are the most accessible. This compliance may be attributed to Section 508, since it is mandatory for all federal agencies [38]. High compliance among sites that fall under this mandate also indicates that legal activities would facilitate the removal of accessibility barriers for people with disabilities.

None of the tested Web sites, including the most accessible government sites, passed the WCAG guideline priority 1 checkpoints, even though the five most frequently violated checkpoints have technically uncomplicated solutions if designers pay attention to them. This may imply that the Web site editor simply overlooked the errors and, for such editors, an automatic Web site monitoring program could be very helpful in identifying and correcting these errors. Other possible reasons for such imperfection are the lack of integrated accessibility tools or functions within Web site editing software. Most Web site editing tools make it optional to strictly follow accessibility rules.

The education Web sites are the second most accessible category. Section 508 is not strictly mandatory for the information technology available on educational Web sites, but high awareness of WCAG rules and legal requirements on most campuses may contribute to better accessibility among the education Web sites. Furthermore, although Section 508 does not mandate all education Web sites, it does apply to educational programs and projects that receive federal funding, as many do, which may explain the high compliance to WCAG rules among education sites.

Web Accessibility and Popularity of the Web Sites

The accessibility of a Web site also correlates with its popularity, possibly implying that people with disabilities are more likely to visit sites that contain fewer or no barriers to them. A more accessible Web site may be more usable for the general population because it can also improve the efficiency, effectiveness, and ease of using the Web site [39]. Meanwhile, accessible Web pages will have better opportunities for indexing by Web search engines, which use programs called crawlers to access Web pages on the Internet and store Web page indexes

in a database for fast Web information retrieval. Web crawlers work similarly to Web users who are blind and using screen reader programs. Therefore accessible Web pages will have more chances to be indexed by a Web crawler [40]. Subsequently the overall popularity of the Web sites increase since they attract a group of visitors who have difficulties accessing other sites containing more Web accessibility barriers. Other reasons for the correlation between accessibility and popularity include the possibility that people may take notice that a Web site is accessible and tend to visit it often, or Web developers of accessible Web sites spend more time ensuring their Web sites are appropriate in following other usability rules that make visiting easier for the public.

Web Accessibility and Importance of the Web Sites

The correlation between Web accessibility and a Web site's importance was not statistically significant in our study, although the correlation between its importance and popularity was statistically significant. The measurement of the importance of a Web site was derived from comprehensive link analysis on the Web. It revealed the value of the Web site by measuring how many and what kind of other Web sites link into it. It does not necessarily reflect the value of other HTML elements, especially those Web accessibility related elements. A Web site can be very important in terms of PageRank because many other Web sites have links to it, even though it is not accessible to persons with disabilities when they directly visit it.

Limitations

Please note that there are several limitations to this study. First, although this study attempts to comprehensively assess the accessibility of a Web site, it is not practical for some Web sites, especially those with large numbers of archived documents. The Bobby program often freezes when checking all layers of a Web site, and this resulted in the decision to check only a manageable two layers of Web pages in this study. A more robust tool needs to be adopted or developed for future studies.

Second, only the checkpoints of Web accessibility that can be examined automatically by a computer program were studied. Many other checkpoints require a manual check of pages to ensure the compliance of the content with the guidelines of Web accessibility. WAI proposed a comprehensive framework for evaluating Web content accessibility which requires multiple steps involving several evaluation tools to ensure the accuracy of the evaluation results. Although this type of evaluation is important for quality assurance of individual Web sites, the cost of such a large operation makes it impractical for an evaluation study involving many Web sites. This study assumes that the checkpoints that can be automatically evaluated will strongly correlate to the manual checkpoints and can be used as a surrogate assessment for accessibility of a Web site. Future studies might explore the agreement between these two groups of checkpoints.

Furthermore, the traffic ranking information provided from Alexa may skew towards users of Internet Explorer on a Windows operating system, underestimating the traffic to sites that are disproportionately accessed by people using other browsers or operating systems. The site most likely to suffer from this bias is AOL (America Online), since their members commonly use AOL browsers to access the site.

The WAB score in the study can be used to measure the degree of accessibility of a site. However, it should not be used as the only indicator for Web accessibility, which includes other checkpoints that can not be automatically assessed by computer programs. An experienced Web developer can fine-tune a Web site to produce a perfect WAB score. However, this does not necessarily mean that the Web site is entirely accessible to people with disabilities when they visit it.

Conclusions

This study evaluates the current state-of-accessibility of consumer health information Web sites for people with disabilities. Accessibility barriers are present in all site categories, especially commercial Web sites. Government and education Web sites show better performance than those in other categories. Accessibility may have an impact on its popularity because people with disabilities will feel more comfortable visiting those sites with fewer accessibility barriers. This study attempts to increase the awareness of Web accessibility among the designers of consumer health information Web sites.

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Conflicts of Interest

None declared.

Appendix A

Consumer Health Web Sites Selected from Google for Accessibility Evaluation

Table A1. Consumer Health Web Sites Selected from Google for Accessibility Evaluation

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
Consumer Reports Online	http://www.consumerreports.org	Information and advice on health products, services, and decisions.	community	2,015	3.44	4
Health A to Z	http://www.healthatoz.com/	Includes a directory of more than 50,000 professionally-reviewed Internet resources, supportive online communities, and a calendar.	community	22,436	2.33	8
Dr. Gabe Mirkin	http://www.drmirkin.com	Reports on health, fitness, and nutrition news from talk show host Gabe Mirkin, M.D., in text and audio form.	community	52,851	3.56	28
Body1.com	http://www.Body1.com/	Health news and medical information community for consumers.	community	211,705	6.99	30
ProWho	http://www.prowho.com/	Locate health professionals anywhere in the world.	community	1,098,188	6.91	34
MDAdvice.com	http://www.mdadvice.com/	Provides health and medical information, health tips, resources, experts, news, chats, and community support.	community	88,689	11.09	45
Askapatient.com	http://www.askapatient.com/	Provides a database of patient opinions and ratings of medicine effectiveness. Also includes weekly consumer opinion polls on healthcare topics, and a health care research assistance section.	community	424,906	3.22	46
Health & Family Resource Guide	http://www.noeasytask.com	Personal and professional sites containing valuable information and links.	community	871,197	2	48
1UpHealth: Your Health Resource on the Net	http://www.1uphealth.com/	Offers information concerning condition and diseases. Listed by alphabet, systems/types, and by demography.	community	57,395	5.67	51
CountryNurse.com	http://www.countrynurse.com	Includes information on clinics, family wellness, disease prevention, diet, exercise and pharmacies.	community	2,742,182	3.45	58
Selfhealth	http://www.selfhealth.com.au/	Consumer health information including a medical Q&A database and an Australian drug database. Covers infertility, emotional health, sexual health & integrative & complementary health issues.	community	1,055,493	4.87	59
Oneday MD Program	http://www.onedayMD.com	A medical e-course, written for the everyday layman. Easy to understand and digest.	community	ND	7.98	60
Wonderful World of Diseases	http://www.diseaseworld.com/	Catalog of links and information on diseases and human conditions. Includes an online bookstore.	community	375,309	4.99	63
Medidoctor	http://www.medidoctor.com/	A home health guide to diagnosis and treatment, and when to see your doctor or go to hospital.	community	603,475	11.98	65
Wellness.com	http://www.wellness.com	Includes health resources, discussion and news.	community	403,791	13.99	72
Digital City - Health	http://www.digitalcity.com/health/	Health resources and providers across the United States.	community	1,030	24.88	77
Discuss Your Health	http://www.discussyourhealth.com/	Discussion forums and health information.	community	ND	24.99	81
Mindy Machanic's Change Pages: Wellness and Health Info	http://www.mindymac.com/Health.html	Articles on healthy foods, cancer and breast cancer. Includes comprehensive links to additional resources for health and wellness.	community	3,156,154	5.99	83

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
Health-Center.com	http://www.health-center.com/default.htm	Resources on numerous health topics. Includes a bulletin board and discussion forum.	community	49,607	5.44	86
C.S.S. Doctor's Credentials Search	http://www.tese.com/css/index.html	Search for a Doctor's Medical School, Board Certification, residence training, licensing, disciplinary action (if any), and other important information.	community	668,459	10.34	88
Health In Depth	http://www.healthindepth.com/	Health information links to newspapers, magazines and internet resources.	community	ND	14.98	89
American Care	http://www.americancare.net/	Provides access to a network of medical professionals and medical facilities.	community	ND	20.99	93
DoctorInfo	http://www.maxpages.com/doctorinfo/	Provides searches for background information on medical doctors or doctors of osteopathic medicine.	community	3,232	21.66	98
Internet Health Library	http://www.health-library.com	Searchable index to healthcare sites.	community	247,229	15.89	103
Urgent Medical Help	http://www.urgentmedical-help.com/	Offers a list of medical topics, and expert advice.	community	ND	16.88	108
Health+Plus / Dr. David Clark [1]	http://communities.msn.com/DrDavidClarkHealthPlus	Information and alternatives on various health challenges.	community		4.66	109
Well-aware	http://www.well-aware.co.uk	Provides information on conditions, complementary treatments and expert views, all written by doctors in the United Kingdom.	community	279,876	6.77	110
AOL Anywhere Health Web Channel: Tests and Tools	http://search.aol.com/dirsearch.adp?query=health%20tools	Informational question and answer tool for assessing your personal health and fitness. Addresses a variety of common conditions, diseases, and disorders.	community	23	10.44	112
SciTalk.com	http://www.scitalk.com/	Science related resources for the public on health and disease. Discussion boards, chat, news, patents, clinical trials and books.	community	831,828	11.21	113
			community			
Health Communication Network	http://www.hcn.net.au/	Provides the up-to-date health information on a variety of subjects.	corporate	62,522	5.928365085	21
BluePrint for Health	http://blueprint.bluecrossmn.com/	A health and wellness portal which provides health information, personalized newsletters and interactive health tools.	corporate	55,309	6.117271677	22
Apples For Health	http://www.apples-forhealth.com/	Consumer news on healthcare topics.	corporate	109,078	2.770206902	26
The Health Resource, Inc.	http://www.thehealthresource.com/	Specialized medical research reports on mainstream, experimental, and alternative treatments, specialists, and support organizations.	corporate	751,741	6.473851872	35
HealthLink Plus	http://www.healthlinkplus.org/	Consumer health information on general health, health care providers, medical research, insurance, wellness, mental health, and alternative medicine.	corporate	1,012,019	9.223706688	49
HealthFrontier.com	http://www.HealthFrontier.com/	Offers information including diseases and conditions, nutrition, exercise, mental health, live discussions and a message board.	corporate	1,118,483	4.706849182	52
Accenthealth	http://www.accenthealth.com/	Database of news, articles, and information about conditions, medications, and tips for living a healthy lifestyle.	corporate	215,095	3.094589415	53

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
HealthStatus	http://www.healthstatus.com	Free reports on body fat percentage, body mass index, calorie burning activities, target heart rate and smoking costs. Online health risk assessment which provides resources based on your health risks.	corporate	100,176	14.48851992	55
Health-MD	http://www.health-md.net	Provides informational links covering all aspects of health.	corporate	1,894,244	14.28787455	57
eCureMe.com	http://www.ecureme.com/	Identify symptoms to make a self-diagnosis; set up online consultations with physicians and therapists; view online medical dictionary of diseases, treatments, drug information.	corporate	28,626	8.174559539	61
Patient Protect	http://www.patientprotect.com/en/	Medical consultation devoted to protecting and defend patients. Contributes to reducing health costs, by preventing abuses, negligences, medical errors and incompetence in the health field.	corporate	ND	14.26290622	62
A Second Opinion Medical Information Services	http://www.physicians-background.com	Medical treatment options, physician background check service, best hospitals and doctors. (Ft. Walton Beach, FL)[Fee based service - ed]	corporate	1,164,345	8.513670197	64
50+Health	http://www.50plushealth.co.uk	Health topics, lifestyle magazine, discussion forum, news and research.	corporate	986,902	8.035373745	66
Medical Elite	http://www.medical-elite.com/	International medical consulting and information company that specializes in locating medical specialists. Translated into English, Arabic, Chinese, Portuguese, Russian, Spanish, and other languages.	corporate	1,574,968	5.083424917	71
GetWell.org	http://GetWell.org/	Offers resources for consumers on medical conditions, treatment and research.	corporate	3,373,473	3.704081763	74
Global Health News and Resources	http://www.globalhealthnews.org/	Offers news and resources in the health industry.	corporate	ND	9.244440892	75
The Lifestyle Doctor	http://www.lifestyledoctor.uk.com/	Information on lifestyle issues and simple ways to help oneself.	corporate	3,097,649	12.39462059	78
UHealthy Network	http://www.uhealthy.com/	Global health information network and community that integrate every aspect of Health and Fitness in one place.	corporate	94,364	4.341446672	80
Vital Star Health, Science and Technology Resource Center	http://www.vitalstar.com/health.html	Free online Medical Check up How healthly your are? Test your eye, BMI, carbs, protein, cholestrol, heart, height, calories, depression. Plus articles, news and updates related to health and fitness.	corporate	1,154,166	11.10723414	84
WoundHeal.com	http://www.woundheal.com/info/infoIndex.htm	Educational information and resources for the non-surgical healing of pressure ulcers, at home.	corporate	2,266,566	14.12597302	85
Wellness Hour Medical Informational Talk Show	http://www.wellnesshour.com	A medical talk show aired in over 100 cities throughout the United States.	corporate	1,523,336	7.012615012	97
Health and Wellness	http://www.health-and-wellness.org/	Explains the importance of "wellness", information on how to rate your own wellness, and how onsite programs can boost employee productivity.	corporate	ND	13.80270648	104
Medical Information Dictionary	http://www.medical-information-dictionary-and-videos.com/	Dictionary with extensive listings on treatments. Current information on new medical procedures and definitions.	corporate	777,994	9.957871849	105
Discovery Health	http://www.discoveryhealth.com/	Offers news and a variety of health information resources.	corporate	495	7.237195863	121

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
			corporate		9.433343772	
HealthAnswers	http://www.healthanswers.com/	Contains health news and information, including a health encyclopedia.	corporate,portal	80,996	12.46205114	119
HealthWindows	http://www.healthwindows.com	A membership healthcare network that helps individuals to become more knowledgeable and active participants in managing their personal health.	e commerce	723,999	2.13913917	23
Quackbusters	http://www.quackbusters.com.au/	Offers nutrition and general health information.	e commerce	507,145	5.362357494	33
Clinnix: Health Care Information	http://www.clinnix.net	Includes daily news, travel information and disease management.	e commerce	802,713	13.12822279	40
Prozac Prescription Online Pharmacy	http://www.prozac-prescription-online-pharmacy.com	Consult this Prozac guide to get prices, medical facts and tips on where to buy. Includes interaction data and uses.	e commerce	2,776,050	15.78729775	68
HealthCheck Risk Assessment	http://www.bodybalance.com/hra/	Useful health risk assessment.	e commerce	606,674	15.26809823	69
Health Depot	http://blakkat.com/health.htm	Directory to health and medical sites about diet, fitness, disabilities, diseases, health resources, products and sales.	e commerce	148,973	15.04753096	76
Alternative Healing and Lifestyles	http://alternatehealing.com	Offering resources ranging from weightlifting to mind, body, and Nutrition. Many links to health sites.	e commerce	ND	15.50132577	100
DoctorOnNet.com [2]	http://www.doctoronnet.com/	Resources for information regarding medicine, doctors, health, fitness and related topics.	e commerce	445,255	8.931488165	102
			e commerce			
CNN Health	http://cnn.com/HEALTH/	Health news, chats and advice from CNN.	education	26	2	1
MCW HealthLink	http://healthlink.mcw.edu/	Features health news and information, produced by the Medical College of Wisconsin.	education	15,109	2.01	5
McGill Molson Medical Informatics: Student Projects	http://sprojects.mmi.mcgill.ca/	A growing collection of multimedia projects in medical teaching. Developed by McGill medical students under the supervision of the McGill Medical Faculty. Includes a student/faculty forum.	education	5,536	1.66	27
Evaluation of English and Spanish Health Information on the Internet	http://www.rand.org/publications/documents/interneteval/	The findings of a large study that describes and evaluates English and Spanish health information on the Internet. Assesses search engine performance and the quality and readability of health information on the Internet, and provides conclusions and recommendations.	education	25,966	4.56	31
Duke University Healthy Devil On-Line	http://gilligan.mc.duke.edu/h-devil/	Online medical resources and information.	education	4,808	3.44	32
Health Leader	http://www.uthouston.edu/hLeader/index.html	A webzine produced by The University of Texas Health Science Center, which provides information to help you make better decisions about your health.	education	563,631	2.44	36
BBC Online	http://www.bbc.co.uk/health/conditions/	Information about a wide range of health conditions, summaries of illnesses and treatments, and details of organizations that can provide medical and emotional help and support.	education	39	1.03	120

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
Your Health IS Your Business	http://weber.edu/hp/Faculty/molpin/bushea/index.html	Site includes information on health and wellness including primarily links to sites on the internet on health and wellness.	education	28,291	1.46	122
BBC Health Your Rights	http://www.bbc.co.uk/health/consumer/index.shtml	Advice on everything from finding the shortest waiting lists to what to do if you think you are a victim of medical negligence.	education	39	1	123
BBC News - Medical notes	http://news.bbc.co.uk/hi/english/health/medical_notes/	Information briefs on health topics related to the news, including several on environmental health topics. Listed alphabetically.	education	39	1	125
			education			
National Institutes of Health -- Health Information Index	http://health.nih.gov	Main consumer health information page for the National Institutes of Health (NIH)	government	286	1.45	2
Healthfinder (tm)	http://www.healthfinder.gov	Resource for consumer health and human services.	government	22,660	1.02	3
Combined Health Information Database	http://chid.nih.gov/	A database produced by health-related agencies of the Federal Government. Provides titles, abstracts, and availability information for health information and health education resources.	government	286	0.97	10
Agency for Health Care Policy and Research	http://www.ahrq.gov/consumer/	Consumer health and patient information on health plans and insurance, prescriptions, conditions and diseases, surgery, quality of care, quitting smoking, and prevention and wellness.	government	68,255	1.63	12
Michigan Electronic Library - Health Information Resources	http://mel.lib.mi.us/health/health-index.html	Extensive resources and links of interest to the health consumer and to professionals.	government	21,404	2.01	29
Buying Medical Products Online	http://www.fda.gov/oc/buyonline/	Information for consumers from the US Food and Drug Administration. How to determine if a site is legitimate; how to spot health fraud; and how to report fraudulent sites.	government	3,067	1.44	114
			government			
MayoClinic.com	http://www.mayoclinic.com/	Clinical experts provide current medical information and news on health topics.	portal	4,156	16.61	6
Dr. Koop's Community	http://www.drkoop.com/	Former Surgeon General Koop's resources for health information. A wide variety of topics, an encyclopedia, pharmacopeia, and resources guide.	portal	14,244	15.06	7
WebMD - Consumer	http://my.webmd.com/	Frequently updated portal for healthcare, chat forums, health quizzes, news and consumer product updates.	portal	514	14.10	9
Diseases, Disorders and Related Topics	http://www.mic.ki.se/Diseases/index.html	Karolinska Institutet, Stockholm, Sweden. Comprehensive listings of links to medical information, most reliable, some not.	portal	9,844	4.94	11
Achoo Healthcare Online	http://www.achoo.com/	Portal and directory for medical news and information.	portal	101,658	12.59	13
Medinex	http://www.medinex.com	Provides a safe health search for medical information available on the internet.	portal	504,726	14.96	14
Healthgrades.com	http://www.healthgrades.com/	Grades the performance of hospitals, physicians, health plans, nursing homes and other health care providers in the United States.	portal	71,775	22.90	15

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
Halls MD	http://www.halls.md/	Clinical calculators of body surface area, breast cancer risk and body mass.	portal	94,880	4.79	16
Health In Focus	http://www.healthinfocus.co.uk/	Independent UK health information and medical information resource.	portal	293,598	16.48	17
Laurus Health Information	http://www.LaurusHealth.com	Information on health conditions, pharmaceuticals, medical news, plus profiles of physicians and hospitals. Free registration.	portal	47,108	4.20	18
Cochrane Consumer Network	http://www.cochraneconsumer.com/	This international group dedicated to the study of evidence-based medicine, explains how to decipher clinical studies and how to use them when making decisions about medical care.	portal	688,474	21.34	19
Internet Pharmacy and Online Pharmacies Verification	http://www.nabp.net/vipps/intro.asp	National Association of Boards of Pharmacy provides searchable listings of approved online pharmacies.	portal	97,563	17.54	20
Medicine OnLine	http://www.meds.com	In-depth information on cancer for health care professionals and patients.	portal	87,469	12.95	25
Find a Doctor in Your Area	http://www.vab.com	Geographic directory of doctors with links to their web sites.	portal	352,920	20.31	37
Best Doctors	http://www.bestdoctors.com/	Comprehensive knowledge-based medical referral service.	portal	102,232	9.47	39
Health Consumer Alliance	http://www.healthconsumer.org	Provides information to consumers and advocates about access to health care for low-income consumers, including consumer education materials in 13 languages.	portal	2,026,586	7.49	42
Doctor Healthynet	http://www.doctorhealthynet.com/	Offers diagnosis and treatment of conditions and diseases, medical procedures, preventive health guidelines, and sources of free medicines.	portal	630,052	18.59	44
AnswerMed.com	http://www.answermed.com/	Provides basic information on medical conditions and procedures including symptoms, diagnosis, treatment, predicted outcome and alternative diagnoses.	portal	1,178,690	3.16	47
Health, Nutrition and Fitness	http://www.health-nutrition-and-fitness.com	Search this extensive directory of sites, focusing on exercise and fitness, nutrition, mental health, depression and therapy, and diseases such as osteoporosis.	portal	ND	7.37	54
Health Plug	http://www.healthplug.com/	Provides information on prescription drugs and other medications, with a message board and news links.	portal	2,136,121	8.01	67
MDinteractive	http://mdinteractive.com/	Providing consumers with healthcare information and resources in every medical specialty. Providing physicians and patients with an efficient way to create and store medical records interactively.	portal	2,494,795	9.17	79
Access Place Health	http://www.accessplace.com/health.htm	Link collection about medical news, health and fitness and some medical specialties.	portal	109,338	3.35	90
SymptomTracker	http://www.symptomtracker.com	An interactive medical diagnosis and treatment reference that uses brief yes/no questions about a users symptoms to arrive at possible conditions and treatments. [Please note the "Warning" before proceeding - ed]	portal	467,922	4.33	92
Surgery Door Home Healthcare Guide	http://www.surgerydoor.co.uk/HomeHealthcareGuide/	Symptoms of common illnesses and ailments. From the UK's on-line health service.	portal		18.73	95

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
iMedNetworks	http://www.imednetworks.com/	An internet-based healthcare network that connects physicians and patients to each other and to a virtual world of medical information, tools, and services.	portal	2,217,720	6.54	111
Germ Detectives [3]	http://www.germdetectives.com/	Portal site to health information, hoax busters, and ways of avoiding Bad Science.	portal		15.78	115
KnockDoctor.Com	http://www.knockdoctor.com	Health portal covering subjects such as family health, beauty, yoga, ayurveda, health and fitness.	portal	3,067,983	22.95	116
MedicalClub [4]	http://www.medicalclub.com	Provides interactive free health information on Womens, Childrens and Family health concerns. The site also includes extensive information on herbal medicines, supplements and First Aid. Bilingual, English/Spanish.	portal		17.81	117
Planetamber	http://www.planetamber.com/	Global International health, medical and disability resources database. Categorized medical condition search for people with disabilities or health impairments, their families and those providing services and support.	portal	2,783,436	10.16	124
Search-It-All	http://www.search-it-all.com/biomedical.asp	Doctor and hospital search, nutrition facts, drug and disease lookup and health information.	portal	4,129,642	5.40	126
			portal			
Mylifepath	http://www.mylifepath.com	Provides information on health and wellness, daily health news and message boards.	Site not available	410,709		24
Consumer Laboratory Testing Information	http://www.ascls.org/labtesting/index.htm	A thorough guide to medical laboratory tests, why they are performed, and what they might mean.	Site not available	933,912		41
Carepanion [5]	http://www.carepanion.com/	Provides life care products, services and tools. Contains links, news, articles and suggested further resources on medical issues.	Site not available	1,097,498		43
The Medical Information Warehouse	http://www.medfindnow.com/	Offers medical and disease information including poison control and child abuse areas.	Site not available	1,498,881		50
SearchPointe [6]	http://www.searchpointe.com/	Free verification of name, location, and education of doctors and chiropractors.	Site not available	3,423,196		56
HealthExpos.com	http://www.healthexpos.com/	Information on upcoming events and expos in Minnesota.	Site not available	ND		70
Health Forums	http://www.healthforums.com/	Customized libraries of health and well-being information. Log in to access an extensive library of resources.	Site not available	ND		73
Livingand-Health.com	http://www.livingand-health.com/	Offers information on topics such as diabetes, irritable bowel syndrom (IBS), hypertension, and epilepsy.	Site not available	16,128		82
No Frills Health	http://www.nofrillsguide.com/health.htm	An easy to use and useful guide to health sites on the net.	Site not available	ND		91
Citypractice.com [7]	http://www.citypractice.com/	Provides information on preventitive approaches in physical, behavioural and emotional healthcare.	Site not available	ND		94

Name	Address	Description	Category	Alexa Rank	Web Accessibility Score	Page Rank
Health4m	http://www.health4m.com	Health forum for support, information, or exchanging ideas. Topics of discussion include general health, fitness, nutrition, diets, women's/teen's/men's issues, depression, A.A/N.A recovery, acne, mental illness.	Site not available	1,454,527		96
Worldnethealth.com	http://worldnethealth.com/	Offers an online medical encyclopedia with a large medical slide library and videos.	Site not available	ND		99
Health and Wellness Topic Center [8]	http://health.medscape.com/wellnesscenter	Provides information and interactive health management tools across a variety of disciplines.	Site not available	514		101
Journey To Wellness [9]	http://www.ihealthradio.com	African American health magazine and radio show. Listen to archived radio programs of the nationally syndicated radio programs, as well as read program related articles and link to credible related resources..	Site not available			106
Medicalresource-susa.com	http://www.medicalresource-susa.com/	Offers guides to American hospitals, health clinics, medical practices and specialties.		ND		38
Healing Action [10]	http://www.healingaction.com/	Health related articles on food, aging, ecology as it relates to health.		3,802,737		87
A Patient's Guide to the Internet	http://www.patientsguide.com	A step-by-step guide for patients seeking medical information on the Internet.		203		107
Building Better Health	http://www.pcsrx-online.com	Provides information on health and wellness, along with daily health news, full-text journal and magazine articles.		4,103,022		118

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Abbreviations

WWW: World Wide Web
WAB: Web Accessibility Barriers
NTIA: National Telecommunications and Information Administration
W3C: WWW Consortium
WAI: Web Accessibility Initiative
WCAG: Web Content Accessibility Guidelines
WUI: Web Usability Index
NCI: National Cancer Institute
PDF: Portable Digital Format
ASP: Active Server Page

JSP: Java Server Page
XML: eXtensible Markup Language
ANOVA: ANalysis Of VAriance
NIH: National Institutes of Health
CHID: Combined Health Information Database

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Original Paper

Efficacy of Quality Criteria to Identify Potentially Harmful Information: A Cross-sectional Survey of Complementary and Alternative Medicine Web Sites

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Abstract

Background: Many users search the Internet for answers to health questions. Complementary and alternative medicine (CAM) is a particularly common search topic. Because many CAM therapies do not require a clinician's prescription, false or misleading CAM information may be more dangerous than information about traditional therapies. Many quality criteria have been suggested to filter out potentially harmful online health information. However, assessing the accuracy of CAM information is uniquely challenging since CAM is generally not supported by conventional literature.

Objective: The purpose of this study is to determine whether domain-independent technical quality criteria can identify potentially harmful online CAM content.

Methods: We analyzed 150 Web sites retrieved from a search for the three most popular herbs: ginseng, ginkgo and St. John's wort and their purported uses on the ten most commonly used search engines. The presence of technical quality criteria as well as potentially harmful statements (commissions) and vital information that should have been mentioned (omissions) was recorded.

Results: Thirty-eight sites (25%) contained statements that could lead to direct physical harm if acted upon. One hundred forty five sites (97%) had omitted information. We found no relationship between technical quality criteria and potentially harmful information.

Conclusions: Current technical quality criteria do not identify potentially harmful CAM information online. Consumers should be warned to use other means of validation or to trust only known sites. Quality criteria that consider the uniqueness of CAM must be developed and validated.

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KEYWORDS

Quality; harm; Internet; medical information; World Wide Web; complementary and alternative medicine

Introduction

Online health information can harm as well as heal. Many quality criteria have been suggested to help consumers identify misleading, inaccurate, or harmful information. Objective quality criteria that offer a limited number of options are particularly promising since they are easier to assess. For example, it is easier to assess whether an author is identified than to determine whether the author is qualified. However, even seemingly objective quality criteria have proven unreliable without specific operational definitions [1]. Further, there is little evidence that these criteria, known as "technical criteria," actually filter out undesirable health information. The few studies that have attempted to evaluate technical criteria reported conflicting

results [2-4]. If harmful information can be effectively identified, this should be publicized. If, on the other hand, currently available quality criteria cannot identify potentially harmful information, then we should caution consumers and work on finding other ways of identifying problematic information online.

In this study, we analyze Web sites that display information about complementary and alternative medicine (CAM). CAM includes "diverse medical and healthcare systems, practices and products that are not presently considered to be a part of conventional medicine," such as dietary supplements, aromatherapy, chiropractic, and homeopathy [5]. Assessing accuracy and quality of CAM Web sites poses unique challenges as there is less documented research on the efficacy of CAM products, yet use is common and the potential for harm remains. There is also no gatekeeper to control and monitor access to CAM. Consumers can choose the product and dosage without having to encounter a healthcare professional. In fact, patients often fail to report CAM use to their physicians [6]. On the other hand, consumers frequently turn to the Internet to answer questions about CAM, and trust and act upon what they see online [7]. However, CAM information online has been found to be commercially driven [8], to be poorly referenced [8], and to contain illegal claims [9], and it may therefore be dangerous to consumers [10]. The combination of accessible, unproven CAM therapies and poor quality online CAM information is dangerous.

"Accuracy is a function of whether a site reflects the use of … agreed-upon benchmark[s] such as clinical practice guidelines." [11] The accuracy of CAM information, which is often not evidence-based and lacks support from the peer-reviewed biomedical literature, is not testable. However, we can assess the potential harm of displayed information, even if we cannot verify its accuracy. Further, if information regarding the safety and efficacy of a product is available, it should be displayed.

Our previous work provides preliminary evidence that breast cancer Web sites that meet more technical quality criteria are less likely to contain false statements [12]. Motivated by a desire to help consumers, we sought to determine whether current technical quality criteria can identify potentially harmful CAM information.

Materials and Methods

Selection of Web Sites

Consumers use general-purpose search engines rather than medical sites or portals to find information, and most do not go beyond the first page of search results [13]. Therefore, we chose the ten most popular search engines (Table 1) to select Web sites that consumers are likely to encounter [14]. The three most popular herbs in the United States (in terms of dollars spent) [15], ginseng, ginkgo, and St. Johns wort, and their most common uses formed the search query. The following three queries were executed in each search engine on July 15, 2003: "ginseng and cancer," "ginkgo and memory loss," and "St. John's wort and depression." All Web sites listed on the first results page, including sponsored or paid links, were analyzed.

Table 1. Search engines used to select Web sites

Search Engine
1. Google
2. Yahoo
3. MSN
4. AOL
5. Ask Jeeves
6. Overture
7. Infospace
8. Netscape
9. AltaVista
10. Lycos

A Web site was included if it contained at least one sentence or phrase of health information on the search topic. Health information was defined as "information intended to be used to maintain or improve health, including to understand disease processes, health care issues, etc… to prevent, diagnose, or treat health problems, to be rehabilitated from the effect of diseases, or treatments, and to seek and select health care plans, providers, and other resources." [16] Duplicate URLs were removed. HTTrack [17], a Web site copier was used to permanently capture each Web site and every directly linked page.

Assessing Technical Quality Criteria

In prior work, we assessed inter-rater agreement for popular technical quality criteria [1]. We assessed the degree to which two raters agreed upon the presence or absence of 22 quality criteria selected from Eysenbach's systematic review [17] of a sample of 21 CAM Web sites. Our preliminary analysis showed poor inter-rater agreement on 10 of the 22 criteria. Therefore, we created operational definitions for each of the criteria, decreased the allowed choices, and defined a location to look for the information. As a result, 15 out of the 22 quality criteria had acceptable inter-rater agreement (kappa > 0.6).

For this study, one evaluator (MW) analyzed all Web sites for compliance with 15 technical quality criteria (Table 2) that we previously determined to be reliably assessable. Therefore, in this study we did not re-calculate inter-observer reliability for these technical criteria.

Assessing Potential Harm

First, a set of critical facts for each of the three herbs was determined by consensus of two clinically trained reviewers (SS, DS); please see appendices 1-3. The sets of critical facts were extracted from two independent sources of CAM information: the Physician Desk Reference (PDR) for Herbal Medicines [19] and the Sloan Kettering database of herbs [20]. After the sets of critical facts were determined, the CAM content displayed on each Web site was independently evaluated by both reviewers. Cases where reviewers disagreed were resolved by consensus. In order to minimize bias, materials identifying each Web site's origin, such as organization name, logo, footers, URLs and hyperlinks were removed. However, no changes were made to the design or layout.

In order to verify the concordance between reviewers, two additional clinically trained evaluators (validation reviewers), who were not aware of the study hypothesis or quality criteria tested, were given 30 randomly selected sites from the same sample looked at by primary reviewers (SS, DS). Inter-rater agreement between the validation reviewers was calculated. The validation reviewers were given the same critical facts documents as the primary reviewers and each validation reviewer assessed every site independently. After each reviewer independently evaluated the Web sites, inter-rater agreement was calculated between the two validation reviewers. Subsequently, cases of disagreement were resolved by consensus. A second inter-observer agreement measure was calculated between the pairs of reviewers (primary reviewers vs. validation reviewers) based on the consensus data.

Content on each page was scrutinized for the presence of misleading statements likely to cause physical harm (acts of commission) and for vital information that was missing (acts of omission). Commission may be thought of as a surrogate for accuracy, while omission has been referred to as completeness, coverage, or comprehensiveness [21]. We based our evaluation on the following framework, adapted from Markman [22]:

1. a. Direct toxicity
   b. Interaction with conventional medical therapy
   c. Delay in diagnosis or conventional treatment
   d. Avoidance of conventional treatment
2. a. Warnings
   b. Drug interactions
   c. Contraindications
   d. Side effects

Statements that suggest use of higher doses of herbs than recommended in the critical facts documents (appendices 1-3) were categorized as causing "direct toxicity." Statements suggesting that the herb protects against disease and encouraging patients to self-medicate instead of seeing a physician were placed in the "delay in diagnosis or conventional treatment" category. Statements that project herbs as an "alternative to conventional treatment" (for example, "the herb is the first choice of treatment for the disease") were categorized as potentially causing "avoidance of conventional treatment." Statements that suggested using herbs with medications known to have drug interactions (for example, using St. John's wort with monoamine oxidase inhibitors) were classified as causing potential harm due to "interaction with conventional therapy." However, while evaluating potential physical harm due to omission of information about interactions, we did not expect Web sites to list all the drug interactions listed in the critical facts documents. Web sites that noted at least one drug interaction were considered not to omit drug interaction information. Web sites with vague statements such as "there are many interactions," were categorized as having "omitted drug interactions." Potential physical harm was present if any error of commission or omission was found.

We recognize that in addition to physical harm due to either commission or omission, CAM information on the Internet may cause other types of harm, such as emotional and financial. Emotional harm may occur because of inaccurate perception of disease or conventional therapy such as exaggeration of side effects of conventional treatment and presentation of alternative treatment as a "natural cure." Financial harm may be caused by the purchase of ineffective or harmful yet expensive CAM products. However, we did not evaluate emotional and financial harm in this study because of the inherent subjectivity involved, and difficulty in quantifying and assessing such measures.

Statistical Analyses

The dichotomous (yes/no) dependent variables were: 1) physical harm from commission and 2) physical harm from omission. The independent variables were also dichotomous and consisted of the 15 technical quality criteria listed in Table 2. In addition, these 15 criteria were grouped into 5 categories [23]: authority, transparency and honesty, updating of information, editorial policy, and other. Web sites were classified into two groups based on whether they complied with the median number of quality criteria. The first group complied with six or fewer technical quality criteria, the second group complied with more than six technical quality criteria.

Inter-observer agreement measures were calculated to assess a) the degree to which validation reviewers agreed among themselves in their assessments of these dichotomous dependent variables (Table 3) and, b) the degree to which the validation reviewers agreed with the primary reviewers (Table 4). Cohen's kappa (K) is a commonly used measure of inter-observer agreement between two observers for dichotomous data. However, because K is affected in complex ways by the presence of bias between observers and by the distributions of data across the categories [24], we computed the prevalence-adjusted bias-adjusted kappa (PABAK), the bias index (BI) and the prevalence index (PI), as well as K, as recommended by Byrt et al [24].

The bias index (BI) is defined as the difference between the proportions of "Yes" for the two raters. The prevalence index (PI) is defined as the difference between the probability of "Yes" and the probability of "No." A BI close to 0 indicates less bias,

while values closer to 1 (absolute value) indicate greater bias. Similarly, a PI close to 1 (absolute value) indicates high prevalence, while a PI closer to 0 indicates lower prevalence. The BI then measures the degree to which one reviewer tends to identify more or fewer occurrences than the other, while the PI measures the degree to which "Yes" agreements or "No" agreements predominate. The PABAK index of agreement between two observers is a measure that adjusts for both bias and prevalence. Although the derivation of the PABAK index is somewhat more complex, in practice it can be calculated as $2P_0 - 1$, where P_0 is the proportion of observed agreement. Consequently, PABAK ranges from -1 to +1 and like K, a value of 0 represents no better than chance agreement, while magnitudes approaching 1 indicate maximal agreement.

Chi-square was calculated for each pairing of an independent variable with a dependent variable. Given the large number of statistical tests performed, significance was set at $\alpha<0.01$. All analyses were performed using SPSS 11.0 statistical software.

Results

A total of 546 Web sites were retrieved. After removing duplicates and checking for eligibility, 150 Web sites remained: 54 for the query "ginseng and cancer," 46 for "ginkgo and memory loss," and 50 for "St. John's wort and depression."

Table 2. Compliance of CAM Web sites with technical quality criteria. Criteria are also grouped into 5 categories (in bold). Values are counts (percentages)

Quality criteria	Number of Web sites (%)
Authority	
Disclosure of authorship	41 (27)
Author's credentials disclosed	17 (11)
Credentials of physicians disclosed	2 (1)
Author's affiliation disclosed	17 (11)
Transparency and Honesty	
Sources clear	100 (67)
General disclosures	147 (98)
References provided	54 (36)
Disclosure of ownership	144 (96)
Currency/ Updating of information	
Date of creation disclosed	31 (21)
Date of last update disclosed	21 (14)
Date of creation or update disclosed	49 (33)
Editorial Policy	
Editorial review process	9 (6)
Others	
Internal search engine present	78 (52)
Feedback mechanism	132 (88)
Copyright notice	105 (70)

Technical Quality Criteria

Most Web sites did not comply with technical quality criteria. On average, a Web site complied with 6.3 (SD±2.6) of 15 criteria. One site failed to comply with any criteria, while three sites complied with 13 criteria. Only 27% of sites disclosed authorship, 36% provided references and 6% mentioned an editorial review process. Table 2 shows the number of Web sites that complied with each of the 15 quality criteria.

Assessing Potential Harm: Agreement among Reviewers

As shown in Table 3, agreement between the two evaluation reviewers was high (all PABAK > 0.67). Although there was little bias, there was a strong prevalence effect. Therefore, the two validation reviewers had a high degree of agreement for all measures of harm from commission and omission. Similarly, as shown in Table 4, consensus agreement between the primary and validation reviewers was also high (all PABAK > 0.73).

Table 3. Agreement among validation reviewers on a sample of 30 Web sites

	P_0	BI	PI	K	PABAK
A. Physical Harm-Commission*	0.87	0	-0.8	0.259	0.73
Direct Toxicity	0.93	0.07	0.93	Undefined	0.87
Interactions	0.97	-0.03	0.97	Undefined	0.93
Delay in diagnosis	1	0	-1	Undefined	1
Avoidance of conventional therapy	0.97	-0.03	-0.9	0.651	0.93
B. Physical Harm-Omission*	0.97	0.03	0.97	Undefined	0.93
Omission of Warnings	0.93	0.07	0.8	0.634	0.87
Omission of Drug Interactions	0.97	-0.03	0.7	0.87	0.93
Omission of Contraindications	1	0	0.8	1	1
Omission of Adverse Reactions	0.83	-0.17	0.77	0.242	0.67

* P_0= observed agreement,BI = bias index, PI = prevalence index, K = Cohen's kappa, PABAK = prevalence-adjusted bias-adjusted kappa. Undefined = SPSS did not compute value due to zero variability in a variable.

Table 4. Agreement between primary and validation reviewers on a sample of 30 Web sites

	P_0	BI	PI	K	PABAK
A. Physical Harm-Commission*	0.93	0.07	-0.73	0.71	0.87
Direct Toxicity	0.93	0.07	-0.8	0.63	0.87
Interactions	1	0	-1	Undefined	1
Delay in diagnosis	0.93	0.07	-0.93	Undefined	0.87
Avoidance of conventional therapy	1	0	-0.93	1	1
B. Physical Harm-Omission*	0.97	0.03	0.97	Undefined	0.93
Omission of Warnings	0.9	0.03	0.83	0.35	0.8
Omission of Drug Interactions	0.97	-0.03	0.7	0.87	0.93
Omission of Contraindications	0.97	-0.03	0.77	0.84	0.93
Omission of Adverse Reactions	0.87	0.07	0.73	0.43	0.73

* P_0= observed agreement, BI = bias index, PI = prevalence index, K = Cohen's kappa, PABAK = prevalence-adjusted bias-adjusted kappa. Undefined = SPSS did not compute value due to zero variability in a variable.

Table 5. Number of CAM Web sites that display potentially harmful information. Values are counts (percentages)

Type of Harm	Number of Web sites (%)
A. Physical Harm-Commission*	38 (25)
Direct Toxicity	19 (13)
Interactions	12 (8)
Delay in diagnosis	5 (3)
Avoidance of conventional therapy	10 (7)
B. Physical Harm-Omission*	145 (97)
Omission of Warnings	121 (81)
Omission of Drug Interactions	124 (83)
Omission of Contraindications	134 (89)
Omission of Adverse Reactions	125 (83)

* Note: Totals in these rows are calculated if any of the four categories of commission or omission were found on the Web site.

Potential Harm

Potential physical harm from omission was more prevalent than from commission (97% vs. 25%, Table 5). However, a substantial number of Web sites (25%) displayed statements that could lead to physical harm. Statements that may cause toxicity if acted upon (direct toxicity) were present in 13% of CAM Web sites, while 7% of Web sites included statements encouraging the avoidance of conventional therapies. Eight percent of sites included information that may lead to harm from interactions if the advice were followed. Most CAM Web sites (97%) omitted vital information such as contraindications (89%) and drug interactions (83%).

Technical Quality Criteria

We found that individual technical quality criteria did not identify sites with the potential to cause physical harm from commission or omission (Table 6). Similarly, when technical criteria were grouped into categories (such as authority, transparency and honesty, etc.), no significant association was found with potential physical harm (Table 7). Even when Web sites were classified into two groups, those complying with more criteria (≥ 6) versus fewer criteria (<6), there was no significant relationship. Overall, 44 hypotheses were tested but none were significant at the $\alpha<0.01$ level, despite our study having 0.80 power to detect significance. Surprisingly, the presence of two quality criteria where a significant association was found at $\alpha<0.05$ ("sources clear" and "editorial review process") indicated a greater chance of potential harm; the reverse of their original intent. However, it is possible that these two significant results may be due to chance since we conducted numerous statistical analyses.

Table 6. Association between individual quality criteria and potential harm. Values are counts (percentages of Web sites complying with that criterion)

	Total number of Web sites complying with criterion	Physical harm by					
		Commission			Omission		
		Present (n = 38)					
Disclosure of authorship	41	11 (29)	30 (27)	0.80	39 (27)	2 (40)	0.52
Author's credentials disclosed	17	3 (8)	14 (12)	0.44	16 (11)	1 (20)	0.53
Credentials of physicians disclosed	2	1 (3)	1 (1)	0.42	2 (1)	0 (0)	0.79
Author's affiliation disclosed	17	6 (16)	11 (10)	0.32	17 (12)	0 (0)	0.42
Sources clear	100	31 (82)	69 (62)	0.02	95 (65)	5 (100)	0.11
Date of creation disclosed	31	8 (21)	23 (20)	0.95	30 (21)	1 (20)	0.97
Date of last update disclosed	21	5 (13)	16 (14)	0.86	20 (14)	1 (20)	0.69
Date of creation or update disclosed	49	13 (34)	36 (32)	0.81	47 (32)	2 (40)	0.72
General disclosures	147	37 (97)	110 (98)	0.75	142 (98)	5 (100)	0.75
References provided	54	14 (37)	40 (36)	0.9	51 (35)	3 (60)	0.26
Disclosure of ownership	144	35 (92)	109 (97)	0.16	139 (96)	5 (100)	0.64
Internal search engine present	78	21 (55)	57 (51)	0.64	75 (52)	3 (60)	0.72
Feedback mechanism	132	32 (84)	100 (89)	0.41	128 (88)	4 (80)	0.58
Copyright notice	105	31 (82)	74 (66)	0.07	100 (69)	5 (100)	0.13
Editorial review process	9	5 (13)	4 (4)	0.03	9 (6)	0 (0)	0.57

Table 7. Association between groups of technical quality criteria and potential harm. Values are counts (percentages of Web sites complying with that criterion)

	Total number of Web sites complying with criterion	Physical harm by					
		Commission			Omission		
		Present (n = 38)					
Authority	41	11 (29)	30 (27)	0.80	39 (27)	2 (40)	0.52
Transparency and honesty	149	37 (97)	112 (100)	0.09	144 (99)	5 (100)	0.85
Currency/updating of information	51	13 (34)	38 (34)	0.98	49 (34)	2 (40)	0.77
Editorial policy	9	5 (13)	4 (4)	0.03	9 (6)	0 (0)	0.57
Others	139	34 (90)	105 (94)	0.38	134 (92)	5 (100)	0.52

Top Level Domain

We also explored the relationship between top level domain and potential harm. Seventy-seven percent of the 150 Web sites analyzed were commercial (.com), 10% organizational (.org), 7% network (.net), 3% educational (.edu), 2% governmental (.gov) and 1% unknown (numerical IP address only). Fisher's exact test statistic was calculated as expected values in some cases were <5, and significance was set at $\alpha = 0.05$ level. Only the network top level domain had a significant relationship with physical harm from omission (Table 8). Of the 10 Web sites with the network top level domain, 20% did not contain harm from omission. In contrast, only 2% of sites that had a top level domain other than network did not have harm from omission ($p<0.04$). However, there was no statistically significant relationship between network and non-network sites with respect to physical harm from commission. Although there were few educational and government sites in our study, it is notable that there were no identified cases of potential harm by commission in these sites. As most Web sites were commercial, it is difficult to draw meaningful conclusions from this analysis.

Table 8. Association between top level domain and potential harm. Values are counts (percentages of Web sites complying with that top level domain)

	Total number of Web sites with top level domain	Physical harm by Commission			Omission		
		Present (n = 38)					
	116	31 (82)	85 (76)	0.65	114 (79)	2 (40)	0.07
	10	3 (8)	7 (6)	0.71	8 (6)	2 (40)	0.04*
	4	0 (0)	4 (4)	0.57	4 (3)	0 (0)	1.0
	16	4 (11)	12 (11)	1.0	15 (10)	1 (20)	0.43
	3	0 (0)	3 (3)	0.57	3 (2)	0 (0)	1.0
	1	0 (0)	1 (1)	1.0	1 (1)	0 (0)	1.0

* Note: Fisher's exact test calculated as expected values in some cases were <5

Intent to Sell Products

In order to explore the relationships between Web sites that sold products and those that did not, two evaluators independently revisited each Web site and identified Web sites that allowed the ordering of products. Agreement between reviewers was high (K=0.95). Fifty-three percent of Web sites (n=79) sold products. There was no significant relationship between selling products and potential harm due to omission (P=0.56) or commission (P=0.02). Although not statistically significant at the $\alpha = 0.01$ level, selling products was actually related to less harm from commission, the reverse of what we would expect. In fact 63% (n=24) of the harmful Web sites from commission were found on sites that did not sell products, while 37% (n=14) were found on Web sites that sold products. Therefore, in our sample there does not appear to be more harmful information on sites that sell products.

Discussion

We found that most CAM Web sites were potentially harmful either by displaying statements which could cause harm, or by omitting vital information. However, our data suggest that available technical quality criteria fail to identify potentially harmful information online.

We found that one quarter of CAM Web sites present information that may cause physical harm if acted upon. These sites encouraged consumers to avoid conventional therapy, presented information on products that may be directly toxic, or presented information on products that may cause interactions with conventional medications. This is potentially dangerous because consumers have easy access to CAM products online and act upon what they see on the Internet [7], often do so without the knowledge or advice of clinicians [25].

Almost all (97%) CAM Web sites omitted vital warnings, drug interactions, contraindications, or adverse reactions. This is concerning because many consumers perceive "natural" products as safe. Further, many herbs that may be safe when used alone interact with conventional medications.

Previous studies have found scientific references [4], absence of financial interest [4], display of copyright [2], and display of editorial policy [3] to correlate with information accuracy. Technical quality criteria evaluated in this study may be unsuitable for CAM information as they seek to identify accuracy, which is difficult to determine for CAM. Surprisingly, even generally accepted measures of content quality such as disclosure of authorship and updating of information had no relationship to potential harm. Other researchers have also encountered difficulty in developing guidelines to evaluate CAM information [26].

Our previous study of breast cancer information online found that sites which complied with >3 JAMA benchmarks [27] (authorship, references, currency, and disclosure) were more accurate than lower quality sites (<3 JAMA benchmarks) [12]. However, in this sample of CAM Web sites we found no such relationship for potential harm resulting from commission (p=0.31) or omission (p=0.21). We are forced to question the assumption, at least for CAM information, that consumers can be taught to discern good content from bad by looking at domain-independent quality criteria. Recommending such criteria may convey a false sense of security, inadvertently causing consumers to trust harmful CAM websites. Although

the technical criteria we assessed had no relationship to potential harm, other criteria or tools not tested may have some value.

Table 9. Web sites that contained no errors (neither commission nor omission)

Company/Organization	Selling Products	Top Level Domain
American Cancer Society	No	.org
About Inc	No	.com
Pagewise Inc	No	.com
Natural Pharmacy	Yes	.net
Vitamin Trader	Yes	.com

Five Web sites contained no harmful information from either commission or omission at the time of our study (Table 9). Four of the five best performing Web sites were retrieved from a search for St. John's wort, and one from a search on ginseng. One of these Web sites was from the American Cancer Society. However, the remaining four Web sites were from commercial or for-profit entities, two of which sold products. We note that Web site content changes frequently. Therefore, it is difficult to endorse any list of Web sites.

The major limitation of our study is the inherently subjective domain. Whether or not information has the potential to harm a consumer is a subjective clinical judgment which defies strict definition. However, relatively high inter-observer agreement among clinically trained reviewers suggests that our definitions were consistent.

Our study was also limited by our sample, which was restricted to Web sites displaying information about three popular herbs. Searches on other herbs or different alternative therapies may have different results. Also, we did not evaluate all possible technical quality criteria. Instead, we evaluated only criteria that were used in three or more studies as reviewed by Eysenbach et al [18] and were found to be reliably assessable using pre-determined operational definitions [1]. It is possible that other quality criteria will be more effective.

Since the primary reviewers (SS, DS) were aware of the study hypotheses, they may have been biased by this knowledge. However, inter-observer agreement between the primary and validation reviewers (who were unaware of the hypotheses) was high. Therefore this potential bias appears to have minimal effect on the results.

As we search for quality measures, we must keep in mind that some potentially useful criteria are easily manipulated. For example, one study found sites that claimed copyright were more accurate [2]. Such very specific and objective criteria are appealing since they may be automatically assessed using software, and evaluated by consumers by simply searching for the word "copyright" or © symbol. However, it is easy for site builders to claim copyright without changing the health information displayed on their site.

Although we restricted our analysis to individual sites, consumers may not make health-care decisions on the advice of one site, but rather on the collective information learned, confirmed or refuted from a multitude of online sources. Future work can assess the degree to which confirmatory evidence present on a range of sites can screen out undesirable information. In addition, it would also be important to understand why consumers search for CAM information. After all, some may turn to CAM only after conventional treatment fails, whereas others may reject traditional therapies.

The Internet provides a constantly changing, endless variety of information from innumerable sources. Ideally, we would like to empower consumers to evaluate health information for themselves. Currently available technical quality criteria, however, are not adequate to evaluate CAM information. For the time being, it may be prudent to recommend that consumers looking for CAM information online rely on known, authoritative providers of information. With this in mind, we must continue to search for ways of alerting consumers to potentially harmful information without restricting them to known sources.

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Conflicts of Interest

None declared.

Appendix 1

Critical Facts: St. John's Wort *(hypericum perforatum)*

INTRODUCTION

Also known as Saint Johns wort, hypericum, goatweed, God's wonder plant, witches herb. Generally is used for depression, seasonal affective disorder, and anxiety. St. John's wort should not be used for patients with severe depression. Studies also show possible efficacy in the management of anxiety and premenstrual syndrome, although additional research is necessary.

INDICATIONS AND USAGE

- Anxiety, depression, fatigue, insomnia, pain, pediatric nocturnal incontinence, premenstrual syndrome, seasonal affective disorder (SAD), depressive moods, inflammation of the skin, blunt injuries, wounds and burns.

WARNINGS

- May cause photosensitivity.
- St John's wort should be discontinued one week before surgery or chemotherapy.

CONTRAINDICATIONS

- Pregnant or nursing women should not consume.
- Simultaneous use of a MAO inhibitor-St. John's wort contains some weak MAOI properties that may add to the effects of other MAOI drugs therefore increasing the risk for hypertensive crisis.

ADVERSE REACTIONS

- General: No health hazards are known in conjunction with the proper administration of designated therapeutic dosages. Tannin content may lead to digestive complaints, such as feeling of fullness or constipation. Patients with previous history of photosensitization to various chemicals should be cautious of direct sun exposure.
- A high concentration of St. John's wort damages reproductive cells and has an effect on fertility.
- Common: Headache, nausea, abdominal discomfort, constipation, dizziness, confusion, fatigue, dry mouth, sleep disturbances, and sedation.
- Infrequent: Photosensitivity or photodermatitis, elevated liver function tests, acute neuropathy, increased PT.

DRUG INTERACTIONS

- MAOI-concomitant use with MAOIs such as tranylcypromine, phenelzine may lead to increased effects and possible toxicity (hypertensive crisis).
- Prudent to avoid concomitant use with β sympathomimetics eg, ma huang or pseudoephedrine.
- Tannic acids may interfere with the absorption of iron.
- Usage with other photosensitizers such as tetracyclines, sulfonamides, thiazides, quinolones, piroxicam, and others should be avoided
- **Cytochrome3A4**: St. John's wort has been shown to induce cytochrome isoenzyme 3A4, therefore affecting metabolism of certain medications and reducing serum concentrations. Drugs metabolized by 3A4 include:
- **Theophylline**: Blood levels of theophylline may be significantly reduced resulting in decreased efficacy.
- **HIV protease inhibitors:** Blood levels of indinavir, nelfinavir, ritonavir, and saquinavir can be significantly reduced, resulting in increased HIV viral load and development of viral resistance. Indinavir: decreases the concentration of the protease inhibitor by inducing the P450 system.
- **HIV non-nucleoside reverse transcriptase inhibitors**: Blood levels of efavirenz and nevirapine can be significantly reduced, resulting in increased HIV viral load.
- **Cyclosporin/ Tacrolimus**: Blood levels of cyclosporin or tacrolimus can be significantly reduced, resulting in decreased efficacy. Levels of cyclosporine have decreased with St. John's wort administration. St. John's wort induces cytochrome P450 enzyme system, the major pathway of cyclosporine metabolism.
- **Diltiazem / Nifedipine**: Blood levels of diltiazem or nifedipine can be reduced, resulting in decreased efficacy.
- **Irinotecan:** Due to changes in hepatic metabolism caused by St. John's wort, levels of irinotecan metabolite SN-38 may be lowered by as much as 40% for up to 3 weeks following discontinuation of St. John's wort.
- **Warfarin:** May increase or decrease activity when administered concomitantly. INR should be monitored routinely. S-isomer may have increased metabolism due to Cyp 3A4 induction. S-isomer may have decreased metabolism due to Cyp 1A2 inhibition.
- **Digoxin:** Prolonged concurrent administration may result in decreased absorption of digoxin with lowered plasma concentrations. St. John's wort decreases the effect of digoxin and [may make] a patient a non-responder whereas increased toxicity may be anticipated after withdrawal of the drug.

- **Triptans:** Increased serotonergic effect and possible serotonin syndrome when combined with sumatriptan, naratriptan, rizatriptan, or zolmitriptan.
- **SSRIs**: Increased serotonergic effect and possible serotonin syndrome when combined with citalopram, fluoxetine, fluvoxamine, paroxetine, or sertraline.
- St. John's wort taken along with SSRI such as fluoxetine, paroxetine, sertraline, fluvoxamine or citalopram leads to an increased effect and possible toxicity "serotonin syndrome" eg, sweating, tremor, flushing, confusion, and agitation.
- **Tricyclic antidepressants:** Increased serotonergic effect and possible serotonin syndrome when combined with nefazodone, amitriptyline, or imipramine. Possible reduction in efficacy of antidepressants due to changes in metabolism.
- **Oral contraceptives:** May reduce blood levels resulting in decreased efficacy (ie, breakthrough bleeding or pregnancy).
- **Alcohol:** May result in increased sedation.
- **Anesthetics:** Case report of cardiovascular collapse (hypotension without anaphylactic symptoms) shortly after induction of general anesthesia with fentanyl, propofol, d-tubocurarine, and succinylcholine followed by nitrous oxide, oxygen and isoflurane.
- **Chemotherapy:** Due to changes in hepatic metabolism caused by St. John's wort, chemotherapy levels may be altered, resulting in increased toxicity or decreased efficacy. Caution should be exercised when administering concomitantly with chemotherapy (ie, cyclophosphamide, paclitaxel, etoposide, irinotecan).
- **Tamoxifen:** Due to changes in hepatic metabolism caused by St. John's wort, levels of tamoxifen may be lowered, resulting in reduced efficacy.
- **Sympathomimetics**: Concomitant administration may produce increased serotonergic activity and possible serotonin syndrome.
- Hypericin causes a reduction in barbiturates-induced sleeping times.

DAILY DOSE

- In general, 200-1000 micrograms of hypericin is recommended for treatment of depression for 4-6 weeks.
- 300 mg of standardized extract should be administered three times daily.
- Dried herb-2 to 4 grams 3 times daily.
- Tea-single dose of 2-3 gms dried herb.
- Liquid extract-1:1 in 25 % ethanol - 2-4 ml, 3 times daily.
- Tincture-2-4 ml, 3 times daily.

Appendix 2

Critical Facts: Ginkgo *(ginkgo biloba)*

INTRODUCTION

- Also known as fossil tree, maidenhair tree, kew tree, bai guo ye, yinhsing
- Ginkgo biloba extract (GBE) is used to treat cerebral circulation, dementia, peripheral vascular disorders, sexual dysfunction resulting from selective serotonin reuptake inhibitors (SSRIs), hearing loss, and more.

PURPORTED USES

- Anxiety, asthma, bronchitis, cardiovascular disease, circulatory disorders, hearing loss, memory loss, Raynaud's disease, sexual dysfunction, stress, tinnitus.

WARNINGS

- Ginkgo biloba extracts should not contain ginkgolic acid.
- Discontinue ginko biloba at least 36 hours before surgery.

PRECAUTIONS AND ADVERSE REACTIONS

- Common: Headache, dizziness, GI upset, flatulence, diarrhea, contact dermatitis, and palpitations.
- Fertility: Ginkgo has adverse effects on oocytes.
- Case reports: Seizures have occurred in patients predisposed to seizures or on medications that lower the seizure threshold (eg, prochlorperazine, chlorpromazine, perphenazine, etc.). Spontaneous bleeding, including hematomas and hyphema, has been noted in the literature.

DRUG INTERACTIONS

- **Monoamine oxidase inhibitors (MAOIs):** Ginkgo may potentiate the effects of MAOIs.
- **Anticoagulants / Antiplatelets:** Ginkgo may induce spontaneous bleeding possibly associated with reduced platelet aggregation resulting from inhibition of platelet activating factor by ginkgolide components.

- **Antipsychotics / Prochlorperazine:** Ginkgo may cause seizures when combined with medications that lower the seizure threshold.
- **Insulin:** Ginkgo can alter insulin secretion and effect blood glucose levels.
- **Cytochrome P450:** Preliminary evidence that ginkgo can affect the cytochrome enzymes 1A2, 2D6, and 3A4, however controversial data exist whether it induces or inhibits the individual enzymes.
- **Trazodone:** Ginkgo extract was associated with coma in a woman with Alzheimer's disease who was also taking trazodone.

CONTRAINDICATIONS

- Patients sensitive to ginkgo.
- Patients with known risk factors for intracranial hemorrhage (hypertension, diabetes amyloid senile plaques) should avoid gingko.

Appendix 3

Critical Facts: Ginseng

A) GINSENG*

DAILY DOSE

- Average daily dose is 1-2 gms root. Infusion may be taken 3 to 4 times a day over 3 to 4 weeks.

INDICATIONS AND PURPORTED USES

- Lack of stamina-fatigue and debility, unproven uses-loss of appetite, cachexia, impotence and sterility, neuralgia, and insomnia.
- Chinese medicine-hemoptysis, gastric disturbances and vomiting.
- Homeopathic-rheumatism and debility.

PRECAUTIONS AND ADVERSE REACTIONS

- General-[to be taken with] caution [by] patients with cardiovascular diseases or diabetes. Hypertension resulting from ginseng abuse syndrome is associated with prolonged high dose ginseng with concomitant use of caffeine. General adverse effects include insomnia, epistaxis, headache, nervousness, and vomiting.
- Mastalgia with diffuse breast nodularity.
- Vaginal bleeding-oral ginseng and ginseng face cream have been associated with post menopausal vaginal bleeding.
- Pregnancy and lactation-maternal use has been associated with neonatal androgenization and it is therefore not recommended for use during pregnancy.
- **Overdoses**-massive overdoses bring about ginseng abuse syndrome characterized by hypertension, insomnia, hypertonia, and edema.

DRUG INTERACTIONS

- Diabetes drugs/ insulin-ginseng has been shown to have hypoglycemic effects.
- Warfarin/ NSAIDS?Antiplatelet agents-ginseng has an anti-platelet effect and [is] to be avoided along with antiplatelet agents/ NSAIDS.
- Phenelzine-headache, tremors, and mania.
- Loop diuretics-germanium (present in most ginseng products) causes loop resistance. Germanium causes nephrotoxicity in the nephron segment where loop diuretics work.

B) ASIAN GINSENG (p*anax ginseng*)*

INTRODUCTION

- Also known as Chinese ginseng, panax, ren shen, jintsam, ninjin, Asiatic ginseng, Japanese ginseng, Oriental ginseng, Korean red ginseng.
- Patients take this supplement to improve athletic performance, strength and stamina, and as an immunostimulant for diabetes, cancer, HIV/AIDS, and a variety of other conditions. It is also widely used as a "Yang" tonic in Chinese herbal formulas.

PURPORTED USES

- Angina, diabetes, health maintenance, HIV and AIDS, immunostimulation, improve clotting, pain, sexual dysfunction, strength and stamina.

WARNINGS

- Discontinue ginseng at least one week before surgery.

DRUG INTERACTIONS

- Monoamine oxidase inhibitors (MAOIs): Panax ginseng may cause manic-like symptoms when combined with MAOIs.
- Insulin and sulfonylureas: Panax ginseng may increase the hypoglycemic effect of insulin and sulfonylureas.
- Anticoagulants: Panax ginseng may antagonize the effects of anticoagulants.

CONTRAINDICATIONS

- Panax ginseng may have estrogenic activity, but data are inconsistent. Patients with hormone-sensitive disease should not consume panax ginseng.

ADVERSE REACTIONS

[Usually well tolerated.]

- Reported: Dry mouth, tachycardia, nausea, vomiting, diarrhea, insomnia, and nervousness.

C) AMERICAN GINSENG

INTRODUCTION

- Patients take this supplement to improve athletic performance, strength, and stamina, and to treat diabetes and cancer. In Chinese herbal formulas, American ginseng is frequently used to nourish "Yin."

PURPORTED USES

- Cancer prevention, cancer treatment, diabetes, health maintenance, immunostimulation, strength and stamina.

ADVERSE REACTIONS

- No significant reactions reported.

DRUG INTERACTIONS

- Monoamine oxidase inhibitors (MAOIs): American ginseng may cause manic-like symptoms when combined with MAOIs.
- Insulin and sulfonylureas: American ginseng may increase the hypoglycemic effect of insulin and sulfonylureas.
- Anticoagulants: Theoretically, American ginseng may antagonize the effects of anticoagulants.

D) SIBERIAN GINSENG (*eleutherococcus senticosus, acanthopanax senticosus*)

PURPORTED USES

- Chemotherapy side effects, health maintenance, immunostimulation, strength and stamina.

WARNINGS

- Case reports in the literature suggest possible contamination with incorrect botanical.
- Analysis of product suggests that labeled concentration differs from listed or assumed contents.
- Products should be tested and standardized to ensure purity and accuracy of content.

CONTRAINDICATIONS

- Patients with hypertension should not consume ginseng.

ADVERSE REACTIONS

- Reported: Insomnia, drowsiness, nervousness, tachycardia, headache, hypoglycemia.

DRUG INTERACTIONS

- Insulin / hypoglycemics: Theoretical additive hypoglycemic effect.
- Caffeine: May have additive effect leading to insomnia or nervousness.
- Hexobarbital: Eleuthero inhibits metabolism possibly by inhibition of cytochrome p450 2C19.
- Digoxin: Elevate[s] serum digoxin levels.

*We evaluated Web sites with content on ginseng using the general ginseng critical facts and Web sites with content on the specific types of ginseng (Asian, American, and Siberian) with the critical facts on the specific types of ginseng.

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Abbreviations

BI: Bias index
CAM: Complementary and alternative medicine
MAOI: Monoamine oxidase inhibitor
NSAIDS: Non-steroidal aniti-imflammatories
PABAK: Prevalence-adjusted bias-adjusted kappa
PI: Prevalence index
SPSS: Statistical Package for the Social Sciences
SSRI: Selective serotonin reuptake inhibitor

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Original Paper

Patient Entry of Information: Evaluation of User Interfaces

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Abstract

Background: Personal health records are web-based applications that allow patients to directly enter their own data into secure repositories in order to generate accessible profiles of medical information.

Objective: The authors evaluated a variety of user interfaces to determine whether different types of data entry methods employed by Personal health records may have an impact on the accuracy of patient-entered medical information.

Methods: Patients with disorders requiring treatment with thyroid hormone preparations were recruited to enter data into a web-based study application. The study application presented sequences of exercises that prompted free text entry, pick list selection, or radio button selection of information related to diagnoses, prescriptions, and laboratory test results. Entered data elements were compared to information abstracted from patients' clinic notes, prescription records, and laboratory test reports.

Results: Accuracy rates associated with the different data entry methods tested varied in relation to the complexity of requested information. Most of the data entry methods tested allowed for accurate entry of thyroid hormone preparation names, laboratory test names, and familiar diagnoses. Data entry methods that prompted guided abstraction of data elements from primary source documents were associated with more accurate entry of qualitative and quantitative information.

Conclusions: Different types of data entry methods employed by Personal health records may have an impact on the accuracy of patient-entered medical information. Approaches that rely on guided entry of data elements abstracted from primary source documents may promote more accurate entry of information.

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KEYWORDS

Medical Records; Internet; User-Computer Interface

Introduction

Personal health records (PHRs) are web-based applications that provide patients with secure access to self-generated profiles of medical information [1,2]. Currently available versions are being promoted as resources to help patients organize and track medical information collected over time from different sources [3].Expectations regarding the use of PHRs in practice are grounded in the notion that they may serve as secondary sources of information to help guide routine medical care, emergency medical care, self-monitoring, and disease management [4- 7].

As part of a previous study, we evaluated the functionality of a selection of PHRs by tracking the entry and display of profiles of representative clinical information [8]. Our investigation led us to conclude that the data entry methods employed by PHRs limit the range and content of patient-entered information related to diagnoses, prescriptions, laboratory test results, diagnostic study results, and immunizations. During the course of our study, we noted that most of the applications we evaluated prompted patients to enter information without any explicit guidance or direction. This led us to consider the question of whether different types of data entry methods employed by

PHRs might have an impact on the accuracy of patient-entered information.

Over the course of the past decade, a number of investigators have contributed to a growing body of research centered on the development of heuristic standards and performance metrics to evaluate the usability of web sites [9- 12]. Most of the laboratory studies conducted by these researchers have focused on tracking the searching and navigation behavior of consumers interacting with commercial and institutional web sites [13- 15]. Those studies that have evaluated the use of patient-oriented health care web sites have tended to focus more on the accuracy and reliability of retrieved content than on usability [16- 19]. To date there have not been any published studies evaluating the performance of patients engaged in direct online entry of personal medical information.

We conducted a study to evaluate the performance of user interfaces that employ different types of data entry methods to collect patient-entered information. To simulate use of a PHR, we developed a web-based application incorporating sequences of data entry exercises. These exercises were designed to be completed by actual patients in real-time study sessions. To limit the scope of variables under consideration, we targeted patients with confirmed disorders requiring treatment with thyroid hormone preparations. This allowed us to focus on a defined range of diagnoses that may be distinguished on the basis of pathophysiologic mechanisms, diagnostic criteria, and goals of therapy. It also provided us with a unique opportunity to evaluate approaches to the entry of prescription information based on the visual identification of tablet shapes and colors.

Methods

Recruitment

To recruit subjects for this study, we sent messages to listed members of the American Foundation of Thyroid Patients, the National Graves' Disease Foundation, the Thyroid Foundation of America, and the Thyroid Cancer Survivors' Association [20- 23]. We also posted messages to the Usenet newsgroup at alt.support.thyroid [24]. These messages directed respondents to a recruitment web site listing information about PHRs, links to PHR web sites, information about the purpose of the study, and an online registration form. Registering respondents were sent a mailing that included study consent forms, release of information forms, medical provider information forms, pharmacy information forms, and task checklists. The task checklists asked respondents to request copies of recent clinic notes and laboratory test reports from medical providers. Respondents were asked to hold these documents in sealed envelopes for use during study sessions. Upon enrollment, each subject was sent a message listing the URL for the study web site along with a user name and password.

Study Application

The application developed for this study was posted on a secure, password-protected web site. Subjects logging on to the web site were asked to complete a series of exercises directing them to enter information related to their diagnoses, current prescriptions, and recent laboratory test results. Each exercise focused on a discrete data entry task involving a specific type of data entry method. Interspersed pages of clearly worded instructions outlined the goal of each exercise.

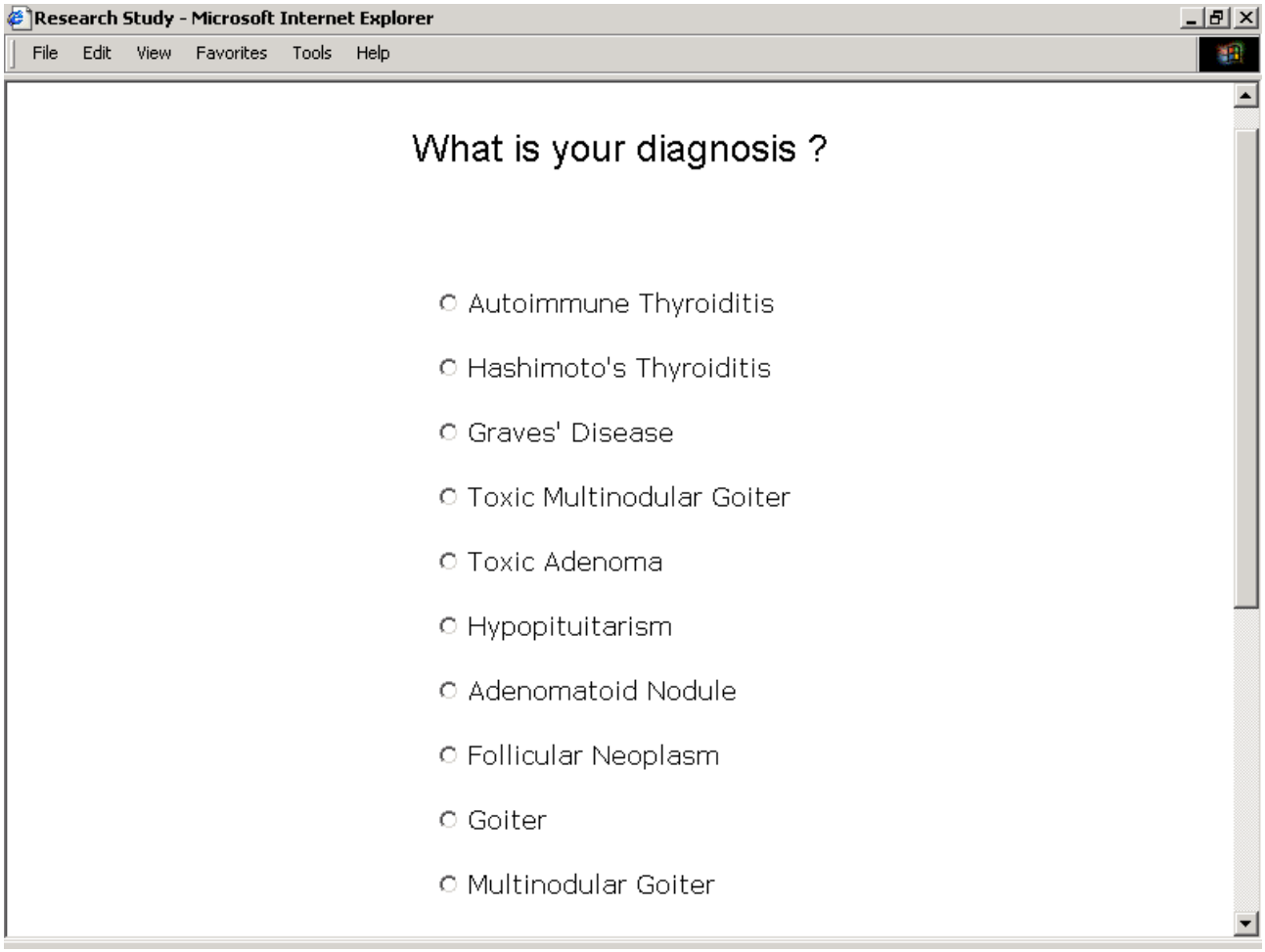
To develop a typology of data entry methods, we systematically reviewed user interfaces implemented by web-based PHRs, health survey web sites, and web-based medication tracking applications [25- 39]. We stratified data entry methods on the basis of the approaches that were adopted and the user interface components were deployed to prompt entry or selection of medical information (Textbox 1). The user interfaces we developed for each exercise incorporated text boxes, pick lists, and radio button arrays that prompted the entry or selection of discrete data elements. Three different sequences of exercises were used throughout the course of the study. Each sequence followed a gradual progression from open-ended responses to constrained selections, staging the exposure of information to limit any bias that might influence subsequent responses.

Textbox 1. Data Entry Methods

- Recollection
  - Free text entry
- Selection
  - Pick list /combo box selection
  - Radio button selection
  - Check box selection
- Exclusion
  - Dichotomous radio button selection
- Abstraction
  - Free text entry
  - Pick list/combo box selection

The first set of exercises in each sequence focused on the entry of diagnosis information. Subjects were directed to enter or select designations of specific disorders. Sequences of exercises prompted free text entry of recalled diagnoses, free text entry of providers' diagnoses abstracted from copies of recent clinic notes, and radio button selection of diagnoses from a categorized list (Figure 2A). Attempts were made to identify disorders on the basis of terms that might be used in discussions between providers and patients. In some instances, this called for the redundant listing of clinical, pathophysiologic, and pathologic terms relating to the same disorder (e.g. "primary hypothyroidism", "autoimmune thyroiditis", and "Hashimoto's thyroiditis"). In other instances, this allowed for the grouping of an array of different disorders under the heading of a single term (e.g. "thyroid cancer").

Figure 2A. Study Application User Interfaces - Diagnoses From a Categorized List



A subset of related exercises directed subjects to identify specific goals of therapy associated with treatment with a thyroid hormone preparation. This approach sought to determine whether subjects understood distinctions between the use of thyroid hormone for replacement to correct primary deficiencies, replacement to correct secondary deficiencies, suppression to prevent growth of benign tissue, and suppression to prevent growth of malignant tissue. Understanding at this level may have a bearing on the interpretation of laboratory test results used to monitor responses to treatment [40,41]. Sequences of identification exercises prompted free text entry of recalled goals of therapy (Figure 2B), radio button selection of goals of therapy from a categorized list, and dichotomous radio button selection of answers to a series of exclusionary yes/no questions (Figure 3).

Figure 2B. Study Application User Interfaces - Recalled Goals of Therapy

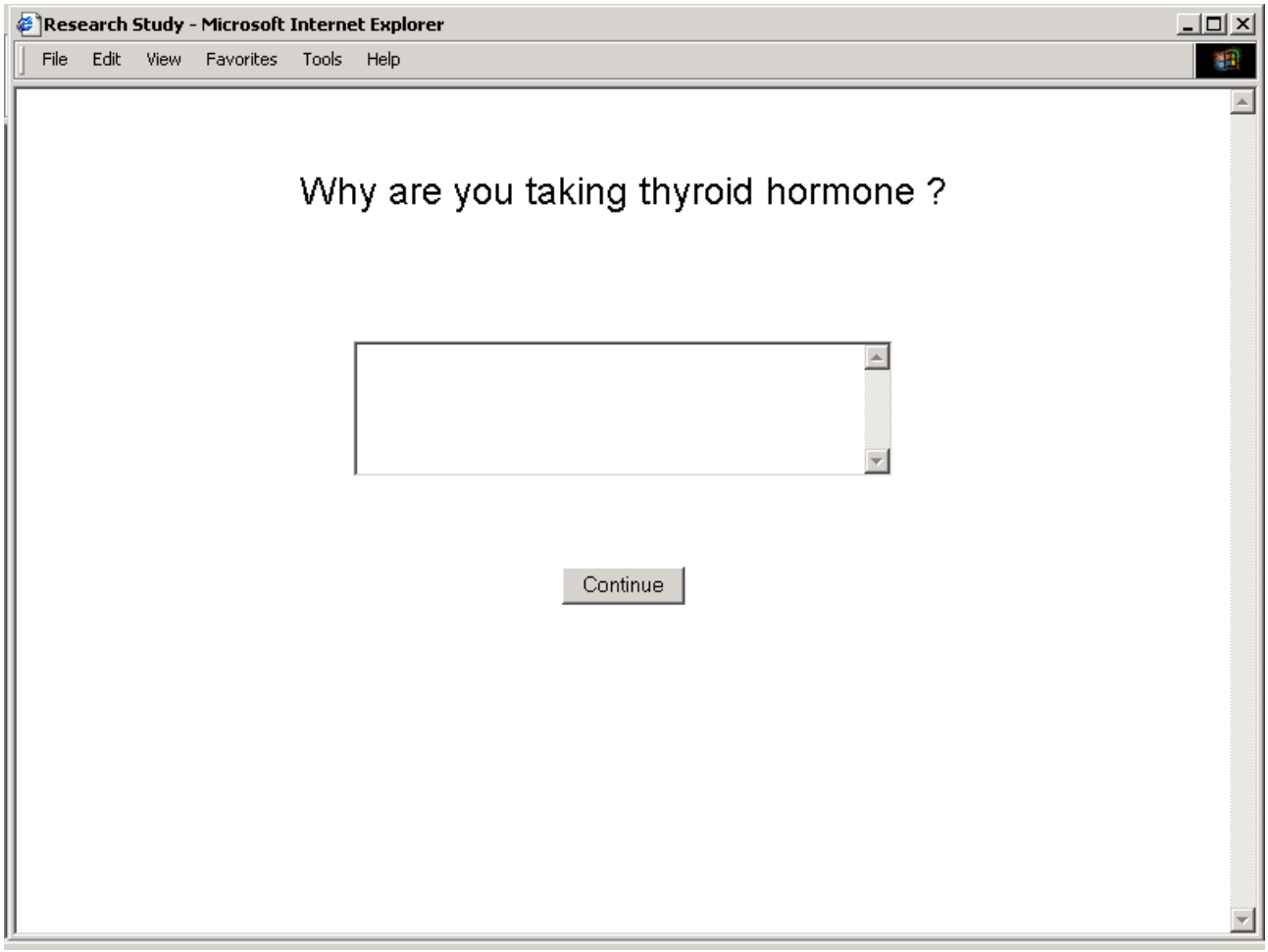
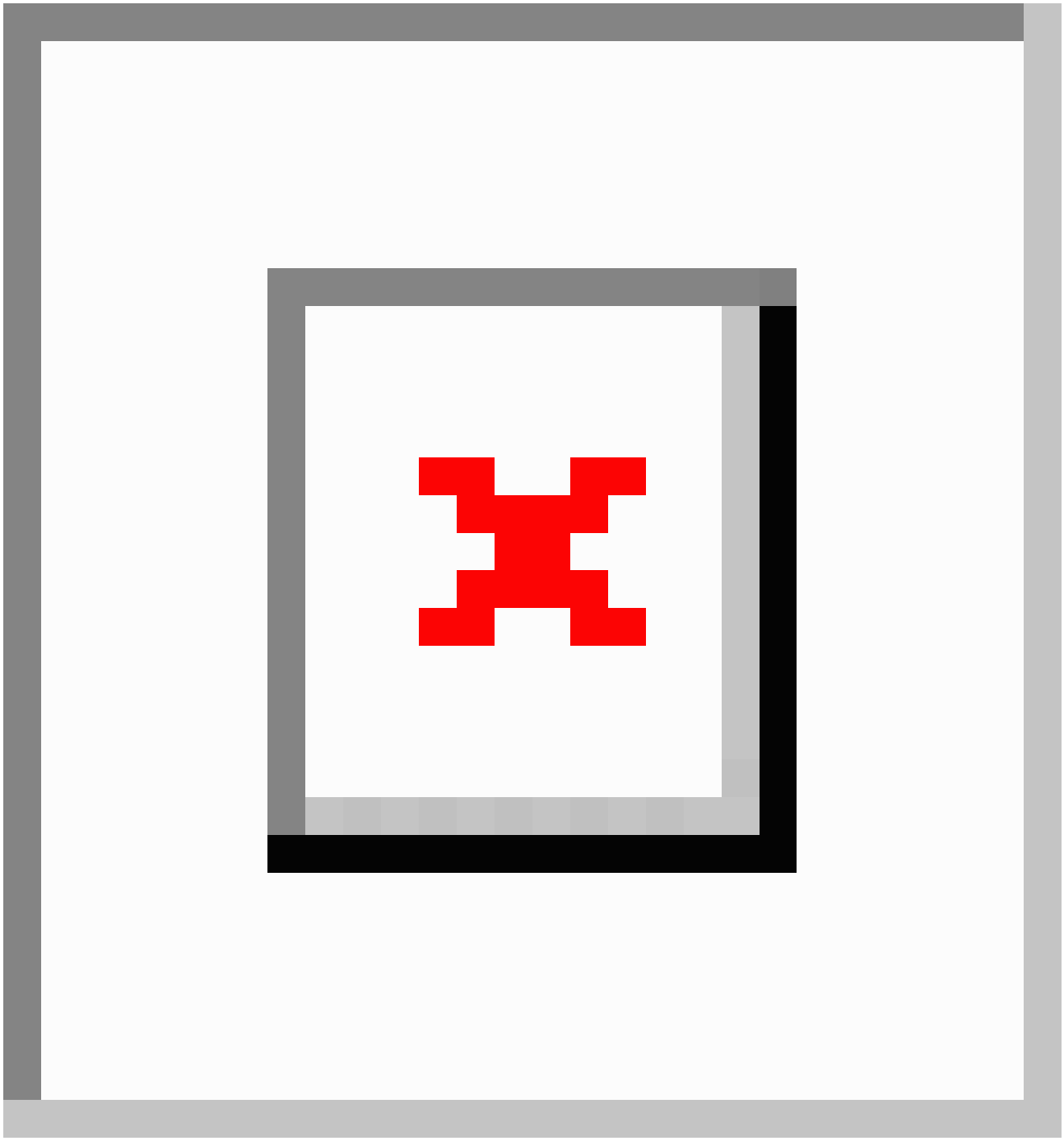


Figure 3. Exclusionary Questions



The second set of exercises in each sequence focused on the entry of prescription information. Subjects were directed to enter or select names of specific thyroid hormone preparations along with the strength, units, amount, and frequency of prescribed doses. A designation exercise prompted free text entry of recalled name, dose, number, and frequency information without any reference to prescription labels. A secondary designation exercise prompted radio button selection of a name from a categorized list. Visual identification exercises directed subjects to inspect their thyroid hormone tablets. This exercise took advantage of the fact that (1) three of the major brands of levothyroxine produced in the United States are manufactured as distinctively shaped tablets, and (2) levothyroxine tablets of different strengths are dyed particular colors according to a conventional scheme. As part of one exercise, subjects were prompted to select tablet shapes and imprints from an array of line drawings (Figure 2C).

Figure 2C. Study Application User Interfaces - Tablet Shapes and Imprints

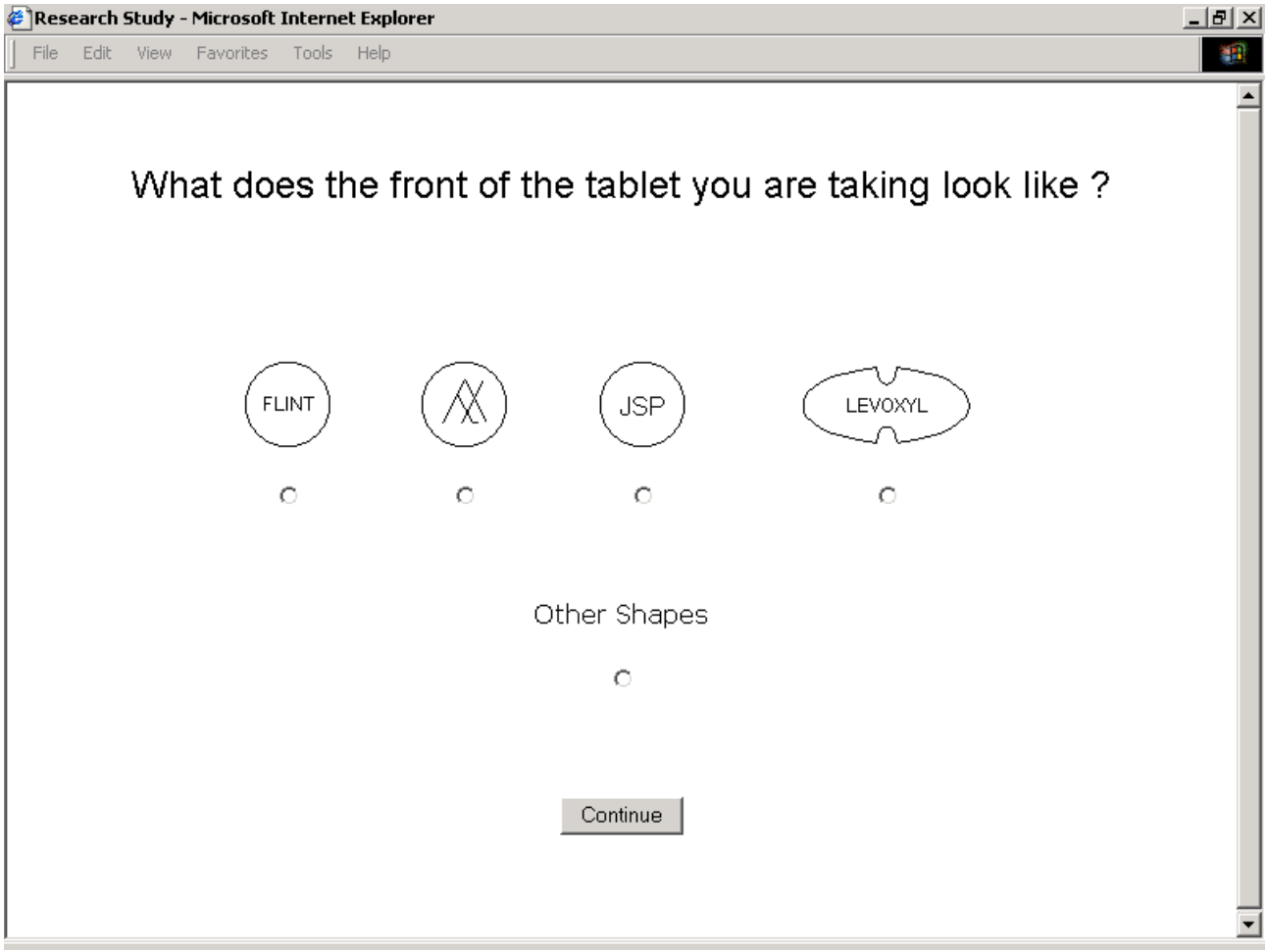
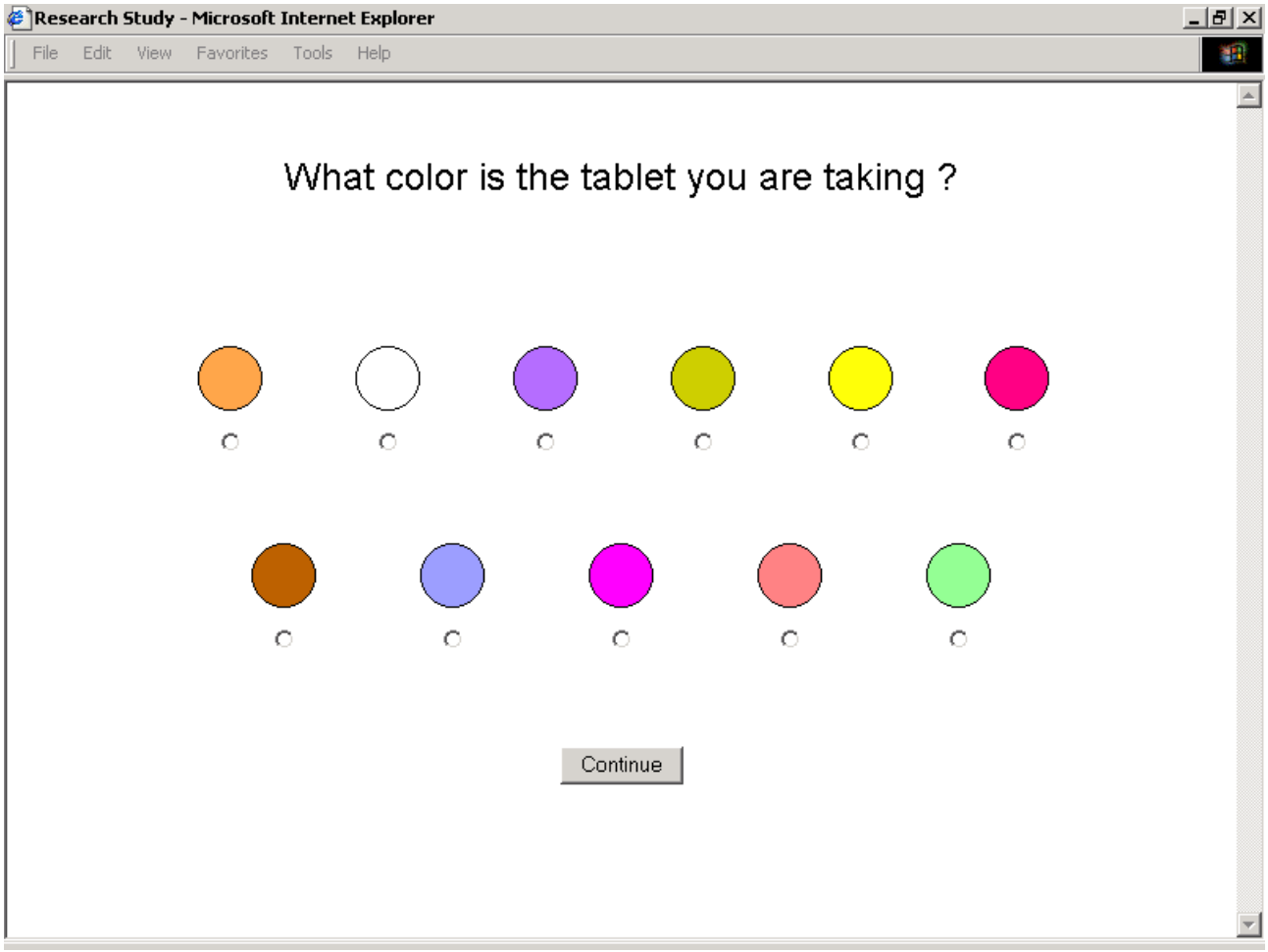
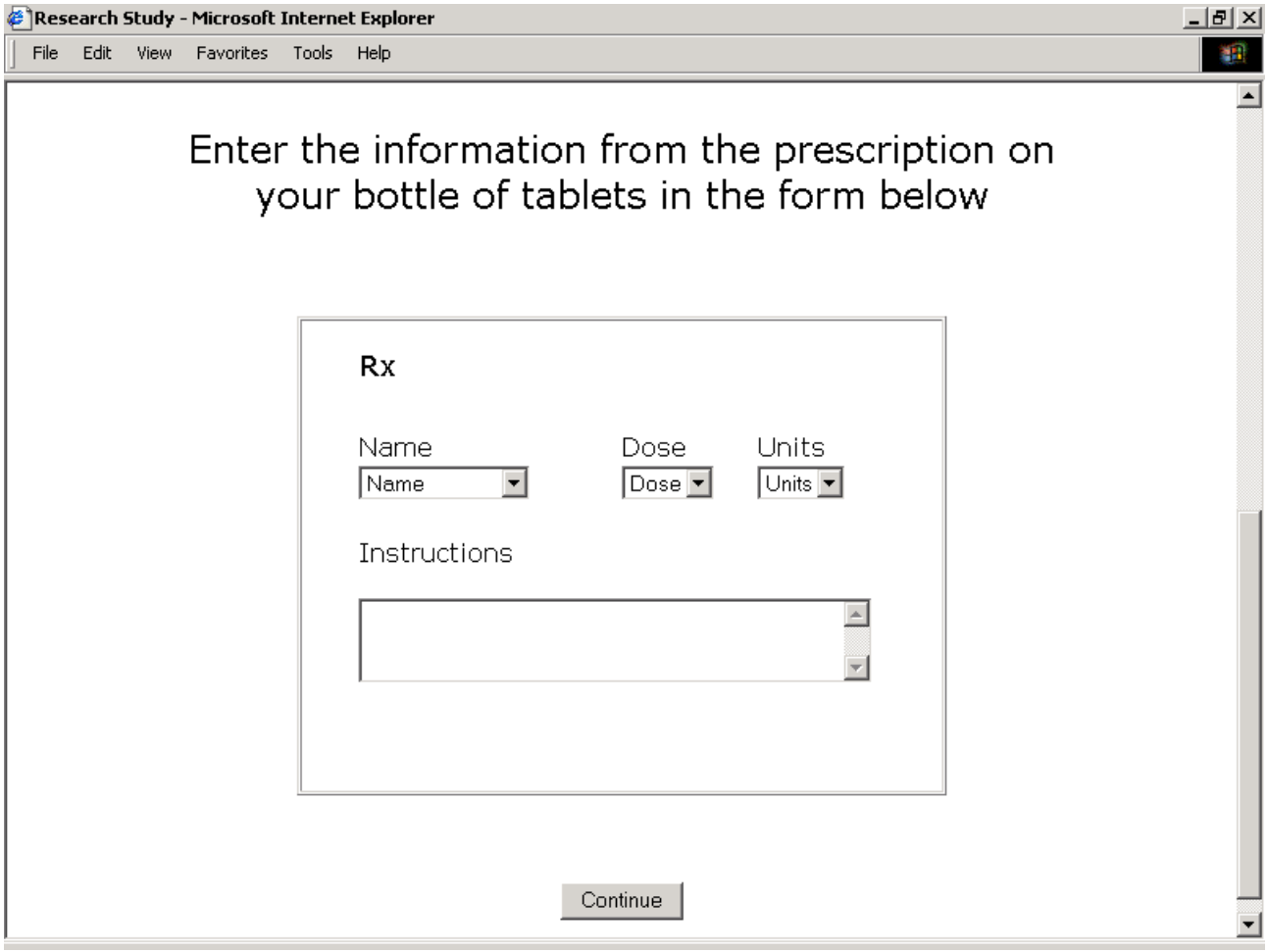


Figure 2D. Study Application User Interfaces - Color Selection



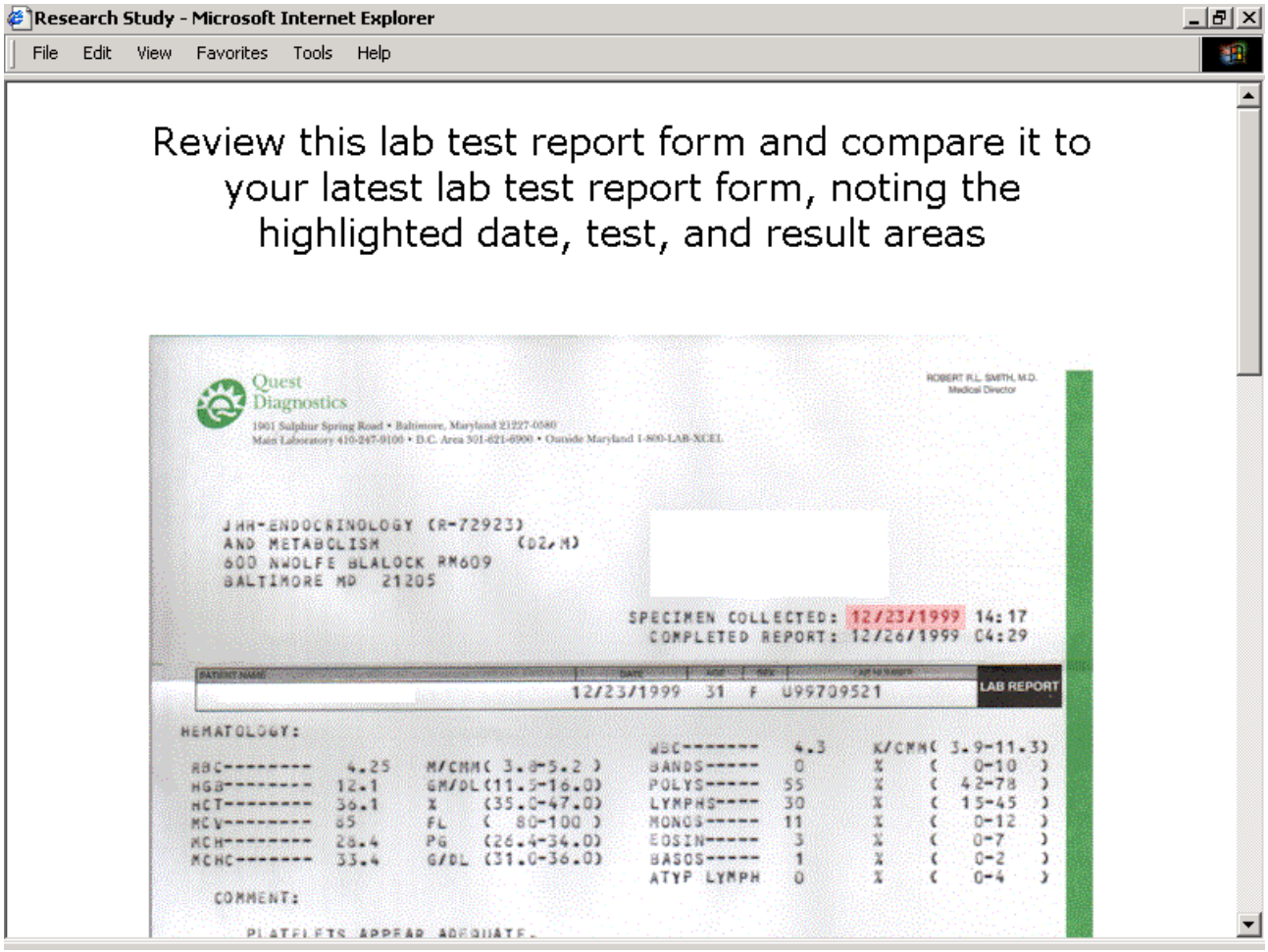
As part of a separate exercise, subjects were prompted to select colors from an array of swatches (Figure 2D). To complete each selection and visual identification exercise, subjects were asked if each preparation was prescribed as a standard amount (one tablet) at a standard frequency (once daily). Subjects who identified nonstandard dosing regimens were prompted to select the number of tablets taken on each day of the week from an array of pick lists divided into half-tablet increments. This approach was adopted to approximate prescription instructions that are commonly issued when nonstandard doses of thyroid hormone are used to suppress the growth of benign or malignant tissue.

Figure 2E. Study Application User Interfaces - Blank Prescription Using Guided Entry of Text or Guided Selection from Pick Lists



A third exercise directed subjects to review printed information appearing on their thyroid hormone prescription labels. Subjects then were prompted to enter the name, strength, units, amount, and frequency into fields similar in appearance those on a blank prescription using guided entry of text or guided selection from pick lists (Figure 2E). Highlighted samples of completed prescription labels were provided for review. Comprehensive pick lists included generic names, brand names, doses in milligrams, doses in micrograms, and amounts listed in half-tablet increments.

Figure 2F. Study Application User Interfaces - Picking Out Specific Report Components



The third set of exercises in each sequence focused on the entry of laboratory test result information. Subjects were directed to enter instances of specific results and identifying information that was associated with a range of tests commonly used to monitor the treatment of thyroid disorders. A designation exercise prompted free text entry of any recalled test names and results. A secondary abstraction exercise prompted free text entry of test names, results, and dates abstracted from entries appearing in copies of recent clinic notes. Primary abstraction exercises directed subjects to review copies of test reports. An initial exercise prompted free text entry of any abstracted information deemed to be important without any specific guidance or instruction. This exercise was followed by prompted entry of abstracted information into arrays of text boxes associated with specific test names. Users were asked to enter the laboratory name and the test date along with a result, unit, upper limit of reference range, and lower limit of reference range for each test. A sample of a composite test report was provided for review, along with a glossary of synonyms and abbreviations associated with different test names. An alternate version of this exercise took advantage of the fact that a significant percentage of laboratory tests ordered in the United States are performed by two commercial laboratories. These laboratories use standard forms to report results associated with designated test names, units, and reference ranges. Subjects were directed to inspect copies of test reports to determine if they bore the logo of one of these commercial laboratories. Subjects identifying commercial test reports were directed to review scanned copies of standard forms highlighted to pick out specific report components (Figure 2F). Text boxes prompted entry of the test date along with a result for each test.

Medical Record Analysis

Subjects' medical providers were contacted to obtain information to be used for reference purposes. Copies of signed release of information forms were faxed to provider offices along with documents requesting faxed or mailed copies of the subjects' most recent clinic notes, consultation communications, and laboratory test reports. Names of relevant disorders were abstracted from the headings of "Impression" and "Assessment" entries listed in problem-oriented clinic notes. Entries listed in consultation communications were given precedence over those listed in clinic notes in cases where there were points of disagreement. Relevant test names and results were abstracted from laboratory reports along with identifying information including laboratory names, test dates, units, and upper and lower limits of reference ranges. Designated pharmacies were contacted directly by phone to confirm recent prescription information. In each case, the last confirmed prescription issued prior to completion of the study was used as a basis for establishing a reference date, preparation, strength, amount and frequency.

Data Analysis and Statistical Methods

Accuracy rates for the entry of different data elements were calculated by comparing entered information to confirmed reference standards. Names and designations entered as free text were checked for spelling errors. When appropriate, designations entered as free text were analyzed to determine whether they included extraneous information. Comparisons between accuracy rates associated with different user interfaces were based on Fisher's exact test calculations which were performed using STATA statistical software. Institutional Review Board approval was obtained prior to beginning this study.

Results

Fifty-one respondents registered for the study. Fourteen registered respondents completed and returned all of the forms necessary for enrollment in the study. Eleven of the subjects who enrolled in the study successfully completed all of the exercises included in the study application. Copies of recent clinic notes and laboratory test reports were obtained from the designated medical providers who were listed for all of the subjects who completed the study. Recent prescription information was confirmed for all of the subjects who completed the study.

Diagnosis

Eleven subjects were prompted to enter recalled diagnoses as free text (Table 1). All of these subjects entered text strings that included a correct diagnosis. Two subjects misspelled the diagnoses. Five subjects included extraneous information (e.g., a subject with a diagnosis of "papillary thyroid cancer" entered "stage IV differentiated carcinoma with marginal extension and Hurthle cell features"). Eight subjects were prompted to abstract diagnoses from copies of recent clinic notes. Seven of these subjects entered text strings that included a correct diagnosis. Four subjects misspelled the diagnoses. Four subjects included extraneous information. Nine subjects were prompted to select a diagnosis from a categorized list. Eight of these subjects selected a correct diagnosis.

Table 1. Diagnosis: Name

Data entry method	Recollection - Free text entry N = 11	Abstraction - From clinic notes - Free text entry N = 8	Selection - Radio button selection N = 9	p
Correct name	(11) 100	(7) 87.5	(8) 88.9	0.505
Correct spelling	(9) 81.8	(4) 50	(9) 100	0.047
No extraneous information	(6) 54.5	(4) 50	(9) 100	0.033
Results reported as (number) percentage				

Eleven subjects were prompted to enter recalled goals of therapy as free text (Table 2). Three of these subjects entered text strings that included a correct principal goal of therapy. Five of the remaining subjects entered a correct related goal of therapy. Eleven subjects were prompted to select a goal of therapy from a categorized list. Six of these subjects selected a correct principal goal of therapy. All of the remaining subjects selected a correct related goal of therapy. Eleven subjects were prompted to identify goals of therapy by selecting answers to a series of exclusionary yes/no questions. All of these subjects identified a correct principal goal of therapy.

Table 2. Diagnosis: Goal of Therapy

Data entry method	Recollection - Free text entry N = 11	Selection - Radio button selection N = 11	Exclusion - Radio button selection N = 11	p
Correct principal goal	(3) 27.3	(6) 54.5	(11) 100	0.001
Correct spelling	(11) 100	(11) 100	(11) 100	0.014
Related goal	(5) 62.5	(5) 100	N/A	0.196
Results reported as (number) percentage				

Prescriptions

Nine subjects were prompted to enter recalled prescription information as free text. In each of these 12 instances, the subjects entered text strings that included a correctly spelled generic or trade name (Table 3). In eight instances these subjects entered correct strengths, in six they entered correct units, in three they entered correct frequencies of administration, and in two they entered correct amounts administered.

Nine subjects were prompted to select generic or trade names from a categorized list. Eight of these subjects selected correct preparations. Ten subjects were prompted to select tablet shapes and imprints from an array of line drawings. In each of the 14 instances these subjects selected correct preparations. Ten subjects were prompted to select colors from an array of swatches. In 8 of 14 instances these subjects selected correct preparations. All of the subjects selecting names, tablet shapes, tablet imprints, and color swatches were prompted to select amounts administered and frequencies of administration from pick lists. In 32 of 37 instances these subjects selected the correct amounts administered and frequencies of administration.

Seven subjects were prompted to enter information abstracted from prescription labels as free text. All of these subjects entered text strings that included correctly spelled names, correct amounts administered, and correct frequencies of administration. Six subjects entered correct units, while four entered correct strengths. Seven subjects were prompted to select information abstracted from prescription labels from pick lists. All of these subjects selected correct names, strengths, units, amounts administered, and frequencies of administration.

Table 3. Prescription

Data entry method	Recollection	Selection			Abstraction		
	- Free text entry	- Radio button Selection - Names	- Radio button Selection - Shapes	- Radio button selection - Colors	- From Prescription labels - Free text entry	- From Prescription labels - Pick list selection	
	N = 12	N = 9	N = 14	N = 14	N = 7	N = 7	p
Correct name	(12) 100	(8) 88.9	(14) 100	(14) 100	(7) 100	(7) 100	0.365
Correct spelling	(12) 100	(9) 100	(14) 100	(14) 100	(7) 100	(7) 100	-
Correct strength	(8) 66.7	(8) 88.9	(14) 100	(8) 57.1	(4) 57.1	(7) 100	0.013
Correct units	(6) 50	(9) 100	(14) 100	(14) 100	(6) 85.7	(7) 100	0.001
Correct amount	(2) 16.7	(32) 86.5			(7) 100	(7) 100	0.001
Correct frequency	(3) 25	(32) 86.5			(7) 100	(7) 100	0.001

Results reported as (number) percentage

Laboratory Test Results

Four subjects elected to enter recalled laboratory test information as free text (Table 4). All of these subjects entered text strings that included correctly spelled test names. One subject entered a correct result.

Nine subjects were prompted to enter laboratory test information abstracted from recent clinic notes as free text. In each of the 11 instances these subjects entered text strings that included correct test names. In one instance a subject misspelled a test name. In 10 instances these subjects entered correct results, while in eight they entered correct dates.

Eight subjects were prompted to enter laboratory test information abstracted from copies of general test reports without any guidance. In each of these11 instances the subjects entered text strings that included correct test names. In one instance a subject misspelled a test name. In nine instances these subjects entered correct results, in three they entered correct dates, in two they entered correct units, and in one instance a subject entered correct upper and lower limits of reference ranges. None of these subjects entered correct laboratory names.

Table 4. Laboratory Test Results

Data entry method	Recollection	Abstraction				
	- Free text entry	- From clinic notes - Free text entry	- From general reports, without guidance - Free text entry	- From general reports, with guidance - Free text entry	- From commercial forms - Free text entry	
	N = 4	N = 11	N = 11	N = 13	N = 8	p
Correct laboratory	N/A	N/A	(0) 0	(12) 92.3	(8) 100	0.001
Correct date	N/A	(8) 72.7	(3) 27.3	(10) 76.9	(6) 75	0.058
Correct test	(4) 100	(11) 100	(11) 100	(13) 100	(8) 100	-
Correct spelling	(4) 100	(10) 90.9	(10) 90.9	(13)100	(8) 100	0.735
Correct result	(1) 25	(10) 90.9	(9) 81.8	(13) 100	(8) 100	0.003
Correct units	N/A	N/A	(2) 18.2	(7) 53.8	(8) 100	0.001
Correct upper limit	N/A	N/A	(1) 9.1	(13) 100	(8) 100	0.001
Correct lower limit	N/A	N/A	(1) 9.1	(13) 100	(8) 100	0.001
Results reported as (number) percentage						

Nine subjects were prompted to enter laboratory test information abstracted from copies of general test reports with specific guidance. In each of the13 instances these subjects entered text strings that included correctly spelled test names, correct results, and correct upper and lower limits of reference ranges. In 12 instances these subjects entered correct laboratory names, in 10 they entered correct dates, and in seven they entered correct units. Six subjects elected to enter laboratory test information abstracted from copies of commercial forms with specific guidance. In each of these eight instances the subjects entered text strings that included correct results, prompting automatic selection of correctly spelled test names, units, and upper and lower limits of reference ranges. In six instances subjects entered correct dates.

Discussion

This study demonstrated that different types of data entry methods may have an impact on the accuracy of patient-entered information. Within each defined category, accuracy rates associated with different data entry methods appeared to vary in relation to the complexity of requested information.

Free text entry of recalled or abstracted information proved to be a fairly accurate means of entering the names of specific diagnoses. This finding was somewhat reassuring in light of the fact that most of the PHRs in current use rely on free text entry of recalled information as a principal data entry method [25-33]. It was interesting to note that subjects entering free text designations were more apt to make spelling errors in the course of entering information abstracted from clinic notes. We initially attributed these errors to illegible handwriting. Review of copies of clinic notes revealed that all but one were typewritten transcriptions of dictated entries. An alternative explanation may lie in the fact that the most of these entries included elements of medical jargon that may not be familiar to patients. This raises the question of whether diagnosis information entered as free text may need to be processed by spell-checkers that recognize acronyms and abbreviations used in clinical documentation. Subjects entering free text designations were more apt to include extraneous information that did not contribute to identification of a primary diagnosis. Most of this extraneous information focused on the assignment of etiologies or estimations of the severity of symptoms. While these modifiers did not necessarily detract from designations under consideration, their presence raised the question of whether diagnoses entered as free text may need to be parsed and sorted to isolate data elements of interest.

When entry of diagnosis information was extended to include goals of therapy, free text entry of recalled information proved to be a less accurate means of identifying principal goals of therapy. This finding was somewhat surprising in light of the fact that most of the subjects were taking prescribed thyroid hormone preparations for purposes of replacement or suppression, which are two well defined models of cause-and-effect relationships. Subjects did not fare any better in attempting to select principal goals of therapy from a categorized list of statements. The approach that focused on the selection of answers to a series of exclusionary yes/no questions proved to be the most accurate means of directing subjects to identify principal goals. This raises the question of the extent to which patients may be relied upon to directly identify their own goals of therapy. Distinction at this level may be important in situations where patients are taking agents that may be prescribed for the treatment of different conditions (e.g., diuretics, beta-blockers, systemic glucocorticoids, antiseizure medications, immunosuppressive medications). Whenever feasible, an indirect approach based on dichotomous responses to structured questions may prove to be a more reliable method of self-directed categorization.

Free text entry of recalled information was an accurate means of identifying specific names and strengths of different thyroid hormone preparations. This might have been anticipated, given the high likelihood of each subject's familiarity with this information when refilling prescriptions. For reasons that were not clear, subjects were less apt to include accurate quantitative information about units, amounts administered, and frequencies

of administration in separate free text entries. This omission may have been based on the notion that this information was implicit, given the widespread use of standard dosing. It seemed less likely that this was due to lack of awareness, given that subjects following standard and nonstandard dosing regimens were able to select accurate quantitative information from pick lists. Visual identification exercises revealed that selection of tablet shapes and imprints led to more accurate identification of preparations than selection of color swatches. This discrepancy may have arisen as a result of differential browser settings, monitor settings, or variations in color perception. It should be noted that the approach based on the selection of distinctive outlines may have been successful due to the fact that all the subjects who completed this exercise were taking distinctive brand name preparations of thyroid hormone. This mode of identification may be limited in settings where the use of generic preparations that vary in shape and appearance may be more common. Direct abstraction of information from prescription labels proved to be an accurate means of entering identifying and quantitative information, irrespective of whether data elements were entered as text or selected from pick lists. Guided text entry of abstracted information might offer the advantage of greater flexibility in situations where highly variable dosing regimens may preclude generation of comprehensive pick lists (e.g., insulin regimens, immunosuppressive regi mens, adjustments of doses in chronic renal failure).

Exercises that focused on the entry of laboratory test result information suggested that the success of each approach depended in part on the source material selected for review and the degree of guidance provided in directing the abstraction of information. While subjects who engaged in free text entry of recalled information were able to identify recent tests, they were less successful in attempts to report quantitative results. Interestingly, subjects who were able to locate test results in the context of clinic notes were generally able to abstract and enter accurate qualitative and quantitative information. This exercise may have been facilitated in part by the fact that most providers documented tests of interest, results, and subsequent directives using unambiguous telegraphic styles of reporting. Approaches that rely on this mode of secondary abstraction may be confounded in situations where providers choose to document directives as annotations to laboratory test reports. Entry of a full range of qualitative, identifying, and quantitative data elements relied on directing subjects to review and abstract information from actual copies of test reports. When left to their own devices, most subjects failed to account for the source, date, units, and limits of reference ranges specified for reported results. The need for this level of detail would likely depend on the anticipated use of this information. Tracking of instances of laboratory testing might only require accurate input of source, date, and test and information. Entry of laboratory test results for purposes of disease management or self-monitoring would likely depend on accurate input of a complete range of data elements. Direct abstraction of laboratory test result information from actual copies of test reports proved to be more successful when subjects were provided with specific guidance regarding the identity, location, and format of requested data elements appearing in printed summaries. For reasons that were unclear, the only discrepancy in the accuracy of input noted was associated with the entry of unit information for requested test results. On the whole, the accuracy of guided abstraction from general format test reports appeared to match that of guided abstraction from standard commercial forms. In this case, accurate entry of information appeared to depend more on the amount of guidance provided than on the degree of constraint imposed on the range of possible entries.

The approach we adopted in designing this study had limitations. Most of the subjects we recruited were members of thyroid patient organizations and support groups. These subjects might be expected to have a certain amount of familiarity with the terminology used to describe different thyroid disorders, thyroid hormone preparations, and thyroid function tests. This may have led to overestimation of the accuracy of data entry methods. On balance, we considered this to be an acceptable risk, given some initial concerns we had about maintaining subjects' interest in participation throughout the course of the study. These concerns appeared to be borne out by the observation that a low percentage of the respondents who registered for the study actually enrolled as participants.

We chose to focus on entry of a relatively narrow range of information drawn from the domain of a particular medical subspecialty. This may have oversimplified the process of information collection by directing subjects to focus on isolated data elements. Exclusion of other diagnostic and therapeutic information may have curtailed any confusion that might have been encountered in the setting of more complex medical histories or prescription regimens.

Many of the exercises included in the study relied on the abstraction of information from documents requested directly from medical providers. While most of the subjects who were enrolled in the study were able to obtain the necessary documents with little if any difficulty, it is unclear whether this experience would be generalizable to the population at large. Given concerns about issues of liability and confidentiality, it might be reasonable to expect that patients who attempt to request documents from medical providers may encounter varying degrees of resistance. Most of the patient-oriented document organization systems in use today advocate this approach to the collection of medical information [42,43].

Conclusions

Different data entry methods employed by PHRs appear to have an impact on the accuracy of patient-entered medical information. Strategic approaches adopted in planning the design of personal health records may need to take intended uses and purposes of entered information into account. Free text entry of recalled information may serve as an adequate means of entering simple designations of diagnoses, prescriptions, and laboratory tests. Accurate entry of more detailed qualitative and quantitative information may necessarily rely on approaches that prompt the guided entry of data elements abstracted from primary source documents. Further investigation should focus on evaluation of the accuracy of patient-directed entry of the full range of information that comprises a detailed medical history.

Conflicts of Interest

None declared.

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Abbreviations

PHR: Personal health record

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