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Viewpoint

An Ecological Framework for Cancer Communication: Implications for Research

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Abstract

The field of cancer communication has undergone a major revolution as a result of the Internet. As recently as the early 1990s, face-to-face, print, and the telephone were the dominant methods of communication between health professionals and individuals in support of the prevention and treatment of cancer. Computer-supported interactive media existed, but this usually required sophisticated computer and video platforms that limited availability. The introduction of point-and-click interfaces for the Internet dramatically improved the ability of non-expert computer users to obtain and publish information electronically on the Web. Demand for Web access has driven computer sales for the home setting and improved the availability, capability, and affordability of desktop computers. New advances in information and computing technologies will lead to similarly dramatic changes in the affordability and accessibility of computers. Computers will move from the desktop into the environment and onto the body. Computers are becoming smaller, faster, more sophisticated, more responsive, less expensive, and—essentially—ubiquitous. Computers are evolving into much more than desktop communication devices. New computers include sensing, monitoring, geospatial tracking, just-in-time knowledge presentation, and a host of other information processes. The challenge for cancer communication researchers is to acknowledge the expanded capability of the Web and to move beyond the approaches to health promotion, behavior change, and communication that emerged during an era when language- and image-based interpersonal and mass communication strategies predominated. Ecological theory has been advanced since the early 1900s to explain the highly complex relationships among individuals, society, organizations, the built and natural environments, and personal and population health and well-being. This paper provides background on ecological theory, advances an Ecological Model of Internet-Based Cancer Communication intended to broaden the vision of potential uses of the Internet for cancer communication, and provides some examples of how such a model might inform future research and development in cancer communication.

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KEYWORDS

Internet; cancer communication; ecological momentary assessment; ecological momentary intervention; ubiquitous computing; ecological models; health behavior

Introduction

The field of cancer communication has undergone a major revolution as a result of the Internet and the World Wide Web. As recently as the early 1990s, paper- and telephone-based platforms were the dominant methods used to exchange information between health professionals and individuals in support of the prevention and treatment of cancer. Interactive media existed, but they usually required sophisticated computer or video platforms that limited availability. The Internet is changing this as it expands in both availability and capability. As described in several other papers in this issue, novel processes of interpersonal communication are mushrooming as a result of the Web, including synchronous and asynchronous one-to-one, one-to-many, and many-to-many approaches.

Gunther Eysenbach's recent comprehensive review of Internet cancer communication identified four broad application areas: (1) communication via e-mail, instant messaging, and voice over Internet protocol; (2) content in the form of the array of multimedia health information available on the Web; (3) community in the form of chat rooms, bulletin board systems, mailing lists, and other forms of groupware; and (4) e-commerce supporting buyers and sellers of cancer-related goods and services [1]. As Eysenbach outlined in the conceptual model in that paper, from a health behavior perspective, these application areas share a common basis as they support intrapersonal and interpersonal needs such as the acquisition of knowledge, shared decision making, social support, and the development of self-efficacy. In this view, the Internet has reduced barriers of time, space, professional distance, and sometimes culture, but it continues to rely heavily on language or visual representations and conscious psychosocial or cognitive processes. While many of these applications have become widely used and favored by those with or at risk of cancer, their ultimate impact on cumulative cancer morbidity, mortality, and related outcomes remain to be seen [1]. An additional question remains: Is the full potential of the Internet and related computing technologies being used to improve cancer outcomes?

A Potential Reframing of Internet and Cancer Communication

The intent of any cancer communication strategy is to create a favorable effect on one or more of the determinants in the pathway of the cancer continuum—etiology, prevention, early detection, treatment, and post-treatment survivorship. Broadly conceptualized, these effects can be the result of a wide range of activities, such as helping individuals avoid exposure to substances that might place them at risk for cancer, effecting positive change in behaviors that place individuals at risk for cancer, enabling and optimizing cancer therapy, and helping with social and psychological support that is often essential to both decision making and quality of life for individuals diagnosed with cancer.

However, two recent phenomena—one health related and the other technology related—suggest that it may be appropriate to extend the conceptualization of the potential contributions of Internet communication for cancer beyond application areas that depend upon intra- and interpersonal psychosocial and cognitive processes. The first is the increasing recognition among public health and health behavior researchers of the limitations of interventions based solely on individual psychosocial and cognitive theories and processes. The second is the transformation of the Internet from a medium requiring conscious engagement through language or visual-based devices to one that supports a wide array of communication through passive "use" while at the same time becoming ubiquitous. This paper provides background on these two phenomena and proposes a model that integrates them into a research agenda for Internet-enabled cancer communication interventions.

The Growth of Ecological Models of Health Behavior

While many theories have been used to help explain health behavior, Bandura's social cognitive theory (SCT) [2] has become one of the primary cornerstones of research into the determinants of health behaviors. SCT has served as the basis for a large proportion of individual-level health behavior interventions, including many Internet-based interventions aimed at preventing cancer or optimizing its therapy once diagnosed. SCT suggests reciprocal causation between behavior and intrapersonal and environmental factors. Intrapersonal factors include individual characteristics (eg, age, gender) and cognitions and attitudes about behaviors (eg, self-efficacy, knowledge, perceived benefits). From the perspective of SCT, environmental factors are typically limited to those in the social and cultural environment. As a result, SCT-based intervention research focuses mostly on individual factors and often lacks meaningful evaluation of the potential impact of the full range of environmental determinants of health behavior. This is particularly unfortunate at a time of increasing understanding of both the importance of and the complex relationships among genetic, behavioral, and environmental factors in the causal pathway for cancer.

To address this, some researchers have begun to recognize the limitations inherent in theories based on cognitive processes and have proposed more comprehensive ecological models and theories that are more inclusive of the many environmental factors that may affect health behaviors [3,4]. Ecological theories posit that health and behavior are influenced at multiple levels, including interpersonal, sociocultural, policy, and physical environmental factors, and that these influences interact with one another [5-8]. For example, ecological models include an emphasis on characteristics of the built environment, such as architecture and community design, access to elements important to behaviors such as tobacco and healthy or unhealthy food, opportunities for physical activity, and the impact of technologies such as television or other media. At the largest level, these models and theories recognize the effect of natural environmental factors such as geography, weather, and climate on health behavior [4].

An example of the utility of ecological models may be found in their ability to explain the levels of intervention that have been shown to be necessary to address tobacco use. As outlined in a recent US Surgeon General report, these include clinical intervention, educational efforts, regulatory efforts, economic policies, and combined efforts at all of these levels [9]. No single element in this set of activities is sufficient, but rather it is the synergistic interaction among all levels that results in sustained behavior changes [10]. Increasing recognition of the limitations of intrapersonal, interpersonal, and cognitive interventions for health behavior change is leading researchers in areas such as obesity [11] and physical activity [12,13] to broaden their perspectives on opportunities for research and public health practice. However, the ecological perspective is rarely evident in research and practice in health behavior interventions utilizing the Internet. The historical roots of cancer communication—oral, written, and visual communication—are highly prevalent today. Little evidence is found in the health communication and health behavior literature about how Internet-based technologies might inform and support health promoting interactions with larger environmental processes.

Ubiquitous Computing

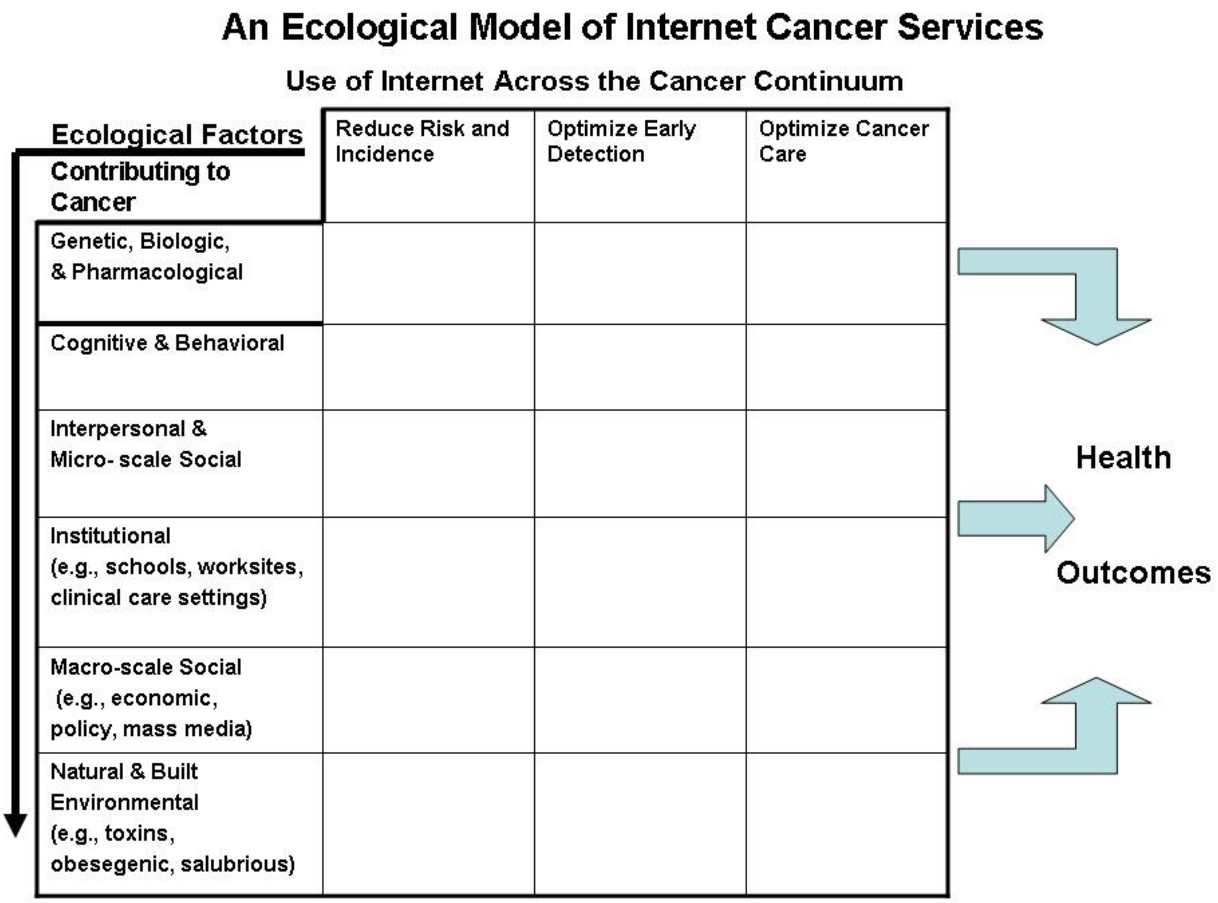
Paralleling the growth of the World Wide Web over the past 15 years has been the related development of ubiquitous computing, first envisioned by Mark Weiser of Xerox PARC as “the idea of integrating computers seamlessly into the world at large” [14]. The prescience of Weiser's vision is remarkable given the current widespread deployment of cell phones, laptops, Wi-Fi, Bluetooth, personal digital assistants (PDAs), and various forms of sensing devices based on digital and radio frequency identification (RFID) technologies. A vast and multilayered infrastructure of ubiquitous computing technologies and applications is emerging. Current functionality predominately supports business and commerce through a myriad of examples, including laptop computers and cell phones with software allowing full-function mobile work; transcontinental tracking of cargo containers with global positioning systems; and RFID-supported inventory and process management systems.

Aboud and Mynatt of Georgia Tech have articulated the challenges for optimizing this “ubicomp” environment as three-fold: (1) developing natural interfaces that facilitate a wide variety of interaction between humans and computational devices; (2) rendering ubiquitous computing devices fully context aware, capable of sensing the physical and natural environments and adapting information gathering and presentation based upon this; and (3) supporting automated capture of experiences in real time to enable subsequent access and use [15]. While their analysis does not specifically address health-related ubicomp research, reports of such work are beginning to appear, including studies that focus on the social interaction needs of elders experiencing age-related cognitive problems [16], hospital-based experiments in context-aware computing [17], and just-in-time dietary behavior intervention [18]. However, an extensive search of the medical (PubMed), psychological (psychINFO), and communication (Communication Abstracts) literatures in July 2004 found no substantive attention to the potential for ubicomp to improve interventions for cancer-related behavior or cancer communication research. Research in the engineering domains has primarily focused on developing new sensors for health monitoring of critical events such as falls or stroke, not on longitudinal evaluation of technologies for health maintenance and well-being.

An Ecological Model of Cancer Communication and Ubiquitous Computing

Until now, one of the reasons for the minimal attention given to the potential contributions that ubiquitous computing might make to cancer prevention and control is that there have been no conceptual models advanced that articulate this potential, especially in ways that are grounded in ecological theory. The model proposed in Figure 1 is an attempt to address this deficit.

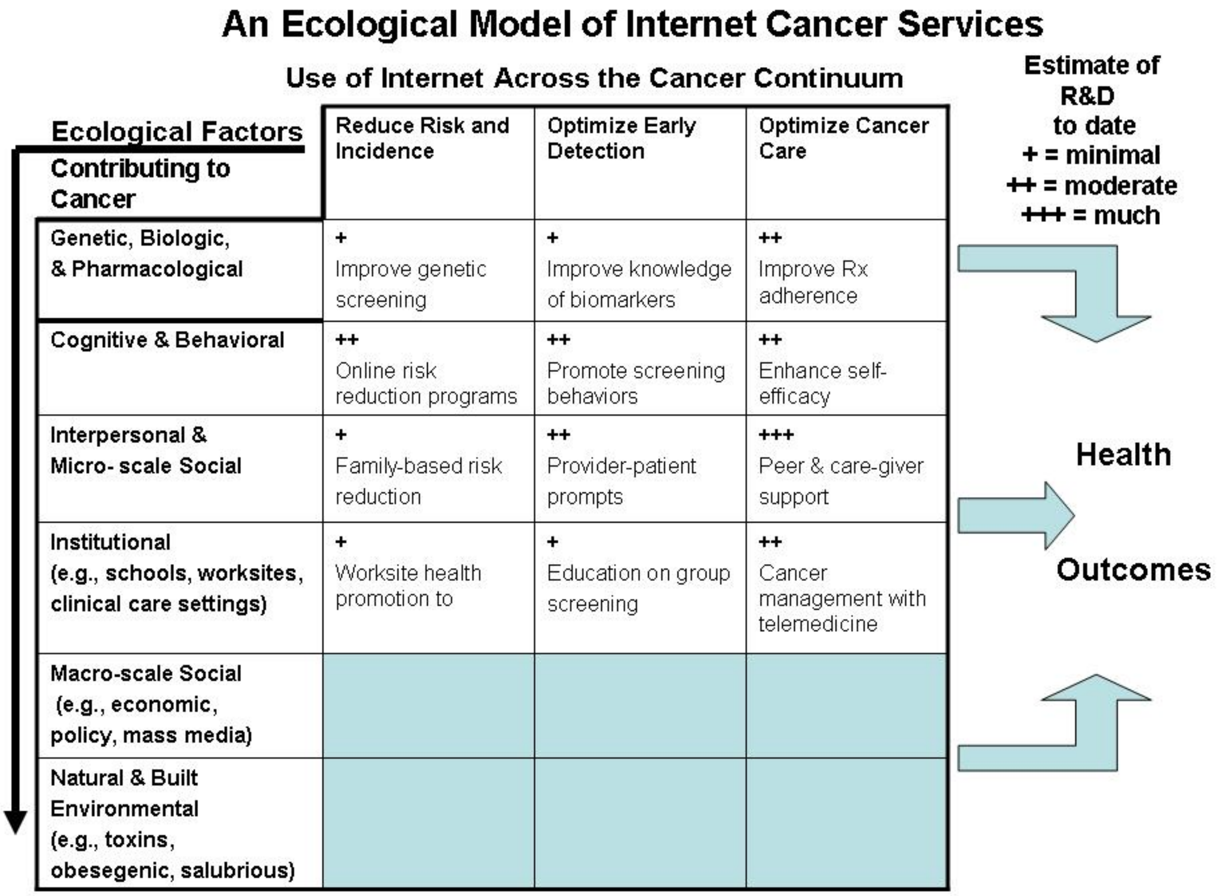
Figure 1. Proposed ecological model for cancer communication



The horizontal axis portrays the cancer continuum from risk and exposure through detection and then to cancer care. The vertical axis portrays the multiple levels at which cancer risk, disease, and treatment determinants and influences act, from micro-scale biological and intrapersonal factors through social, institutional, and cultural factors, and ultimately to macro-scale built and natural environmental factors. Because ubiquitous computing is not necessarily dependent on conscious intrapersonal and interpersonal processes and may link more to such things as geospatial and object-to-object relationships, these larger ecological levels portray where the potential for ubiquitous computing effects might exist.

As an ecological model, the intent is to be comprehensive and encompass the universe of Internet-based cancer communication interventions. If it accomplishes this, the model can then help inform us about where we have made progress to date and where we have yet to make meaningful impact. While gauging the amount of effort to date is difficult, Figure 2 displays a crude estimate of the level of current research and development in each of these areas. For example, the functions outlined in Eysenbach's recent comprehensive review, communication, content, community, and e-commerce [1], can be apportioned as appropriate into various combinations of cells in the top four rows of the model. In this model, Web-based programs aimed at reducing cancer risk through efforts such as smoking cessation, physical activity promotion, and dietary change would primarily be apportioned to row 2, column 1. Systems deployed by health plans that target—and sometimes tailor—Web-based outreach to enhance mammography utilization can be apportioned to row 4, column 2. Peer-to-peer systems that improve the quality of life of cancer survivors represent activities depicted in row 3, column 3.

Figure 2. Estimate of progress to date on research of Internet cancer services



Ecological Factors Contributing to Cancer	Reduce Risk and Incidence	Optimize Early Detection	Optimize Cancer Care
Genetic, Biologic, & Pharmacological	+ Improve genetic screening	+ Improve knowledge of biomarkers	++ Improve Rx adherence
Cognitive & Behavioral	++ Online risk reduction programs	++ Promote screening behaviors	++ Enhance self-efficacy
Interpersonal & Micro- scale Social	+ Family-based risk reduction	++ Provider-patient prompts	+++ Peer & care-giver support
Institutional (e.g., schools, worksites, clinical care settings)	+ Worksite health promotion to	+ Education on group screening	++ Cancer management with telemedicine
Macro-scale Social (e.g., economic, policy, mass media)			
Natural & Built Environmental (e.g., toxins, obesegenic, salubrious)			

As outlined in the papers in this special issue of the Journal of Medical Internet Research, Internet-based systems that support several related functions are gaining in both sophistication and use. But what of the areas in this model that remain relatively unexplored? Are there any traditional Web- or Internet-based interventions that could help fill these gaps? And what is the potential for interventions and applications based on ubiquitous computing to help fill these gaps?

One example of a Web-based desktop application that might be apportioned to row 6, column 1 is a design tool for home customization that could help a homeowner reflect upon the tradeoffs involved as he or she makes home design decisions. Desktop simulation tools are being conceptualized at Massachusetts Institute of Technology (MIT), for example, that help people consider not only immediate concerns such as cost and aesthetics but also long-term implications of design decisions that might impact health and aging in place. Included in row 5, column 1 could be a Web or mobile phone application used by television viewers to instantly register impressions of the content they are watching. Such a system could be used to create a health behavior advertisement that changes in real time based upon who is watching and what opinions the viewers express through the Internet. Widespread distribution of wireless pedometers that attach to shoelaces and automatically send data via the Internet could allow macro-scale monitoring of recovering cancer patients and allow researchers to study correlations between exercise patterns and cancer recovery, an application that would be apportioned to row 5, column 3.

Ubiquitous computing technologies such as wireless communication, sensors, context aware devices, and automated data capture, synthesis, and feedback might contribute to cancer communication in a variety of ways. Initial insight into how this might happen can be seen in the field of ecological momentary assessment (EMA), a method of data collection increasingly used in research that requires the collection of self-reported data on people's experiences as they go about their everyday lives [19,20]. EMA methods have emerged in response to the problems inherent in retrospectively collecting data on such things as mood, pain, and sense of well-being. As these may vary in intensity, duration, and frequency from day to day, hour to hour, or minute to minute based upon ecological context, the validity and reliability of after-the-fact assessments are highly suspect. On the other hand, frequent instantaneous reports of these phenomena have been shown to minimize recall bias and more faithfully represent the true natural history of transitory states.

Systems for EMA were initially developed around paper-based data collection methods. With the advent of technologies such as PDAs, handheld computers, and cell phones, this process of prompting for collection of data and the act of data collection itself have become both less cumbersome and more able to incorporate expert logic to facilitate more complex data gathering needs. For example, an expert-system platform can enable certain responses to questions to automatically present more detailed questioning in situations in which richer detail is needed about a given ecological moment.

It requires only a modest extension of logic to envision how EMA systems might begin to incorporate elements of tailored intervention on the very behaviors they are used to measure. Such “ecological momentary intervention” (EMI) could be capable of providing instantaneous and personalized feedback based on a given measured state—and perhaps based on other environmental data like physical location or other contextual factors like social settings. When viewed from the perspective of the ecological model presented in this paper, a technology that, for example, provides a prompt of self-efficacy to avoid calorie dense food in a fast-food establishment could begin to populate the bottom rows of the model. This example of EMI acts on two levels in the model. First, behavioral risk is influenced at the individual level through some form of communication device that provides a message supporting a psychosocially mediated behavior. Second, the device intervenes at the environmental level as it is linked to a wearable sensor triggered by technologies embedded within the built environment, in this case the restaurant.

What of the potential for ubiquitous computing to help complete other cells in the model? Technologies embedded within the environment might assist with home monitoring and adherence to selected elements of cancer therapy. The CareMedia project at Carnegie Mellon University is exploring video monitoring of residents of skilled nursing facilities to enable the analysis of specific individual activities [21]. Given the growth of the elderly population, the emphasis on aging-in-place, and the epidemiology of cancer and many other diseases in this population, there would be considerable value in systems to help monitor things like medication adherence, diet, physical activity, and other behaviors that improve cancer outcomes and enable independent living [22]. Users of these systems could be families of patients who are geographically separated, lay caregivers who may need extra assurance that they are providing the right types of care, or professional case managers. The central function in common, however, would be the presence of monitoring and prompting systems that help optimize the cancer intervention through sensing and monitoring technologies embedded in the physical environment.

The prevention research community can play an important role in ensuring that ubiquitous technologies already being incorporated into the built environment will be available for cancer-related EMI applications. By proposing, prototyping, and validating innovative approaches *now* that populate each of the boxes in the model, health researchers may spur public and private entities to design digital infrastructures so that they are compatible with end-user applications that promote health and well-being. Businesses are actively developing what could be called “ecological momentary advertising” to exploit ubiquitous computing to encourage consumption, but they will not necessarily design the systems to support health applications unless the public, the government, or the health community provides an incentive to do so. Relatively inexpensive modifications to existing devices, such as digital cash registers that can provide an electronic record of what someone bought or ate, could enable powerful new intervention technologies to be created that tailor information at the micro scale and influence policy at the macro scale. Fortunately, even without active participation from companies, emerging mobile devices will be able to gather some information about the built environment, such as where people are and, to some degree, what they are doing. However, built environments that explicitly provide information to enable proactive health applications will enable applications to acquire and exploit detailed records on health-related behaviors with little or no proactive effort on the part of the end user. Simplicity of use transformed the Internet from an unknown technical novelty into a pervasive global information source and communication mechanism in less than 15 years. Simplicity of use of ubiquitous computing devices could enable emergence of innovative data collection and intervention delivery opportunities in a similarly short period of time. The examples in this paper are meant to be illustrative only and derive from current research on the application of ubiquitous computing to health. As with the history of other technologies, it is impossible to predict the type and extent of future applications of technologies that are themselves undergoing rapid change and evolution. Also, perhaps more than many other areas of health research, what is explored—and how—will be heavily influenced by privacy, confidentiality, and “social” issues [15] such as the security of observation and sensing systems, privacy of any recorded data, and the trust required for coexistence with systems that are always “on” and “in control” of selected aspects of daily life.

Conclusions

The Internet has mushroomed into a vast and important source of information for individuals with health-related concerns in general and cancer-related concerns in particular. Eysenbach estimates that 39% of persons with cancer use the Internet, and an additional 15% to 20% “use” it indirectly through the support and information it provides to their family and friends [1]. While it is not yet clear whether the net impact of Internet use on cancer outcomes is positive, the general sense is that it is, especially when considerations of quality of life are included. Thus, it is incumbent on cancer researchers to explore how to extend the reach of the Internet to all individuals and all relevant domains of the cancer continuum—prevention, early detection, treatment, survivorship, and end-of-life care. Accomplishing this will require conceptualization of the determinants of each of these phases in the broadest possible sense and may be helped through use of ecological models of health. Such models are particularly relevant for Internet cancer communication research given recent trends in ubiquitous computing and the presence of computing and communication technologies of every scale and in essentially every dimension of everyday life. Ubiquitous computing provides the platform to expand psychosocial and cognitive-based cancer communication interventions to include processes embedded in the larger built and natural environments. In the end, the result may be a seamless and continuous support system that optimizes health outcomes at every stage of the cancer continuum.

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Viewpoint

The Role of User Input in Shaping Online Information From the National Cancer Institute

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Abstract

The National Cancer Institute (NCI) was among the first federal agencies to recognize the potential of the Internet for disseminating health-related information. The evolution and refinement of NCI's online cancer information has been substantially “user driven”—from the launch of CancerNet in 1995 to the recent redesign of its award-winning successor, the NCI website. This article presents an overview of NCI's multi-pronged approach to gathering input about its online information products, including stakeholder meetings, focus groups, standard and customized online user surveys, usability testing, heuristic reviews, and search log analysis. Also highlighted are some of the many enhancements that have been made to NCI's online cancer information products based on user input.

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KEYWORDS

Cancer information; Internet; online information; usability; website

Introduction

The National Cancer Institute (NCI) was among the first federal agencies to recognize the potential of the Internet for disseminating health-related information, and it launched its CancerNet website in 1995. This site was a natural extension of NCI's information dissemination efforts, which have been carried out in response to mandates from Congress in the National Cancer Act of 1971 [1] and subsequent legislation. Table 1 outlines major milestones in the development of NCI's Web presence.

Table 1. Milestones in the development of NCI's website

Year	Milestone
1995	CancerNet website is launched.
1999	cancerTrials website is launched.
1999	CancerNet website is redesigned.
2002	NCI's overarching website [2] is redesigned; CancerNet and cancerTrials websites are subsumed into the redesigned site.
2004	NCI website is redesigned.

A large part of NCI's pre-1995 information dissemination efforts was targeted at health professionals through the Physician Data Query (PDQ®) cancer information database, which contains information summaries on numerous cancer-related topics and a cancer clinical trials registry. PDQ was available to medical librarians, physicians, oncology nurses, and other professionals through the National Library of Medicine's online information system [3-6].

There was, however, a new dynamic in the development of the Web. Cancer patients were coming online in large numbers, seeking to be informed decision makers in their own care. Simultaneously, the patient advocacy community was becoming more vocal in requesting that NCI provide products geared to patients. NCI responded to this growing audience by organizing the CancerNet website by audience type, with entry points for patients, health professionals, and researchers, and with information categorized accordingly.

The evolution and refinement of NCI's online cancer information has been notably “user driven.” NCI has adopted a multifaceted approach to gathering feedback and other information about how its information products are used. This has included pre- and post-design tests in usability labs, heuristic or expert review, informal user feedback, standard online user surveys, focus groups, analysis of site usage and search logs, and special user survey projects. Each generation of NCI's Web presence has been informed by user feedback. NCI staff members were crucial leaders in developing usability guidelines and standards that are now widely accepted in the industry, and NCI was one of the first federal agencies to conduct systematic usability testing with its CancerNet website.

This article presents an overview of the methods NCI has used to gather input about its online information products and services. It is not the result of research projects that set out to test specific hypotheses about the impact of specific user-driven enhancements. Rather, it presents an approach to information architecture and design of a website that uses a variety of methods to gauge user behaviors and preferences. It highlights some of the many enhancements that have been implemented in response to user data and feedback. While NCI's website contains a wealth of additional information about cancer research opportunities, funding, NCI programs/initiatives, cancer statistics, and information for the news media, space limitations prevent a discussion of the role of user input in the design and implementation of these areas. The focus of this article will be enhancements to patient-oriented cancer information and information about clinical trials.

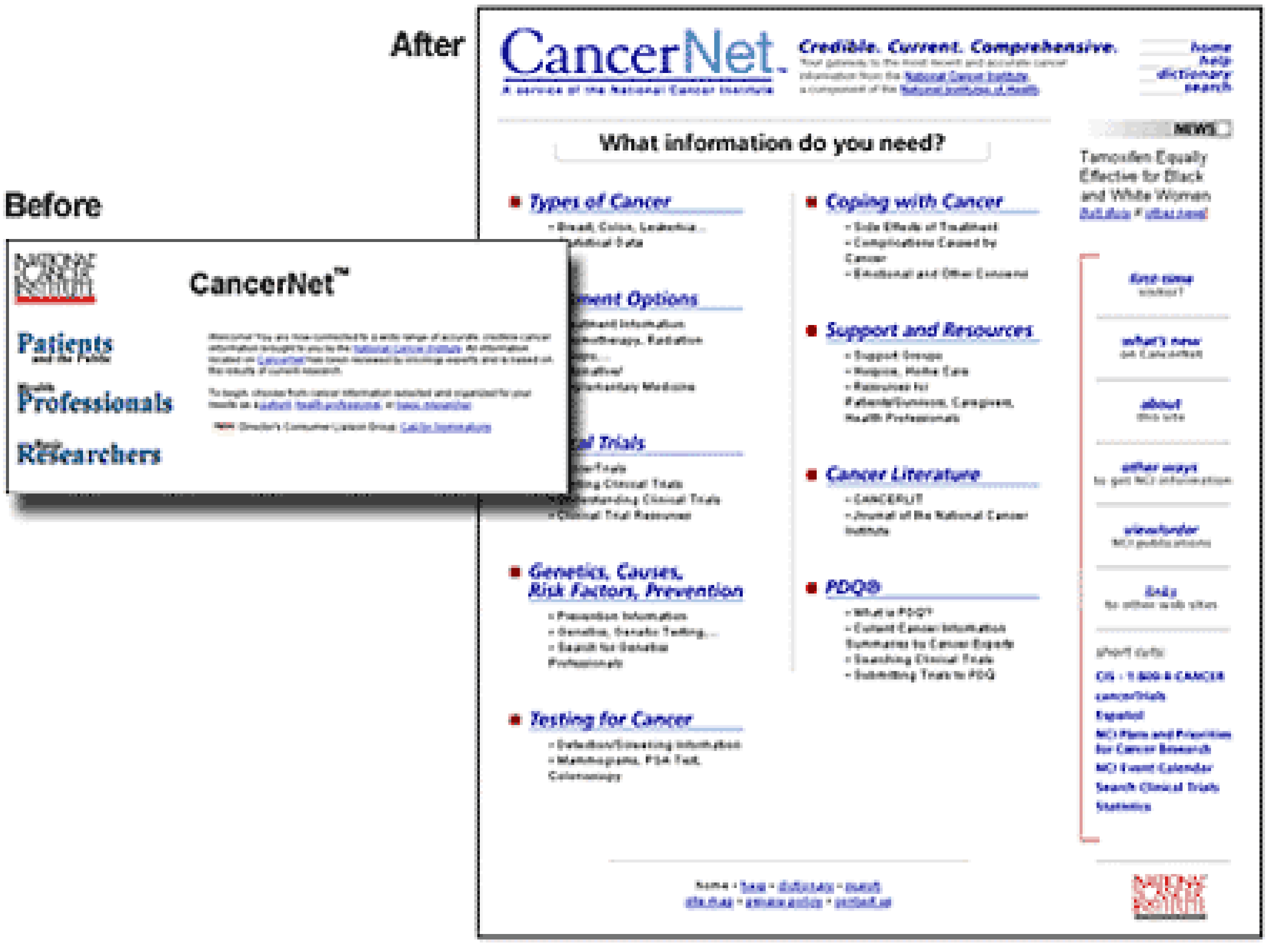
How NCI Gathers User Input and Feedback

Stakeholder Input

NCI solicits user input prior to any major online system design or redesign. For example, in response to a growing need for clinical trials information, and prior to a major redesign of the backend database and the user interface of its CancerNet website, NCI organized the Clinical Trials Information System meeting in Chantilly, Virginia, USA, in 1998.

Approximately 200 patients, advocates, clinicians, oncology nurses, clinical investigators, and health information providers representing the core users of NCI's online information resources came together to brainstorm the design of a clinical trials information system.

Figure 1. Before and after screen shots of the CancerNet home page, showing a shift in focus from audience to topic with the 1999 redesign



After

CancerNet.

Credible. Current. Comprehensive.

What information do you need?

Types of Cancer

Coping with Cancer

Support and Resources

Cancer Literature

Genetics, Causes, Risk Factors, Prevention

PDQ®

Testing for Cancer

Before

CancerNet™

Patients

Professionals

Researchers

Some of the key recommendations of the meeting were the following: (1) that the NCI website avoid segmenting information pathways according to type of user (patient, physician, researcher); (2) that information be customized to provide varying degrees of technical detail, complexity, and reading level; and (3) that users be able to easily move between these levels. It was also recommended that the NCI website integrate clinical trials information with the full spectrum of cancer information; include information about clinical trials, patient rights, and the informed consent process; and include a feature covering news topics related to clinical trials.

One of the outcomes of this meeting was the development of a new NCI website, cancerTrials, to provide an educational context for the PDQ clinical trials registry that was offered on CancerNet. The cancerTrials website was launched in 1999. In addition to guidance on how to search the PDQ registry, visitors to the new site were offered original articles explaining what cancer clinical trials were, how they worked, and where to find them. They also were offered brief summaries of recently announced cancer trial results and other timely news related to the US clinical trials system.

The subsequent redesign of CancerNet in 1999 [7] carried out the Chantilly recommendation to abandon the partition of the site by audience (Figure 1). Now, the site gave all users information organized around a standard set of topics. Information was presented at varying levels for most of the common cancers—including the “What You Need To Know” series for the most basic introduction, patient and health professional versions of the PDQ cancer information summaries, and abstracts (summaries) of clinical trial protocols written for patients and health professionals. The new design also made it easy for users to switch between the different information levels. Input obtained at the Chantilly meeting continues to influence the development of NCI's cancer information products and their presentation to users.

Ongoing Feedback from CIS Information Specialists

Information specialists at NCI's Cancer Information Service (CIS) are the front line of NCI's interactions with the cancer community, particularly the public [8]. Through the CIS toll-free telephone service (1-800-4-CANCER) and “LiveHelp” online chat sessions, information specialists help individuals who are seeking cancer information. As needed, they can assist callers and website visitors with NCI online tools and resources. As “power users” of the NCI website, they often help test new features. Regular feedback from the CIS to website staff helps drive website improvements.

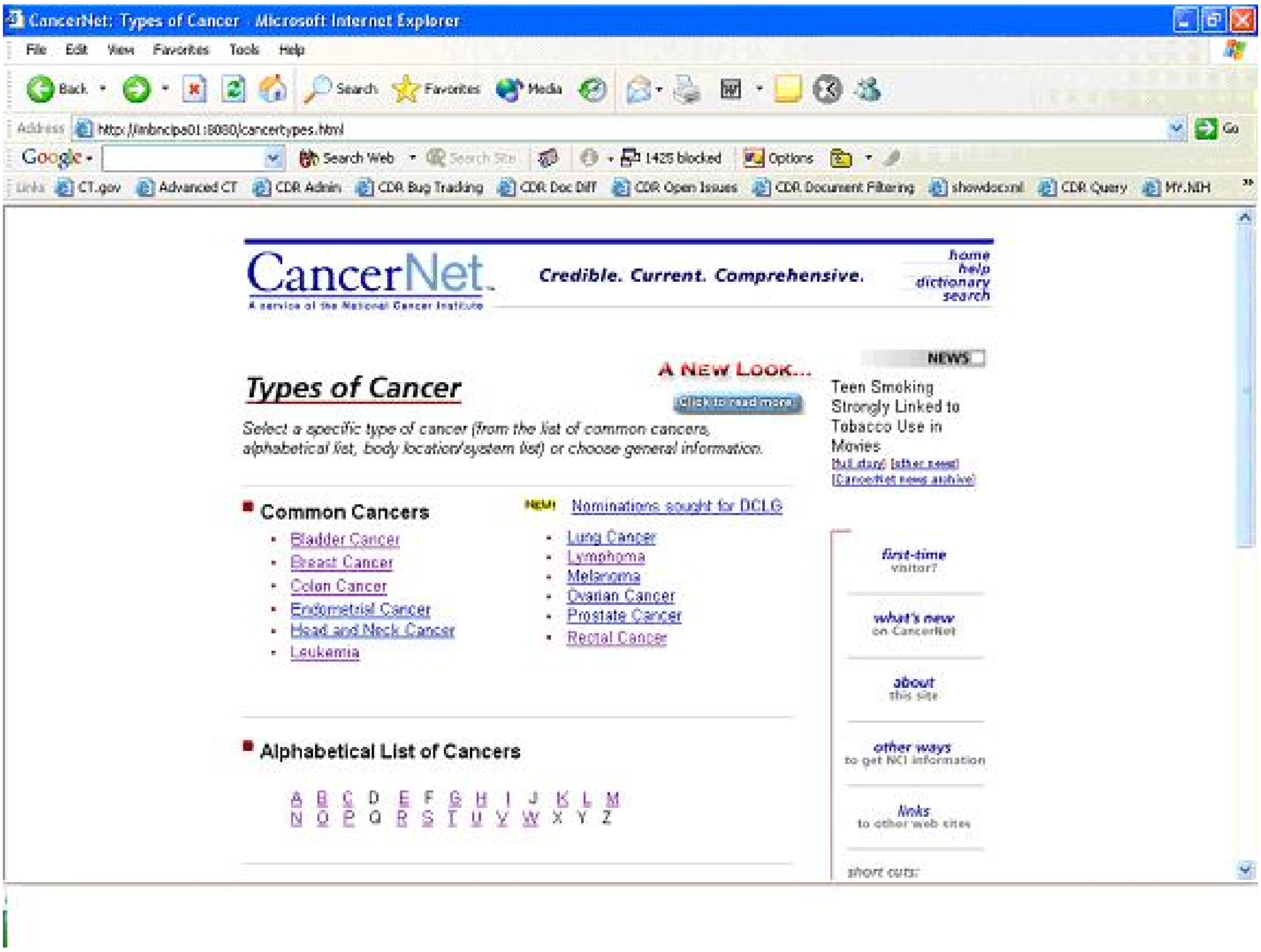
User Surveys

A critical factor in achieving continuous improvement of NCI's Web resources is soliciting user feedback to learn what works, what doesn't, and where gaps in information or functionality exist. In preparation for the 1999 redesign of CancerNet, an online survey asked users to identify the information they were seeking (Table 2), difficulties they encountered on the site, features they found useful, and additional information or features that were needed. Users were also asked about their general Web usage and basic demographics.

Table 2. Type of information users were seeking on CancerNet (1999)

Percentage of Respondents (N = 780)	Information Sought
22.8	Information on a specific type of cancer
18.6	Treatment information (general and specific)
11.3	Clinical trial information (specific trials, general information, trial results)
8.1	Symptoms of cancer, causes, risk factors, detection, diagnosis, prevention
6.8	Specific term (type of tumor or other term—not by name of cancer)
4.7	Cancer literature/articles
4.5	New treatments, news, recent findings, current research projects
3.5	Patient support (pain relief, diet/nutrition, survivorship, exercise, follow-up, questions to ask doctor)
3.1	Side effects
2.9	Statistics (incidence rates, survival rates, mortality rates)
2.8	Drug information
2.8	Access to other cancer resources (treatment facilities, physician names/specialties, national tumor registry, cost information, insurance coverage, patient support group)
2.2	Caregiver information (how to help patient, what to expect as disease progresses, how to talk to patient, etc)
2.1	History of cancer research, information for reports/projects
1.8	NCI publications (ordering information)
0.8	Alternative treatments
0.6	Genetic information (general and specific)
0.4	Search engine for the site
0.3	Information about oncology professions

Figure 2. The “Types of Cancer” page on CancerNet



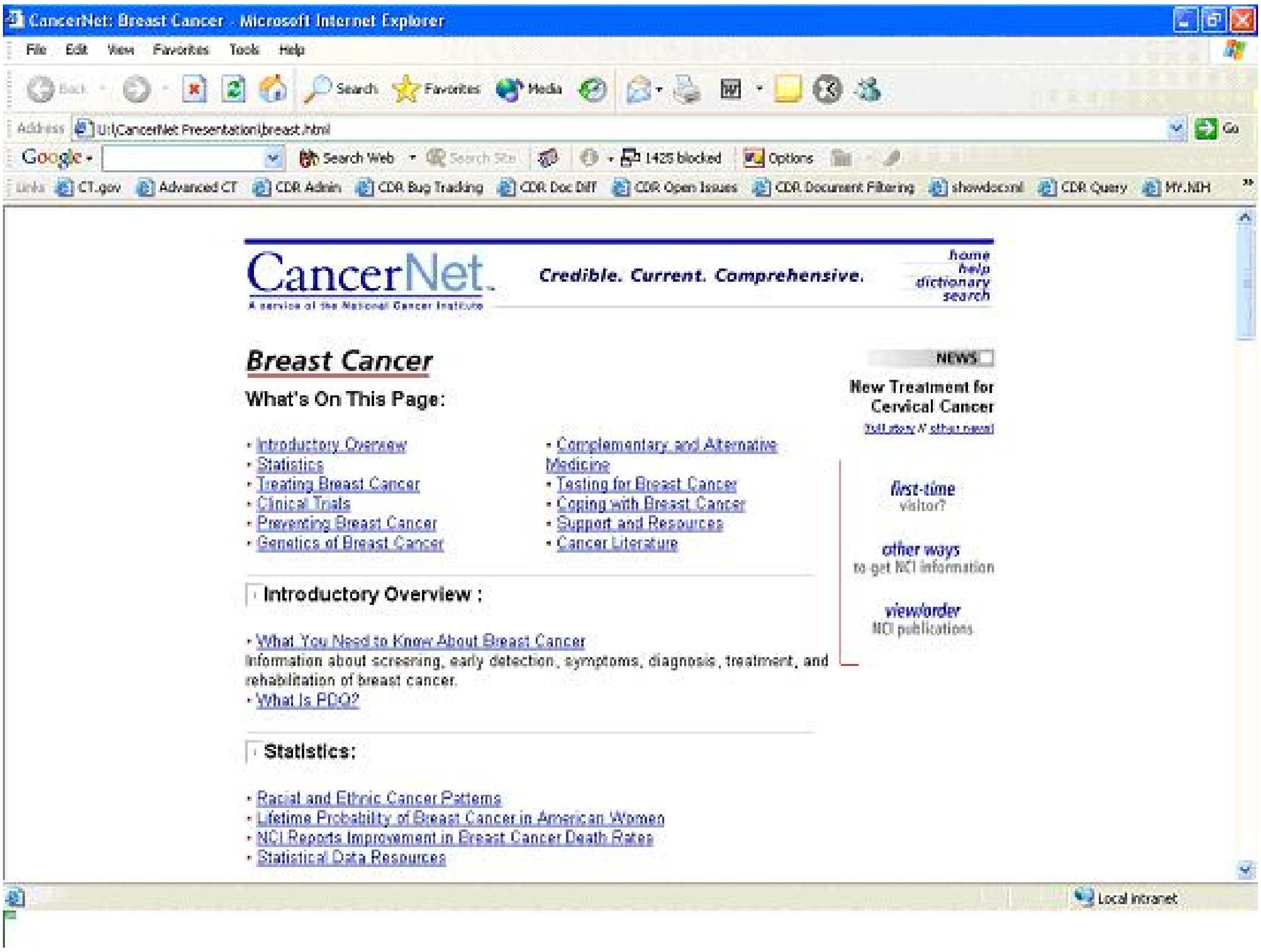
Types of Cancer

Select a specific type of cancer (from the list of common cancers, alphabetical list, body location/system list) or choose general information.

Teen Smoking Strongly Linked to Tobacco Use in Movies

Feedback from the online survey, along with input from the Chantilly meeting, guided the redesign of CancerNet in 1999. On the redesigned site, users could start with the “Types of Cancer” page (Figure 2), which enabled users to quickly find information about specific cancers. They could then choose a cancer-specific home page (Figure 3), where information related to the cancer was organized by topics such as “Introductory Overview,” “Statistics,” “Treatment,” and “Clinical Trials.”

Figure 3. The “Breast Cancer” page on CancerNet, an example of a cancer-specific home page



CancerNet
A service of the National Cancer Institute

Credible. Current. Comprehensive.

home
help
dictionary
search

Breast Cancer

What's On This Page:

- Introductory Overview
- Statistics
- Treating Breast Cancer
- Clinical Trials
- Preventing Breast Cancer
- Genetics of Breast Cancer
- Complementary and Alternative Medicine
- Testing for Breast Cancer
- Coping with Breast Cancer
- Support and Resources
- Cancer Literature

NEWS

New Treatment for Cervical Cancer

first-time visitor?

other ways to get NCI information

view/order NCI publications

Introductory Overview :

- What You Need to Know About Breast Cancer

Information about screening, early detection, symptoms, diagnosis, treatment, and rehabilitation of breast cancer.

- What Is PDQ?

Statistics:

- Racial and Ethnic Cancer Patterns
- Lifetime Probability of Breast Cancer in American Women
- NCI Reports Improvement in Breast Cancer Death Rates
- Statistical Data Resources

In 2002, NCI's overarching website was redesigned, and the CancerNet and cancerTrials websites became the Cancer Information and Clinical Trials portal areas of the redesigned site. In 2004, the NCI site underwent another redesign, once again guided by extensive evaluation and user input.

NCI's early decision to provide information tailored for patients and their families continues to be supported by surveys conducted during the past five years. Data from 1999 showed that 44% of visitors to the site described themselves as cancer patients or family members or friends of a cancer patient. Data from the American Customer Satisfaction Index (ACSI) survey posted on the NCI website in 2004 showed that more than 50% of respondents identified themselves as cancer patients or family or friends. The next largest audience in 2004 was health care providers, about 13%. NCI continues to keep the patient at the center of many of its online resources—PDQ's cancer information summaries and clinical trial abstracts, clinical trial results summaries, fact sheets and other information products, and the website's dictionary are all written for lay audiences.

American Customer Satisfaction Index (ACSI Survey)

Both before and after the 2004 redesign, the website displayed the ACSI survey [9]. This survey gathers input from users at points within the website. The ACSI survey can be utilized site-wide or for a certain URL. One version of the survey can be posted to appear randomly on all pages of the site (Appendix 1), and another can be set to appear on a group of related pages to collect in-depth data on a particular subject.

The ACSI methodology provides continuous online feedback and is a uniform, national, cross-industry measure of customer satisfaction. A core set of ACSI questions measures overall satisfaction, and customized questions can be added regarding individual websites or pages.

Data from the survey are helpful in supporting or dispelling impressions of who uses a site and what their information needs are. For example, data from the 2004 ACSI survey showed that approximately 57% of NCI's website visitors are first-time users of the site. This underscores the need for intuitive site structure and navigation tools that can be easily grasped by users with no prior knowledge of the site. Multiple paths to core information, such as cancer-specific home pages and clinical trial search tools, were created in 2004 to help new users easily find the most sought-after information. While we cannot make a direct correlation between these enhancements and increased customer satisfaction, the ACSI survey results published in December 2004 named the NCI website the “best in customer satisfaction” in the portal/department main site category [10]. Overall satisfaction among visitors to major government online portals was 72.1, on a scale of 0 to 100. The NCI website led the category for government sites with an overall satisfaction score of 80. In the first quarter of 2005, the NCI website was again the highest scoring government portal site, with a score of 80. NCI expects to further analyze ACSI data to inform additional improvements to the website.

Usability Testing and Expert Review

Usability testing helps ensure that products and services address the needs and interests of website visitors [11,12]. In lab sessions with representative users, testers pose scenarios (see Appendix 2) and solicit comments to gauge the effectiveness of page designs, functions, navigation paths, labels and terminology, and other elements. Data from iterative testing inform the refinement of key pages and the development of new features. NCI also consults with experts on user-centered design to help ensure that its information products keep pace with current standards and trends. For example, prior to the launch of the redesigned NCI website in 2004, a panel of experts was involved in heuristic reviews, and their recommendations led to additional refinements prior to the launch.

Search Log Analysis

Search log analysis played an important role in the 2004 redesign of the NCI website. Each year, users enter approximately 2.5 million free-text searches in the basic search box on the site. More than 50% of searches are for types of cancer or specific body systems or locations. To give visitors immediate access to information on the most common cancers, prominent links for each of these cancers were added to the site's home page, along with multiple links to an A to Z list of cancers to enable easy information retrieval (Figure 4). The same selection of links to common cancers and the A to Z list was also placed on the site's Cancer Topics portal page (which replaced the Cancer Information portal page introduced in the 2002 redesign). (For more information about search log analysis, see “Best Bets on the Website” below.)

Figure 4. The home page of the current NCI website, prominently featuring “Types of Cancer” and links to “Common Cancer Types”

Selected User-Driven Enhancements

Best Bets on the Website

When the NCI website was redesigned in 2002, the site's search tool was supplemented with a “Best Bets” feature that gives users a concise list of editorially selected NCI sites and pages that are displayed above the full set of search results. Whereas the full set of search results, which are generated by a free-text search of NCI's Web content, can number thousands of documents for a given search term, the Best Bets offer an average of two links, with a range of one to 18. There are currently 677 Best Bets categories (eg, lung cancer, mammography, cancer diagnosis program) with selected Spanish-language categories included.

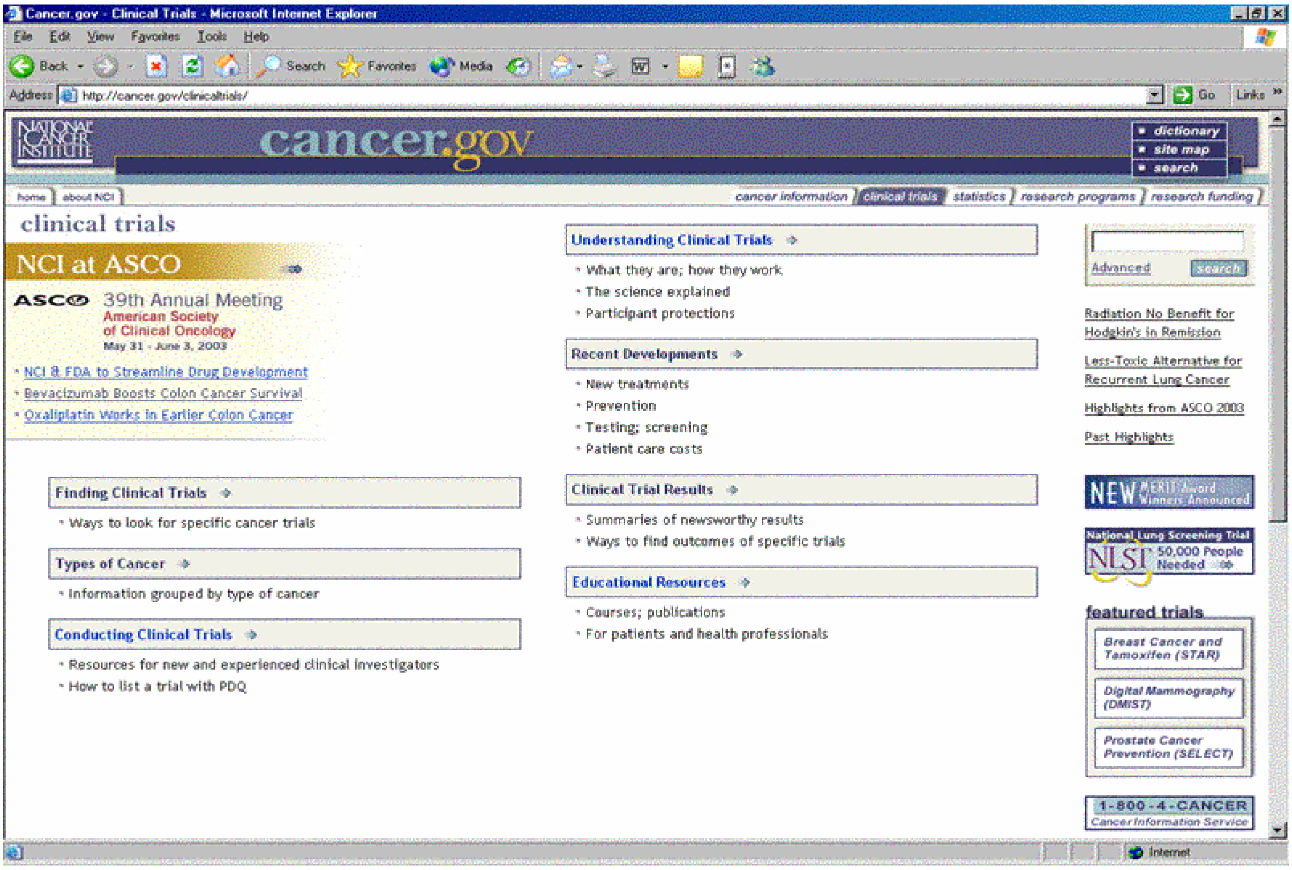
To populate Best Bets initially, a team of information experts identified cancer-related information categories, selected the most relevant NCI sites and pages for each, and created a table of related terms for each category name. When a search term is entered in the search box on the site and a category name or related term matches the term or any part of the term, the associated list of Best Bets is displayed.

Search log analysis after the launch of the Best Bets feature in 2002 validated the choice of category names and related terms, the majority of which proved to be among the more popular search terms. Since 2002, the Best Bets database has been edited by NCI staff as needed, on the basis of periodic analysis of search logs and knowledge of new and changing NCI Web content. Log analysis has prompted a considerable expansion of the Best Bets database by suggesting new category names and related terms. In addition, there have been a few instances in which the large number of searches on a topic indicated the need for new content. These findings have already led to the creation of two important pieces of content (which, in turn, were classified as Best Bets), namely a fact sheet about cancer staging and a substantial resource on the NCI website called the “Tobacco and Cancer” home page. Best Bets categories, related terms, and links have also been added in response to comments from users.

Clinical Trials Portal Redesign

In the summer and fall of 2002, NCI initiated a multi-pronged review of the Clinical Trials portal of its website (Figure 5) to determine whether the portal was meeting the needs of its users. Particular attention was given to the Clinical Trial Results section of the portal; articles in the section are also referred to as “news summaries” [13].

Figure 5. The Clinical Trials portal home page on NCI's website (2002)



Evaluation Methods

The 2002 evaluation used six qualitative and quantitative methods:

1. The initial phase of the evaluation involved *key informant interviews* with NCI staff integral to the development of the portal.
2. A *diary activity* was conducted to capture feedback from users who were representative of three of the portal's target audiences, including patient advocates, oncology nurses, and CIS information specialists. Participants were asked to complete a written, formatted diary entry for each visit they made to the portal in the course of their regular activities over a period of one month.
3. *Focus groups* and *in-depth interviews* were later conducted to gain more feedback.
4. Two *online surveys* were posted in the Clinical Trials portal of NCI's website. A general survey was presented to each user who visited any page of the portal except for news summaries. A news summary survey was presented to users who visited news summaries. Session cookies were used to recognize possible repeat visitors and to serve up the survey once per visitor during a 30-minute time period (to minimize both the burden on the public and duplicate responses). Once duplicate responses were eliminated, the adjusted survey sample contained 1589 general survey responses and 207 news summary survey responses.
5. *Usability testing* was conducted to determine whether users could easily find and understand the news summaries. Perceived usefulness of the news summaries was also explored in usability testing with six participants.
6. Server log file entries were analyzed using WebTrends *log analysis* software to collect the following usage statistics: unique visitors, visitors who visited once, visitors who visited more than once, sessions, median visit length, page views, and visits from referring sites.

Key Findings

Several key findings emerged from these evaluation methods [14]. The top three categories of information that visitors were looking for were (1) specific cancer clinical trials (ie, they wanted to search the PDQ registry); (2) recent research results about a specific cancer treatment, test, or prevention; and (3) recent research about a specific type of cancer.

With regard to the Clinical Trials portal, most users found the information they needed, were able to understand it, and found it useful. However, they had difficulty finding their way to the Clinical Trial Results news summaries, even though this type of information was among the top three categories of information desired. When directed there (or when identified as having been there via the pop-up exit survey), users found the summaries to be useful, understandable, and well organized.

Informed Changes

These findings were used to inform changes to the content and design of the Clinical Trials portal over the course of 2003 and again during the 2004 redesign of the NCI website (Figure 6). For example, to make it quicker and easier for users to search the PDQ clinical trials registry, the website's basic search form for clinical trials was added to the Clinical Trials portal home page [15]. Links to this form are also located throughout the pages of the Clinical Trials portal and elsewhere on the site.

Figure 6. The Clinical Trials portal home page on the 2004 redesigned NCI website

To further help visitors locate specific trials in which they might be interested, a new section was created called Featured Clinical Trials [16]. This section is updated on a weekly basis and includes brief profiles of key NCI-sponsored clinical trials, with links to more detailed information about the trial. Both the Featured Clinical Trials and the Clinical Trial Results sections were redesigned to allow users to browse by type of cancer and to search the collections by keyword from anywhere in the sections.

In addition, links to the Clinical Trial Results pages organized by type of cancer are more prominently displayed on the Clinical Trials portal home page, and teasers (brief description and link) for the two most recently posted Results articles are prominently displayed on the Clinical Trials portal home page.

Improved Searching for Clinical Trials

The PDQ clinical trials registry has been a key component of NCI's online cancer information services from its inception in the 1980s [3]. Originally designed for health professionals, the registry is now also widely used by patients and is one of the most popular features of NCI's website. Since January 2003, more than 50000 visitors per month, on average, have searched for clinical trials. Designing a search application that works equally well for patients, caregivers, health professionals, and researchers has been a major challenge, and NCI has relied on feedback from users as well as insight from experts to guide each version of the clinical trials search form.

Since its appearance on the Web on CancerNet, the complexity of the clinical trials search form has been a topic of discussion within NCI. The PDQ clinical trials registry began as part of a DOS-based, menu-driven system used almost exclusively by health professionals, medical librarians, and cancer information specialists. Developers were wary of transplanting the sophisticated search functionality of this system to NCI's website because many of the site's visitors had little familiarity with clinical trials, cancer staging, treatment choices, and other elements in the original system. Initial methods of clinical trial searching on NCI's CancerNet website included a form with limited search options and clinical trial descriptions written in technical language, a legacy from the original system. Simply written, patient-friendly descriptions of clinical trials were introduced in 1997.

Two-Step Search Form

The second-generation search form that was launched in 1999 was based on recommendations from the Chantilly meeting, data from an online feedback form on the website, analysis of the search form, and personal interviews. In addition, a prototype of the form was developed through iterative rounds of usability testing. A two-step search form was designed to allow users to search by common search parameters, such as type of cancer, type of trial, and geographic location. Users could then review their search results or choose to narrow their search with other parameters, such as stage of cancer, drug (including brand and generic names), type of treatment, and trial sponsor. Users were also given the option of viewing two descriptions of each clinical trial, one for patients and one for health professionals.

Other changes to the search form based on usability testing included a user's guide for less experienced users, annotated labels for search parameters with links to more detailed explanations, and explanations of how to select multiple items per field (eg, selecting several stages of breast cancer).

Audience-Focused Search Form

In the 2002 redesign of the NCI website, the clinical trials search form was included in the Clinical Trials portal of the site, giving users a more integrated information pathway that grouped information such as patient safety, informed consent, and insurance issues with the listing of clinical trials.

A major consideration in this redesign was the addition of a specific new group of users—information specialists from the CIS, whose duties include assisting patients, their families, and health professionals in identifying clinical trials of interest. Information specialists had previously used the DOS-based, menu-driven PDQ search system that allowed them to perform complex searches, review results, refine as needed, and then prepare an “information packet” that could be emailed or mailed to callers. Web designers visited a CIS regional office to understand the needs of this group of users and did extensive usability testing with them prior to launching the revised form.

Given the diversity of users, it became clear that a single search form was not ideal. Some users found the detailed choices on the form confusing and beyond what they needed. An interactive search form that guided users through the search process was considered, but such a form would require JavaScript, which does not meet Web accessibility requirements for federal government websites. It was determined that the best approach was to develop two search forms with different levels of complexity. Web accessibility requirements could be satisfied by creating one form without JavaScript, and a more complex, interactive form could be created with JavaScript.

The basic search form, designed for the patient, caregiver, or busy health professional, provided three search options—cancer type, type of trial, and zip code proximity. The results were also presented in a format more suited to the casual Web user, who was accustomed to clicking on a search result link to go to a page that contained more information. Usability testing had also indicated that users did not normally click on the check boxes that were provided with the search results in order to prepare a “package” for viewing or printing as a batch.

The advanced search form [17] was JavaScript enabled with key enhancements that included (1) dynamic population of the cancer subtype/stage search options based on cancer type selection, and (2) expanded trial site and location searching, including searches by zip code proximity and hospital. In addition, browse lists for drugs, hospitals, and investigators were added to support more precise searching. Users could search for a character string and find appropriate values to add to the search form, or they could browse data-generated pick-lists alphabetically for drug, hospital, or investigator.

In addition, for the CIS users, the search results display was developed to enable information specialists to read a preliminary result set, so they could identify the most appropriate trials for their callers and prepare an “information packet.”

Better Visibility for Search Forms

The 2004 redesign of the NCI website saw further changes in clinical trials searching. Based on user input, the ability to narrow a search to subtype or stage of cancer was added to the basic search form. User feedback also indicated that physicians preferred trials to be listed by phase rather than by title, so the default display of search results was changed to a listing by phase, with phase IV and phase III trials appearing before phase II and phase I trials. The most substantial change, as a result of the Clinical Trials portal review, was adding the basic search form to the top of the Clinical Trials portal home page to give more ready access to the form [15]. With continued feedback from users, the search forms will be improved further to allow more precise clinical trial searching—for example, an interactive format may be developed to help identify trials with eligibility criteria that match patient characteristics.

Patient-Oriented Clinical Trial Abstracts

In the summer of 1996, NCI collaborated with the National Alliance of Breast Cancer Organizations (NABCO) to develop patient-oriented abstracts (summaries) of clinical trial protocols for breast cancer trials. By October 1996, these clinical trial abstracts were available on the NABCO and CancerNet websites in a one-paragraph format. After seeking input from many advocacy organizations, the patient-oriented clinical trial abstract format was redesigned, writing guidelines were developed, and the project was expanded to include all cancer types. By September 1998, patient-oriented abstracts for all active clinical trials were available on CancerNet. Since that time, clinical trial abstracts have been written according to the original guidelines.

In November 2001, selected patient-oriented and corresponding health professional clinical trial abstracts were evaluated. As a result of this evaluation, several problems were identified in the guidelines for writing the patient-oriented abstracts, including a lack of specificity in some respects and inconsistent application and interpretation of the guidelines. These findings led to the recommendation that the guidelines be redefined and expanded. Consequently, a qualitative and quantitative evaluation of the needs and preferences of users of the patient-oriented abstracts was undertaken. This evaluation included the following two elements: (1) a written survey of advocacy organizations, members of NCI's Consumer Advocates in Research and Related Activities (CARRA) Program, members of the NCI Director's Consumer Liaison Group (DCLG), comprehensive cancer center directors and administrators, cancer cooperative group chairs/administrators, and oncology nurses; and (2) in-depth interviews with CIS information specialists.

Written Survey

A 10-question survey was mailed to nearly 400 organizations and individuals, with a 43% return rate. A key question focused on whether or not users could understand and act on the information provided in the clinical trial abstracts for patients. Results showed that 82% of users could explain the rationale or purpose of the clinical trial, 93% could determine if basic eligibility requirements were met, and 73% could understand the treatment plan.

The organization and layout of the clinical trial abstracts were rated “excellent” or “good” by 72% of the respondents. Three samples of text written at 5th-, 8th-, and 12th-grade reading levels were included with the survey. The different reading levels were preferred by 37%, 42%, and 20% of the respondents, respectively.

The results of the survey were better understood when viewed in the context of comments from individual respondents. Taken as a whole, the respondents' comments were varied and, at times, contradictory. Several themes, however, emerged related to language and readability, access to other resources, and pursuing participation in a clinical trial. Although 27% of the respondents indicated they could not understand the treatment plan, few specific suggestions were offered for improvement.

Interviews with CIS Information Specialists

Structured interviews were conducted with staff in six CIS offices in different geographic areas of the United States in order to obtain their perceptions of users' needs, preferences, and comprehension of the standard elements (title, rationale, purpose, eligibility criteria, treatment, and study contacts) of the patient-oriented clinical trial abstracts. The CIS information specialists interact directly with users of the abstracts by answering their questions and by guiding their use of the abstracts online during a phone call or through LiveHelp. The information specialists emphasized the need to use consumer-oriented language and the fact that users “skip” disclaimer-type information.

Based on these findings and on published principles [18], improvements to the patient-oriented abstracts were implemented as part of the 2004 redesign of the NCI website (Table 3). An example of the current abstract format [19] can be viewed online.

Table 3. Selected improvements to the patient-oriented clinical trial abstracts

Criteria	Improvement
Use of Language	Provide both simplified and health professional versions of the title. Avoid technical terms if a more common term is available (eg, “removed in surgery” instead of “resected”). Aim for an 8th-grade reading level or lower, except for drug names and medical or scientific terms defined in the website's dictionary (terms are linked to dictionary definitions).
Readability	Write sentences that are as short as the content will allow. Divide lengthy treatment descriptions into smaller paragraphs. Use bullets to separate information about different treatments.
Content Display	Emphasize how users who are interested in participating in a clinical trial can seek further information. Incorporate disclaimer information into the eligibility and trial contact information sections. Provide a boxed sidebar containing links to complementary information about clinical trials and drug information in the National Library of Medicine's MedlinePlus. Keywords in the title should not be linked to dictionary definitions. They should be linked from the purpose or treatment sections rather than the title.

Web-Friendly Cancer Information Summaries for Patients

The PDQ cancer information summaries are descriptions of the latest cancer information on treatment, supportive care, screening, prevention, genetics, and complementary and alternative medicine that are reviewed and updated monthly by cancer experts. Most of the summaries are available in two versions: one written for health professionals and a corresponding patient version written in lay language. (A small number of the summaries are available only in the health professional version.) In 2000, in response to the Chantilly meeting, work was initiated to reformat the patient-oriented information summaries. The goal was to present the information in a format and style of language that was easier to read and understand, to provide more detailed information, and to take advantage of features afforded by new Web technology.

Based on design concepts that enhance readability, as well as on strategies used in information mapping, the process of reformatting and reorganizing the patient-oriented summaries was begun. “Key Points” boxes that highlighted critical concepts and linked to explanatory information in the body text were added. Links to pop-up definitions from the website's dictionary and to clinical trials information were included. For users who wished to print documents, a printer-friendly version was added that included dictionary terms and their definitions as an appended glossary.

Usability testing was done to assess the ease of learning, efficiency in information gathering, and recall of information from the online documents. Based on testing results and Web design and usability guidelines [18], the template for the patient-oriented summaries was further refined, and the redesign has been well received by users. An example of the current summary format [20] can be viewed online.

Conclusion

NCI's website is a leading resource for cancer information on the Web, consistently appearing high on the list of retrievals using search engines such as Google, Yahoo, MSN, and AltaVista. It has been awarded the Freddie Award in the website category of the 2004 International Health and Medical Media Awards, and it placed first or as an honorable mention in seven out of eight categories in the 2005 Medicine on the Net Web Excellence Awards. Its success can be at least partly attributed to NCI's efforts to make the site highly responsive to the needs of its users.

The large volume of traffic that the site receives offers tremendous opportunities to study user patterns, gather feedback, and test new ideas and designs. Online surveys are an efficient way to solicit opinions from users, and analysis of website logs provides insight into user needs. NCI's relationships with members of the cancer research and advocacy communities also facilitate the gathering of advice, suggestions, and other feedback related to NCI information products. The growing body of Web-design literature and advice from usability experts are important to the development of new Web features, but input from the site's wide range of users promises to have the greatest impact on shaping online information from the National Cancer Institute.

Acknowledgments

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Conflicts of Interest

None declared.

Appendix 1

American Customer Satisfaction Index (ACSI) Survey

The following questions are from the American Customer Satisfaction Index (ACSI) survey currently used on all pages of the NCI website (except pages selected for a customized survey). In this pop-up survey, each of the first 16 questions is followed by a numbered scale (1 = poor, 10 = excellent; or 1 = not very likely, 10 = very likely), and the final 12 questions are followed by pull-down menus, a field for typing text, or lists of choices with check boxes or radio buttons. (Copyright 2004 by ForeSee Results)

1. Please rate the **accuracy of information** on this site.
2. Please rate the **freshness of content** on this site.
3. Please rate the **usefulness of the information provided** on this site.
4. Please rate the **ability to accomplish what you wanted to** on this site.
5. Please rate the **ease of navigation** on this site.
6. Please rate how this site **provides comprehensive search results**.
7. Please rate the **organization of search results** for this site.
8. Please rate the **speed of loading the page** on this site.
9. Please rate the **consistency of speed** on this site.
10. Please rate the **reliability of site performance** on this site.
11. What is your **overall satisfaction** with this site?
12. How well does this site **meet your expectations**?
13. How does this site **compare to your idea of an ideal website**?
14. How likely are you to **return to this site**?
15. How likely are you to **recommend this site to someone else**?
16. How likely are you to use this site as your **primary resource**?
17. How **frequently** do you visit this site?
18. Which of the following best describes your **role** in coming to Cancer.gov?
19. If you answered “Other” for your role, please specify.
20. Please complete this sentence: I am visiting Cancer.gov today to find information on ______.
21. If you answered “Other” or “Other cancer-related information” for why you are visiting this site, please specify.
22. Please rate how much you agree or disagree with the following statement: The information I found on this site was too hard to understand.
23. Which of the following best describes the highest level of education you have completed?
24. What is your **gender**?
25. How do you describe your **ethnicity**?
26. How do you describe your **race**?
27. Please select the category that includes your age.
28. If you could make one improvement to this site, what would it be?

Appendix 2

Sample Scenarios for Usability Testing of the NCI Website

1. Can you find NCI press releases about breast implants?
2. You want to know if NCI will fund research on tobacco control for ethnic populations. Where would you look?
3. Where can you find the policies for protecting people who participate in clinical research studies?
4. Where can you find an online (electronic) publication that explains radiation therapy?
5. You'd like information about Hodgkin's disease. What can you find?
6. Where can you find a list of the NCI's clinical research labs/branches in Bethesda, Maryland?
7. Where would you look to find clinical research results reported at scientific meetings?
8. There was a news story about a drug called cyproterone acetate, used to reduce hot flashes following surgery for prostate cancer. You want to know if a man with prostate cancer in Augusta, Georgia, can enroll in a clinical trial that uses this drug.
9. You are looking for a list of phase II melanoma trials that use vaccine therapy and are being conducted at the NIH.
10. A women's group is planning a breast cancer awareness seminar and would like a list of breast cancer screening and prevention studies in their 07112 ZIP Code.
11. You are looking for information about a trial called CLB-49907.
12. There was a newspaper article about a physician, Dr. Tanya Trippett, at Memorial Sloan-Kettering in New York, who is conducting a breast cancer trial. You don't remember the name of the study but would like to get in touch with Dr. Trippett.

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Abbreviations

ACSI: American Customer Satisfaction Index
CIS: Cancer Information Service
NCI: National Cancer Institute
PDQ: Physician Data Query database

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Viewpoint

Reducing the Cancer Burden of Lifestyle Factors: Opportunities and Challenges of the Internet

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Abstract

This paper focuses on the Internet as a tool for enhancing behavior and lifestyle changes to reduce the burden of cancer at a population level. The premise of this paper is that the Internet can and should be leveraged to bridge the chasm between basic science, clinical trials, and public health. Our focus is specifically on the opportunity to disseminate effective behavioral science interventions via the Internet in order to decrease the prevalence of behavioral risk factors for cancer. The examples herein are primarily drawn from tobacco use to illustrate issues that can be applied more generally to other behavioral risk factors for cancer. Four areas will be addressed: (1) the scientific basis and rationale for delivering lifestyle behavior change interventions via the Internet; (2) the need to determine the quality of Internet interventions; (3) methodological considerations in conducting evaluations of Internet interventions; and (4) recommendations for a transdisciplinary approach to Internet intervention development and evaluation.

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KEYWORDS

Cancer; Internet; behavior; lifestyle interventions; transdisciplinary; dissemination

Cancer and Behavior

Cancer is the second leading cause of death in the United States, accounting for 23% of all deaths [1]. In 2004, approximately 563700 people were expected to die of cancer, and the overall costs for cancer in 2003 have been estimated at $189.5 billion [2]. Behavior plays a key role in many aspects of cancer from prevention through treatment through survivorship [3]. Specifically, tobacco use, poor diet, physical inactivity, alcohol abuse, overexposure to sunlight, and risky sexual activity are associated with 50% to 70% of all cancers [4]. Translated to actual numbers, between 281000 and 395000 cancer deaths each year are entirely preventable. Tobacco use is the largest contributor to the cancer burden, accounting for one third of all cancer deaths and 87% of lung cancer deaths each year [2].

Prevalence of Behavioral Risk Factors

Millions of Americans continue to engage in risky behaviors and fail to proactively adopt protective behaviors for cancer. Approximately 23% of adults smoke [2]. Less than one in four adults eats the recommended servings of fruits and vegetables, and about 38% of all adults do not engage in any physical activity during their leisure time [2]. The prevalence of obesity has increased to 28% for men and 33% for women [2].

In addition to engaging in behaviors that put them at risk for cancer, many adults do not follow recommended cancer screening guidelines. Cancer screening has been shown to reduce mortality from cancers of the breast, uterine cervix, colon, and rectum through early detection and treatment [2]. Yearly mammograms are recommended for all women beginning at age 40, yet the prevalence of mammography in women 40 years and older was only 62% in 2000 [5]. Annual fecal occult blood tests and flexible sigmoidoscopy every five years are recommended for colorectal cancer screening for adults age 50 and over. In 2002, only 22% of age-appropriate adults received a fecal occult blood test, and 41% underwent flexible sigmoidoscopy [5].

The Need for Improved Dissemination

Significant reductions in the burden of cancer are possible through changes in health behaviors. It has been estimated that the rate of new cancer cases would decline by 19% and the rate of cancer deaths would decline by 29% if proven behavior change interventions were put into practice [6]. Effective and rigorously tested interventions do exist for reducing tobacco use [7], increasing physical activity [8], reducing sun exposure [9], and reducing alcohol misuse [10]. Although these interventions have been effective in producing meaningful (and at times sustainable) behavior change in clinical trials, they need to be proactively marketed, disseminated, and made accessible on a much larger scale if they are to make a population impact on cancer. The impact of behavioral interventions on cancer prevention and control is limited by the failure to transfer evidence-based findings into the widespread delivery of both individual and population health care. It has been estimated that Americans receive only about half of recommended medical care [11]. As stated in a recent report by the Institute of Medicine, “The American health care delivery system is in need of fundamental change.... The care delivered is not, essentially, the care we should receive.... Between the health care we have and the care we could have lies not just a gap, but a chasm...” [12] (p. 1).

Opportunities of the Internet for Cancer Prevention and Control

Consumer Demand for Online Health Information

The Internet may be the most important dissemination vehicle to improve individual and overall public health at reasonable societal cost. Breakthroughs in informatics and computer technology come at an opportune time to advance individual level behavior change on a population-wide basis. With thousands of health-related Web sites in existence, the Internet now plays a meaningful role in the health care system and is increasingly available to those with lower incomes and education [13]. Approximately 80% of adult Internet users (estimated at 93 million Americans) have searched for health information [14]. The majority looks for information on a specific disease or condition, and many users report looking for information related to lifestyle behavior change: 36% have searched for information on exercise or fitness, 10% for sexual health information, and 6% for information on how to quit smoking [14]. Six percent of 93 million translates to more than 5.5 million individuals who have looked for smoking cessation information. Not surprisingly, individuals living with a chronic illness or disability are more likely to search for health information online than those who are healthy (85% vs 61%). The majority of health information seekers search for information every few months or less, primarily around a specific health concern. For those who do not have access to a health care provider, information and treatment resources on the Internet may represent their only contact with the health care system. These data paint a clear and promising picture of a strong market demand for accessible health information.

Individual Level Behavior Change

Tailored print materials [15-18] and interactive behavior change programs [19] have been shown to have modest efficacy compared to more intensive, clinical programs. However, given the increasing penetration of the Internet in the United States (68.3% as of December 2004 [20]), delivery of such interventions via the Internet (mass customization) can reach much larger numbers of individuals than clinical trials, ultimately affecting population impact (impact = reach × efficacy [21]). Much work has been done to translate proven clinic-based interventions into more broadly available programs. However, the knowledge base in tailored and interactive behavior change programs has not been rigorously tested within the unique context of the Internet. It is critically important that interventions are evaluated within the dissemination context within which they will be used because interventions evaluated in clinical settings or in other modalities (eg, print) may not generalize to the Internet.

Systems Level Behavior Change

The Internet and related data management systems can also be used at higher organizational levels to impact the broader socioenvironmental context within which individual cancer prevention behaviors occur. For example, Internet-based systems can be used to conduct assessment and surveillance within communities, worksites, or schools; to evaluate baseline provision of best practice services; and to track critical targets to achieve cancer prevention and treatment goals in real time. Specific to behavioral risk factors, the Internet can be used to remind primary care physicians to counsel their high-risk patients to change risky behaviors and to get age-appropriate screens done for uterine, breast, prostate, and colorectal cancer. It can produce “report cards” regarding the percentage of hospitals, worksites, schools, and communities that meet minimal standards (eg, HEDIS, JCAHO) for providing behavioral change interventions. The Internet can also be used as a tool to test market new interventions, to conduct qualitative research (eg, focus groups, targeted social marketing research), and to gather program and process utilization data in preliminary research studies (eg, [22]).

Integrating Internet Approaches Into the Health Care System

Internet technology alone will not, in and of itself, be sufficient to reduce the cancer burden at the population level. Rather, the Internet should be conceptualized as a tool embedded within the *context* of the health care and the public health delivery systems and the direct-to-consumer marketing movement. The “Push-Pull” model for translating evidence-based health and behavior research into practice put forth by Orleans et al [23,24] provides a useful framework for thinking about the role of the Internet in cancer prevention and control. The model proposes three activities that are crucial to the dissemination of evidence-based care: (1) “push” of science by proving or improving an intervention for wide population use; (2) “pull” for science by boosting market demand for proven interventions; and (3) building the capacity of relevant systems to deliver or implement them. For those who are actively seeking information via the Internet, there is clearly market demand, or "pull," for tailored, evidence-based interventions that educate and empower consumers. However, for the vast majority of those at high risk (especially those in low socioeconomic and underserved groups) who are not actively seeking information online, the Internet needs to be conceptualized as simply another channel to "push" evidence-based interventions. Internet-based approaches to cancer prevention and control need to be thoughtfully integrated with efforts from third party payers, for-profit ventures, employers, clinicians, and health care and public health practitioners. Although the Internet has great potential to significantly improve public health and reduce the burden of cancer, there are significant challenges that must be overcome before this potential is realized.

Challenges of the Internet for Cancer Prevention and Control

Challenge #1: Quality

Despite the clear role that the Internet now plays in the health care system, there are no data on the impact that the thousands of health-related Web sites have had on public health [25]. Few randomized controlled trials of Internet interventions to modify cancer risk factors have been conducted [26-28]. Taking smoking cessation interventions as an example, the field is very much still in its infancy. Several pilot and uncontrolled studies have been conducted [22,29-32].

In addition, the quality of information on the Internet is a concern. The negative impact of online health information that is inaccurate or misleading, difficult to locate, or difficult to understand may be stronger than the positive impact of high-quality, accurate, evidence-based information. Misinformation on the Internet may have serious and wide-ranging negative consequences, including delays in seeking treatment, violations of privacy and confidentiality, and loss of trust in the health care provider [33]. Limited time with a health care provider may be used inefficiently or unproductively discussing misinformation, ineffective therapies may be chosen over evidence-based treatments, and money may be wasted on sham products and services.

Indeed, numerous studies have documented inadequate coverage of key content areas across a variety of health websites [34-44]. In a recent review of tobacco cessation websites, Bock et al [45] found that of 246 cessation-related websites, only 46 provided actual cessation treatment, and only 5 of those received high ratings for content and usability based on evidence guidelines. The authors concluded that smokers who search the Internet for cessation assistance are unlikely to find high-quality, evidence-based treatment resources. Given that more than 5.5 million smokers search the Internet for information to quit smoking each year [14], and that many arrive at cessation sites when they are most ready to make a quit attempt [22], this is truly a missed opportunity for tobacco control.

Methods for Determining Quality

Unfortunately, consumers have few tools at their disposal to determine the quality of information that they find online. According to the Pew Internet & American Life Foundation [46], consumers judge the quality of a website based on whether information is consistent with prior health beliefs, whether information is repeated on multiple sites, whether a site appears commercially driven, and whether the source of the content is available. Numerous measures and tools to evaluate the quality of health information have been developed or proposed (see [33]), including accreditation by an independent entity, rating systems, the use of various seals or logos (eg, HON Code seal), and disclosure of key information about a site. However, none of these methodologies have been applied in any systematic fashion to health behavior change websites. Until there is consensus regarding an appropriate methodology to monitor online content, consumers of online health information are forced to rely on available information to determine quality and trustworthiness of what they read. Thus, disclosure of key information by health websites is vital to empowering consumers to make accurate judgments about quality. Six criteria for rating quality have been proposed by the Commission of the European Communities [47]:

1. **Transparency and honesty:** The provider, purpose, target audience, and funding of the site should be easily identifiable.
2. **Authority:** The source of information should be clear, including credentials of all authors.
3. **Privacy and data protection:** The privacy and data protection policy should be clearly defined.
4. **Updating of information:** Information should be regularly updated to ensure relevance.
5. **Accountability:** Oversight of the website, relationships with partner sites, and selection of content should be held to the highest standards.
6. **Accessibility:** Guidelines on physical accessibility and usability should be followed.

Challenge #2: Evaluation Models and Methods

In addition to these six criteria for rating quality, we believe a seventh dimension should be added—effectiveness. *Effectiveness* is the effect of information and treatment resources on desired behavioral and/or health outcomes. To date, scientific evaluations of behavior change programs on the Internet reveal no uniform reporting standards regarding effectiveness. While standards exist for evaluating behavioral and pharmacological clinical trials (eg, CONSORT [48], QUORUM [49]), such guidelines have yet to be developed for the specific outcomes evaluation requirements needed for Internet programs [50,51]. One challenge in developing such guidelines is that Internet programs are inherently at the interface between clinical trials research and larger scale dissemination and community demonstration projects, each of which has its own set of guidelines for conducting program, process, and outcomes evaluations. Flay [52] defines an efficacy trial as a well-controlled test of an effect under ideal conditions, which is compared with an effectiveness trial that studies the strength of an intervention effect under real-world conditions. The vast majority of outcomes research to date has been limited to research models based on drug development, such as testing pharmacological and behavior change interventions in small-scale randomized clinical trials under ideal conditions with highly motivated, educated, and self-selected volunteers (clinical efficacy trials). Clinical trials typically focus on initial efficacy in a randomized controlled study conducted with a relatively small sample of a larger target audience. The emphasis is largely on internal validity. Even if multiple clinical trials are conducted, it is still difficult if not impossible to estimate the potential impact of the intervention when adapted and delivered to the whole target population. In contrast, dissemination and community demonstration projects focus on effectiveness of programs when implemented in real-world settings with large target populations. The emphasis is on external validity and the degree to which programs can reach an intended audience. Given the unique ability of Internet programs to bridge basic, clinical, and dissemination research, evaluation standards that are specifically designed for Internet behavior change programs and that balance tensions between internal and external validity need to be developed.

The RE-AIM Model

The RE-AIM model of Glasgow et al [53,54] provides a useful model for moving from translational to dissemination research and implementation. Briefly, the RE-AIM framework focuses on five dimensions for evaluating public health interventions: reach, efficacy/effectiveness, adoption, implementation, and maintenance. The RE-AIM framework was designed to address aspects of both internal and external validity that are important in the translation of research to practice [21,55,56]. Reach is defined as the percent of potentially eligible individuals who participate in the intervention study, and how representative they are of the target population from which they are drawn. Efficacy/effectiveness is the intended positive impact of the intervention and its possible unintended consequences on quality of life and related factors. Reach and efficacy/effectiveness operate at the individual level. Adoption is the percent of potential settings and intervention agents that participate in a study and how representative they are of targeted settings/agents. Implementation refers to the quantity and quality of delivery of the intervention's various components. Adoption and implementation are setting-level dimensions. Finally, the maintenance dimension includes individual- and setting-level indices. At the individual level, maintenance is defined as the longer term efficacy/effectiveness of an intervention. Outcomes at 6 months post-intervention contact reflect longer term individual maintenance. The setting-level definition of maintenance refers to the institutionalization of a program and is assessed according to the percent of settings that continue the intervention program, in part or in whole, beyond the study duration [53,54]. The RE-AIM framework forms a useful heuristic to guide the field by the general principles needed to achieve a successful dissemination research knowledge base for a mode of intervention delivery such as the Internet.

More rigorous dissemination research is essential if the full potential of Internet lifestyle change programs is to be realized. At the present time there are few studies of dissemination that address the criteria specified in the RE-AIM model. Dzewaltowski et al [57] reviewed 27 community-based dissemination intervention studies that “promoted good nutrition, physical activity or smoking cessation/prevention” and evaluated the extent to which each study reported on elements of the RE-AIM model. Although most studies (88%) reported participation rates among eligible members of the target audience (“reach”), only 11% of studies reported the participation rate (“adoption”) among eligible organizations or settings. Even fewer studies reported if participation was representative of those found in the broader population. Although 59% of studies reported whether the intervention was delivered (“implementation”), few reported whether individuals maintained the behavior change (30%) or whether organizations institutionalized interventions (0%). The authors concluded that “…to increase the potential to translate community research findings to practice, studies should place a greater emphasis on obtaining and reporting external validity information, such as representativeness” [57].

Application of RE-AIM to Internet Research

Many of the emergent challenges to conducting community-based dissemination research in general also apply to Internet-based research specifically. Dzewaltowski et al [57] recommend that dissemination studies include “a comparison of the study sample with either the broader target population or with those that decline, with respect to basic demographic data (Reach). This comparison can often be made using available datasets (eg, census data). Where such data is unavailable, researchers should attempt to gather basic demographic data on all participants contacted for recruitment and subsequently compare those that agreed to participate with those that declined” [57] (p. 242). They also recommend “that researchers record the level of fidelity with which the intervention is delivered (Implementation). This evaluation should include how much of the intervention protocol was followed as intended, the timeliness of protocol implementation, and any adaptations of the intervention protocol (ie, any deviations from a treatment protocol developed in an ideal clinical trial context)” [57] (p. 243).

The Need for Standards

The need for a new and broader set of standards for dissemination research trials in general and for Internet programs in particular presents a formidable challenge to the field. In considering the criteria for these standards, a balance needs to be found between preserving internal validity and maximizing external validity. On the one hand, the best research designs and methods derived from clinical trials research guidelines (eg, CONSORT) need to be retained where feasible. On the other hand, evaluating interventions as they are being used in the real world may require methods other than randomized controlled trials (eg, [58]). Despite the daunting challenges, we recommend that specific criteria be developed for reporting results of program, process, and outcomes evaluation of Internet programs. These criteria should specify the minimal acceptable standards of evidence for success, building on guidelines like the CONSORT criteria and others that have advanced the evidence base by improving the rigor of clinical trials. Standard methods of reporting the population parameters of dissemination research are needed to create a level playing field in order to make meaningful comparisons between intervention studies. For example, to define the “Reach” of an intervention, all study “denominators” should be documented, starting with the entire defined population from which the participants were drawn.

A Transdisciplinary Science Approach

There are numerous conceptual and practical issues and various perspectives at different levels of analysis that must be integrated to address the many challenges outlined thus far in this paper. To speed the development and evaluation of evidence-based Internet interventions, we recommend that a team approach to research be adopted to (a) encourage a coordinated and more rapid shift from basic to clinical trials to dissemination research; (b) capitalize on the Internet's real time tracking capability to enhance basic research (treatment components, mediators, and moderators) and to link program and process evaluation to outcomes; (c) involve practitioners, policy makers, other stakeholders, and business leaders in the research process (eg, incorporating a business model within a rigorous research framework); and (d) involve consumers so that the end users of programs are included from the very outset of the development and evaluation in order to ensure credibility, marketability, and utility. Another key to successful dissemination research is the team approach used in models such as “practice based networks” [59] and action research strategies [60]. The movement towards transdisciplinary science in fields that cut across traditional boundaries appears to be particularly applicable to address the challenges in development and evaluation of Internet behavior change interventions.

We believe that transdisciplinary science is a way to address the challenges in harnessing the potential of the Internet for cancer prevention and control. In defining transdisciplinary science, Rosenfield [61] made the following distinctions:

- **Multidisciplinarity** refers to a process in which researchers in different disciplines work relatively independently, each from his or her own disciplinary perspective with limited direct interaction and little cross-fertilization among disciplines.
- **Transdisciplinarity** is a process by which collaborators work jointly on a common problem from the very outset, using a shared conceptual framework that draws together discipline-specific theories, methods, and measures into a new synthesis.

Transdisciplinary research involves joint, coordinated, and continuously integrated research done by experts with different disciplinary backgrounds, working together and producing joint reports, papers, recommendations, and plans. Ideas from each participant are so thoroughly interwoven that the specific contributions of each participant tend to be obscured by the joint product. Early hallmarks of transdisciplinary science are the development of new approaches to theory, design, methods, measurement, and data analysis.

A transdisciplinary framework is needed because the challenges facing Internet research cannot be readily resolved by any one scientific discipline, group of stakeholders, or methodological approach to evaluation. A transdisciplinary approach recognizes that increasingly complex problems such as evaluating Internet behavioral interventions require a “team science” solution. The potential success of Internet behavior change programs is compromised at this time because the various groups involved in the design and delivery of such programs (eg, basic and applied scientists, health care providers, insurers, entrepreneurs, consumers, other stakeholders) have generally not collaborated in all phases of program development. As a result, there is great variability in the quality of existing Internet programs in terms of content, usability, and outcomes evaluation data.

The Internet offers unique opportunities to the transdisciplinary team to advance theory and to understand the basic mechanisms that lead to successful behavior change. The technological capabilities of the Internet permit a fine-grained collection of a wide variety of information and measures over time. In typical clinical trials or dissemination research, such detailed levels of tracking in real time are virtually impossible. In contrast, it is possible to track which specific components of an Internet intervention are used by each individual as well as the intensity of use. In addition, tracking of utilization data can be done across thousands of users, and the data can be automatically stored and “mined” at little or no additional cost. Metrics such as number of log-ins, total time spent online, average time per session, and number of page views are some of the more basic methods of establishing whether an intervention was delivered and received as intended (ie, internal validity). The mediators and moderators of successful or poor outcomes can also be analyzed. For example, researchers can determine what proportion of participants used a specific feature of an Internet program, what cognitive or behavioral factors changed as a result of program use, and which particular participants benefited most. Perhaps of greatest interest is the opportunity to link treatment utilization data with behavioral outcomes. An example of this type of analysis would be examining to what extent the intensity of online social support (eg, total time spent in a chat room, number of bulletin board posts in a one-month period) is related to a desired outcome (eg, changes in perceived quality of life, increases in physical activity).

Case Example: Online Social Support for Smoking Cessation

To illustrate the capability of the Internet to advance theory, we present a brief example from our research on the role of Internet-based social support in smoking cessation [22]. It is well established that the social environment plays an important role in smoking cessation. High levels of social support have been related to better cessation outcomes in clinical trials [7]. However, attempts to enhance the effectiveness of smoking cessation interventions by manipulating social support have achieved only modest success in most smoking cessation clinical trials [62]. Experimental manipulations of social support have included interventions designed to create new social networks, to train smokers to influence their own networks, or to train network members to be more supportive of the smoker. One reason for this modest success is that a “critical mass” of diverse, accessible, and anonymous sources of social support is simply not available in clinical settings where treatment is delivered to individuals or small groups on a weekly basis. We were interested in determining if perceptions of support and the use of online “support services” (eg, email, chat rooms, ask an expert) were associated with improved cessation outcomes among users of a broadly disseminated, evidence-based [45] smoking cessation website (QuitNet). Our interest in the construct of social support on the Internet derives from the thriving and naturalistic occurrence of Internet-based social support on this website.

Evaluation of QuitNet

We conducted a large-scale, preliminary evaluation of QuitNet (see [22] for details). Consecutive registrants to the QuitNet site (N = 1501) were surveyed 3 months after they registered in order to assess 7-day point prevalence abstinence. Process-to-outcome analyses indicated that the use of social support was associated with more than three times greater point prevalence abstinence, and more than four times greater continuous abstinence [22]. Not surprisingly, those who were quit at follow-up participated more extensively in the various opportunities for social support than those who were still smoking. It is noteworthy that baseline motivation was not significantly correlated with website use (intensity, use of social support) or with smoking outcomes.

We also examined whether greater duration and frequency of treatment (ie, intensity) was associated with better cessation outcomes as reported in the US Public Health Service guideline [7]. Using logistic regression with a post hoc median split of “high” vs “low” intensity website use as the predictor, analyses indicated that high website users were more than twice as likely to be continuously abstinent for 2 months compared to low website users. A composite measure of website utilization intensity (number of log-ins × duration in minutes per log-in) was very highly correlated with use of support resources (number of emails sent, number of emails received, number of email senders, number of email recipients). Since intensity and social support predicted cessation outcomes, and since social support increases with intensity, we then examined whether the degree of social support mediated the effect of intensity on cessation [63]. Confirming the mediation hypothesis requires that the effect of intensity be attenuated after adjusting for the effect of social support in a regression analysis. Indeed, mediation was found with smoking cessation as the outcome: the odds ratio for the effect of intensity declined from 2.34 to 1.52 after adding social support to the model [22]. On the other hand, high social support continued to almost triple the odds of quitting relative to low social support even after adjusting for intensity of website use (see [22] for more details).

Future Directions for Internet Behavior Change Research

The brief case example illustrates how the Internet can provide a platform to test theories of how social support may be used to enhance behavior change and maintenance of behavior change. Indeed, the Internet provides the tools for fine-grained data collection from large numbers of participants as they interact over time. Simply studying the natural emergence and evolution of Internet-based support groups may even provide opportunities to develop new theories and measures (see below) of how different kinds of social support systems motivate and mediate behavior change for different types of users at different times during the change process.

Another advantage of the Internet for advancing basic science is that new methods can be applied to the massive amounts of available data. For instance, patterns and content of online interactions between and among individuals participating in smoking cessation chat rooms can be analyzed using qualitative and quantitative analytic methods. Pennebaker et al have used innovative techniques derived from psycholinguistics and other disciplines to conduct studies of Internet and real-world support groups for 20 different diseases [64]. They also have described an analysis of over 1000 people who wrote online journals in the weeks before and after the terrorist attacks on September 11th [65]. Perhaps these techniques can be applied to understand how Internet social support helps smokers to quit, to maintain abstinence, and to prevent relapse.

The transdisciplinary science team must not only build on what is already known but must also develop new conceptual models that enhance the goals of maximizing the specific mode of Internet-delivered programs. Specific challenges include understanding how to best (a) reach, attract, and retain consumers in using appropriate (ie, evidence based) websites; (b) facilitate initial behavior change and provide knowledge and skills for successful change; (c) enhance consumer motivation to engage in behavior change activities over time; and (d) ensure that initial change is maintained. The Internet may not only be a tool for large-scale dissemination research, but it may also be useful for advancing theories of behavior change and developing new theories and ways to improve future Internet interventions.

Conclusions

There is great potential for the Internet to impact cancer prevention and control. The Internet can be used to promote lifestyle change across the cancer continuum, from primary prevention to treatment to survivorship. In addition, high-quality, evidence-based information and treatment resources can empower individuals, families, and communities to become educated consumers, to become active in their own preventive health care, and to demand more of the health care system with regard to health promotion and disease prevention. For this to happen, Internet interventions are needed that are known to be efficacious, low cost, accessible, sustainable, and that can reach large target populations. Policy makers, practitioners, and the general public cannot wait until definitive evidence regarding behavior change programs for delivery via the Internet is available. A consumer-driven thirst for health information is currently being met by the Internet with its myriad websites, many of poor quality. Scientific experts and public health practitioners must provide consumers with tools to find and use high-quality information and evidence-based treatment programs on the Internet. New transdisciplinary research domains are needed that bridge the basic, clinical, public health, and policy arenas, placing special emphasis on dissemination research. The science to practice gap must be closed to integrate basic mechanism research with translational and dissemination outcomes research for delivery of health information via the Internet. Critical to the successful emergence of better practices is the need to communicate to consumers the latest information about the quality, credibility, usability, and content of programs available on the Internet. Together, new technology in informatics and a transdisciplinary approach to product development and evaluation can improve the quality and cost-effectiveness of behavior change programs in order to reduce the burden of cancer.

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Conflicts of Interest

None declared.

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
HEDIS: Health Plan Employer Data and Information Set
JCAHO: Joint Commission on Accreditation of Healthcare Organizations

QUORUM: Quality of Reporting of Meta-Analyses

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Viewpoint

Online Health Behavior and Disease Management Programs: Are We Ready for Them? Are They Ready for Us?

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Abstract

Advancing the science and practice of health promotion and disease management on the Internet requires a systematic program of research examining the population impact of such programs. With impact described as the combination of effectiveness and participation, such research needs to include the examination of the quality and effectiveness of programs that are available to the general public, as well as descriptive and predictive knowledge about population readiness to participate in such programs. There have been few studies examining the quality of interactive health behavior change (HBC) programs on the Internet, and even fewer investigations of the effectiveness of such programs. Based on the review of over 300 HBC programs on the Internet using the “5 A's” of Health Behavior Change on the Internet (HBC-I Screener), which represent standard minimum guidelines for evaluation, it appears HBC on the Internet is in the early stages of development. As health behavior change on the Internet matures from the provision of health information to meeting the requirements necessary to produce health behavior change, and as program developers take advantage of the interactive nature of the Internet, the basic screening and expanded evaluation criteria developed in this project will provide templates for both consumers and developers of programs. The second component necessary for evaluating the impact of HBC on the Internet is the extent to which the population is ready to participate in such programs. We need to move beyond a narrow focus on early adopters and produce a population perspective that includes those not ready, those getting ready, and those ready to use such programs, as well as those already participating. By understanding participation levels of such programs, and what drives this participation, the development and dissemination of practical tailored and targeted interventions can help maximize population participation in Internet programs for health behavior change.

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KEYWORDS

Health behavior; Internet; disease management; health promotion; evaluation studies

Introduction

Advancing the science and practice of health promotion and disease management on the Internet requires a systematic program of research examining the population impact of such programs. With impact described as the combination of effectiveness and participation, such research needs to include the examination of the quality and effectiveness of programs that are available to the general public, as well as descriptive and predictive knowledge about the population readiness to participate in such programs. This paper describes initial research examining the two areas that affect the impact of Internet based programs: (1) the status of health behavior change on the Internet, including the types and quality of sites available; and (2) individuals' readiness for using the Internet for health behavior change.

Are We Ready for Them?

Although several guidelines for evaluating health on the Internet have been published (for a sample list see [1]), few of those include specific criteria relevant to the area of health behavior change and disease management. Established criteria have often been designed specifically for websites that provided health information rather than programs aimed at helping individuals manage their health. As part of a larger study examining the impact of health behavior change on the Internet, a set of screening criteria was adapted from the Public Health Service's *Clinical Practice Guideline for Treating Tobacco Use and Dependence* [2]. The “5 A's” portion of those guidelines represent five major, but brief, intervention steps that can be used in the primary care setting for those patients who use tobacco. The “5 A's” represent generic counseling steps that can be used for most health behavior risks and that form the basis for the development of brief criteria for the basic elements needed in Internet programs designed for health behavior change. These criteria do not assure efficacy for behavior change, rather they are assumed to provide the minimum criteria for a program to have the potential for producing behavior change.

Development of the HBC-I

The original intent of the first of the Tobacco “5 A's,” *Ask*, was to systematically identify all tobacco users and ensure that every patient's tobacco-use status was asked and documented. Since websites inherently assume that a visitor has a specific concern related to the content of the site (eg, the visitor to a smoking cessation site wants to quit smoking or help someone quit smoking), the *Ask* criteria was not included in the HBC-I.

The second strategy, *Advise*, involves practitioners urging tobacco users to quit. For the HBC-I guideline, this was expanded to include advising the individual about a particular behavioral risk and about the need to change the behavior.

Assess is the third strategy, in which practitioners assess a patient's willingness to quit. For the variety of behaviors for which programs exist on the Internet, there are many variables, such as self-efficacy and psychosocial variables, which are important for providing appropriate strategies for the individual. Therefore, within the HBC-I, *Assess* was expanded to include the assessment of many possible variables that could impact behavior change.

The Tobacco *Assist* criterion was divided into two separate criteria for the HBC-I. The first, *Assist*, includes providing support, understanding, praise, and reinforcement; describing intervention options; negotiating intervention plans; and/or providing general assistance in making changes. This assistance should include the tailoring of messages based on the assessment from the Internet *Assess* criterion. The second criterion, *Anticipatory Guidance*, was derived from the Tobacco *Assist* strategy and anticipates triggers or challenges that can lead to relapse. The adapted HBC-I *Anticipatory Guidance* criterion includes providing counseling for potential relapse problems and addressing issues of relapse prevention.

Arrange Follow-up for Tobacco includes scheduling at least one future contact and suggesting further steps to take during that contact. The HBC-I version includes arranging a follow-up session, reaffirming a plan of action, advising when it would be best to come back to the program, and advising about an appropriate type of follow-up even if the program itself might not provide it.

Two versions of the HBC-I assessment tool were developed to assess these five specific criteria: HBC-I Screener and HBC-I Expanded.

Application of the HBC-I Screener

The first application of the HBC-I Screener was conducted with 294 websites representing seven targeted behaviors (alcohol use, diet, exercise, smoking, asthma management, depression management, and diabetes management) [3,4]. Sites were identified through online searches, medical information journals, articles, and ads in the popular press. A total of 273 valid websites were evaluated using the HBC-I Screener. Two masters-level reviewers rated the websites on the presence of each of the five HBC-I criteria. The kappa statistic was calculated for each criterion to assess the agreement between the raters, or inter-rater variability. The kappa values for the five categories ranged from 0.84 to 0.93 (mean = 0.88). Kappa values between 0.80 and 1.00 represent almost perfect agreement. A third individual reviewed a site when the two raters disagreed.

Websites were given an overall score ranging from 0 to 5 depending on how many of the criteria were met (Table 1). Overall scores were normally distributed with an average of 1.45 (SD = 1.64) criteria met. Only 8.1% (n = 22) of the websites met all five criteria of the HBC-I Screener, while 7.3% (n = 20) met four. The criterion which most websites met was *Assess* with 51.6% (n = 141). The criterion which the fewest sites met was *Anticipatory Guidance* with 11.4% (n = 31). Table 2 presents the number of websites meeting each of the “5 A's” criteria by behavior. Of those sites meeting four or more of the criteria (n = 42), the behavior most represented was smoking (n = 12; 28.6%), followed by diet (n = 11; 26.2%) [4].

Table 1. Number of websites meeting HBC-I screening criteria

Number of Criteria Met	**Websites**
	No. (%)
0	113 (41.4)
1	57 (20.9)
2	34 (12.5)
3	27 (9.9)
4	20 (7.3)
5	22 (8.1)

Table 2. Number of websites meeting HBC-I screening criteria, by behavior

Behavior	Assess No. (%)	Advise No. (%)	Assist No. (%)	Anticipatory Guidance No. (%)	Arrange Follow-up No. (%)
Asthma	11 (33)	10 (30)	3 (9)	2 (6)	5 (15)
Alcohol	10 (37)	3 (11)	1 (4)		
Diet	33 (67)	25 (51)	18 (37)	6 (12)	14 (29)
Exercise	30 (73)	19 (46)	15 (37)	7 (17)	14 (34)
Depression	19 (46)	9 (22)	3 (7)	1 (2)	1 (2)
Diabetes	21 (51)	18 (44)	7 (17)	2 (5)	9 (22)
Smoking	16 (44)	24 (67)	14 (39)	13 (36)	10 (28)
Total websites meeting criteria	**141 (51.6)**	**108 (39.6)**	**62 (22.7)**	**31 (11.4)**	**54 (19.8)**

Results from a 1-way ANOVA examining the differences in number of criteria met by the different behaviors showed significant results ($F_{7,272} = 5.89$, $P < .001$, $eta^2 = .14$). Websites in the areas of diet, exercise, and smoking met significantly more of the criteria than sites in the areas of alcohol and depression management. Websites in the areas of exercise and smoking received significantly higher overall ratings than sites in asthma management [4].

It is clear from the analyses that the majority of sites readily available to consumers do not meet minimum criteria for health behavior change on the Internet as defined by the HBC-I. The criterion that sites did the best in was *Assess*, and the area with the lowest percentage meeting criterion was *Anticipatory Guidance*. Only 8.1% of the sites received credit in all of the five categories, while 7.3% received four credits. The greatest number of sites meeting four or more of the criteria was in the area of smoking, with diet having the second greatest number. None of the alcohol sites and only one of the depression sites received credit in four or more of the criteria. These results indicate that the development of websites in the areas of diet, exercise, and smoking is much further along in terms of providing the necessary components of health behavior change on the Internet than that in the areas of asthma, alcohol, and depression [4].

Application of the HBC-I Expanded

An expanded version of the HBC-I Screener was developed to provide more in-depth review criteria concerning the “5 A's” criteria of the HBC-I. Twenty-one behavior change criteria were developed around the five HBC-I screening criteria, and two questions were added to specifically address five major health behavior change theories and variables. The behavioral criteria for the HBC-I Expanded can be found in Cummins et al [1]. As part of the study described above, the HBC-I Expanded was used to evaluate those sites that met a minimum of four of the five HBC-I Screener criteria. Evers et al [3] outlined the results of the reviews, which were conducted by two independent masters-level reviewers on 12 smoking, 11 diet, six exercise, seven diabetes, two asthma, and one depression site. The following highlights are primarily from the “5 A's” criteria:

1. **Advise:** A total of 54% of the sites (n = 20) clearly identified their intended audience, 84% (n = 31) explicitly stated their goals, while 14% (n = 5) implicitly stated their goals. These criteria help guide consumers to appropriate sites.
2. **Assess:** Within each site, assessments were evaluated individually. The types of assessments were dependent on the specific behavior (eg, BMI, exercise level, and stage of change for diet; nicotine dependence, stage of change, and tempting situations for smoking; blood glucose levels for diabetes management).
3. **Assist:** Ninety-seven percent of the sites (n = 36) provided feedback strategies to assist users in achieving health behavior change. The majority of the sites targeted feedback based on the assessments by segmenting the population into specific categories rather than providing individualized feedback. With segmented tailoring, participants were grouped based on a specific variable, and feedback was the same for everyone in that group. However, there is a growing consensus that individually tailored health communication represents one of the most promising modalities for health behavior change [5].
4. **Anticipatory Guidance:** For this criterion, 73% of sites (n = 27) offered some form of anticipatory guidance through information on managing tempting situations (n = 11), preventing relapse to unhealthy behaviors (n = 9), and maintaining the behavior change or staying motivated (n = 17). (Sites could be using more than one type of anticipatory guidance.)
5. **Arrange:** In terms of arranging follow-up, 11% of the sites (n = 4) specified when the user should come back to the program, and 22% (n = 8) used daily email reminders to keep users in touch with the program. Other suggestions ranged from coming back to the site to reassess behavior after a period of time to day-to-day participation.

Summary

The HBC-I (“5 A's” for Health Behavior Change Treatment on the Internet) criteria were developed to meet the specific needs of behavior change on the Internet. The five basic criteria of the HBC-I (advise, assist, assess, anticipatory guidance, and arrange follow-up) do not assure efficacy for behavior change, rather they outline the minimum criteria for a program to have the potential for providing behavior change. Systematic empirical evaluations of program efficacy would be needed to ultimately demonstrate efficacy. It was discouraging to learn that Evers et al [3] found that none of the sites evaluated included statements about how the program was being evaluated for effectiveness.

Since the development of the two measures of the HBC-I, other studies have used similar frameworks to evaluate behavior change programs on the Internet. For example, Bock et al [6] applied the US Public Health Services “5 A's” [2] to the assessment of the quality of interventions for smoking cessation that are available on the Internet. Two assessment instruments were developed based on the “5 A's” (STS-C and STS-R), in addition to a third which focused on the usability of the website (STS-U). Those instruments were used to evaluate 46 smoking websites. Bock et al [6] found that over 80% of the websites that were evaluated did not include one or more of the key components of tobacco treatment that are recommended in the guidelines [6].

The HBC-I Screener and HBC-I Expanded provide templates for developers of programs, consumers looking for quality sites, and health professionals seeking to recommend the best sites for disease management and prevention. As health behavior change on the Internet matures from the provision of health information to meeting the requirements necessary to produce health behavior change, and as program developers take advantage of the interactive nature of the Internet, criteria such as those in the HBC-I will be essential. Those criteria can instill developers and consumers with confidence that particular programs are at least providing components that meet the minimum conditions for effective behavior change.

Are They Ready for Us?

In order to maximize the overall impact of health behavior change programs on the Internet, developers and researchers need to move beyond a narrow focus on early adopters and produce a population perspective that includes those not ready, those getting ready, those ready to use such programs, as well as those already participating. This knowledge base can lead directly to the development and dissemination of practical tailored and targeted interventions that can help maximize population participation in Internet programs for health behavior change.

In order to generate both cross-sectional and longitudinal data on a representative population of Internet users' readiness to use the Internet for health behavior change and on the barriers to use, measures were developed based on the Transtheoretical Model of Change [7]. An assessment was administered through two different recruitment methods: proactive recruitment through an invitational phone call to a random sample of Internet users purchased from a list broker, and reactive responses to recruitment letters, posters, or email invitations to participate [8].

Baseline Assessment

In the first half of 2002, 413 participants completed the first administration of the assessment (baseline). However, only 375 individuals were eligible to participate in the full assessment (eligibility requirements included use of the Internet and specific health risk behaviors). The national sample was similar in demographics to other national samples of Internet users conducted during the same time period. However, the current sample was significantly more highly educated and included more females [8].

The majority of respondents (80.5%) had used the Internet to get health information. However, only 24.7% used the Internet for health behavior change or disease management programs [8]. The majority (62%) had no intention of starting to use health behavior change programs on the Internet in the foreseeable future. Of those who reported using HBC programs on the Internet, 40% were not using programs that met a minimum of four of five criteria on the HBC-I Screener.

Follow-Up Assessment

The second administration of the survey was conducted one year post baseline. Two hundred and eighty seven participants completed the follow-up survey, resulting in a 77% retention rate. Of those individuals who were using HBC Internet programs at baseline, the majority were no longer using those programs, and 40% had no intention of starting use in the future [8]. The development of measures of the pros and cons of using the Internet for health behavior change and of measures of informed decision making provided insight into the issues surrounding the use or lack of use of such programs [8].

Summary

The development of a valid, parsimonious set of assessments for readiness to use the Internet for health behavior change (and components related to use, such as informed decision making) provides researchers, program developers, and the health care system with a way to assess their population's readiness to use such Internet programs and thereby guide plans for program development. In addition, the use of such instruments will allow Internet developers, researchers, and program administrators to identify major concerns, benefits, and barriers regarding their populations' use of the Internet-based health behavior change programs.

The results of this survey present a very pessimistic view of the current potential for adoption of the Internet for health behavior change on a population basis. A large majority (about 80%) of the contacted population in the United States was not interested or willing to complete the survey. Of those who were, the clear majority (more than 80%) was not using the Internet for health behavior change and was not intending to. The cons of using the Internet for health behavior change showed no significant decrease as individuals adopted Internet use, indicating that even once individuals start using these programs, the drawbacks of using them are still high. If the Internet is to fulfill its potential as the least costly modality for delivering tailored communication for health behavior change, then considerably more research will be needed to determine what type of interventions, if any, can help significant percentages of populations progress to enhancing their health via the Internet.

The next generation of research needs to take this challenge rather than examining the efficacy of Internet programs with select samples that represent relatively small percentages of at-risk populations. Until the field solves the problem of helping significant percentages of populations progress toward effective action and maintain such action, Internet programs will not be able to realize their potential to be the lowest cost modality for delivering tailored communications that can have the highest impacts on health promotion, disease prevention, and disease management.

Conclusions

Health behavior change on the Internet appears to be in the early stages of development. A good base has been established, but much work is needed in the future. The examination of the quality and effectiveness of programs available to the general public, as well as descriptive and predictive knowledge about population readiness to participate in such programs, needs further research. Results presented here suggest that many health-related sites do not include the basics of health behavior change, and those that do need improvements in many of the areas believed to be important for the quality and efficacy of health behavior change programs on the Internet. The second portion of the impact equation, participation, also seems to be low, specifically for health behavior change on the Internet. Although many people use the Internet for health in general, few are using health behavior programs, and those that do discontinue use. If the Internet is to fulfill its potential as a cost-effective modality for delivering tailored communication for health behavior change, then considerably more research will be needed to determine both the types of interventions that can help significant percentages of populations progress toward enhancing their health via the Internet and the types of interventions that can help maximize population participation in Internet programs for health behavior change.

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Conflicts of Interest

None declared.

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Abbreviations

HBC: health behavior change

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Viewpoint

The Need for Online Information on the Economic Consequences of Cancer Diagnosis, Treatment, and Survivorship

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Abstract

The Internet is commonly used to provide treatment information to patients diagnosed with cancer. Notably missing from the existing websites is information on the cost of cancer care in terms of medical costs to the patient and work-related consequences. The purpose of this paper is to describe what is known about the economic cost of cancer and to describe how this information can be structured so that it is of more benefit to patients. This paper first provides an overview of the information available regarding medical expenses and productivity costs associated with cancer survivorship, particularly with respect to cancer and employment. Second, it draws attention to the sparse economic information available online to cancer survivors. Patients can find information on sources of financial assistance, but they cannot estimate from the available information the cost of their care or anticipate the impact that cancer and its treatment may have on their jobs. Finally, a strategy for filling the void in online economic cancer information is described. Substantial opportunity exists to provide economic information to cancer patients and their families. The Internet is a natural forum for gathering and disseminating economic information. A unique advantage of the Internet is its ability to put information immediately in the hands of cancer patients and their families—assisting them to become informed consumers and skilled negotiators.

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KEYWORDS

Internet; cancer; health care costs

Introduction

The US National Cancer Institute (NCI) has made several calls for research with regard to the economic aspects of cancer diagnosis, treatment, and, ultimately, survivorship. A major impetus for such research is that the prevalence of early stage disease is rising and the number of long-term survivors now approaches 10 million as many cancers are becoming chronic conditions. Yet our understanding of how newly diagnosed cancer affects the economic viability of survivors and their families is remarkably incomplete. Economic information is largely absent from common Internet websites that offer information to cancer patients and their families—leaving patients in the untenable position of having to make treatment choices without fully understanding the costs and the impact on their ability to work.

Two important dimensions of economic data—medical and productivity costs—are relevant to patients, physicians, and society. This paper takes the patient's point of view. Direct medical costs are defined as the cost of medical care, including inpatient, outpatient, physician and other provider services, pharmaceuticals, and supportive care. From a patient's perspective, these costs are highly relevant since the costs associated with cancer care can be very expensive and perhaps prohibitive—even for patients who have generous health insurance benefits. As these costs rise, physicians and other health care providers may find themselves in the position of discussing with patients the trade-offs of treatment in terms of their relative costs and benefits. As aptly noted by Fryback and

Craig, “Sooner or later a balance must be struck between the cost of interventions and their effectiveness” [1].

Productivity costs are defined as the time loss from work or the inability to fully function on the job when present. Documenting health-related economic losses is of great interest to patients and employers, who share the economic burden of illness. The probability of developing cancer is 1 in 12 for individuals aged 40 to 59 [2] and is likely to rise as screening is routinely recommended for younger individuals. Thus, the need for information that can assist this growing population of cancer survivors to minimize the economic consequences of their treatment decisions is vital.

The purpose of this paper is to describe what is known about the economic cost of cancer and to describe how this information can be structured so that it is of more benefit to patients. This paper first provides an overview of the information available regarding medical expenses and productivity costs associated with cancer survivorship, particularly with respect to cancer and employment. Second, it draws attention to the sparse economic information available online to cancer survivors. Finally, a strategy for filling the void in online economic cancer information is described.

Economic Cost of Cancer

Treatment Costs

Nationally, the direct cost of cancer care was approximately US $60.9 billion in 2002 [3]. However, at the individual patient level, we know very little about the cost of cancer care [1]. In the absence of clinical consensus in favor of one treatment (as is becoming the case with routine use of combination therapies), cost factors become more important in the treatment decision. Among the many studies of cancer cost found in the literature [3-16], few studies describe cost in terms of burden to patients. More commonly, studies approach cancer care cost estimation by segmenting the course of disease into phases (eg, first 6 months after diagnosis, the last 6 or 12 months of life, and the time between the first and last intervals) [8-11]. Other studies address isolated points in the range of cancer sites and treatments [4,5,12].

These studies provide useful information to health care providers, payers, and perhaps policy makers, but they are less beneficial to patients who need to consider cost in their treatment decisions. In addition, these studies fall far short of describing the range of treatment options available for different types of cancer. Fryback and Craig argue that, in many cancer interventions, the patient can be considered a provider of care along with the oncologist [1]. Patients and their families must find time and financial resources to complete lengthy treatment protocols that often involve toxic side effects and short-term disability.

Because not all costs apply to all patients due to variations in health insurance benefits and other financial arrangements, the current methods used for collecting and estimating economic cost are not useful to patients. Thus, alternative methods for estimating the economic costs for patients and families are required. In the scientific literature, some studies have counted resources used to treat patients for cancer [13-15]. A cost can be applied to these “counts” of resources depending on the patient and treatment scenario offered. Rizzo et al [16] used a validated and reliable questionnaire for purposes of collecting patient-level costs for patients undergoing bone marrow transplants. By and large, such information regarding patient costs is not widely available and little is known about how to collect, organize, and analyze patient-level costs [17].

The economic burden on patients and their families for cancer treatment may include the immediate cost of treatment, out-of-pocket expenses (eg, supportive care medication, co-payments, child care), and future costs required for cancer surveillance, follow-up care, and treatment of persistent symptoms (eg, pain, fatigue) [18]. Out-of-pocket expenses will be incurred by all patients, and these costs can vary widely depending on where the patient lives and shops. For example, prescription drug costs vary from local pharmacies, to discount pharmacies, to Internet pharmacies. Other out-of-pocket costs include transportation, child care, and home care services—all of which can add to a significant amount of money. More significantly, out-of-pocket expenses can also include the cost of participation in a clinical trial.

The availability of economic information can greatly affect health outcomes. For example, a woman choosing between mastectomy and breast-conserving surgery needs to know if she can afford chemotherapy, radiation, and tamoxifen following lumpectomy. She and her family must consider the resources (eg, transportation, time away from work, child care) required to complete radiation and chemotherapy. If she cannot complete the care regimen following lumpectomy because of financial concerns, mastectomy may be a more optimal choice for her long-term survival. On the other hand, if the woman chooses a lumpectomy because of rapid recovery time and lower immediate costs, but later becomes non-adherent to chemotherapy and radiation therapy, she will jeopardize her long-term health. Unfortunately, less than optimal treatment choices are likely to be made by patients who have the fewest resources to rely upon.

Incorporating an economic dimension into cancer care raises deeply rooted ethical concerns and contradicts a notion of cure at any cost. However, ignoring the financial burden of cancer care may jeopardize patient outcomes if patients choose a course of treatment but alter the dose (as they can with oral medications) or prematurely cease treatment. Patients and their families need to consider treatment choices in light of economic costs.

Work Loss

Turning the discussion to work loss, the literature is unequivocal about work loss attributable to cancer. In addition, as more and more working-age individuals are screened for cancer, employed, as opposed to retired individuals, will be treated for cancer. For example, the US Preventive Services Task Force found evidence that annual prostate cancer screening can detect early-stage prostate cancer in men age 50 and over [19]. For African American and asymptomatic men with a family history of prostate cancer, screening is recommended to start at age 40 [20].

Some studies [21-26] have focused on survivors' subjective impressions of the impact of cancer on their lives. These studies suggest several negative factors that can reduce employment, including physical disability (eg, limitations in upper body strength [22]), memory loss [27], lack of control over schedules, need for transportation, type of work performed [28,29], and, in some cases, discrimination on the part of employers [30]. Chirikos et al [31], in their study of 5-year breast cancer survivors, reported that 41% required special accommodations to perform their jobs. These survivors were nearly three times more likely to be impaired relative to their non-cancer peers. The literature on the impact of cancer on work does not extend to cancer's impact on productivity for employed patients who continue to work while undergoing treatment. While it would not be surprising that treatments such as chemotherapy lower productivity, the absence of estimates regarding the amount and duration of productivity losses is somewhat remarkable.

Research using data from the Health and Retirement Study examined labor market participation, wages, and earnings of breast cancer survivors relative to a nationally representative non-cancer control group [32,33]. These women were statistically significantly less likely to work (by approximately 9 percentage points) relative to women who never had cancer. A more recent study examined post-treatment changes in labor supply among women working prior to a breast cancer diagnosis and among men working prior to a prostate cancer diagnosis relative to a control group of initially working women and men. Women with breast cancer were about 17 percentage points less likely to be employed 6 months following diagnosis relative to women in the control group. Among women employed prior to diagnosis, 12% appeared to move out of the labor force altogether by retiring or becoming disabled [34]. The nonemployment effect of breast cancer appeared to be about twice as strong for African American women [34]. To put these findings in perspective, the American Cancer Society predicts 140000 cases of breast cancer in women under age 65 each year. If we estimate that 50% of these women are working, approximately 70000 women will experience labor market consequences each year attributable to breast cancer.

Research has found that men who are treated for prostate cancer have substantial complications that may interfere with their activities of daily living including their ability to work [35]. Research has shown that men with prostate cancer were less likely to be working 6 months following diagnosis relative to men without prostate cancer [36]. Cancer and its treatment interfered with some men's ability to perform physical and cognitive tasks once they returned to work. While early detection and treatment have positive implications for mortality, they may inflict morbidity—at least in the months immediately following treatment—that will interfere with patients' ability to work.

Few studies have measured absenteeism for those who remain employed while undergoing treatment and who return to their jobs after completing treatment. The Midlife Development in the United States Survey asked respondents questions about how many out of the past 30 days they were either totally unable to work or perform normal activities because of health problems (work loss days), or had to cut back on these activities because of health problems [37]. Although only 0.5% of the sample reported that they had cancer, cancer had the highest prevalence of any 30-day work impairment. Approximately 66% of those with cancer reported that the average number of days they were impaired was 16.4 [37]. These days were attributed to physical symptoms, primarily fatigue. It is interesting that employers often encourage their employees to use preventive health care services like cancer screening but are left in a quandary about how to manage an employee whose screening resulted in cancer detection. Likewise, physicians are left in a quandary when patients do not adhere to treatment regimens that interfere with their jobs.

Scarcity of Internet Economic Information Available to Patients

Clearly, cancer patients and their caregivers already access and rely upon the Internet for information regarding treatment and advocacy. One study reports that 58% of cancer patients and their companions have access to the Internet from a home computer [38]. Patients and their companions routinely used information that described drugs, treatments, side effects, physicians, and hospitals.

Although there is a plethora of websites that provide cancer treatment information, few websites provide economic data. For example, Kelahan [39] reviewed 373 sites of organizations that sponsored clinical trial research, promoted patient advocacy, and oversaw clinical trials and found that less than 5% of them contained reimbursement information for medical expenses incurred under the auspices of the clinical trial. Without this critical economic information, patients cannot adequately evaluate their ability to participate in clinical trials.

A recent online article unfolded a story of rising costs of cancer drugs that extend life for only a few months beyond what can be achieved with standard therapies [40]. Drug costs alone can exceed US $250000 for a few months of treatment. Many patients may simply be unable to pay for these therapies—even if their out-of-pocket contributions are relatively low in comparison to the cost of care.

Financial Assistance

Some websites offer assistance with regard to seeking financial resources. For example, the NCI website lists states that require health plans to cover patient care costs in clinical trials [41]. This same site offers a resource guide on clinical trials and insurance coverage that provides patients with procedures to follow for finding reimbursement for care provided under the auspices of clinical trials. It also lists organizations that provide financial assistance for cancer care. One commercial site, for example, provided a list of financial options for cancer patients on how they might receive funding for their health care [42]. Likewise, a number of charitable organizations have websites that direct patients on how to obtain supportive care products (eg, wigs, home health equipment). The American Cancer Society website offers a comprehensive description of how medical insurance, financial assistance, and cancer intersect [43]. This website not only lists organizations offering financial assistance, but it also makes suggestions to patients for becoming familiar with their insurance coverage, submitting insurance claims, and keeping records. This website attempts to explain government sponsored insurance programs and is to be applauded for explaining viatical or living benefits. It further offers extensive assistance for those who are uninsured. Finally, a nonprofit organization, Cancer Care, provides a list of programs offering financial assistance to patients with cancer [44].

Treatment Costs

Taken together, the websites that broadly address cancer care and cost include information on clinical trials and insurance coverage, lists of organizations that provide financial assistance to patients with cancer, options for uninsured patients, and general guidance for seeking information regarding health insurance coverage. Absent from all of the websites reviewed is information that allows patients to estimate their costs prospectively so that they know and understand prior to seeking treatment the costs that they may incur. Although many patients are overwhelmed with their diagnosis, they require tools (eg, standardized worksheets, organizers) to help them plan for the expenses they may incur and to initiate discussions regarding cost with their providers before choosing a treatment path. Patients also require information on how to identify charges that are unrelated to their care and to alert their health care providers about inappropriate charges. Finally, patients need to be aware that they can negotiate with health care providers regarding payments and scheduling treatments so that the impact on work is lessened.

Brown et al lamented that acquisition of data to operationalize economic measures is far from complete [45]. This concern has been echoed throughout the literature (see [17] as an example). In a recent review of economic studies of cancer care, Fryback and Craig speculated that perhaps one day researchers will have standardized data collection tools and techniques to gather patient cost data. The means for collecting and documenting cost information, however, can be effectively and immediately placed in the hands of the patients and their families. The Internet is an ideal forum for exchanging information among patients regarding their care, for providing patient-centered worksheets for estimating costs, and for seeking assistance and resolution for charges. Without economic information, patients cannot make fully informed choices regarding their care.

Work Loss

Research published in the scientific literature has linked cancer with substantial work loss. Yet, an Internet search of websites that address return-to-work issues for cancer survivors revealed a segmented approach to cancer treatment and returning to work. One site phrased its introduction to work issues as “When you're finally able to concentrate on something besides your cancer treatments, chances are you'll look forward to getting back to a more normal routine—this may mean going back to work” [46]. However, cancer treatment and employment are interdependent, rather than separate, occurrences. Many patients continue to work while undergoing the treatment. The website also provides considerable information on two policies particularly relevant to cancer patients—the Americans with Disabilities Act (ADA) and the Family Medical Leave Act (FMLA). The ADA requires employers to make “reasonable accommodation” for employees with a disability. The FMLA gives employees the right to take time off (up to 12 weeks of unpaid leave per year) due to their own illness, without the threat of losing their jobs.

Worthy of note is that the general tone of most websites describing the ADA and FMLA is litigious in nature. A legal perspective is partially relevant because many employed patients may be unaware that cancer is a condition covered by the ADA and their employers may inadvertently (or intentionally) violate the rights of these employees. However, a proactive, problem-solving approach to planning time away from work and to job restructuring could potentially be more constructive for patients than guidance on how to seek remediation after a violation has occurred. Patients need assistance with planning time away, negotiating with employers, and remaining in contact with employers and coworkers. Patients need to prepare for time away from work and should have reasonable expectations regarding their work performance while undergoing treatment. Patients who plan ahead may be more effective at negotiating with their employers and securing their jobs during treatment. Information on these topics is largely absent from the Internet—as well as other sources of patient information.

The many websites providing information on treatment, side effects, and methods for managing side effects make no mention of how treatment may interfere with patients' abilities to perform their jobs. Furthermore, many treatments have effects that may influence patients' job performance far into the future. The stimulus for work-related information may need to come from patients, advocacy groups, and government agencies. As cancer becomes a chronic condition, it is unrealistic and perhaps unwise to expect patients to quit their jobs altogether while undergoing treatment or to be unprepared for changes in job performance that extend beyond the active treatment period. Discussion about the integration of work and treatment along with strategies for lessening the burden of cancer and its treatment would be highly beneficial to cancer survivors and their families.

Recommendations

This paper describes two important economic dimensions—medical costs and productivity costs—that are vital to patients diagnosed with cancer and to their families (Table 1). The Internet is a common means to convey information and assistance to those who are in need of guidance. While efforts have been made to translate scientific information regarding treatment, side effects, and outcomes to lay audiences, this effort has not expanded to the translation of economic data. Considerable opportunity exists to remedy the omission of economic information from credible websites, such as the ones sponsored by the NCI [41]. Information relevant to employed cancer patients, in particular, is sparse.

Table 1. Economic information needed by cancer patients

Medical Costs	Productivity Costs
Inpatient costs	Treatment side-effects specific to job performance
Outpatient costs	Expected absenteeism
Provider services	Protective laws and regulations
Supportive care	Strategies for negotiation with employer
Comparative treatment costs	Guidance for remaining employed
Insurance coverage	Guidance for understanding sick leave, vacation, and retirement benefits
Out-of-pocket costs	

Unfortunately, much of the information that would be helpful to patients does not yet exist, but it may become available in the future as more studies of the economic burden of cancer are sponsored. Nevertheless, intermediate steps can be taken toward providing information that may be very helpful to patients. First, websites containing clinical trial information should also contain cost and payment information. As part of this data, patients should be directed to explore payment options prior to enrolling in a trial or undertaking any treatment that may not be covered by their health insurance.

Second, websites and patient listservs that already provide a forum for patients to exchange information can be expanded to include the cost of care and help patients become more informed consumers (eg, [47]). These websites and online support groups offer an existing infrastructure for the collection, organization, and validation of cancer's economic costs.

Third, a website offering guidance to patients on how to organize their insurance information and charges for health care services by provider and date could be designed. This activity can help patients be more effective advocates for payment and readily address claims for service that have been denied by the health insurance. Charges and payment for health care services can be extraordinarily complicated and daunting under the best of circumstances. However, when faced with a potentially life-threatening disease requiring coordination of care across many providers, the task can be overwhelming for patients who are unprepared or less vigilant about ensuring that payment has been rendered for their health care.

Fourth, patients need information on how treatment may affect their ability to perform their jobs. Side effects of treatment are routinely described; however, the discussion of these side effects needs to be placed in the context of job performance. For example, statements about how fatigue may hinder some patients from performing theirs jobs, particularly if the job involves physical activities such as heavy lifting, walking, and standing for long periods of time, could be valuable to some patients who may not be aware that treatment may affect their job performance.

Fifth, patients require guidance on how much time away from work can be expected and how to proactively discuss absenteeism and job restructuring with their employer. Just as patients are encouraged to seek financial advice prior to initiating treatment, patients need to open communication with employers and coworkers about possible periods of absenteeism.

Finally, patients need to be encouraged to seek information on their sick leave, vacation, health insurance, and retirement benefits prior to initiating treatment. Without this information from their employer, patients may make decisions prematurely that can affect their future as well as their immediate economic well-being. In addition, through discussions with employers, coworkers, and other cancer survivors, patients may discover options for absenteeism and job restructuring that they had not previously considered. These recommendations are summarized in Table 2.

Table 2. Summary of recommendations

Medical Costs
Include cost information along with treatment information. Disclose the range of costs that patients may incur.
Provide a forum for patients to exchange information on medical costs and payment resolution. Capitalize on existing Internet infrastructure (eg, support groups, listservs, and chat rooms).
Guide patients on how to estimate costs and organize insurance information, provider charges, and payments.
Productivity Costs
Include information on how cancer treatment may affect job performance.
Offer guidance on expected absenteeism and how to plan and negotiate for time away from work.
Direct patients to explore health insurance, sick leave, vacation, and retirement benefits prior to initiating treatment.

Long-range plans for filling the void of economic information require further planning and execution. Some suggestions for how to proceed include the following: (1) formally assess patient needs for economic information; (2) sponsor studies to fill the void in information identified by patients; (3) sponsor the development of a specific site dedicated to economic information; (4) provide an online forum for patients to share their experiences in paying for care, resolving medical bills, and obtaining resources for payments and to share their work experiences, both positive and negative; (5) develop a range of strategies for negotiation with employers and planning time away from work; and (6) take measures to more fully understand and report the impact that cancer treatments have on patients' ability to work.

The President's Cancer Panel 2003 Annual Report identified several issues affecting cancer survivors across the life span [48]. Among these issues were the following: (1) cancer survivors and their families need better information about existing laws and regulations that may protect their employment, insurance, and assets; (2) education about cancer, cancer treatment, and survivorship needs is inadequate; and (3) existing insurance systems are an impediment to appropriate care for people with a cancer history. This final point is elaborated upon by stating that the link between employment and insurance disadvantages cancer survivors who risk losing both their employment and insurance during treatment. The Internet is a means by which to fill the gaps in information and to add the needed economic dimension to the discussion of cancer treatment and survivorship. The opportunity is substantial as the Internet can immediately put information in the hands of patients and their families—assisting them to become informed consumers and skilled negotiators—so that their economic viability can be preserved along with their lives.

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Abbreviations

ADA: Americans with Disabilities Act
FMLA: Family Medical Leave Act
NCI: National Cancer Institute

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Viewpoint

Emerging Technologies for Cancer Prevention and Other Population Health Challenges

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Abstract

Emerging technologies, such as information and communication technologies (including future versions of the Internet), microelectromechanical systems, nanotechnologies, genomics, robotics, artificial intelligence, and sensors, provide enormous opportunities for enhancing health and quality of life. Population health technologies (PHTs) encompass the various applications of emerging technologies to improve the health of populations and communities. These technologies may change many population health paradigms, including those related to cancer prevention and control. In the future, emerging technologies will allow true customization of health communication to individuals, and existing tailoring approaches will be considered very crude. Environmental monitoring systems based on emerging technologies could also provide real-time information that health officials and community residents could use immediately to ameliorate potential carcinogenic or unhealthy exposures. Accelerating the application and diffusion of emerging technologies to population health challenges will require a multipronged approach, including new transdisciplinary programs, increased funding, supportive infrastructure, and policy changes.

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KEYWORDS

Public health; public health informatics; population surveillance; cancer; prevention

Emerging Technologies and Health

Technological advances, such as pasteurization, sanitation, childhood immunization, food fortification, and car safety belts, have contributed substantially to the reduction of mortality and morbidity during the last two centuries. During the past several decades, the pace of technological innovation and discovery has been exponential. For example, when the first mainframe computer was built in the 1940s, it weighed more than 30 tons and occupied a room the size of a house. In 2002, standard microprocessors found in personal computers were more than 100000 times more powerful, and their weight is measured in grams. Years from now, DNA-based computers may be many times faster than today's advanced supercomputers, and their weight will be measured in nanograms [1].

At the beginning of the twenty-first century, emerging technologies provide enormous opportunities for further improvements in health and quality of life. These emerging technologies are being applied to many areas in medicine, including cancer diagnosis and treatment, where they are being deployed in applications such as detection of early cancer precursors, minimally invasive surgery, and molecular level diagnosis and treatment [2,3]. Recent cancer-related technologies have had considerable impact on cancer care and survival. As cancer care technology advances, it is possible that many cancers will eventually be viewed as chronic diseases.

Whereas there is substantial research, development, and investment in advancing the use of emerging technologies in biomedical interventions such as diagnostics and treatments, there is considerably less funding and interest in applying new technologies to population-oriented interventions. The application of emerging technologies to population health problems represents an exciting opportunity to address long-standing population health problems related to cancer prevention and control.

Population Health Technology

Population health technologies (PHTs) encompass the various applications of emerging technologies to improve the health of populations and communities [4]. Examples of emerging technologies that have direct applications to population health include information and communication technologies (including future versions of the Internet), microelectromechanical systems, nanotechnologies, genomics, robotics, artificial intelligence, and sensors [5,6].

A population health model focuses on issues and interventions that impact populations and communities rather than individuals. It emphasizes prevention and focuses on those eHealth technologies that improve health on a population level rather than in an individually focused, medical care context. Thus, PHTs tend to include preventative, behavioral, environmental, social, and systems-oriented technologies rather than biomedical ones, such as diagnostics and treatment modalities.

The core principles of PHTs include a collaborative, multidisciplinary approach to development of health interventions. Relevant disciplines include the biological, physical, and social sciences; engineering; health care; public health; and business. Although PHTs by definition employ leading edge technology, the technology is often as transparent as possible as the developers focus on people and processes rather than on the technology.

Potential health issues that could benefit from the use of emerging technologies include the following:

- Disease (health) surveillance and control
- Environmental monitoring and pollution prevention
- Food and water safety
- Health communication and behavior change
- Self-care and chronic disease management
- Population screening
- Injury prevention and control
- Wellness and social isolation
- Health disparities

Given the great spectrum of possible technological solutions for population health, a comprehensive discussion of PHTs is not possible in this paper. Instead, two of the more compelling potential PHT applications related to cancer prevention and control—tailored health communication and environmental monitoring—are highlighted to illustrate the potential impact of PHTs. Given that PHT is an emerging field, there are limited data, scientific literature, and project experiences to support some of the concepts in this paper.

Tailored Health Communication

Some eHealth developers vary the content, presentation, and/or medium of health content to an individual user based on knowledge about that individual. The expectation is that a tailored message or experience engineered to appeal to a specific individual is more likely to move the user along the stages of the change continuum compared to a generic message or experience [7].

Tailored online communication is typically based on a limited set of variables that are thought to influence the individual's receptiveness, comprehension, and perceived relevancy of the message. Currently, tailoring approaches include those based on user demographics, self-reported preferences, and usage of a website or technology. Technically, most current tailoring approaches are really not “tailored,” but rather, they are based on gross generalizations about heterogeneous groups of people. The most common set of tailoring variables used for online communication seems to be demographic attributes. Examples of this include the segmentation of Web pages and, in some cases, entire Web domains, into age (eg, children, teens, and seniors), gender, and racial/ethnic groups (eg, African, Asian, Hispanic, and Native American). Another commonly used approach to online tailoring is to vary messages depending on self-reported preferences. Individual preferences may include specific forms of media (eg, text, audio, or video), user interfaces or display formats (eg, personal computer, PDA, or wireless phone), or reading level. Such preferences may be collected through brief one-time online questionnaires presented to users or through user registration forms for those who want access to additional functionality or content as a registered user.

A less common but emerging approach to online tailoring is to vary messages based on an individual's use of a website or technology. Software technology, usually in the form of a “cookie,” is used to track viewed pages and other movements of an individual within or across websites. Specific pages are presented to the user based on assumptions that depend on his or her usage patterns. Such assumptions may be based on simplistic deductions about the user (eg, if someone clicks on a hyperlink to a page about cancer among women, then the user is probably a woman), or they may be based on fairly complex algorithms. To the author's knowledge, few if any widely used health websites employ the latter technique.

In the future, emerging technologies will allow true tailoring of communication to specific individuals, and existing personalization approaches will be considered very crude. The advent of sophisticated devices and systems for collecting, transmitting, and interpreting data generated by individuals and the environment may serve as the nidus for the development of tailoring algorithms that may surpass our current abilities to match messages with users. Not only will we be able to better match messages to the individual, but we will be able to match versions of such messages in the context of the user's microenvironment at the time of decision making. This is because specific versions of a message may be more appropriate for certain decision-making contexts than others. In addition, we may be able to create “dynamic” messages, which can adapt themselves depending on minute changes in the user's microenvironment. Thus, the permutations of possible messages and their presentations to the individual could be in the millions as opposed to the dozens many online communicators now employ.

It is possible that future tailoring schemas will be based on classes of variables that describe individual attributes that have not been accounted for by current developers, including the following:

- Who you are – motivations, personality profile
- What you have experienced – social, health, and medical history
- What you are – genetics, physiological profile, medications
- Where you are – physical setting, microenvironment, point in the decision-making continuum
- How you are – physical and mental status, mood

The technologies required in order to implement the advanced tailoring approaches described above include ubiquitous electronic health information systems and devices that collect data from both health care and non-health care settings. The huge volume of data generated by these emerging devices means that robust data storage and transmission infrastructures are needed. And, in order to provide "just-in-time" personalization, sensors will need to be developed that can capture information about the individual's microenvironment at the time of decision making. Sophisticated algorithms will also be needed to interpret multiple streams of data from sensors in order to accurately describe changes in the microenvironment.

Environmental Monitoring

Many types of cancer are associated with exposure to environmental toxins. These toxic substances may be found in air, water, food, and soil. Lifestyle and work choices are important determinants of exposure to environmental toxins.

Various governmental jurisdictions have formal programs to monitor air, water, food, and soil for known environmental toxins. However, despite recent attempts to update such systems, most environmental monitoring systems have substantial shortcomings. For example, in the case of ambient air monitoring, only a small number of pollutants is tested and only periodic testing is conducted [8]. In addition, air sampling stations are usually placed high on buildings rather than at the level where people typically breathe. As a result, the data generated by current monitoring programs are only representative of a small number of locations at limited points in time. They typically are not representative of the microenvironments experienced by individuals during their daily activities. And, because reporting of most monitoring data is delayed and not available in real time, the data are not actionable and are relatively inaccessible to the people who are the ultimate users of the data.

Emerging technologies may be applicable in developing environmental monitoring systems that can provide accurate and timely assessments of environmental health hazards. Monitoring systems based on emerging technologies could provide real-time information that health officials and residents could use immediately to ameliorate potential carcinogenic or unhealthy exposures. Providing real-time, continuous information about the air that actually surrounds individuals during daily activities would offer a more accurate and representative picture of the public's exposure to toxins.

There are several possible models for real-time, representative air pollution monitoring systems, all of which would require the enhancement of existing technologies. One possible system would consist of representative individuals (ie, citizen sentinels) who volunteer to wear a sensor during their daily activities. The wearable sensor would sample small amounts of air and analyze them for specific pollutants many times an hour or continuously. The data would be transmitted wirelessly in real time to central servers. These servers would then use complex algorithms to analyze and interpret the data for health officials and the public. Finally, easy to understand interpretations of the data and action-oriented messages (eg, "unhealthy air—limit outdoor activity now") for the public could be shown on public displays (akin to highway message signs) or sent to subscribers to their preferred messaging device. Such a system would allow the public to take appropriate action to limit exposure to pollutants, which should be the primary objective of pollution monitoring systems.

Cautionary Factors

As we move forward in developing and deploying PHTs, developers and policy makers should address the following issues to ensure that these products actually benefit public health and do not have unintended consequences.

Privacy, Confidentiality, and Security

Many PHTs, especially those related to cancer prevention and control, will collect, analyze, and transmit sensitive health information. The ability of developers to balance public concerns about privacy with the data needs of PHTs will be an important determinant of success. Government regulations are typically behind the pace of technological innovation and are often not responsive to cutting-edge technologies or business models [9]. Thus, robust policies, voluntary or otherwise, will be needed to comprehensively address the upcoming exponential growth of health data generated by networked devices, such as information appliances and sensors. Failing to address the public's concerns about privacy, confidentiality, and security would jeopardize the widespread adoption of many PHTs.

Unintended Effects and Quality and Effectiveness

Rigorous outcome studies of PHT products are limited because these products have not been widely deployed. Given that many PHTs, by definition, will use technologies that have not been used widely in the marketplace, the potential for unintended errors and ineffective products is real. In addition, it is possible that some emerging technologies, such as nanotechnologies, may have deleterious health effects [10]. When possible, PHT developers should consider the evidence base for their technologies, integrate quality improvement and evaluation processes into the product development lifecycle, and build evaluation components into their product development and implementation plans [11,12].

Sustainability

There are legitimate concerns about the sustainability of many PHT and other eHealth products [13]. Because many PHTs do not have precedents, the strength of market demand for these technologies is largely unknowable until they are introduced to consumers and consumers are educated about the benefits of such technologies. Public funds have traditionally been the primary source of support for population health programs, but other possible sources of support, including end users and health intermediaries (such as corporations, employers, health care providers, and health plans), should be explored. Given the uncertainly of funding, PHT developers will need to examine new business models for sustaining PHTs.

Technological Divide

As the field moves forward, developers and policy makers will need to ensure equal access to technologies that improve population health [14]. One approach may include subsidizing the use of PHTs among underserved populations from a portion of the proceeds of sales to organizations with greater resources. It is likely, however, that some type of government or foundation support for the use of PHTs among certain underserved populations will be needed.

Moving the Field Forward

Although some PHTs have begun to emerge in response to the recent threat of bioterrorism, emerging technologies are rarely being applied to population health problems. The author is not aware of any formal public or private programs that explicitly fund development and dissemination of PHTs.

Reasons for the lack of focus on PHTs include the following:

- There is a lack of national and global leadership and infrastructure to promote and support the development and dissemination of PHTs. Some government programs support technology research and development in specific interest areas, but none focus on population health.
- Most research, development, and investment activities related to emerging technologies focus on individually oriented medical care interventions (eg, pharmaceuticals, medical devices, diagnostics) rather than on population health opportunities.
- Development of PHTs requires a multidisciplinary and multisector approach involving stakeholders who do not usually communicate or collaborate with each other.
- Public health institutions have not been successful in technology transfer and commercialization of innovations primarily because they often lack the entrepreneurial capacity or market understanding to transform technological concepts into viable products.
- There is a lack of professional and public understanding of PHTs.

Accelerating the application and diffusion of emerging technologies to population health challenges will require a multipronged approach. Several key areas will need to be addressed to lay the foundation for this new field of endeavor.

Promoting Transdisciplinary Approaches

Because technologies with population health applications will likely originate from a variety of sectors, such as computer science, health care, public health, genomics, nanotechnology, environmental science, and engineering, networks of individuals and organizations in these disciplines will need to be created. The silo nature of health professional and technology education at universities should be re-examined to see how students can concurrently develop skills and experience in multiple areas, including population health, technology development, and business. In addition, more networking opportunities for professionals, such as the annual eHealth Developers' Summit, that foster business relationships and collaboration among health technology developers and funders from commercial entities, academia, government, and nonprofits are needed [15].

Increasing Funding

Given the high risk but high societal impact of most PHTs, government agencies and private foundations should consider more funding for PHT research, development, and dissemination. Private investors will need to be educated about the market opportunities around these technologies in order to encourage more private sector investment.

Developing Infrastructure

National and global infrastructures need to be enhanced to support PHT development and adoption, especially in underserved areas. Government initiatives, such as the National Health Information Infrastructure, should more explicitly support the development of infrastructure to enhance population health—not just for patient safety, health care quality, and bioterrorism prevention [16]. Supportive programs to help PHT developers produce viable products in the marketplace are also needed.

Changing Policy

Potential policy changes that could promote widespread adoption of PHTs include reimbursement for effective technologies, realignment of incentives to reward quality and positive health outcomes, incentives for consumers to make healthy decisions, and redefinition of the roles and responsibilities of health professionals and institutions.

PHTs have the potential to positively change many paradigms in cancer prevention and control and other population health areas. With these technologies, it may be possible to cost-effectively screen entire at-risk populations for dozens of cancers and cancer precursors with a single drop of body fluid. It may be possible to detect individual and group exposures to carcinogens early enough to prevent disease. In addition, imagine being able to empower people to make the best health decisions at the exact time of decision making, and to enable communities to monitor and address local health and environmental issues before they become significant health hazards.

Transdisciplinary programs, increased explicit funding, supportive infrastructure, and policy changes will help accelerate the development and availability of a new breed of technologies that are likely to have substantial impacts on cancer prevention and other population health challenges.

Conflicts of Interest

None declared.

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Abbreviations

PHTs: population health technologies

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Viewpoint

Attributes of Interactive Online Health Information Systems

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Abstract

The development of online communication systems related to prevention, decision making, and coping with cancer has outpaced theoretical attention to the attributes that appeal to system users and that create effective interactions. This essay reviews a number of sociotechnical attributes related to online discussion systems and tutorials, including interactivity, presence, homophily, social distance, anonymity/privacy, and interaction management. These attributes are derived from different theoretical perspectives which have led to clinical trials and other empirical studies demonstrating effectiveness or attraction to end users. The effects of a subset of these attributes are connected to learning, social influence, and coping, as illustrated in evaluations of an interactive smoking prevention site and a cancer advice/support discussion system.

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KEYWORDS

Cancer support; interactivity; presence; homophily; social support; sociotechnical factors

Introduction

The Internet has become a beacon of information and support to many patients, caregivers, and survivors of cancer. Numerous statistics show the popularity of the Internet among this population, numerous efforts continue to grow in the purposeful development and refinement of online services for these individuals, and numerous groups continue to expand and refine their own self-organized, informal online discussion and chat systems to help support information exchange and coping. Despite their potential, online health systems have only recently become the topic of scientific investigation with healthy, but at-risk, populations in community settings. Studies on programs intended to teach healthy eating habits [1-4], promote healthy body images [5-8], manage weight [9,10], promote tobacco cessation [11,12], and increase physical activity [4] have been reported. Some of these programs merely provided online information, while a few attempted to capitalize on the medium's interactivity to deliver content tailored to the user. The results are mixed, at present, with some studies finding benefits from Internet programs [3,5,7,10] and others not [1,8].

While efforts in all these directions are inspiring and encouraging, the advancement of practical efforts requires theoretical understanding of the potentially unique and variable attributes that online information systems and peer discussion systems offer for their users. By understanding what works in native and purposive Internet environments, we can identify those elements that offer the most promise and effectiveness for the specific design of Internet-based systems to enhance and facilitate cancer patients' health and well-being. This review will focus on several attributes of social technology that have been identified in online support groups and online information systems. They include interactivity, presence, social network attributes (expertise and distance), homophily, anonymity, and interaction management. Not all of these attributes are most pertinent in every type of Internet health support system, but each holds promise for the relative attractiveness and effectiveness of different Internet health information venues.

The relationships of some of these variables—especially interactivity and presence—are linked through learning, social influence, or other moderating perceptions to attitudinal and potential behavioral responses related to cancer prevention, decision making, and coping. Results of previous studies and ongoing development illustrate some of these relationships and suggest hypotheses for additional understanding and future directions for system development.

Attributes

Interactivity

Interactivity has been called a defining feature of online technologies, with a particular focus on tailoring content to users, increasing engagement in decision making, improving learning, increasing attractiveness, and enhancing the influence of online services [13]. Most definitions require an exchange of information, responsiveness, and some variation on user control.

Human communication processes and outcomes vary systematically with the degree of interactivity—some form of interdependent exchange—in a communication modality [14-17]. Interactivity includes structural principles of contingency (tailored responses to user queries), participation (active rather than passive user behavior), synchronicity (real time rather than delayed exchange), proximity (in the geographical sense), and richness of nonverbal contextual information. Experientially, it includes individual involvement (cognitive, sensory, visceral), mutuality (interdependence, shared understanding), and individuation (well-defined actors). With database functions and dynamic Web page technology, online health information systems can collect information from users and adapt content to them immediately, in real time and at any time (contingent and synchronous) [18]. Interfaces can be programmed to permit self-navigation (user involvement) among databases and multimedia programs using seamless hypertext links [19-21], without resorting to complicated, expensive expert systems. Chat room, bulletin board, and email technologies can deliver prevention messages to users, and online counseling can heighten the sense of mutuality and individuation [22,23].

Presence

Current explications of presence [24] make several key distinctions worth repeating here. First, presence is not defined either by technology or by the situation the person is in; instead, presence is a human perceptual response subjectively created by an interaction of situation, technology, and individual needs and expectations. Second, these explications distinguish between physical, social, and self domains for the experience of presence and then cross these domains with the distinction between whether the object experienced is real, but not present, or is only virtual. Thus, computer-stimulated physical presence occurs when the user subjectively experiences non-present real or virtual objects. Social presence involves perceived contact with real or imaginary others. And self presence occurs when the computer interaction produces revelations or alterations of self-perception.

In line with the definitions above, it is important to note that presence, like interactivity, does not depend on real-time message exchange. While real-time, or synchronous, interaction is appealing to some users some of the time, asynchronous technologies have a valuable place in cancer support. Indeed, the manner in which online message storage systems arrange postings by topical “thread” and archive messages for opportunistic browsing by users wherever and whenever they have the time to find them does not diminish the level of emotion or perceived reality of the shared experiences of participants.

Of these, physical presence may be irrelevant to typical cancer patients' experiences with interactive cancer communication systems. (Some video games, mainly aimed at children, involve blasting cancer cells and could conceivably offer some sense of physical presence and efficacy.) Whether or not online discussion systems or expert advice systems stimulate physical, or merely virtual, presence seems unclear at this point, and perhaps it is theoretically meaningless. However, we argue that social presence, both with real and virtual others, is important and consequential for cancer patients.

Lee [24] has proposed that interactivity may be a necessary condition for presence. That is, a system over which a user has complete control (as in easily locating content within a book or library) may not offer this sort of interactivity and thus necessarily no opportunity for an experience of presence. Implicitly, this argues that there must be a second actor or agent, at least partially independent of the human user, so that the user can detect this agency and infer presence.

While research has intentionally varied and developed different levels of interactivity and presence in cancer-related Internet communication venues (to be discussed below), there are a number of other attributes we have identified through observational research that also deserve consideration. Indeed, in hundreds of support groups operating on the Internet ad hoc as self-organizing conversations with no particular oversight or administration, important communication characteristics may offer valuable considerations and modifications of developing communication support systems. Organic Internet discussions, such as Usenet support groups, range from noncancer topics about social situations (eg, alt.support.divorce) to other health-related topics. Among the several cancer-related discussions, participants discuss pharmacological questions and answers, as well as exchange coping and emotional advice. These discussions are surprisingly revealing, with participants often baring their souls with highly intimate narratives. They feature all the categories of traditional social support, such as information, esteem, network, and emotional support; whereas, due to the distributed, electronic nature of the interaction, material support is less frequently arranged via these verbal relationships [25]. A number of characteristics of these online discussions warrant attention as well.

Homophily

One of the most striking benefits of online support groups is the way they bring out common experience, or homophily, among participants. Perceived similarity is well known to produce feelings of attraction and increase a person's tendency to be persuaded in communication of all kinds. Some of the earlier theories and commonplace assumptions about computer-mediated communication suggest that similarity might be hard to detect online: “As a result of limited nonverbal cues in on-line environments, individuals may find it difficult to assess similarity” [26] (p. 48). However, several factors mitigate this potential problem. First, according to the social identity/deindividuation model of computer-mediated communication [27], it is the social identity, or social similarity of online communicators who have a common life experience, that drives identification and relating in online interaction. Research on the “hyperpersonal model” of computer-mediated communication [23] shows how intense relationships develop through language alone among online cancer support group members over time [28]. Participants in an online support group select the group and know the purpose, and they relate to one another very strongly based on a well-founded and high degree of similarity.

The messages on these systems are often narrative and conversational in form, helping users to relate to common situations and experiences, thereby reinforcing the value of these interactive discussions [29]. In many cases, discovering that there are others going through the same physical and emotional experiences provides a good deal of psychotherapeutic value in and of itself. It is common to see message postings praising the existence of an online venue that has shown a newcomer that there are hundreds of others “just like me.” Finding someone “just like me” is not only possible, it is more probable in a group of hundreds of online cancer patients than among a small circle of close offline friends. Indeed, Wright [26] found a significant empirical relationship between a measure of homophily and support satisfaction in a survey of online support group users.

Social Distance: Expertise and Stigma Management

Although the homophily principle highlights the benefits of perceived similarity among users of an online cancer discussion, the differences among users and the fact that they do not know one another offline—their “social distance”—adds complementary benefits. Applying sociometric principles to online social support, Walther and Boyd [30] identified some advantages of communicating with strangers in their analysis of the attractions of online support. The first advantage draws on the notion of “the strength of weak ties” [31]. This principle highlights that our common groups of friends and acquaintances—our “strong tie network”—often does not contain people with expertise or familiarity with an issue that might be beneficial to us on a specific issue such as cancer treatments. Indeed, the literature on traditional, face-to-face social support suggests that close friends and family members may become uncomfortable, and are often ineffective, when trying to help patients or other people with problems address their concerns [32]. However, in online discussions, people with different expertise, at different stages of illness or recovery, yet whose experience maps on to support seekers in some way, are available at the click of a mouse. This distributed expertise represents a bona fide advantage to cancer patients looking for advice from online support groups.

The fact that online support providers are not part of support seekers' day-to-day physical lives offers another benefit: the management of stigma and embarrassment. Social support seekers are, by definition, having trouble. Describing the emotional, physical, and social problems they are dealing with often means admitting vulnerability or disclosing potentially embarrassing conditions. In some cases, it would be more embarrassing for one's day-to-day colleagues and friends to be aware of either the problems or of the lack of control implied by needing help [33]. As well, face-to-face friends tend to minimize and downplay the seriousness and distress of individuals who seek support for their problems [32], which, while well intended, is ineffective and may further one's embarrassment. Moreover, discussing breasts or testicles or other “private parts” violates mores in other social contexts. When dealing with groups and individuals whom one knows strictly online, however, and whose existence does not intrude on other social or professional social networks, these negative impacts are ameliorated. There is less reason to hold back and less fear of embarrassment since the confessors are unlikely to run into each other elsewhere or share information with people in other domains of their lives. Things confessed online are unlikely to travel back to the office rumor mill.

Anonymity and Privacy

This segregation of support sources is further enhanced by another feature of online support—anonymity. Anonymity online comes in several forms. The relative anonymity of interacting online with a set of people who are segregated from regular social partners, as discussed above, is one version. By using email addresses or log-on names that are not immediately traceable to offline identity, social support users may take further advantage of the ability to post personal questions and details of their problems or solutions without having this information connected to their offline lives. The use of a “hotmail.com” address or the deployment of anonymous Internet-based message systems (see [34]) provides various levels of masking the identity of the message sender from the content of the message. In this day and age of traceable, searchable Web archives, the ability to use a pseudonym and be anonymous when exchanging personal information (in a way that is impossible to link the information to the author) is rare and potentially valuable.

In a related vein, online health information systems can create a sense of privacy [35,36] similar to that achieved in interpersonal interactions because of the one-on-one interaction with the computer. Privacy is important for users in order to disclose risky health behavior [37]. It also may be a factor that determines whether individuals will seek information on health problems, particularly those that carry some stigma (eg, HIV/AIDS) or are illegal (eg, smoking by adolescents).

Interaction Management

Interaction management is a concept reflecting another attribute of online cancer support that is more difficult to capture in offline support dynamics. According to Walther and Boyd [30], interaction management occurs at two levels: the degree of participation a participant wishes to have in an online group, and the way that individuals are able to express themselves when they participate. In online support groups, support seekers may avail themselves of system resources opportunistically, seeking or providing information when the need arises and retreating when their information needs recede. Although reciprocity and presence are important aspects of a vibrant community, online or off, there are times when a participant may be too ill, or too depressed, to wish to witness others' exchanges. Likewise, there are times when individuals are not strong enough to reciprocate the advice they have received, and online support groups allow users to retreat, without contest, when they need to do so. In offline relationships—especially the intimate ones in which social support is exchanged—obligations to reciprocate and aid others may persist, even when it is all one can do to cope with one's own illness or life circumstance.

Interaction management at the level of individual expression refers to the manner in which computer-mediated communication allows us to craft the messages we share with others, in ways that are often uncommon in face-to-face speech. Far from being the cold and empty vessel for communication that early theories and research described online interaction to be, research and experience show that social and emotional presence are real virtues of online groups. Computer-mediated communication allows us to create messages asynchronously, in the absence of our addressees, and provides editing capability. These technological attributes facilitate the purposeful and deliberate choice of words users employ as they describe difficult issues or work to provide sensitive responses. Recent research has documented that, in computer-mediated communication sessions, users take more time and edit messages more when they are addressing an audience that matters to them. They engage greater cognitive resources and make messages friendlier and more sophisticated when attempting to craft impressions on others online [38]. Online communicators are no less effective emotionally when relying on words alone than are counterparts in face-to-face interactions, who have both words and nonverbal cues at their disposal [39]. Indeed, one respondent in Walther and Boyd's study [30] described the communication in online support groups as “a purer form of communication” than face-to-face interaction: “Writing is a lot different means of communicating than we are all used to. Our questions and answers are more articulate, more meaningful, and can be viewed over and over again until we get the message. It is my belief that the discussion is easier and healthier…” (p. 180).

Outcomes of Internet Communication Attributes

What are the known and suspected effects of variations in the attributes of cancer-related communication systems? Obviously, the ultimate ends will be prevention, better decision making, better health, and coping. In order to achieve these objectives, communication must achieve intermediate-level outcomes such as learning and social influence.

Learning

The presentational format in online health information programs can affect learning of its content. Recent studies found that user control enhances elaboration and learning of complicated concepts that require understanding linkages between concepts. However, user control also increases selective scanning of online information that can interfere with learning, especially of simple content that mainly requires comprehension and memory [40,41]. To the extent that interactivity produces a sense of mutuality and involvement, source credibility should be enhanced, improving the believability of information conveyed. Thus, interactive interfaces may be most effective when teaching users complicated concepts that require deeper thought and understanding of relationships between information. The delivery of simple straightforward information may be most effectively done with less interactivity, to insure that users learn the information and do not miss it as they scan Web pages and email messages.

Social Influence

Patient compliance is a problem in medicine and especially when patient lifestyle changes are considered [42]. Explanations for the success of compliance-gaining communication strategies suggest that compliance depends on perceptions of reciprocity, social obligation, and source credibility (built upon a sense of relationship with the source, even in fleeting interchanges) [43-45]. Interactive methods using telephone or interpersonal contact for recruiting patients to health services such as smoking cessation programs are much more successful than passive recruiting methods that rely on mass media or direct mail [46]. Interactivity of online health information services has the potential to create a sense of mutuality, connection, common ground, and shared understanding, and, ultimately, participation in medical decision making [47]. This should heighten positive feelings toward health care providers and increase their credibility and the trust placed in them [48,49] to improve interpersonal influence [50,51]. The credibility of information can also increase as a medium becomes “richer” in sensory channels [52,53], such as when online systems utilize the multimedia features of the World Wide Web. Alternatively, new features related to the Web itself may promote or hinder credibility, such as the top-level domain of a health Web site, and the interaction effects of domain and the presence or absence of advertisements [54]. As noted earlier, online services can create a sense of privacy that may be important for promoting the exchange of information, perceptions of reciprocity and obligation, and ultimately compliance. Recently, one study was able to implement Internet-based recruitment strategies for an online smoking cessation program that were found to be more effective than traditional nonelectronic ones [55]. It is important to note, though, that the increasing amount of unsolicited email or “spam” threatens to reduce the credibility of online information. However, spam may mostly affect the credibility of *unsolicited* online communication. Online communication generated from known individuals or through a process called permission-based marketing—where users agree to receive follow-up information after obtaining services over the Internet—should continue to have the potential to influence [56].

Two Exemplars

How do these attributes and their intermediary effects combine to affect prevention, decision making, and coping? Two examples are offered. Interactivity has been demonstrated to have valuable direct and indirect effects in different Internet systems related to cancer. We will review its indirect relationship, through its effect on presence, further below. In another case, interactivity in terms of tailoring specific information for different computer users has been shown to have positive effects on smoking prevention and smoking cessation through its enhancement of learning and social influence. Recent innovative uses of computerized and Internet programs to prevent risk behaviors by adolescents have had some success, including Web-based programs to reduce adolescent smoking.

Interactivity, Learning, and Influence in “Consider This”

An original online tutorial system, Consider This, was developed by one of our authors and his colleagues to be part of school curricula, with the following principles of interactivity in mind: “[to] tailor program content to adolescents' intentions and experiences with smoking to counter desires to try smoking, provide support for not smoking in social contexts with opportunities to smoke, and address experiences with cigarettes that can promote further smoking…. Tailored content is provided through software routines controlled by a backend SQL database…allowing it to be delivered in real time as the person uses the program” [57]. Interactivity and message tailoring were facilitated by having adolescents respond to online questions and by tracking their use of program activities.

The Consider This Web program featured 73 online activities organized into six interactive multimedia modules based existing smoking prevention and cessation programs for youth, as well as other sources. The modules employed a host of interactive activities using audio narration, sound effects, and music in order to engage users' senses, and they featured attractive peer models in order to engage adolescents' attention. The content was “designed to create positive outcome expectancies for not smoking, negative outcome expectations for smoking, and self-efficacy expectations for avoiding or stopping tobacco use” [57]. The activities in the modules provided non-directive counseling with reasons for not smoking, and, employing the interactivity of the system, matched smoking avoidance arguments with core personal values through a motivational interviewing technique.

Consider This was tested in parallel randomized efficacy trials from 2001 to 2002 in the United States and Australia. The study found evidence that Consider This was successful at moving perceived norms and beliefs related to smoking in the desired direction (ie, to be less favorable about smoking). There were differences between the national samples in terms of specific behavioral outcomes, but both samples showed a reduction in intention to smoke—a critical variable in the age group studied—among those who used the program.

Interactivity, Presence, and Coping in CHESS

For the past 15 years, a subset of our authors has been developing and testing generations of an interactive cancer communication system (ICCS) called CHESS (Comprehensive Health Enhancement Support System). This ICCS is an online system that integrates a range of services that can be described as information (ask an expert, questions and answers, instant library, resource guide, personal stories, Web links), support (online discussion group, ask an expert, personal stories), and skills building (journaling, decision making, action planning, managing distress, healthy relating). Over a series of randomized clinical trials, this ICCS has demonstrated significant improvements in cancer patients' quality of life, especially for underserved audiences [58].

As part of the activities of the Center of Excellence for Cancer Communication Research (funded by the National Cancer Institute), research and development over the last year have been directed toward amplifying a sense of presence in the CHESS system. In the following discussion we review the relationship between presence and interactivity, the methods intended to heighten cancer patients' sense of presence in this specific ICCS, how this sense might mediate effects on quality of life, and how these mediation effects may be measured.

A major strength of this and similar ICCS programs is that they are indeed systems. Whereas most websites provide a single approach to content, forcing a user to browse from site to site to meet different kinds of needs, an integrated system of services meets the varying needs of its users (eg, a breast cancer patient) at different times and in different situations. The systems approach not only makes it far easier for users to find what they need, but it may also encourage them to see connections between physical, emotional, and social aspects of their illness.

CHESS is also interactive in the sense that it maximizes opportunities for user control and allows users to feel that the ICCS is responsive to them [59]. Lee's argument that there is an inextricable link between interactivity and social presence [24] dictates that interactivity is likely a necessary condition for online presence to occur. However, dealing with the relationship between interactivity and presence raises some distinctions within interactivity that must be considered. One current project is attempting to decompose CHESS to determine which kinds of content are responsible for its benefits. From this perspective, despite the depth and quality of CHESS modules during the past decade, and its characterization as a purportedly “interactive” medium, dividing the many services into distinct elements makes it evident that the various components represent three very different kinds of interactivity, which can be understood through the following three metaphors.

- The ICCS as a “book index”: Users control where they go, but the system is not proactive.
- The ICCS as a “telephone”: The system connects human users (via email, bulletin boards, Web logs).
- The ICCS as “coach/collaborator”: The system tracks and remembers the user and responds in accord with that history.

This breakdown makes several conclusions stand out. First, connections to real individuals have been an important part of

CHESS from the beginning, but the recognition of the contributions these connections make to social presence and its potential benefits are just becoming clear. Second, new developments and expansions of what were rudimentary capabilities have the opportunity to create a virtual social presence of the CHESS system itself, and new designs are being undertaken with presence explicitly in mind.

A prime example of connection to other real people is CHESS's bulletin-board style Discussion Group, which has always been a central focus for users, often accounting for two-thirds or more of all uses of the system [58]. Drawing on many of the attributes enumerated above, patients report in many ways that it is not merely the additional information that sharing experiences provides that is important about the Discussion Group. Instead, there is a sense of community and social support. In other words, breast cancer patients see the CHESS Discussion Group as providing social presence through connecting them with other real women. Similar reactions occur to Ask an Expert, in which users can write questions that a human expert (usually a Cancer Information Service information specialist) will answer within 24 to 48 hours. Here, the social presence is again in the connection with another real person, but with a professional rather than a peer.

Social presence should also increase as CHESS expands coaching and adds collaborating to its services. Implementations such as Action Plan and Decision Aid have always provided guidance for users making decisions or attempting behavior change. But the construction of additional modules, such as Managing Distress and Healthy Relating, adds the tools for much more assessment and feedback, based both on users' response choices and on their individual situations and perceptions. That is, to effectively “coach” a patient who is developing and beginning to employ new skills, the system will provide example situations and evaluate patient response choices. Although there is no human behind the machine in this case, this clearly still meets the criterion of interactivity through interdependent exchange of information since the patient gets feedback and guidance from the system.

The “collaborator” role of tailoring the system to the patient is a fresh addition to CHESS. Whereas tailoring attempts such as Consider This and others deliver the most relevant and beneficial message to a user [60], such an approach is not appropriate for a large system of information, support, and tools designed to be used repeatedly over time. As things change over time, the appropriate message must change too. As in all tailoring, CHESS assesses the user's situation and status, and then the system uses that information to help the user get to the content that will be most relevant and beneficial.

Future CHESS Research

It would be unfair to present the initial CHESS system as a full-fledged expert system, but the constraints and commonalities of the breast cancer situation offer the opportunity to do a great deal with relatively simple algorithms. For example, knowing the calendar of a woman's treatment plan (obtained from the medical record at recruitment and alterable by the user at any time) allows us to present a narrow set of treatment tips that match what the woman is experiencing, or will shortly experience. Beyond this, she is encouraged to report her current emotional and functional status and concerns, which further allows the system to recommend a narrower version of CHESS content that is better suited to her. To keep this functioning, her personal home page contains a link (“What CHESS knows/assumes about you”) so that she can review and alter this at any time. She can also elect to turn off tailoring and use the system in “index” mode. And as with coaching, these collaborations should provide considerable virtual social presence.

However, beyond connection to real others and the virtual presence of a coach/collaborator, investigation of social presence within CHESS has revealed other potentially fruitful avenues. It is possible that even an effective Google search can create a sense of presence; the AskJeeves search engine, which shows what queries other users have recently made, seems designed to do just that. If search engine sites can create presence, we need to reconsider the nature of agency as a necessary condition. Perhaps the social presence some people experience from Google stems from its typical performance of providing both highly appropriate links and some surprise or unpredictability in what it returns. Alternatively, highly experienced Google users probably understand its algorithm and may be finding presence in the feeling that its results provide a sense of collective behavior of many Web users.

Attention should focus on the combination of two attributes—appropriateness and unpredictability of response. A “book index” type of ICCS takes the user directly to highly appropriate but very predictable content. Other humans posting to discussion groups provide appropriate (though variable) responses to the user, but with some degree of unpredictability that is characteristic of independent agency. Programming-based coaching or collaborating can potentially be both highly appropriate and unpredictable, though achieving this is difficult and errors can be costly.

Perceptions and Mediation

For the most part, breast cancer patients are likely to experience CHESS's social presence because of the Discussion Group's ability to connect them with other women, the coaching of skill-training components, and the collaboration of tailoring CHESS to their situation. Based on the following assumptions, several hypotheses can be articulated regarding the kinds of perceptions that will then mediate greater CHESS effects:

- The Discussion Group, especially, should produce a sense of community with shared experiences.
- A variety (or combination) of CHESS interactive components should provide some sense that the patient is being watched over and protected, no matter whether it is a group of real women who are keeping track of her or a computer coach/collaborator.
- With Ask an Expert as well as the computer coach/collaborator, this protection comes with the additional perception of expert reliability and power. However, for some patients, support from fellow cancer patients is particularly powerful because of the expertise of having been or currently being cancer patients themselves [61,62].

These perceptions should lead to several mediating effects that will then lead to an increase in the degree to which CHESS affects such things as emotional well-being, functional well-being, information competence, and effective interaction with health care providers. Hypothetically, all these perceptions, especially if they are enhanced by perceived expertise, should buffer negative affect. This is important because negative affect can be debilitating and can shut off effective coping behaviors. Also, the encouragement and support provided should bolster self-efficacy, the sense that the individual is capable of effective actions. Further, guidance from the collaborator should focus patients' use of CHESS on more effective varieties of use [63]. For example, use of Discussion Group appears to be more beneficial if combined with the use of other kinds of CHESS services or if the user is an active contributor instead of just "lurking" and reading messages [64]. Finally, by providing patients more individually relevant information and tools, the perceived utility of CHESS content should be greatly enhanced overall, which should increase system "stickiness." In past studies, substantial proportions of patients have used CHESS for only a few weeks and then discontinued use. Some of them may well have gotten all they needed from the system. Others probably would have benefited from returning as their situations changed (eg, as treatment continued or ended), and greater stickiness should enhance this.

Caveats

The preceding review has focused on structural system and social characteristics of several types of interactive online health information systems and has discussed the potential benefits of various combinations among them. While this review has focused on characteristics of the online modality, it is important to recognize that communicators often effectively compensate for structural shortfalls if given adequate time and motivation [23,65] and adapt technology to existing communication practice [66-68]. The combination of communication outcomes, modality features, and audience characteristics will determine the success of Internet health information programs.

Clearly, a bias throughout much of the above has been that social presence is desirable and that ICCS designers should enable users to perceive it as much as possible. In part, this results from the perception that current ICCS users are likely to experience relatively little social presence, so that increasing it would clearly be a step in the right direction.

Nonetheless, we must recognize that social presence is not automatically desirable here or in other computer-based health enhancement systems. Patients may regard the social presence as an unwelcome "big brother" who knows too much about them or is being too intrusive. And errors (responding inappropriately to user) could undermine system credibility or produce boomerang effects.

The response so far has been to push forward, but with several safeguards. First, the CHESS project is pilot testing the tailoring mechanisms in paper prototype and pilot versions with prior CHESS users to try to establish what levels of system activity stimulate presence perceptions without producing negative reactions. And, second, even when new additions to the system roll out, plans call for users to be allowed to turn off or avoid these features at their own discretion.

Another final caveat is raised by the emerging problem of low return use or drop off in use of online health information systems. Many of the programs evaluated recently depended upon the user to initiate contact and "pull" information from them, and there was no guarantee that the at-risk population would use them just because they were available, even when assigned to do so [1,7]. Low use can reduce the effectiveness of Internet health information systems [6,7,10,69]. There is scant information on the factors that improve website use; use may be higher among young users, those recently diagnosed with a disease, and users expressing intentions to change or who are actually making a change [70]. Some advertising researchers have speculated that interactivity of these systems increases return visits [71]. Recently, a few researchers have observed that email notifications (a crude form of interactivity) increased use of Internet health programs [9,10,72].

Conclusions

Continued study of the efficacy of online health information systems is essential because they are expensive to create and governmental and non-governmental health organizations are quickly embracing them. Different levels of access to the Internet can present barriers to the production and delivery of these systems [69,73]. Fortunately, many of the disparities in Internet access based on gender, race, and socioeconomic circumstances have shrunk substantially in the United States: Internet access is nearly universal in schools [74] and is present in over half of US households [75]. Government and nongovernmental organizations that seek to deliver health information must have a good understanding of how to deploy the features of online health information systems most effectively, about which, unfortunately, current knowledge is limited. There is a risk that health professionals will become disenchanted with these Internet health information systems unless researchers test how the features affect important outcomes that determine the health of populations.

Conflicts of Interest

None declared.

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Abbreviations

CHESS: Comprehensive Health Enhancement Support System
ICCS: interactive cancer communication system

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Viewpoint

Online Cancer Services: Types of Services Offered and Associated Health Outcomes

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Abstract

There are advantages and disadvantages associated with utilization of online health services among individuals living with cancer. Accessing accurate, reliable health-related information online gives patients the power to enhance their understanding of information they obtain from their health care providers. However, online health information can often be confusing for patients to interpret, and it can sometimes be conflicting or incorrect. Based on a framework by Eysenbach, the following paper discusses various types of cancer services that are available online, and it addresses both positive and negative health outcomes that have been linked to utilizing such services.

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KEYWORDS

Electronic mail; health outcomes; Internet; online cancer services; online support group

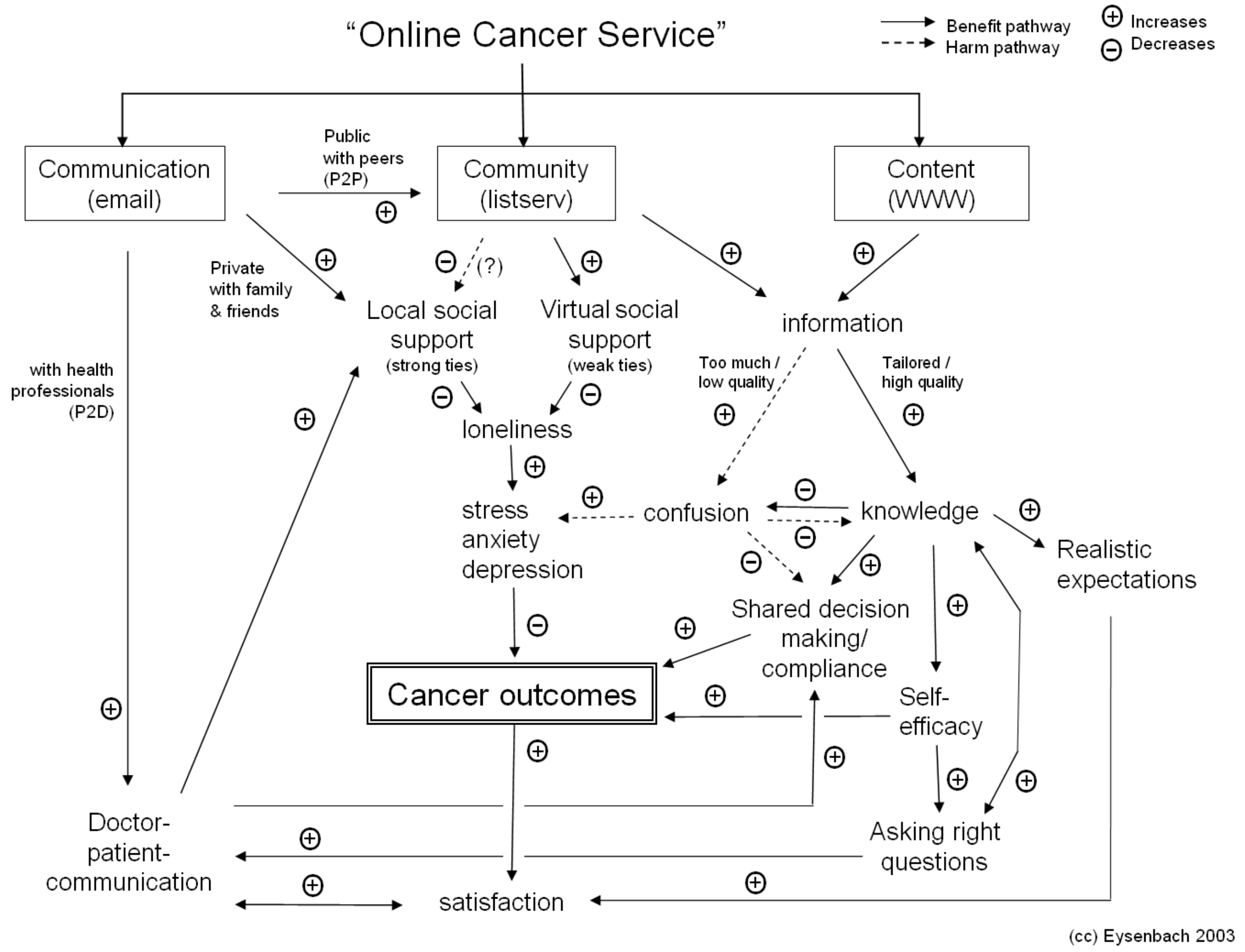
Introduction

According to a recent systematic review and meta-analysis of cross-sectional surveys from various health care institutions, approximately 39% of individuals living with cancer use the Internet [1], indicating that online health services have become an important information source for many patients. Such services are prevalent and are varied in their scope, ranging from electronic mail communication with health care providers, friends, family members, and other patients to virtual support groups for patients and caregivers. Due to the vast availability of online health services today, as well as increased patient interest in knowing about the diagnosis, treatment, and follow-up of cancer [2], continued investigation into their impact on the health outcomes of patients with cancer is imperative.

Cancer Services Offered Online

The World Wide Web is the first thing that comes to mind for many people when they hear the phrase “online health services.” However, as noted by Eysenbach [1], while the Web is certainly a common source of health-related information for patients, caregivers, and health care providers alike, online health services encompass quite a bit more than the Web or Internet alone, and a framework of outcomes should be best discussed under the headings “Communication,” “Content,” and “Community” (Figure 1).

Figure 1. Eysenbach's framework of online cancer services and their possible relationships to health outcomes (reproduced with permission from [1], © Lippincott Williams & Wilkins)



Communication

The primary channel for promoting cancer prevention is communication [3]. Effective health communication—either delivered via a health care provider or via online health services—can have a profound effect on the lives of patients living with cancer. For example, constructive communication about health-related issues can promote prevention of cancer, inform detection and diagnosis of cancer, direct decisions surrounding options for cancer treatment, enhance the ability of cancer survivors to cope with life after the disease, and encourage the best possible end-of-life care [3,4].

Interestingly, as noted by Eysenbach [1], despite the astounding—and frequently overwhelming—amount of information available on the World Wide Web, Internet users cite electronic mail as the number one reason for being online [5]. In his paper, Eysenbach goes on to note that, despite patients' interest in communicating with their physicians via email, less than 10% of patients in the United States have done so [6] because physicians have not yet adopted email as a regular method of communicating with patients out of fear of an increased demand on their time [1]. Furthermore, some physicians have expressed concern about being able to incorporate email communication with patients into their daily routine, about responding to patient email inquiries in a timely manner, and about dealing with content that could be potentially inappropriate or urgent in patient email messages [1].

Eysenbach stresses that communicating with physicians is not the only health-related use patients find for email. Given that family and friends are one of the most frequently cited sources of information for patients with cancer [7], many patients also utilize email to communicate with these family members and friends about issues related to their disease. Additionally, email has the potential to create a sort of virtual support group for patients living with cancer. Often, family and friends of individuals with cancer connect their loved ones with others in their lives who have also been affected by the disease.

In addition to email communication, the general public now has access to real-time assistance through applications such as *LiveHelp*. *LiveHelp* is an instant messaging service initiated as a pilot project in the year 2000 by the Office of Communications at the National Cancer Institute's (NCI's) Cancer Information Service (CIS) [8]. The goal of the service is to assist users with navigating the NCI website in an efficient, confidential manner. Not long after the service was first introduced, almost 4000 *LiveHelp* user sessions transpired from April through December 2001, which is an average of 444 user sessions per month [8]. In general, user feedback and comments about the service have been overwhelmingly positive [8].

LiveHelp is available to any individual who has access to the Internet, as no additional computer software or hardware is needed to utilize the service. While public response to the service has generally been positive, the NCI's CIS also has information specialists who are able to answer cancer-related questions via telephone for those who prefer this method of communication and for individuals who cannot readily access the Internet. Through the CIS toll-free telephone number (1-800-4-CANCER), callers have the ability to speak with knowledgeable information specialists who have a lot of experience explaining medical information in easily comprehensible terms [9], which is a particularly important consideration given the vast proliferation of often confusing medical information currently available online.

Content

Although electronic mail may be the number one *reason* cited by users for being online, it has been argued that the most common *use* of the Internet is information seeking related to medical assistance [10]; however, it has recently been shown that health-related searches actually constitute only 4.5% of all searches in general search engines [11]. Accessing medical information about specific health-related issues on the Internet has been shown to have positive health outcomes for patients with breast cancer in particular [12]. While accessing medical information on the Internet may result in certain positive health outcomes for some patients, there are inherent disadvantages as well to accessing this type of online health service.

One of the biggest challenges when accessing medical information online is the potential for the information to be inaccurate as the Internet contains a staggering amount of medical misinformation [13]. Health care professionals have expressed other concerns about content on the World Wide Web as well. Using a structured search experiment, researchers assessed the accessibility of health information on breast cancer, depression, obesity, and childhood asthma using 14 Internet search engines. Amazingly, less than 25% of the search engines' first pages of links connected the user with relevant, usable content [14]. Additionally, 100% of the English websites and 86% of the Spanish websites required at least a high school reading level [14]. Authors of studies such as these have argued that health-related content found online can often be hard to access and, if found, can be difficult to comprehend.

Community

The last group of online health services reviewed by Eysenbach [1] is virtual support groups. Similar in nature to traditional, face-to-face support groups, online groups offer patients the opportunity to gain support from someone who has experienced their same illness or from someone who has been through similar treatment [15]. Such groups can be particularly beneficial to cancer patients who may be experiencing pain and/or additional side effects from their disease or treatment as they can participate in an online support group without having to physically travel, provided that they have access to the Internet at home. In addition to the convenience and comfort of participating in an online support group from home, patients have the ability to access social support online anytime day or night. Unlike traditional face-to-face support groups that are scheduled at a particular time in a specific location, patients can participate in online support groups at a time that best meets their needs. Furthermore, provided that they have readily available Internet access, they can participate in online groups instantly. Once again, this is especially beneficial to patients with cancer, whose illness may keep them awake during the night, because the ability to instantly connect with people who have had similar experiences may serve to alleviate some of the anxiety surrounding their illness [15]. Echoing the findings of positive health outcomes for breast cancer patients who access medical information on the Internet, researchers found that women with breast cancer who participated in an online support group also achieved positive health outcomes [16].

Health Outcomes Associated with Utilization of Online Cancer Services

Researchers' knowledge about factors that facilitate or impede communication, such as access to, sources of, and trust of cancer-related information, is limited. In an attempt to improve such understanding, the NCI developed the Health Information National Trends Survey (HINTS), the first survey of its kind, to collect data on how Americans seek and use cancer information [17]. First administered in 2001, the survey will be conducted every two years to advance understanding and to bridge the gaps between the information patients want and need about cancer and the information they actually receive.

While the development of the NCI's HINTS instrument is an impressive step in facilitating awareness of the many ways in which individuals receive health information, perspectives on whether online health services have more positive or negative effects on patients remain varied. For example, researchers who conducted a study of Canadian oncologists and their patients determined that patients were three times more likely than oncologists to view Internet information as helpful to their ability to cope with their disease [18]. However, while a commonly held view on whether online health services are more helpful or hindering to patients does not exist, it is indisputable that accessing these services has some sort of impact on patients and their health outcomes.

As previously mentioned, researchers have discovered a positive connection between accessing information on specific health issues online and the psychological health of women with breast cancer. Of 188 women who were interviewed for a study examining the potential psychological benefits of using the Internet to access information related to breast health, 42% of the respondents used the Internet [12]. Using validated scales to measure social support and loneliness among the women with breast cancer, researchers determined that those individuals who used the Internet for medical information on issues surrounding breast health had more social support in their lives and experienced less loneliness than their counterparts who used the Internet for other purposes or who did not use the Internet at all [12].

Another study of women with breast cancer found that a 12-week, Internet-based social support group—*Bosom Buddies*—had a distinct impact on the health of the participants.

Based on responses to six self-report scales and one group-report scale completed by the 72 women who participated in the study, researchers concluded that the *Bosom Buddies* support group effectively reduced participants' depression levels, perceived stress, and cancer-related trauma [16].

In an investigation of the relationship between the use of health information on the Internet and patient behavior and self-efficacy, results of a study conducted with individuals newly diagnosed with cancer indicated significant relationships among the variables. Specifically, researchers reported several notable findings: (1) 74% of Internet users compared to 54% of nonusers described their relationship with their physician as a partnership; (2) 81% of Internet users prepared a list of questions for their physician prior to their scheduled visit, while only 54% of nonusers prepared a question list; (3) Internet users (48%) asked six or more questions during the medical visit more often than nonusers (32%); and (4) when compared with nonusers, Internet users felt more confident in being able to participate in treatment decisions and to ask questions of their physicians [19].

Another outcome associated with utilization of online health services is the impact Internet health information has on the physician-patient relationship. In a telephone survey of a nationally representative sample of the American public, researchers found that 31% of the 3209 respondents had sought out health information on the Internet within the previous 12 months [20]. Overall, data from the study indicated that patients believe that online health information positively impacted their relationship with their physician [20]. Patients who perceived their physicians as having poor communication skills were typically the ones who reported that health information found on the Internet had a more negative effect on the physician-patient relationship [20].

While the aforementioned study does not relate solely to patients with cancer, findings from a similar study conducted exclusively with patients living with cancer echo the previous findings. In an attempt to examine Internet use among Australian oncology patients, researchers administered questionnaires to patients in two teaching hospitals in Sydney in 1999 and 2001. Data from both years suggested that information acquired from the Internet was perceived by patients as having either a positive or neutral influence on their relationship with their physician [21]. Notably, none of the 142 patients who completed the questionnaire during the 1999 study and a mere 3% of the 153 patients who participated in the 2001 survey indicated that online cancer information had a negative impact on the physician-patient relationship [21]. The impact of online health services on the physician-patient relationship may not be viewed as an outcome directly related to a patient's physical health. However, it is an important impact to address nonetheless as the quality of the physician-patient relationship has been shown to influence areas that *are* directly linked to a patient's health. Several studies have demonstrated a positive link between physician-patient communication, patient satisfaction, and positive health outcomes [4,22-24]. For example, after administering satisfaction surveys via telephone interviews with more than 230 adults who had seen a primary care physician within six months of the call, researchers determined that positive interaction and relational communication between physicians and patients significantly affected health outcomes such as compliance with medical treatment [23]. Consequently, the value of examining the impact of online health services on the physician-patient relationship should not be underestimated.

Most of the health outcomes mentioned here related to accessing online health services have been positive; however, negative effects have been reported as well. For example, 38% of 1050 physicians surveyed about their perceptions of the impact of Internet health information on the physician-patient relationship, health care, and workload indicated that clinical visits were less time efficient when patients brought information retrieved online [25]. Only 16% of the physicians surveyed believed that the effect of the patient bringing medical information retrieved online was beneficial [25]. Furthermore, an overwhelming 75% of the physicians noted that the online health information made no difference to the patient's health outcomes; 4% believed that the information was actually harmful to the outcomes [25].

Another study examined depression in people living with cancer using Internet and face-to-face support groups. Researchers found that patients with cancer who are more depressed, as measured by the Center for Epidemiologic Studies Depression Scale (CES-D) [26], use Internet support groups instead of face-to-face groups [27]. Considering that researchers have also found that people—not necessarily people with cancer, but people in general—become more depressed as they spend more time online [28], this finding may have further implications for the health outcomes of people living with cancer.

Conclusion

While obvious benefits are associated with utilization of online health services among individuals living with cancer, such services are not infallible, as shown by several studies illustrating negative health outcomes that may be attributed to online health service use. By accessing accurate, reliable health-related information online, patients have the ability to equip themselves with information that enhances their understanding of and supplements the information they garner directly from their health care provider. However, online health information can often be confusing for patients to decipher, and, perhaps more importantly, it can often be conflicting or erroneous [14].

Notably, more than 70% of Internet users report that their treatment decisions are influenced by health information they find online [6]. For this reason, it is essential that investigation into the accuracy and dependability of online health information as well as the outcomes associated with utilization of online health services remains ongoing. Furthermore, as researchers begin to better understand the short-term impact online health services have on patients, they need to begin to address whether long-term effects exist as well.

Conflicts of Interest

None declared.

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Abbreviations

CES-D: Center for Epidemiologic Studies Depression Scale
CIS: Cancer Information Service
HINTS: Health Information National Trends Survey
NCI: National Cancer Institute

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Original Paper

How New Subscribers Use Cancer-Related Online Mailing Lists

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Abstract

Background: Online cancer-related support is an under-studied resource that may serve an important function in the information seeking, care, and support of cancer patients and their families. With over 9.8 million cancer survivors (defined as anyone living with cancer) in the United States alone and the number growing worldwide, it is important to understand how they seek and use online resources to obtain the information they need, when they need it, and in a form and manner appropriate to them. These are stated cancer communication goals of the US National Cancer Institute.

Objectives: Our purposes are to (1) present background information about online mailing lists and electronic support groups, (2) describe the rationale and methodology for the Health eCommunities (HeC) study, and (3) present preliminary baseline data on new subscribers to cancer-related mailing lists. In particular, we describe subscribers' use of mailing lists, their reasons for using them, and their reactions to participating shortly after joining the lists.

Methods: From April to August 2004, we invited all new subscribers to 10 Association of Cancer Online Resources mailing lists to complete Web-based surveys. We analyzed baseline data from the respondents to examine their perceptions about cancer-related mailing lists and to describe how cancer patients and survivors used these lists in the period shortly after joining them.

Results: Cumulative email invitations were sent to 1368 new mailing list subscribers; 293 Web surveys were completed within the allotted time frame (21.4% response rate). Most respondents were over age 50 (n = 203, 72%), white (n = 286, 98%), college graduates (n = 161, 55%), and had health insurance (n = 283, 97%). About 41% (n = 116) of new subscribers reported spending 1 to 3 hours per day reading and responding to list messages. They used the mailing lists for several reasons. Among the most frequently reported, 62% (n = 179) strongly agreed they used mailing lists to obtain information on how to deal with cancer, 42% (n = 121) strongly agreed they used mailing lists for support, and 37% (n = 109) strongly agreed that they were on the mailing lists to help others. Smaller proportions of new subscribers strongly agreed that others on the mailing lists had similar cancer experiences (n = 23, 9%), that they could relate to the experiences of others on the lists (n = 66, 27%), and that others on the list gave them good ideas about how to cope with cancer (n = 66, 27%).

Conclusions: Cancer-related online mailing lists appear to be an important resource, especially for information seeking but also for support of cancer survivors. These were the primary motivators most members reported for joining mailing lists. The modest proportion of subscribers who strongly agreed that they could relate to others' cancer experiences (as well as similar responses to other process questions) is undoubtedly due at least in part to the short duration that these subscribers were involved with the mailing lists. Emerging data, including our own, suggest that mailing lists are perhaps under-used by minority patients/survivors. These preliminary data add to a growing body of research on health-related online communities, of which online mailing lists are one variant.

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KEYWORDS

Internet; cancer; patients; survivors; online communities; mailing lists; online support groups, listservs

Introduction

Use of the Internet for Health Information

Recent data indicate that 65% of men and 61% of women in the United States go online [1]; the average American spends over 11 hours online each week [2]. Moreover, it is estimated that 56.3 million people in the United States actively seek online information about chronic diseases [3], and 74% of all US adults who use the Internet report that they had looked for health information online in 2004 [4]. By 2005, it is estimated that approximately 88.5 million adults will use the Internet to seek online health information (eHealth) [5]. Although some researchers have questioned the precision of these estimates, it is clear that millions of people use the Internet for health information and that the Internet is an increasingly important health information source [6-8].

By 2001, there were approximately 9.8 million cancer survivors in the United States [9]. Since survivors are defined as anyone living with or surviving cancer, this is a large population of potential eHealth users. Understanding how they seek and use online resources is important if we are to assure that they have the information they need, when they need it, and in a form and manner appropriate to their needs. These are communication goals of the National Cancer Institute (NCI) [10].

The purposes of this paper are as follows: (1) to present background information about online mailing lists and electronic support groups (ESGs), (2) to describe the rationale and methodology for the Health eCommunities (HeC) study, and (3) to present preliminary baseline data on new subscribers to cancer-related mailing lists who chose to respond to an online survey. In particular, we describe subscribers' use of mailing lists, their reasons for using them, and their reactions to participating shortly after joining.

Use of the Internet for Support

The rise in Internet use has led to an increased number of people who seek support and information online. Some sources estimate that as many as 90 million Americans have participated in online support groups and that 1 in 4 people seeking disease information join online discussion groups [11]. Reportedly, 23 million Americans are very active in online communities [12]. A recent count found over 25000 health-related online self-help groups at one portal alone [13]. While the estimates vary greatly, whatever the correct number, millions of people in the United States turn to online support groups to deal with their health concerns.

Electronic support groups (ESGs), which include mailing lists, are much like self-help groups in that they are composed of members who share a common condition, situation, heritage, symptom, or experience [14]. They are self-governing, usually, with clear rules about acceptable behavior. ESGs range from highly structured therapeutic groups to moderated and unmoderated chat rooms and mailing lists. ESGs and mailing lists share the common goal of helping people learn about and cope with a variety of risk factors, diseases, and conditions. Some ESGs are closed groups with substantial professional moderation, such as those reported by Winzelberg et al [15] and Lieberman et al [14]. However, most of these moderated groups have been implemented as part of research projects. It is not clear whether such structures are viable as ongoing services that can be sustained over time.

Currently, most ESGs appear to be unmoderated and are more like self-help or mutual help groups than face-to-face support groups [16]. The mailing lists we are studying are characterized by wide reach and minimal intervention by most listowners who manage them. These lists are not moderated by health professionals although many of the listowners are extremely knowledgeable about health and cancer, and they intervene online and offline to correct misconceptions, enforce group norms, and provide information.

Potential Positive Effects of Participating in ESGs

Patterson et al [17] identified three types of beneficial health outcomes for computer health care services: (1) education of people, (2) provision of social support or assistance in obtaining social support, and (3) change in health behaviors. Online support groups, including mailing lists, may provide both instrumental and social support [17-20].

Cancer patients use mailing lists and other Internet resources for many reasons. These include seeking and obtaining information and support, seeking second opinions, and getting information needed to interpret information from health providers [21]. In the process, the experience also may improve patients' self-esteem by putting them on a more comfortable basis with their health professionals. For patients with rare cancers, online groups may be the only way to get sufficient numbers of people together to form support groups [22]. By sharing practical advice with one another, users may gain the wisdom that experience brings [23].

ESGs may offer privacy and convenience, and people who do not feel well can participate from home. Moreover, people can communicate on the basis of shared experiences and concerns, not shared social characteristics (such as age, race, or gender) [14]. Internet-mediated support may be especially important for people who are geographically isolated and those with rarer cancers [24] and may be particularly valuable for minorities and people in rural areas because of documented disparities in their access to health care and health information [25]. Neuhauser and Kreps [26] cited other advantages of ESGs: the potential to be more interactive, participatory, and persuasive and to provide customized and contextualized information. Mailing list participation may have more reach and therefore greater population impact than in-person groups [27]. However, while there are a growing number of reports about patients' experiences with health-related mailing lists, to date, we are aware of no published outcome studies in this area.

Participation in ESGs may help patients be more involved in their care, find information, obtain support, and formulate questions to ask health providers [28]. Like other self-help groups, ESGs provide experiential knowledge and peer support [29]. Documented benefits of Internet applications range from decreases in pain and inappropriate health care use to improved quality of life [30]. Decreased anxiety and/or depression have resulted from both online therapy [31,32] and participation in ESGs for women with breast cancer [33]. Lieberman [14] also found positive increases in two subscales of the Posttraumatic Growth Inventory. Lorig et al [34] randomized arthritis patients to treatment consisting of a closed, moderated email discussion group plus book plus videotape or a control group. The treatment group had significant improvements in pain, disability, role function, and health distress and made fewer physician visits than the control group.

Access to health information through ESGs may serve an especially important communication function (eg, enhancing confidence in asking questions of one's physicians) [35]. Women with breast cancer who participated in the Computer Health Enhancement Support System (CHESS) were more competent seeking information, more comfortable participating in their care, and had greater confidence in their doctors. At five months follow-up, the group reported greater social support and information competence compared to nonusers of CHESS [36,37].

Potential Limitations of Participating in Mailing Lists and ESGs

Online support groups have many of the same potential disadvantages as other forms of Internet communication, such as email. For example, there may be more hostile messages or “flaming” than would occur outside the Internet [22], and statements may be misinterpreted, causing discomfort and anxiety [22]. Offers of instrumental help are infrequent, and if people develop friendships, those relationships usually exist outside the mailing list where perhaps more instrumental social support can be provided [38]. Long-term relationships between individuals may be unusual [18]. There is still debate about whether computer use and, by extension, mailing lists/ESGs, promote social isolation, for example, by providing a more accessible but less sufficient substitute for meaningful social support [39]. Not surprisingly, mailing list postings include both information and misinformation. It is not known how these factors affect participants. In addition, some advice may encourage some people to adopt unconventional therapies [40]. As Lamberg [41] noted, finding the right ESG may take some work, and quality may vary even more than in community support groups. In the current milieu, selected messages may be blocked to protect against spam, potentially isolating some users.

The Science Panel on Interactive Communication and Health [42], while generally positive about the Internet, noted that there are some potential risks of using the Internet to obtain health information, including that patients could turn to inappropriate complementary and alternative treatments or that they could lose faith in their physicians. To date, there is little evidence of such effects [43]. Evaluations of Internet-based services should include both potential benefits and limitations. It is essential to understand both the strengths and limitations of mailing list participation.

The State of the Evidence

Overall, Lieberman and Russo [14], based on a qualitative review of the literature, concluded that the impact of ESGs appears positive. Moreover, this seems to be a consequence of the qualities they share with in-person support groups (eg, people communicate with high levels of support, acceptance, positive feelings, normalization, and the perception of finding others like themselves and receiving meaningful information and support). Yet, as Eysenbach et al [13] concluded recently, based on a systematic review of all longitudinal studies, including cohort studies, before-after designs, and randomized trials, “No robust evidence exists for consumer-led peer to peer communities, partly because most peer to peer communities have been evaluated only in conjunction with more complex interventions or involvement with health professionals. Given the abundance of un-moderated peer to peer groups on the Internet, research is required to evaluate under which conditions and for whom electronic support groups are effective and how effectiveness in delivering social support electronically can be maximized” [13]. Today, therefore, the evidence is scant [13,23].

Methods

Health eCommunites Study Overview

Health eCommunities (HeC), funded through the Robert Wood Johnson Foundation's Health eTechnologies Program, is assessing the impact on cancer survivors and their caregivers of participating in mailing lists sponsored by the ACOR (Figure 1). HeC is based upon a partnership of ACOR and the School of Public Health at The University of North Carolina at Chapel Hill to assess the impact of participation in cancer-related mailing lists managed by ACOR. As part of the larger HeC study to understand the role that online cancer-related mailing lists play in the lives of people living and coping with cancer, we conducted an online survey of new cancer-related mailing list participants to address several research questions, including the following:

1. Why do new mailing list subscribers join cancer-related mailing lists?
2. What are new subscribers' expectations regarding mailing lists?
3. How frequently do new mailing list subscribers use the mailing lists?
4. How do they assess the lists shortly after joining, in terms of the similarity of their experiences to those of others and on several aspects of information seeking and social support?

The preliminary baseline data reported here were collected as part of a larger impact evaluation. Understanding why people join these mailing lists and how they use them will enhance what is known about online health support.

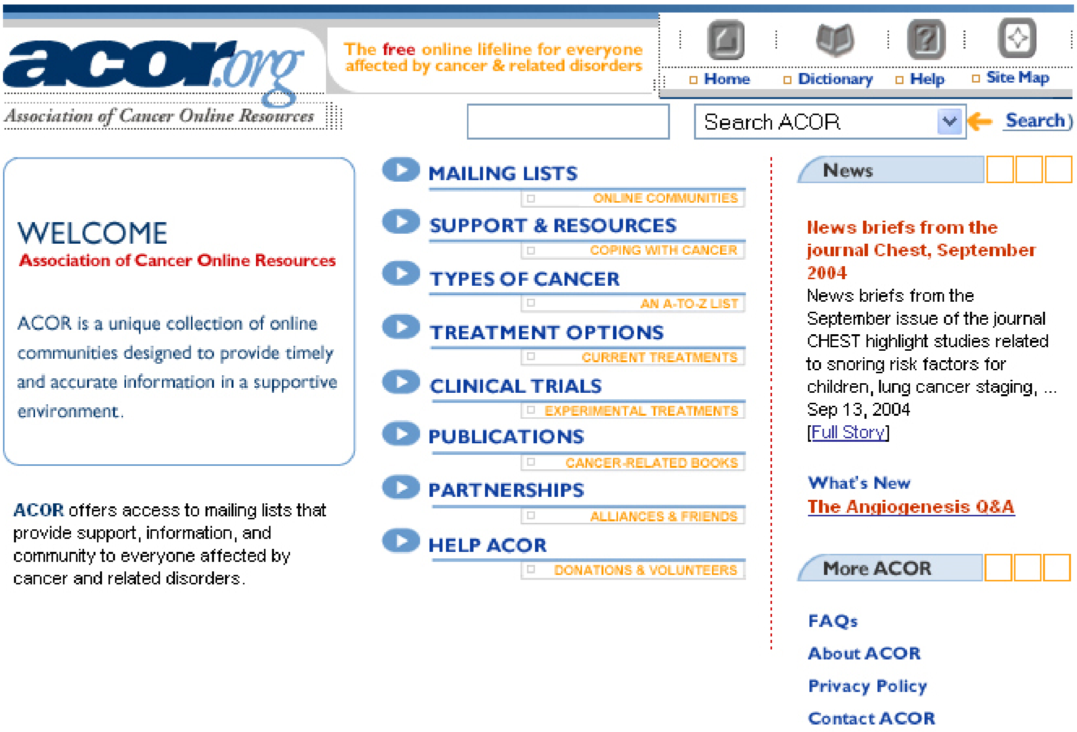


Figure 1. ACOR home page

WELCOME
Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

News briefs from the journal Chest, September 2004

News briefs from the September issue of the journal CHEST highlight studies related to snoring risk factors for children, lung cancer staging, ...
Sep 13, 2004
[Full Story]

What's New
The Angiogenesis Q&A

Theoretical Approach

Our approach to understanding cancer survivors' use of cancer-related mailing lists is informed by theories on stress and coping [44-46] that emphasize primary appraisals of susceptibility to threats and perceptions of the severity of threats. Coping is the process of managing internal and external demands that are appraised as exceeding individual resources [47]. Lazarus and Folkman [48] identified two broad categories of coping strategies—problem focused and emotion focused. Either can lead to positive or negative outcomes. In problem-focused coping, also referred to as problem management, a person takes constructive action to deal with threats. This might include joining a cancer-related mailing list. In emotion-focused coping, also referred to as emotional regulation, a person acts to control emotional responses to a threat. This may include seeking social support, venting feelings, or practicing avoidance and denial.

Heightened perceptions of risk can cause distress, disengagement, and avoidance behaviors [44,45] but may also motivate problem management coping in the form of seeking information and social support. Current models of the processes by which people confront stress propose that a number of variables, such as personality characteristics, external resources, and social support, can influence coping, thereby mediating the effect of coping on psychological outcomes [49]. In particular, social support can facilitate an individual's positive efforts to cope, and it has the potential to bolster both positive problem-focused and emotion-focused coping. Further, the absence of a social support network has been tied to a more rapid course of illness (although these data should be received as preliminary) and to more depression [50]. Thus, seeking social support through mailing list participation may be a useful strategy that ultimately can improve a person's quality of life and health behaviors. Whether those factors can improve health outcomes remains to be seen.

Survey Methods

We are using a longitudinal cohort design to assess the impact of ACOR mailing lists on selected outcomes for new subscribers; however, we only report cross-sectional baseline data in this preliminary paper. For the pilot study, new members were recruited to participate about a week after they subscribed to one of 10 ACOR mailing lists. (However, some subscribers may have waited several days to respond or may never have responded.) Invitations to participate were sent to new ACOR members via email. Willing participants could either follow hyperlinks to Web-based surveys or request that they be interviewed via telephone. As less than 1% of respondents requested telephone interviews, we will not discuss telephone interviews further in this paper. Up to three post-notification contacts were made to each non-respondent by email to increase responses [51,52]. All survey instruments and materials were reviewed by The University of North Carolina Institutional Review Board.

Study Variables

For analyses reported here, we focused on information seeking and the processes by which new subscribers used the mailing lists. We also examined how new subscribers responded to the surveys through analysis of time-stamp data (described below). Relevant survey items are summarized as follows:

1. **Sociodemographic and medical variables.** We collected data on variables such as age, race, ethnicity, education, marital status, health insurance, and type of cancer. Because of sample size limitations, we did not examine differences among respondents according to these categories.
2. **Information seeking.** Information seeking items were drawn from the National Cancer Institute's Health Information National Trends Study (HINTS) [53].
3. **Mailing list use processes.** Adapting questions used by King [54], we collected information on the number of times subscribers read mailing list messages, the average number of minutes they spent reading/posting messages, how often they posted messages, and how often they contacted mailing list members outside of mailing list postings.

Results

Time-Stamp Data and Assessment of Nonresponse

Throughout the pilot phase, we collected data on survey usage patterns through time stamps. The online survey took a “stamp” of the time when respondents continued to another page of the survey, saved their progress, and completed the survey. See Table 1 for an example of time stamps for three respondents. These data were invaluable in revising surveys. During a pilot test, we cut over 1.5 minutes from the average survey completion time by adjusting pages that were particularly time consuming and demanding. We also reviewed where break-offs occurred and rearranged questions to maintain respondents' interest. When we saw that break-offs were clustered around a particular group of questions, we changed the order and broke those questions up into separate pages. Subsequently, break-offs became random and fewer, suggesting that time-stamp data permitted us to gain valuable insights into the way users were responding to surveys. The average time to complete the survey was 21.5 minutes. Data from incomplete surveys were excluded from the data reported here.

Table 1. Time-stamp data for three respondents*

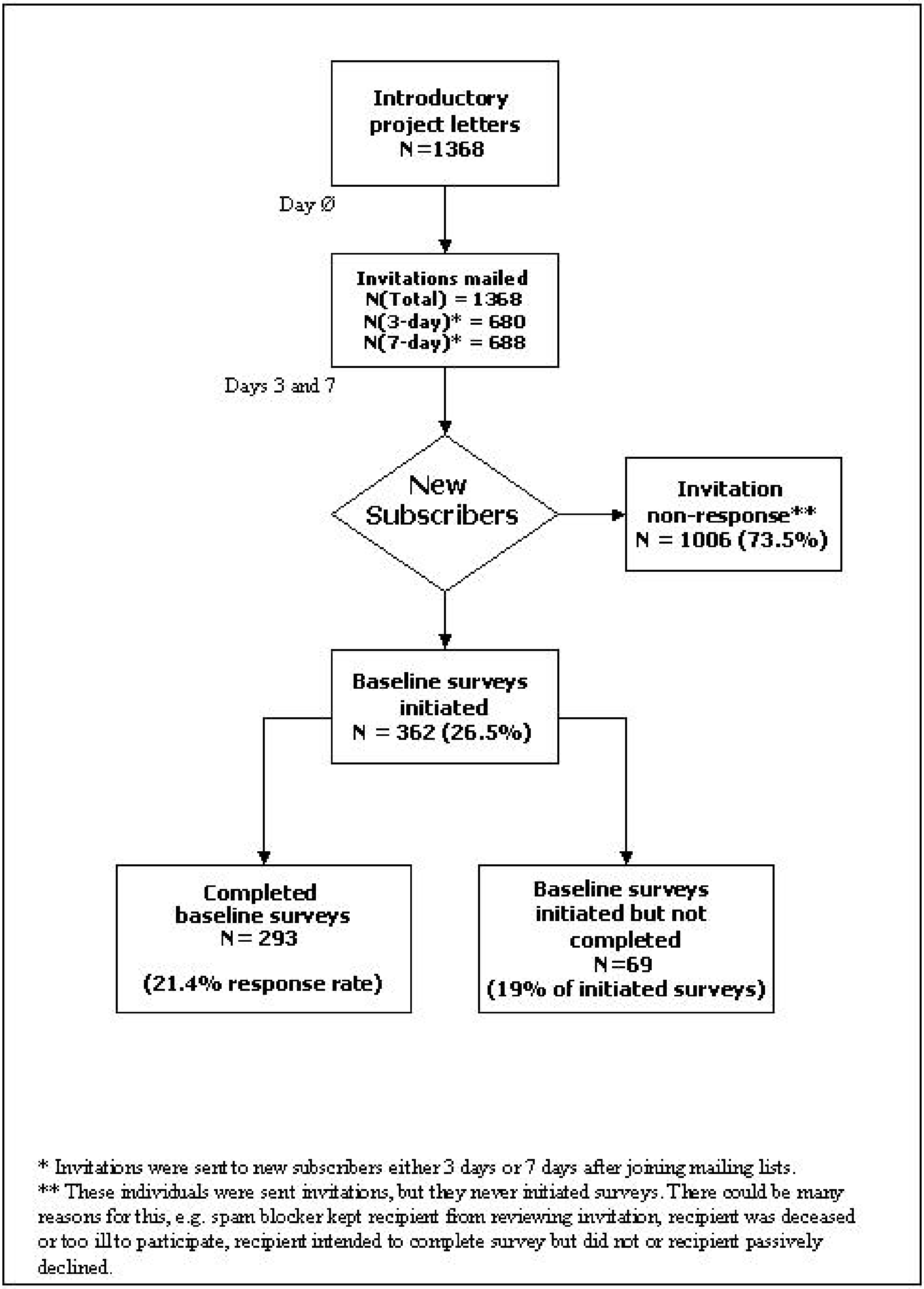
Page Number of Survey	Time of Page Submission	Page Time	Cumulative Time	Status
1	6/17/04 5:42	New Record	0:00:00	
2	6/17/04 5:43	0:00:51	0:00:51	
3	6/17/04 5:44	0:00:21	0:01:12	
4	6/17/04 5:44	0:00:08	0:01:20	
5	6/17/04 5:44	0:00:23	0:01:43	
6	6/17/04 5:45	0:00:52	0:02:35	
7	6/17/04 5:46	0:00:54	0:03:29	
8	6/17/04 5:46	0:00:32	0:04:01	
9	6/17/04 5:47	0:00:21	0:04:22	
10	6/17/04 5:47	0:00:16	0:04:38	
11	6/17/04 5:47	0:00:27	0:05:05	
12	6/17/04 5:48	0:00:28	0:05:33	
13	6/17/04 5:49	0:00:46	0:06:19	
16	6/17/04 5:50	0:01:32	0:07:51	
17	6/17/04 5:51	0:00:47	0:08:38	
18	6/17/04 5:52	0:00:30	0:09:08	
19	6/17/04 5:53	0:01:15	0:10:23	
20	6/17/04 5:54	0:01:05	0:11:28	
21	6/17/04 5:54	0:00:16	0:11:44	
22	6/17/04 5:55	0:00:31	0:12:15	
23	6/17/04 5:55	0:00:09	0:12:24	Completed
1	6/17/04 7:43	New Record	0:00:00	Break-off at page 1
1	6/17/04 8:02	New Record	0:00:00	
2	6/17/04 8:03	0:01:11	0:01:11	
3	6/17/04 8:04	0:00:18	0:01:29	
4	6/17/04 8:04	0:00:12	0:01:41	
5	6/17/04 8:05	0:01:10	0:02:51	Break-off at page 5

[*] One respondent completed the survey in 12:24 minutes, and two respondents broke off (one at less than 1 minute and one at 2:51 minutes).

Response Rates and Challenges of Gaining Adequate Participation

Cumulative email invitations were sent to 1368 new mailing list subscribers; 293 Web surveys were completed (21.4% response rate). Figure 2 shows the flow from initial emails to survey distribution. Ideally, the response rate should be corrected for undeliverable email addresses and ineligibles. This is extremely challenging, much more so than for traditional survey methodologies, such as mailed surveys in which undeliverable letters can be obtained through the post office. It also is more difficult than for telephone surveys, in which ineligible numbers can be identified. When email invitations are sent, many will not be delivered for a variety of reasons, such as powerful spam blockers, changed email addresses, people who no longer use the mailing list but have not officially unsubscribed, and people who died or are now too ill to participate. Because people often turn to the lists when they are initially diagnosed or are suffering recurrences, subscribers may be preoccupied with doctors' visits and may have little discretionary time for other activities. Unfortunately, we cannot identify these sources of nonresponse.

Figure 2. Project flow



* Invitations were sent to new subscribers either 3 days or 7 days after joining mailing lists.

** These individuals were sent invitations, but they never initiated surveys. There could be many reasons for this, e.g. spam blocker kept recipient from reviewing invitation, recipient was deceased or too ill to participate, recipient intended to complete survey but did not or recipient passively declined.

Survey Respondents

As Table 2 shows, most new mailing list subscribers were aged 50 or older (72%) and had insurance coverage (97%). Subscribers were nearly evenly divided between men and women. Most were married (80%), had no young children living in the household (79%), were white (98%), and had at least some college education (86%). The majority described their health as good or very good despite having had a cancer diagnosis. Most respondents were diagnosed with cancer in their 50s and reported being in treatment.

Table 2. Sociodemographic characteristics of respondents (N = 293)

Characteristic	Respondents[*] No. (%)
Health Status	
Excellent	40 (14)
Very good	90 (31)
Good	89 (30)
Fair	50 (17)
Poor	23 (8)
Age	
< 40	21 (7)
40s	60 (21)
50s	105 (37)
60s	71 (25)
≥ 70	27 (10)
Gender	
Male	149 (51)
Female	144 (49)
Employment Status	
Employed for wages	103 (35)
Self-employed	30 (10)
Out of work/unable to work	57 (20)
Homemaker/student/retired	101 (35)
Marital Status	
Married or living as married	233 (80)
Divorced/separated/widowed/never married	58 (20)
Race	
American Indian or Alaska native	2 (1)
Asian	3 (1)
Black or African American	1 (0)
Native Hawaiian or other Pacific Islander	0 (0)
White	286 (98)
Highest Grade Completed	
High school (grade 12), GED, or less	42 (14)
College, 1 year to 3 years (some college or technical school)	90 (31)
College, 4 years or more (college graduate)	161 (55)
Have Medical Coverage	
Yes	283 (97)
No	9 (3)

[*] Percentages may not add to 100% due to rounding.

Use of the Internet and Mailing Lists

We asked why respondents used the Internet over the past 30 days (Table 3). New members indicated that they often used the Internet to find out more about cancer (61%), to find information on general health issues (26%), and to communicate with others with the same condition (21%). In the last 30 days, 17% often used the Internet to find information on prescription drugs, and 12% often used the Internet to find information on health-related products such as herbal remedies and vitamins. Only 7% said they often used the Internet to communicate with doctors or other health professionals.

Table 3. Purpose of Internet use over past 30-day period (N = 293)

	Respondents* No. (%)			
Purpose	**Not At All**	**Rarely**	**Sometimes**	**Often**
Find out more about cancer	11 (4)	13 (4)	91 (31)	176 (61)
Find information on general health issues	33 (11)	60 (21)	123 (42)	76 (26)
Communicate with other people who have the same condition	68 (24)	49 (17)	111 (38)	61 (21)
Find information on prescription drugs	75 (26)	69 (24)	97 (33)	49 (17)
Find information on health-related products such as herbal remedies and vitamins	105 (36)	82 (28)	70 (24)	35 (12)
Communicate with doctors or other health professionals (including email)	162 (56)	64 (22)	45 (15)	20 (7)

* Rows may not add to 100% due to rounding.

New mailing list members said they used ACOR mailing lists for a variety of purposes (Table 4), including information and support. For example, respondents strongly agreed that they were participating in the mailing lists to find out about the latest cancer treatments (64%), to get information about how to deal with cancer (62%), to find out how to deal with side effects (53%), to get information about treatment options (53%), to see how other patients with the same cancer were doing (48%), and for support (42%). Even among these new subscribers, 37% strongly agreed they were on the mailing lists to help others. Less important reasons, but still strongly endorsed by one-third or more of respondents, were to get ideas about how to talk with doctors, to get help with decision making, and to reduce uncertainty.

Table 4. Reasons for using mailing lists (N = 293)

	Respondents* No. (%)			
Reason	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
Find out about the latest treatments for cancer	6 (2)	9 (3)	89 (31)	184 (64)
Get information about how to deal with cancer	1 (0)	6 (2)	105 (36)	179 (62)
Find out how to deal with the side effects of cancer treatments	1 (0)	17 (6)	118 (40)	156 (53)
Get information about treatment options	6 (2)	11 (4)	120 (41)	153 (53)
See how other patients with my cancer are doing	3 (1)	12 (4)	137 (47)	138 (48)
Get support from other people with my cancer	6 (2)	30 (10)	133 (46)	121 (42)
Help me make decisions about what is the best cancer treatment for me	12 (4)	26 (9)	134 (46)	117 (41)
Help reduce my uncertainty about which treatments are best for me	12 (4)	32 (11)	131 (45)	114 (40)
Help others	3 (1)	26 (9)	153 (53)	109 (37)
Get ideas about how to talk with my doctor about my illness	11 (4)	41 (14)	135 (47)	103 (35)
Feel less lonely	28 (10)	73 (25)	100 (35)	87 (30)

* Rows may not add to 100% due to rounding.

We asked these new subscribers to specific ACOR mailing lists how they used the mailing lists in the past seven days since they had subscribed. This information was intended to serve as the baseline for subsequent comparison: 78% said they checked their email for messages four or more times in the last seven days; 41% of new subscribers reported spending 1 to 3 hours per day reading and responding to mailing list messages; and 30% said they exchanged private emails with 1 to 3 subscribers (Table 5). Only small proportions of respondents reported private emails or phone calls with group members.

We also assessed reactions to group processes that took place on the mailing lists. Of new ACOR subscribers, 9% strongly agreed (62% agreed) that others on the list had similar experiences, 31% strongly agreed that they could express their opinions on the mailing lists, 27% strongly agreed that they could relate to other members' cancer experiences and that others on the mailing list gave them good ideas about how to cope with cancer, and 12% strongly agreed that they could disagree with other members' statements (Table 6). We asked how much help new members received from being on the mailing lists (Table 7): 39% indicated that other members gave them quite a bit/very much help, while only 7% said they gave quite a bit/very much help to other members. Fifty percent of new subscribers said listowners provided quite a bit/very much information that members needed, and 43% said that listowners helped with discussion quite a bit/very much.

Table 5. Mailing list use (N = 292)*

Mailing List Use	Respondents No. (%)				
	0	**1–3**	**4–6**	**7–9**	**10**
Number of times subscribers checked their mailing list email	41 (14)	23 (8)	60 (20)	87 (30)	81 (28)
Hours spent each day reading and responding to messages from mailing list	155 (54)	116 (41)	9 (3)	3 (1)	4 (1)
Number of different mailing list members with whom subscribers exchanged private emails	155 (54)	87 (30)	33 (12)	5 (2)	6 (2)
Number of times subscribers exchanged private emails with other mailing list members	177 (62)	65 (23)	27 (9)	7 (2)	12 (4)
Number of mailing list members subscribers called on the phone	269 (93)	18 (6)	1 (1)	0 (0)	0 (0)

[*] Number may vary slightly due to skip patterns.

Table 6. Evaluation of mailing list experiences (N = 252)*

	Respondents No. (%)			
Evaluation of Experiences	**Strongly Disagree**	**Disagree**	**Agree**	**Strongly Agree**
Cohesiveness				
Overall, my experiences were similar to those of other members.	7 (3)	63 (26)	154 (62)	23 (9)
I could relate to other members' experiences about cancer.	3 (1)	19 (8)	160 (65)	66 (27)
Normalization, Role Modeling				
Other people on the mailing list gave me good ideas about how to cope with cancer.	3 (1)	33 (13)	147 (59)	66 (27)
Conflict Management				
I felt it was OK to express my opinions in the group.	2 (1)	18 (7)	149 (61)	77 (31)
I felt it was OK to disagree with other members' statements.	4 (2)	48 (20)	160 (66)	30 (12)

[*] Number may vary slightly due to skip patterns.

Table 7. Help provided by the mailing lists (N = 276)*

	Respondents No. (%)				
Help	**None**	**A Little Bit**	**Some**	**Quite a Bit**	**Very Much**
How much did the listowner (or listowners) give information that group members need?	18 (7)	27 (11)	80 (32)	80 (32)	46 (18)
How much did the listowner (or listowners) help the discussion?	31 (13)	27 (11)	83 (33)	71 (29)	36 (14)
How much help did other mailing list members give you?	27 (11)	32 (12)	97 (38)	67 (26)	33 (13)
How much did the listowner (or listowners) help group members resolve conflicts?	65 (28)	23 (10)	74 (32)	50 (21)	21 (9)
How much help did you give to other mailing list members?	125 (49)	48 (19)	63 (25)	16 (6)	3 (1)

* Number may vary slightly due to skip patterns.

Discussion

The picture that emerges from Web surveys completed by cancer survivors who were new subscribers and received invitations to participate within about a week after subscribing to ACOR mailing lists is one of people who turned to the mailing lists for information and support, especially information. They particularly were looking for information about treatment, coping with side effects, and treatment options, with half or more of new subscribers providing these as reasons for joining mailing lists. Over 40% also cited support as one of the reasons they joined the lists. Although only 37% of respondents noted helping others as one of the reasons they joined the list, it is striking that even this proportion of people saw helping others as a reason for joining mailing lists. It is possible that helping others and receiving support become more important over time as the lists become more useful and central to subscribers when their tenure on it increases. Reading and responding to messages accounted for one to two hours a day, on average, for survey respondents. Follow-up survey data will help to put these numbers in context. We cannot predict whether the amount of time will increase, decrease, or stay the same. Also, we do not know the accuracy with which people report time spent online.

In view of their newness to the lists, it would be expected that many new subscribers would watch and wait, perhaps even *lurk*, before playing an active role. Moreover, we would expect some of their assessments and perceptions to change over time. Several days into their use of a mailing list, many subscribers would not have observed conflicts or even be aware of listowners' actions to facilitate improved group processes. In fact, many of these interventions occur behind the scenes. Since this is a longitudinal study, we will be able to assess changes in participation patterns one and four months later as participants become more comfortable and perhaps more active on the mailing lists. Our larger study will also assess whether there are changes over time in subscribers' assessments of mailing list processes. We expect that the amount of help subscribers perceive themselves having received and given will be a function of many factors, including their illness trajectory, type of cancer, other support and information available to them, and the lists to which they subscribe.

Limitations

Although our full study will examine changes over time in subscribers' use of mailing lists and other outcomes of interest, here we focused only on the preliminary baseline survey, which would have the same strengths and weaknesses as similar cross-sectional surveys. For example, we can only report what subscribers said and cannot infer causal relationships.

It is unfortunate that so few minorities completed surveys. We do not know if that is a reflection of a small number of minorities using mailing lists, their lesser inclination to complete this survey, or both. Recent data indicate that 46% of African American adults are online versus 64% of white and 63% of Hispanic Americans [2]. Thus, blacks still are using the Internet at a lower rate than whites but at a higher rate than our data would suggest. Fogel et al [55] found lower use of Internet listserv and self-help groups by minority breast cancer patients. McTavish et al [56] analyzed differences between black and white women who used online support. Black women were more likely to be lurkers, spent less time online, and wrote more messages about breast cancer and fewer messages about everyday life than white women. Klemm et al [57] reported that, in 10 studies they reviewed, most users of online support were white.

Only 14% of the respondents in Schmidt and Andrykowski's study of Internet support for breast cancer were African American [58]. However, the authors showed that Internet use for breast cancer information was associated with greater social support, and minorities showed greater gains than whites as a result of exposure to the intervention. Gustafson et al [36] and Shaw et al [24] similarly demonstrated that minority women with breast cancer benefit from use of the Internet. If, as Lieberman and Russo [14] concluded, ESGs are similar to face-to-face self-help groups in their beneficial impact, it may be appropriate to develop more proactive strategies to encourage diverse cancer survivors to use mailing lists and other ESGs.

More research is needed to understand the many issues involved in asking patients to complete Web surveys, from assessing the physical, psychological, and cognitive demands of different question formats to examining ways to estimate true response rates. Online and other survey methods are substantially different. The lessons of one method cannot be transferred to others without more research [59].

Our conservatively calculated response rate of 21.4% is less than one would expect based on other survey formats. However, as Kraut et al [59] and others noted, online surveys yield lower response rates than other survey methods. A recent report from RAND showed wide variation in response to Web-based surveys [60]. For example, Fogel et al [55] reported a 9% response rate of cancer patients to their online survey. Our results appear to be within the range of what has been reported for other online surveys of cancer patients. However, it is striking how few Internet-based survey reports contain response rates. It is likely that a substantial component of non-response may occur because of constraints inherent in online research, such as powerful spam blockers and changing email addresses.

Unique Web-Based Tools

Finally, although there is much that is challenging about Internet research, especially when conducted among cancer survivors, the Internet also offers tools not available in other modes. For example, we found time-stamp data extremely valuable in overcoming break-offs by permitting us to pinpoint areas in the survey that respondents had trouble answering. Moreover, the potential to include people from around the world is an attractive aspect of Web surveys.

While our data do not yet answer Eysenbach's questions about the impact of online communities [13], the data do begin to paint a more complete picture of why cancer patients turn to the Internet, how they use mailing lists, and how they rate the processes of using the lists. As comments from subscribers show, this is a powerful world that is compelling and, potentially, not only supportive and informative but perhaps, sometimes, lifesaving as well. Creative research strategies will be needed to assess the many important questions related to use of online support by cancer patients and others. Among the intriguing questions are whether and how online support differs from in-person support and whether some people are more likely to benefit from one modality over another.

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Conflicts of Interest

None declared.

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Abbreviations

ACOR: Association of Cancer Online Resources
CHESS: Computer Health Enhancement Support System
ESGs: electronic support groups
HeC: Health eCommunities
RWJF: Robert Wood Johnson Foundation

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Original Paper

Cancer Internet Search Activity on a Major Search Engine, United States 2001-2003

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Abstract

Background: To locate online health information, Internet users typically use a search engine, such as Yahoo! or Google. We studied Yahoo! search activity related to the 23 most common cancers in the United States.

Objective: The objective was to test three potential correlates of Yahoo! cancer search activity—estimated cancer incidence, estimated cancer mortality, and the volume of cancer news coverage—and to study the periodicity of and peaks in Yahoo! cancer search activity.

Methods: Yahoo! cancer search activity was obtained from a proprietary database called the Yahoo! Buzz Index. The American Cancer Society's estimates of cancer incidence and mortality were used. News reports associated with specific cancer types were identified using the LexisNexis "US News" database, which includes more than 400 national and regional newspapers and a variety of newswire services.

Results: The Yahoo! search activity associated with specific cancers correlated with their estimated incidence (Spearman rank correlation, $\rho = 0.50$, $P = .015$), estimated mortality ($\rho = 0.66$, $P = .001$), and volume of related news coverage ($\rho = 0.88$, $P < .001$). Yahoo! cancer search activity tended to be higher on weekdays and during national cancer awareness months but lower during summer months; cancer news coverage also tended to follow these trends. Sharp increases in Yahoo! search activity scores from one day to the next appeared to be associated with increases in relevant news coverage.

Conclusions: Media coverage appears to play a powerful role in prompting online searches for cancer information. Internet search activity offers an innovative tool for passive surveillance of health information–seeking behavior.

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KEYWORDS

Internet; neoplasms; health education

Introduction

Health care providers [1-3] and their patients [4-7] regularly search for health information online. Internet users generally begin looking for health information using a search engine [8-12], an Internet tool that searches for Web pages containing terms specified by users [13]. In February 2004, Google and Yahoo! were the most popular search engines in the United States, with 38% and 32% of market share, respectively [14].

To date, few studies of Internet search activity related to health topics have been published. Most analyzed the proportion of health and non-health searches on various search engines and found that health searches constituted a small percentage of total searches [15-18]. This finding is not surprising given how infrequently Internet users search for health information compared with how often they look for news reports, product information, and other topics [19]. In any case, a small percentage of total Internet searches translates into thousands of health searches each day [16], and an estimated 95 million Americans have used the Internet at least once to search for health information [20].

Cancer appears to be a health topic of some interest to Internet users. Eysenbach and Köhler [16] found that searches for cancer information accounted for 5% of health-related searches on the search engine MetaCrawler. Phillipov and Phillips [18] found that "skin cancer" was one of only 17 health-related search terms among the most popular 300 Internet keywords identified by Wordtracker, a private research company. Bader and Theofanos [21] studied cancer searches conducted using the search engine AskJeeves during a 3-month period and found the most commonly searched cancers were digestive/gastrointestinal/bowel, breast, and skin. This study also compared the incidence of selected cancers with their associated search activity. While this relationship was not statistically tested, the authors observed that some rarer cancers constituted a higher proportion of total searches than their proportion of total cancer incidence. In addition, Bader and Theofanos, as well as Phillipov and Phillips, noted that media coverage appeared to prompt Internet searches for health topics, but they did not systematically investigate or test the relationship.

The study reported here builds on this prior work by analyzing cancer-related searches conducted in the United States from 2001 to 2003 using the search engine Yahoo! Specifically, we investigated three potential correlates of Yahoo! cancer search activity—estimated cancer incidence, estimated cancer mortality, and the volume of cancer news coverage. Cancers that afflicted more individuals, claimed more lives, and generated more news coverage were expected to be associated with more Internet search activity than other cancers, given the interest generated by relevance and publicity. In addition, we assessed the periodicity of Yahoo! cancer search activity and examined sharp increases in Yahoo! search activity related to specific cancer types.

Methods

This analysis included three types of 2001–2003 US data: Yahoo! cancer search activity, cancer burden (estimated incidence and mortality), and cancer news coverage. The study protocol was reviewed by the Institutional Review Board of the National Center for Chronic Disease Prevention and Health Promotion and was designated as "research not involving human subjects."

Yahoo! Cancer Search Activity

During 2001 (the beginning of the study period), Yahoo! was the most popular US search engine, with a 49% market share; however, in 2003 (the end of the study period), Google surpassed Yahoo! as the leading US search engine [22]. Yahoo! remains a widely used search engine; more than 45 million US Internet users conducted Yahoo! searches in February 2004 [14].

Yahoo! maintains a database of search activity called the Yahoo! Buzz Index [23]. This index provides a search activity score for individual search terms—the words or characters that users type into the Yahoo! search box. Each point of a Yahoo! Buzz Index score equals 0.001% of users searching Yahoo! during the time period of interest (day, week, or month). For example, if 250 out of a total of 1 million users searched for "breast cancer" on January 1, 2001, the Yahoo! "breast cancer" search activity score on this day would be 25 (250/1 million × 100000). For a search term to register a search activity score, it must generate at least 50 searches during the time period for which the score is calculated. Yahoo! search activity generated by search terms can be segmented by country, US state, or selected US cities. This study used daily US Yahoo! search activity data from January 1, 2001 (the earliest date for which Yahoo! search activity data are available) to December 31, 2003. We limited our analysis to Yahoo! searches because at the time of this study no other Internet search engine offered a dataset like the Yahoo! Buzz Index, which provides search activity scores adjusted for the size of the population searching for online information.

Yahoo! employs professional "surfers" or content indexers who manually classify Web pages into one of more than 2000 content categories, such as "movies," "footwear," "astrology," or "cancer or neoplasms." The Yahoo! Buzz Index classifies search terms in the same content category as the first Web page link that a user "clicks" or activates after conducting a search. For instance, if a user entered the search term "colon" and then clicked on a cancer website, "colon" would be classified as a "cancer or neoplasms" search term. If the user clicked on a grammar website, however, "colon" in that instance would be classified as an "education" search term. When a user does not click on a Web page link or when a user clicks on a Web page link that has not been classified, the Yahoo! Buzz Index categorizes the search term using a variety of algorithms that analyze recent content viewed by the user.

To identify commonly used Internet search terms related to specific cancers, we reviewed the search terms classified in the "cancer or neoplasms" category of the Yahoo! Buzz Index, which generated at least 50 searches in any month from January 2001 to December 2003. This search strategy identified 76 unique search terms, of which 23 were included in the analysis (Table 1). The remaining 53 terms were discarded because they did not relate to a specific cancer or included non-English words. Discarded terms included drug names or treatment modalities, such as "chemotherapy" (n = 19); the names of organizations or events, such as "Race for the Cure" (n = 16); general cancer or anatomy terms, such as "oncology" (n = 11); names of celebrities, such as "Gilda Radner" (n = 5); and the carcinogen "DES" (n = 1). Also, "leucemia" (n = 1), the Spanish word for "leukemia," was discarded because the Yahoo! Buzz Index does not consistently track foreign words, as it excludes search terms that contain non-English characters. For instance, the Yahoo! Buzz Index would not capture a search term with an accent mark, such as "cáncer colorectal" (Spanish for "colorectal cancer").

Cancer Burden

The estimated incidence and mortality for 23 cancers during the study period were obtained from annual burden reports published by the American Cancer Society [24-26]. All cancers with at least 7500 new cases in 2001, 2002, or 2003 were included in the analysis (n = 23) whether or not they were associated with Yahoo! search activity.

Cancer News Coverage

News reports associated with specific cancer types were identified using the LexisNexis “US News” database, which includes more than 400 national and regional newspapers, such as the *Wall Street Journal* and the *Baltimore Sun*, and a variety of newswire services, such as the Associated Press and UPI (United Press International). News reports published from January 1, 2001, to December 31, 2003, related to specific cancer types were found by locating reports with the identified Yahoo! search activity terms (eg, “breast cancer”) in their headlines. In the case of cancers located in the esophagus and oral cavity, for which no Yahoo! search activity terms were associated, the terms “esophageal cancer” and “oral cancer” were used as the headline search terms.

Analysis

Descriptive statistics were calculated for the Yahoo! search activity score, estimated incidence, estimated morality, and news coverage volume associated with the cancers included in the study. Spearman rank correlations were used to establish the consistency of these variables across the study period, and the data were aggregated. Next, the relationships between Yahoo! search activity and the potential correlates of interest were tested using Spearman rank correlations.

The relationship between Yahoo! search activity and news coverage was further analyzed for the five cancers with the highest daily Yahoo! search activity. The number of news reports published each day was transformed into a categorical variable with four levels (0 news reports, 1–2 news reports, 3–4 news reports, and 5 or more news reports), and one-way analysis of variance (ANOVA) was used to compare mean daily Yahoo! search activity scores at increasing levels of news coverage. To detect possible periodicity effects, Yahoo! search activity data were visually inspected. Three possible periodicity effects were noted: a rise during weekdays (Monday–Friday) compared with weekends; a rise during national cancer awareness months compared with other months; and a decline during summer months (June–August) compared with other months. These possible effects were tested using *t* tests. Finally, the Yahoo! search activity associated with several cancers was marked by sharp increases of 100% or more from one day to the next. For these cancers, we identified the three highest peaks in 2003 Yahoo! search activity and investigated corresponding news events.

Results

We found Internet search terms generating Yahoo! search activity associated with 21 of the 23 cancers included in the study (Table 1). Of these, 19 cancers were associated with only one Yahoo! search term each. The 2 remaining cancers were associated with two search terms each: cancers of the brain (“brain tumor” and “brain cancer”) and multiple myeloma (“multiple myeloma” and “myeloma”). In these cases, the daily Yahoo! search activity scores associated with each term were summed into a composite score for these cancers.

The highest mean daily Yahoo! search activity scores were generated by breast cancer (mean = 14.37), lung cancer (mean = 9.08), and leukemia (mean = 7.15). Cancers with the highest US 2001–2003 incidences were breast (n = 611300), prostate (n = 608000), and lung (n = 510800). For cancer mortality, lung (n = 469500), colorectal (n = 170400), and breast (n = 120800) cancer were the leading causes of death. Breast cancer (n = 5840), leukemia (n = 2143), and prostate cancer (n = 1822) were associated with the most US news reports from 2001 to 2003. Some cancers, such as leukemia, ovarian, and testicular, appeared to be associated with more Internet search activity than their burden would dictate.

Cancers were ranked by mean daily Yahoo! search activity score, estimated incidence, estimated mortality, and number of related news reports for each year in the study period (2001 to 2003). To explore the consistency of ranks over the study period within each variable, Spearman rank correlations were determined for each pair of years (2001 and 2002, 2002 and 2003, 2001 and 2003). We found statistically significant correlations ($P < .001$) between all year pairs tested (data not shown). Because the ranks associated with these variables were highly consistent from 2001 to 2003, we aggregated the data across the study period.

Table 1. Mean daily Yahoo! search activity score (United States, 2001–2003), estimated incidence, estimated mortality, and number of news reports, by cancer

Cancer	Yahoo! Search Terms	Mean Daily Yahoo! Search Activity Score* (Rank)	Estimated Incidence (Rank)	Estimated Mortality (Rank)	Number of News Reports (Rank)
Breast	“breast cancer”	14.37 (1)	611300 (1)	120800 (3)	5840 (1)
Lung	“lung cancer”	9.08 (2)	510800 (3)	469500 (1)	918 (5)
Leukemia	“leukemia”	7.15 (3)	92900 (10)	65100 (7)	2143 (2)
Colorectal	“colon cancer”	7.08 (4)	43120 (4)	170400 (2)	617 (6)
Prostate	“prostate cancer”	6.13 (5)	608000 (2)	90600 (4)	1822 (3)
Ovary	“ovarian cancer”	3.71 (6)	72100 (13)	42100 (9)	458 (8)
Lymphoma	“lymphoma”	3.54 (7)	185500 (5)	78100 (6)	480 (7)
Uterine, cervix	“cervical cancer”	2.53 (8)	38100 (20)	12600 (19)	392 (9)
Melanoma	“melanoma”	2.25 (9)	159200 (7)	22800 (16)	376 (10)
Brain	“brain tumor” “brain cancer”	1.52 (10)	52500 (16)	39300 (10)	925 (4)
Liver	“liver cancer”	0.70 (11)	50100 (17)	42600 (8)	110 (14)
Testis	“testicular cancer”	0.62 (12)	22300 (23)	1200 (23)	50 (17)
Pancreas	“pancreatic cancer”	0.23 (13)	90200 (11)	88600 (5)	185 (11)
Multiple myeloma	“multiple myeloma” “myeloma”	0.11 (14)	43600 (18)	32900 (15)	185 (11)
Stomach	“stomach cancer”	0.08 (15)	65700 (14)	37300 (13)	50 (17)
Uterine, corpus	“uterine cancer”	0.012 (16)	117700 (8)	20000 (18)	17 (22)
Larynx	“throat cancer”	0.012 (16)	28400 (21)	11500 (21)	30 (20)
Bladder	“bladder cancer”	0.010 (18)	168200 (6)	37500 (12)	118 (13)
Soft tissue	“sarcoma”	0.009 (19)	25300 (22)	12200 (20)	25 (21)
Thyroid	“thyroid cancer”	0.002 (20)	62200 (15)	4000 (22)	40 (19)
Kidney	“kidney cancer”	0.001 (21)	94500 (9)	35600 (14)	77 (15)
Oral cavity	-	0.000 (22)	86700 (12)	22400 (17)	69 (16)
Esophagus	-	0.000 (22)	40200 (19)	38100 (11)	13 (23)

* Each point of a Yahoo! search activity score equals 0.001% of the population searching Yahoo! on any day.

Correlates of Yahoo! Cancer Search Activity

We tested the relationships between variables by determining Spearman rank correlations between each pair. Statistically significant correlations were found between all variable pairs (Table 2).

Table 2. Spearman rank correlations between mean daily Yahoo! search activity score (United States, 2001–2003), estimated incidence, estimated mortality, and number of news reports

	Spearman Rank Correlation[*]		
	Mean Daily Yahoo! Search Activity Score	**Estimated Incidence**	**Estimated Mortality**
Number of news reports	.88[†]	.62[‡]	.74[†]
Estimated mortality	.66[†]	.71[†]	-
Estimated incidence	.50[§]	-	-

[*] Spearman rank correlations were done on the rankings reported in Table 1.

[†] $P \le .001$

[‡] $P = .002$

[§] $P = .015$

The relationship between Yahoo! search activity and its most statistically significant correlate—news coverage—was further analyzed for the five cancers with the highest daily Yahoo! search activity (breast, lung, leukemia, colorectal, and prostate). For these cancers, the number of news reports published each day was transformed into a categorical variable with four levels. The mean daily Yahoo! search activity at each level was compared using ANOVA, and all tests were statistically significant ($P \le .001$). For all five cancers, the mean daily search activity score was higher at each increasing level of news coverage (Table 3).

Table 3. Mean daily Yahoo! search activity score (United States, 2001–2003), by number of news reports published daily and cancer

Cancer	**Mean Daily Yahoo! Search Activity Score**[*][†] **(Number of News Reports)**			
	Days With 0 News Reports	**Days With 1–2 News Reports**	**Days With 3–4 News Reports**	**Days With 5+ News Reports**
Breast	10.09 (81)	11.49 (278)	13.36 (252)	17.27 (484)
Lung	8.27 (633)	10.00 (362)	10.54 (71)	11.71 (29)
Leukemia	6.89 (248)	7.07 (523)	7.18 (232)	8.26 (92)
Colorectal	6.72 (739)	7.44 (297)	8.25 (43)	13.92 (16)
Prostate	5.30 (390)	6.40 (467)	6.72 (150)	7.43 (88)

[*] Each point of a Yahoo! search activity score equals 0.001% of the population searching Yahoo! on any day.

[†] ANOVA was used to compare the mean daily Yahoo! search activity at each level of news coverage. For all five cancer sites, a statistically significant difference ($P \le .001$) was found.

Periodicity of Yahoo! Cancer Search Activity and News Coverage

Three possible periodicity effects were tested: a rise during weekdays (Monday–Friday) compared with weekends; a rise during national cancer awareness months compared with other months; and a decline during summer months (June–August) compared with other months. To test for these potential effects, we used the five cancers with the highest daily mean Yahoo! search activity scores (breast, lung, leukemia, colorectal, and prostate) (Table 4). For all five cancers tested, both mean daily Yahoo! search activity scores and mean daily news reports were higher Monday–Friday than they were Saturday–Sunday ($P < .001$). Higher mean daily Yahoo! search activity scores were found for breast cancer ($P < .001$), lung cancer ($P < .001$), and colorectal cancer ($P < .001$) during their respective national awareness months. The number of mean daily news reports related to breast cancer ($P < .001$), colorectal cancer ($P < .001$), and prostate cancer ($P = .007$) rose during their respective national awareness months. Mean daily Yahoo! search activity scores for breast cancer ($P < .001$), lung cancer ($P < .001$), and leukemia ($P < .001$) were lower during the summer months than during the rest of the year. While mean daily news reports about breast cancer also decreased during the summer ($P < .001$), mean daily news reports about prostate cancer rose ($P = .01$).

Table 4. Periodicity of mean daily Yahoo! search activity score (United States 2001–2003) and mean daily number of news reports, by cancer

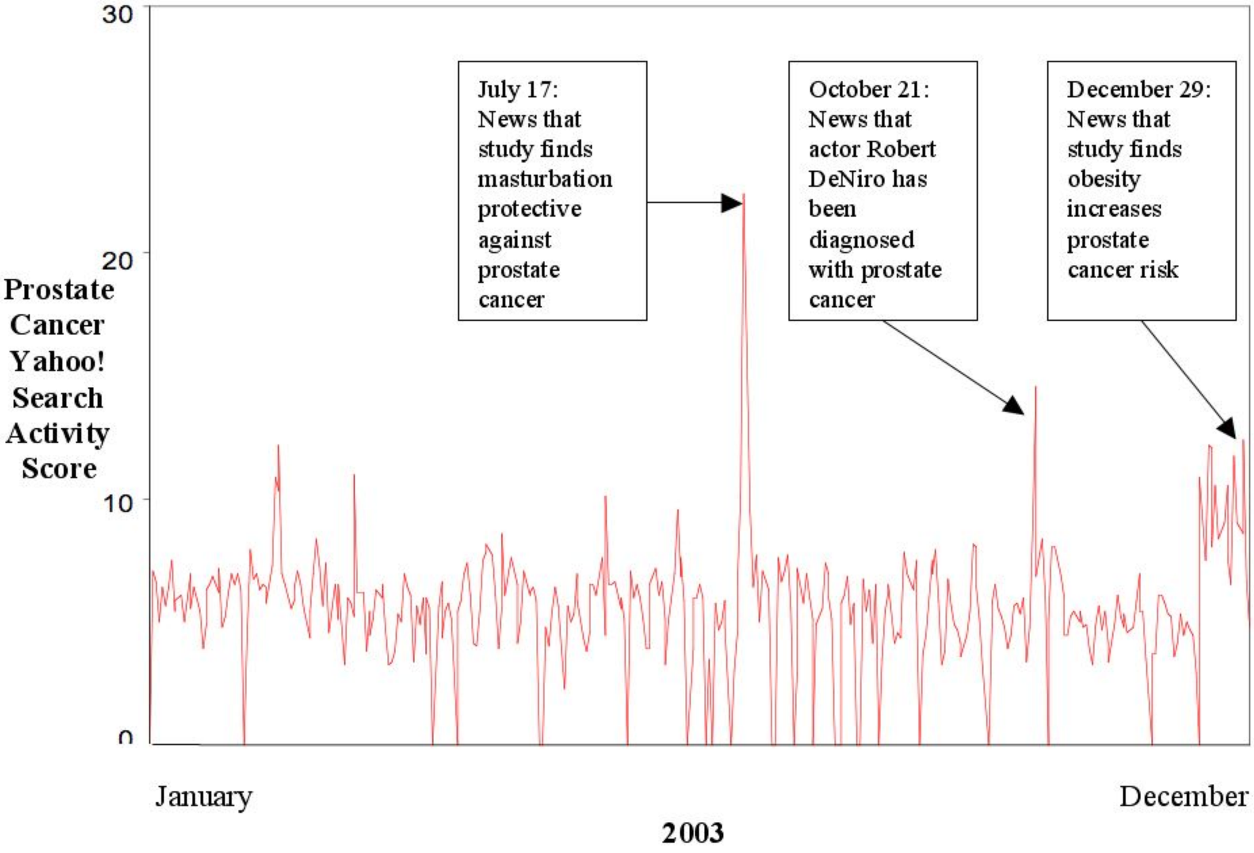
Cancer		Weekdays	Weekends	*P* value	Awareness Month	Non-Awareness Months	*P* value	Summer: June-August	Non-Summer	*P* value
Breast	Mean Daily Yahoo! Search Activity Score[*]	15.78	10.84	< .001	26.33	13.26	< .001	10.78	15.58	< .001
	Mean Daily Number of News Reports	6.26	3.02	< .001	15.30	4.41	< .001	4.19	5.72	< .001
Lung	Mean Daily Yahoo! Search Activity Score	10.31	6.00	< .001	11.69	8.84	< .001	5.76	10.20	<.001
	Mean Daily Number of News Reports	1.03	0.37	< .001	1.03	0.82	.226	0.70	0.89	.086
Leukemia	Mean Daily Yahoo! Search Activity Score	8.13	4.70	< .001	6.65	7.20	.093	5.65	7.66	< .001
	Mean Daily Number of News Reports	2.20	1.34	< .001	1.51	2.00	.036	1.88	1.98	.506
Colorectal	Mean Daily Yahoo! Search Activity Score	7.73	5.44	< .001	10.46	6.77	< .001	6.83	7.17	.081
	Mean Daily Number of News Reports	0.68	0.27	< .001	1.55	0.47	< .001	0.49	0.59	.214
Prostate	Mean Daily Yahoo! Search Activity Score	6.82	4.41	< .001	5.68	6.18	.044	6.14	6.13	.997
	Mean Daily Number of News Reports	2.03	0.74	< .001	2.39	1.60	.007	2.14	1.50	.010

[*] Each point of a Yahoo! search activity score equals 0.001% of the population searching Yahoo! on any day.

Peaks in Yahoo! Cancer Search Activity and News Coverage

On several occasions, Yahoo! search activity scores associated with breast cancer, colon cancer, and prostate cancer were marked by sharp increases of 100% or more from one day to the next. We investigated news events that corresponded with the highest three spikes in 2003 Yahoo! search activity for these cancers. These peaks in “breast cancer” and “colon cancer” search activity all occurred during their respective national awareness months and appeared to be related to news coverage promoting the awareness months. The highest peak in “prostate cancer” search activity (22.34) occurred on July 17 after news reports of a study [27] exploring the association between sexual behavior and prostate cancer risk (Figure 1). These news reports generally focused on the possible protective benefit of masturbation. This study was not covered widely by the US news media, but it generated substantial news coverage in Australia and filtered onto the Internet via chat rooms, message boards, and medical news Web pages. While there was no corresponding spike in “masturbation” search activity, there was a 117% increase in the search activity score (from 61.88 on July 16 to 133.08 on July 17) for “masterbation,” a common misspelling. The second highest spike in “prostate cancer” search activity (14.59) occurred on October 21 after news broke that Academy-Award-winning actor Robert DeNiro had been diagnosed with prostate cancer. This story was widely covered by the US news media, and a 277% increase in “Robert DeNiro” search activity was observed on the same date (from 15.87 on October 20 to 59.90 on October 21). The third highest peak in “prostate cancer” search activity (12.41) occurred on December 29, when a study linking obesity with increased prostate cancer risk [28] was covered by several US news outlets. No corresponding rise in searches for the terms “obesity,” “overweight,” or “weight loss” was observed.

Figure 1. 2003 US prostate cancer Yahoo! search activity (each point of a Yahoo! search activity score equals 0.001% of the population searching Yahoo! on any day)



Discussion

This study suggests that media coverage plays a powerful role in prompting online cancer information seeking. News coverage correlated significantly with Yahoo! search activity ($P < .001$). Also, Yahoo! search activity was found to rise as news coverage increased, and sharp rises in search activity from one day to the next appeared to be associated with increases in relevant news coverage. This study also suggests that the Internet can rapidly disseminate health news: the highest spike in 2003 US “prostate cancer” Yahoo! search activity seemed to be generated largely by news coverage in Australia that rapidly filtered onto the Internet via chat rooms, message boards, and medical news Web pages. Thus, it possible that a news story does not necessarily have to be covered by the US news media in order to generate US Internet search activity.

News coverage volume also correlated with estimated cancer incidence ($P = .015$) and mortality ($P < .001$). This is interesting because past studies [29-33] on this topic have not generated consistent findings, with most [30-32] finding no relationship between disease burden and news coverage volume. However, none of the past studies focused on cancer, and none used our method for identifying news reports. While the news coverage of specific cancers generally matched their burden, we noted that some cancers, such as leukemia, ovarian cancer, and testicular cancer, were associated with more Internet search activity than their burden would suggest. A similar observation was reported by Bader and Theofanos [21], who suggested that this discrepancy may result from more searches being required to locate online information about less common cancers. The high correlation between cancer-specific news coverage and associated online search activity in the present study suggests another explanation: some cancers received a disproportionate share of news coverage relative to their incidence and mortality, and online search activity, often prompted by news coverage, reflects this imbalance.

We detected several periodicity effects in US Yahoo! cancer search activity, which tended to be higher on weekdays and during national cancer awareness months but lower during the summer months. It should be noted that these observations are not artifacts of the size of the online population during these periods because Yahoo! search activity scores are based on the percentage, not the number, of total users. One explanation for these results is that the volume of cancer news coverage tended to follow these trends. It is also possible that users tend to search for online cancer information from school or work settings. As a result, Yahoo! cancer search activity would be expected to drop during weekends when people are at home and over the summer months when many students are out of school and many workers go on vacation.

Although Yahoo! is a leading US Internet search engine, the extent to which the findings of this study can be generalized to other search engines is not known. Also, we were unable to discern the motivations of Yahoo! users searching for cancer information. For instance, news coverage of a breast cancer drug might be associated with an increase in “breast cancer” search activity. While the Yahoo! Buzz Index would detect this rise, it cannot tell how many searchers were breast cancer patients or family members and how many were investors interested in buying stock in the company developing the drug.

Internet search activity offers an innovative tool for passive surveillance of health information–seeking behavior. While our work focused on cancer, Internet search activity may be useful in gauging health information seeking related to other diseases. For example, the volume of Internet searches related to symptoms or conditions might be used to predict disease outbreaks (eg, influenza) or to assess mental health following a disaster. Researchers at the Centre for Global eHealth Innovation have begun to experiment with analyses of this type [34,35]. The Yahoo! Buzz Index is unique among Internet search datasets because it provides search activity scores adjusted for the size of the population searching for online information, which has steadily grown each year [19]. Perhaps in the future, other Internet search engines will offer databases similar to the Yahoo! Buzz Index, and research could be conducted using a combination of search engines.

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Conflicts of Interest

One of the authors, KP Mallon, was employed by Yahoo! Inc at the time of this study and owns Yahoo! corporate stock.

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Original Paper

Cancer Patients' Self-Reported Attitudes About the Internet

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Abstract

Background: Increasing numbers of cancer patients are using the Internet, but little is known about their attitudes toward online health care.

Objective: The purpose of this substudy was to analyze cancer patients' attitudes toward online health care.

Methods: This was a substudy of 41 persons with cancer who used the Internet for health care information and support and who completed the Attitudes Toward Online Health Care (ATOHC) survey.

Results: The majority of study participants were married, held graduate degrees, and had high incomes. Using a five-point Likert scale, means for the five dimensions of the ATOHC survey were as follows: community and news 3.22 (SD = 1.01), outcomes 3.20 (SD = 1.08), trusted information and advice 2.73 (SD = 0.66), self-efficacy in evaluating information and intention 3.46 (SD = 0.65), and disclosure 3.15 (SD = 1.06). The average response fell between “About half the time” and “Usually.” Favorite websites for content were Medscape and WebMD, while favorite sites for support were WebMD and Mediconsult.

Conclusions: Respondents were generally eager to obtain and offer cancer information and support online, but they were skeptical of unknown sources. They were comfortable both giving and receiving information and support. Respondents were interested in the experiences of other patients and benefited by their direct and indirect interactions with them. Respondents felt that they coped better with their illness and experienced less uncertainty and anxiety as a result of their online experiences. They reported a certain level of trust, primarily for established reputable sources of information, and they were confident in their ability to evaluate the information, including research reports. In addition, cancer patients displayed a healthy skepticism when presented with the option of divulging their personal health information; however, they were willing to provide personal details if, as a result, a website provided them with individualized information.

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KEYWORDS

Breast neoplasms; Internet; information dissemination; computer communication networks; trust; disclosure; social support; Health Insurance Portability and Accountability Act

Introduction

The Internet is rapidly becoming an indispensable resource for persons with cancer. Over 50% of adults in the United States have searched online for health information, and 80% of all US Internet users have searched online for at least one major health topic. This makes searching for health information the third most common online activity after email and researching a product or service [1]. In the United States, there will be an estimated 1.3 million cases of cancer diagnosed in 2005; over 800000 persons will survive [2]. Considering the growing number of cancer survivors, which has increased from 3 million in 1971 (1.5% of the US population) to 9.8 million (3.5% of the US population) in 2001 [3], it is obvious that the need for information and support in cancer care is continually growing. Many persons newly diagnosed with cancer, as well as survivors, are turning to the Internet for assistance with their physical symptoms and psychological distress [4]. There is also a need for information and support for friends and family members, particularly caregivers [5].

Although the number of persons who seek cancer health care information online is difficult to measure [6], it has been reported as high as 41.5% of study participants [7]. Cancer patients who use the Internet are generally younger and have completed more education [8-10]. The type of cancer among Internet users varies. In one survey, 15% of respondents had digestive/gastrointestinal/bowel cancer, 11.7% had breast cancer, 11.3% had skin cancer, and 10.5% had genitourinary cancer [11]. Information and support needs change over time. In women with breast cancer, 49% reported using the Internet for information and support up to eight months after diagnosis, and 40% used it for up to 16 months [12]. Persons with cancer who seek online information and support add an average of 10 minutes to each clinical encounter with their oncologist. They may be more emotionally distressed as the information they uncover may cause them confusion and anxiety in addition to increasing their knowledge and sense of hope [13].

The Online Social Support Theory [14] and the Expanded Model of Health Care Consumer-Provider Interaction [15] suggest a relationship between online patient support groups and health outcomes. A specific framework for cancer patients has also been proposed [5]. Models such as these address the influential factors involved in seeking online health care, but they also address the complexity of factors that influence patients' attitudes about seeking online information and support in addition to traditional means. Unique factors to seeking health information online play an important role in a patient's level of involvement in online health venues. These factors include participation in a community with similar patients, the ability to rapidly obtain news and research findings, confidence in the ability to use the Internet, and the desire to gain some control of the illness through knowledge and support. This involvement with online health care is tempered by the decisions patients must make regarding their level of trust in this alternative system and their level of disclosure in order to obtain individualized information.

Dimensions of Online Health Care

The concept of online health care encompasses a number of factors. Five particular factors that have been represented in the literature are community and news, outcomes, trusted information and advice, self-efficacy in evaluating information and intention, and disclosure.

Community and News

The Internet, as a collective entity of health professionals, peers, and other concerned international citizens, has responded to cancer patients' needs with a profusion of online community and news mechanisms for support and information. For psychosocial connection with others in a similar situation, cancer patients may choose from a variety of formats and venues: they can join email newsgroups and web-based discussion boards, or they can chat in real time. They can find general support groups or ones that are specific to their type or stage of cancer. Groups may be run by fellow patients, or, less frequently, by licensed health care providers. In addition to online community support, Internet news formats for cancer patients are steadily evolving and taking various forms, such as electronic newsletters and dedicated information sites, or a combination of community and news. For breast cancer alone, it is estimated that 2.4 million Web pages of information are available [16]. What features are rated most highly in a cancer website? In a survey of most preferred Web pages for prostate cancer patients, 59% cited websites that involved understanding diagnosis and treatment, 49% cited online help lines, and 44% preferred news sections [17]. In a survey of breast cancer sites rated by popularity in the search engine Google, 48% of the most popular sites offered opportunities for psychosocial support, 27% provided information on ongoing clinical trials, and 12% presented results of clinical trials [18]. Within Internet-based message boards, a frequent theme is concern regarding treatment, support, and side effects over time [19].

Outcomes

The ultimate test of the effectiveness of online health sites for cancer patients, particularly the effect of online support interventions, is their influence on health outcomes. Analysis of outcomes has been hampered by study designs that fail to distinguish between different types of support, for instance, support provided by peers, support provided with or without the presence of health care providers [20]. In a review of research literature related to online cancer support groups, Klemm et al [21] concluded that, in 9 out of 10 studies, persons with cancer coped better with their disease as a result of online participation. In general, persons with cancer enter online support groups significantly more depressed than their counterparts in face-to-face support groups [22]. In breast cancer patients, online support groups have been found to reduce depression and cancer-related trauma [23,24], loneliness [25], and reaction to pain [23]. They have also been associated with an increase in post-traumatic personal growth [23] and interpersonal social support [25].

Trusted Information and Advice

A very salient aspect of life for cancer patients is trust. Because of existential concerns and their need for hope, cancer patients are a vulnerable population [26,27]. Alternative treatments are often explored and may be considered an option to alleviate distressing physical and psychological symptoms [28]. This may precipitate a search for online information and support [26]. In one study, 63% of breast cancer patients researched alternative treatments, yet 53% were undecided about the trustworthiness of the information [10]. Trust of online sources among cancer patients may be influenced by age, time since diagnosis, ability to cope with having cancer, and the perceived credibility of the source [26]. In one study of breast cancer websites, only 31.6% offered information on the credentials of the site's operator [29].

Self-Efficacy in Evaluating Information and Intention

The knowledge gained from accessing online information and support and from participating in community and news venues of health websites can enhance one's self-efficacy and sense of empowerment. Through online health settings, cancer patients can develop a “social fitness” [30] as well as “cyber-agency” [31] concerning their disease that enables them to communicate more knowledgeably with health care providers. According to one study, 80% of cancer patients are interested in information related to treatment, 70% in conversations with physicians via the Internet, and 65% in online support groups [32]. Enhanced self-efficacy and a greater sense of control have the potential to increase patients' participation in their care, which may impact health outcomes.

Disclosure

In order to receive optimal benefit from online health venues, cancer patients may be asked to disclose personal health information, such as the stage of their cancer or the presence of metastasis. Because of the Healthcare Information Portability and Accountability Act (HIPAA) in the United States [33], disclosure of personally identifiable health information is tightly regulated in regard to research situations and existing health care organizations and agencies. Although websites that provide health care information may not be subject to this act in the strict sense of the law, it can be inferred that the passing of this legislation has raised consumer awareness. Even if organizations are not governed by law, ethical issues may still arise. Online users may encounter situations in which they will be unable to obtain the information they are seeking unless they disclose personal information about their health. This is particularly true in sites that present individualized information.

Methods

ATOHC Instrument

The Attitudes Toward Online Health Care (ATOHC) survey was developed to measure the attitudes of people who engage in online health care activities. The instrument was originally comprised of 51 items on a 5-point Likert scale. Possible responses included the following: 1 (Never), 2 (Seldom), 3 (About half the time), 4 (Usually), and 5 (Always) [34,35].

An exploratory factor analysis of 265 respondents who used online health care services was conducted using methodology outlined by Gable and Wolf [36]. According to RK Gable (March 2000), although 6 to 10 respondents are recommended per item, convergence occurred at 5.3. Five dimensions emerged: (1) community and news—supportive exchanges from other patients with similar conditions, and receipt of relevant information from other patients as well as health care professionals; (2) outcomes—psychological and physical changes in the individual as a result of having participated in online health care; (3) trusted information and advice—confidence in information provided by health authority figures and organizations; (4) self-efficacy in evaluating information and intention—individuals' belief in their ability to evaluate the quality of the information they receive, the qualifications of those providing it, and the intent of the requestor; and (5) disclosure—willingness to provide personally identifiable information. Alpha internal consistency reliability scores for the five dimensions were .95, .93, .84, .62, and .77, respectively [34]. Based on the results of poorly performing items in the factor analysis, the instrument was shortened to 42 items reflecting the five factors, for a final of 6.3 respondents per item. Only the 42 questions that were retained in the instrument were analyzed in this substudy; however, responses to one item of the instrument (“I trust online advice given by a Registered Pharmacist.”) were omitted due to a coding translation error from the Web page to the server. Therefore, only 41 items were analyzed, and possible scores for the ATOHC scale ranged from 41 to 205.

Study Design

This was a descriptive study using a subsample of cancer patients from the total sample of those 265 persons who participated in the Attitudes Toward Online Health Care (ATOHC) study [34,35]. Two of the surveys were submitted twice on the website, leaving 263 usable questionnaires. Surveys in which participants listed a primary or secondary diagnosis of cancer were included in this substudy. There were a total of 41 surveys that met the criteria, with 39 persons listing a primary diagnosis of cancer, and five with a secondary diagnosis. Three persons listed both a primary and secondary diagnosis of cancer. A total of 39 persons with a primary diagnosis of cancer, and two with a secondary diagnosis of cancer are profiled.

Participants were recruited by one of three methods: (1) email discussion groups, (2) Web-based discussion groups, and (3) referrals from other websites. For the email discussion groups, a general invitation to participate was sent to a various groups asking for volunteers to complete the survey. An attempt was made to approach groups dealing with diverse medical conditions, such as heart disease, cancer, lupus, and those with general disability issues. In addition, messages were sent to a number of health professional discussion lists, including those for nurses, physicians, and physician assistants, asking those who personally utilized online health care services to volunteer. A similar procedure was followed for the Web-based discussion groups, with the exceptions that the message was posted on existing websites and potential respondents did not receive the notice automatically as they would with an email. For the referrals from other websites, arrangements were made with webmasters at two Internet health sites, Healthanswers.com and Askphysicians.com, to refer participants via links on these sites.

Data were collected from March 14, 2000 through March 28, 2000. Participants completed a demographic form and the ATOHC survey in a Web-based format. An additional free-text area asked the question, “What changes has receiving online health care information and support caused in your life?” Data were analyzed with the Statistical Package for the Social Sciences (SPSS), Version 11.0.0 [37]. Demographic characteristics, diagnoses, and favorite websites for content and support were analyzed by frequency tabulation. Means, standard deviations, and total scores overall and for each dimension were calculated from responses on the ATOHC scale for individual items.

Results

Demographic Characteristics

The mean age of respondents was 57.68 years (SD = 10.15; range 37–79). Slightly more than half, 53.7%, were male (n = 22), 78.9% were married (n = 32), and 90.2% were living in the United States (n = 37). Table 1 provides a summary of the demographic characteristics of the respondents.

Table 1. Demographic characteristics of respondents (N = 41)

	n	%
Sex		
Female	19	46.3
Male	22	53.7
Marital Status		
Married	33	80.5
Divorced	3	7.3
Single	3	7.3
Unspecified	2	2.9
Education		
High school diploma	5	12.2
Some college/associate's degree	11	26.9
Bachelor's degree	6	14.6
Graduate degree	18	43.9
Unspecified	1	2.4
Annual Income		
$5000–14999	3	7.3
$15000–34999	7	17.0
$35000–49999	7	17.1
$50000–74999	10	24.4
≥ $75000	7	17.1
Unspecified	7	17.1
Work Status		
Working full time	15	36.6
Not working: retired	13	31.7
Working part time (39 hours or less per week)	7	17.1
Not working: disabled or other reason	6	14.6
Country		
United States	37	90.2
Other	4	9.8

Diagnoses

Participants were asked to select their primary and secondary diagnoses from a list by checking the relevant boxes on the online form. A separate area was provided to enter their diagnosis if it was not included in the list. For primary diagnoses, the majority of respondents elaborated on their type of cancer, whereas for secondary diagnoses, more non-cancer conditions were listed (Table 2).

Table 2. Respondents' listing of diagnoses and comorbid conditions (N = 41)

	n	%
Primary Diagnosis		
Cancer[*]	39	95.1
Cardiac	1	2.4
Fibromyalgia/chronic fatigue	1	2.4
Secondary Diagnoses		
Cancer[†]	5	12.2
Depression	3	7.3
Diabetes	2	4.9
Epstein-Barr	1	2.4
Huntington's Disease	1	2.4
Post-Traumatic Stress Disorder	1	2.4
Rhabdomyosarcoma	1	2.4
Seizure Disorder	1	2.4
Unspecified	26	63.4

[*] Of the 39 persons listing cancer as a primary diagnosis, 11 specified the site (7 prostate, 2 breast, 1 colon, 1 chronic lymphocytic leukemia).

[†] Of the 5 persons listing cancer as a secondary diagnosis, 2 specified the site (1 prostate, 1 kidney). Three respondents listed cancer as both a primary and secondary diagnosis. For the other two persons, the corresponding primary diagnoses were 1 Grave's disease, 1 unspecified.

ATOHC Scale

In this sample, scores ranged from 50 to 172, with a mean of 128.46 (SD = 25.98). Thirty-six items had a scale range of 1–4, and 5 items had a range of 1–5. Pearson *r* correlations were performed between the continuous demographic variable, age, and total scores and factor scores. None were significant. The data are summarized in Table 3.

Table 3. ATOHC scores by dimension

Dimension	Mean Score[*]	SD	Actual Range	Potential Range
Community and news	41.84	13.19	13–64	13–65
Outcomes	28.80	9.72	9–42	9–45
Trusted information and advice	27.27	6.58	10–37	10–50
Self-efficacy in evaluating information and intention	24.24	4.54	7–31	7–35
Disclosure	6.29	2.12	2–10	2–10

[*] Higher scores indicate a greater degree of positive agreement.

The three highest ranked items were “I want to know how my online health information will be used before providing information” (mean = 3.93; SD = 1.29); “I am comfortable in evaluating the quality of online medical research reports” (mean = 3.83; SD = 0.89); and “I like to give online support to other patients who have my condition” (mean = 3.56; SD = 1.32). The item ranked lowest was “I tend to trust the products that other patients sell online” (mean = 1.63; SD = 0.77), followed by “I trust online summaries of health research articles even when I am not told who wrote them” (mean = 2.37; SD = 1.07). For the third lowest mean ranking, two items had a mean of 2.44: “I trust online healthcare advertising that has been sponsored by pharmaceutical companies” (SD = 0.95), and “I tend to trust a site more that has a seal of approval, even if I don't know the organization that is awarding it” (SD = 1.05). Outcomes related to depression fell between the highest and lowest scores. Table 4 presents the highly ranked items for each dimension, as well as the strength of the factor loadings of each item from the parent study.

Table 4. Highest mean scores on each dimension of the ATOHC survey (N = 41)

Item No.	Item	Loading	Mean	SD
Factor I: Community and News (13 items)			3.22	1.01
42	I like to give online support to other patients who have my condition.	.78	3.56	1.32
10	I like to participate in e-mail based discussion about my condition.	.75	3.54	1.25
14	I like to read online biographies of other patients that have had my condition.	.53	3.49	1.10
Factor II: Outcomes (9 items)			3.20	1.08
20	As a result of visiting health-related web sites, I have less uncertainty about my condition.	.69	3.51	1.21
40	As a result of visiting health-related web sites, I am better able to cope with my condition.	.80	3.46	1.16
12	As a result of visiting health-related web sites, I am less anxious about my condition.	.75	3.37	1.26
Factor III: Trusted Information and Advice (10 items)			2.73	0.66
49	I trust online reports of medical studies that have already been published in a journal.	.44	3.44	0.87
13	I trust online advice given by a Medical Doctor (MD).	.33	3.44	0.87
35	I trust a site that has been endorsed by a health authority.	.54	3.12	1.08
Factor IV: Self-Efficacy in Evaluating Information and Intention (7 items)			3.46	0.65
43	I want to know how my online health information will be used before providing information.	.36	3.93	1.29
11	I am comfortable in evaluating the quality of online medical research reports.	.48	3.83	0.89
41	I feel that online health information is at a comfortable comprehension level.	.36	3.61	0.89
Factor V: Disclosure (2 items)			3.15	1.06
3	I will disclose my email address to an online healthcare website.	.58	3.51	1.05
19	I will give my name to an online healthcare website if I will receive personalized information.	.44	2.78	1.31
Entire scale			3.13	0.63

Favorite Websites for Content and Support

Participants were asked to select their favorite websites for content, as well as for support, from a drop-down menu offering a listing of popular sites. One of the options was “other,” in which case they could enter the name of a site using a text box. Medscape and WebMD were the most frequently mentioned favorite sites for content (31.7% each), while WebMD was the favorite site for support (17.1%). Favorite websites for content were primarily those sponsored by large organizations and by government agencies, such as the American Cancer Society and National Cancer Institute. Other favorite sites for support included a number of smaller, more specific sites such as Avon Crusade message boards and psa-rising.com. Favorite content and support sites are listed in Table 5.

Table 5. Favorite websites for content and support[**]

Content	n	%	Support	n	%
Medscape.com	13	31.7	WebMD.com	7	17.1
WebMD.com	13	31.7	Mediconsult.com	3	7.3
Intelihealth.com	2	4.9	Medscape.com	2	4.9
Mayohealth.com	2	4.9	Onhealth.com	2	4.9
Other	22[*]	51.2	Other	24[†]	53.7
Prostate Help Mailing List (PHML)[‡]	3	7.2	PHML[‡]	3	7.3
CancerLit (cancer.gov/search/cancer_literature/)	2	4.8	“Mailing lists”	2	4.8
Cooleyville.com	2	4.8	MSN communities (groups.msn.com)	2	4.8
Prostatepointers.org	2	4.8			
Sites listed once: about.com, Association of Cancer Online Resources (acor.org), American Cancer Society (cancer.org), drkoop.com, healthcentral.com, helioshealth.com, mediconsult.com, ostomyinternational.org, National Cancer Institute (nci.nih.gov), “Oncology Journals,” oncology.com, onhealth.com, prostate-cancer.org, “web2.air-mail.net/lorac1”			Sites listed once: about.com, Association of Online Cancer Resources (acor.org), Avon Crusade Message Boards (avoncompany.com/women/avoncrusade/bbsindex.htm), cooleyville.com, “Doctors Guide to the Internet,” drkoop.com, “Heart Bypass and Transplant Support Board,” intelihealth.com, ostomyinternational.org, ivillage.com, Mass General NeuroWebForum (brain.hastypastry.net/forums/), “MS Breast Cancer Link,” onhealth.com, Patient to Physician (P2P) Mailing List[§], Prostate Problems Mailing List (PPML)[‡], prostate-cancer.org, prostatepointers.org, psa-rising.com, The Circle Mailing List[§]		

[**] Websites listed in quotes are entries as listed by respondents that were not specific enough to identify a particular site or organization.

[*] 21 persons listed “Other” favorite content sites. One respondent listed two sites; thus, there are 22 sites listed. Sites are in formats as listed by respondents.

[†] 22 persons listed “Other” favorite support sites. Two respondents listed two sites each; thus, there are 24 sites listed. Sites are in formats as listed by respondents.

[‡] The Prostate Help Mailing List (PHML) and Prostate Problems Mailing List (PPML) are sponsored by the Association of Cancer Online Resources (acor.org).

[§] The Patient to Physician (P2P) Mailing List and The Circle Mailing List are sponsored by Prostatepointers.org.

Discussion

The results of this analysis indicated that although respondents were generally married, they were otherwise from diverse backgrounds, with a tendency toward a higher level of education and income. This was consistent with previous studies. Based on the type of cancer and favorite websites, prostate cancer appeared to be the most common in this group, followed by breast cancer. Respondents utilized a variety of methods to obtain information and support about their cancer, including general medical sites such as WebMD, cancer-specific organizations such as the Association of Cancer Online Resources, patient-run cancer sites such Cooleyville.com, and specific mailing lists such as Prostate Problems Mailing List (PPML).

When responses to the ATOHC scale were analyzed, means for the five dimensions were more consistent than the means for individual items, ranging from 2.73 to 3.46 with standard deviations of 0.65 to 1.08. Mean scores for individual items demonstrated some variability, ranging from 1.63 to 3.93. However, the overall mean of 3.13 indicates that the average response was nearer to “About half the time” than “Usually” on the Likert scale. This demonstrates that respondents perceived some benefit as a result of obtaining health information and support online. This finding, in consonance with previous studies, is more reflective of the use of online health care as an adjunctive rather than a predominant modality of care. Although the use of online health care is rapidly increasing, obtaining health care information and support face-to-face remains the norm in the United States as well as internationally. Although the number of persons in the United States who have sought online health care information has just passed 51% of all adults, or 111 million people, a third of them accessed health information only on an infrequent basis, and not within the previous month [38].

There are several implications of this study for the care of cancer patients. First, patients are comfortable giving as well as receiving cancer information and support online and are comfortable evaluating it. They are interested in the experiences of other patients and derive benefit by interacting with them directly, through venues such as discussion boards and email lists, or indirectly, through activities such as reading biographies.

Second, cancer patients perceived better outcomes after using online health information and support. This was manifested as being able to cope better with their condition, as well as having less uncertainty, anxiety, and, to a lesser extent, depression. Cancer patients have a certain level of trust in online information, primarily for information obtained from established reputable sources such as studies in journals and advice given by medical doctors. They also trust websites endorsed by health authorities. They are confident in their ability to evaluate information, including comprehension of research reports. In addition, cancer patients display a healthy skepticism when presented with the option of divulging personal health information. Some patients are willing to provide email addresses, and, if they receive personalized information, they are comfortable disclosing their identity.

Although results of the ATOHC survey with cancer patients are consistent with the parent survey, the current study needs to be replicated with a larger sample, and websites need to be validated to reflect their current Internet usage in light of mergers and acquisitions since the original study. In addition, correlation with variables such as coping and avoidance, as well as involvement in treatment decision-making [39], could shed light on the clinical outcomes of cancer patients who use the Internet compared to those who do not. Although cancer patients' attitudes about online health information are similar to those of persons with other chronic diseases, a comparison with other diagnoses may reveal unique characteristics and needs of cancer patients and assist in the development of evidence-based interventions. In addition, identification of what constitutes a successful outcome for differing populations of Internet users (eg, typical higher-income, more-educated users compared to users from an underserved population) would add to the growing knowledge base of persons with cancer who use the Internet. Based on the findings of this study, the results clearly demonstrate an untapped opportunity to improve the online information and support delivered to cancer patients. There are numerous opportunities along the treatment continuum to educate patients and family members about diagnostic and therapeutic options, as well as to correct misconceptions about cancer treatment. Although there has been significant progress in the provision of cancer treatment information and support, patients' needs often continue after the completion of primary therapy as they may have persistent symptoms, develop late effects, or face psychological challenges as they transition to survivorship. A percentage of patients also experience cancer recurrence. Any or all of these situations may prompt a need for additional information and support for patients and caregivers. There are also implications for HIPAA and the burgeoning use of web-based modalities for contact with health care providers [5]. Organizations and providers that deliver Internet-based care to cancer patients must be mindful of regulations related to disclosure and of distinctions that must be addressed in an electronic environment.

Limitations

There were several limitations of this study which prevent the generalization of study results beyond the study sample population. First, the sample size is small and may not be representative of all persons with cancer who use the Internet. Second, the original ATOHC survey sample was comprised of a volunteer population of self-selected persons with chronic health issues. Third, because the cancer patients in the current study were primarily educated with higher incomes, generalization to underserved populations or to those who do not have Internet access cannot be made. Finally, since the data were collected in the year 2000, a number of the websites mentioned have consolidated, merged, or are no longer active. Thus, the study provides a snapshot of a point in time and cannot be inferred to be representative of current attitudes of cancer patients.

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Conflicts of Interest

None declared.

Multimedia Appendix

The Attitudes Toward Online Health Care (ATOHC) Scale. [DOC file, 104 KB - jmir_v7i3e22_app1.doc]

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Original Paper

Utility of Two Cancer Organization Websites for a Multiethnic, Public Hospital Oncology Population: Comparative Cross-Sectional Survey

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Abstract

Background: While information websites have been developed by major cancer organizations, their appropriateness for patients in multiethnic, multilingual public hospital settings has received limited attention.

Objective: The objective of the study was to determine the utility of cancer information websites for a public hospital patient population.

Methods: A 70-item questionnaire was developed to evaluate cancer information seeking behavior, Internet access and use, and content appropriateness of two cancer information websites: People Living with Cancer from the American Society of Clinical Oncology (ASCO) and Breast Cancer Info from the Susan Komen Breast Cancer Foundation (SKF). Interviews were conducted with consecutive consenting oncology patients seen in a public hospital oncology clinic.

Results: Fifty-nine persons participated in the survey. The response rate was 80%. Participants were Caucasian (25%), African American (19%), Hispanic (42%), and Asian/Pacific Islander (11%). English was the primary language in 53% of participants, 56% had a high school education or less, and 74% had an annual income less than US $35000. With respect to computer and Internet use, 71% had computer access, and 44% searched for cancer information online, with more being interested in obtaining online information in the future (63%). Participants who had computer access were likely to be English speaking ($P = .04$). Those less likely to have previously used a computer tended to have a lower annual income ($P = .02$) or to be males aged 55 years or older ($P < .05$). When shown sample content from the two websites, almost all participants stated that it was “easy to understand” (ASCO 96%, SKF 96%) and had “easy to understand terms” (ASCO 94%, SKF 92%). Somewhat fewer respondents agreed that the websites provided “information they could use” (ASCO 88%, SKF 80%) or that they would return to these websites (ASCO 73%, SKF 68%). The majority planned to “discuss website information with their oncologists” (ASCO 82%, SKF 70%).

Conclusions: Multiethnic, multilingual cancer patients at a public county hospital commonly had Internet access and found the content of two websites representative of major cancer organizations to be both understandable and useful.

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KEYWORDS

Internet; Internet access; computers; cancer; cancer website; race; racial/ethnic minority

Introduction

The Internet has become an increasingly common source of medical information for patients with cancer, with 6% to 43% of this population now using this resource [1-3]. Major cancer organizations have created patient-centered websites to provide comprehensive information about specific cancers [4,5]. Use of the Internet to access cancer information has been correlated with younger age (age less than 60 years), higher income, higher education, and Caucasian race [1,6,7]. However, a recent review found little empirical research on Internet cancer information use among minority racial/ethnic groups or on the appropriateness of available websites for such populations [8]. We therefore developed a survey instrument in a multiethnic, multilingual public hospital population to explore Internet access and to determine the appropriateness of websites from two major cancer organizations: the People Living with Cancer website from American Society of Clinical Oncology (ASCO) and the Breast Cancer Info website from the Susan G Komen Breast Cancer Foundation (SKF).

Methods

Study Design and Eligibility

The survey was conducted between March 2003 and August 2003 at Harbor-UCLA Medical Center. A questionnaire was administered face-to-face by trained research interviewers to consecutive patients seen at the medical oncology clinic and the oncology infusion clinic areas. Eligibility was limited to oncology patients age 18 and older who were English or Spanish speaking and who were without major cognitive or physical impairment by physician assessment. Verbal consent was obtained from all participants, and information was collected without patient identifiers. The study protocol and consent process were approved by the institutional review board.

Survey Instrument

The survey instrument was developed by initially conducting an extensive literature search to determine information seeking methods of cancer patients, including frequency of Internet use. Then, cancer care providers and a cancer social worker were interviewed to determine their perspectives and to inform the design of the questionnaire. Once a questionnaire was devised, a six-member expert panel including medical oncologists, cancer care nurses, and a cancer social worker evaluated content validity. Items deemed not relevant or incongruent were either deleted or revised.

The developed 70-item questionnaire has four sections. The first section (17 items) contains demographic information on age, sex, ethnicity, language, education, income, cancer type, and any current medical information seeking approaches. The second section (11 items) addresses baseline computer use, computer access, and attitudes toward computer use. The third section (22 items) examines the patient's unmet content needs, including satisfaction with the medical oncology clinic, medical information needs, any language barriers, and social support service needs. The fourth section (20 items) evaluates the usability and content of two websites. Participants were presented printouts of sample information from two major cancer websites, the ASCO People Living with Cancer website [4] and the SKF Breast Cancer Info website [5]. No prior computer or Internet experience was presumed, and participants were instructed to focus on information content as presented and not on the Internet or computer aspect. Literacy level was also not presumed as research associates read scripted information from the website to each participant. Content and usability were evaluated in terms of the participants' interest in the content, their ease in understanding the material and finding information, their assessment of the utility of the information, and their likelihood of discussing the information with medical providers in the future.

Spanish-speaking patients were known to account for a large proportion of the patient population; therefore, a Spanish questionnaire was developed. Spanish-speaking research interviewers were available to administer the Spanish-version questionnaire to patients identifying themselves as Spanish speaking. Questionnaires and interpreters were not available for other languages.

Categories of ethnicity/race were based on a self-report from five offered categories: American Indian/Alaskan Native, Asian/Pacific Islander, Black/African American, Hispanic, and White.

Subjects

Of the 86 persons approached for participation, 12 (14%) were ineligible mainly due to absence of a cancer diagnosis. An additional 15 were eligible but declined participation. The main reasons were “not enough time” and “not interested.” Therefore, a total of 59 out of 74 eligible persons participated (80% response).

Analysis

Microsoft Access 2000 was used to compute descriptive statistics. For each item, the proportion of persons endorsing each response category was calculated, and descriptive statistics were generated. Items assessed using a 5-point Likert scale (strongly agree to strongly disagree) were categorized as agree or not agree. Differences in subjects' evaluation of the two websites were compared using the McNemar test. Differences in responses to the information seeking and computer use section were compared according to demographic characteristics (gender, age < or ≥ 55 years, English or non-English primary language, annual income < or ≥ $35000) and were evaluated with the Fisher exact test. Similarly, subjects' responses to the website evaluation section were compared according to the same demographic characteristics and were evaluated with the Fisher exact test. Interactions between pairs of demographic characteristics were assessed by stratification and the Breslow-Day test. Level of statistical significance was set at .05, and no formal adjustment was made for multiple statistical tests.

Results

Characteristics of Respondents

In terms of demographics, most participants were female (66%). Participants included Hispanics (42%), Caucasians (25%), African Americans (19%), and Asian/Pacific Islanders (11%). The primary language was English in 53% of participants, 56% had a high school education or less, and 74% had an annual income less than $35000. The mean age was 52.1 years.

In terms of cancer type, 51% had breast cancer, 14% had lung cancer, and 10% had colorectal cancer. The mean time from cancer diagnosis was 2.5 years, with a range of 2 months to 15 years. Many respondents identified cancer as their only medical condition (51%). Other common medical conditions were hypertension (21%) and diabetes (14%).

Information Seeking and Computer/Internet Access

Respondents identified additional sources of medical information, besides their physicians, including pamphlets (53%); friends, family, and other patients (48%); and the Internet (35%). Overall, 61% of participants had used a computer before, and 45% stated that they owned a computer. However, 71% stated they had computer access at locations such as home, work, the homes of friends and family, and the library. About 54% had used the Internet, and 44% had researched cancer online; a larger percentage (63%) stated interest in using the Internet as a cancer information source in the future, with particular interest in issues related to cancer treatment and emerging research. When asked if they could trust information from the Internet, 64% agreed online information could be trusted, while 27% were ambivalent (Table 1).

Table 1. Summary of information seeking and computer use

Statement	Number (N = 59)	Percent
Have used a computer before	36	61
Own a computer*	26	45
Have been online	32	54
Have access to computer	42	71
Where patient accesses computer†		
Home	28	48
Work	2	3
Friend, family	15	25
Library	7	12
Other	3	5
None	14	24
Have researched cancer online	26	44
Interested in cancer info online	37	63
Trust online information		
Agree	38	64
Disagree	5	8
Neutral, do not know	16	27

* N = 58

† Respondents could include more than one answer; percents do not add to 100.

As Table 2 shows, fewer participants whose primary language was not English had computer access compared to those whose primary language was English (57% vs 84%; *P* = .04). This difference remained after stratifying by age, gender, and income. The combination of being male and older (at least 55 years) was significantly (*P* < .05) associated with being less likely to have used a computer before, to have been online, and to have an interest in cancer information online. Specifically, the percentages of females and males younger than 55 years, and females and males 55 years and older who had used computers were 68%, 67%, 80%, and 23%, respectively. The percentages who had been online (for the same categories of females and males as above) were 70%, 67%, 80%, and 8%. Similarly, the percentages who were interested in cancer information online were 83%, 83%, 77%, and 25%. There were no significant differences in computer use and Internet access when stratified by income level below $35000 versus $35000 or more. However, when using an income level of $20000, significant differences were observed. Fewer participants earning less than $20000 per year owned computers (29% vs 60%; *P* = .02) or had used computers (45% vs 77%; *P* = .02) compared to other participants.

Table 2. Comparison of sample items by language, gender, and income level

Item	Non-English Primary Language (%)	English Primary Language (%)	*P* value
Have computer access	57	84	.04
Info on ASCO website more useful as pamphlet	90	55	.01
Info on SKF website more useful as pamphlet	86	45	.004
Info on ASCO website more useful as pamphlet in my language	81	10	< .0001
Info on SKF website more useful as pamphlet in my language	76	10	< .0001
	Female (%)	**Male (%)**	
Find info I need easily on ASCO site	89	50	.006
Would discuss ASCO site info with doctor	92	52	.006
SKF site has info I can use	89	54	.04
Plan to go back to SKF site	78	38	.01
	Income < $35000 (%)	**Income ≥ $35000 (%)**	
Plan to discuss ASCO site with doctor	75	100	.04
Plan to discuss SKF site with doctor	64	86	.18
	Income < $20000 (%)	**Income ≥ $20000 (%)**	
Have ever used computer	45	77	.02
Own a computer	29	60	.02

Evaluation of Websites

Participants' evaluation of the People Living with Cancer website and the Breast Cancer Info website is outlined in Table 3. As seen, when shown sample content from the two websites, the majority stated that it was "easy to understand" (ASCO 96%, SKF 96%) and had "easy to understand terms" (ASCO 94%, SKF 92%). Somewhat fewer agreed that the websites provided "information they could use" (ASCO 88%, SKF 80%), and that they would return to these websites (ASCO 73%, SKF 68%). A sizable proportion of the sample stated they would prefer that the information in the websites be presented in a printed pamphlet format (ASCO 69%, SKF 62%). The majority planned to "discuss website information with their oncologists" (ASCO 82%, SKF 70%). When asked if they would use this information to inform their medical decisions, most agreed (ASCO 69%, SKF 70%). There were no statistically significant differences between subjects' evaluation of the two websites.

Table 3. Evaluation of the American Society of Clinical Oncology and Susan G Komen Breast Cancer Foundation websites (n = 50)

	ASCO Website		SKF Website		*P* value
Statement	**Number Agreeing**	**Percent**	**Number Agreeing**	**Percent**	
This website is easy to understand	49	96	48	96	.32
This use of medical terms and explanation is easy to understand	48	94	46	92	.32
I can find information I need easily	41	82	41	82	.32
This website has information I can use	45	88	40	80	.06
I plan to go back to this website	37	73	34	68	.32
The information on the website would be more useful to me as a printed pamphlet	35	69	31	62	.48
The information on the website would be more useful to me as a printed pamphlet in my language	19	37	19	38	.65
I would use this information to make medical decisions	35	69	35	70	.65
I plan to discuss information from this website with my doctor	41	82	35	70	.06

More women than men reported that on the ASCO website they could "find information I need easily" (89% vs 50%; $P = .006$), and that they would "discuss information from this website with my doctor" (92% vs 52%; $P = .006$). Proportionally more women than men stated that the SKF website “has information that I can use” (89% vs 54%; *P* = .04); that they “plan to go back to this website” (78% vs 38%; *P* = .01); and that “the information on the website would be more useful to me as a printed pamphlet” (73% vs 31%; *P* = .02). Significantly more participants whose primary language was not English reported that “the information on the website would be more useful to me as a printed pamphlet” (SKF: 86% vs 45%; *P* = .004; ASCO: 90% vs 55%; *P* = .01), and that “the information on the website would be more useful to me as a printed pamphlet in my language” (SKF: 76% vs 10%; *P* < .0001; ASCO: 81% vs 10%; *P* < .0001). There was a tendency for fewer participants with annual incomes less than $35000 to “plan to discuss information from this website with my doctor” (ASCO: 75% vs 100%; *P* = .04; SKF: 64% vs 86%; *P* = .18). There were no significant differences in evaluation of the websites when stratified according to age.

Discussion

The results of our survey suggest that multiethnic, multilingual cancer patients at a public county hospital commonly have Internet access and find the content of two websites representative of major cancer organizations (the American Society of Clinical Oncology and the Susan G Komen Breast Cancer Foundation) to be both understandable and useful.

Internet Use to Access Cancer Information

Medical information seeking on the Internet has been previously shown to statistically correlate with higher income, higher education, and non-minority race [1-3]. Our sample was predominantly non-Caucasian (75%), commonly had a high school education or less (56%), and had an annual income less than $35000 (74%). Nonetheless, 44% of this multiethnic, lower-income cancer population reported using the Internet to access medical information regarding their cancer, a result similar to that seen for more affluent cancer populations in which 6% to 43% of cancer patients have been reported to use the Internet for cancer-related information [6,9,10]. Our findings are also comparable to the frequency of Internet use for medical information reported in non-cancer populations. In two large surveys which focused on the general population (N = 3209) and on primary care patients (N = 512), using the Internet to access general medical information was reported for 31% and 54% of participants [9,11]. Such results suggest that the previously identified “digital divide”—less access to Internet information based on socioeconomic status [12]—may be decreasing as the Internet becomes increasingly available.

Factors Influencing the “Digital Divide”

The “digital divide” in our population is influenced by language, age, gender, and income. Compared to participants whose primary language was English, those who reported another primary language were less likely to have computer access. This difference remained after stratifying by age, gender, and income. The combination of being male and 55 years or older was significantly associated with being less likely to have prior computer or Internet use or interest in cancer information online. There were no significant differences in computer use and Internet access by annual income level (above and below $35000) in this population. However, a difference was observed using a lower income level ($20000). Participants with an annual income below $20000 were significantly less likely to own a computer and to have used a computer compared to other participants.

Utility of Website Information

In our study, when participants were shown sample pages from two major cancer organization websites, both sites received favorable overall reactions. Significantly, participants generally agreed that both were easy to understand and had information they could use. When asked what they would do with such information, the majority indicated that they would include website information in discussions with their physicians (82%) and in making medical decisions (69%). Even in our small sample, significant differences emerged between genders and reported primary languages in evaluation of the two websites. Significantly, more women than men stated that the ASCO website had information they could find easily and that the SKF website had information they could use. Not surprisingly, respondents' primary language influenced their preference for printed information versus website information. Compared to respondents whose primary language was English, persons who reported another primary language significantly preferred to have the website information as a pamphlet, particularly a pamphlet in their language.

Cancer patients seek information to regain a sense of control, learn about treatment, and inform their medical decisions [13-16]. The growth of the Internet has prompted concerns regarding the reliability of online medical information and the absence of a system to help patients navigate the vast numbers of websites or appraise their quality [10,17]. In fact, patients typically start their Internet search with a search engine and visit the first few sites listed [18]. Many major cancer organizations provide websites with comprehensive, current information that may be useful as reliable sources of patient education; however, patients may have difficulty finding such websites. To add another layer of complexity, little is known regarding how disadvantaged groups find reliable sites. Thus, new strategies are needed in order to help all cancer patients find reliable cancer information online.

Strengths and Limitations of the Study

Strengths of this study include collection of detailed questionnaire information through interviews conducted in English and Spanish and evaluation of website content using a procedure independent of computer and language skills (a visual presentation of materials with spoken explanation). Study limitations include the modest sample size and findings based on self-report. The study targeted a specific multiethnic, multilingual, predominantly lower-income cancer population at one public hospital, and findings, therefore, cannot be generalized to other populations. Our study did not assess behavior after exposure to the website information. Further research is needed to study how exposure to health information on such websites influences patients' behavior.

Conclusions

In summary, our study indicates that website information from both the American Society of Clinical Oncology and the Susan G Komen Breast Cancer Foundation appears to be appropriate, understandable, and accessible to multiethnic, multilingual cancer patients in public hospital settings. If issues related to finding such appropriate sites are addressed, these sites may represent a valuable resource for cancer information in such patient populations.

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Conflicts of Interest

None declared.

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Abbreviations

ASCO: American Society of Clinical Oncology
SKF: Susan G Komen Breast Cancer Foundation

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Original Paper

An Internet-Based Cancer Clinical Trials Matching Resource

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Abstract

Background: Many patients are now accessing the Internet to obtain cancer clinical trials information. However, services offering clinical trials recruitment information have not been well defined.

Objectives: This study describes one of the first Web-based cancer clinical trials matching resources and the demographics of users who were successfully matched.

Methods: OncoLink is the Internet-based educational resource managed by the University of Pennsylvania Cancer Center (UPCC) and serves between 1 and 2 million pages per month to over 385000 unique IP addresses. OncoLink launched one of the first clinical trials matching resources on the Internet that allowed patients to enter demographic data through a secure connection and be matched to clinical trials. For patients with matches to potential trials, appointments were facilitated with the principal investigators.

Results: While we did not keep track of patients who could not be matched, 627 patients who submitted online applications between January 2002 and April 2003 were successfully matched for potential enrollment in clinical trials. The mean age of the patient population was 56 years (range 18–88 years). Males represented 60% of the patient population, and over 90% of users were Caucasian. Most of the applications were from patients with colorectal cancer (13%), lung cancer (14%), melanoma (10%), and non-Hodgkin's lymphoma (9%).

Conclusions: This report shows that a significant number of patients are willing to use the Internet for enrolling in clinical trials. Care must be taken to reach patients from a variety of socioeconomic and racial backgrounds. This Internet resource helps to facilitate a consultation with a cancer patient who is prescreened and motivated to enroll in clinical trials.

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KEYWORDS

Internet; neoplasms; clinical trials

Introduction

Clinical Trials Recruitment

Recruitment of cancer patients to clinical trials in the United States has remained stagnant for a number of years. Only 2% to 4% of all adult patients with newly diagnosed cancer participate in clinical trials [1]. Because of the low accrual rate, many clinical trials have lacked the power to make significant conclusions [2].

A host of physician-related and patient-related factors have led to the low rate of enrollment in clinical trials for adult cancers in the United States. The prevalent theme among studies examining the barriers to enrollment has been the lack of physician and patient awareness of open clinical trials and the unavailability of protocols to both the patient and physician at the time of consultation. Less than half of eligible patients are even considered for clinical trials [3-5]. Many physicians have concluded that approaching a patient about a clinical trial intrudes upon the patient-physician relationship [6-10]. Also, many physicians do not have the appropriate protocol available to them when evaluating a potentially eligible patient [3]. Patient-related factors that limit enrollment in clinical trials include absence of knowledge about clinical trials, unwillingness to be randomized to treatment, time constraints, distance from treatment center, insurance denial, and distrust of the medical establishment [3,7-12]. Once a clinical trial is offered to a patient, the overall rate of acceptance is 15% to 40% [1,6,11]. Thus, there is clear potential for improvement in clinical trials enrollment.

Cancer Patients' Use of the Internet

Cancer patients are increasingly using the Internet as a source of medical information. This is a reflection of the overall availability of computers and access to the Internet. Forty to fifty percent of cancer patients use the Internet to search for information, and this number continues to rise [13-16]. Many are looking for information regarding cancer clinical trials [14,15]. The Internet is a resource that can rapidly reach a wide geographic population that otherwise may not have access to clinical trials information. However, there are concerns that minority and elderly patients are less familiar with and have limited access to the Internet [17,18]. Recently, a number of services have been offered over the Web to facilitate enrollment in clinical trials. The increasingly widespread use of the Internet makes it a potential source by which patients can become aware of and enroll in clinical trials, improving the rate of clinical trial enrollment.

Internet-Based Clinical Trials Recruitment

Although a number of clinical trials services have arisen on the Internet over the past few years, data regarding these services are lacking. The first reported Web-based matching services for clinical trials appeared in the HIV community [19,20]. However, these services did not use complex algorithms because they were dealing with a single disease with a small number of variables. Previous Internet-based cancer clinical trials information has solely been listings of available trials or limited matching to a specific type of cancer [21-23]. This study describes the first broad Web-based matching service and the initial demographic parameters of the patients using the resource.

Methods

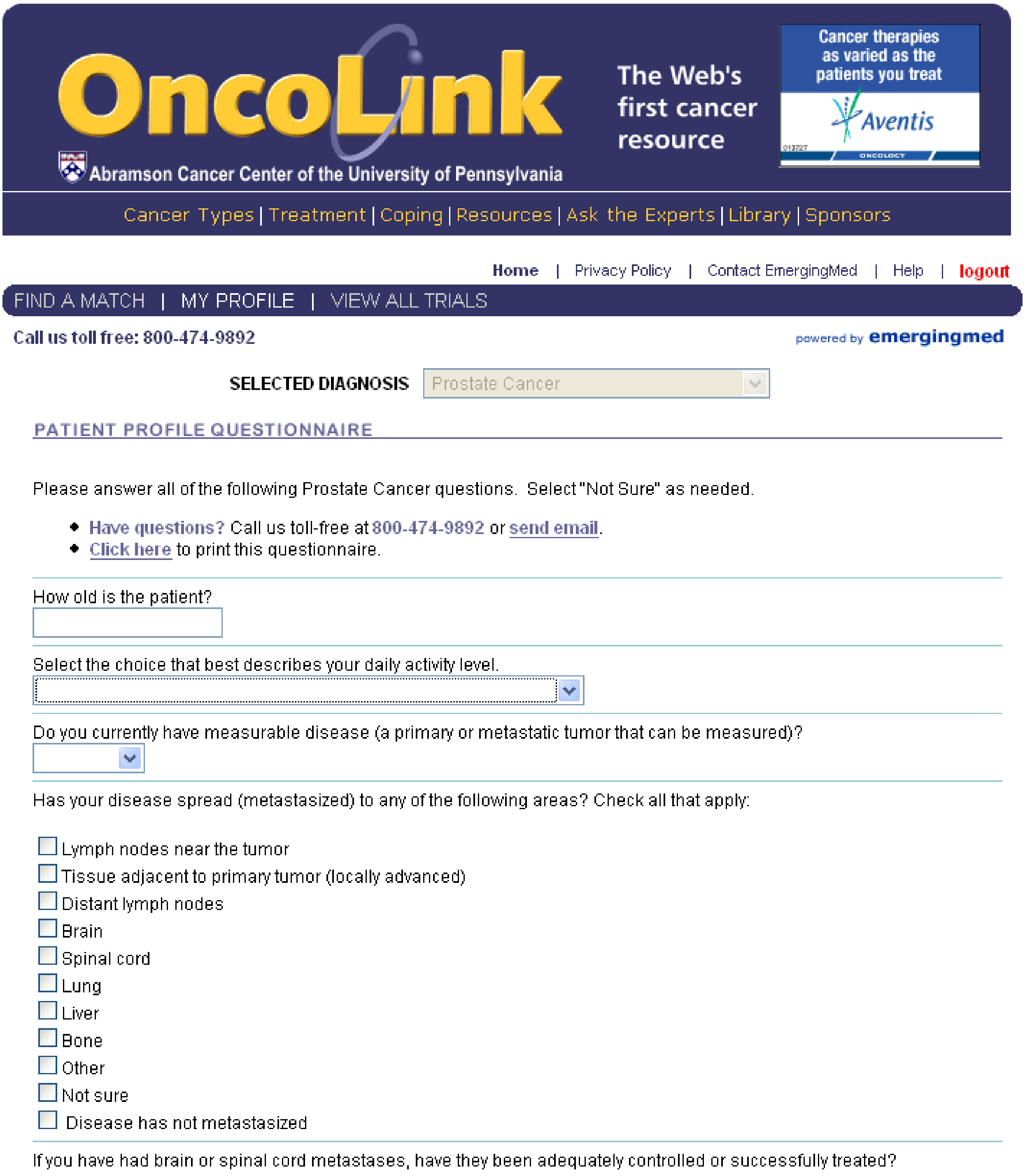
OncoLink's Clinical Trials Matching Resource

OncoLink (www.oncolink.org) is the oldest and one of the largest general cancer information resources on the World Wide Web. It was established in 1994 to provide educational information to patients, families, and health care providers. OncoLink is based at the University of Pennsylvania Cancer Center (UPCC) and currently serves between 1 and 2 million pages per month to over 385000 unique IP addresses.

OncoLink launched the first broad cancer clinical trials matching resource on the Internet in January of 2002 in conjunction with EmergingMed (New York, NY). The resource was designed for patients to enter basic demographic data through a secure Internet connection (Figure 1). This information was then cross-matched with the inclusion and exclusion criteria of the protocol, and the patient was offered a matched list of potential trials for enrollment. For patients with an interest in obtaining more information or potentially enrolling in a matched clinical trial, appointments were facilitated with the principal investigators of the trials through personal communication.

Individuals interested in participating in the clinical trials matching service are encouraged to review the privacy policy of this resource. This details the purpose and use of the database as well as the use of the participant's personal information. By accepting entry into the matching service, participants agree only to allow matching to clinical trials approved by the institutional review board (IRB) and to facilitation of an appointment with the principal investigator should they meet enrollment criteria. This electronic consent is not a surrogate for study-specific consents, which must be obtained by the individual investigators after seeing and evaluating the patient personally. Each clinical trial in the database had specific IRB approval for inclusion in the matching service.

Figure 1. Screen shot of the OncoLink trial matching questionnaire



SELECTED DIAGNOSIS Prostate Cancer

PATIENT PROFILE QUESTIONNAIRE

Please answer all of the following Prostate Cancer questions. Select "Not Sure" as needed.

- Have questions? Call us toll-free at 800-474-9892 or send email.
- Click here to print this questionnaire.

How old is the patient?

Select the choice that best describes your daily activity level.

Do you currently have measurable disease (a primary or metastatic tumor that can be measured)?

Has your disease spread (metastasized) to any of the following areas? Check all that apply:

☐ Lymph nodes near the tumor
☐ Tissue adjacent to primary tumor (locally advanced)
☐ Distant lymph nodes
☐ Brain
☐ Spinal cord
☐ Lung
☐ Liver
☐ Bone
☐ Other
☐ Not sure
☐ Disease has not metastasized

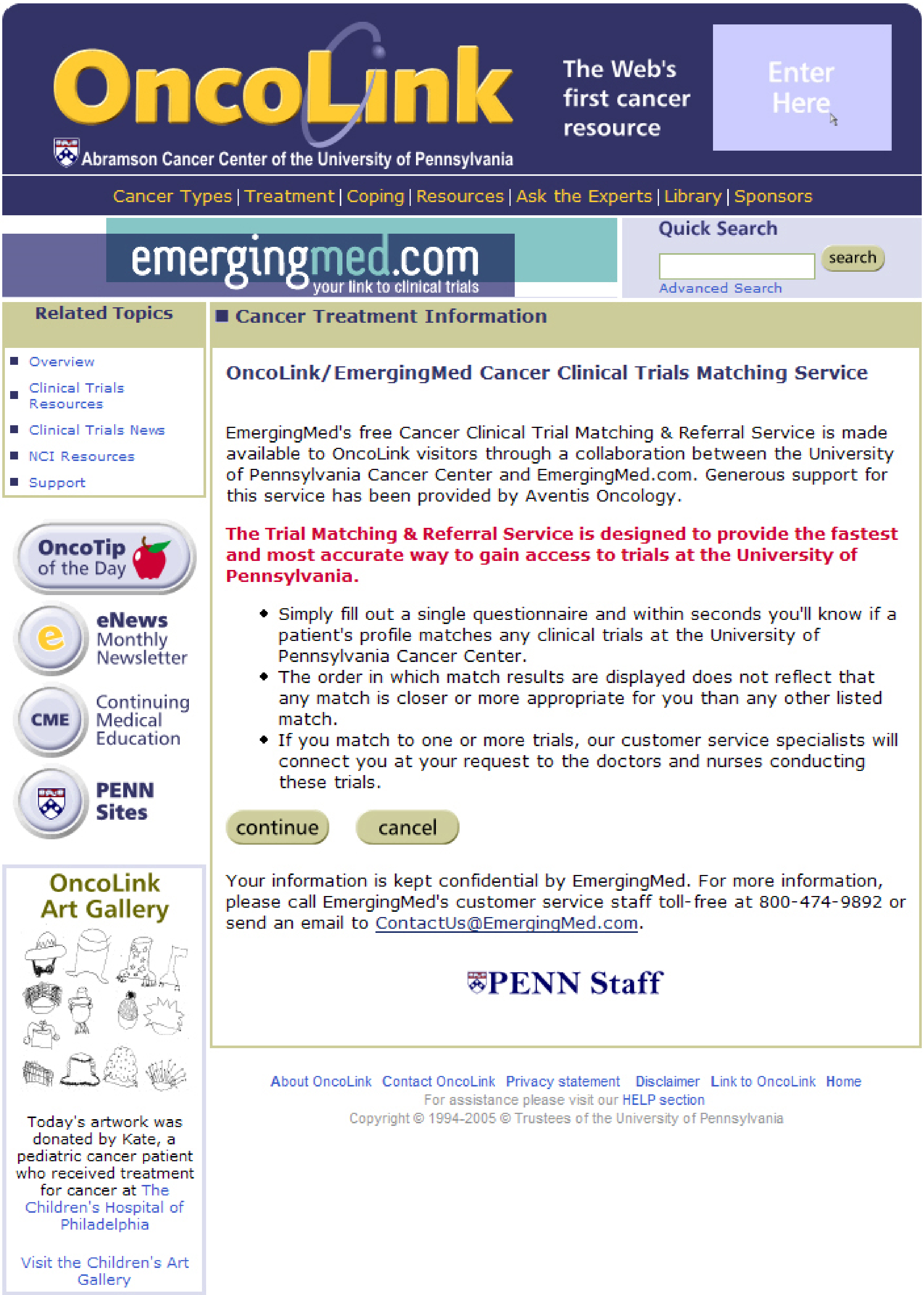
If you have had brain or spinal cord metastases, have they been adequately controlled or successfully treated?

Clinical Trials Matching Technical Details

Internet enrollment was conducted through the OncoLink website and data were held on a physically and electronically secure SQL server using secure socket layer (SSL) technology. In June 2004, the system was matching patients to 155 IRB-approved clinical trials at the UPCC. All currently open treatment trials are included in the system unless the principal investigator does not want the trial listed. There is no paid inclusion by the pharmaceutical industry to have a trial listed on the OncoLink service, and the matching is free from commercial bias. The initial pages of the matching service are shown in the screen shots in Figures 2-4. Additional pages are dependent on the specific cancer the individual is interested in matching. For those patients who do not live within the UPCC local area, a second-pass match is offered on a national level based on trials from the NCI PDQ® database, participating cancer centers, and industry sponsored trials. In June 2004, this second-pass national match contained 2395 trials. This second-pass match, which is outside the scope of the OncoLink website and the University of Pennsylvania, may include trials whose inclusion is paid for by the pharmaceutical industry on the EmergingMed website. However, this paper only discusses the use of the OncoLink clinical trials service and website.

Figure 2. OncoLink home page

Figure 3. OncoLink subpage for entrance into the clinical trials area



OncoLink/EmergingMed Cancer Clinical Trials Matching Service

EmergingMed's free Cancer Clinical Trial Matching & Referral Service is made available to OncoLink visitors through a collaboration between the University of Pennsylvania Cancer Center and EmergingMed.com. Generous support for this service has been provided by Aventis Oncology.

The Trial Matching & Referral Service is designed to provide the fastest and most accurate way to gain access to trials at the University of Pennsylvania.

- Simply fill out a single questionnaire and within seconds you'll know if a patient's profile matches any clinical trials at the University of Pennsylvania Cancer Center.
- The order in which match results are displayed does not reflect that any match is closer or more appropriate for you than any other listed match.
- If you match to one or more trials, our customer service specialists will connect you at your request to the doctors and nurses conducting these trials.

Your information is kept confidential by EmergingMed. For more information, please call EmergingMed's customer service staff toll-free at 800-474-9892 or send an email to ContactUs@EmergingMed.com.

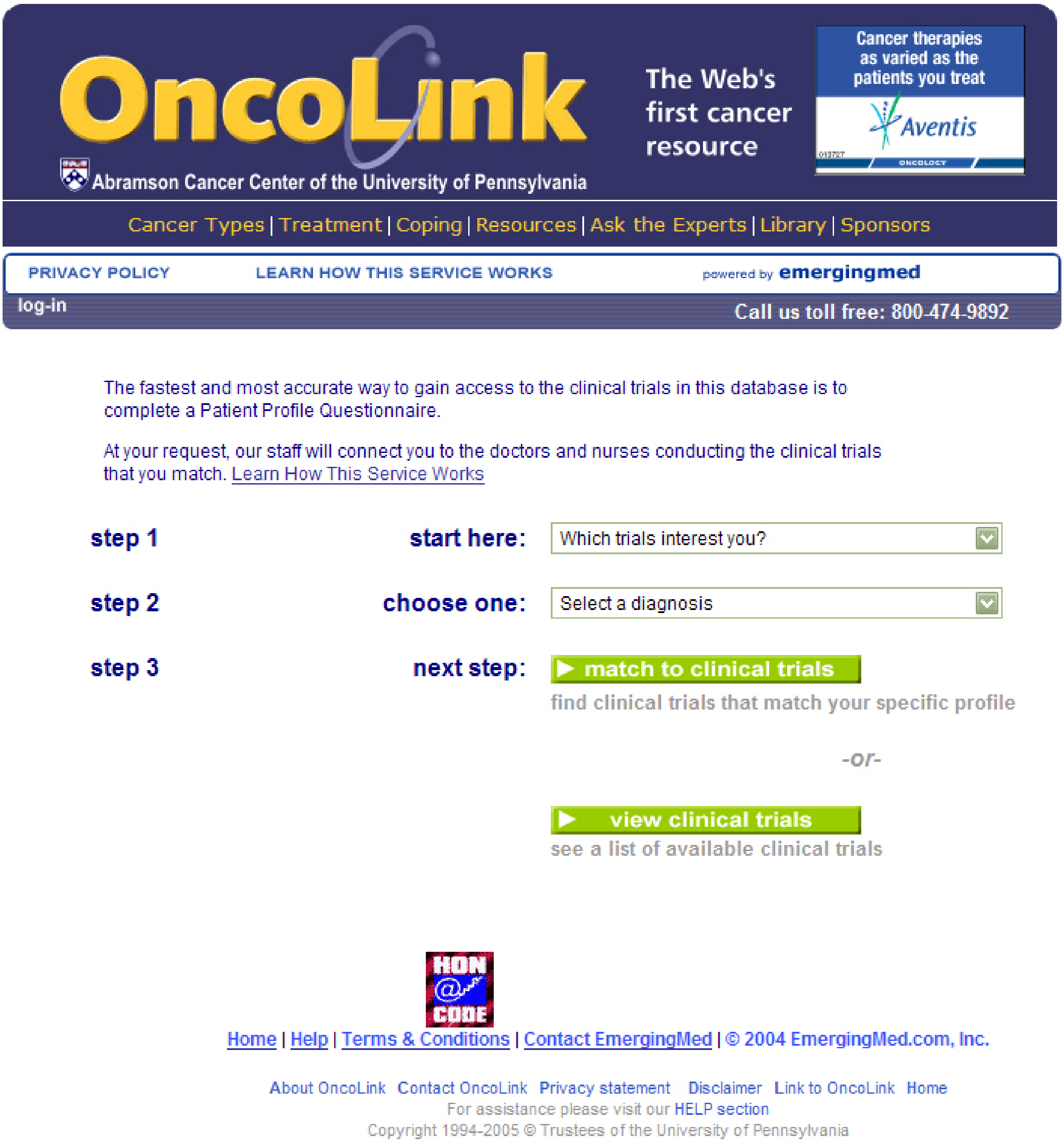
Today's artwork was donated by Kate, a pediatric cancer patient who received treatment for cancer at The Children's Hospital of Philadelphia

Visit the Children's Art Gallery

For assistance please visit our HELP section

Copyright © 1994-2005 © Trustees of the University of Pennsylvania

Figure 4. The first page of the matching service



The fastest and most accurate way to gain access to the clinical trials in this database is to complete a Patient Profile Questionnaire.

At your request, our staff will connect you to the doctors and nurses conducting the clinical trials that you match. Learn How This Service Works

step 1	start here:	Which trials interest you?
step 2	choose one:	Select a diagnosis
step 3	next step:	match to clinical trials find clinical trials that match your specific profile -or- view clinical trials see a list of available clinical trials

For assistance please visit our HELP section

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Patient Questionnaire

The patient questionnaire contained queries regarding demographics, contact information, personal medical history, cancer diagnosis, and treatments to date. There was an internally validated questionnaire for each disease site that was developed based on the inclusion and exclusion criteria of all available trials. The questionnaire was designed to be interactive; therefore, individuals answered differing numbers of questions since follow-up questions were asked depending on previous responses. As some patients may not have known the specific details of their medical condition (eg, number of positive lymph nodes at time of resection), participants could score these answers as unknown. Data were only collected on patients that were actually matched to specific trials.

Statistical Analysis

Statistical analysis was performed with SPSS software (version 9.0 for Windows; SPSS Inc, Chicago). Descriptive statistics were used to determine prevalence rates and demographic patterns of the individuals registered in the database. We did not keep track of patients who could not be matched.

Results

Between January 2002 and April 2003, 627 patients submitted online applications and were matched for potential enrollment in cancer clinical trials through OncoLink. The mean age of the patient population was 56 years (range 18–88 years). Females were slightly younger than males (54 years vs 57 years; $P \leq .05$). Males represented 60% of the patient population. Over 90% of patients using this service were Caucasian. Of the 627 individuals eventually matched to clinical trials, online applications were initially submitted by 315 patients (50%), 293 family members (47%), 9 friends (1.5%), and 9 physicians (1.5%). For one patient (0.2%), it was unknown who entered the information into the system.

Cancer Diagnosis of Participants

Table 1 shows the range of cancer diagnoses included in the population. The largest number of applications came from patients with colorectal cancer (13%), lung cancer (14%), melanoma (10%), and non-Hodgkin's lymphoma (9%). Stage IV disease was present in many patients using the Internet to match to clinical trials: breast cancer (50%), colorectal cancer (62%), lung cancer (41%), non-Hodgkin's lymphoma (41%), and head and neck cancer (45%).

Table 1. Distribution of patients by cancer diagnosis

Diagnosis	Number (N = 627)	Percent
Bladder	9	1.4
Brain	16	2.6
Breast	50	8.0
Cervical	12	1.9
Colorectal	83	13.2
Endometrial	4	0.6
Esophageal	6	1.0
Head and neck	22	3.5
Hodgkin's lymphoma	3	0.5
Kidney	12	1.9
Leukemia	17	2.7
Liver	13	2.1
Lung	90	14.4
Melanoma	60	9.6
Multiple myeloma	16	2.6
Non-Hodgkin's lymphoma	57	9.1
Ovarian	46	7.3
Pancreatic	40	6.4
Prostate	19	3.0
Rare tumors	16	2.6
Sarcoma	23	3.7
Stomach	12	1.9
Testicular	1	0.2

Phase of Matched Trials

Table 2 shows the phase distribution of trials for those patients that applied for enrollment after review of their matches to specific trials. The median number of trials each patient was matched to was six.

Table 2. Phase of clinical trial for those who applied for enrollment after review of matched trials

Phase	Number	Percent
Pilot	1	0.4
I	63	22.0
I/II	28	9.8
II	96	33.7
III	48	16.8
Other	49	17.2

Discussion

This study shows that patients are willing to use the Internet to find clinical trial information and enroll in trials for which they may be eligible. Motivated patients can research available trials and arrange a consultation appointment with the principal investigator of a specific trial. From the principal investigators' perspective, they are seeing a prescreened patient based on the inclusion and exclusion criteria of the trial who is already motivated to find a clinical trial that is right for them. This bypasses some of the major roadblocks that have been identified in the problem of clinical trials recruitment [3-12].

Prevention Trials vs Treatment Trials

This matching service was developed based on the experience of OncoLink housing the National Colorectal Cancer Research Alliance (NCCRA) database for colorectal cancer prevention and treatment trials [24]. This database allows patients to answer a questionnaire detailing patient demographics, health parameters, and family history. After successful completion of the questionnaire, patients are entered into a large database that serves as a warehouse of patients interested in colorectal cancer prevention trials. The principal investigator of a trial may then search the database for participants that match the prevention trial parameters and contact the interested participant to discuss the trial. This type of database works well for prevention trials and genetic studies; however, it is not a good mechanism for cancer treatment trials. Patients with cancer need to make decisions on a tight timeline and need to know about potential trials in short order.

Thus, the current system was developed for immediate matching of patients with any cancer diagnosis with available trials. Although the matching system is completely automated, some personal interaction is still required, and appears to be desirable to the end users. Once patients are matched to clinical trials, they give permission to be contacted in order to facilitate an appointment with the clinical investigator. At the time of this phone contact, the patient's information is verified as is the trial information. The principal investigator (or designated nurse representative) is contacted to verify that the trial is still open and there have been no changes in the enrollment criteria prior to setting up the consultation. Any changes in the status of the trial are updated in the system, which serves as an internal validation.

Cancer Diagnosis of Participants

The participants using this resource have a wide range of cancer diagnoses as shown in Table 1. Twenty-three different tumor types were classified in the system. The more common tumors, such as lung, colorectal, and breast, are seen frequently in patients using the system, as expected. Interestingly, patients with some less common malignancies, , such as melanoma, non-Hodgkin's lymphoma, and ovarian cancer, also showed a high utilization of the system. It may be that patients with these diagnoses are more actively searching the Internet for clinical trials information. However, this study was not designed to evaluate patients' reasons for using the Internet to identify clinical trials.

Phase of Matched Trials

There was a broad listing of clinical trials to which the patients were matched (Table 2). There was no significant difference between the phases of trials which were matched with the exception of pilot studies. There were only a few pilot studies in the system at the time of this analysis, which most likely contributed to the low number of matches to this type of trial. The website is designed to match patients to all available trials without bias to any phase, sponsor, or specific trial design.

Patient Enrollment by Surrogates

Family members entered 47% of the applications for patients enrolled in the system. It must be recognized that many patients rely on family and friends to obtain Internet-based information. A questionnaire study by Vordermark et al evaluated 139 German radiation oncology patients [25]. The Internet was used by 12% of patients to obtain information about their cancer, but an additional 15% received Internet-derived information about their cancer from friends or family members. This should be considered a conservative estimate since some patients (and family and friends) may not disclose their sources of information to physicians. Yakren et al analyzed the use of media information, including the Internet, among cancer patients and their companions at Memorial Sloan-Kettering Cancer Center [26]. Of the 443 individuals who returned completed surveys, 44% of the patients and 60% of the companions reported use of the Internet to obtain cancer-related information. The use of surrogates to obtain cancer clinical trials information and the high utilization of the system by family members have implications for the development of future versions of the software in order to ease the utilization of the system by these surrogates.

Challenges of a Matching System

The Internet-based matching system requires a dedicated individual to keep an up-to-date and accurate listing of all trials, contact information, and inclusion and exclusion criteria. Although there is a national second-pass match in this system for those that cannot travel to the University of Pennsylvania, the upkeep of the basic data is outside the control of the resource.

There are some significant challenges for the establishment of a true national matching system for cancer clinical trials. The national infrastructure is not in place to accurately present clinical trials information from all institutions. No matter what computer program is utilized, the final product is dependent on correct and updated data from which it is derived. Most of the systems rely on listings from a variety of websites, most notably the National Cancer Institute (NCI). Unfortunately, much of this information is out of date, with incorrect contact information and trial listings (personal communication, October 2004). The principal investigator is often responsible for updating the system with any changes in contact information, posting of new trials, and removal of trials once they are closed. For those patients that do find a trial in which they are interested, many have difficulty contacting the investigator or ultimately find that the trial is not open for recruitment. This can be very frustrating for the end user.

Recruitment of Minority Populations

Over 90% of the users of this clinical trials matching service were Caucasian. This underscores the importance of reaching other ethnic populations. Despite the potential benefits of this clinical trials matching service, there is a distinct risk of recruiting a biased population into the database. Historically, several subsets of patients have enrolled in clinical trials at an even lower rate than the general population. Minority enrollment has been relatively low, in part due to a lower willingness of African American patients to enroll in clinical trials [27-30]. Minorities and patients receiving their care from non-academic or community-based hospitals (eg, Veterans administration hospitals) also lag behind the general population with regards to Internet access and use [17,18]. Such a discrepancy can potentially bias the population registering through the Internet, subsequently biasing the population enrolling in clinical trials through the matching system. Minorities are more likely to cite distrust of the medical establishment as a reason for not enrolling in clinical trials [28,30-33]. Less then 10% of individuals who registered with the online matching system were minorities, which is lower than that seen for minority enrollment in cancer treatment trials at the NCI [34]. Enrollment of older patients has also lagged behind enrollment of other patients [5,35,36]. Older patients are less likely to have access to or utilize the Internet [17]. The lower rate of enrollment of older patients and minority patients limits the ability to generalize the results of many clinical trials. These populations appear to be underserved with regards to Internet usage.

Conclusions

This is the first report of a broad Web-based cancer clinical trials matching service. This study shows that cancer patients are willing to use the Web to assist them in finding clinical trials. Strategies must be developed to ensure that underserved populations are included in clinical trials matching and recruitment services. As the data set matures, future reports will address recruitment to specific clinical trials.

Conflicts of Interest

Courtney Hudson is chief executive officer and owner of the EmergingMed.com clinical trials matching resource.

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Abbreviations

HIV: human immunodeficiency virus
NCI PDQ database: National Cancer Institute Physician Data Query database
SQL: structured query language

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Original Paper

Use of Internet Audience Measurement Data to Gauge Market Share for Online Health Information Services

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Abstract

Background: The transition to a largely Internet and Web-based environment for dissemination of health information has changed the health information landscape and the framework for evaluation of such activities. A multidimensional evaluative approach is needed.

Objective: This paper discusses one important dimension of Web evaluation—usage data. In particular, we discuss the collection and analysis of external data on website usage in order to develop a better understanding of the health information (and related US government information) market space, and to estimate the market share or relative levels of usage for National Library of Medicine (NLM) and National Institutes of Health (NIH) websites compared to other health information providers.

Methods: The primary method presented is Internet audience measurement based on Web usage by external panels of users and assembled by private vendors—in this case, comScore. A secondary method discussed is Web usage based on Web log software data. The principle metrics for both methods are unique visitors and total pages downloaded per month.

Results: NLM websites (primarily MedlinePlus and PubMed) account for 55% to 80% of total NIH website usage depending on the metric used. In turn, NIH.gov top-level domain usage (inclusive of NLM) ranks second only behind WebMD in the US domestic home health information market and ranks first on a global basis. NIH.gov consistently ranks among the top three or four US government top-level domains based on global Web usage. On a site-specific basis, the top health information websites in terms of global usage appear to be WebMD, MSN Health, PubMed, Yahoo! Health, AOL Health, and MedlinePlus. Based on MedlinePlus Web log data and external Internet audience measurement data, the three most heavily used cancer-centric websites appear to be www.cancer.gov (National Cancer Institute), www.cancer.org (American Cancer Society), and www.breastcancer.org (non-profit organization).

Conclusions: Internet audience measurement has proven useful to NLM, with significant advantages compared to sole reliance on usage data from Web log software. Internet audience data has helped NLM better understand the relative usage of NLM and NIH websites in the intersection of the health information and US government information market sectors, which is the primary market intersector for NLM and NIH. However important, Web usage is only one dimension of a complete Web evaluation framework, and other primary research methods, such as online user surveys, usability tests, and focus groups, are also important for comprehensive evaluation that includes qualitative elements, such as user satisfaction and user friendliness, as well as quantitative indicators of website usage.

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KEYWORDS

Internet; World Wide Web; information services; information dissemination; audience research; evaluation studies

Introduction

Shift to the Internet

The advent of the Internet and World Wide Web has fundamentally changed the competitive environment for health information services of all kinds. Over the last decade, the National Library of Medicine (NLM), like many others, has made a major transition to Internet and Web-based dissemination of health information. Dissemination of information via varied websites is by far the dominant channel used by NLM and by most other units of the National Institutes of Health (NIH) for making health information available to consumers, health professionals, librarians, and researchers.

The shift to the Internet has necessitated a rethinking and transition in information dissemination evaluation methods as well. In the pre-Internet days, NLM relied heavily on user surveys targeted to identifiable users who were known to NLM because of the requirement to register. Now, in the Web environment, most NLM (and other NIH) Web-based information services do not require registration; indeed, NLM in particular emphasizes the protection of user privacy and does not collect, as a matter of routine, any identifiable information about its users. The only exceptions are specialized services such as email updates or stored searches where users, of their own volition, provide contact information in order to receive these services.

This situation has vastly compounded the difficulty of not only getting feedback from users, but of understanding and tracking the relative market positions of health information providers. To a significant degree, all health information providers face similar challenges. However, federal government providers, such as NLM and other NIH units, are further limited because of the prohibitions on the use of persistent cookies, behavioral tracking, and personal identifiers—restrictions that do not apply to many private sector health information providers.

Multidimensional Approach

In order to address the challenges of evaluating Web-based information dissemination, NLM has developed a multidimensional approach to Web evaluation [1] (also see [2,3]). This approach includes the following dimensions: usability testing (heuristic or expert review, usability lab testing, informal usability feedback); user feedback (online user survey, online survey of external panel, online or face-to-face focus group, nationwide syndicated survey, unsolicited user feedback); usage data (Web log data analysis, Internet audience measurement); Web/Internet performance (page download times, latency and traceroute, throughput); and special outreach projects.

This approach is intended in part to better understand NLM's position in the health information arena. The focus of this paper is NLM's use of Internet audience measurements services as a primary methodology to estimate NLM's and NIH's share of the health information market. To a large degree, Internet audience measurement services offer the only viable means to obtain market-wide usage data, since Web log data from other information providers typically are not available. This is the case in both the public and private sectors.

Additionally, Web log data definitions are highly variable from site to site and depend on site- and software-specific details. This can limit the validity (and utility) of log data for comparative purposes. Internet audience measurement services offer the possibility of applying the same methodology and definitions across the board, for all websites and subsites being measured and compared.

In this paper, we apply the Internet audience measurement methodology to develop estimates of NLM's and NIH's positions in the health information (and also federal government) market sectors. We also examine, as a case study, both MedlinePlus Web log data and external Internet audience measurement data on the most heavily used cancer-specific health information websites.

Methods

Measuring Internet Audience

NLM realized early in its transition to Internet and Web-based information dissemination that new audience measurement methods would be needed. NLM now has several years' experience with various Internet audience measurement services and currently subscribes to two commercial services—comScore [4] and Nielsen/NetRatings [5]. comScore had its early roots in the now defunct PCData measurement service, which was transformed in 2001 by comScore into the now defunct netScore measurement service, which was further transformed in 2003 by integrating it with the MediaMetrix service. Nielsen/NetRatings is a wholly owned subsidiary of AC Nielsen, well known for the use of panels for measuring television audience shares. NetRatings began independently and was acquired by AC Nielsen in the 1990s.

Both services use a similar overall approach in that estimates of overall website usage are developed based on actual Web usage by panels of users. The two services vary in their approaches to panel recruitment, size and scope of panels, estimating algorithms, projection methodologies, and geographic and sectoral coverage. At the core, however, both use panels of Web users who volunteer to have their Web usage monitored 24 hours a day, 7 days a week. The raw Web usage data are then adjusted using US census data and other survey data to produce estimates extrapolated to the defined market sector. The specific estimating algorithms used by each company are considered proprietary and differ considerably.

Comparing the Services

Nielsen/NetRatings uses a panel of about 60000 persons in the United States, and it prepares estimated usage levels for the US home and office markets and total US market. Nielsen/NetRatings has affiliates in select other countries but does not as yet prepare integrated global usage estimates. comScore uses a panel of about 1.2 million persons in the United States augmented by about 300000 persons in other countries. comScore provides usage estimates for the US home, office, and school markets and total US market plus the non-US usage, which together provide global usage estimates.

Both services use similar metrics. The primary metrics used by NLM for Internet audience measurement, whether based on external panels or internal Web log software, are the following: unique visitors (number of different users); total visitors (total number of users including repeat visitors); total visits (number of times the NLM sites are visited in a given period); and pages downloaded (total number of Web pages downloaded by all users).

For this paper, we have used only Internet audience measurement data from comScore because it is the only one of the two vendors that provides estimated worldwide website usage. This is particularly important in the case of NLM, since half or more of NLM's Web usage originates from countries other than the United States. Also, worldwide usage data are the only data that can reasonably be compared with Web log data. Also, in this paper, we use only the comScore data based on measurement of traffic from the computers of participating panelists. These are known as machine-based panel data and are more comparable to the data collected by Web log software. Machine-based panel data could undercount the total number of users due to multiple persons using the same computer. All data in this paper are machine-based—either from the comScore panel or from NLM's Web log software—in order to help assure comparability to the extent possible.

Results

Cross-Validation with Web Log Data

NLM has made efforts to cross-validate Internet audience measurement data from external panels against internal Web log data. Only comScore data can be used for this type of cross-correlation, since the Web log data measure global usage. As noted, the comScore methodology measures Web usage of panel members and then extrapolates to US and global estimates based on demographic factors and assumptions. In comparison, Web log software measures the number of IP addresses that visitors are using, not the users directly, and includes IP addresses from any locale worldwide. The assumption is that the number of different IP addresses measured in a given period of time roughly correlates with the number of actual users. But single users with dynamic IP addresses and multiple users with the same IP address are two examples of ways in which the IP data could be misleading. Thus, both methods are subject to varied sources of error, and precise correlations between Web log data and external Internet audience data would not be expected.

Table 1 shows comparisons between comScore global usage data and Web log data for the two most heavily used NLM websites—PubMed and MedlinePlus—for three metrics, in September 2003. Table 2 shows the same information for October 2004.

Table 1. Comparison of comScore and Web log data for PubMed and MedlinePlus, September 2003

	Unique Visitors (millions)	Total Visits (millions)	Total Pages Downloaded (millions)
PubMed			
Web log[*]	4.2	7.6[†]	193
comScore	3.8	10.2	62
MedlinePlus			
Web log[‡]	2.7	5.6	23
comScore	3.4	5.2	20

[*] Data are from custom Web log software installed on PubMed server.

[†] Estimated

[‡] Data are from WebTrends Web log software installed on MedlinePlus server.

Table 2. Comparison of comScore and Web log data for PubMed and MedlinePlus, October 2004

	Unique Visitors (millions)	Total Visits (millions)	Total Pages Downloaded (millions)
PubMed			
Web log[*]	10	21[†]	235
comScore	5.7	12.8	117
MedlinePlus			
Web log[‡]	6.2	10.5	59
comScore	5.6	8.7	30

[*] Data are from custom Web log software installed on PubMed server.

[†] Estimated

[‡] Data are from WebTrends Web log software installed on MedlinePlus server.

The usage data compare very well for MedlinePlus across all metrics—unique visitors, total visits, and total pages downloaded—in the first sample month (September 2003) and for unique visitors and total visits in the second sample month (October 2004), but not total pages downloaded. The comScore data appear to undercount the number of MedlinePlus pages downloaded in October 2004, which may reflect differences in definitions of what data are captured and in usage patterns of the comScore panelists. For example, tutorials are one of the most popular MedlinePlus features, and the Web log software equates each tutorial to many pages downloaded (each sequential view of the tutorial is counted as a separate page). It is unclear to what extent the comScore methodology captures tutorial use and other MedlinePlus special features, such as the link-outs, on a basis directly comparable to Web log software.

For PubMed, the September 2003 data compare very well for unique visitors, fairly well for total visits, and not very well for total pages downloaded; the October 2004 data suggest that comScore is undercounting PubMed usage across all three metrics by 50% to 75%. The PubMed discrepancies are probably due in part to the under-representation of researchers and scientists on the comScore panel, as well as to differences in definitions of what is considered a “page viewed” with Web log data versus comScore data. Researchers and scientists are a core PubMed user group and likely are very intensive users. This would translate into a heavy volume of visits and pages downloaded; thus, if they are under represented on the panel, this would result in lower than expected usage data. While the comScore panel gives special attention to the college sector, the emphasis is primarily on students, not on faculty and research scientists who would likely be the more intensive users of PubMed. Overall, the apparent correlation between comScore and Web log data was judged to be good in September 2003 but mixed in October 2004 due to the PubMed undercounting. The latter may be exacerbated in recent months because Google has indexed PubMed, which appears to have significantly further increased the number of site visitors.

NLM as a Percentage of NIH Web Usage

One of the goals of NLM's use of Internet audience measurement data is to better understand NLM's position within the broader NIH Internet and Web usage environment. This is important to know because the Internet audience measurement services generally collect data by top-level domain, such as NIH.gov. This makes it difficult to track subdomain usage unless the subdomain (or group of subdomains) represents a large part of the top-level domain usage.

Accordingly, NLM has requested special drill-down data from both vendors in order to be able to separate usage of NLM websites from usage of other NIH websites. Table 3 shows the estimated percentages of total NIH Web usage that are attributable to NLM's National Center for Biotechnology Information (NCBI), including, predominately, PubMed, MedlinePlus, and other NLM websites combined.

Table 3. NLM website usage as a percentage of NIH usage, October 2004, based on comScore data

	Unique Visitors (Reach) (%)	Total Pages (Share) (%)
NCBI (including PubMed)	45	64+
MedlinePlus	39	14
Other NLM websites	4	1
Totals	55-75 (estimated; not additive)	80+ (additive)

Unique visitors are not strictly additive since users can visit more than one NIH website in a given month. However, the usage data suggest that an estimated 55% to 70% of the total unique visitors per month to all NIH websites are accounted for by usage of NLM websites. Total pages downloaded per month are additive, and these data highlight the large percentage of pages downloaded that is attributed to users of NLM websites—about 80% (or more, if the comScore data undercount PubMed pages downloaded).

Overall, these results suggest that, at least as a rough approximation, NIH top-level domain usage data can be used as a reasonable surrogate of NLM website usage, since NLM website usage accounts for such a large part of overall NIH website usage.

US Home Health Information Space

The next step in the analysis was to look at the US home health information space with regard to the leading general purpose health information sites. (Specialized websites such as ediets.com were excluded for this purpose.) Using US home data from comScore, the top five websites in terms of monthly unique visitors for September 2004 were the following:

- WebMD: 2.5 million
- NIH.gov: 2.4 million (top-level domain inclusive of NLM)
- AOL Health (powered by WebMD): 1.7 million
- Yahoo! Health: 1.2 million
- MSN Health (at the time, powered by WebMD): 950000

Thus in the US home market, WebMD and NIH.gov were virtually tied in usage, although WebMD would be the clear leader if credited with the usage on AOL Health and MSN Health that both use WebMD for their consumer health information portals.

The second tier of health information websites in the US home market includes the following (numbers are unique visitors per month):

- CDC.gov (Centers for Disease Control, US Department of Health and Human Services): 740000
- MayoClinic.com: 427000
- KidsHealth.org (Nemours Foundation): 448000

- Medscape.com (geared to physicians and other health professionals; now part of WebMD): 263000
- FamilyDoctor.org (American Academy of Family Physicians): 243000
- HHS.gov (the main DHHS website): 384000
- AMA-assn.org (American Medical Association): 174000
- Intelihealth.com (with Harvard Medical School): 120000

Taken as a whole, it would appear the WebMD and NIH.gov are the clear leaders in the US home health information market based on unique visitors per month.

Global Health Information Space

Over the last several years, NLM has detected an increase in non-US usage of NLM websites. This trend was confirmed by Internet audience measurement data. The global increase has been significant enough to keep NIH.gov overall Web usage in the number one position in the global health information space, with WebMD.com close behind in number two (Table 4), as measured by unique visitors per month. In terms of total pages downloaded per month, NIH.gov Web usage maintained a significant edge over WebMD (due mainly to large page downloads by PubMed users). comScore believes that most of the increase in WebMD usage can be attributed to an increase in advertising and promotion of the WebMD brand combined with WebMD's strategic partnerships and acquisitions.

Table 4. NIH.gov versus WebMD usage in the global health information space, based on comScore data

	Sept 2002	Sept 2003	Sept 2004
Unique Visitors per Month (millions)			
NIH.gov	6.6	9.8	12.3
WebMD	5.3	5.9	11.1
Total Pages Downloaded per Month (millions)			
NIH.gov	87.7	114.8	184.0
WebMD	64.6	81	107.8

Table 5. Illustrative worldwide leading health information websites, April 2004 and April 2005, based on comScore data

Website	Unique Visitors in April 2004 (millions)	Unique Visitors in April 2005 (millions)
NIH.gov (all websites)	11.3	17.2
NLM websites (subset of NIH.gov)	7.6	12.1
WebMD (main corporate website)	7.5	15.5
AOL Health[*]	4.9	6.1
PubMed (subset of NLM)	3.8	7.4
Yahoo Health	5.0	6.5
MedlinePlus (subset of NLM)	4.1	5.4
MSN Health[†]	3.7	10.1
iVillage Health	2.1	1.5
KidsHealth.org	1.5	2.9
Medscape.com	1.7	1.8
MayoClinic.com	1.1	2.0
FamilyDoctor.org	.465	1.4
AMA-assn.org	.928	1.3
Cancer.org	.690	1.1
Cancer.gov	.652	.704
Intelihealth sites	.545	.597
Breastcancer.org	.168	.327

[*] AOL Health is powered by WebMD.

[†] MSN health was powered by WebMD in 2004 but not in 2005.

As shown in Table 5, as of April 2005, measured usage of the NIH family of websites still exceeded that of WebMD. However, in terms of individual websites, WebMD still was the number one single website, and it exceeded the combined usage of NLM's (and NIH's) two most heavily used websites—PubMed and MedlinePlus. Further, if AOL Health was counted as part of the WebMD network (on the argument AOL uses the WebMD health portal), then the WebMD network of websites would exceed the NIH family of websites as measured by unique visitors per month. Note that MSN Health used to include the WebMD health portal, but in 2005, it changed its partnership such that WebMD still provides the content but without using the WebMD brand on MSN. Thus it can be argued that MSN Health is no longer part of the WebMD family from the perspective of Internet audience measurement of branded websites.

Global Cancer Information Space

The two primary types of websites for disease-specific health information are general purpose health sites that include information on a wide range of diseases and conditions, and specialty websites focused on a single disease or condition.

MedlinePlus is an example of a general purpose health information portal website. For purposes of this paper, we focused on cancer information. Three major types of cancer information available through MedlinePlus are (1) individual downloadable Web pages that include cancer-related content, (2) interactive tutorials that address cancer-related topics, and (3) link-outs (known as “redirects”) from MedlinePlus to other websites that, in turn, have cancer-related content.

MedlinePlus Web log data for October 2004 indicate that about 4% of the top 360 pages downloaded are pages with cancer-related information. The topics covered included the following types of cancer: breast, prostate, skin, cervical, lung, ovarian, stomach, lymphoma, colon, bone, Hodkgin's lymphoma, colorectal, and throat or larynx. The October 2004 data show that about 16% of the tutorial usage related to cancer and covered the following topics in one way or another: prostate cancer, chemotherapy, colon cancer, mammography, brain cancer, breast lump biopsy, breast cancer, ovarian cancer, radiation therapy, skin cancer, early screening and cancer prevention, lung cancer, and melanoma.

The October 2004 Web log data also show that about 4% of all MedlinePlus link-outs (users linking or clicking out from MedlinePlus to an external website) clearly were to cancer-related websites. Three sites accounted for most of these link-outs: www.cancer.gov (National Cancer Institute), www.cancer.org (American Cancer Society), and www.breastcancer.org (maintained by an independent non-profit organization). The topics covered in these link-outs included the following: actinic keratosis, Hodgkin's disease, stomach cancer, skin cancer, prostate cancer, cervical cancer, ovarian cancer, myeloma, bone cancer, non-Hodgkin's lymphoma, stomach cancer, uterine cancer, gallbladder cancer, breast cancer, kidney cancer, liver cancer, pancreatic cancer, thyroid cancer, and endometrial cancer. It would be expected that other general purpose health websites, such as MayoClinic and WebMD, would also have a significant percentage of cancer-related page downloads and website link-outs.

Another way of looking at the data is by NIH institutes and centers. Among all the NIH units with websites, the Web log data show that, in October 2004, the second largest percentage of MedlinePlus link-outs went to the National Cancer Institute (about 4% of all link-outs).

With regard to cancer-specific websites, a review of the comScore worldwide data for August 2004 indicated that the top three sites were www.cancer.gov, www.cancer.gov, and www.breastcancer.org. Thus the global data based on the comScore external panel and the MedlinePlus Web log data appear to be consistent in identifying the most heavily used cancer-specific websites. However, it should be emphasized that there no doubt are other useful cancer-specific websites but with lower usage levels that are below the minimum cutoffs for monitoring by comScore.

Global US Government Information Space

NLM and NIH are responsible for websites that operate in both the health information space and the US government information space. Table 6 illustrates the impact of global Web usage on the relative rankings of the top eight US government websites or top-level domains. For the months of September 2003 and September 2004, NIH.gov ranked consistently in the top three US government websites in global unique visitors and in the top four in global total pages downloaded. NOAA, USPS, and NASA, along with NIH, are in the leading group, joined by the IRS and US Department of Education during peak tax and student financial aid seasons, respectively.

Table 7 shows comparisons between the NIH.gov top-level domain and other well-known US government top-level domains. NIH.gov had several times the number of unique visitors per month than any of the other domains listed. By comparison, NIH.gov had roughly six times the number of visitors as WhiteHouse.gov and about the same number of visitors as the combined total of the WhiteHouse.gov, Army.mil, Navy.mil, AF.mil (Air Force), and CIA.gov. Using the ratios discussed earlier, the NLM subdomain usage would be roughly equivalent to, for example, the combined total of the WhiteHouse.gov, House.gov, Senate.gov, and CIA.gov (or other equivalent combinations).

Table 6. Relative global rankings of the top eight US government websites or top-level domains, based on comScore data

Web Domain	September 2003				September 2004			
	US Unique Visitors	Global Unique Visitors	US Total Pages	Global Total Pages	US Unique Visitors	Global Unique Visitors	US Total Pages	Global Total Pages
NIH.gov	3	1	4	1	3 —	2 ↓	4 —	3 ↓
NOAA.gov	2	2	2	3	1 ↑	1 ↑	1 ↑	1 ↑
USPS.com	1	3	1	2	2 ↓	3 —	2 ↓	2 —
NASA.gov	6	4	6	5	6 —	4 —	5 ↑	5 —
LOC.gov	8	5	8	7	8 —	8 ↓	8 —	8 ↓
ED.gov	4	6	3	4	4 —	5 ↑	3 —	4 —
CDC.gov	7	7	7	8	7 —	6 ↑	7 —	7 ↑
IRS.gov	5	8	5	6	5 —	7 ↑	6 ↓	6 —

Note: Arrows indicate direction of change (increase or decrease) in relative ranking (— denotes no change in ranking).

Table 7. NIH.gov Worldwide usage compared with other US government top-level domains, April 2005, based on comScore data

Web Domain	Unique Visitors (millions)	Total Pages Downloaded (millions)
NIH.gov	16.8	287.3
Army.mil	4.2	162.6
Navy.mil	3.0	43.1
CIA.gov	2.9	12.2
AF.mil (Air Force)	2.0	47.2
WhiteHouse.gov	2.3	24.8
House.gov	1.5	7.5
Senate.gov	.978	6.2

Discussion

Overall Value

The use of Internet audience measurement services based on external panels of Web users has proven invaluable to NLM. This method is the only known means by which NLM can understand where NLM (and NIH) websites fit into the health information and government information sectors.

The comScore Internet audience data indicate that NLM websites collectively account for the majority of NIH website usage, and that, in turn, NIH websites collectively are the most heavily used among all US government health agencies. Overall, in the global health information space, based on April 2005 data, the top six websites in terms of usage on a single site basis appear to be WebMD, MSN Health, PubMed, Yahoo! Health, AOL Health, and MedlinePlus. Given the uncertainties in the extrapolated usage data, it could be argued that these websites are in the same ball park in overall usage. On a corporate basis, NIH.gov (all websites, but powered in large part by PubMed and MedlinePlus) would appear to have somewhat greater usage than WebMD. However, WebMD would have greater usage if the traffic of its strategic partner AOL Health was included.

There is no perfect methodology for estimating website usage. Interpretation and use of such usage data should take into account the inherent limitations of the data collection and extrapolation methodology, whether it is the use of external Internet audience panels or Web log software.

Relative Advantages

Many websites, and most major websites such as NLM's, have Web log software installed on the Web servers. The Web log software captures data on website usage, including total number of visits and visitors, unique visitors, pages downloaded, and various other usage metrics. The Web log data provide reasonable estimates of usage of the website on which the software is installed. The Web log data are subject to some error factors since the data are based on IP addresses using the website, which are used as a surrogate of the actual human users. Complications arise for users with dynamic IP addresses since a single user (especially a dial-up user) might have a new IP address assigned at each log-in. This could artificially inflate the number of unique users in a given month. On the other hand, users at universities or companies may be undercounted since these institutions often use proxy servers, which Web logs record as a single IP address. Thus, multiple users would be counted as only one user since the IP address remains the same for each user. Proxy servers can also cache downloaded pages thus also undercounting the number of pages downloaded.

Internet audience measurement data based on Web usage by external panels offer a complementary method for estimating usage, even of one's own website. Of course, the external panel methodology is itself subject to some error factors, such as variable methods of panel recruitment, selection bias in populating the panel, and uncertainties in extrapolating from panel usage to sectoral, national, or even global usage estimates. On the other hand, Web robots, agents, and crawlers may impact and possibly distort the Web log data, but not the panel data. NLM has found that the global Web usage estimates do correlate reasonably well (typically +/- 10% to 15%) for MedlinePlus when compared with Web log usage data for comparable time periods. However, it now appears that the comScore data undercount PubMed usage by 50% to 75% or more. It remains to be seen in coming months whether this difference is due to the Google indexing, under-representation on the comScore of some primary PubMed users groups (eg, biomedical scientists), or to some other factors as yet unidentified. Only global usage estimates can be compared since it is very difficult to parse out IP-based usage data for specific geographical areas or user sectors.

Market Aggregation and Drill Down

In addition to augmenting Web log data, Internet audience measurement data based on external panels has the decided advantage of being able to provide usage estimates for other websites. Further, the data can be aggregated into market segments, and provide the basis for estimating market shares for specific websites of interest. In theory, such market share estimates could be constructed from Web log data. But as a practical matter, Web log data are considered by many organizations to be proprietary, and such data are very difficult to access by anyone outside of a website's own organization.

Based on NLM's own experience with using external Internet audience measurement data, it would appear that such data can be used to paint a reasonably accurate picture of the relevant market sectors—in NLM's case, the health information sector and US government information sector. NLM's websites are situated at the intersection of these two market sectors, or spaces.

NLM also has found the Internet audience measurement data useful for better understanding the usage distribution within a top-level domain, in this case, NIH.gov. NIH is a very large organization with over 125 websites managed by several dozens of separate organizational units. It has proven difficult to collect Web log data across so many websites. Thus, Internet audience measurement data are a more viable way to at least estimate relative usage of websites within the NIH.gov top-level domain. In earlier years, NLM requested so-called subdomain drill down data from the vendors as a custom service. Today, however, subdomain data are available, at least for websites with adequate traffic, as part of routine online data reporting.

NLM's efforts to understand and track Web usage are somewhat easier because two of NLM's websites, MedlinePlus and PubMed, appear to be the two most heavily used US government health-related websites. Together they account for between half and four-fifths of all NIH Web usage, depending on the metric used.

The dominance of the usage data by MedlinePlus and PubMed in the public sector, and by WebMD in the private sector, should not, however, obscure the importance of many health-related websites with lesser usage levels. At NLM and NIH, there are many so-called niche-market websites that focus on health information related to a specific disease, condition, or research or application area. The usage of these websites can also be tracked with Internet audience measurement data, at least for websites with 50000 to 100000 monthly unique visitors. Below that level, the panel usage data are usually too limited to assign statistical significance.

The cancer information case study illustrated how both Web log data and Internet audience data can improve understanding of usage of disease-specific health information websites.

Conclusion

In summary, overall, Internet audience measurement data based on Web usage of external panels have proven to be quite useful to NLM. These data have allowed NLM to better understand the overall health information market space and the positioning of NLM websites within that market. The Internet audience data also lend themselves to various types of demographic and geographic analyses, which NLM intends to compare with other types of usage data, such as Web log data, and with the results of user surveys.

The external measurement approach is an important tool in NLM's arsenal of Web evaluation methods. It must be kept in mind, however, that Web usage statistics such as unique visitors and pages downloaded per month, while important, do not address the perceived quality, usefulness, or user friendliness of the referenced websites. For these key dimensions of website performance, other Web evaluation methods are needed. These include, in particular, surveys of Web users. NLM has made extensive use of online surveys of NLM website users, while these users are on the website. As a complement, members of external panels, including the Internet audience measurement panels, could be surveyed as well. We end where we began, with an emphasis on the need for a multidimensional approach to Web evaluation, of which Internet audience measurement is one of several important methods.

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Conflicts of Interest

None declared.

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Abbreviations

IP: Internet protocol
NCBI: National Center for Biotechnology Information
NIH: National Institutes of Health
NLM: National Library of Medicine

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