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The Internet and Health Communication: An Overview of Issues and Research

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Health issues are becoming increasingly important for the public agenda. The same is true of new communication technologies, especially the Internet. The intersection of these two highly significant social trends creates a rich, consequential, and challenging domain for users, health providers, researchers, and policymakers.

New communication media and information systems will likely transform the way health care is provided in at least as profound a way as did the movement of the site of health care delivery away from the barbershop. People will be empowered to gain expert insight into their problems and assess the options available to treat them. Diagnosis and cure will be dispensed interactively and electronically. At the same time, there are many opportunities for incorrect, misleading, fraudulent, and dangerous practices. Serious questions also arise about the ability of those with economic, intellectual, or physical limitations to participate effectively in this new environment.

This chapter reviews the primary issues and research surrounding the use of the Internet for health communication. The following sections review three major categories of applied and research issues: (a) Coverage and use of Internet health communication, (b) major communication issues, and (c) major industry and policy issues.

COVERAGE OF INTERNET AND HEALTH COMMUNICATION IN RECENT PUBLICATIONS

Table 9.1 shows the growing interest in this area, based on very specific key word searches in three major commercial publication databases. The major growth has occurred in just the last or three or four years.

Table 9.1. Growth of Articles Concerned with Internet and Health Communication Retrieved from Professional, Business and Medical Publication Databases, 1991-2000, as of November 2001.

| Year | Dow Jones News and Business | ABI/INFORM | Medline |
|-------|-----------------------------|------------|---------|
| 2000 | 147 | 1620 | 2270 |
| 1999 | 18 | 19 | 15 |
| 1998 | 46% | 34% | 23% |
| 1997 | 29 | 22 | 20 |
| 1996 | 15 | 15 | 12 |
| 1995 | 18 | 26 | 15 |
| 1994 | 9 | 16 | 26 |
| 1993 | 7 | 13 | 18 |
| 1992 | 5 | 9 | 7 |
| 1991 | 2 | 3 | 4 |
| 1990 | 1 | 2 | 1 |
| 1989 | 1 | 1 | 0 |
| 1988 | 1 | 1 | 0 |
| 1987 | 1 | 1 | 0 |
| 1986 | 1 | 1 | 0 |
| 1985 | 1 | 1 | 0 |
| 1984 | 1 | 1 | 0 |
| 1983 | 1 | 1 | 0 |
| 1982 | 1 | 1 | 0 |
| 1981 | 1 | 1 | 0 |
| Total | 3816 | 1465 | 236 |

Note: Search query (on November 25, 2001): ((Internet) or (WWW)) and ((health communication) or (medical information)).

2000 figures may be underestimated as many items are added to databases several months after their publication date. Database coverage and content changes, so these figures for prior years are different from results from searches conducted in prior years.

- Dow Jones Interactive News and Business Headlines—6,000 leading U.S. and international business newspapers, magazines, trade journals, newsletters, television, and radio transcripts; searched fulltext.
- ABI/INFORM—1,000 U.S. and international professional publications, academic journals, trade magazines; searched fulltext.
- Medline—3,900 journals covering medicine and health care, communication disorders, population biology, and reproductive biology; searched all fields.

GENERAL USAGE OF THE INTERNET FOR HEALTH INFORMATION AND COMMUNICATION**General Use**

Use of computers and the Internet in the United States is, by now, widespread, and significant percentages of the public are already using the Internet to get health information. Nationally representative surveys of adults between 18 and 60, and then children between 10 and 17, in December 1999, found that once people have access to the Internet, differences in accessing health information associated with the "digital divide" tend to disappear (Brodie et al., 2000). Of the 53 percent of adult respondents who have access to the Internet or e-mail at home, more than half reported using the Internet "to get health or medical information." Women are more likely than men (62% vs. 48%) to use the Internet at home to access health information. Of American adults under 60 who use computers at home to get health or medical information, 63 percent are looking for "information about how to treat a disease [they] or a family member have" or "information about medicines or prescription drugs" (60%), and 53 percent are looking for "information about ways to prevent illnesses." Over a quarter (28%) are looking for "information about a health care provider, such as a doctor or a hospital", and 19 percent are looking for "information about sexual health issues" such as birth control, human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), or sexually transmitted diseases (STDs). Only about 20 percent of children (girls, 22%; boys, 13%) who have a computer at home use the Internet "to get health or medical information." Among kids who use their home computers for this purpose, 65 percent are looking for "information about diseases," 51 percent are looking for "information about ways to prevent illnesses," and 44 percent are looking for "information about diet, exercise, or how to look your best." Around one-fourth are looking for "information about sexual health issues such as birth control, HIV, AIDS, or STDs" (28%) and "information about doctors, hospitals, or how to find a clinic" (22%). Health is one of the few areas of Internet usage where women users outnumber men (53% to 47%) (Goldman-Sachs, 1999).

A CyberDialogue/Internet Health Day survey of 2000 Internet users estimated that over 24.8 million people sought online health and medical content in 1998, up 44 percent from the prior year (*Trenton Times*, 1999). About 52 percent of users sought information on diseases, about one third sought information on diet and nutrition, pharmaceuticals, and fitness, and about 15 percent sought information on children's health. About one quarter of the disease-related searchers had joined an

online support group (MSNBC, 1999). The 2001 CyberDialogue/Internet Health Day survey reported 41 million, or 54 percent of all U.S. adults, using the Internet for health information. Twenty-two million went online to research a specific condition, with the three most heavily researched topics being obesity, allergies, and cancer. Some studies report that as many as 86 percent of adult users have accessed the Internet for health information (Harris Interactive, 2000).

Web Sites

There were around 26,000 health-related Web sites in 2001 at the prime tier of both the Yahoo and Netscape directories (Firstman, 2001). Many of these are commercially based, and represent a market capitalization of over \$1 billion. In 1998, the U.S. Department of Health and Human Services site, *www.healthfinder.gov*, received about 4.7 million hits per month from 8,000 people per day. After the National Library of Medicine provided free Web access to MEDLINE in June 1997, usage jumped 100 percent to 75 million searches per year (Lindberg & Humphreys, 1998). The National Library of Medicine has just opened an Internet-based registry of all ongoing clinical trials looking for participants (<http://clinicaltrials.gov>).

There are now so many Web sites about any given topic that specialist meta-search engines, directories, and gateways are emerging to help provide evaluations and guidance. Invisible Web (*www.invisibleweb.com*), which is a meta-search engine that returns specialized rather than general lists or sites, provided 26 "health" subcategories pointing to 640 sites, and Yahoo! provided 43 "health" subcategories pointing to over 19,000 sites. The U.S. Department of Health and Human Services provides the "healthfinder" site (*www.healthfinder.gov*), a gateway site with links to nearly 6,000 online resources from federal and nonfederal organizations covering over 1,000 health topics (Baur, Deering, & Hsu, 2001). There are also many medical journals online (*www.yahoo.com/Health/Medicine/journals*), with a growing number of them full-text and peer-reviewed.

Mailing Lists and Newsletters

A search on *Liszt.com* provided nearly 300 health-related mailing lists. Topics ranged from ethnicity-specific health issues, managed health care, and women athletes, to hypnosis and past lives, occupational health, distance health education, and holistic and natural health care. *Liszt.com* also found nearly 400 commercial lists (ads, press releases,

announcements) in 28 categories ranging from allergy supplies, aromatherapy, and how to stop smoking, to natural healing, stress management, and vitamins and minerals. *Meta-List.net*, a search engine for nearly a quarter-million online newsletters and discussion lists, returned over 500 results for the term "health communication" (such as a list for health-promotion and disease prevention researchers). The E-Zine-List (www.meer.net/~johnl/e-zine-list) shows that of the 80 most frequent keywords used to index and retrieve online newsletters and e-zines, "health" was 18th, with 180 e-zines.

Newsgroups

In 1995, the last time individual newsgroup readership figures were provided, of the top 10 Usenet newsgroups (each with from 8,000 to 22,000 readers monthly), half were concerned with health topics. In decreasing order, they were: depression, diet, cancer, eating-disorder and arthritis (Walther & Boyd, 2001). More recently, *DejaNews.com* listed seven main categories of "health and fitness" newsgroups. A *Listz.com* search of newsgroups that had the words "health communication" found 111 groups, and 169 groups with the words "medical information".

Medical/Professional Sites and Networks

The rise of the Internet for health communication is just one subcomponent of ongoing developments in medical computing and information systems, large-scale changes in the health care industry (such as managed care/health maintenance organizations and integrated delivery systems), community health information networks (CHINS), and new kinds of health information users (such as medical suppliers, pharmaceutical companies, and health information system service providers). There are several comprehensive reviews and analyses of CHINS, medical informatics, medical information systems, medical computing, online practice guidelines, telemedicine, Web-enabled hospitals, the Internet, and telemedicine (Anderson et al., 2000; Armoni, 1999; Bashshur, Sanders, & Shannon, 1997; Coiera, 1997; Committee, 1997, chapter 1; Dowling, 1997; Eder, 2000; Eder & Wise, 2001; Kissinger & Borchardt, 1996; Rubin & Aukema, 1997; U.S. Congress, 1993, Chapter 3; Winkler & Silber, 1998). Eng (2001) and Mittman and Cain (2001) provide a comprehensive discussion and assessment of current and potential "eHealth" stakeholders, issues, concerns, and trends. Ehealth tools include information presentation; information search assistance; health behavior change; informed decision making; distance learning and train-

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ing; clinical and public health information systems; health services and information systems integration; administrative transactions; clinical and biomedical research; messaging, information exchange, emotional support, and community building; e-commerce and shopping; care coordination and information portability; electronic health records; shared clinical decision-making; expert systems; disease management; and telemedicine/telehealth.

Several integrated Web-enabled systems have been developed at national levels. For example, the Australian "Doctor's Desktop" plan suggests bringing together four major application groupings: practice administration, practice scheduling (including capabilities to support preventative medicine), pharmaceutical services, and clinical supply chain (pharmaceutical developers, vendors, hospitals, patients, insurance companies) is being integrated (More & McGrath, 2001). And the United Kingdom's National Health Service network aims to support all clinical and administrative functions by 2005 (Hackney & McBride, 2000).

A related development is the use of networked retrieval systems to diffuse medical information among doctors, clinicians, and researchers (Baujard et al., 1998; Detmer & Shortliffe, 1997). However, in spite of the comprehensive National Library of Medicine's MEDLINE system, which provides access to 30 years of medical literature and 9 million records, many doctors are unaware of recent relevant information or have limited time and expertise to use such systems. More accessible and widely used web-based online health information databases and search tools include: (a) Internet Grateful Med (igm.nlm.nih.gov), the free Web-based interface to the MEDLINE database, which has specialized features such as the ability to convert common query terms into specific NLM medical thesaurus terms, and general and detailed displays of results; (b) PubMed (ncbi.nlm.nih.gov/pubmed), which provides a simpler interface to MEDLINE, though it does offer a "see Related Articles" (based on similarity of content) link and a special specialized filter for clinical queries; and (c) the Medical World Search (msearch.com), which allows searching of thousands of medical sites using the NLM thesaurus (Rampil, 1998).

MAJOR COMMUNICATION ISSUES

Healthcare requires accurate, accessible information and timely and effective communication within and among various stakeholders, in various formats, and through a variety of features.

Patient-Physician Communication

Online information could have potentially substantial benefits in reduced patient anxiety and decreased time and cost in obtaining health information, in better evaluations of potential doctors, and in better informed patients who can then engage in deeper discussions with their physicians, and are more likely to follow recommended treatments. Online communication may improve interaction among other health care providers, increase interaction and intimacy between doctors and patients, enable the discussion of sensitive topics, provide easy access to quick opinions, avoid telephone tag, improve patient compliance with treatments, and increase patient health knowledge (Hodge, Gostin, & Jacobson, 1999; Lemaire, 2000; Spielberg, 1998; Turner, 2000; Weinberg et al., 2000).

Certainly the current status of patient-physician communication has room to improve. A large-scale survey of patients ($n=1008$) and physicians ($n=230$) (Harris & Associates, 1997) reported that physicians and patients feel that communication with each other needs significant improvement. Consequences of these problems include patients avoiding seeing their doctors, withholding important information, not following medical directions, not asking questions or talking about their health problems. Reasons that patients turned to other sources for health care information included "easier accessibility/quicker" (52%), don't want to "waste" the doctor's time (14%), and "feel more comfortable" (11%).

The Internet is beginning to challenge, redefine, resolve and even increase these communication problems. Davis and Miller (1999) reported that more and more patients are showing up with Internet printouts, becoming more informed about a particular topic than their doctors. A late 1998 survey of New Jersey physicians reported that nearly 60 percent reported seeing a patient within the past month who discussed with the physician information obtained from the Internet (Aspden & Katz, 2001). Although some doctors resist patients who come in with Internet research (Kahin & Keller, 1995), which may be incomplete, misinterpreted, or outright quackery, other physicians know that well-informed patients are better patients. Thus recommendations include providing good review and summary sites for patients, providing them accurate search terms, requesting copies of materials be sent to them before the scheduled appointment, and indicating how much extra charge for consultation will be involved (Lowes, 1997). Potential patients can now even check up on the medical backgrounds, licensing information, and legal cases of their physicians (Cornell, 2001).

But some people may substitute Internet health information for physician interaction: according to a 1998 survey of over 1,000 California

residents, those with Internet access were less likely than were those without access to consult their physicians and health care providers for information about medical conditions (Fennbridge, Moya, & Rodrigues, 1999). And online clinics are providing information and diagnosis to thousands of medical consumers (Stroh, 1999) who tend to be less passive. Such clinics attempt to avoid liability issues by warning that the online doctors will not "enter into a physician-patient relationship" or "engage in any conduct that involves the practice of medicine" (p. 2), facilitated by enforced anonymity. However, it is possible that physicians may be held legally responsible for not becoming aware of relevant medical information that would be easily obtained through the Internet or other medical information systems (Hodge, Gostin, & Jacobson, 1999).

Although more than half of one survey's respondents indicated they would like to communicate via e-mail with their health care providers, only 6 percent of them have done so (Sittig, King, & Hazlehurst, 2001). Borowitz and Wyatt (1998) report on the development, content, and effort associated with providing e-mail physician-patient consultation. They reviewed nearly three years of e-mail consultation requests ($N=1239$) sent to one division at the University of Virginia Children's Medical Center. Nearly one out of 10 of the requests sought a second opinion, implying one interesting use of online resources—avoiding questioning doctors face-to-face—and 22 percent requested general information. Hodge et al. (1999) review other studies of physician-patient e-mail interaction.

Early physician e-mail users note a variety of advantages, such as a better medical record (indeed, to avoid liability, such messages must be stored as part of the patient's record, rather than treated as casual, ephemeral conversation), more considered response, reduction of media costs, increased service provision through Web site e-mail addresses, the use of online forms for patient information collection, and hypertext links to online resources (Spielberg, 1998). However, physicians are not necessarily exemplary Internet health information users. Eysenbach and Diepgen (1998) surveyed 58 physicians and Web masters (found on Web sites for dermatological information retrieved through search engines) concerning their attitudes toward unsolicited patient e-mail requests for medical advice, stimulated by a fictitious acute skin problem described in an e-mail sent out by the researchers. Half of the physicians responded to the request, 31 percent of those would not provide advice without seeing the patient's skin, 93 percent recommended that the person see a physician, and 59 percent actually referred to the correct "diagnosis." Thus standards are needed to protect both physicians and patients.

Physician-Physician Communication

There is great potential for improving the communication and service provision among the 650,000 physicians, 2 million nurses, tens of thousands of medical researchers, and 1 million administrative healthcare professionals in the United States (Goldman-Sachs, 1999). A Healthcon Corporation survey reported that 85 percent of the 10,000 surveyed physicians were using the Internet (Stroh, 1999). A recent survey of over 1,000 office-based U.S. physicians by the AMA found that usage of the Web by doctors rose from 20 percent in 1997 to 37 percent in 1999, with 58 percent of physicians who had a computer but not Web access planning on getting Web access within the next half year (AMA, 1999). As of October, 1999, up to 80 percent of all U.S. physicians were online (Credit Suisse First Boston, 1999), though Goldman-Sachs (1999) suggests the use of the Internet and the Web is more likely 30 percent–40 percent, with the rest referring only to regular e-mail.

Many sites, such as Australia's *www.medeserv.com.au* and *www.hcn.net.au*, provide extensive online services and resources for health professionals, such as evidence-based research databases, tutorial, textbooks, news, Web site indexes, pharmaceutical databases, full-text, world health sites, discussion forums, and so forth. Many companies are beginning to offer full-service Web-based support for enrollment, eligibility, and claims process, such as *MedOffice.Medscape.com*. The American Medical Association has developed a 30-city physician continuing medical education course on advanced Internet applications for health care, an extension of its more basic Physicians Accessing Internet program (AMA-Internet Health Road Show, 1999).

One study of a physician/researcher discussion list (an anesthesiology discussion group; Worth & Patrick, 1997), based on a content analysis of 635 consecutive messages in one month and surveys from 28 participants, found that the practitioners rated the overall quality of responses to clinical questions at 7.1 (from 1, poor, to 10, superb), and their likelihood of using the list again for such questions at 8.7. Practitioners in solo or small group practices were more likely to use the discussion list for consultation, and rated the quality of information higher than did those in large practices.

Patient-Patient Support Communication

One of the most discussed uses of the Internet for patient communication is online support groups. Walther and Boyd (2001) identified four primary dimensions of reasons for, and benefits from, online support groups: the social distance provided greater expertise, management of

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potential stigma, and candor; anonymity helped protect their personal identity concerning sensitive topics; characteristics of the medium allowed users to manage their interactions with respect to expressiveness, stigma, and obligations; and access was available any time and any place. Several selected studies of online support groups provide some quite positive descriptions.

The Johns Hopkins Pancreatic Cancer Web site (*pathology.jhu.edu/pancreas*) receives very large numbers of accesses and posted messages (Coggins et al., 1998). Indeed, these amounts far exceed what might be expected from the number of patients diagnosed with pancreatic cancer annually, indicating considerable unmet medical information and care needs. Over three-quarters of the discussion board posters were female, and nearly 90 percent were relatives of patients, indicating a powerful emotional and cognitive support resource. In February 1998, 14.5 percent of the messages requested information, 12.8 percent requested or acknowledged support, 34.1 percent provided information, and 33.6 percent provided emotional support. The site also generated a number of referrals to the Johns Hopkins hospital. The authors propose that sites dedicated to diseases for which the providers have specialist expertise, such as university health centers, help guarantee quality information and stimulate usage.

Hemophiliacs, like groups of people with other medical conditions, have particular needs, categorized by good medicine, good physicians, good information, good education, peer support, and economic support. The analysis of 2,259 messages over 18 weeks among 58 members of the HICNet messaging system for hemophiliacs indicated that training was a potent influence on system usage (Scheerhorn, 1997). Messages concerned six themes: education, outreach, advocacy, improved psychological and physical health, business, and cost savings. One critique of online support groups is that because they involve primarily text-based, computer-mediated interaction, they cannot provide significant emotional support. However, Preece and Ghazali (2001; also Preece, 1998) analyzed 100 text-based Internet communities and found that empathy is present to some extent in most (81%) of them. Although hostile messages also occurred in 36 percent of the 100 communities very few online communities devoted to patient support and emotional support, and few moderated communities had hostile messages. Unfortunately, there's no guarantee that the person posting messages to such groups has the illness they are discussing or is even the person he or she claims to be; some people use support groups to play out "sick roles" and exhibit "facitious disorders" (Stephenson, 1998).

There is even an online discussion group concerning painful hand and arm conditions (*sorehand@ucsfvm.ncsf.edu*). Culver, Gerr, and Frumkin (1997) analyzed 1,658 consecutive messages posted to this

group by 313 authors during five months in 1994. Nearly three-quarters (72%) of the messages were posted by an affected person, and only 0.3 percent by a physician, with 68 percent of the messages providing information and 21 percent requesting information. Of the 56 percent messages addressing a medical topic, 79 percent provided medical information, with 89 percent of them provided by users without professional medical training! Nearly one third of this information was coded as being inconsistent with generally agreed medical practice. Sources of evidence were as follows, for nonprofessionals and then professionals: personal experience (61% vs. 13.5%), no source (29.8%, 67.6%), and published source (9.2%, 18.9%). There was very little challenging of advice, information, or conclusions drawn from experiences, though 10 percent of the messages expressed frustration or complaints about medical care. Culver et al. conclude that medical discussion groups are a mixture of "snake oil" and "self help"; "appropriate diagnosis and treatment may elude participants in such electronic bulletin board discussions, on a scale that is unprecedented" (1997, p. 470).

Interactive Media and Health Promotion

One aspect of communication and information technology with great implications for health promotion is interactivity, both with a system or data and with other people (Brennan & Fink, 1997; Manning, 1997; Rimal & Flora, 1997; Street & Rimal, 1997). Street and Rimal argue that the defining dimensions of interactivity are *user control* (the extent to which a user can modify the content or form of the mediation) and *responsiveness* (or extent to which a response takes into account a prior action). Interactive media can improve health promotion because of increased learning, information seeking, information processing, and individualized knowledge by current or potential patients or interested parties. Computer networks increase the potential of interactive systems by making available a wide variety of resources, participants, and applications through one system. Street and Rimal's review of past research on interactive health systems reveals considerable confounding among treatments, media features, and content, so that it is hard to draw definitive conclusions as to benefits of interactivity. They integrate this research with the concept of interactivity by proposing a three-stage model of health promotion using interactive technology: implementation and use (influenced by institutional, technological, and user factors), the user-media-message interaction, and health outcomes (intermediate attitude and cognitive outcomes, and longer-term health and prevention outcomes) influenced by psychosocial factors.

Rimal and Flora (1997) consider the distinctions among media features that may be best associated with specific health domain attributes (such as addictiveness, skills, and heredity) and individual attributes (such as demographics, psychographics, and sociocultural aspects). These distinctions include (a) multimodality, (b) networkability, (c) temporal flexibility (asynchronicity), (d) segmentation capability, (e) interactivity, (f) sensory vividness, (g) modifiability, (h) availability, (i) cost, and (j) ease of use. For example, temporal flexibility, modifiability and interactivity foster cognitive rehearsal of the desired behavior, increasing the likelihood that the behavior will be applied in actual situations. Or individuals with low involvement may well benefit from less-interactive media, such as videos.

Online Health Communication Campaigns

Many communication campaigns are beginning to integrate interactive Web sites into overall communication strategies. Indeed, the Internet and other information systems can be used to help develop and tailor health messages and campaigns based on the needs, interests, and concerns of specific groups or individuals (Kreuter et al., 2000). These online campaigns typically are well grounded in theory and extensive formative and summative evaluation.

Theories about health information seeking in general could provide useful guidance for both understanding why consumers do or do not search for relevant health information and for designing online health prevention and intervention campaigns. For example, Napoli (2001) describes three models explaining general health information seeking. The synergy model (Schooler, Flora, & Farquhar, 1993) shows how mass media stimulate general awareness; interpersonal networks reduce uncertainty, provide support and feedback, and contextualize information; and subsequent specific media are used for depth and detail about the health situation. The *comprehensive model of information seeking* (Johnson & Meischke, 1993) synthesizes the health belief model, uses and gratifications research, and media exposure and evaluation, to propose that various health-related factors influence perceptions of channel characteristics and utility that in turn affect information-seeking actions. And the *sense-making approach* (Dervin & Frenette, 2001) emphasizes how meaning about one's situation as one confronts gaps or discontinuities in experiences or knowledge while attempting to achieve a goal is constructed through communication; the model highlights the importance of the closest or most convenient information sources, usually friends or nearby people (see, for example, Amigbogu & Rice, 2001, for an in-depth study of one woman's search for online infertility informa-

tion). Napoli concludes with a review of source and channel selection, highlighting the importance of credibility and accuracy, currently two weaknesses of much Internet health information.

Skinner and Kreuter (1997) summarize theoretical foundations for identifying the kind of health behaviors (asymptomatic screening, lifestyle modifications, cessation of addictive behaviors, medical regimen compliance, precaution adoption) that would respond to particular interactive media interventions. Reviewing the health belief model, efficacy theory, attribution theory, the theory of reasoned action, and the transtheoretical model, they show what specific behaviors and interventions would be motivated by each theory, using different kinds of new media to enable, reinforce, and predispose. For example, an interactive program can identify salient health beliefs and then provide simulations or information geared to those assumptions. Segmentability of the content, such as through using Web "cookies" (short lines of data stored in a user's browser directory, depending on the user's acceptance of them, that indicate the prior use of a specific web page or service) to tailor Web content to prior searching behavior would increase the matching of information provided by the system to a user's readiness for change. A system that has diagnosed the self-efficacy level of a patient can help focus the person on internal or external causes for a particular unhealthy behavior. The theory of reasoned behavior would propose that individuals be connected to influential or knowledgeable others, say in a support group, to increase the persuasability of suggested health behaviors. The transtheoretical model (also called "stages of change" model; Prochaska, Redding, & Evers, 1997) proposes that people can be in any one of five stages of change concerning a health behavior—precontemplation, contemplation, preparation, action, or maintenance—and a variety of 10 processes might be appropriate to help move someone from one stage to another. Thus, theoretically, a health Web site could provide an interactive evaluation of a user's stage of change with respect to a health behavior, such as smoking cessation, and then provide strategies for progress suited to that person's situation (Witherspoon, 2001).

DiabetesNet, an Internet resource providing care and resources to people with diabetes, was designed in line with the three stages of the model of health promotion using interactive media summarized above (Street & Piziak, 2001). First, use of the site can be increased by engaging health care providers, administrators, and patients aware of and knowledgeable about the site. Second, involvement in message processing can be increased through well-designed navigational and search tools, applying multiple media features for users with high-end technology as well as for those with minimal technology, and using credible message sources. Finally, health behavior and outcomes can be improved through content that is appropriate for the user's psychosocial issues

and needs, interaction among users with common conditions, and communication between providers and patients.

Successful Web-based prevention or intervention campaigns, as with communication campaigns in general (see Rice & Atkin, 2001), require considerable development, planning, and formative and summative evaluation. The REACT campaign, designed to disseminate process and outcome information from a program to reduce the time between heart attack onset and treatment (Finnegan et al., 2001), applied a process similar to social marketing, which "requires setting measurable objectives, gathering formative data to segment target audiences in communities, developing and implementing an appropriate campaign to achieve objectives, and measuring impact and effects" (p. 151). The design team obtained information about end-user Web access and skills, browser capabilities, Web site organization and layout, use of multimedia content, copyright requirements and fees, site and links maintenance, and usage monitoring and evaluation.

The federal Medicare Web site was designed using a similarly comprehensive and rigorous design and evaluation (Schneider et al., 2001). The researchers not only reviewed and applied prior Web site evaluation criteria, but also brought to bear health-related Web site criteria such as accessibility by those with visual disabilities. Their evaluation, which involved general Internet users, online visitors to the site, expert Web designers, and focus groups (involving a variety of Medicare stakeholders, including one focus group of visually impaired Internet users) assessed awareness of the site, preferred sources of Medicare information, site usability, usefulness of the content, and visual accessibility. The multiple sources of feedback provided a detailed list of site design and content recommendations. Similarly, the DiabetesNet evaluation analyzed system log data about site "hits," unique users, and most popular topics; frequency and types of messages posted to the DiabetesNet listserve; and online surveys (Street & Fizak, 2001). Another recent Web-based health campaign—Consider This—was designed primarily to help young teenagers experimenting with cigarettes to stop smoking before they became addicted to nicotine, through emphasizing skills adolescents need to take control of their lives (Buller, 2001). The site contains six 50-minute modules, covering topics such as media literacy, relationship development and management, addition recognition and stress management, applying decision-making skills to tobacco use, clarifying values related to tobacco use, and strategies for resisting social influences to smoke. It also provides a conference site for posting messages discussing the modules, or asking questions. Hypertext links provide access to related information, and online assignments allow users to assess their performance. Buller et al. discuss how they referred to social cognitive theory as the basis for

developing sequences that used vivid materials and salient peer models to engage users' attention, and created positive outcome expectancies, greater self-efficacy, and more accurate perceptions of tobacco use norms. The actual messages were designed on the basis of communication and persuasion theories (such as the transtheoretical model) to help avert the psychological reactance typically found in adolescents' responses to messages warning about negative consequences of various behaviors. Like the other Web-based campaigns noted here, the Consider This site required extensive research, pilot testing, formative evaluation, user feedback and redesign.

Health Website Features

Such thorough and well-informed analyses of health sites seem rather the exception than the rule, as indicated in various interface evaluations of health Web sites. For example, content analysis of 11 top-ranked HMO (Health Maintenance Organization) Web sites found that none offered e-mail links to practitioners, slightly more than half offered feedback mechanisms, none offered access to a print newsletter or online discussion group, and only two offered online registration for health classes (Witherspoon, 2001). The sites offered varying levels of information supporting a healthy lifestyle; few offered online lifestyle appraisals or other information supporting preventive care; few offered information supporting management of several chronic illnesses; and few offered the current date of publication (and some had considerably out-of-date information). Witherspoon concludes that many of the Web sites of these "top" HMOs "did not fully exploit the potential of the Web to provide useful health information that could reduce operating costs by helping to maintain the wellness of their members" (p. 208).

Rice, Peterson, and Christine (2001) compared the features of 20 commercial and 11 government health database sites, using a typology developed from prior studies and refined through pilot studies. The typology included seven general coding categories (noninteractive substantive content; e-commerce; multimedia content; navigation/assistance; search methods; interactivity; and policy) involving 74 specific features. On average, commercial sites offered 22.5 of the 74 features compared to 14 offered by government health database sites. Eng (2001, Appendix 2) compares the 25 most popular online health sites as of Fall 2000 as to the number of unique users per month, target audience, site type, resources (news and information, risk assessment tools, provider/facility database, chats and bulletin boards, ask the expert, professional continuing education, electronic health records, and shopping), credibility and privacy (separates ads from content, collects per-

sonal data, provides a comprehensive privacy policy, tracks users, has a secure server with encryption, subscribes to health codes, provides disclaimer or warnings, has peer-reviewed content, and has an external editorial/advisory board), and other commercial relations (ads, business-to-business, electronic commerce, mergers and acquisitions, and links to offline media).

MAJOR INDUSTRY AND POLICY ISSUES

Online Medicine

Online medical advertising is growing rapidly, from \$58 million in 1999 to a projected \$265 million in 2002, still small compared to the total medical advertising and promotion of \$8 billion spent in the United States in 1998 (Goldman-Sachs, 1999). Online pharmaceutical sites are generating considerable revenue. In May, 1999, they took in nearly \$1 billion for prescription drugs, \$300 million for over-the-counter drugs, \$434 million for vitamins and supplements, and \$700 million for personal care products. One survey found that almost half of the respondents (18% "often" and 31% "most likely") indicated that they would use the Internet to order prescription refills and make doctor's appointments (Pennbridge, Moya, & Rodrigues, 1999). Users are still wary of commercial health Web sites, however, indicating they are more likely to go to nonprofit, hospital, patient advocacy, other, and pharmaceutical Web sites first (Goldman-Sachs, 1999).

Online sales of medications has generated considerable controversy. Cross-border commerce via the Internet can escape regulatory evaluation, so some products are promoted for symptoms that do not correspond to their intended use; also, quality, manufacturing, purity, safety, efficacy and enforcement cannot be guaranteed. The purchase of medical products via the Internet allows patients to avoid medical advice and treatment, including an understanding of drug interactions and side effects (WHO Drug Information, 1999).

Online pharmacies per se are "just another channel of distribution" as long as a physician-patient relationship exists (Cohen, 1999). Although it is not strictly illegal to do so, providing prescriptions to patients that a doctor has not physically examined is considered unethical by the AMA, unacceptable by the National Association of Boards of Pharmacy, and likely to be fined by medical quality assurance commissions (Stoiberg, 1999a, 1999b). However, of 77 Web sites offering online purchase and direct delivery of Viagra, 52 required users to release the company from liability, only 42 required users to complete an online

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medical history questionnaire that could have provided information on whether Viagra would be safe and effective for the patient, and only 27 of those indicated that a doctor would review the information (Armstrong, Schwartz, & Asch, 1999).

One of the problems is that jurisdiction is widely and partially scattered among federal regulators, FDA, FTC, and state agencies. However, the National Association of Boards of Pharmacy has begun to develop a process to certify legitimate Internet drugstores (Cohen, 1999). This Association requires online pharmacies to be licensed in all the states to which they ship drugs; upon verification, they are allowed to display the Verified Internet Pharmacy Practice Sites (VIPPS) icon. Some services, such as Cyberdocs, avoid many of these problems by being insured for malpractice, having doctors provide advice only in their areas of expertise, and only dealing with patients from states where the doctors are licensed. The World Health Organization has proposed a range of recommendations for discussion, including review of legislation of cross-border activities, establishment of informational web sites, development of voluntary codes of conduct, consideration of cooperative licensing, reporting of problem cases to WHO and Member States, and so forth. (WHO Drug Information, 1998).

Credibility of Online Health Information

Analyses of Web sites raise significant questions about the relevance, coverage, and legitimacy of much Internet health information (Adelhard, 2000). One analysis of 629 pages retrieved from Metacrawler, based on 50 questions selected from a database of clinical questions, concluded that the results were "neither clinically applicable nor of high quality"; 89 percent were not even applicable to the search question, and most pages had no more than one "quality" measure (such as site affiliation) (Hersh, Gorman, & Sacherek, 1998, p. 1307). Rose, Bruce, and Maffulli (1998) identified the 25 most frequently used terms obtained from 100 orthopedic patients as best describing their medical condition and entered them as search terms into five search engines. (As an aside, 20% of the terms had been misspelled by patients, implying that regular users may not find relevant Internet results for a good proportion of their searches because of unfamiliarity with the appropriate terms!) Of the 5947 retrieved pages, 20 percent contained patient information, 19 percent professional information, 9 percent commercial information, 2 percent sports news, 8 percent unavailable, and 41 percent other (non-English pages, chat rooms etc.) The primary result was that only 7 percent of the pages they retrieved (in this case about fever in young children) were actually relevant to the patients' conditions.

Impicciatore et al.'s (1997) study similarly found that relatively few of the pages provided complete and accurate information. Biermann, Golladay and Baker (1999) searched for Web sites concerning a specific form of cancer, Ewing's sarcoma. Based on 400 of the 27,000 resulting sites using four search engines, only half actually contained information on this topic, and, of those, only 60 percent had peer-reviewed information. McClung, Murray, and Hellingger's (1998) study of 60 articles from the first 300 hits on a search for information about childhood diarrhea found that only 20 percent conformed to the current diagnosis and treatment guidelines of the American Academy of Pediatrics, so 80 percent had inaccurate or out-of-date information. A study of 25 health websites and 14 search engines providing both English and Spanish content concluded that search engines did not provide efficient access to relevant content and that coverage of clinical information was poor and inconsistent (Berland et al., 2001). Eng (2001) summarizes other recent studies that also find online health information to be incomplete or inaccurate.

Healthy People 2010, the major planning document of the U.S. Department of Health and Human Services, explicitly suggests increasing the extent to which health-related websites provide information that can be used to assess the site's quality (Baur, Deering, & Hsu, 2001). Because of the consequentality of health information, there are several initiatives to develop credibility and accuracy standards for online information. These include the Health On the Net Foundation's HON label (HON, 1998), the Australian Department of Health and Aged Care's site (*healthinfo.gov.au*, which emphasizes reliable and relevant health information, based on a contracted "information Partnership" between the site and accredited/evaluated organizations, which then receive the HealthInfo website web page icon), the New York Online Access to Health (Voge, 1998), the Argus clearinghouse (*clearinghouse.net*) Rees's consumer health information source book (Rees, 1998), the Health Summit Working Group (1998), the Internet Healthcare Coalition, TRUSTE (TRUSTE, 2000), BBBOnline, Secure Assure, and the American Accreditation Healthcare Commission (URAC) (Eng, 2001), and other approaches (Jadad & Gagliardi, 1998).

In June of 1999, the Federal Trade Commission initiated a program to fight false and deceptive health claims for products advertised or sold via the Internet, including the application of existing legislation. The E-Health Ethics Summit, sponsored by the Internet Healthcare Coalition (including actors such as America Online, *drkoop.com*, Healthwise, Medscape, Healthon, and *WebMD*), proposed a voluntary code of conduct for Web site's collection and use of personal information (Woody, 2000). Standards include informed consent, editorial control over accepting advertising content, disclosure of all sponsorships or

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financial incentives (*ihealthcoalition.org*). Another ethics code push comes from an organization called the Internet Healthcare Coalition. In addition to involvement from the American Medical Association (Winker, Flanagin, & Musacchio, 2000), the IHC also represents the views of profit-making companies such as those affiliated with the HI-Ethics committee, as well as nonprofits, academic journals, advocacy groups, and other Web-based medical information services. Other recent federal actions aimed at reducing online health fraud include Operation Cure.All, coordinated by the Federal Trade Commission and the Food and Drug Administration.

Privacy and Liability

Issues of privacy, confidentiality, and security in both well-recognized and enterprise-specific medical information systems (Lindberg & Humphreys, 1998) are compounded by the interorganizational linkages characteristic of CHINs, networked health systems, and Internet-based organizations (Barrows & Clayton, 1997; Donaldson & Lohr, 1994; Pemble, 1997). There is extensive sharing of even the most basic health transaction data, and many points where Web site interaction can be collected and subsequently shared (Katz & Aspden, 2001).

Three primary information security goals in health care include prevention of "unauthorized disclosure of information . . . unauthorized modification of information . . . and prevention of unauthorized or unintended withholding of information or resources" (Barrows & Clayton, 1997, p. 300), leading to 14 areas needing security policy development for computer health networks, ranging from user authentication, data protection, hard copy materials security, legal and liability issues, and system reliability and backups, to audit trails and informed consent. Other aspects of privacy and confidentiality noted in other sources include: authentication of and security profiles for individuals; validating individual access to systems and databases; levels of priority and associated access means; levels of security associated with different information; policies and procedures for those who have the responsibility of protecting and maintaining the confidentiality of information they can access, ensuring integrity and protection of transferred patient-client information; applying privacy policies and measures to interdependencies among various databases; ensuring protection during transmission and conversion from manual to computer systems; access and integrity audits; validating and maintaining passwords; firewalls; access to patient information by third parties, disaster recovery; protection of remote access interfaces; encryption; electronic authentication, and so forth. The U. S. Institute of Medicine and the National Academy Press

published a comprehensive book on this issue (Committee, 1997). The Office of Technology Assessment, before it was dissolved, released at least three related reports on this topic (U.S. Congress, 1993).

Credibility and privacy of health information are directly related to legal issues (Hodge, Gostin, & Jacobson, 1999). Personally identifiable health information is now more available through intra- and interorganizational networks, providing benefits such as greater patient autonomy, improved treatment, faster diagnoses, reduction of adverse drug interactions and reactions, broader dissemination of medical research and practice, improvements in research, better monitoring of morbidity and mortality, and increased security and audit trails. However, such systems also generate legal challenges associated with privacy of identifiable health information, data reliability and quality, and tort-based liability (p. 1466).

There are complex legal and ethical issues related to online physician-patient communication. Encryption will increase a sense of confidentiality, but can never guarantee it, which is still a physician's responsibility, subject to legal statutes and regulations, including the Electronic Communications Privacy Act, which protects against eavesdropping on most phone and digital communications. Even encrypted messages, if sent to a patient at the employer's email address, are legally susceptible to monitoring and search by the employer. E-mail privacy against governmental searches is not protected unless both the sender and receiver can show they had exclusive access to their messages, which is typically unlikely. A related issue is the need for informed consent associated with e-mail communication, as supported by the American Medical Association (Spielberg, 1998, p. 1356). And the actual identity of either patient or physician is currently difficult to guarantee via e-mail.

There is no comprehensive federal legal protection of personally identifiable health information; instead, there is a wide variety of existing federal and state privacy laws (Baur, Deering, & Hsu, 2001; Hodge et al., 1999; Katz & Aspden, 2001). This patchwork approach is reflected in a recent study that found that most popular eHealth websites do not meet even the minimum fair information practices (Goldman & Hudson, 2000). The Health Insurance Portability and Accountability Act of 1996 (HIPAA) has led to national standards for electronic health and medical records and billing transactions, such as new physician-patient privacy rules imposed late in 1999. Patient advocacy groups argue these rules are too weak, whereas physician groups such as the AMA feel the rules will increase physician paperwork, cost, and complexity (such as having to verify that business partners also comply) (Guglielmo, 2000). Physicians must take "reasonable" steps to protect electronically trans-

mitted patient information, inform patients how their medical data will be used, acquire permission before using it, and share only the minimum amount necessary to accomplish the task. This would seem fairly comprehensive, but there are several significant exceptions, such as treatment, payment, or health care operations, and national health care priorities. Other documentation, training, safeguard, complaint, and sanction procedures are also required.

There are also many questions about implications of these procedures, such as use of mailing lists, and whether medical records can be altered or just appended. Further, HIPAA regulations release in December of 2000 provide legal protections only to users of traditional health care providers, health insurance plans, and health care clearing-houses, but not to users of Web sites providing general fitness and nutrition, medical conditions, treatment options, selling drugs without a prescription, online mental health counseling sites accepting only credit card payments, and pharmaceutical company Web sites (Health Privacy Project, 2001). Other relevant legislation includes the Children's Online Privacy Protection Act, which requires sites to obtain verified parental consent to collect personal data from children online.

Policy and Access

In spite of the promise of computer-based and computer-mediated medical information and communication, it is still true that people with preventable health problems who have little or no health insurance are also those least likely to have access to the necessary technologies (Eng, 2001; Eng et al., 1998). Even those with access to home computers may well be highly inexperienced in using the Internet or in making sense of online health information (see Anigbogu & Rice, 2001). Barriers both to individuals and to institutions interested in using the Internet for health care include cost, location, illiteracy, physical ability, security concerns, mixed quality of online information (due to ease of online publishing, anonymity, pressure on health publishers to post recent findings, and little regulation), ambivalence by physicians, incompatible and dynamic standards, competing and uncoordinated health care information systems, and capacity (Eng, 2001; Mittman, & Cain, 2001). In some cases, organizational culture and implementation strategies can provide major barriers to Internet resources, such as online continuing medical education courses (Whitten, Eastin, & Cook, 2001).

Public and governmental efforts are needed to reduce the gap between health information "haves" and "have nots." Eng et al. (1998) discuss a number of these, from providing public and residential access, to diverse applications, improving access through research, increasing

health and technology literacy, and integrating universal access into health planning at the levels of private-sector health services, federal and state funded health programs, federal grants, charitable organizations, corporate marketing, and private and public long-term community investment.

Healthy People 2000 (National Disease Prevention and Health Promotion Objectives, 1990), identifies and explains those activities that should have the greatest influence on improving health status, with 300 objectives in 21 priority areas. The 2010 guidelines place greater emphasis on health literacy and the quality of online health resources, with 460 objectives in 28 focus areas. Central to such efforts are patient education and counseling, both information-based efforts. The Federal Government, through agencies such as the Office of Disease Prevention and Health Promotion (ODPHP) within the Department of Health and Human Services (DHHS), as well as many others (see Baur, Deering, & Hsu, 2001, Table 16.2) assumes considerable roles and responsibilities in helping to achieve these goals. The U.S. Public Health Service intends to take advantage of the recent national initiative to wire schools, libraries, clinics, and hospitals to create an interactive, highly integrated information-based health support system. Perhaps the most accessible of these public health information services is Internet Grateful Med, noted above. Major health agencies are moving towards providing many services through Web-based forms. Neu, Anderson, and Bikson (1999), for example, provide a case study of current and potential uses of the Internet to provide Medicare services. Vickery (1995) discusses how new media might improve the management of health services demand through self-care, as the management of supply is insufficient. Four components of demand are considered: morbidity (illness, prevention, health habits, accidents, secondary prevention through screening), perceived need (knowledge of risks and benefits, assessing medical problem, severity of problem, ability to self-treat, self-efficacy—all influenced by knowledge, education, culture, social support, attitudes of health providers—these explain over 40 percent of variance in decisions to seek care), patient preference (economic appropriateness, informed choice, risk aversion, care for terminal illnesses) and nonhealth motives (sick leave, disability, compensation benefits). Self-care interventions involving lifestyle, immunization, safety, self-management, informed choice self-help, life management, screening and provider information are associated with a variety of medical benefits and cost savings. While mediated self-care would provide immediately available, personalized, and multimedia information, it would be less successful at providing emotional and social support. Thus a fully integrated infrastructure would “support interactions among individuals, the demand management system, and the medical care system” (Vickery, 1995, p. 58).

SUMMARY

Clearly, the intersection of the Internet and health communication is a socially significant, ethically and politically consequential, dynamic and innovative, intriguing and interesting, and methodologically challenging arena. Katz and Rice (2001) summarize some of these intersections by identifying two primary dimensions of interest: fundamental health care processes and stakeholders, and salient and challenging research issues. Health care processes include:

- Care (synchronous, asynchronous, expert system, prevention, treatment . . .)
- Community of interest (physicians, caregivers, HMOs, patients, support network . . .)
- Computers and software (types of client servers, Web browsers, chat rooms, listservs, MUDS, wearable devices . . .)
- Connectivity (open/closed, public/private, wired/wireless networks . . .)
- Content (journal articles, supplies, information, emotional support . . .)
- Costs and revenues (ads, information disclosure, usage, subscription, products. . .)
- Quality (regulations, rules, standards, boards, laws, genres, security, privacy . . .)

And selected research interests include:

- Access and equity
- Barriers to adoption, use, evaluation
- Communication flows and networks
- Digital divide
- Health efficacy
- Individual and social network decision making
- Organizational and community decision making
- Attitudes toward privacy and security
- Research methods, data, analyses
- Service and financial efficiency
- Theoretical frameworks appropriate for different issues, users, contexts

Internet health communication system designers, implementers, managers, users, patients, family and supportive friends, evaluators, researchers, legislators and policy makers all have significant interests

in, and potential contributions toward, better understanding, access to, and use of, health communication and health information through the Internet.

AUTHOR NOTE

This chapter is a revised, shortened, and updated version of Rice (2001) and summarizes primary topics covered in Rice and Katz (2001). All in-text Web site addresses were verified as working as of November 27, 2001.

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