

Internet and Health Communication

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With the popularity of the Internet, more and more people are turning to their computers for health information, advice, support, and services. This chapter provides an analysis of the changes in healthcare communication resulting from the Internet revolution. It provides a variety of examples, including information about health websites and portals, online patient communities, Internet pharmacies, and web-enabled hospitals.

The chapter's general structure is from the most simple uses to the more complex, from information retrieval and use, through situations where information is exchanged, either between patients and physicians or in patient online communities. Health interventions using the Internet are next. These consultations, promotion programs, and clinical applications involve actual medical treatment. Since the more complex health-related uses of the Internet rely heavily on infrastructure, we conclude with a discussion of computerized physician order entry (CPOE) and electronic health records. Each section concludes with a discussion of issues, implications, and challenges. Throughout, we have maintained a focus on how the Internet is affecting health *communication*. Economic, technical, and regulatory aspects of changes in healthcare are addressed only secondarily.

Information

Online health information

Perhaps the most widely felt impact of the Internet on communication in healthcare is in the widespread availability of, and interest for, health information on the web. A 2005 Harris Interactive poll of 1000 Americans suggested that approximately 75 percent of US adults have gone online to look for health or medical information. What is more, the frequency of searching is impressive: almost 60 percent reported that they had looked "often" (25 percent) or "sometimes" (33 percent), whereas the percentage saying that they rarely searched for

health information fell to 14 percent, down from 24 percent the previous year. Some 85 percent of those who had looked for health information had done so in the previous month. On average, respondents reported searching for health information seven times a month (up from three times per month in 2001). A large majority (89 percent) were successful in their searches, and nine out of ten believed that the health information they found online was reliable (37 percent very reliable and 53 percent somewhat reliable).

The World Wide Web offers an environment that provides free access to a global repository of information on a large variety of topics. It has become easy to search for and consult information on health or lifestyle matters. Widespread availability of information may ultimately lead to better quality healthcare, since decisions can be based on a larger pool of evidence. This rise of the Internet health consumer¹ has the potential to increase awareness of the variety of medical choices available. This may result in a number of changes in the healthcare relationship, with well-informed patients potentially more active participants in managing or directing their care. This shift is not automatic, however. It takes work to become an informed patient. For example, in assessing web-based health information, users must be able to conduct a search and find the “right” sites. They must also be able to judge the quality of information provided and synthesize that information into a useful form for their particular purpose.

By far the most studied aspect of health information on the Internet has been the problem of how to determine and guarantee its quality. Fears that Internet health information is inaccurate, unreliable, biased, unsanctioned, and unrefereed are widespread. Obviously this is an important issue, since faulty health information can have disastrous consequences. Based on a thematic review of a random sampling of 200 abstracts in the area of Internet and consumer health information, Powell, Lowe, Griffiths, and Thorogood (2005) identified what they term as an obsession with the quality of health information on the Internet. Over 80 percent of the articles reviewed described evaluations of the quality of information consumers might find in an Internet search. Despite this concern, Powell and colleagues found that most of the studies were small and failed to address shortcomings that had been identified in an earlier review, concluding that, at most, the studies demonstrate that the quality of information available online is variable and that health professionals are concerned about the results of misinformation.

Are these concerns justified? There is, as yet, limited literature on why health consumers go online, what they actually look for, or how they use the information they find. It is extremely difficult to associate health outcomes with consumer use of the Internet for health information.

A counterpoint to the literature about the questionable reliability of health-related websites is the problem of too much information. The sheer volume of information may represent a significant obstacle to health consumers. How can lay people sift through, digest, interpret, and evaluate the significance or relevance of the health information they find?

Clearly, as the Internet grows in popularity, so does the need for evaluating information quality and appropriateness. A number of initiatives and approaches have developed to help health consumers find accurate and relevant information on reliable sites. Increasingly, consumers are offered access to sites that propose pre-selected information as well as guidelines for patients to use in checking the characteristics of the information they find (author, date, sources, site sponsorship, etc.) Health consumers can use government-provided links or portals, click on pre-approved seals of approval or trustmarks provided by non-profit or non-governmental organizations, follow checklists created by professionals or health educators, and download special toolbars, all of which will help them find and evaluate information on the web.

Many governments support portals of carefully selected and freely available consumer health information. For example, the US Department of Health and Human Services provides a portal with contact information for organizations (www.healthfinder.gov) and the National Library of Medicine provides a portal with health content from the National Institute of Health (www.medlineplus.gov). Outside the US, the United Kingdom's National Library for Health (NLH) and its associated web-based programs offer a mix of freely available and password-protected subscription access to a wide range of information sources. In Canada, the Public Health Agency offers a good public service that does not reproduce already existing health information but provides links to more than 12,000 web-based resources that have been rigorously evaluated for quality. Similarly, within Europe the focus has been on networks and on managing access and quality rather than creating content. The Catalog and Index of French Language Health Internet Resources (CISMef) project in France describes and indexes the principal French-language health resources, while the primary website for health information in Germany is Medizin-Forum AG. Finally, this type of pre-selection and filtering initiative is not limited to national governments. The Health on the Net Foundation (HON), an independent foundation based in Switzerland, provides medical information, while the World Health Organization (WHO) provides an online list of recommended websites for information.

Another approach to ensuring quality and reliability of health information is third-party certification. Most popular, the quality label Health On the Net's (HON) logo graces over 3000 sites, signifying conformity with HON's eight principles: authority, complementarity, confidentiality, attribution, justifiability, transparency (authorship), transparency of sponsorship, and honesty (www.hon.ch). The Utilization Review Accreditation Program (URAC) is an increasingly popular independent third-party certifying organization. Launched in 2001, with the goal of patient empowerment and consumer education and safety, URAC's accreditation is voluntary and indicates adhesion to a series of ethical and quality standards that address several issues, including privacy protection, security, and the process used for developing content (<http://www.urac.org>). These approaches rely essentially on the structural characteristics of the sites they evaluate, however. They are proxy measures and address the comprehensiveness, currency, and accuracy of

information contained on the sites only indirectly. The challenge of developing criteria to evaluate content is enormous, especially since health information changes rapidly.

An alternative approach is to use a user-rating tool, such as the Health Information Technology Institute Information Quality Tool developed by the Health Summit Working Group. Reviewers fill in a questionnaire based on the information they can find on a given site and submit it. A report is returned with a review of answers, a score, and information on what is missing in the site. The overall purpose is to educate health consumers. Here again, the list of criteria is a mixture of standard information quality measures, security and privacy concerns, and web content management issues, but it may do little to help consumers assess the actual medical information contained in a given site.

Finally, filtering using web technologies is an emerging approach. Search tools accept or reject entire sites based on preset criteria (i.e. they may accept only online journal articles or those from professional associations). For example, the MedCIRCLE concept uses the semantic web to evaluate a combination of quality assurance systems, strictly managed metadata or tags, and third-party ratings.

All these measures rest on assumptions that lay people cannot adequately assess the reliability of Internet health information. Adams, de Bont, and Berg (2006) is one of few empirical studies to examine how lay people actually assess the value of health-related information they find on the web. The authors found that, while patients did not utilize special user tools (checklists, seals, portals) to assist in searching for and evaluating information, they did develop explicit strategies for checking information within their established patterns of searching, such as on- and offline triangulation of information and checking the information provider and dates. More research of this type is required to develop a better idea of how patients assess information and then how these assessments influence subsequent actions.

It is extremely difficult to try to apply a regulatory approach to authorizing sites that deliver health information, and this problem will only grow as the web develops. As filtering technologies become more sophisticated, they may offer a way to filter out either substandard medical information or sites that do not meet quality standards. In addition, it is vital that users be able to apply their own quality standards.

Health information for professionals

Just as patients look up information on the Internet, health professionals are also accessing Internet information to support healthcare in various ways. Most recent surveys suggest that the percentage of clinicians and other health professionals using the Internet is increasing steadily. The American Medical Association's 2002 study on "Physician Use of the World Wide Web" reported that 78 percent of physicians went online in their practice and that more than two thirds of this group used the web daily. According to the study, about half felt that the Internet has had a major impact on the way they practice medicine.

A 2004 update of the study reported that most physicians “believe it is important for patient care.”

For the most part, it appears that the Internet tends to be used as an additional resource to complement or to replace libraries and other formal, printed sources of information. A 2002 study from Harris Interactive (2003) revealed that increasing numbers of physicians are using the Internet to research clinical information (90 percent compared to 19 percent in 2001) and to search for medical journal articles (74 percent). Online databases, combined with instruments such as BlackBerries and PDAs, enable easy access to timely information, best practices, and decision chains. The trend to evidence-based medicine is strongly supported by Internet technologies.

Some national government also provide portals for their health professionals, linking to major resources such as the National Library of Medicine’s PubMed site or the UK National Health Service’s Bandolier. In the US, for example, the PubMed website (www.ncbi.nih.gov) currently attracts over 30 million searchers per month. Highly specialized databases give practicing physicians easy access to information that was previously too difficult to follow consistently, given its specificity. For instance, the National Library maintains a database of trials of alternative and complementary medicines. Similarly, the UK’s National Cancer Research Institute hosts an international information exchange for cancer research. Finally, the Online Database of Unknown Clinical Cases provides an environment for collecting knowledge about rare pathologies that are difficult to classify and potentially life-threatening.

The problem with online databases is the work and resources required to maintain their currency. Given the volume and rapidly changing nature of health information, only major international and collaborative initiatives can reasonably target sustainability.

Exchange

Online support for patients

The Internet is not just a repository of information. It has also given rise to new forms of interaction and new groupings, or communities, that can bring together people across geographical space and time in all spheres of life. In the field of health, patient advocacy sites and online social support, such as that found in chat rooms and discussion lists, have been established by major research groups, foundations, and voluntary patient-driven groups. Such sites typically target chronic conditions, critical illness, or caregivers. They usually offer a mix of informational support (information, advice, feedback), tangible support (direct forms of aid), and social and emotional support. They vary widely in size, from less than a hundred participants to tens of thousands.

One such mega community, the Association of Cancer Online Resources (ACOR, www.acor.org) has thousands of active participants and hundreds of thousands of

registered but silent readers. The heart of ACOR is a large collection of cancer-related Internet mailing lists, which deliver over 1.5 million email messages weekly to subscribers across the globe. In addition to supporting the mailing lists, ACOR develops and hosts Internet-based knowledge systems that allow the public to find and use credible information relevant to their illness. ACOR also hosts several Wikis and a blog. As it notes on its website, "ACOR is also invested in researching medical online communities and has helped to produce some of the most important and groundbreaking projects designed to understand how the Internet helps people to become informed patients, able to maximize the quality of medical care they receive." In this, they are at the forefront of using the participatory web (or Web 2.0) in the field of health.

Research on online social support for health conditions typically falls into one of two categories: analysis of interactions in various communities or identification of reasons for using online social support. Compared with the information-use literature, this literature tends to be more qualitative in nature.

Josefsson (2005) argues that the specific driving forces and dynamics of patients' online communities (POC) differ from those in other online communities of shared interests. These communities are initiated and maintained because people's lives are changed, sometimes drastically and overnight, by illness. One of the major coping strategies of patients is to get more information, both medical and on how to manage in daily life. The goal is to acquire an in-depth understanding of the condition and also to be able to discuss it knowledgeably with the doctor. Patients and caregivers dealing with only one condition have time and energy necessary to explore and evaluate resources thoroughly. They may make important contributions to the identification and dissemination of high-quality health information for both patients and health professionals.

A central component of a POC is usually one or more online discussion spaces for synchronous (chats) or asynchronous (forums or distribution lists) exchange. Such spaces provide a communication channel for interaction between people facing the same or a similar situation. Several research studies report the benefits of such social support (Reeves, 2000; Eysenbach et al., 2004) that can complement or even replace traditional patient support groups. Participants share technical information about new treatments, discuss their experiences, and encourage each other. A considerable body of experiences is created as different patients describe how they discovered the disease, how they were diagnosed, and how they have experienced various treatments. In addition, these informative practices are accompanied by interpretive practices, when fellow patients help each other interpret what physicians and their health professionals are saying about test results, examinations, and so on. The possibility of sharing experiences creates a sense of belonging. Uncertainties and anxieties can be dealt with as they arise, not only in the doctor's office.

Participation in POCs may be more or less active, and participants may tailor their participation to support their individual needs for information and social support. "Lurking" (listening without contributing) is described as a good way of

becoming informed as well as of confirming personal experience (Josefsson, 2005). Writing about health problems and formulating disclosure of personal concerns have been shown to be therapeutic in and of themselves (Wright & Bell, 2003). In addition, POCs allow patients to help others, another important coping strategy. For instance, in a study of HIV-positive individuals, Reeves (2000) found that the opportunity to help others was a central motivation for participating in online discussions and it was judged the most rewarding.

When compared with other online communities or face-to-face patient support groups, the therapeutic value of POCs is evaluated very positively by their members. POCs also demonstrate higher levels of expressed emotional support, empathy, and self-disclosure than face-to-face self-help groups. Josefsson (2005) suggests that the maintenance of behavioral norms is extremely important since participants are particularly vulnerable and the subject matter is close to them. The reduction of social-status clues brought about by being online supports anonymity, disclosure, and more heterogeneous supportive relationships.

Potential problems of POCs include concerns about privacy and the inappropriate use of information that is posted by participants. As everywhere, there is a risk of unreliable information and the difficulty of sifting through masses of information to find what is most appropriate. For example, reading about the advanced stages of a disease or all potential complications of a treatment may be devastating for an individual who has just been diagnosed and is not ready for that information.

POCs often include an extensive mixture of translated, rewritten, and combined medical information together with personal experiences and beliefs about a given disease. This collection of lay and professional information empowers e-health consumers to become producers of medical information. More importantly, this mix plays a central role in meeting patients' requirements for specific experience and knowledge about a certain condition. Finally, the possibility of influencing public opinion may be an explicit goal of some POCs. They may seek to increase awareness of some lesser-known diseases – among patients as well as in the population in general, or even lobby for governmental policy changes. The spaces may also provide a field for recruiting for clinical trials and collecting data on heredity patterns and rare diseases.

Online support for clinicians

While Internet-based information is increasingly substituted for libraries and other formal, printed sources of information, it does not replace colleagues and specialists, who remain physicians' preferred sources of information for reasons of credibility, availability, and applicability. A consulting physician can tailor his or her answer to a question so that it is concise and sufficiently complete, with explanations and process information that will allow the requesting physician to implement any suggestion with the appropriate level of confidence. Berg (2004) reports that half of information demands in clinical practice are met by colleagues

rather than document sources. He also notes that about 60 percent of clinician time is devoted to talk.

The Internet is providing opportunities here, too. A 2002 Harris Interactive study reported that 63 percent of physicians were communicating with colleagues on the Internet. Email is the most obvious connection but online mailing lists and discussion forums also offer the opportunity to discuss emerging scientific issues and trends with peers, often in real time. This is a growing phenomenon in medical associations in several countries. Professionals are connected with each other so that they can share knowledge and support each other in their work.

Hara and Hew (2007) report on knowledge sharing across organizations by an online community of nurses. They detail the activities and types of knowledge shared in a large (1300 members) online listserv involving professional nurses in critical care. This decade-old community was well established. Members interviewed noted that participation enabled them to connect with other nurses (to ask questions or seek pertinent knowledge), and that the listserv was a means of compensating for isolation due to job function and geographic location. Through participating the nurses also strengthened their identity as advanced care nurses, either explicitly through discussions about nurses' roles and responsibilities, or indirectly through the sharing of their everyday practices which, taken as a whole, provides a detailed portrait of what it means to be an advanced nurse. Content analysis of the activities on the listserv revealed that knowledge sharing was most common (51 percent), followed by solicitation, i.e. asking for information or advice (33 percent). In sharp contrast with patients' online communities, emotional communication such as compliments, statements of appreciation, or empathy was minimal. The authors suggest that this type of communication was likely directed off-list through individual emails. Finally, approximately half of all knowledge shared was information on institutional practices, i.e. how do you do it where you work. Clearly, this listserv fulfills an important function in keeping the nurses involved informed of best practices in their field and in allowing them to communicate with a large number of individuals with similar experiences.

The Heart Health project is another example of an online community for health professionals. Cardiac nurses from hospitals, health centers, and heart-care institutes in three Canadian provinces came together over a six-month period to discuss problems affecting the cardiac patient population. They moved through brainstorming and knowledge sharing in discussions and eventually to the production of a co-authored document, the Heart Health Kit (Campos, 2007). The toolkit was later produced as a resource to help community groups plan and deliver heart health workshops with the support of public health nurses.

As in other spheres, Internet technologies are finding their way into the classrooms of medical students and enabling new forms of learning – through online discussions, blogs, etc. Computer technologies also enable students to practice their skills virtually, but a discussion of this aspect is beyond scope of this chapter.

To maintain certification, many health professionals must accumulate a certain number of credit hours. This ensures that they are up to date on developments

in their field. The Internet has become a very popular, medium for delivering continuing professional education (CPE). The ability to transcend distance produces a larger population base and thus enables providers to offer a wider variety of subjects. Sometimes CPE courses also integrate a videoconferencing component, which can increasingly be conducted with webcams. Delivering CPE courses over the web enables professionals who have trouble attending live sessions due to time or budgetary restrictions to continue to learn. In Nunavut (northern Canada), for example, nurses can attend virtual sessions from their communities, whereas previously they had to find replacements in order to leave the community, a difficult undertaking in a context of chronic understaffing.

The changing practitioner–patient relationship

The rise of the Internet health consumer suggests a shifting of power within the healthcare relationship. An informed patient is potentially a more active participant in his or her care. This may have consequences for the physician–patient relationship. When patients arrive at a medical encounter “empowered” with information, blind trust in medical expertise may yield to “informed trust.” Physicians who are more accustomed to an authoritative or expert role may have difficulty collaborating rather than directing. Informed patients may be perceived as a challenge to medical authority. While the issue of the changing nature of relationships with health professionals has been raised, there has been little empirical work on the question, however.

A Harris Interactive poll in 2005 suggested that around half (53 percent) of patients sometimes discuss information found online with their physician, while 70 percent had gone to the Internet for additional information following discussions with their doctors. Several studies of physicians’ use of the Internet investigate how physicians deal with the increasing trend of patients to bring information from the Internet to a consultation. In two separate studies, one in Switzerland and the other in New Zealand, around 90 percent of physicians reported this behavior, but not from a substantial proportion of their patients in either study. Murray, Lo, Pollack, Donelan, Catania, Lee, Zapert and Turner’s (2003) report of a random US survey of physicians found that, if physicians felt that the information was accurate and relevant, they judged it to be beneficial, but inaccurate or irrelevant information was felt to harm health outcomes. A substantial minority (38 percent) believed that patients bringing in information made the visit less efficient in terms of time, and some admitted to acquiescing to what, in their view, were inappropriate clinical requests by their patients either to save time or to avoid damaging the physician–patient relationship.

Despite concerns about unfiltered, unreliable information and the need to interpret and evaluate this in context, physicians generally welcome patients taking an interest in their own care and their efforts to participate and become more knowledgeable. The advantages of a well-informed patient are higher likelihood of compliance to treatment and improved health outcomes. Similarly, Rice and

Katz's (2006) review of physician–patient interaction suggests that “despite physicians’ concern over web quality, and lack of confidence in their patients’ ability to accurately judge and use such information, . . . the literature overwhelmingly describes the favorable impact of patient-found Internet information on doctor–patient communication” (pp. 157–8). They conclude that there is little foundation for fears of challenges to authority and that the research literature overwhelmingly indicates that patients would much rather discuss Internet information with their doctors than use it to replace them. This is borne out by Umefjord, Hamberg, Malker and Petersson (2006).

Treatment

Online medical consultations

For more than a decade, studies have consistently shown that some members of the public want access to Internet-based communication with healthcare providers, with preference estimates for online patient–provider communication ranging from 40 percent to 83 percent (Burke Beckjord et al., 2007). Surveys of the general American public in 2005 and 2006 (Harris Interactive, 2007) suggest that they would like to receive online reminders to visit their doctors (77 percent), communicate with their doctors by email (74 percent), schedule appointments online (75 percent) and receive test results by email (67 percent). Online patient–provider communication remains relatively uncommon, however. Estimates vary widely, with commercial survey estimates generally between 20 percent and 40 percent. More systematic, larger-scale studies such as the Pew Internet and American Life Project and the Health Information National Trends Survey (HINTS), which surveyed over 3000 respondents, put these figures much lower, with only 7 percent (in 2003), 10 percent (in 2005) or 11 percent (2006) of adult Internet users having communicated with their physician using the Internet (Burke Beckjord et al., 2007; Kolbasuk McGee, 2007).

Ferguson (2001) proposes a distinction between two types of physician–patient relationship in online consultations. A Type 1 relationship is one in which a patient contacts a health provider with whom he or she has no previous relationship. This type of relationship is patient-driven and may be likened to a coach–consultant relationship in which the physician typically answers questions, recommends other information sources, and offers an informal second opinion. There is typically no diagnosis, treatment, or prescription involved. In contrast, Ferguson’s Type 2 relationship is one where the patient has a pre-existing clinical relationship and where the physician assumes some form of contractual responsibility for ongoing care.

Free services, supported by government agencies or charitable medical foundations, are a common model of online “Ask the Doctor” services. For example, Sweden’s Karolinska Institutet, Europe’s largest medical university, runs a portal listing several hundred Ask the Doctor and Second Opinion services. This extensive site has an online medical encyclopedia and covers medical topics in depth. Users’

questions are answered briefly by a physician, who may direct the user to other online sources. Another model is a subscription-based site such as WebMD which offers information services, personalized advice and chat rooms in which physicians may sometimes participate. Concerns about liability and insurance costs constrain the offer and activities of this type of site. In the past, there have been online services offering treatment or prescriptions, but we could not find any at the time of writing.

There is little research on what may incite patients to seek online consultations with strangers. Umefjord and colleagues (2006) reported on a survey of over 3500 users of a Swedish Ask the Doctor service. Convenience and anonymity were reported as the major reasons for recourse to such a service, with frustration with previous doctors' visits also cited as a reason. Approximately a third of patients wanted a preliminary diagnosis of symptoms, and another third a more complete information or explanation, while lesser numbers were interested in a second opinion or alternative treatment options. Following their session, about half reported that they had found what they needed, while about a quarter said they would return to their previous physician. The appreciation of the service was generally positive and many respondents endorsed the service as a valuable complement to regular healthcare.

Despite over a decade of research and the availability of guidelines for use of Internet-based communication by healthcare providers (Kane & Sands, 1998), online patient-provider communication remains a marginal practice. Its use is increasing but at a much slower pace than Internet use in general. User satisfaction and impacts on healthcare have been generally favorable among both healthcare consumers and healthcare providers (Burke Beckjord et al., 2007). It seems likely that systemic factors and policies (for example, concerns with being paid for time spent online) rather than attitudes may be at issue here (Weiss, 2004). Increased availability and integration of electronic health records will likely affect the prevalence of online patient-provider communication, as will policies promoting the use of health information technology.

Health promotion and interventions

Increasingly, the Internet is being used as a channel for delivering health education and promotion programs as well as chronic disease management tools. Programs exist in a variety of fields such as smoking cessation, obesity and physical activity, diabetes, cardiac health, HIV/AIDS, eating disorders, and mental health. Cognitive behavior therapy is also being given over the Internet for conditions such as tinnitus, migraine, and panic disorders. A number of constants emerge across this wide variety of fields. Most programs aim to take advantage of technological features of the Internet: the ability to reach large populations, easy storage of large volumes of information, quick updating of information, and the ability to provide personalized feedback (Griffiths, Lindenmayer, Powell, Lowe, & Thorogood, 2006).

A major motivation for designing programs for delivery over the Internet involves reducing costs and increasing convenience for users – saving time, and allowing access anytime anywhere. This mode of delivery is also seen as a way of reducing costs and increasing accessibility. Limited numbers of a target group in a given area, such as rural women with chronic disease or diabetes, may make program delivery over the Internet a viable, cost-effective solution. In other cases, isolation may be the result of a lack of mobility or physical restrictions, for example caregivers who find it difficult to leave their homes, people living with HIV/AIDS, or children with cystic fibrosis.

In certain cases, the anonymity of Internet delivery can be used to advantage, for instance in cases where their condition may cause participants embarrassment or stigmatization. Griffiths et al. (2006) offer a number of examples, such as interventions targeting obesity if people are feeling embarrassed about failure to lose weight, programs for young women with eating disorders, and breast cancer patients.

Many developers of health interventions on the Internet suggest that users can tailor the information they receive to meet their own needs or go through the program at their own pace. This enhances their sense of control and empowerment. The depersonalization afforded by the Internet may make it an ideal channel for the delivery of carefully structured, step-by-step self-help programs, particularly if they are supplemented with individualized email feedback.

Despite the enormous potential and interest in Internet delivery of health education and promotion, there have been few direct comparisons between Internet and face-to-face delivery. Griffiths and colleagues (2006) call for such studies in order to evaluate possible unintended consequences, such as reduced availability of face-to-face interventions or reducing the visibility of certain groups or issues outside the anonymity of the Internet.

Telehealth

We define telehealth as the use of information and communication technologies to deliver clinical services at a distance. Increasingly, telehealth is being delivered using the Internet, often in combination with other technologies, such as videoconferencing using webcams or with mobile telephones. It may involve patient-provider consultation, including physical exams using peripheral equipment. There are two basic models of telehealth: real time and “store and forward.” In real-time telehealth, the parties are online together. For example, a telehealth session may involve a consultation with an ophthalmologist in one location and a patient and health professional in another. The health professional manipulates an ophthalmological scope and the image it produces is transmitted to the specialist, who can see inside the patient’s eye and advise on diagnosis and treatment.

The term “store and forward” refers to the concept that data (such as images, video and sound clips, and other patient information) can be transmitted between computers, stored electronically, and retrieved at a later time (often at a distant location) by another health professional. If bandwidth is sufficient and both ends

have compatible software, patient information can travel using an Internet protocol over standard channels. Security measures integrated in the software ensure the confidentiality of patient information. The Alaska Federal Healthcare Access Network (AFHCAN, www.afhcan.org) is a good example of store-and-forward telemedicine. Begun in 2000 to provide healthcare to 248 villages and military installations across Alaska, AFHCAN integrates web-based technologies and satellite links. Essentially, the software stores all user input in a server until a case is sent. If a system crashes, a real possibility in low- or fragile-connectivity environments, that information is still available the next time the user logs in from a different machine. Using a combination of small transmission packets and multiple retry attempts, it is even possible to send cases over satellite connectivity that is too poor to permit phone, fax, or email connections.

Telehealth also encompasses consultations between professionals and the transfer of medical data. Monitoring at a distance is also a major telehealth application. For example, patients with renal disease may be discharged from hospital on the condition that they do their own dialysis and hook themselves up to a monitor that automatically takes and transmits the appropriate data. Other monitors, such as those for patients with cardiovascular disease, may be worn continuously and automatically send data to the local hospital. Since this type of application involves less communication between persons, we will not discuss it here. Whatever the application, telehealth depends heavily on appropriate infrastructure.

Infrastructure

Computerization and the easy, secure exchange of information are at the heart of modern healthcare. There are a number of issues to be addressed, among them system interoperability, data security, and economics. Ideally, all data would be interchangeable and it would only go to those who need it; duplicate entries would be eliminated and the entire process would be streamlined, leading to better healthcare and lower costs. Although there is still a long way to go to reach this ideal, concrete steps are being taken. We will discuss two such initiatives: computerized physician order entry and the electronic health record.

Computerized physician order entry (CPOE)

Computerized physician order entry (CPOE), or e-prescribing, refers to the process of sending prescriptions directly from the physician's office to the pharmacy. Gone is the little white slip of paper with often illegible writing. CPOE systems facilitate the process of entering prescriptions into the computer. They are often linked to electronic health records (EHRs) and incorporate clinical decision support algorithms. A CPOE system will typically suggest optimal choices, often proposing generic drug equivalents, and provide alerts to potential adverse reactions, contraindications, or incorrect dosages. All of this relies heavily on infrastructure.

By proposing generic equivalents and reducing prescription errors or duplications, including prescription fraud or abuse, CPOE generates cost savings that have been estimated at \$29 billion yearly in the US alone (Hopkins Tanne, 2004).

CPOE systems can also track compliance (physicians may receive alerts when their patients refill prescriptions), thus enabling better follow-up and standard of care. At another level, widespread use could make CPOEs invaluable public health tools. They could be used to monitor abnormal prescription patterns in real time – for example, increased prescriptions for upper respiratory infections, which could indicate the arrival of a strain of flu virus.

In addition to physician e-prescribing, patients are able to directly access online pharmacies. Online pharmacies may be grouped into three general categories: independent, Internet-only sites; online branches of established pharmacy chains; and sites that represent partnerships among neighborhood pharmacies. Potential benefits of online pharmacies are increased access, lower transaction and production costs, and greater anonymity. However, different standards of practice have resulted in vast differences in the quality of online pharmacies. The nature of the Internet and the difficulty of controlling e-commerce in general make online pharmacies difficult to regulate. There are concerns about the ease with which patients may obtain drugs, sometimes without valid prescription. For example, if patients do not fully disclose symptoms to a “cyberdoctor,” they may expose themselves to dangerous drug interactions and/or adverse effects. The importation of prescription medicines is another area of concern. Although the importation of unapproved, misbranded, or adulterated drugs is unlawful in the US, some sites may dispense expired, sub-potent, contaminated, or counterfeit products (Fung, Woo, & Asch, 2004). Cross-border traffic is a complicated regulatory, jurisdictional, ethical, and commercial issue. In Canada, for example, there has been concern that online sales of drugs to the US, estimated at \$1 billion per year, could threaten domestic supply and drive lower Canadian prices up.

Electronic health record (EHR)

Also known as digital medical records, an electronic health record is essentially a longitudinal collection of electronic health information about an individual. Data are generally entered in EHRs by different groups of healthcare professionals, although patients may sometimes enter data that is later validated. EHRs may include some or all of the following components: daily charting, medication administration, physical assessment, admission nursing note, nursing care plan, referral, present complaint (e.g. symptoms), past medical history, lifestyle, physical examination, diagnoses, tests, procedures, treatment, medication, discharge, history, diaries, problems, findings, and immunization. The extent of file sharing also varies widely, from files compiled within single departments or practices to sharing across institutions in primary, secondary, and tertiary care (Häyrinen, Saranto, & Nykänen, 2007).

The changing role of the general physician, shifting power of insurance companies, and the role of the patient are all bound up with the introduction

and development of the EHR. The need for a closer link between medical (patient record) and financial (hospital bill) information is a major incentive for introducing the EHR. In addition to its obvious cost-saving advantages, several studies suggest that an EHR is conducive to more complete and accurate documentation by health-care professionals. Electronic record systems can help reduce medical error, eliminate handwritten notes, enable error-reducing technologies, increase consistency in records, and provide data for research. They also speed up transfer of information between healthcare professionals and institutions. For example, a digital x-ray can be sent from the radiology department to the physician's desktop, or test results from a clinic to the general practitioner and a consulting specialist.

The extent of actual use of EHRs varies widely according to the context of each country. In Scandinavian countries, which have a long tradition of computerization and e-health infrastructure, penetration is high. For example, in Sweden about 90 percent of patients have an EHR.

Unlike the healthcare systems of many Western countries, the US system is composed of private, independent individual and group providers, hospitals, ambulatory, and long-term care centers that compete with one another. The system is decentralized with multi-payers. This climate of competition offers few incentives for information sharing and consolidation. In the US, although 70 percent of hospitals had full or partial EHR systems, penetration of integrated records was estimated at about 4 percent in 2006.

Somewhere between these two extremes, is the UK National Health Service (NHS) Connecting for Health program. It provides an example of what the future face of healthcare may look like. Begun in 2000, Connecting for Health aims to link all 30,000 NHS professionals and 300 hospitals, creating an active EHR for each citizen, and implementing nationwide booking and electronic prescription services. The NHS Care Records Service contains two types of records: detailed records (held locally) and the summary care record (held nationally). Detailed records can be securely shared between different parts of the local NHS, such as the physician's office and the hospital. Patients will be able to access their summary care record, a summary of their important health information, using a secure website and make it available to authorized NHS staff throughout England. There is also a service for direct, secure transfer of files between physicians (GP2GP) and a PACS (Picture Archiving and Communication System) that stores images such as x-rays and scans electronically, creating a near filmless process and improved diagnostic methods. Doctors and other health professionals in any hospital in England can access and compare images at the touch of a button. England's national electronic referral service, Choose and Book, gives patients a choice of place, date, and time for their first outpatient appointment in a hospital or clinic. Patients can choose their hospital or clinic, and then book their appointment to see a specialist with a member of the practice team at the general practitioner's surgery, or at home by telephone or over the internet at a time more convenient to them. As of March 2008, Choose and Book was being used for around 50 percent of NHS referral activity, and over 85 percent of practices were participating. The system also

incorporates an electronic prescription service that enables prescribers to send prescriptions to a dispenser of the patient's choice. EPS was being used for over 17 percent of daily prescription messages in 2008. All of these possibilities rest on the underlying network, N3 (National Network for the NHS), a secure broadband virtual private network (VPN). In addition to transmitting digital images, it also has a voiceover IP component that enables health professionals to talk to each other over the Internet.

Despite the explosion of EHR initiatives in the Western world starting in the 1990s, the technical, social, and organizational complexity of widespread implementation has become increasingly apparent. Most initiatives have been only marginally successful or have evaporated quickly. They have proved to be extremely costly and difficult to maintain, with important privacy and security questions. Clearly, data must be interoperable and travel over secure channels. Who should have access to the information contained in an EHR? If access extends from primary-care physician and patient to health insurance companies, boundaries between medical and financial issues may become blurred. For example, could insurance coverage be denied or premiums increased because of some information contained in an individual's health record? In a 2003 Connecting for Health (UK) survey of online users, nearly all (91 percent) were "very concerned" about privacy and health information security.

In the US, the most notable legislation relevant to EHRs is the Health Insurance Portability and Accountability Act (HIPAA), which is designed to ensure the integrity of patient information as it travels between healthcare providers, insurers, and data clearing-houses. Since 2000, HIPAA has required healthcare organizations to inform patients about how their health information is collected and used, how its security is guaranteed, and how they may access their medical records, correct errors, and control most disclosure of their information to people outside the healthcare system.

While the advantages of EHRs are increasingly recognized, the problems of integration and interdependency, not to mention lingering security questions, have led to a less ambitious, more gradual approach in the twenty-first century. The emphasis is shifting to certain elements, particularly order entry and decision support as means to reduce errors and ensure more streamlined, legible, and traceable actions.

Studies focusing on the content of EHRs are needed, especially studies of nursing documentation or patient self-documentation. The challenge for ongoing national health record projects around the world is to take into account all the different types of EHRs and the needs and requirements of different healthcare professionals and consumers in the development of EHRs.

Theoretical Approaches to Health and the Internet

Current research in the field of health communication and the Internet tends to be problem driven. When theories are evoked, they tend to focus on functions

of media use. Uses and gratifications theory – how media are used and the effects they produce – has been widely applied to new communication technologies for various purposes, including health. A number of key concepts underpin this theoretical framework: communication behavior is goal-directed; individuals select and use communication channels to satisfy perceived needs; individual communication behavior is moderated by a multitude of social and psychological factors; and media compete amongst each other and with other forms of communication, such as discussion with friends and family. People's goals shape the media types they selected and their subsequent processing of media content. This approach typically emphasizes the active audience, a concept that is particularly important in considering the Internet, and increasingly the participative web (Web 2.0). Uses and gratifications theory is also used to explain why people adhere to online patient communities.

In particular, theories that seek to explain why people seek information and how they use it are well represented in research on health information on the Internet. A number of models exist, but most come back to the idea of motivation. Selective processing refers to the idea that individuals orient to specific stimuli in the environment that are consistent with existing beliefs and attitudes and avoid information that might require them to rethink or re-evaluate their frames of reference. For example, Dutta-Bergman (2004) has demonstrated that individuals who are highly engaged in health-related issues are more likely to seek out health-specialized media content than individuals who are not particularly health-conscious. Compared to traditional mass media, the interactivity of the Internet facilitates selective processing of information: a visit to a particular Internet site is likely based on the interest of that user in the information content of the site.

Motivation is also an important factor in studies about health promotion and intervention campaigns since these initiatives seek to understand engagement in health behaviors, particularly what makes people change their behavior. The health belief model suggests that motivation is based on an individual's perception of consequences, benefits, justifiable costs, and cues to action (such as an enticing incentive or a brush with illness). Social cognitive theory views people as reasonable, rational decision-makers who make decisions based on the interplay of internal factors, such as knowledge, skills, emotions, etc., and environmental factors such as social approval, physical environment, or institutional rules. Particularly interesting for health campaigns on the Internet is the transtheoretical model, which suggests that people may not proceed directly from thinking about a problem to changing their behavior. Change typically involves five stages: pre-contemplation (not aware of the problem), contemplation, preparation (deciding to take action), action, and maintenance (Prochaska, DiClemente, & Norcross, 1992). The implication is that people may react differently to health-promotion efforts depending on the stage they are in. Therefore, information alone is not sufficient to change behavior. This theory is especially important for Internet campaigns since the medium allows for personalization. Once an individual's readiness is assessed, subsequent messages may target specifically the stage of the person receiving them.

Future Directions

The Internet provides a global repository of information of all kinds, including health information at various levels of specialization. It also offers people a way to connect with each other, minimizing distance and time constraints. Whether we use it for looking up information, for exchanging with others, for medical consultations, or for largely invisible applications such as streamlining medical records, the Internet has become an integral tool for communication in healthcare.

Special-purpose systems and dedicated health networks continue to exist but are increasingly interfaced with the larger Internet. As information infrastructures develop, this interconnection will likely intensify. In first-world countries the Internet health revolution is well underway, but it is also gaining momentum in developing nations. The Internet's ability to telescope distance makes it an invaluable aid in making health information and expertise available even in areas where physicians, nurses, and medical libraries are scarce. Future developments, particularly with secure transmission and wireless technologies, should further propel the use of the Internet in healthcare.

The human and social side of the health communication and Internet equation is developing more slowly than its technical possibilities. It takes time for people to adjust their practices to new realities and possibilities. The Internet is not likely to replace patient-provider interaction, although it may shape it in new ways as expectations evolve. Telehealth provides one more option for service delivery but is unlikely to replace most face-to-face consultations. Most interestingly, people are inventing new ways of using the Internet to advantage. Health education and promotion campaigns are now routinely using the Internet as a channel for program delivery, and are finding new ways to take advantage of its unique characteristics to personalize feedback and reach dispersed groups. Perhaps the best example of invention is the development of online, patient-driven communities that provide resources and social support on a scale that would have been unthinkable before the widespread diffusion of the Internet. In the future, we are likely to see many more initiatives of this type, as the web moves toward enabling participation and user-generated content – the famous Web 2.0, or participatory web.

Note

- 1 Discussions about empowering patients and the role of web-based information have led to the semantic challenge of properly naming non-medically trained individuals who search for information online. For example, the term patient does not include those persons who search for information about the health situation of a friend or family member. Throughout this article, we have tried to use the term health rather than medical, because it is more inclusive, and we have dealt with the problem of user initiative differently according to the context. For example, although “health-information consumer” has its own connotations, we have used this term when users appear primarily

to be finding and using information without transforming it. In other situations we have used the word “patient” as appropriate.

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