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13. e-health networks and social transformations: expectations of centralization, experiences of decentralization

James E. Katz, Ronald E. Rice, and Sophia K. Acord

We subtitled our edited volume, *Internet and Health Communication* (R and Katz, 2001), "Experience and Expectations" to suggest that, by refl ing on early experiences with e-health, leaders in academic research : healthcare planning might have more temperate expectations. In this ch ter, we reverse the order of the terms, identifying not only where histori expectations concerning e-health have been fulfilled but also where tl have missed the mark, and suggesting areas where additional progress mi make the strongest contributions to public and individual health.

The chapter is organized around four analytical themes, all of which st from the fact that the Internet has given a large portion of the general pul and most healthcare professionals an opportunity to gain medical and hea information and communication resources. Anticipatory of and reactive the opportunity that is created by the social interaction between health inf mation technology and participant desires, (1) there has been substan resource commitment, resulting in the creation of many useful centrali services (some commercial, some governmental); (2) however, despite th utility, perceived and actual inadequacies of these services have stimula disparate groups to organize their own compensatory, decentralized a local networks of health information resources. In both centralized a decentralized Internet health resources, though, there are still many issues be resolved, such as (3) reconfiguring physician/patient relationships in light of new technology, and (4) creating socially sensitive e-health servi that are also socially equitable in terms of accessibility.

Each of the above four analytical themes implies both an original pr lem, which gives rise to specific forms of Internet use, and subsequently contradictions, which suggest potential, often novel, solutions. A recipro consideration, then, is to examine some of the ways in which people try to use the Internet to serve their own needs, and how, when doing so, they bump against the logic and vested interests of health institutions and information systems. Hence, we strive to locate structural constraints that, if successfully addressed, could improve e-health systems in networked societies.

Inescapable questions underlie these themes. First is the inherent bureaucratic logic of one-way information flow. This logic governs traditional relations of healthcare organizations with their clients (as it does in other topical domains as well), even as these operations are extended to their online operations. Further, as this process unfolds, it often includes within it a market logic of packaging information for profit. This packaging is sometimes done in ways that are anything but clear to the consumer. Second, to survive, organizations must attend to their vested interests. These yield some inherent limitations for organizations. Moreover, the specific area of health is further complicated by considerations of (and conflicts among stakeholders over) value orientations toward the rules governing commercial free speech, access to markets, legal and medical regulations, and effectively informing, protecting, and enabling patients as well as physicians and other healthcare workers. Thus, responses to identified problems that do not address these limitations are unlikely to be viable.

Before delving into the themes, we should mention our perspective, which we dub "syntopian" (Katz and Rice, 2002). The syntopian perspective rejects both dystopian and utopian perspectives on the social uses and consequences of information and communication technology. Rather, it emphasizes how people use and reinvent (Johnson and Rice, 1987; Katz, 1999, 2003; Rice and Gattiker, 2000) technologies to make meaning for themselves relative to others. Hence, while possibilities are limited by the nature of the given technological tools, systems and their uses are (potentially) surprisingly flexible. Thus technology becomes altered by individual needs and social contexts. The perspective also highlights that the internal logic of both formal organizational systems and personal social systems are fully extensible to the Internet (Castells, 2000). Finally, although we do cite examples from many countries, most of our analysis focuses on the United States.

The following sections place our four analytic themes within the context of the growing magnitude and intensity of Internet use in the US for medical and health information.

A POPULAR SOURCE OF HEALTHCARE INFORMATION

The Internet makes it much easier for people to seek health information and become more competent concerning their own healthcare (Hardey, 1999). As

early as 1997, in what appears to be the first national random surv comparing users to non-users regarding healthcare, 41 percent of I Internet users had gone online to access healthcare information resourc (Aspden and Katz, 2001). By 2002, surveys commonly reported that in t region of 60 percent of online users in America have sought healthca resources on line, notably for other people besides themselves (Pew, 200. (Some research, however, suggests that this percentage is exaggerated; f example Tu and Hargraves, 2003.)

Table 13.1 shows the percentage distribution of the US population terms of Internet use, and various types of medical and health informati seeking behaviors, in 1997, 2000, and 2002. Over half of the population us the Internet; of that half, two-thirds use it to seek healthcare informatio with perhaps one out of 20 using it for that purpose within any given da Clearly, then, at least in the US, the populace has embraced the online wor as an important health resource. Those with more education are dispropo tionately more likely to be health seekers than just Internet user Concerning race, whites and "other" use the Internet more than blacks, b are even greater health information seekers than Hispanics and black

Table 13.1 Use of the Internet and Internet healthcare resources by the U public, 1997–2002

	All respondents (%)	Internet users (%)			
Date	Internet user	Ever seek online health info	Sought online health info yesterday	Ever go to health websites	Went to health website yesterday
December 2002	57	66	6	54	4
September 2002	59	62	6	47	5
June 2000	47	55	5	36	3
November 1997	30	41	n.a.	n.a.	n.a.

Health website = a site that provides information or support for specific conditions or person situations.

Source: Katz and Aspden (2001); Pew Internet and American Life Project (2003b)

Those with higher income are more likely to be Internet users, and more likely to be health seekers.

People with a specific question or issue they need addressing are often motivated to access the web for health information. One study found that 77 percent of patients did this (Boston Consulting Group, 2001). Understandably, people engage in wide-ranging search behavior in order to meet these specific aims (Malin, 2002). In 2001, 65 percent of health seekers used general search engines and banner ads to find information, 24 percent used general health portals, and 11 percent used disease-specific websites (Boston Consulting Group, 2001). Whether searching for more information on clinical diagnoses or alternative treatments, 80 percent of health seekers say that they found most or all of the information they were looking for the last time they logged on (Pew, 2002). Of those in the September 2002 survey ($n = 2092$ respondents, 1318 Internet users) who do seek healthcare information online, 58 percent reported that they would first go online for reliable healthcare information, while 35 percent said they would first contact a medical professional. Percentages for all Americans were 31 percent turning to the Internet and 59 percent contacting a medical professional.

We will now turn to our four analytical themes to explore the issues and conundrums regarding healthcare in a network society.

THEME 1: CENTRALIZED ONLINE VENTURES HAVE STRENGTHS, BUT THEIR WEAKNESSES CREATE NEEDS FOR SELF-ORGANIZED LOCAL SYSTEMS

Centralization Failures

Centralized medical initiatives dominated the early Internet expectations for health resources. Government resources such as Healthfinder.com, academically oriented databases such as The National Library of Medicine's PubMed for Medline, commercial offerings such as drkoop.com or Pointcastnetwork.com, institutional sites such as the Healthscout or American Medical Association, and search engines such as the Medical World Search all had an early presence online. Those centralized sources that have survived play an important role in distributing quality health information. Indeed, their technological infrastructures make health seeking accessible to the larger population, and a bridge to span various digital divides. They also have the strategic location, if not the resources, to engage in vigorous website certification and verification roles for quality information. Medical documents that were conventionally out of reach in terms of patient access and circulation are

now being made accessible by the Internet. For example, Wikgren (2001 found that the bulk of citations in discussion group postings came fro abstracts of professional journals, such as the Medline database.

However, despite the fact that centralized sources could (and in many case do) provide up-to-date and individualized assistance, too often they do not Few take advantage of website certification services. Varieties of helpfu services, which are technologically feasible, are also often not available fro leading institutions of centralized medical care (discussed below). Despite th impressive promise of Internet technology, substantial numbers of these top-down initiatives have been weak (though many have valuable and timel information and have been a success). For instance, a surprising number o sites have out-of-date or misleading information; and many of those that d not are but little visited, which often means closure. Six factors may accoun for poor performance.

- Nonprofit, centralized sources may not be widely promoted to the relevant audiences – online or offline. Sigouin and Jadad (2002) studie cancer patients, their general practitioners, and all oncologists an oncology nurses at the Hamilton Regional Cancer Center in Ontario They found that few patients were aware of local, official cancer information websites (3 percent) or Medline (13 percent). While oncologist reported high levels of awareness, less than a third of family practitioners had used any online sources other than Medline.
- To use centralized sources, training is often required. Even if users o systems do not require training, they invariably have to face a learnin curve. Further complicating matters is the fact that different protocol are usually required for each e-health resource. For instance Surgerydoor.com (a British commercial health website) offers a specialized search engine linked to high-quality medical information However, Williams et al. (2002) note that even deft users had difficult using it as they were accustomed to generic search engines.
- Old habits die hard. Bamford et al. (2003) implemented a country-wid network of physician webcams throughout 35 histopathology departments in the UK. A year after installation, they found that 71 percent ha not been used, due to the physicians' excessive workloads and IT staf reluctance, but above all, because of negative attitudes toward the technology. Technology in general, and centralized systems in particular, d not seem to fit in with the "social side" of how people – whether physicians, nurses, technicians, administrators, or patients – gain and evaluate health information and participate in medical service (Rice, 2004).
- While centralized sources use peer-reviewed literature, which tends t have the highest quality, this literature is also the most difficult to read.

As a partial solution, Till (2003) proposes that “e-prints” be marked by commissioned reviews as well as unsolicited comments.

- Centralized sources lack local representation. Mendelson and Salinsky (1997) found that the failure of many community health management information systems (CHMIS) (similar to CHINS or community health information networks) was due to the lack of local and private sector support for integrated, state-wide systems.
- Centralized sources often lack emotional, personalized, and subjective aspects. Many potential users want this quality.

Commercialization of Health Websites

Much of the health information on the Internet is commercialized, either directly or indirectly. Most patients end up using commercial web-health portals such as WebMD.com for information, followed by other commercial and pharmaceutical sites. Many fewer patients go to educational and academic sites (Boston Consulting Group, 2003). Suarez-Almazor et al. (2001) searched for “rheumatoid arthritis” using WebCrawler, a popular search engine. Of the 388 unique and functioning websites out of the 537 returned hits, 51 percent were posted by a for-profit industry, one-third carried educational (nonprofit or university) sponsorship, and 17 percent were posted by an individual.

Although some people may judge the quality of online health information based on nontraditional or even misleading criteria such as a commercial brand or logo (Eysenbach and Kohler, 2002), other users may even be unaware of the commercial aspects of a health site. The late 1990s' revelation that the drkoop.com site, founded by the former Surgeon General of the US, failed to disclose financial ties and the fact that hospitals paid to be listed on the site, led to the resignation of its executive team, as well as a plummet in its market capitalization (Charatan, 1999a, b, 2000; the site has now closed entirely). More generally, those who report reading online commercial health information are more likely to report reading unreliable health information; thus, overt commercialism may be a turn-off to health seekers (Aspden and Katz, 2001).

Commercial health sites are, indeed, noticeably different from nonprofit or governmental sites. A content analysis of commercial and government health website features found that academic materials, search methods and tools, and topic headings were more frequently available on government than on commercial sites, while commercial health websites provided more interactivity among users, such as chat rooms and newsgroups (Rice et al., 2001). Street and Rimal (1997) note that the interactivity of the Internet provides a modicum of control to users; they can modify content and respond to prior actions and other participants, for example. A more radical form that this interaction can take may be shown in the case of MedicineOnline.com, which even

offers an auction service in which patients can elicit physician bids for sur eries (Baur et al., 2001). More typical is HealthCentral.com, which allo users to create their own health profiles and provide personal feedback (Alle 1999). However, such interactive websites are not without problems.

One particularly sensitive area is that of privacy. An online pharmacy, dru store.com, sold information it collected from visitors to its website to a pha maceutical marketing company. Thus, if someone purchased or asked abo drug X from drugstore.com, that person might find herself solicited “couponed” by the maker of drug Y, a competitor of drug X. The w company drkoop.com sold, as part of its bankruptcy liquidation, some of t personal information about site visitors that it had collected. These da included personal medical and financial information on many consumers w collected or shared information via interactive chat rooms or used interacti tools for searching the web (Health Data Management, 2003).

Other types of e-health privacy abuses are more subtle. Companies inclu ing Doubleclick.com and Amazon.com work with their partner sites to colle individually identifiable data on web surfers through “cookies,” which ser to draw ever-more precise pictures of an Internet user. So, for instance, a surf who reads an Amazon.com review about a book on depression and later clic on a bulletin about a Hollywood star's suicide could potentially have data his book-buying and news-reading habits, his name, address, and pho number, and much else besides, sold to a life insurance company (who mig cancel his policy), a drug marketer (who would send him product solicit tions), or even a cemetery (offering “pre-planning”). The more participati sites a user visits, the more detailed and inter-related becomes the person portrait. Privacy-abusive practices are disturbing to privacy advocates, a alarming to e-health seekers, and in some cases are deterring surfers fro using Internet resources. Ultimately, these practices could erode the ability the Internet to provide services to precisely those who would most bene from the web.

Quality of Online Health Information

The prospect of easily accessible, high-quality health information was anoth early appeal of the Internet. The hope was that, by having quality certificati (such as is offered by the “Health on the Net” [HON] Foundatio [www.hon.ch], created in 1995), users would patronize certified cites, an inaccurate medical information or practices would be disputed and dimi ished. Yet researchers consistently find problems with the quality of onli health information, in commercial sites as well as discussion lists, usen newsgroups, and online support groups (Kassirer, 1995; Jadad and Gagliard 1998; Consumers International, 2003).

Eysenbach et al.'s (2002) analysis found that the quality of information on the web was noted as a problem in 70 percent of the articles reviewed, while the 9 percent of articles that did not indicate a problem scored significantly lower in search and evaluation methodology. Internet health and medical information, Eysenbach et al. conclude, deviates from recognized safety standards, is seldom updated, does not offer advice on avoiding drug interactions, and promotes unconventional medicine (see also Rice, 2001; Currò et al., 2003). Veronin (2002) collected data in 1998–9 on 184 websites with health information, and attempted to assess the same sites in 2002. By then, the majority of the original sites (59 percent) had disappeared, one in six (17 percent) had moved to a new URL address, and only about a quarter (24 percent) of the sites could be found from their original URLs. Of the 45 websites still in existence at their original locations, only a minority (38 percent) provided information that was updated from the original posting. Rose et al. (1998) noted that of 5,947 retrieved pages in a search for fever in young children, only 7 percent were actually relevant to the condition. Wikgren (2001) found that no health-oriented personal home pages offered citations of references to other sources of data. In an online survey of 800 web-using doctors in the UK (94 percent response rate), only 20 percent believed Internet health information to be "usually" or "sometimes" (48 percent) reliable (Potts and Wyatt, 2002).

The high ideals of the initial claims about improved online health information have also struggled as ludicrous health conspiracy theories and implausible "alternative" health sites thrive. To cite but one recent study demonstrating the problem, physicians analyzed 443 popular websites involving the eight most widely used herbal products. Of those, 273 sites boasted health claims for the herbs. The majority of those (149) held that these products could "treat, prevent, diagnose or cure specific diseases." Moreover, 39 percent of the 62 kava retail sites made no mention of a US Food and Drug Administration (FDA) advisory connecting that herb to liver toxicity (Morris and Avorn, 2003: 1506).

Yet users overall tend to be quite positive, or, possibly, quite unaware of accuracy and validity criteria. While 28 percent of health seekers note that they have seen some bad information, 69 percent report seeing no wrong or misleading data online (Pew, 2002). And although 73 percent of health seekers say they have rejected data at some time or another, 72 percent of health seekers think that "almost all" or "most" of the health information they find on the Internet is credible, a 20 percent rise from 2000 (Pew, 2000, 2002). Clearly, then, many Internet offerings are fraught with problems of quality and conflict of interest. At the same time, consumers seem to prefer the empty promises over the careful, limited (and limiting) offerings available through careful and conservative systems of that involve hierarchies of approval, peer review, evaluations of conflicts of interest, and re-verification.

As noted above, there were many enthusiastic expectations about the pro sion of health information through centralized and commercial Inter websites, and indeed such sites have many advantages. We can ask how m difference these technologies are actually making in practical terms. One way assess this is to ask if they allow providing organizations to be more efficient one considers samplings of success stories from hospitals and medical practic the answer would clearly be that, if the innovations are well considered a implemented, they save money for the practitioner and the supporting organi tion (Landro, 2003). Does it make a difference in terms of quality of care for t patient? The answer would seem to be, in many cases, yes. The informati resources of the Internet have enabled many to find solutions to their needs a take greater responsibility for their health. (This conclusion is supported anecdotal as well as survey data of both health-seekers and physicians as sho below.) There is much to be proud of in this record of achievement.

However, despite enormous progress on the technological front, most lar high-quality sites still fall far short of what might be offered that would ser the needs and convenience of patients qua individuals. A review of major si shows that, while they have much that benefits patient-clients, they rema incomplete successes since they have not offered a wide variety of possi services. As table 13.2 shows, despite the fact that some of these premier si have seemingly interactive features, most have not addressed users' needs f more social interaction with healthcare providers (which, in turn, would al increase the burdens on the care providers). As this is the situation not only f

Table 13.2 *Comparison of features of Internet patient decision-support to of some leading providers*

	Patient video interviews	Online social or community network support tools	Offers user-specific outcomes data	Free public access on the web
FIMDM	No	No	No	Subscribers on
CHESS	Yes	Yes	No	Limited to consortium member group
NexCura	No	No	Yes	Access throug co-branded partner site; registration required
DIPEx	Yes	No	No	Yes
MayoClinic.com	Yes	No	No	Yes

Source: Adapted from Schwitzer (2002)

the identified sites, but is characteristic of centralized e-health services generally, it is understandable (as the next section argues) that users have applied and reinvented features of the Internet to try to resolve some of these problems themselves. That is, the Internet has provided the potential for self-organization among many kinds of social networks, especially along the lines of personal and group identities.

THEME 2: STRAIN TOWARD SELF-ORGANIZATION

Online Support Group Communities

Groups and networks of interacting participants use technology to decentralize health information and unite global networking and information flow with the human experience of their own illness or suffering (Izenberg and Lieberman, 1998, cited in Napoli, 2001). The developing complex network society is one in which distant, global edges are combined with many local, organizational clusters (Castells, 2000: 369). Networking thus becomes a self-organizing human activity, as health seeking is based primarily upon information sharing and development (Wellman, 1995).

The Internet has the capabilities to support virtual health communities (Wynn and Katz, 1997; Patsos, 2001; Katz and Rice, 2002). Such communities (as well as mediated relationships between physicians and patients, discussed in the following section) possibly represent a transforming relationship between lay and medical knowledge (Hardey, 2001, 2002; Loader et al., 2002). Such communities are particularly useful for patients with rare diseases, as these people are by definition relatively few in number; they are usually also dispersed geographically, lack specialized care or even acceptance in their local environment. Social distance offers the opportunity for having expertise available while (seeming) anonymity reduces the reluctance to discuss sensitive topics; these, of course, are characteristics of the Internet, which enable users to manage their interactions with respect to expressiveness and stigma. Access is readily available at any time and from many places (Rice, 2001). As a quick illustration of these processes in action, we note that individuals with depression, diabetes mellitus (a gastrointestinal disorder), or a gynecological condition were more likely to use online groups than those suffering from other illnesses (Millard and Fintak, 2002).

Centralized medicine typically works to treat the individual patient, often ignoring the suffering or therapeutic contributions of their loved ones. Online websites and support groups provide information, support, acceptance, and a sense of real-time understanding to patients and their families and friends (Wellman, 1995; Till, 2003), and, in conjunction with physical communities,

apply cultural or generational norms and customs (Burhansstipanov et
2001; Hanson et al., 2002). Empathy is stronger in online support and pati
groups, especially in moderated ones, than in other kinds of discussion gro
(Preece and Ghozati, 2001). As many online support groups are peer-mod
ated rather than professionally moderated, Till (2003) suggests that vete
members or survivors often function as tacit but highly effective peer navi
tors. Partially because of the lack of moderation by medical experts, howev
Culver et al. (1997: 471) concluded that online support groups are a mixt
of "snake oil" and "self-help," preventing appropriate diagnosis and treatm
(see Rice, 2001).

Aspden and Katz (2001) note that 73 percent of health seekers discuss th
Internet information with others. For example, online users report medi
data from the *Journal of the American Medical Association* and Medline
each other as persuasive techniques in support groups (Wikgren, 200
Paterniti et al. (1999) evaluated postings on breast cancer-focused compu
bulletin board systems, and found that participants discussed strategies
health seeking and worked together to make decisions on clinical recomme
dations and treatment options. Sharf (1997) studied an online breast-canc
discussion group and concluded that it was a powerful force in informati
exchange, social support, and personal empowerment.

While support groups appear to heal the soul and feed the mind, there
some evidence about the crucial question of whether they help to heal the bo
as well. While, at most, only 9 percent of health seekers have participated
an online support group of any sort, those that have do report notable benef
(Celio et al., 2000; McKay et al., 2001; Pew, 2002). These benefits m
include reductions in depression, cancer-related trauma, and perceived stre
these were the benefits that accrued among 72 women with primary bre
carcinoma participating in a 12-week web-based support group (Winzelberg
al., 2003). McKay et al. (2001) found that patients taking part in an onli
diabetes education and support group saw their blood glucose levels lower
more than those in the control group. Likewise, in a randomized controll
trial, participants in a back pain e-mail discussion group noted significa
improvements in pain, disability, role function, and health distress, compar
to a control group (Lorig et al., 2002). In a controlled experiment compari
Internet and classroom-delivered psychoeducational interventions for eati
disorders, Celio et al. (2000) found that measures of body image and eati
disorders were significantly reduced in the Internet group in comparison to t
classroom group. These studies suggest that the Internet is not only an equ
to face-to-face support groups, but may produce beneficial and unique resul
Overall, online support groups had some benefits not found in face-to-fa
relations, including seeming anonymity, which moderated inhibitions towa
discussing sensitive topics, and around-the-clock access (Rice, 2001).

Taking Care of One's Own Care

Whereas centralized top-down Internet based initiatives have not delivered as promised, localized applications have indeed produced successful results. The Internet can be used not only to find new health information, but also to disseminate health knowledge to monitor conditions. Using the Interactive Multimedia Program for Asthma Control and Tracking, patients saw their asthma symptom days decrease from 81 to 51 a year, and their emergency room visits decrease from an annual mean of 1.93 to 0.62 (Krishna et al., 2003).

In another example, patients with access to their medical records primarily used the system to review their laboratory results, resulting in enhanced understanding on the part of the patients and improved communication with their physicians (Cimino et al., 2001). These expert-run cases of health seeking on the Internet seem successful because they are based on the self-service and convenience aspects that empower patients (93 percent of health seekers value convenience according to the Pew 2000 survey), while providing quality information. (There are also manifold reports of abuse and exploitation via these technologies as well, however.)

Thus, users are accessing the Internet not only to obtain health information that they could not otherwise easily obtain, but also to create contexts for social interaction, empathy, and emotional support. As with other human activities, this self-organization has both benefits and disadvantages. Among the disadvantages is the tremendous amount of mis-information, disinformation, and duplicity that is propagated by these unregulated forums. However, due to their many advantages, it remains likely that online interfaces between the centralized and decentralized, such as between physicians and patients, could possibly become valuable sites for transforming social relations in the pursuit of health.

THEME 3: EXPECTING/RESISTING TRANSFORMATIONS OF PHYSICIAN/PATIENT RELATIONSHIPS

As part of the widening use of the Internet for obtaining information, and, as we noted above, communicating with other patients and supporters, patients are also pushing for online communication with their physicians. Some 90 percent of Americans would like to be able to contact their physician online or by e-mail, and 40 percent of respondents would be willing to pay for this service (CyberAtlas, 2002). Indeed, 26 percent of medical practices were engaging in online communication with patients in 2001, with another 13 percent planning to start in the following 18 months (Harris Interactive, 2001).

The incursion into centralized care by a decentralized medium has the pote tial to affect social relations among multiple stakeholders. Anderson et (2003), in a study of unsolicited patient e-mails at a university dermatologi hospital, observed that, over time, the tenor of e-mail content shifted fr patients' self-perception as passive recipients of medical care to acti consumers and demanders of health information. Anderson et al. (200 attribute this shift to at least four factors.

- Both patients and physicians perceive greater dissatisfaction wi medical services due to the limited time patients have with physicia In all, 93 percent of physicians believe that many serious proble could be avoided with more discussion, according to a 1997 Har study. However, 67 percent of the same physicians note that not havi enough time to spend with patients is a very serious problem (cited Rice, 2001). Hence, the Internet may provide a way to increase comm nication with one or more medical sources.
- People feel the cost-saving pressures of healthcare plans, and thus ta quality control into their own hands. Surveys suggest that about percent of US adults are not satisfied with their doctor's accessibili while the Internet is available around the clock, every day (Reents a Miller, 1998, cited in Anderson et al., 2003).
- Increasingly, legal and ethical standards require patients to ma informed choices. Yet it is difficult for them to be as informed as th wish. For instance, in a 2002 survey of Canadian cancer patients, on 54 percent who wanted information about their disease felt that they h obtained an adequate amount of information from their healthca providers (Chen and Siu, 2001). Given this perceived need, many w be turning to the Internet in order to meet their information needs well as their perceived responsibilities.
- There is simply a new wealth of accessible and inexpensive sources information. Thus, there is a reluctance to accept one physician discouraging prognosis or to rely solely on a single traditional sourc On a typical day, 6 million Americans seek health information onlin more than the number who visit or contact a physician (Pew, 2002), a 48 percent of health seekers have looked for information about altern tive or experimental treatments and medicines. Although 83 percent patients continue to rely on their doctor as the main source of inform tion, 71 percent search elsewhere.

Health seekers are increasingly bringing Internet information with them to th doctor visits. Their motivations include seeking to increase their (1) time wi the doctor, (2) level of informed decision-making, and (3) individualization case and needs. One study reported that over 90 percent of physicians and nurses in one hospital said that patients had shown them information from the Internet (Jadad et al., 2001). Overall, 41 percent of health seekers who got Internet information prior to a visit discussed this information with their doctors, and those that did rated the quality of the information higher (Diaz et al., 2002). While 79 percent noted that the physician was "very interested" or "somewhat interested," 13 percent felt that they were given the "cold shoulder" (Pew, 2002). Patients empowered by the Internet say that they are more likely to ask informed questions of their physicians and to comply with prescribed treatment plans because they feel that they are taking part in the decision and understanding the reasoning behind it (Harris Interactive, 2001).

Expectations of the Internet were that it would provide an informational resource to aid patients, but not replace the physician's role in diagnosis and treatment. Although a third of health seekers in one survey reported that the Internet affected a decision about their healthcare (Baker et al., 2003), the great majority of patients trust their doctor above all; in a 2003 survey, 62 percent of respondents reported this view (Tu and Hargraves, 2003). A 2002 survey found that 83 percent continued to rely on their doctor as the main source of information despite advances in online services (*Impact*, 2002). It may well be that a primary reason for such faith is the personalized nature of the service that physicians deliver via their interaction with patients and the physicians' seemingly individualized response concerning the patients' reports of health problems.

PHYSICIANS' USE OF THE INTERNET

Physicians are positive about using the Internet for their own work. A survey of primary care practitioners in Scotland found that 67 percent use the Internet, with 54 percent of those users rating the Internet as "useful" or "very useful" for work-related purposes (Moffat et al., 2001). A 2001 survey of 1,043 US physicians found that 62 percent used the Internet for their practice, and of those who did only about 15 percent said they communicated with at least some frequency with patients via e-mail. However, physicians are less positive about the role of the Internet in providing their patients with quality information, support, and communication. Only 14 percent of the representatives of online practices in one study felt that it helped to deliver better care (Harris Interactive, 2001). As table 13.3 shows, while 60–90 percent of physicians indicate that they use the Internet to obtain journal information or to interact with colleagues, the use of e-mail and Internet communication technologies falls off dramatically when it comes to their interaction with patients. Almost two-thirds say that they never have any e-mail contact with patients.

Table 13.3 Use of online resources by physicians in the United States

	Often	Sometimes	Hardly ever	Never
Obtain professional information resources (treatment guidelines, journal articles)	34.2	54.0	10.2	1.5
E-mail and communication with colleagues	23.2	39.7	19.5	17.6
Obtain patient clinical information, test results	13.6	14.4	17.1	54.9
E-mail and communication with patients	3.7	11.6	20.1	64.6

n = 1022.

Source: Adapted from The Robert Wood Johnson Foundation data (2001)

The possible tools for helping patients are not being widely adopted. This is shown by the example of what is known as remote disease management (RDM), which includes the collection, analysis, and reporting back of data on patients, as well as physician-initiated communication to help patients manage disease, including lifestyle recommendations. A 2003 study reported that a mere 7 percent of doctors who were already online use RDM technology (mainly for monitoring patient blood glucose levels), an insignificant growth from 5 percent two years earlier (Boston Consulting Group, 2003).

Physicians and their Patients' Use of the Internet

Although healthcare seekers may be using the Internet avidly, and claim to be discussing their findings with physicians (Aspden et al., 2001), physicians do not notice substantial proportions of their patients discussing their findings with them. This is suggested by table 13.4, which shows the results of a Robert Wood Johnson Foundation survey of 1,050 physicians in 2001. One out of six physicians reported that, over the prior year, none of their patients had discussed anything concerning information they had seen on the Internet with them. About half reported that a few of their patients had done so. Less than 10 percent reported that more than half of their patients had done so. A small survey of New Jersey physicians, also supported by The Robert Wood Johnson Foundation, found physicians reporting somewhat higher rates of patients discussing Internet information with them (Aspden et al., 2001). About 30 percent of 201 physicians said patients had discussed Internet information with them within the last week, though 10 percent reported that few or none of their patients had ever discussed such information with them. It seems, then, that even if many patients are using the Internet to get healthcare information, relatively little of it is being discussed with their physicians.

Nonetheless, the majority of physicians have positive views toward patients

Table 13.4 Physician reports of the percentage of their patients who talked to them in person about information that the patient has obtained from the Internet

Almost all (81–100%)	0.2
Most (61–80%)	1.9
About half (41–60%)	6.3
Some (21–40%)	25.6
Few (1–20%)	48.7
No discussion of Internet material with any patient in past 12 months	14.7

n = 1022.

Source: Adapted from The Robert Wood Johnson Foundation data (2001)

presenting them with information from the Internet (see table 13.5). The substantial majority finds the information accurate, feels that this use of online information shows that patients are taking responsibility for their healthcare, and that such presentations are not challenges to physician authority. (Notably, positive attitudes seem inversely related to physician's age.) Those who considered such presentations as challenging physician authority were less likely to view the experience positively, but this still only amounted to a third of those who viewed matters in this light.

In sum, there is little to support the notion that physicians, especially younger ones, discourage patients from bringing healthcare information from the Internet to the attention of their physicians. Despite the fact that there is apparently a great deal of health information seeking on the part of patients, large proportions of patients do not seem to bring such material to the attention of their physicians. One possible explanation for this conclusion is that patients are investing their new-found knowledge in non-traditional, or at least non-physician, relationships, such as the support groups noted above or family and friends.

Physician Interaction with Patients via E-mail

One expectation was that patients would be able to have ready contact with physicians via the Internet. Similar expectations accompanied the adoption of an earlier technology, the telephone (Spielberg, 1998). For the same reasons, in neither the case of the telephone nor the Internet have these technologies led to substantially more open access to the physician. In various e-mail surveys of physicians, the majority noted a low response rate from their subjects. Schmidt et al. (2003) reported a 38 percent response rate when a fictitious patient e-mailed members of the Association of Reflexologists. In a similar study, Oyston (2000) received a 54 percent response rate from anesthesiologists in Canada. In most cases, the health professional responded by advising the patient to go to a medical professional: 85 percent (Schmidt et al., 2003) and 83 percent (Oyston, 2000). Few attempted to make a diagnosis or suggest underlying causes: 29 percent (Schmidt et al., 2003) and 41 percent (Oyston, 2000). Thus, even in those cases where the physician responds, no new information is usually communicated over the medium.

A report from Forrester Research (cited in Schachtman, 2000) notes that 72 percent of healthcare professionals would not personally respond to patient e-mail, while an additional 19 percent said that they would only if compensated. Similar findings are reflected in our analysis of The Robert Wood Johnson Foundation-sponsored data reported above. Some medical societies discourage the use of e-mail by physicians to communicate with patients. "On the whole, it's not a good idea," according to Linda Millington, a spokesperson for

Table 13.5 Physician assessment of effect on physician/patient relationship of patient presenting Internet-derived information

	Effect on physician/patient relationship (%)			No. of physicians responding to question
	Improved	No difference	Worsened	
How accurate was the information?				
Very / somewhat	44	52	5	298
Not very / not at all	22	59	19	106
Did you feel the patient was taking responsibility for his/her health?				
Yes	43	51	6	313
No	23	62	15	89
Did you feel the patient was challenging your authority?				
Yes	24	40	35	68
No	41	56	3	337

All questions p (chi-square) <0.001; $n = 405$.

Source: Adapted from Murray et al. (2003)

the British Medical Association (BMA). In addition to putting patient confidentiality at risk, among the reasons she cited are that it is difficult to ascertain exactly with whom physicians are communicating and that there is no personal contact which is necessary for picking up crucial diagnostic clues (Pincock, 2003). (The BMJ's discouraging views are presented at bma.org.uk/ap.nsf/Content/Consultingmodernworld.) On the other hand, the American Medical Association is more moderate. While it does urge caution and mandates follow-up in-person visits, it does see substantial benefit to e-mail communication. Indeed, it has undertaken a joint venture in this area. Private firms, for example, WebMD, also are seeking to turn small-scale experiments into full-fledged profit centers.

Physician Websites

Health seekers are increasingly requesting reliable websites and recommendations from their local medical practitioners. Over two-thirds of patients consider websites recommended by their physicians to be the most reliable, 61 percent consider their physician's website to be most reliable, and over half of patients trust health sites affiliated with other local medical authorities (LaurusHealth survey, cited in Pastore, 2000). One survey found that nearly two-thirds of consumers would change to a doctor who provided a website with credible content, appointment scheduling capabilities or secure communication (Pastore, 2001). However, according to another survey, only 40 percent of physicians had a web page, and the majority of such sites lack the sort of depth sought by patients (Pastore, 2000). Sanchez (2002) notes that the vast majority of physician websites focus on practice enhancement tactics, rather than concrete patient service.

Hence, we suggest that, just as the Internet is providing a context for reinventing or renegotiating the relationships between centralized and decentralized sources of health information, it is doing so also for actors within traditional small practices of "street-level" healthcare. As individuals and groups are becoming more active, seeking out and creating their own information and communication resources, they are increasingly, though not dramatically, turning to physicians as expert guides and interpreters of the information they find as well as seeking reassurance or innovative steps from them. While patients still think of their physician as their trusted medical agent, they are turning to other sources, even those that question traditional Western medicine, and using that information as part of interactions with their physician.

Physicians, for their part, are attempting to maintain as well as extend their ambit to include a virtual side. They do this by becoming more involved in Internet communication, drawing on the Internet for information, extending

patient communication to include Internet information resources, and developing their own websites. However, for reasons of professional role definition, not to mention practicality and legality, they are reluctant to become a node in the patients' self-organized network. Instead, they seem more inclined, but only slightly so, to make patients part of their own organized system of health delivery. Ultimately, as was the case with the professionalization of healthcare in earlier times, the logic of information networks, combining expertise and economics, leads them to look for ways to retain centrality and efficiency in an environment where authority is increasingly challenged and constrained.

THEME 4: POTENTIALS OF NEW TECHNOLOGY NOT MET

Overcoming Access Inequities

Internet health information, as with other Internet resources, remains inaccessible to large and specific parts of the population (Katz and Rice, 2002). Least likely to have the tools to seek health information online are those with preventable health problems or without health insurance (Eng et al., 1998). Race, at first blush, appears to be an important factor in determining potential access as 87 percent of health seekers are white (Houston and Allison, 2002), and gender is also correlated with access behavior (Nicholson et al., 2003). However, statistically speaking, both race and gender gaps in general Internet use is closing, if they have not disappeared entirely, once other demographic factors such as income are controlled for (Katz and Rice, 2002). Our studies (Katz and Aspden, 1997; Katz and Rice, 2002), as well as others (Kakai et al., 2003; Mead et al., 2003; Peterson and Fretz, 2003), show that educational achievement and income, not race or gender, are the primary drivers of inequality in Internet access in the US. That is, little or no inequality exists in terms of Internet access among these groups at any particular income level. It is, of course, the case that the mix of groups in terms of percentages varies greatly by income level, but it remains the case that the income level is the driving factor in terms of statistical variation. Indeed, a "reverse" gender gap may emerge, as women and older people are more likely to use the Internet for healthcare than are men or younger people.

Physically impaired and disabled people, though, are clearly still at a disadvantage despite the shift toward a networked society. In an evaluation of 500 websites representing common illnesses, only 19 percent were accessible to visually impaired readers using automated screen readers (Davis, 2002). Pew (2002) found that only 38 percent of Americans with disabilities go online, versus 58 percent of all Americans; and, of disabled health seekers, one-fifth reported that their disability makes it difficult for them to go online (Pew, 2003a). While deplorable, these findings are not unexpected. As we wrote during the early days of the Internet, the physical and visual demands of computer use are substantial barriers to the very people who were most expected to benefit from the Internet (Katz and Aspden, 1997). This observation seems as valid today as when we first evaluated the results of our 1995 survey. Finally, as noted above, Internet-based services fail to offer many existing technologies that could tangibly improve matters for the ill and their caregivers. This gap is even more profound for those who are, even under the best of circumstances, beset with physical limitations.

CONCLUSION

The Internet has made prior health information tools more available, allowing those with initiative to use the technology get information (but also mis-information) and obtain emotional and local support. The Internet makes novel approaches possible. Yet, despite some dramatic changes, startlingly little has altered in some areas. In fact, a surprising – and perhaps even widening – gap exists between what could be and what is available using the ever-rising capabilities of "off-the-shelf" technology.

Thus, in spite of the most utopian expectations, experiences are not only a product of individual and group choices and interactions, but also of institutional, infrastructural, social, and economic constraints. This may be seen not only in the absence of readily available and extremely helpful technologies that could serve the patient, but also in the persistent inequities, based on education and lifestyle, in the way in which new technologies are made available to various socio-demographic groups, and the growth and use of unevaluated alternative-style health models.

The perceived need for emotional support and personal relevance has mobilized the creation of "the people's Internet," a loosely connected (or entirely isolated) set of self-organized networks, offering expertise and assistance. This move toward a degree of self-care is, nonetheless, not independent of physicians or the medical establishment; rather it grows alongside, complementing these systems even while challenging them. Yet a bulwark of expertise and professional support, which can be made available by centralized systems, is necessary as quality control against a rising tide of bogus and exploitative pseudo e-health activities on the Internet.

Perhaps the biggest need is to help centralized systems, which have many other strengths, to include resources at the level of individualized patient, caregiver, and counselor; resources that are grounded in local and other social contexts and networks. There is a great need for increased sensitivity to cultural norms as well as truly individualized applications. The problem, though, is at its core less financial than sociological. This is because the institutional dynamic is powerful and often threatens to eclipse the nominal purpose of a web-based health initiative. Earlier expectations of centralization in mediated health information continue to affect program planning and deployment, perhaps diminishing positive experiences that might grow from community produced and locally consumed mediated health information.

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