Special Section: The Newest Frontier: Ethical Landscapes in Electronic Healthcare

An Analysis of Factors Underlying E-Health Disparities

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The potential public and individual health consequences of unequal access to digital technologies have been recognized in the United States for at least a decade.[1] Unequal access to the Internet and related technologies has been characterized as a "digital divide"; naturalistic trends toward broader access across the population and targeted intervention to increase access are described as progress toward "digital inclusion."[2] The problem of the digital divide has been characterized as one of healthcare justice.[3] The idea that everyone should have access to the telecommunications grid—telephone and computer—is a central tenet of the U.S. universal service policy.[4] With the diffusion of broadband technologies, the issue of digital access includes not only access to the Internet but also access to new levels of service, such as broadband, to support a wide range of emerging applications.[5] The large number of persons who use the Internet to search for health information and seek social support indicate public demand for emerging e-health services, many of which require broadband access.[6]

Although there is a large and growing literature on the nature, scope, and consequences of health disparities, little research has been conducted on the connection between disparities in health outcomes and issues of access to e-health information and services.[7] The same population groups that have poorer health status also have less access to the Internet and health information.[8] One of the two overarching goals of Healthy People 2010, the disease prevention and health promotion objectives for the Nation, is to eliminate health disparities.[9] Healthy People 2010 includes multiple objectives that address inequities not only in access to health services and health outcomes, but also in information and communication. The objectives to increase access to the Internet (Objective 11-1) and improve health literacy (Objective 11-2) are especially relevant to a discussion of health disparities and e-health.[10]

The accelerated diffusion of health information technology (health IT) creates a moral and public health imperative to address e-health disparities. Healthcare and personal health management are highly information intensive activities. They require access to health IT and information exchanges among consumers, patients, and healthcare and public health systems.[11] Limited access to health IT and appropriate information will make such exchanges difficult if not impossible. Segments of the population are likely to be excluded from the tools and information they need to manage their own health and benefit from advances in public health and medicine.[12] The Office of the National Coordinator for Health Information Technology in the U.S. Department of Health and Human Services recognizes consumer engagement in health IT and information exchange

Cambridge Quarterly of Healthcare Ethics (2008), **17**, 417–428. Printed in the USA.

0963-1801/08 $20.00
doi:10.1017/S0963180108080547

as a critical element of safe and effective healthcare and has made consumer empowerment and personal health records cornerstones of the national strategy.[13] At the same time health IT is becoming a policy priority, other programs in the federal government that support Internet access in communities have been reduced in funding or discontinued.[14]

The focus on health IT coincides with a push in public policy as well as in healthcare services for individuals and communities to take greater responsibility for their health and safety.[15] In an era of rising healthcare costs, escalating obesity rates, and major public health threats, such as bioterrorism and pandemics, individuals and communities must be prepared to seek out and use information to protect themselves and live healthier lives. Currently, though, many individuals and communities do not have the capacities to assume these responsibilities, nor are healthcare and health information systems designed to provide information usable by average Americans.[16] Results from the 2003 National Assessment of Adult Literacy shows that adults with the most limited understanding of health information have the highest levels of poor self-reported health.[17]

This article uses the concepts of meaningful access and health literacy to analyze the factors that create and sustain e-health disparities. Meaningful access pertains to creating the conditions for people to have ongoing access to appropriate technology and information. Health literacy identifies the environmental and human factors that influence the ways in which people understand and apply health information and interact with the healthcare system. Meaningful access and health literacy share a fundamental principle: people have the right to the technology tools and information they need to achieve their goals. The article begins with a brief discussion of the ideas of meaningful access and health literacy, then reviews multiple dimensions of disparities that produce e-health disparities and analyzes the implications of these disparities, and concludes with a vision of consumer e-health tools for all.

Meaningful Access and Health Literacy Explained

To use e-health tools, people obviously must own or have access to technology, including hardware, software, and Internet connections. This type of basic or physical access to technology, however, has been found to be insufficient to promote or sustain technology use among some groups of users.[18] Users may not have the skills or resources they need to use technology, diagnose and solve technical problems, afford continuous service charges, or locate and understand content.[19] The lack of physical access, skills, or resources creates multiple obstacles that must be identified and overcome. Even if people have access to technology, however, inappropriate content diminishes the value of access.

Consequently, researchers and practitioners working on issues of technology access have developed the concept of ''meaningful access'' to encompass equipment, Internet connections, skill development, ongoing technical support, and appropriate content.[20] For millions of Americans, access problems have more to do with their ability to use digital technology and the appropriateness of the information resources available to them than with having the right equipment. Being connected to the Internet has little meaning in itself if users cannot find relevant content and services. Similarly, the health literacy construct recognizes that capacities, access, and understanding must be considered together, although it has rarely been applied to the analysis of technology use.[21] Both concepts highlight the importance of understanding users' capacities and characteristics in light of systemic barriers that inhibit the full exercise of capacities.

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[22] Literacy skills include not only reading and writing but also numeracy, oral communication, and use of different types of documents, such as forms. Individual and population health literacy is dependent on a mix of individual and systemic factors, including the communication skills of both laypersons and professionals, lay and professional knowledge of health topics, cultural factors, the demands of the healthcare and public health systems, and the demands of the situation or context.[23] According to the Institute of Medicine and the Agency for Healthcare Research and Quality, large amounts of health information are too complex for approximately half of all adults to understand and use.[24] Analyses of health information on the Internet (reviewed below) indicate that the same problems with print information are being reproduced in e-health tools.[25]

Disparities in Access to Technology

Healthy People 2010 includes an objective to increase Internet access in the home, confirming the critical nature of Internet access for the health of the entire population.[26] Considerable progress has been made since the late 1990s, when the U.S. Department of Commerce report *Falling Through the Net* called the digital divide "one of America's leading economic and civil rights issues."[27] Nevertheless, segments of the population—primarily defined in existing studies by race and ethnicity, income, age, and disability—still lack access when compared to the segments with the highest rates. Adults 65 and older, African Americans, and lower income adults are all less likely to use the Internet.[28] Some of the gaps are large. For example, 88% of 18–29-year-olds go online, whereas only 32% of adults 65 and older use the Internet.[29] Only 29% of adults who have not graduated from high school use the Internet, in contrast to 89% of college graduates who are Internet users.[30] Approximately one quarter of the adult population does not live in households with Internet access nor have they used the Internet elsewhere, a proportion that has held steady for the last several years.[31]

Survey research from the Pew Internet & American Life Project indicates broadband is emerging as the new standard at the same time income divisions between broadband and nonbroadband users become sharper.[32] Total population use of broadband technologies increased to 47% by early 2007; notably, 76% of households with annual income over $75,000 have broadband access, whereas 30% of households with annual income below $30,000 have broadband.[33]

Although the cost of technology and Internet access plays a part in keeping Americans disconnected, attitudinal and experiential barriers also have a role. Many of the reasons offered by survey respondents indicated fear or lack of experience with technology.[34] The USC Digital Future study found that only 9% of respondents not connected to the Internet reported the cost of technology as the reason. An additional 24% reported that they had no interest in being on the Internet, and another 18% said they did not know how to use the Internet.[35]

A small study in San Diego, California, found that psychosocial factors, such as embarrassment at not knowing how to use a computer, were more important than cost in explaining why low-income residents did not purchase computers or were not learning how to use computers at local community centers.[36] Moreover, in this same study, residents reported ownership of other types of technology, such as DVD players and cell phones, which suggests that their concerns were specifically with computers and not technology in general. Research from the Pew Internet & American Life project supports this finding with data showing that technology gaps by racial group and age are not as great for cell phones as for computers.[37]

Access to Internet-ready devices such as cell phones and Personal Digital Assistants (PDAs) can remedy the lack of a computer. However, the attitude that Internet access is not necessary for daily life may itself become an important source of social division, according to Jeffrey Cole, Director of the USC Annenberg School Center for the Digital Future. He notes that people who live daily life disconnected from the Internet may face real costs—financial and social—not simply inconveniences: "People who do not want to perform those chores (pay bills, send letters, make appointments, and so on) online will find it increasingly difficult and expensive to avoid doing so."[38]

As an increasing number of health plans, employers, and healthcare providers develop Internet-based resources, their beneficiaries, employees, and patients will have fewer real choices about receiving information and services in a non-digital form. Beneficiaries, employees, and patients who do not have Internet access or choose not to use it will find that either they do not have access to vital information and services or they have to rely on intermediaries who will use these technologies on their behalf. Because non-Internet users are disproportionately old and poor,[39] the emergence of broadband and multimedia applications, including most e-health tools, will likely reinforce existing disparities.[40] Broadband makes it more likely that people will use the Internet and for longer periods, which are requirements if people are going to incorporate e-health tools into their routines.

Learning more about the one quarter of the population who may become isolated by their attitudes toward digital technologies and the options that will be required to continue to serve them is an emerging research and policy issue. Intermediaries or "infomediaries" have been suggested as a solution for some users who do not want to seek out information themselves or use technology directly; this strategy assumes, however, both that the intermediaries have the necessary access and skills and that they are available when and where users need them.

Disparities in Information Seeking

Studies of population differences in seeking out health information show that there are differences based on many of the same demographic factors as Internet access: age, race and ethnicity, education, and income. Younger, more well-educated, and higher income persons seek out more health information on the Internet than older, less educated, and poorer persons.[41] Gender is an important difference between Internet access and information seeking. Although approximately the same proportions of men and women use the Internet, 70% of women have looked online for health information in the previous 12 months, in contrast to 57.5% of men.[42] The Pew Internet & American Life Project estimates that 80% of Internet users have looked for health information.[43] Numerous studies show that women are the primary information seekers not only for themselves but also for loved ones.[44] A study of health information seeking (not specific to a communication channel) indicates that level of education is the most important predictor of health information seeking; 55% of persons with postgraduate education said they sought health information, compared with 25% of those without a high school diploma.[45] The 2003 National Assessment for Adult Literacy (NAAL) included a first-ever assessment of the adult English-speaking population's skills in understanding health information. The NAAL results show that 80% of adults with below basic health literacy skills do not get health information from the Internet; in contrast, 63% adults with the highest level of health literacy use the Internet ''some'' or ''a lot'' for health information.[46]

Research on factors other than demographics is providing insights into the psychosocial dynamics of obtaining, processing, and using health information. The focus of this research is not disparities but identifying and measuring attitudinal and motivational variables that affect patient activation, that is, patients' decisionmaking and self-management abilities.[47] Researchers and expert observers classify people in terms of their degree of independence and initiative in relation to healthcare and health information seeking. For example, research by the communication firm Porter Novelli found that the public can be segmented into five health information types, based on two broad sets of characteristics—degree of reliance on physicians for health information and level of activity in seeking out such information.[48]

Disparities in Literacy Skills

Population-based research on literacy skills measures the ability of English-speaking adults (persons 16 years old and older) to search, understand, and use a variety of written materials.[49] Some of the materials require reading and interpretation; others require filling out forms or performing calculations. Respondents were scored as below basic, basic, intermediate, or proficient, depending on the level at which they could complete the literacy tasks. For example, a person with below basic skills could search a simple text to find information related to a medical test, whereas a person would need proficient skills to interpret a table about blood pressure, age, and physical activity.[50] Forty-three percent of adults scored basic or below basic in prose literacy, 34% basic or below basic in document literacy, and 55% basic or below basic in quantitative literacy.[51] In all three literacy categories, whites and Asians/Pacific Islanders had higher scores than African Americans and Hispanics, and adults 65 and older have the lowest literacy skills. The same barriers presented by reading print materials are being transferred to the Internet and compounded by the need to acquire additional skills to use the Internet and related devices.

Numerous research studies have evaluated the reading grade level and/or the readability of information on the Internet and uniformly found the information too difficult to be understood by the average adult, let alone those with the most limited literacy skills.[52] A few studies on small numbers of persons have attempted to undercover how limited literacy skills affect persons' abilities to use computers and the Internet. An observational study of adults in a reading program focused on their search for and explanation of information they found on the Internet.[53] The researchers found that the adults had poor navigational skills, problems spelling terms used for searches, an inability to distinguish between sponsored and nonsponsored links, and difficulty explaining in their own words the information they found. Notably, the participants reported feeling comfortable with the Internet and searching and confident that they had found trustworthy information. A study of low literacy English- and Spanish-speaking adults and their use of health web sites had similar findings: The participants had trouble remembering basic functions, such as scrolling, struggled with spelling, and were distracted by graphics.[54]

Disparities in the Usability of Content

In addition to limited literacy skills, several other factors limit the accessibility and appropriateness of content. Studies by advocacy and research groups such as The Children's Partnership and One Economy Corporation show findings similar to the research studies on readability: that the overwhelming amount of information on the Internet is not usable by low literacy, non-English-speaking persons, nor is it appropriate for their information needs.[55] The organizations report there is not enough content in languages other than English, and even for those groups with functional English skills, the content is not culturally appropriate. A comparative study of English and Spanish language content on the Internet indicates that in both languages, the relevance of content is often low, coverage of topics is often incomplete, and readability is high, although the Spanish language content reviewed in this study was better in many ways than the English.[56] A study of unpaid adult caregivers found that, in general, only 5% of the multiracial and ethnic sample reported that finding non-English educational materials on the Internet was an unmet need, although 16% of Asian-American caregivers expressed an unmet need.[57]

Engaging persons with low income or education, different ethnic groups, and adults with limited literacy skills in e-health requires sophisticated audience segmentation techniques that involve intended users of the information in interactive roles.[58] Targeting (audience segmentation) and tailoring on communication factors are considered promising strategies for user-centric design in the electronic environment.[59] Both are employed to engage users by personalizing and individualizing information based on demographic, behavioral, motivational, psychosocial, or physical characteristics.[60] An environmental scan of 40 consumer e-health tools indicates that developers are looking for ways to enhance linguistic and cultural relevance to intended users.[61] Developers may be limited in how much they can customize, however, if the audience segments to which they are trying to appeal are small in size or do not have access to or want to use the Internet.

Significance of Multiple Disparities and Ethical Dilemmas

So far, this paper has documented multiple types of disparities that affect the way people interact with e-health tools. Some segments of the population do not have

Internet access, others do not have Internet ready devices, whereas others can access the Internet but cannot find content they can read, understand, and apply to their own situations. On the other hand, most healthcare in this country is still nondigital, and organizations continue to disseminate large amounts of health information in multiple formats that do not require Internet access. Given that health information and services are still primarily accessible in nondigital forms, how significant are these inequities? Might e-health truly be a niche market serving people who have gravitated to the online life of banking, shopping, socializing, and being entertained?

The answer is, apart from searching for information on the Internet and participating in online social support, consumer demand for the broad range of e-health tools is still unknown.[62] Research on consumer e-health tools has, for the most part, been conducted with persons who already have computers and with samples that do not have much diversity.[63] Some research on interest in and use of personal health records is emerging, but the focus is on population level acceptance and diffusion issues. Consequently, the effect of multiple inequities has not been studied yet in a comprehensive, systematic way. Conversely, the interventions required to address multiple capacity issues—technology, health literacy, content—are only emerging. The push from employers, insurers, government programs, and healthcare organizations to bring health IT into the mainstream of healthcare, however, is already underway. The anticipated outcome is that the entire population will need to engage on some level with e-health to participate fully in an information-intensive healthcare system and maximize the value of prevention and self-care. Identifying strategies to address the lack of Internet access, appropriate content and necessary user skills is critical to realizing the full benefit of social investments in health IT.

An ethical framework for health information management (HIM) professionals to assess their role in facilitating consumer e-health has been proposed.[64] The authors posed the following questions for consideration. These questions apply equally well to all the organizations listed above as well as to communities seeking to conduct a broad assessment across their population groups.

- Does excitement about e-health's possibilities obscure multiple access issues for those who do not have regular sources of healthcare and who have not been early adopters of the Internet?
- How will consumers, patients, and caregivers who are reluctant to use e-health technologies manage their health information in the future?
- Will consumers be expected to document everything about their health, no matter how private they consider it, once we come to expect cradle-to-grave, portable health information systems?
- Do healthcare organizations and professionals have an obligation to promote access to e-health systems to those who cannot afford to buy access?
- What are the ethical implications of developing e-health applications that require high-end technologies to function?
- What ethical questions are raised by e-health services in terms of the quality of the content?
- What ethical issues must be addressed regarding the privacy policies (and security features) of e-health services?

A Vision of Consumer E-Health Tools for All

The first step in ensuring that the benefits from e-health investments accrue to all segments of the population is to outline a vision of what is required. A study of the potential utility and value of consumer e-health tools for populations that experience health disparities proposes the following vision of consumer e-health tools for all.[65] The essence of the vision is a user-centered approach that places the needs, preferences, capacities, values, and goals of e-health users at the core rather than the periphery of health IT.

- Consumers with diverse perspectives, circumstances, capacities, and experiences are included in the design of and have meaningful access to evidence-based e-health tools with strong privacy and security protections.
- Diverse consumers have the skills and support to evaluate, choose, and use e-health tools to derive benefits for themselves and those they care for.
- Healthcare organizations and practitioners use the full range of e-health tools to engage and support diverse consumers in their own health management as a routine element of care.
- Local, state, and national policies and programs support the sustainable development and dissemination of evidence-based consumer e-health tools to diverse individuals and communities, including those served by safety-net providers.
- Alliances and partnerships facilitate sustained consumer access to and use of e-health tools, consistent with the value propositions and perspectives of each participating stakeholder.
- Appropriate funding and incentives exist in public policy and the market to enable sustainable business models for tools with demonstrated effectiveness.

Conclusion

The paper opened with the statement that it is a moral and public health imperative to address issues of disparities and e-health. E-health disparities not only concern the equitable distribution of valuable resources in our society but also the ability of health professionals and the public to exchange information and communicate about critical health and safety matters. The public's ability to respond to and manage a host of critical events, such as a pandemic, depends on easily accessible health information, recommendations, and tools. The diffusion of digital personal health records makes e-health resources even more valuable because they will serve as an individual's lifelong health "story." The paper presented data and research findings that show existing disparities in income, education, literacy, and health status are mirrored and possibly reinforced by differences in access to the Internet. The Internet access data show the importance of income, as well as attitudes, in creating and sustaining the digital divide.

Many organizations share responsibility for assessing the extent to which e-health disparities affect their communities. These organizations include healthcare facilities; provider groups; insurers; employers; technology companies; government agencies, including those in charge of education, healthcare, and social services; foundations; nonprofit and service organizations; faith-based groups; and community technology centers. Some communities are beginning to build partnerships across traditional boundaries and are others are poised to do so.[66]

Existing research suggests that linkages between e-health disparities and long-standing disparities in income and education should be explicitly acknowledged and addressed. Exploring more closely the reasons approximately one quarter of the population does not go online is critical to begin to address disparities. Even those who have Internet access but make limited use of online health resources should be considered part of the divide and the factors related to their limited use explored. If e-health is to have the transformative impact on healthcare and public health that many people hope for, then there must be a concerted effort to understand and address the persistent disparities of which technology is now a part.

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