Consumer Use of Internet Health Information Resources

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Patients seeking care rarely think of themselves as consumers. The reasons for this are two-fold. First, patients pay flat fees for services and therefore are insulated from the true cost of treatments. Second, those who need medical care have been socialized to defer to the doctor’s judgment rather than their own. When a person is ill, the only thing he or she thinks about is getting better; this can cloud practical reasoning about clinical and financial matters.

This is changing. With the rise and expansion of consumer health information resources, patients, families, caregivers, and consumers have been empowered by new sources of information to make medical treatment and care decisions based on both medical and financial considerations.1 Internet-based consumer health information resources (“E-health communication”) have the potential to improve value-based decisions and ultimately foster better public health outcomes.2

I. TRENDS IN E-HEALTH COMMUNICATION HAVE THE POTENTIAL TO TURN PATIENTS INTO INFORMED CONSUMERS

Many Americans are selecting their own health care coverage components from a complex array of various insurance companies, personal savings accounts,

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2 Id.
and managed care options.  

Consumer directed health care ("CDHC") is defined by interwoven components that together enable a consumer to exercise the right to choose health coverage within their own framework of personal priorities. The first element is a high-deductable health insurance product that protects the individual against the risk of catastrophic health care costs. This is coupled with an individually managed, tax-exempt, interest-bearing health savings account ("HSA") which is used to pay for routine and preventative health services that fall below the deductible amount of the insurance plan. The plan requires an increased level of information to enable the consumer to exercise choice intelligently. Generally, this information is offered through the internet from various sources. Without accessible information about health care, patients will not benefit from CDHC. Ill-informed decision-making is not only risky for the consumer, but could also negate the increased efficiency and effectiveness promised by CDHC.

Many health care consumers are already using the internet to access health care information. According to a study by PEW Internet and American Life study, between 75-80% of internet users have looked online for health information. Internet users with a chronic disease or disability were found to be even more engaged in e-health with 75% of them saying that their last health search affected a decision about how to treat a condition compared with 55% of other users.

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4 Id. at 106-07.
5 Id. at 107-08.
6 Id. at 108.
8 Id.
11 Id.
“Consumer engagement in decisions about coverage, provider and treatment choices, and purchasing is central” to lowering healthcare costs.12 State governments, the federal government, and insurance companies have all developed websites that let consumers compare hospitals on cost, quality and ratings by patients.13 Proponents of CDHC say that it is crucial for consumers to have convenient access to “an adequate amount of relevant, accurate and comprehensible information.”14 In recent years there has been a “veritable explosion of health care information,” with more sources coming online everyday.15

PatientsLikeMe is an online community built to support information exchange between patients.”16 “The site provides customized, disease-specific outcome and visualization tools to help patients understand and share information about their condition.”17 Members of the community locate others with similar experiences to answer specific health-related questions, to share personally acquired disease-management knowledge, and to foster relationships based on shared concerns.18 A 2008 report on the PatientsLikeMe website, found that people with rare life-changing diseases benefit most from sites like this because it allows those afflicted to build communities despite geographic distances and mobility constraints.19

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14 Rosoff, supra note 7, at 23.
15 Id.
16 Jeana H. Frost & Michael P. Massagli, Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another’s Data, 10 J. MED. INTERNET RES. 1, 1 (2008).
17 Id.
18 Id.
19 Id. at 2.
In another online community, multiple sclerosis patients assist each other online during painful self-injections.\textsuperscript{20} Multiple sclerosis patients from around the world coordinate weekly injections and meet in a chat room to self inject at the same time.\textsuperscript{21} Patients find spiritual and practical support during this painful procedure by sharing the experience.\textsuperscript{22} While much of the information shared in these communities is unregulated, an analysis of a breast cancer support group found that only a small percentage of posts were inaccurate and the inaccuracies were quickly corrected by another community member.\textsuperscript{23} Some of these non-traditional e-health information sources may be more useful to patients because official sites for specific diseases may be more difficult to decipher.

II. DIGITAL HEALTH INFORMATION CHALLENGES

The rise of patients-as-consumers is evident in the recent investment in E-health informatics. As a society (or as policy) we have decided that adults are capable and willing to exercise health care related autonomy. However, both direct and indirect barriers hinder access to internet-based information. For example, those who most need health information often lack the means, knowledge, and skills necessary to benefit from internet health resources.\textsuperscript{24} Although the percentage of adult Americans with home broadband internet connections has risen from 47\% in 2007 to 55\% in 2008, lower income Americans saw no growth in home internet access in the past year.\textsuperscript{25} According to one December 2007 study, 23\% of the population have no access to the Internet while 13\% of the population have only dial-up access.\textsuperscript{26} This low-access

\textsuperscript{20} Keselman et al, supra note 1, at 475.
\textsuperscript{22} \textit{Id}.
\textsuperscript{23} Keselman et al, supra note 1, at 475.
\textsuperscript{24} \textit{Id}.
\textsuperscript{26} \textit{Id}.
population was found to be lower income, older, and less educated than those with broadband access at home or at work.\(^{27}\)

Another barrier to providing health resources to the medically underserved is health literacy.\(^{28}\) Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health decisions.”\(^{29}\) Health literacy involves the “core competencies which are required to retrieve and process information online.”\(^{30}\) Skills include general literacy, numeracy skills, conceptual knowledge, health vocabulary, technological fluency, and rhetorical skills.\(^{31}\) About 50% of U.S. adults do not possess adequate health literacy skills.\(^{32}\) Studies suggest that individuals of all education levels have trouble interpreting probabilities, understanding the equivalence between percentages and proportions, and taking risks into account.\(^{33}\) Evidence suggests that inadequate health literacy can have negative effects on clinical outcomes.\(^{34}\) A patient who gets a doctor’s advice might disagree with his advice and search for alternative treatments online. A health consumer struggling with health literacy might not always be capable of understanding their condition and the available treatment options in order to independently make decisions in their best interest. Also, when patients make decisions based on cost, there is a danger that consumers cannot always tell where desirable economy ends and dangerous thriftiness begins.\(^{35}\) While the availability of health information can reduce consumer confusion, the question remains: is an individual better off being informed and treated by a physician or by the internet? Ill-informed decision-making can minimize efficiency benefits and subject patients to higher risks of injury.\(^{36}\) Patients become vulnerable consumers when they find themselves trapped in a

\(^{27}\) Keselman et al, supra note 1, at 476.

\(^{28}\) Id.

\(^{29}\) Id. at 475.

\(^{30}\) Id.

\(^{31}\) Id.

\(^{32}\) Keselman et al, supra note 1, at 476.

\(^{33}\) Id.

\(^{34}\) Id.

\(^{35}\) Rosoff, supra note 7, at 27.

\(^{36}\) Madison, supra note 9, at 1579.
market without access to accessible information, unable to make a prudent choice. Access to information may or may not lead to increased quality of care. For example, one study reported that “only 34% of a [Consumer Driven Health Plan’s] participants at the University of Minnesota visited the plan’s informational web site in the year under study.” Thus, even if consumers have access to information it is not clear that they can or will use it effectively.

Proponents of CDHC suggest that through the doctrine of informed consent, patients exercise autonomy when making clinical decisions and should therefore also be entrusted with decisions relating to insurance coverage and treatment options. However, some argue that autonomy may be better served in some instances by giving the patient a more passive role rather than expecting proactive “shopping behavior” at every stage of the care process. A more passive role may entail relying on the judgment of professionals but still retaining veto power in ultimate decision making.

III. CONCLUSION

If CDHC is to have real potential to empower consumers and let them apply their available resources in a way that most suits their needs, than real, accessible, personalized information is critical. Being a health care consumer is “harder than it looks, especially when buying unfamiliar things in unfamiliar situations.” Consumers often fail to inform themselves fully in order to understand and choose wisely. Ill informed consumers do not understand

38 Rosoff, supra note 7, at 25.
39 Id.
40 Kapp, supra note 3, at 117.
41 Rossoff, supra note 7, at 26.
42 Id.
43 Id. at 20.
44 Hall & Schneider, supra note 37, at 650.
45 Id.
enough about their options. With better information about health care, consumers will be able to take greater responsibility for their choices.

46 Id.