

Improving Consumer Health Literacy with Information Technology

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INTRODUCTION

Before the Internet became popular as a device for distributing and sharing information, people turned to friends, books, and their doctors when they had medical questions. Today, many more options exist (Figure 1). Hundreds of Web sites provide health information and opportunities for interaction among patients, doctors, and caregivers. Estimates differ, but all surveys show that millions of people search online for health information. A Pew survey estimates that 80% of adult Internet users, about 93 million Americans, searched online for at least one of 16 major health topics (Fox & Fallows, 2003). Baker, Wagner, Signer, and Bundorf (2003) estimate that 20% of the U.S. population uses the Internet to find health information. A larger proportion (71%) of older people (50 to 64 years old) compared to 53% of younger people (18 to 29 years old) turn to the Internet for health information (Fox & Rainie, 2002). Although there is a digital divide, use of information technology is not simply decided by race or social class. Safran (2003) found that Medicaid families, who are believed not to use these new technologies, accessed their online Baby CareLink from the hospital, work, library, or other public access points. Gustafson et al. (2002) point out that poverty is the prime indicator for lack of technology use.

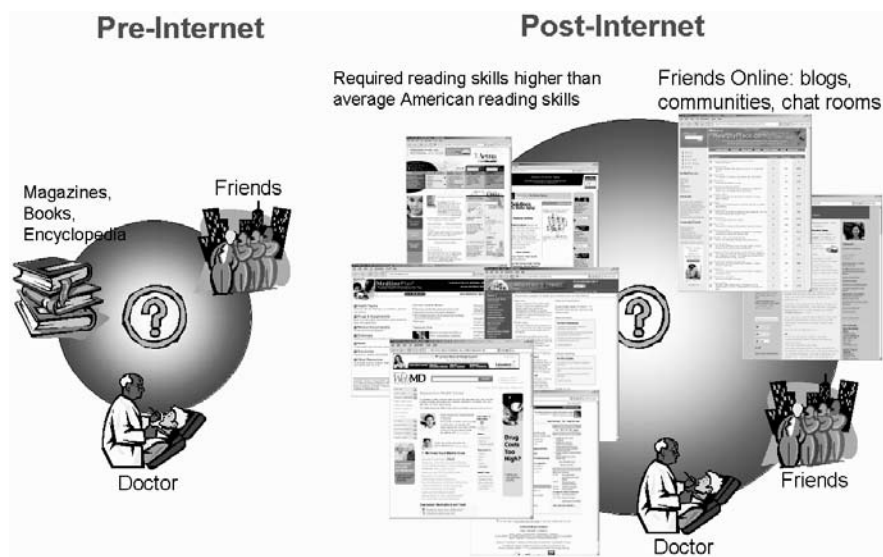
The problem we address in this chapter is consumers' lack of understanding of the available information. This is extremely important since for at least a third of these consumers, the information affects decisions about their health, health care, and visits to a health care provider (Baker et al., 2003). Warner and Procacino (2004) found a much higher percentage in his interviews with women; more than 80% responded that the information they found online affected their decisions about treatments.

BACKGROUND

Thousands of Web sites provide information and additional opportunities to share information in an interactive format. The information can be targeted at the general public or a specific subgroup, and there are several advantages to this trend. Foremost, consumers will be more informed. This is a benefit because it empowers them to ask more informed questions when seeing their caregivers and lessens their fears of the unknown (Fox & Fallows, 2003). Often, physicians want to refer their patients to Web sites and printed patient educational material for additional information (Brawn, 2005). The online information is especially beneficial for consumers who need more detailed information than their health care provider can give in a limited amount of time. For example, Rosmovits and Ziebland (2004) conducted in-depth interviews with cancer patients and found that they have complex information needs that were not met by their health care providers. They felt they received incomplete and sometimes contradictory information from their caregivers. Consumers also interact with each other online to provide information and support. There are many support groups where members share advice or provide support in difficult times (e.g., multiple sclerosis patients supporting each other during painful self-injections) (Johnson & Ambrose, 2006).

Unfortunately, there are also disadvantages associated with health information as it is currently provided online. The disadvantages can be classified into two groups related to incorrect information and incorrect understanding of information. Since the Internet is not regulated, there is no guarantee that the information provided is correct and trustworthy. The general public should be educated in the usage of this information. Murray, et al. (2003) questioned physicians and found that 75% of the respondents felt that health information on the Internet was a good thing. However, the quality

Figure 1. Information sources for consumers



of online information affected the health care outcome and the patient-physician relationship. Accurate and relevant information had a beneficial effect on both. In addition, the outcome and relationship were also influenced by the physician's perceived threat to his or her authority, especially when the patient wanted something inappropriate. The second group of problems centers on health consumers' lack of understanding of this information (Berland et al., 2001; D'Alessandro, Kingsley, & Johnson-West, 2001; Root & Stableford, 1999) and has consequences for health care at large. The Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs (1999) found that misunderstandings in health information increase the risk of making unwise health decisions leading to poorer health and higher health care costs. For example, Garbers and Chiasson (2004) showed that Latinas with low health literacy were significantly less likely to have preventive cervical cancer screening. Kalichman, Benotsch, Suarez, Catz, Miller, and Rompa (2000) found that HIV/AIDS patients with low literacy levels were more likely to (incorrectly) believe that antiviral drugs would help prevent transmitting HIV during unprotected sex.

Figure 2 shows how technology can help improve understanding of health information. Current research is still in the early stages and has not advanced much beyond measuring reading levels and describing these in numerous studies of consent forms and patient leaflets for a variety of afflictions. Existing interventions focus

on tailoring information to specific groups (tailored information) or individual people (targeted intervention) (McCray, 2005). In general, newly written text should take writing guidelines into account, and simple versions of the material should be available where possible. There are several guidelines that can be consulted: MedlinePlus (<http://www.nlm.nih.gov/medlineplus/etr.html>) provides guidelines for writing easy-to-read versions of documents; the National Institutes of Health (NIH) provide the Plain Language Initiative (<http://execsec.od.nih.gov/plainlang/index.html>); the state of California provides the California Health Literacy initiative (<http://cahealthliteracy.org/>); and the Health & Literacy Special Collection (<http://lincs.worlded.org/>) also provides advice. Regrettably, it is impossible to provide simplified versions of all information because the content itself may be too complex. It is also infeasible to rewrite all existing text even if one were to limit it to English. Automated tools need to be developed to help consumers understand text.

Three approaches can be followed and combined to help increase understanding of the information. First, the language and grammar used in the text can be simplified (text simplification). Second, the structure of the text can be visualized and simplified so the document is easier to follow (structure simplification). Finally, important information can be simplified, visualized, and emphasized (text visualization). These techniques

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