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.

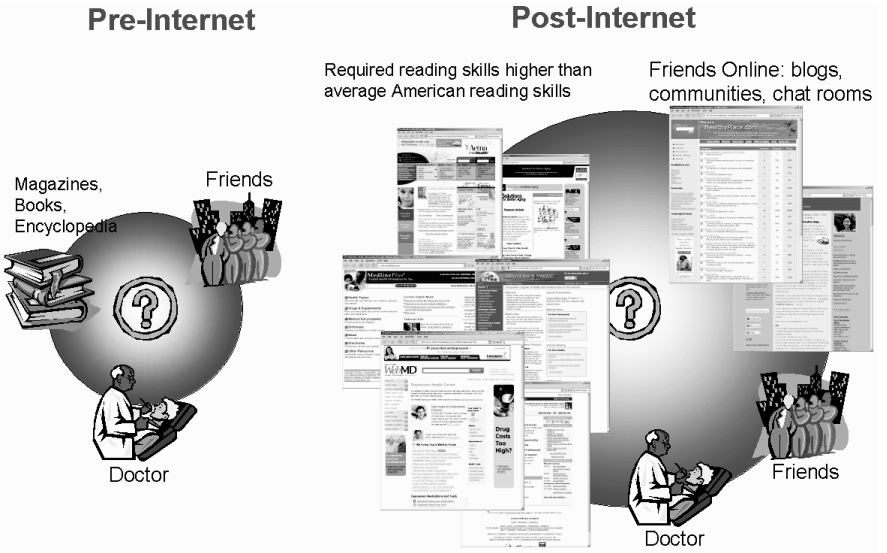
The problem we address in this chapter is consumers' lack of understanding of the available information. This is extremely important since for at least a third of these consumers, the information affects decisions about their health, health care, and visits to a health care provider (Baker et al., 2003). Warner and Procaccino (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

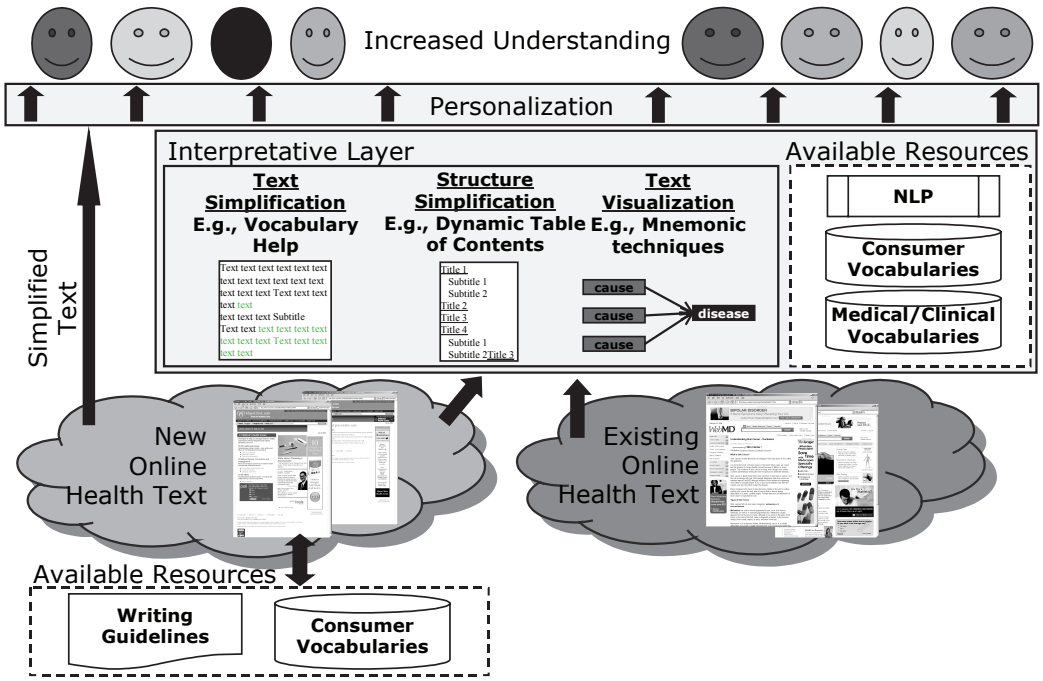


of online information affected the health care outcome and the patient-physician relationship. Accurate and relevant information had a beneficial effect on both. In addition, the outcome and relationship were also influenced by the physician's perceived threat to his or her authority, especially when 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 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

Figure 2. Making health information understandable for consumers



should be partially or completely automated and optimized for various consumer groups.

In the following, an overview is provided of current research that fits into this framework. The focus is on English language Web sites. Then, key consumer groups who would benefit most are discussed. Finally, future trends are described.

INTERPRETATIVE LAYER

Text Simplification

Several formulas are commonly used to measure readability (Berland et al., 2001; D'Alessandro et al., 2001; Root & Stableford, 1999), and all studies using them show that a significant portion of information is too difficult for average adults to read. Most evaluation studies use the Flesch readability scores or the Flesch-Kincaid grade levels to evaluate text. These formulas use syntax, word counts, and word length to assign readability levels and are easily available with Microsoft Word. An additional popular measure is the SMOG measure (McLaughlin, 1969), which is based on syllable count. Freda (2005), however, found the SMOG measure assigned reading levels 2 or 3 grades higher than the Flesch-Kincaid grade levels. Most English sites require at least a 10th grade (Flesch) reading level, and more than half present information at college level. This is perhaps a partial explanation of the fact that Internet usage for health information is strongly associated with higher education (Baker et al., 2003; Fox & Fallows, 2003).

Additional metrics exist to approach the problem from the consumer side and focus on a person's health literacy level instead of the difficulty of the text. For example, the Test of Functional Health Literacy in Adults (TOFHLA), its shortened version STOFHLA (Parker, Baker, Williams & Nurss, 1995) and the Cloze procedure (Taylor, 1953) are often used. The Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) is one of the most popular measures (Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005). These metrics provide a common method to evaluate consumer understanding of common medical and health terminology and have led to surprising findings. For example, Zun, Sadoun, and Downey (2006) found that nurses and doctors overestimate written English competency in their Hispanic patients when compared to test results with the REALM and STOFHLA. Al-

though these measures are commonly used, few studies directly compare performance of individuals (health literacy) with different text reading levels (readability measures). A recent exception is the work by Trifiletti, Shields, McDonald, Walker, and Gielen (in press) who evaluated text of different grade levels and performed the Cloze test on these texts. The Cloze test removes the n^{th} word from a text and then requires people to fill in the blanks. They found that more people performed at an acceptable level with lower grade level texts. Similarly, Pignone, et al. (2005) provide a review of studies focusing on text simplification and showed improved understanding in the low literacy group when texts were simplified.

There are two components that can be focused on to automatically simplify texts and lessen the aforementioned difficulties. The first is grammar; the second is vocabulary. Grammar and sentence structure simplification would lower the readability grade levels. For example, using active instead of passive sentences or right branching instead of embedded or left branching sentences increases readability. However, simply lowering the required reading level will be insufficient. Leroy, Eryilmaz, and Laroya (2006) found that difficult documents measured with the Flesch readability formulas not only use more complex sentence structures but also use more complex vocabulary and often discuss more difficult topics. These results correspond with Boulos' (2005) conclusion that some documents will remain difficult, and other means of user support will be needed.

Structure Simplification

Most research has concentrated on visualizing large collections of entire documents or visualizing information extracted from all those documents. Little research focuses on facilitating content access for a single document and even less on medical or health text. However, previews of single documents have been found to expedite review of documents (Greene, Marchionini, Plaisant & Shneiderman, 2000; Marchionini, Plaisant & Komlodi, 1998). A preview extracted from the original document acts as a surrogate. It is effective when it communicates sufficient information to the user about individual information items. For example, most search engines provide an excerpt of text called a "snippet." Some simply show the first few lines of text; others display the text surrounding keywords, use heuristics to select sections of documents (Amitay & Paris, 2000), or provide a document summary.

The previews can be textual, graphical, or a combination of both. Woodruff, Rosenholtz, Morrison, Faulring, and Pirolli (2002) compared textual and graphical (thumbnail) summaries and found the best results with a combination of both types. Manber (1997) combined color with the original text and proposes highlighting as a preview for documents. By keeping a personal list of keywords and highlighting these in a document, users can rapidly determine their interest in it. Hornbæk & Frøkjær (2001, 2003, 2004) studied linear, fisheye, and overview+detail interfaces to facilitate reading of electronic documents. They compared their subjects' essay, question-answer task performance, and user satisfaction. They manipulated how much text was visible to users at any time but did not extract any text or information from the text. Even so, the overview+detail interface helped their subjects understand main ideas better, and the fisheye interface helped them answer questions faster. The linear text interface was worse than the other two in most aspects. This approach is rarely evaluated for health information, with a few exceptions. Ogozalek (1994) used text and multimedia interfaces to provide prescription drug information to the elderly and found that the subjects answered questions better with the multimedia interface. There was no effect on retention of the information. Miller, Leroy, and Wood (2006) are working on dynamically generating tables of contents for WebMD documents using UMLS semantic types as entry points.

Text Visualization

More advanced approaches extract and visualize pertinent information from individual documents. This approach is being tested for biomedical text and biomedical researchers. For example, in Genescene (Leroy & Chen, 2005), an interactive graph visualization of biomedical relationships is shown. Researchers can browse the graphs and drill down to the underlying text. A simpler approach is used by Beier and Tesche (2001), who provide an overview of a metasearch based on the origin of the results, such as Internet sites or journals. However, no such tools are currently tested for or made available to health information consumers.

HEALTH INFORMATION CONSUMER GROUPS

Improved access, understanding, and retention of health information would benefit the general population. However, three groups in particular deserve special attention: non-native English speakers, the elderly, and patients. These three groups have special health information needs, which we will discuss in more detail, and are a growing group online. For example, Gustafson et al. (2002) focused on underserved African Americans, the elderly, and HIV patients, and found that these three groups tend to use mostly information and analysis services and not so much communication technology such as the discussion boards. As such, increasing their understanding of online health texts should be a key focus.

Many online readers who do not speak English as their native language still read information in English. To fully appreciate the problem, think about a second or third language you speak and how difficult it would be to understand the health information in that language. This is problematic and affects health care outcomes. The effect will be stronger when information is only available in English. In addition to the text, several other factors, such as cultural differences, structure of pamphlets, difficult images, and lack of definitions, affect health literacy (Hunter, 2005). Few realistic and feasible approaches are proposed in the literature. Popular advice is to provide translations of all text. However, Becker (2004) found that only 10% of state sites in the United States provide Spanish translations, and many buttons and links are never translated. Moreover, Parker and Kreps (2005) illustrated that translating all texts is not a scalable solution since health care organizations may need translations in 40 or more languages. Translations will not be available for everyone, and so this multilingual consumer group will benefit most from text simplification.

A second growing online group is the elderly. There have been large survey-based studies that looked at the relationship between Internet usage and demographic variables, such as race, gender, and age. Ito, O'Day, Adler, Linde, and Mynatt (2001) studied SeniorNet, an online community with more than 20,000 members and 4,000 volunteers. They found that seniors do not see themselves as different or technologically challenged. Even so, with increasing age, people encounter problems that may interfere with optimal Internet usage. Vision deteriorates, requiring bigger font sizes and more contrasting colors. Mouse and keyboard skills are often lower due to physical problems such as arthritis, tremors, or lack of experience with computers in general. Learning becomes slower and more difficult with longer training times and more attention problems (Hanson, 2001; Nielsen, 2000). This group may benefit especially from improved text structure since they perform as well as younger adults in recalling stories when events are in canonical order (Wingfield & Stine-Morrow, 2000). Although elder users do not see themselves as less experienced, Chadwick-Dias, Tedesco, and Tullis (2004) demonstrate that self-reported Web experience is not the same as actual Web expertise. Older users received lower scores on an expertise quiz, even when controlled for self-reported Web experience. The quiz consisted of a list of images and their possible meanings (e.g., a back button).

Patients are a third growing online group. This group is very diverse, and different types of patients have different needs. Most representative of this group are individuals who need information on a recently diagnosed disease. Depending on the seriousness of the illness, these patients are more or less stressed, tired, and fearful. All these factors may affect how well they grasp health information. For example, Van Servellen, Brown, Lombardi, and Herrera (2003) found that increased stress was significantly correlated with poorer recognition of HIV terms in their group of low-income Latinos. Most patients in this group will not understand all the vocabulary and information presented online. In contrast, there is an additional group of expert patients who have different needs. Although there are different opinions on what an expert patient is (Shaw & Baker, 2006), in the best scenario, these are patients with chronic diseases who are involved in the management of their disease and who collaborate with health care providers for the best outcome (Badcott, 2005). This expert patient group will have more background knowledge, use a much more advanced vocabulary, and understand more complicated documents.

FUTURE TRENDS

In the future, two broad trends can be expected. The first will be studies that focus mainly on user groups. There will be an increasingly sophisticated knowledge base that can distinguish between various user groups

and their ability to learn and remember information in interaction with various types of technology. Both cognitive science and educational methodologies will play a significant role. Although this chapter focused on adults, children will become a much more important consumer group.

The second trend will be complementary and will comprise various types of technology and media and their interaction with various consumer groups. Computational linguistics and computer and information science will drive these trends. For example, text simplification will benefit consumers directly, but may also lead to better machine translation. Visualization can be used to visualize the structure of text, but also for treatments and interventions. Text visualization may be adapted and act as summaries or previews. PDA or Smartphone users with smaller screens would particularly benefit from previews. Such previews may also become relevant for medical professionals in the field when dealing with emergencies that require them to find new information. Voice recognition combined with wireless search engine technology to retrieve information and show this on small displays (e.g., watches, glasses) will also become available. More advanced visualization such as automated translation from text to graphical novels or movies and animation would be especially beneficial for low literacy groups and children.

CONCLUSION

Understanding health information is an important aspect of our health care. It leads to more informed and more comfortable patients and better adherence to therapies. Many studies show that the general public does not understand the information from which they would benefit. Current research to facilitate this understanding is in the early stages. Most research has focused on demonstrating the problem. Some are now evaluating how to simplify the information, but approaches are manual. To tackle the problem in an efficient manner, automated approaches are needed that can scale up. This research is in its infancy, but the benefits will be enormous as it matures. More and better-informed health consumers from all walks of life will benefit. And research which focuses on related problems such as summarization, visualization, or even machine translation may also be affected.

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KEY TERMS

Cloze Procedure: A procedure to measure readability of text by deleting the n^{th} word and asking readers to fill in the blanks. This procedure was originally developed by Taylor (1953).

Consumer Health Informatics: Research that focuses on health information, the consumers who read the information, and the interaction between the two.

Flesch Reading Ease: A readability measure that provides an estimate of the readability of a text and the

required grade level to understand the text. It is based on syntactic and word level considerations.

Health Literacy: The ability to understand health and medical information and act upon that information correctly.

Readability: The difficulty level of a text, usually measured by formulas such as the Flesch Reading Ease.

REALM: Rapid Estimate of Adult Literacy in Medicine.

STOHFLA: Short Test of Functional Health Literacy in Adults (Davis et al., 1993).

TOFHLA: Test of Functional Health Literacy in Adults (Parker et al., 1995).