

Application of Information Technology ■

Promoting Health Literacy

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Abstract This report reviews some of the extensive literature in health literacy, much of it focused on the intersection of low literacy and the understanding of basic health care information. Several articles describe methods for assessing health literacy as well as methods for assessing the readability of texts, although generally these latter have not been developed with health materials in mind. Other studies have looked more closely at the mismatch between patients' literacy levels and the readability of materials intended for use by those patients. A number of studies have investigated the phenomenon of literacy from the perspective of patients' interactions in the health care setting, the disenfranchisement of some patients because of their low literacy skills, the difficulty some patients have in navigating the health care system, the quality of the communication between doctors and their patients including the cultural overlay of such exchanges, and ultimately the effect of low literacy on health outcomes. Finally, the impact of new information technologies has been studied by a number of investigators. There remain many opportunities for conducting further research to gain a better understanding of the complex interactions between general literacy, health literacy, information technologies, and the existing health care infrastructure.

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Addressing health literacy—the ability to understand and act on health information—is one of the most pressing issues in our health care system today. Perhaps one of the most significant challenges we face is to make health information accessible to everyone, regardless of background, education, or literacy level.

In 1999 the American Medical Association convened an ad hoc committee to look at the problem of health literacy. The committee recommended four areas for future research: (1) health literacy screening, (2) improving communication with low-literacy patients, (3) costs and outcomes of poor health literacy, and (4) causal pathways of how poor health literacy influences health.¹ United States Surgeon General Richard Carmona has recently identified three evidence-based priorities during his tenure. Each of them—public health preparedness, health care disparities, and prevention—depends critically on the health literacy of our citizens. He has said that health literacy is “the currency of success” for everything he is doing as Surgeon General. He echoes the results of numerous research studies when he says, “Today, low health literacy is a threat to the health and well-being of Americans and to the health and well-being of the American medical system.”² The problem is also recognized by the Institute of Medicine (IOM), which has recently published a study that reviews health literacy research and recommends actions to promote a health literate society.³ The

IOM report defines health literacy 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.”³ The IOM views the issue as one that involves matching the needs of the individual to the information and services provided by the health care system. In our current health care environment there often is, however, a serious mismatch between an individual's background, skills, and expectations, and the information and services that are available to that individual.

Background

This report reviews some of the extensive literature in health literacy, much of it focused on the intersection of low literacy and the understanding of basic health care information. (See Rudd et al.⁴ and others on this topic.^{5–8}) Articles and other documents for this review were selected by searching MEDLINE and related databases, such as Web of Science, CINAHL, ERIC, PsychINFO, BIOSIS, and LISA; by consulting existing bibliographies; by using both forward and backward reference chaining techniques; and by tracking recent national activities in health literacy. References that were primarily anecdotal or that were only peripherally related to the topic were excluded.

The basic literacy skills of the U.S. population are reported by the Department of Education in its National Adult Literacy Survey report.⁹ Citing this survey and other evidence, many studies address the issue of limited literacy in the context of the health care system. Several of these articles describe instruments that have been developed and used to assess health literacy as well as instruments that have been developed to assess the readability of texts, although generally these latter have not been developed with health materials in mind. Other studies have looked more closely at the mismatch between patients' literacy levels and the readability of materials intended for use by those patients. Some investigators have attempted to devise guidelines for creating accessible and

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readable materials for people of all literacy levels. With the specific goal of increasing understanding of health concepts by the general population, several groups have advocated and, in some cases, implemented standards for health curricula in K through 12 education. A number of studies have investigated the phenomenon of literacy from the perspective of patients' interactions in the health care setting, the disenfranchisement of some patients because of their low literacy skills, the difficulty some patients have in navigating the health care system, the quality of the communication between doctors and their patients including the cultural overlay of such exchanges, and ultimately the effect of low literacy on health outcomes. Finally, the impact of new information technologies has been studied by a number of investigators. Much of this literature concerns the vast amount of health information that has become available on the Internet and deals with either issues of quality or the shift that this may presage in the doctor-patient relationship. Some of the research deals with consumer health interventions with a small number of studies actually reporting on controlled experiments measuring the effects of such interventions.

Adult Literacy and Health

The National Adult Literacy Survey (NALS) involved literacy assessments of more than 26,000 adults in the United States in 1992.^{9*} This survey reflects a major effort to better understand how well the population is able to read, understand, and ultimately to act on the types of materials that are encountered as part of daily life. Survey tasks involved demonstrating proficiency in understanding prose, primarily expository texts such as newspaper articles, brochures, pamphlets, but also including some stories and poems; being able to interpret and fill out documents, such as application forms, maps, and bus schedules; and demonstrating quantitative literacy, such as being able to balance a checkbook, calculate a tip in a restaurant, or compare unit prices in a grocery store. Based on their performance, participants were classified as falling into one of five literacy levels.⁹ About 21% to 23%, representing 40 to 44 million adults, performed at the lowest level, and another 25% to 28%, representing about 50 million adults, fell into the second level. At the lowest level, tasks involved reading a short text or document and locating some information in it as well as performing single named arithmetic operations. At the second level, tasks involved reading a text or document and then locating and integrating or contrasting several pieces of information and performing a single arithmetic operation that could be determined from the format of the information presented in the text. The study also looked at the correlation of these lower literacy levels with a variety of demographic and socioeconomic factors. Individuals in the two lowest levels were more likely to be unemployed or underemployed and living in poverty, were less likely to read print sources for staying informed about current events or civic matters, and were much less likely to vote.

The NALS has had a major impact on subsequent literacy research and has, in some cases, even been interpreted to have

demonstrated that almost half of our population is functionally illiterate. There is, however, a distinction to be made between illiteracy and limited literacy. Many of those who performed at Level 1, the lowest NALS level, were able to read and act on simple short texts and documents. Further, in a technical report issued in 2001, the original manager of the survey within the Department of Education reassesses the results, arguing that the criteria were too stringent for placing individuals in each of the five literacy levels.¹⁰ While the data are clear with regard to the abilities tested, the author maintains that a somewhat different interpretation would place a much smaller percentage of the population at the lowest levels of literacy.

Rudd et al.¹¹ have recently analyzed the health-related items found in both the NALS and the International Adult Literacy Survey (IALS), a survey involving some 20 countries conducted between 1994 and 1998 and sponsored by the Canadian government.^{12,13} On the basis of 191 health-related items found in these two large-scale surveys, they developed the Health Activities Literacy Scale (HALS) that is linked to the five literacy levels in the NALS. They looked at the spectrum of health activities that the items represented. Because of the authors' conviction that the literacy demands of health material are dependent not only on the difficulty level of the material itself but also, very importantly, on the processing tasks that are required to act on the material, they further coded each of the 191 items according to their task difficulty. The work represents a nuanced approach to the problem of health literacy and places health literacy in the context of broader public health and societal issues.

Nutbeam¹⁴ also argues that health literacy involves a complex constellation of skills that are needed to function effectively in the health care setting. He distinguishes between what he calls the "narrow" definition of health literacy, namely, the basic reading and writing skills to function effectively in everyday situations and two other types of health literacy. Interactive literacy involves the more advanced cognitive and social skills that allow an individual to extract and derive meaning and to apply new information to changing circumstances, and critical literacy involves the advanced cognitive skills to critically analyze information and use this information to exert greater control over life's situations. Weiss gives specific examples of the types of tasks for which health literacy skills are necessary.¹⁵ These involve administrative tasks, such as scheduling appointments, filling out insurance forms, and understanding consent forms as well as clinical tasks, such as explaining a medical history to a doctor and understanding and following instructions for diagnostic procedures, treatment, and postoperative care.

National Standards for health education in grades K through 12 have been developed, and some states have adopted them as part of the regular school curriculum.¹⁶⁻¹⁸ Seven standards are promoted, and performance indicators for each of the major grade levels (approximately elementary, middle, and high school) are listed. Although it is not clear how effective these standards and their implementation have been, the standards themselves indicate some of the aspects of health literacy that merit further investigation. Some investigators have also argued for the inclusion of health concepts in adult literacy programs, arguing that literacy educators should partner with health care professionals in such an effort.^{19,20}

*The 2003 National Assessment of Adult Literacy (NAAL), a follow-on to the 1992 survey, has been conducted, but the findings have not yet been released. (<http://nces.ed.gov/naal/>.)

These educational interventions could lead to more effective communication between doctors and patients in the health care setting and give patients better access to health information and services, allowing them to play a more active role in their health care.

Mismatch between Literacy and Readability

A substantial portion of the literature on health literacy addresses the problem of the basic literacy level of the patient, the readability of the health-related materials that the patient is expected to read, and the frequent mismatch between the two. This has led to the development of a variety of instruments to measure the health literacy level of the patient²¹ as well as to the use of a number of existing readability instruments to calibrate the reading level of health texts. The rapid estimate of adult literacy in medicine (REALM) was first developed in the early 1990s and is a test that is intended for easy and quick use in the health care setting.²²⁻²⁶ It consists of 66 words arranged in three columns in increasing order of number of syllables and difficulty. Patients are asked to read the words aloud, and the grade-level reading ability of the patients is assessed based on the number of words they are able to read and pronounce correctly. The instrument was validated against other reading recognition tests, and others have developed versions of the REALM for specific medical specialty areas or specific tasks.^{25,26}

The primary advantage of the REALM test is that it takes only a few minutes to administer. It is seen as a useful indicator of whether a patient can read at all, and it gives some indication of the level of ability. However, it says little about whether patients comprehend the words they are reading. The test of functional health literacy in adults (TOFHLA) and its shortened version, the S-TOFHLA, were developed to address this problem.²⁷⁻²⁹ (An earlier example of a test that was designed to test comprehension asked patients to orally define medical terms taken from patient education materials, but this does not seem to have been widely adopted.³⁰) The goal of the investigators was to create an instrument that would test patients' functional health literacy, that is, their ability to "use reading, writing, and computational skills at a level adequate to meet the needs of everyday life situations."²⁷ The test contains short passages from commonly used health texts, including samples from patient education materials, application forms, prescription labels, and informed consent forms. Administration of the full test takes up to 22 minutes, and the shorter version takes about 12 minutes.

A number of findings have shown that the literacy levels of patients in the health care setting is inadequate. The measured literacy level of an individual is often several years below what would be predicted by the number of years of schooling completed. Williams et al.³¹ in a heavily cited study, showed that at two public hospitals, 42% of the patients tested could not understand directions for taking medication on an empty stomach, 26% could not understand the information on an appointment slip, and 60% could not understand a standard informed consent form. Others have found similar results, and, in many cases, it has become clear that patients are embarrassed by their limited abilities, rarely ask for help, and have developed a variety of strategies to mask the fact that they are unable to read the materials they are given.³²⁻³⁷ Several studies have found an association between

aging and literacy levels, indicating that the elderly may be more likely to have lower literacy levels.³⁸⁻⁴³

Assessing patients' literacy levels leads to the question of how difficult the materials are. The readability instruments developed by the K through 12 educational community for assessing the grade levels of curricular materials have been used by many investigators who evaluate the readability of health materials.^{38,39} Health documents are analyzed to determine whether, for example, they are written for the third-grade level, the sixth-grade level, and so forth. The formulas are based on words per sentence, syllables per word, or word familiarity, which requires the use of a predetermined grade-level word list.⁴⁴⁻⁴⁹ These readability formulas have been used often to assess the readability of health materials in an attempt to show that there is a serious mismatch between the literacy levels of the intended audience and the materials that have been created for that audience.⁵⁰⁻⁵⁸ In some cases, studies have been conducted with a specific set of patients whose literacy level is assessed, and then the readability of the materials that are intended for that specific group is evaluated, in all cases showing that the materials are too difficult for the intended audience.⁵⁹⁻⁶⁶ Some investigators have been concerned about the cultural appropriateness of patient materials, particularly with regard to health beliefs.⁶⁷⁻⁷⁵ Recently, some have begun to look at the readability of health information posted on the Internet, but this research is in its early stages.⁷⁶⁻⁸⁰

A variety of techniques and checklists have been suggested for improving the accessibility of materials created for patients. (See *Reference* list for examples.⁸¹⁻¹⁰¹) These suggestions include readability guidelines, guidelines relating to the content of the materials, and presentation and page layout guidelines. Many investigators suggest preparing materials at the fifth- or sixth-grade reading level, rather than the 10th- or 11th-grade level at which many patient materials are written. They suggest using simple, common words and short sentences and writing in the active voice and in a conversational and personalized style. Culturally appropriate relevant content focused on actions and behaviors rather than underlying principles is preferred. The purpose of the communication should be clear, and essential information should be presented in a direct and specific way. Aspects of layout, such as large mixed-case font, question-answer format, bulleted lists, and illustrations are preferred over other presentation formats. Several investigators suggest use of audiovisuals, such as videos for low-literacy patients. However, visuals will need to be carefully selected, because they, too, have their own literacy demands. Although these suggested techniques may appear to make sense, very few have been tested rigorously (see Moulton et al.¹⁰²) to see whether they, in fact, lead to the desired outcomes.

Some of the same criticisms that have been made of literacy tests can also be leveled against readability formulas. Counting words and syllables and consulting a grade-level word list are most likely not sufficient to determine how readable a text is. In an early experiment, Duffy and Kabance⁸¹ modified texts using simpler sentence structure and easier words, reducing the difficulty of a text by six grade levels, but they saw no equivalent increase in comprehension by their subjects. Reid⁶⁴ points out that modifying texts based on the results of readability formulas can lead to problems

in comprehension, rather than improving comprehension. "When a writer shortens sentences, he/she may omit phrases that help to organize the material, and in general decrease redundancy, so that the reader has a greater comprehension burden." Brandes⁸⁷ points out that health professionals may be concerned that by simplifying materials they become legally liable for not transmitting full and accurate information to their patients. Shepperd et al.⁹⁴ point out that readability assessments do not take either the prior knowledge or the motivation of the patient into account, and they argue that the "evidence base of the information and the involvement of consumers in the production of the material base should be considered." This view is echoed in a recent study conducted for the U.S. Department of Education. The study views reading comprehension as a process, one that involves the features of the text that is to be read, the purpose for which the reading is being done, and the characteristics of the reader.⁹⁹

Patients, the Health Care System, and Literacy

Navigating today's health care system carries with it a high literacy burden. Patients need to interact in a variety of health care settings, including doctors' offices, clinics, and hospitals, and they need to interact with a broad range of health-related information, including therapeutic instructions, patient education materials, prescriptions, bills, and insurance forms. In addition, they are being asked to take increasingly greater responsibility for their own health care and disease management. Parker points out that the "roots of health literacy problems have grown as health practitioners and health care system providers expect patients to assume more responsibility for self-care at a time when the health system is increasingly fragmented, complex, specialized, and technologically sophisticated."¹⁰³ Many patients, while perhaps welcoming the opportunity to be better informed, find the information requirements overwhelming. One of the findings of the IOM report similarly states, "Demands for reading, writing, and numeracy skills are intensified due to health-care systems' complexities, advancements in scientific discoveries, and new technologies."³

A number of researchers have investigated the relationship between health literacy and the disproportionately poor health outcomes among those with limited literacy.^{104–117} Some studies have shown that low-literacy individuals have less knowledge of their health conditions and treatment regimens, have lower self-management skills, have higher rates of chronic illnesses, and do not effectively participate in preventive care. Limited literacy has also been shown to be associated with higher health care costs, greater use of health care services, higher rates of hospitalization, and lower use of screening and other procedures. Persons with inadequate health literacy often have poor understanding of disease processes, poor recall and comprehension of advice and instructions, health beliefs that interfere with care, and poor problem-solving skills. A recent systematic review prepared for the Agency for Healthcare Research and Quality suggests that more rigorous studies need to be conducted to gain a better understanding of whether inadequate literacy is the cause of adverse health outcomes or whether it is simply a marker for "low socioeconomic status, poor self-efficacy, low trust in medical providers, or impaired access to care."¹¹⁶

Communication and opportunities for miscommunication between health care professionals and their patients has been the focus of a number of studies. Some studies have investigated the ability of patients to understand the terminology used by doctors and nurses.^{118–123} They have found that although patients may state that they understand what is being said, once this assumption is tested, in many cases their understanding is, in fact, incomplete or incorrect. Successful communication, however, goes well beyond the use of terminology, with one study finding that although doctors were not using medical jargon when speaking with their patients, they were using a conversational style that emphasized the inequality in the power relationship between patients and health care professionals.¹²¹ A number of studies look at successful doctor-patient communication in the context of patient adherence or compliance to a prescribed medical regimen.^{124–130} Doctors are encouraged to assess patients' literacy skills, avoid medical jargon, and elicit patients' concerns and expectations. Schillinger et al.¹³⁰ exemplify this line of discussion when they talk about using an "interactive educational strategy," also called the "teach back," or "show me" approach, the goal of which is not only to confirm that a patient has understood what has been said but also to open a dialogue. Successful doctor-patient communication can be seen in the context of giving greater control to patients, allowing them to engage actively in the decision-making process.^{131–135} Auerbach¹³³ provides an extensive literature review on the topic of patients as collaborators in health care decision making. His review shows that patients want to be involved to the extent that this involvement will increase their chances of a positive outcome; that patients process and retain information better if it is directly relevant to their concerns; and that although there are individual differences in the degree to which they want to be involved, patients generally respond positively to enhanced information provision.

Davidoff¹³⁶ suggests that with the trend toward shorter office visits, there is not enough time for doctors to communicate effectively with their patients even when they have the desire to do so. Lee and Davidoff later go on to say "... the pressure to cram more—more patients, more procedures, more curriculum—into every waking moment, a seemingly universal and irresistible drive, that, if not biologically determined, has certainly become a social and technological imperative."¹³⁷ Berry et al.¹³⁸ suggest that what is required is systemic change that puts patients at the center of the health care system, involving access to information and assistance when and where it is needed, including the appropriate use of communication technologies.

Information Technologies, Interventions, and Use

The Internet is undeniably contributing to greater public access to and perhaps even a greater desire for health care information. Consumers of this information include not only patients, but also healthy individuals and caregivers as well as health professionals. A National Academy of Sciences report notes that the Internet is an "increasingly accessible communications channel for a growing segment of the population" that may lead "to significant changes in consumer behavior,"¹³⁹ and Eng¹⁴⁰ speaks of the "e-health landscape," suggesting that the Internet together with other information and communication technologies promises "to usher in

a wealth of innovative solutions for seemingly intractable problems in health and health care ..."

Cline and Haynes¹⁴¹ suggest that we view health information seeking on the Internet not simply as an information dissemination activity but rather as a communication process. The Internet, in their opinion, "reflects a paradigm shift by offering interactivity and reciprocal influence, pointing toward transactional rather than one-way processes, and blending interpersonal and mass communication processes."¹⁴¹ Several investigators have suggested that the Internet has the potential to transform the doctor-patient relationship, although there are some cautionary notes, including a challenge to the status quo, the possibility of longer consultations in an already time-limited environment, potential malpractice liability for e-mail and other electronic interactions, and the quality of the information found on the Internet.¹⁴²⁻¹⁵⁵ Some call for a greater role for informatics interventions that are focused on the patient, "... medical and health informaticians need to build informatics tools that support the patient as a partner in health care and focus on the consumer, not the provider or institution."¹⁴⁸

The recently formed Connecting for Health, a public-private collaborative, comprises more than 100 participants focused on addressing the policy, technical, and legal barriers to establishing an interconnected health information infrastructure. An area of concern to this group is the development of an infrastructure for the personal health record, such that patients are able to access their medical records at any time. A recently released report from this group makes the sobering observation that "for many patients, health and healthcare remain something of a black box, a realm in which they are neither able nor welcome to participate."¹⁵⁵

Survey projects specifically looking at Internet use have found that a large percentage of American adults use the Internet on a regular basis, and of those who are online, a large percentage pursue health-related questions.¹⁵⁶⁻¹⁶⁵ One group estimates that more than 63% of adult Americans use the Internet, and that over the last few years there has been a strong increase among those who have used the Internet to look for health or medical information,¹⁶² although some question how significant that increase has been.¹⁶³ Internet users search for a variety of health information ranging from information about particular conditions and treatments to information about diet, general fitness, health insurance, and specific doctors or hospitals. The type of information sought varies by the health status of the information seeker. Those who are well tend to do episodic searching about prevention, pregnancy, anti-aging, and short-term acute illnesses; those who are newly diagnosed generally conduct intensive searches about their particular condition; and those who are chronically ill do regular searching on favorite sites and are more likely to discuss the information they found with their doctors.^{159,160} People tend to value the anonymity and 24-hour availability of the Internet and are more likely to search for health information from home rather than the workplace.

Women are more likely to look for health information not only for themselves but also for their family members. Older Americans are less likely to use the Internet, but that may be changing. Currently, only about 17% of persons

aged 69 and older use the Internet, but some 46% of those aged 59 to 68 have access, and 62% of those aged 50 to 58 are online.¹⁶⁵ Until recently, the Internet was still used less often in comparison with other communication media for gaining health information. According to one survey of a few years ago, users received 69% of their health information from newspapers or magazines, 56% from television, 32% from the Internet, and 30% from radio.¹⁵⁸ This same survey found that older adults, those who lived in rural areas, and those with 12 or fewer years of education were less likely to use the Internet.

There has been some concern that those at lower socioeconomic levels do not have equal access to Internet health resources.¹⁶⁶⁻¹⁶⁸ Access to computers may be limited, literacy abilities may be insufficient, and basic computer skills may be lacking. Whereas it is still true that the largest percentage of Internet health information seekers have at least a college degree, increasingly other segments of society are gaining access to the Internet, and, when they do, they are likely to search for health information.¹⁶⁴

Increased consumer use of Internet health resources has led many to be concerned about how consumers look for and find high-quality information on the Web.¹⁶⁹⁻¹⁷⁸ One author has said, for example, "The advent of the internet has vastly increased the availability of information, but often what it offers is untailored, incomplete, irrelevant, and plain wrong."¹²⁸ An IOM study of a few years ago said, "The Internet is a bit like the Wild West: It has vast amounts of unregulated territory and no one in charge."¹⁷⁹ A Pew survey found that 86% of consumers said they worried about getting unreliable health information on the Web.¹⁵⁶ Eysenbach and Köhler found that although consumers are concerned about Web site quality, they rarely check the "about" section of the Web site, nor the disclaimers or disclosure statements.¹⁷⁴

A variety of criteria have been established for evaluating the credibility of Web sites, either by consumers themselves or by third-party groups that attest to the quality of a site.¹⁷⁸ Most guidelines include such quality criteria as currency, sponsorship, accuracy, completeness, and relevance. Others include readability, Web site navigability, and design and aesthetics. Several investigators have pointed out, however, that there are few operational definitions of such quality criteria, and that the criteria themselves have not been validated.^{175,176,180} Terry¹⁷² points to the potential legal exposure of third-party groups that attempt to rate and label the quality of health Web sites on behalf of consumers. Delamothe,¹⁸¹ on the other hand, wonders whether quality control on the Web is really necessary. He suggests that for other information media, such as newspapers, magazines, books, and television programs, consumers are able to make quality assessments on their own, and that "We naturally gravitate to products that reliably give us what we want."¹⁸¹

Information interventions that are in many, but not all, cases Internet-based have been the subject of a number of studies in recent years.¹⁸²⁻¹⁹⁶ Revere and Dunbar¹⁸⁸ review computer-based interventions that include a variety of delivery devices—print, telephone, computer, and wireless communication—and a variety of intervention types—generic, personalized, targeted, and tailored—which are on a continuum from least to most individualized. A mass-produced generic

handout becomes personalized, for example, by simply writing the patient's name on the handout. Targeted interventions generally are customized for a particular sociodemographic group or subgroup. Tailored interventions, however, are specialized for a specific individual. This may be done by taking into account a patient's medical history, replies to specific questions, or stage of the patient's disease. Tailoring may be done either manually or algorithmically, for example, by choosing messages from a large pool of possible messages. Kreuter et al.^{190,191} speak of "cultural tailoring," whereby an intervention takes into account not only sociodemographic characteristics, such as a group's cultural values, health beliefs, and behaviors, as might be the case in targeted interventions, but also an individual's level of identification with that particular group. Gustafson et al.^{184,186} have developed CHES, a home-based computerized system that provides patients with tailored health information, decision support, advice, and ready access to health care professionals and other patients. In testing the impact of their system, they found that those who participated were more competent at finding information, were more comfortable in participating in care, had more confidence in their doctors, and reported higher quality of life. Tailored interventions have been rated as being more relevant, have been associated with higher levels of patient satisfaction, and have resulted in intentions to change poor health behavior more often than have generic information interventions.¹⁸⁷ The literacy demands of these personalized, targeted, and tailored information interventions have not been seriously studied and, if mentioned at all, are often only alluded to.

Most information interventions have not been evaluated rigorously, and there have been some attempts to develop guidelines for doing so.¹⁹⁷⁻²⁰⁰ Robinson et al.¹⁹⁸ report on the findings of a panel of experts convened to develop a set of evidence-based approaches to improve the quality of interactive health communication (IHC) technologies. The panelists caution that the "growing use of IHC applications should raise legitimate questions about their quality, cost, and potential to cause harm." They propose a methodology for evaluating and reporting on such applications that would maximize the significant benefits of interactive health communication technologies, including opportunities for receiving tailored information, anonymous access to multimedia up-to-date information on demand, potential for networking with other patients, and better access to health care professionals.

Discussion

While there has been significant research in some of the areas discussed in this review, there are many opportunities for further research at the intersection of literacy and health. The concept of literacy itself is not entirely straightforward, and the term is used and interpreted variously in the literature. Traditionally, it has meant the ability to read and write, such that an illiterate individual would be one who could neither comprehend nor produce the written word. The term refers primarily to adults, who are expected to have acquired these skills by the time they reach adulthood. This traditional definition of literacy has, however, been expanded in recent years to include the basic skills that are necessary to function in modern society. The National Institute for Literacy, a Federal interagency group involving the Department of

Education, the Department of Labor, and the Department of Health and Human Services, for example, has adopted the following definition: "an individual's ability to read, write, speak in English, compute and solve problems at levels of proficiency necessary to function on the job, in the family of the individual, and in society."²⁰¹ ProLiteracy Worldwide, a nonprofit international literacy organization that was formed by the merger of two well-established literacy groups, Laubach Literacy International and Literacy Volunteers of America, "pursues a mission of sponsoring educational programs that help adults and their families acquire the literacy practices and skills they need to function more effectively in their daily lives."²⁰² These more expansive definitions of literacy are implied in much of the literature reviewed here, but the actual studies generally use instruments that are only weakly connected to this broader understanding of literacy.

While the National Adult Literacy Survey (NALS) also uses an expanded definition of literacy, its results have in some cases been more narrowly interpreted, particularly when the results have been linked to grade levels. The NALS itself does not assign grade levels to the literacy levels assessed, but the Health Literacy Project has interpreted them as follows: level 1 is functionally illiterate and reflects 0 to fifth grade reading ability; level 2 is marginally literate and reflects sixth to eighth grade reading ability; and levels 3 through 5 are highly literate, reflecting ninth through 16th and over grade levels.⁸⁷ So there has been somewhat of a slippery slope by virtue of this and other (re)translations of literacy, making it once again equivalent to reading ability. Thus, it is often said that texts, to be understood by the majority of Americans, should be written at the sixth through eighth grade level. This then has led many to apply readability formulas, which have themselves been subject to some criticism, since they generally measure very low-level aspects of the text, such as word or sentence length. It is obvious that these aspects play a role in understanding texts, but it is equally obvious that there is a great deal more involved. The special characteristics of health texts need to be considered as well. More important even than the often opaque specialized terminology used in these texts is the fact that many implicit assumptions underlie the concepts being discussed. A text, for example, that talks about the risks and benefits of undergoing a certain medical procedure or that talks about the chances of having a child affected with a particular genetic disorder, assumes many things, including that the reader has a basic understanding of the concept of risk. Better methods for assessing and ensuring the comprehensibility of health texts are clearly needed.

Additional research in achieving greater consonance between the literacy level of an individual or a group of individuals and the information intended for these individuals is needed. An individual's competence in understanding health materials is undoubtedly influenced by a variety of factors. For example, irrespective of one's literacy level, a serious illness or a distressful setting, such as a hospital emergency room, can have a dramatic negative impact on comprehension of complicated health information. Further, an individual who has just been diagnosed with a serious condition will have quite different information needs from someone who suffers from a chronic condition. These latter individuals may be quite sophisticated in their understanding of the particulars

of their disease, and yet they may be seriously challenged by materials outside of this circumscribed domain. Nonetheless, they may be highly motivated to go quite deeply into material that appears relevant, even if it is intended for an entirely different, perhaps specialist audience. Informatics applications can play an important role here. For example, information can be targeted at various levels of sophistication and depth, with the most straightforward information being presented first. Then, as the user is ready to learn more, additional "just-in-time" information might be presented, allowing the depth of investigation into the topic to be decided by the user. There is much still to be learned about the design and evaluation of such informatics interventions.

Much of the literature reviewed here has focused on the serious problems that people with low literacy face when interacting with the health care system. This is often viewed, quite appropriately, as a health disparities issue, particularly since those with low literacy have been shown to suffer worse outcomes than those with higher levels of literacy. However, while individuals with low literacy will certainly find it extraordinarily difficult to navigate today's complicated health care system, the IOM also reminds us that, "Even people with strong literacy skills may have trouble obtaining, understanding, and using health information: a surgeon may have trouble helping a family member with Medicare forms, a science teacher may not understand information sent by a doctor about a brain function test, and an accountant may not know when to get a mammogram."³ This may mean that we need to look at a very large continuum of needs for those who are at the lowest end of the literacy spectrum to those who are at the highest end, but it may also turn out to be the case that an entirely different model is required to understand and address the health literacy needs of otherwise literate individuals.

A good deal of the literature in the last decade that has reported on the impact of information technologies on consumers has concentrated on Web resources and, more specifically, on the quality of health Web sites. While this is not surprising given the multitude of health Web sites that have been developed during this period, there are, nonetheless, many additional issues to consider once the quality of the content has been assured. The lack of substantial research at the intersection of informatics and literacy is illustrated by a recent National Library of Medicine Current Bibliography in Medicine on health literacy. Disappointingly, this bibliography has only one page, representing 20 references of a total of 38 pages on the topic of "Internet, E-Health, and Informatics" (as this relates to literacy).⁶ This would seem to indicate that there are many opportunities for developing and evaluating information interventions that can be used, understood, and appropriately acted on by our target audiences.

Recently, there have been a number of developments at the national level that may be worth noting in the context of this review. The U.S. Department of Health and Human Services (DHHS) has recently issued a program announcement on health literacy.²⁰³ The program announcement invites research proposals that "increase scientific understanding of the nature of health literacy and its relationship to healthy behaviors, illness prevention and treatment, chronic disease management, health disparities, risk assessment of environmental factors, and health outcomes..."²⁰³

This program announcement is supported by 12 NIH institutes, the Office of Behavioral and Social Sciences Research at NIH, and the Agency for Healthcare Research and Quality, indicating a rather broad interest in the topic. Further, on the occasion of the recent National Health Information Infrastructure meeting, DHHS released a report that states, "Many envision a health care industry that is consumer-centric and information-rich, in which medical information follows the consumer, and information tools guide medical decisions."²⁰⁴ One of the four major areas of emphasis in this report relates to consumer access to information: "Consumer-centric information helps individuals manage their own wellness and assists with their personal health care decisions. This information could include consumer-specific health findings, health status monitoring tools, or customized prevention and self-care information. Such personalized care information could be adapted for diverse individual needs, cultural traditions, reading levels, or socioeconomic modulators of illness."²⁰⁴ This emphasis on consumer-centric information offers many opportunities to study the full spectrum of health literacy issues.

Conclusion

There has been substantial research in identifying the significant aspects of health literacy; however, there remain many opportunities for conducting further research to gain a better understanding of the complex interactions between general literacy, health literacy, information technologies, and the existing health care infrastructure. As the recent IOM report points out, literacy involves a complex set of skills.³ It involves reading and writing, or "print literacy"; listening and speaking, or "oral literacy"; numeracy; and cultural and conceptual knowledge. A good deal of the literacy literature has concentrated on one aspect of print literacy, namely readability, and occasionally numeracy. Some of the literature in the investigational area known as "doctor/patient communication" has addressed the oral aspects of literacy. Some attention has been given to other types of knowledge, but this is often done in the context of health care disparities.

The role of the Internet and other communication technologies in the health care system is just beginning to be understood. Still needed are better tools to assess and modify the comprehensibility of health materials, methods for improving access to information, and the development of evaluation metrics for assessing usability and impact of information interventions. Health informaticians, developers of health information, health educators, and health care providers all need to work together to ensure that everyone has an equal opportunity to access, understand, and use health information.

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