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Understanding Health Literacy

Implications for Medicine and Public Health

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chapter 5

Literacy Demands in Health Care Settings: The Patient Perspective

Rima E. Rudd, MSPH, ScD; Diane Renzulli, MSPH; Anne Pereira, MD, MPH; and Lawren Daltroy, DrPH†

Functional literacy assessments, as discussed in the previous chapters, measure an adult's ability to use the written word to accomplish specific tasks. Materials used in these assessments are drawn from many different contexts to represent the types of tasks adults might be expected to perform in everyday life. Findings from the 1992 National Adult Literacy Survey (NALS) indicate that 90 million adults, almost all of whom can read, have difficulty using the written word to accomplish everyday tasks with consistency and accuracy.[1,2]

Nonetheless, our industrialized nation is an environment that assumes the population has high levels of literacy. Signs and billboards are ubiquitous and include place markers, advertisements, and warnings. Streets, public squares, buildings, agencies, and institutions are named and numbered. The inside hallways and offices of government programs and service agencies are replete with signs and postings. US adults are surrounded by the written word in public locations and within public and private institutions. They are expected to use reading, writing, and mathematical skills to locate places, follow posted and oral directions and instructions, and complete needed forms.[3] For example, consider the demanding environment of a community-based social security office:

> The Social Security Office is located on a very large and busy street. The waiting room, which has no social security professionals except for a security guard who occasionally chats with visitors, is one large rectangular room with 8 windows facing the entrance. Each window has a number above it. In the middle of this wall of windows, messages run across a computerized sign

† Dr Daltroy died in September 2003.

directing visitors to take a number, fill out a form before heading to a window, or to call a toll free Social Security number for help. The messages, written fairly simply, would be easy to understand if they were not sweeping so rapidly across the screen. At the entranceway, a standing sign meant to direct visitors to the appropriate line fails to tell visitors where to get Medicare information. No other flyers or posters indicate that this office serves to provide Medicare information. While a rack with various types of forms contains a Medicare application, it has no further information on the service itself.

Alice Kuo, ScM, Student, Health Literacy Graduate Course at the Harvard School of Public Health; 2002; Boston, Mass.

The ability to read quickly is critical in this case. However, print is irrelevant for people with significant literacy problems. Purcell-Gates[4] captures the experience of Jenny, a married woman with children living in a Midwestern city, who cannot make use of the postings, the packaging, or the tools of modern society. Jenny is a nonreader. A native-born English speaker with a seventh-grade education, Jenny is able to recognize some words but only in context. Thus, she relies on what she knows and has experience with and uses people as well as location tools, such as color and shape, to help her navigate the world of print. While Jenny's total lack of reading skills is unusual, she has developed the kinds of coping mechanisms that are used by many adults in our society, including those who can read.

Any number of coping strategies may work, on average. However, these strategies can also result in errors, inconveniences, and limitations. Errors become more than inconvenient when they occur in health-related settings and health activities. When a person's literacy skills are limited and/or when the demands exceed the skills of the average person, results can be harrowing and may directly affect a person's health.

This chapter focuses on the mismatch between the average functional literacy skills of US adults and the literacy-related demands of the health care setting. It begins with a description of health contexts and the literacy demands encountered within various settings, including health care settings. Next, health literacy is examined from the perspective of patient rights and patient-provider interaction. The chapter concludes with a discussion of implications and needed actions.

HEALTH CONTEXTS

Functional literacy always takes place within a particular context. However, there are multiple health activities and the contexts vary. Throughout any given day, adults engage in a wide variety of health-related activities such as promoting and protecting health, preventing disease, or seeking care and treatment. These activities take place at home, in the workplace, in the community, and in health care settings.

In the home, mundane activities may include reading nutrition labels or directions for household products, following instructions for cleaning agents or equipment, taking care of ill children or elders, monitoring symptoms of a chronic disease, following instructions for follow-up care, and, increasingly, completing paperwork for government or private insurance. Furthermore, adults read, watch, and listen to news stories and discuss health issues with family and friends. At work, employees rely on right-to-know information about a wide variety of substances and on postings and specialized equipment for safety. They make health and safety decisions alone and with friends and colleagues. Other health-related activities are linked to actions for disease prevention or early detection measures. Public health announcements in the news or letters from schools to parents about available screening tests are meant to be useful tools and guides for action. In addition, adults take action in the voting booth and contribute to health policy and the formation of regulations. Of course, adults may also be patients and, in this role, they are expected to engage in dialogue and discussion with health care providers and follow up with recommended action. Thus, the home, the workplace, the community, and various health care settings are all "health contexts."[5]

A cacophony of voices surrounds and invades these contexts. Health, after all, is a topic of critical concern and holds high interest for the general public. People share stories and both give and receive advice. This interest in health is reflected daily on television and radio, in newspapers and magazines, within Internet chat rooms, through government and private sector Web sites and print materials, as well as in multitudes of visual, oral, and print commercials.

Materials on the Internet, in the Media, and in Health Care Settings

Some studies have examined the accessibility of health-related messages and information delivered through various media. Approximately 6 million US adults go online for medical advice on a typical day—more people than actually visit health professionals.[6] Yet research to date suggests the average person will have difficulty understanding health information on the Web because it is often written at very high reading levels (tenth grade or higher).[7] For example, the Children's Partnership study of 1000 Web sites related to education, family, finance, government, health, housing, jobs, and personal enrichment found only 10 (1%) that were appropriate for adults with literacy skills below the high school level.[8]

Graber and colleagues,[9] in a study of privacy policies on Internet health sites, found that the average readability level of sites with privacy statements required 2 years of college education. Croft and

Peterson[10] examined asthma education information on the Web and found a mean reading grade level of 10.3, as scored by the Flesch-Kincaid formula. Overall, initial inquiries indicate that information on many Web sites is not necessarily any more readable than the information printed in booklets and brochures.[11]

Although advertisements successfully sell health-related products, important health-related details are often not clearly communicated or easily understood. Bell and colleagues,[12] for example, found that many direct-to-consumer magazine advertisements only provided superficial coverage of medical conditions and their treatments. Kaphingst[13] noted that some risk statements in direct-to-consumer advertisements lacked important contextual information, that the readability scores of referenced text materials were in the high school–level range, and that the brief summary sections of print advertisements were in the college-level range.

A substantial body of literature yields consistent findings that the reading level of health education materials far exceeds the reading skills of the public for whom they were developed.[14] Some researchers assessed the readability of materials targeted at specific diseases, such as cancer, diabetes, asthma, or HIV, and other materials that examined a specific type of material and documents needed for actions involved in medications, self-care, or consent. More than 250 studies indicate that materials are written at grade-level equivalents far above the eighth or ninth grade reading skills of the average US adult.[14]

This documented mismatch between available materials, whether on the Internet or in text, serves to limit access to information and, ultimately, to inhibit action.[15–17] Consequently, the average adult is challenged to differentiate among various sources of information as well as various solutions to health problems. Health researchers have not yet fully examined the match between the skills of the average person and the cognitive demands placed on individuals by all of these information sources. However, researchers are starting to look more closely at literacy demands in formal health care settings such as hospitals, health care centers, and health professionals' offices and to reexamine the underlying assumptions that shape these demands.

Prevailing Assumptions

Expectations and assumptions about average skills may account for a mismatch between people's actual skills and health system processes and procedures. For example, public health campaigns often rely on an understanding of complex concepts such as risk and probability.[18] Many health professionals assume that the average person knows the names, locations, and functions of various organs and systems of the human body, although this information is not uniformly part of any curriculum

in kindergarten through 12th-grade state educational systems. Private insurance and public beneficiary programs shape procedures and forms that are based on assumptions about people's familiarity and ease with forms, legal and bureaucratic language and procedures, and arithmetic calculations. For the most part, these assumptions are faulty.

Findings from the first national literacy assessment of adults were published in 1993, and in-depth analyses of US and international findings were published in 2000 and 2001.[1,2,19] The mean score for US adults falls at the cusp of the NALS levels 2 and 3. As noted in Chapter 3, educators and education economists agree that NALS level 3 skills are needed for full participation in the economic and civic life of the US in the 21st century.[20,21] However, diffusion of information across disciplines is often slow, and many of those responsible for crafting health-related signs, messages, informational booklets, patient brochures, forms, and documents may not be aware of these findings or their implications.

Consequences

NALS analysis indicated that people with limited literacy skills rarely identify themselves as struggling with literacy issues.[1] Consequently, people who need help may not actively seek it. Indeed, health literacy research indicates that limited reading skills may be accompanied by feelings of embarrassment or shame.[22]

Health literacy research studies conducted since the NALS have identified additional consequences or associations for patients with low or limited literacy skills. Patients with inadequate reading skills (as measured by the Test of Functional Health Literacy in Adults [TOFHLA] or the Rapid Estimate of Adult Literacy in Medicine [REALM], described in Chapter 10) are more likely than are patients with adequate skills to report their health as poor,[23] to be hospitalized,[24] to have less knowledge of their chronic disease and how to manage it,[25–28] or to have more advanced disease when they are first seen by their doctor.[29] These and other findings are addressed in greater depth in subsequent chapters. Overall, research indicates that health professionals must consider the implications of low or limited literacy skills for patients' health outcomes.

HEALTH CARE SETTINGS AND THEIR LITERACY-RELATED DEMANDS

In its broadest sense, navigating the health care system includes a range of activities that involves accessing information and resources, participating in decisions and actions, and implementing needed procedures and protocols. People may encounter difficulties finding

and entering a health or dental care facility, using materials or tools for navigation, filling in needed forms, offering consent for procedures, and finding the vocabulary to describe feelings and experiences.[30]

Physical Navigation

Tools such as maps, directions, signs, and schedules are posted or readily available to help the traveler or the visitor navigate the physical pathways of health care environments. However, both the postings and the tools that infuse our health care environments require literacy skills that many of us take for granted. Some materials contain dense or cumbersome prose, and many document formats and design elements pose additional difficulties that require sophisticated skills and keen eyesight. Postings and directional signs on buildings, hospital lobbies, and hallways often include sophisticated words and phrases that are difficult to read or pronounce. For example, hospitals frequently have multiple entrances named with terms such as "admitting," "receiving," "ambulatory care," or "emergency entrance." The use of "ambulatory" in place of "walk-in" can easily lead to confusion because, after all, ambulances have an entrance as well. Also, many hospital signs are topped, in headline fashion, by the name of a donor. The average person might not be able to differentiate between proper names and medical terms.[30,31] Subsequent errors and accompanying costs, lost time, and feelings of inadequacy are rarely documented.

Overall, settings with an array of signs and postings have a high literacy demand. People entering such settings might feel overwhelmed by print. This is captured in the following vignette:

> Before getting to the pediatric radiology department, a patient must first navigate the public areas of this large private hospital. Imagine a dense and busy environment, with directional signs both overhead and mounted on walls, posters on easels, display cases filled with flyers, and many plaques on the walls identifying rooms, highlighting donors, or giving historical information. Symbols announce toilets, payphones, and ATMs; arrows are used to indicate directions and turns; and hallways are color-coded. While an information desk directly opposite the main entrance could help people with limited literacy, it is not always staffed.
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> ***Paul Gilbert***, ScM, Student, Health Literacy Graduate Course at the Harvard School of Public Health; 2002; Boston, Mass.

Settings dense with the written word can confuse the best reader. So too might the use of esoteric terms. For example, an observer noted the use of the word *triage* on an entry post to a hospital emergency department:

> As a parent enters an emergency department waiting room, a glass wall stands in front of her, next to a seating area filled with chairs, a fish tank, and other child-friendly paraphernalia. On the glass, the word TRIAGE is written sideways along the left edge. No other cues suggest to the parent that this is the first place where she should stop. Many parents walk past this reference point and migrate deeper in the room, noticing a sign announcing REGISTRATION with desks and staff sitting at computers. Along the way, human interceptors—a security guard, the triage nurse, or the registration secretary—may redirect the parent back to the TRIAGE sign.
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> ***Stephen C. Porter***, MD, Student, Health Literacy Graduate Course at the Harvard School of Public Health; 2002; Boston, Mass.

The word *triage*, borrowed from another language and difficult to pronounce, carries a meaning that may be foreign to the general public. As a result, the sign does not serve to simplify a process but instead requires vigilance on the part of staff and possible embarrassment for the visitor.

Those working in medical care facilities understand the terms used for specific practices and tests; the general public, however, may rarely encounter these terms in the outside world. Thus, medical jargon and abbreviations used on directional signs and place postings, such as "Nuclear Medicine," "EEG," "EKG," "EMG," "Pulmonary Diseases," "Nephrology," or "Rheumatology," add to the burdens of navigation.[31] Educators suggest that the literacy skills of the audience, the context of the communication, the tasks people need to perform, and the difficulty of the text itself must all be considered. Adequate communication takes place only when all these components match.[2,4] While such matching is not possible on an individual level, health care systems and the text produced could incorporate everyday language and aim for a match with "average skills," often calculated at approximately the eighth-grade reading level.

Documents and Open Entry Forms

Documents (ie, short forms or graphical displays of information, such as job applications, transportation schedules, and maps) can be more difficult to use than materials presented in prose format, partly because documents do not use full sentences and paragraphs. NALS findings indicate that adults have less proficiency with documents than with prose.[1] Nonetheless, documents and open entry forms, in particular, which contain blank spaces to be filled in by users, are critical and ubiquitous within health care settings.

> When you have medical forms and stuff, I don't think it should be complicated for a person to not understand what it's saying. I think it should be... more cut and dry.
>
> ***Margarite Smith***, parent, *In Plain Language* video transcript, 2002.

Access to care may be limited by the ritual-like requirement of filling in forms. These can include insurance forms, Medicaid or Medicare forms, and medical or dental history forms.[32,33] In addition, follow-up information and test results are often presented in document format without prose discussion and explanation. Consider the forms and follow-up letters patients encounter at a hospital mammography department:

> Each patient must complete a mammography questionnaire, available in English and Spanish, written at a post high school reading level (SMOG reading assessment). After the exam, test results are mailed to patients. While state and federal regulations require mammography facilities to provide patients with written mammography results using "lay terms," the mammography report reads at a post high school level (SMOG reading assessment). The report contains many unexplained technical terms and words that could be substituted with simpler language. Neither the questionnaire nor the mammography report was developed with feedback from the intended audience, as is recommended by health literacy researchers.
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> ***Rosemary Frasso Jaramillo,*** ScM, Student, Health Literacy Graduate Course at the Harvard School of Public Health; 2002; Boston, Mass.

Oddly, the burdensome structure, format, and language used in forms as well as in mailed letters and test results often necessitate staffing dedicated to helping people understand, manage, and respond appropriately. Consequently, those who can turn to community resources, including librarians, adult educators, and social service agency staff, to help them interpret materials and complete needed forms. This level of assistance is invisible and unpaid.[34,35]

Written Directions

Health care systems rely on printed materials to convey directions and instructions related to procedures, medicines, side effects, and self-care. These materials are often written at readability levels that exceed the reading ability of the average adult. Several researchers found that package inserts from pharmaceutical companies, nonprofit organizations, and commercial vendors had an average readability score of grade 10.[36,37] Emergency department discharge instructions have been assessed at readability levels that range from grade 6 to above grade 13.[38,39] National guidelines for asthma management plans set a goal of grade levels at or below fifth grade reading; however, researchers found that none of the plans in 2002 achieved this goal.[40] While written directions are developed to supplement oral communication, materials written above the eighth-grade level do not adequately serve the average US adult nor do they serve people with limited or low literacy skills.

PATIENT RIGHTS

Few studies have examined health literacy from the perspective of social justice and rights. US adults may regularly come across health-related information that is not clearly presented, but this obstacle may pale in comparison to limitations on access to information related to their rights. Patients' rights and responsibilities are posted in hospital and health center entrances or are available as handouts. This important information speaks to critical issues of dignity and autonomy and can be prepared in a variety of ways. Some hospitals and health care facilities draft the information legally with formal language and complex sentence format. For example, the wording below is taken from a hospital posting of patients' rights (calculated with a SMOG score of grade level 21):

- Upon request to obtain from the facility in charge of his care the name and specialty if any, of the physician or other person responsible for his care or the coordination of his care.
- To have all reasonable requests responded to promptly and adequately within the capacity of the facility.
- To prompt lifesaving treatment in an emergency without discrimination on account of economic status or source of payment and without delaying treatment for purposes of prior discussion of the source of payment unless such delay can be imposed without material risk to his health, and this right shall also extend to those persons not already patients or residents of a facility if said facility has a certified emergency care unit.

In contrast, the same listing of rights, rewritten for parents (calculated at SMOG grade-level 12) is posted in the entrance of a children's hospital:

- There are many people who take care of your child in the hospital. You have the right to know who they are and what they do.
- You can ask what is happening to your child and why. We will do our best to explain information to you, in ways you can understand, and in your own language.
- Your child has the right to emergency, lifesaving treatment whether or not there is a source of payment. This applies to children who are already patients of the hospital, as well as new patients.

The two postings make very different demands. The first erects an unreasonable barrier and compromises rights. After all, posted information that is not intelligible is technically not available.[30,31]

Privacy Rights

The federal privacy standards of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) went into effect in April 2003. Originally designed to give patients more control over how their medical records are used and disseminated, the regulations require that health care providers disclose to their patients how the providers may use personal medical information. Patients' rights must also be specified. What is not required, however, is evidence that patients *comprehend* their new rights. The law requires that patients sign off noting that they *received* a description of the new rules and regulations. Nothing in the regulations mandates a statement of understanding, nor do the regulations suggest an appropriate readability grade level for the text or propose a writing style and format. Consequently, language used in the forms may well obfuscate statements of rights. Consider, for example, how one health clinic chose to inform patients that they have the right to change their mind when it comes to sharing their health information with outside interests:

> You may revoke your authorization or any written authorization obtained in connection with your "Highly Confidential Information," except to the extent that we have taken action in reliance upon it, by delivering a written revocation statement to the Privacy Officer identified below.

In contrast, one hospital's notice of privacy practices states:

> You may cancel your permission in writing at any time.

Informed Consent

Whenever adults participate in a research project, they must sign an informed consent form.*[1] Federal law requires formal research consent statements to describe research, tests and procedures, and possible outcomes. The purpose of informed consent for research is to ensure participants' autonomy as they consider whether or not to take part in a study. Thus, the formal aspect of consenting is a critical aspect of health literacy and requires comprehension. However, over the past three decades, published reports have highlighted difficulties with the highly technical vocabulary in informed consent documents.[41–45] Cumbersome sentences and scientific terms obscure meaning. Consequently, US adults may not be in a position to truly offer informed consent.

> They had tons and tons of papers for me to sign . . . I signed them, but . . . I wasn't knowing what I was signing.
>
> ***Karen Rivera***, parent and patient, In *Plain Language* video transcript; 2002.

* Informed consent is discussed in greater detail in Chapter 8.

Cox's[46] research of patients in nine clinical trials found that all of the patients in the study felt that some of the information was too difficult to understand and that half indicated that the information was useless. Paasche-Orlow and associates[47] found that the mean readability scores for sample text provided by Institutional Review Boards (IRBs) exceeded the IRB's stated standards by 2.8 grade levels. The legal ramifications of an adult's inability to comprehend the technical language of informed consent documents have yet to be fully explored.

PATIENT-PROVIDER COMMUNICATION

An analysis of patient-provider communication is offered in Section 3 this book. However, it is noted in this chapter that health care professionals use their own language, provide unusual services, and require people to engage in technical procedures with which they are not familiar and may not fully understand:[48]

> Sometimes the doctors and pharmacy use the type of words that, you know, they're sometimes hard. . . . They be using those fine words, those college words, that's hard for people like me to understand and read.
>
> ***Miguel Cruzado, Sr***, Public Works Department Employee. *In Plain Language* video transcript; 2002.

Reading is only one part of a complex phenomenon. As people develop literacy skills, they develop a number of other skills, including reading for meaning (vs decoding of individual words), the ability to describe with accuracy, and ability to give and understand instructions without relying on face-to-face interaction and shared context, a large working vocabulary, and an understanding of abstract concepts.[49] Linguists and reading experts have established links among a variety of skills such as reading, verbal presentation, and oral comprehension.[50] Thus, the relationship between health outcomes and patients' skills and competencies is not limited to reading but may instead be related to the full spectrum of literacy skills.

Medical, nursing, dental, and mental health encounters rely on patients' oral skills. Patients are expected to describe experiences and symptoms so that a practitioner can complete a diagnosis. Auditory skills, better known as oral comprehension skills, are critical as well. The practitioners' talk and commentary, presentation of findings, and advice for action are important components of care and self-care. Consequently, patients' oral presentation and comprehension abilities can enhance or limit their experiences.

Patients with high levels of oral presentation and comprehension abilities may still experience problems when they communicate with their health care providers, because status and power differentials shape discussions and interactions. In addition, a patient may be physically or cognitively impaired due to illness, stress, fear, or

discomfort. Shame or feelings of embarrassment, as noted earlier, might diminish a person's capacity to express his or her concerns in a health care setting's highly literate environment.[51,52] Patients' weak or strong literacy skills are further affected by the scientific language and jargon used by health professionals in writing and in speech. While the literacy skills of patients are of critical importance, so too are vocabulary and communication skills of those in the health fields.

Health practitioners need to continuously improve the clarity of their written and spoken health information. Reading, writing, and presentation skills, finely tuned in institutions of higher learning, are geared for dialogue and discussion among members of highly educated and often specialized audiences. Plain-language communication should be considered a critical skill, along with other professional competencies for those in health professions.

IMPLICATIONS AND NEEDED ACTIONS

As illustrated in Chapter 1, health literacy is a dynamic skill that ebbs and flows in response to other factors, including health materials, communication skills of those delivering the message, changes in life experience, education, and the presence of comorbid conditions such as functional status, mental illness, stress, or depression. Health literacy must also be understood in terms of having multiple antecedents and/or confounders. They include not only such obvious factors as educational attainment but also such factors as dyslexia or social deprivation. Further exploration of these issues is needed.[3]

The 1998 Socioeconomic Status and Health Chartbook summarizes a wide array of research findings linking education, income, and health status.[53] Family income increases with each higher level of education. Life expectancy is related to family income. Death rates for chronic diseases, communicable diseases, and injuries are all inversely related to education. Health-damaging activities such as smoking, sedentary lifestyle, and heavy alcohol use are associated with lower income and lower education. Dental visits, screening, and avoidable hospitalization are associated with higher income and higher levels of education.[53] Of course, the cited research uses education and/or income as markers of socioeconomic status and not as variables to be examined. Until recently, few inquiries had looked more closely at factors associated with education such as literacy. The National Institutes of Health began to support explorations of possible pathways from education to health in 2003.

Health literacy is still a new field of inquiry. Innovative and rigorous research inquiries will contribute to the pool of knowledge, while well-tested interventions that incorporate the needs and perspectives

of the patient can improve health care and health outcomes. First, however, faulty assumptions about health literacy skills of adults entering the health care system must be corrected.

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