

Health Literacy

Why Is It a Public Health Issue?

More than half the adults in the United States find it difficult, if not impossible, to understand their health plan coverage, read instructions for taking medications and drug interactions, or understand and act on public health warnings. These tasks are a function of health literacy, which we can begin defining as a person's ability to find, understand, and act on health information. While we will expand and elaborate on this definition throughout this book and present a new framework for understanding health literacy, this chapter establishes the fundamentals of why health literacy is a major public health issue that can and should be addressed by health professionals in many fields. (A number of important government and academic initiatives are now focused on health literacy: Ad Hoc Committee on Health Literacy, 1999; U.S. Department of Health and Human Services, 2000; Schwartzberg, VanGeest, & Wang, 2005; Partnership for Clear Health Communication, 2003; Nielsen-Bohlman, Panzer, & Kindig, 2004.)

Low health literacy contributes to a number of difficulties:

- Improper use of medications
- Inappropriate use or no use of health services
- Poor self-management of chronic conditions

- Inadequate response in emergency situations
- Poor health outcomes
- Lack of self-efficacy and self-esteem
- Financial drain on individuals and society
- Social inequity

The following are three examples of the dire consequences of the inability to successfully educate people about better health prevention and disease management in the United States:

- *Type 2 diabetes.* Diabetes is the seventh leading cause of death in the United States, directly affecting 6.2 percent of the population (17 million people). The disease disproportionately affects minority populations. Non-Latino blacks, Latino Americans, American Indians, and Alaska Natives all have a higher prevalence of diabetes than non-Latino whites. American Indians and Alaska Natives have the highest prevalence of diabetes (15.1 percent) of any racial/ethnic group studied (National Diabetes Information Clearinghouse, 2002). Type 2 diabetes is largely a lifestyle illness.

- *HIV/AIDS.* The rate of HIV infection has hovered at over 40,000 new cases per year since 1998. The rate of decline has slowed significantly, from 13 percent in 1997 to 3 percent in 1999. Minority groups disproportionately represent the highest rates of new infections. Blacks represent 12 percent of the general population yet make up 54 percent of new infections. Women between the ages of 13 and 24, especially women of color, make up 47 percent of HIV cases. There has been a resurgence of cases in young men who have sex with men, a group that previously showed dramatic declines in infection rates associated with intense education (Centers for Disease Control and Prevention, 2001).

- *Maternal and newborn health.* Roughly 4 million infants are born in the United States each year. Among developed countries,

the United States is ranked 25th in infant mortality (National Center for Health Statistics, 2001) and 21st in maternal mortality (World Health Organization, United Nations Population Fund, United Nations Children's Fund, & World Bank, 1999). While the infant mortality rate dropped more than 22 percent in the United States between 1991 and 2000 (6.9 percent of live births), black infants are more than twice as likely to die as white infants, and Hispanic women are three to four times as likely to die in childbirth in the United States (Division of Reproductive Health, n.d.). Preterm births occur in 9.7 percent of all U.S. births, yet the rate for blacks is double that of whites and the rate is 25 percent higher for Hispanics than for whites (Reagan & Salsberry, 2004). The proportion of all babies born with low birth weight in the United States between 1991 and 2000 increased 7 percent (March of Dimes, 2003). Financial cost is also embedded in these statistics. The average cost of caring for the tiniest newborns now exceeds \$200,000, according to researchers (Preidt, 2005).

The role of women's health literacy is important in these sobering statistics. For example, while it is believed that up to 70 percent of birth defects of the brain and spinal cord may be prevented if women take 4 milligrams (4,000 micrograms) of folic acid daily prior to and during early weeks of pregnancy, in 2002 only 31 percent of nonpregnant women surveyed said that they were taking a daily multivitamin containing folic acid. And those least likely to be consuming folic acid included women ages 18 to 24, women who had not attended college, and women with annual household incomes under \$25,000 (March of Dimes, 2003).

The greater prevalence of chronic disease, technological and scientific revolutions, and globalization, including both the quicker spread of communicable diseases and the threats of bioterrorism, all set the stage for substantive changes in what public health means and how to attain it for the largest number of citizens (Institute of Medicine, 2003). The terrorist attacks on the United States of

September 11, 2001, demonstrated both weaknesses and strengths in the public health system (Institute of Medicine, 2003). Much criticism points beyond infrastructure problems and toward communication problems—for example, federal, state, and local officials’ inadequacies in communicating with one another and the general public (Connolly, 2001). The Institute of Medicine (2003) summed up this critical need: “Therefore, the committee recommends that all partners within the public health system place special emphasis on communication as a critical core competency of public health practice. Government public health agencies at all levels should use existing and emerging tools (including information technologies) for effective management of public health information and for internal and external communication. To be effective, such communication must be culturally appropriate and suitable to the literacy levels of the individuals in the communities they serve” (p. 125).

As we will discuss next, health literacy refers to more than reading and writing. It refers as well to the powerful skills that make it possible for people to talk about, know, and organize health information.

Definitions of Key Terms

Often the terms *health communication*, *health promotion*, and *health education* are used interchangeably. Because the discussion throughout this book uses all of these terms, we will use the following definitions, based on the 1998 WHO Health Promotion Glossary, greatly influenced by the Ottawa Charter for Health Promotion and the Jakarta Declaration of 1997 (Nutbeam, 1998).

Health promotion is the “process of enabling people to increase control over and to improve their health” (World Health Organization, 1998, p. 11). The mission of public health is actualized through health promotion and disease prevention. Health promotion relies on health education and health communication, as well as systems and policies that advance the public’s health status.

Health education is the full range of activities that involve communicating health information to people. It attempts to address the gap between what we know about health and what people actually practice (Glanz & Rudd, 1990; Griffiths, 1972). Health education can take place anywhere: in the home or community, schools and health care settings, work sites, and the consumer marketplace (Glanz & Rudd, 1990).

Health communication is the use of human and mass or multimedia and other communication skills and technologies to educate or inform an individual or public about a health issue and to keep that issue on the public agenda. Study after study has concluded that most consumers want more and better health information. A key objective is to construct linguistically, culturally appropriate, and innovative communications using the public health system and to have better patient-provider encounters.

Social marketing is the merging of traditional marketing and advertising strategies to persuade people to act in specific ways on social issues such as health and the environment (Andreason, 1995; McKenzie-Mohr & Smith, 1999). Social marketing focuses on designing and evaluating messages and campaigns through careful audience analysis, segmentation, identification of target audiences (market segmentation), understanding those audiences, and ultimately tailoring communications for a desired effect. Instead of starting with what an audience does not know and needs to know, the social marketer begins with knowing what people do and do not do, and why. The goal is behavior change.

Consumer decision making involves the active cognitive and emotional roles individuals play in attending to, evaluating, and acting on health information. Ever more frequently, health consumers are required to become more active coparticipants in their health and health care. Some examples are making medical treatment decisions, choosing health plans, or making decisions about lifestyle changes.

Health literacy is the wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health

information and concepts to make informed choices, reduce health risks, and increase quality of life. (We elaborate on this definition in Chapter 3.)

Medical Information

If the quantity of health information were the litmus test for a health-literate population, there would not be a health problem in the United States. Information about health in the United States is ubiquitous. As a society, we are awash with health messages—most too complicated, many often misleading. We receive health information from many sources: doctors, family and friends, television, newspapers, magazines, and the internet. Direct-to-consumer marketing by the pharmaceutical industry as well as online purchase of medications has created a climate in which the consumer is more and more able to ask for and receive commercially marketed products (David & Greer, 2001; Kaphingst, Rudd, DeJong, & Daltroy, 2004a).

Complexity of Health Information and Materials

Health education and promotion are critical for reaching and empowering the public in general and vulnerable people in particular. And yet much health education and promotion material in print and on the internet is written at the tenth-grade reading level or higher, far out of the reach of the average patient or consumer (Doak, Doak, & Root, 1996; Williams et al., 1995; Zarcadoolas, Ahern, & Blanco, 1997). The most easily identifiable complexity comes in the sentences and words we use. For example, the following health information texts are at the 12th- to 15th-grade level:

Navigating the Health Care System: Medicaid

The law cited below [not included here] requires that all conditions of eligibility must be verified at each redetermination of eligibility unless the verification is pending from a third party and the recipient has cooperated in obtaining the verification. Since you have not provided

the necessary verification or you have failed to cooperate in obtaining verification from a third party, your cash and/or medical assistance must be stopped.

This is very hard to read for several reasons:

- High-level vocabulary (*cited, eligibility, redetermination, and verification*, for example)
- Long and complex sentences
- Passive versus active sentences (“the recipient has co-operated in obtaining . . .”)

Unfortunately, it is rare that only the vocabulary or sentences are complex. The following example is from a fact sheet on colorectal cancer from the American Cancer Society (2006) titled “What Are the Risk Factors for Colorectal Cancer?” Here, two important ingredients add to the complexity: the reader needs to know some basics about risk and risk factors and also needs to have skill in numeracy to understand personal risk.

A *risk factor* is anything that increases your chance of getting a disease such as cancer. Different cancers have different risk factors. For example, unprotected exposure to strong sunlight is a risk factor for skin cancer, and smoking is a risk factor for cancers of the lungs, larynx, mouth, throat, esophagus, kidneys, bladder, colon, and several other organs. Researchers have identified several risk factors that increase a person’s chance of developing colorectal polyps or colorectal cancer.

A family history of colorectal cancer: If you have a first-degree relative (parent, sibling, or offspring) who has had colorectal cancer, your risk for developing this disease is increased. People who have two or more close relatives with colorectal cancer make up about 20 percent of all people with colorectal cancer. The risk increases

even further if the relatives are affected before the age of 60. About 5 percent to 10 percent of patients with colorectal cancer have an inherited genetic abnormality that causes the cancer. One abnormality is called *familial adenomatous polyposis (FAP)* and a second is called *hereditary nonpolyposis colorectal cancer (HNPCC)*, also known as Lynch syndrome. These abnormalities are described later in this document. No other clearly identified genetic abnormalities have been described at this time.

And when complex messages convey complex issues, low-literate people are placed in a kind of triple jeopardy: they cannot understand the information, they cannot judge the trustworthiness of the information, and they are forced to rely on information that is difficult to understand and may be unreliable (for example, a community rumor, a sensationalist media broadcast, or scare tactics of special interests groups.)

Consider the following example of a communication about BSE from a U.S. Department of Agriculture (2005) press release:

Since the USDA enhanced surveillance program for BSE [bovine spongiform encephalopathy] began in June 2004, more than 375,000 animals from the targeted cattle population have been tested for BSE using a rapid test. Three of these animals tested inconclusive and were subsequently subjected to immunohistochemistry, or IHC, testing. The IHC is an internationally recognized confirmatory test for BSE. All three inconclusive samples tested negative using IHC.

Earlier this week, USDA's Office of the Inspector General (OIG), which has been partnering with the Animal and Plant Health Inspection Service, the Food Safety and Inspection Service, and the Agricultural Research Service by impartially reviewing BSE-related activities and making recommendations for improvement, recommended that all three of these samples be subjected to a second internationally recognized confirmatory test, the OIE-recognized SAF

immunoblot test, often referred to as the Western blot test. We received final results a short time ago. Of the three samples, two were negative, but the third came back reactive.

Because of the conflicting results on the IHC and Western blot tests, a sample from this animal will be sent to the OIE-recognized reference laboratory for BSE in Weybridge, England. USDA will also be conducting further testing, which will take several days to complete.

Regardless of the outcome, it is critical to note that USDA has in place a sound system of interlocking safeguards to protect human and animal health from BSE—including, most significantly, a ban on specified risk materials from the human food supply. In the case of this animal, it was a non-ambulatory (downer) animal and as such was banned from the food supply. It was processed at a facility that handles only animals unsuitable for human consumption, and the carcass was incinerated.

This press release combines all of the sins of failed health communication, with the result that it is incomprehensible to the vast majority of the U.S. population. It contains high-level language and obscure scientific terms that unnecessarily complicate the message. Buried at the end, implied, but never directly stated, is the reassurance the public needs: “don’t worry—the government is able to safeguard your supply of meat—you won’t be poisoned by sick cows.” Of course, health communicators must be careful to stick to the known facts rather than to simply attempt to persuade the public that all is well when it is either not well or unknown. The early British government response to BSE in which John Gummer, then the secretary of state for the environment, created a photo opportunity by stuffing a hamburger into his little daughter’s mouth is now a notorious example of an ill-conceived strategy to calm the public when scientific uncertainty about the threat remained high. The outcome of efforts that are not based in honest communication strategies can often be increased distrust and outrage (Jasanoff, 1997).

Providing Information in Languages Other Than English

Perhaps as important as addressing complexity are the lack of availability of easy-to-read and understand materials in languages other than English and the need for health promotion methods that are culturally sensitive.

As indicated by the 1990 Census, 14 percent of the population in the United States speaks a language other than English (31.8 million persons). The main languages spoken are English, Spanish, Chinese, French, German, Tagalog, and Vietnamese.

Regardless of language or culture, one thing that appears to be universal is that people want and need information about their health, especially when they or their family members are ill. Yet often people do not have the answers to their basic questions:

- What is the medical problem, and how is it diagnosed?
- What is the right treatment for me?
- Can I trust the information I am getting?
- What do I have to do to be healthier?
- What are my risk factors for a disease?
- How do I use the health care system effectively?
- How does my medical insurance work?

The Relationship Between Health and Literacy

Low literacy, poor health, and early death are strongly linked in this country and around the world (Clenland & Van Ginniken, 1988; Grosse & Auffrey, 1989; Hohn, 1997; Tresserras, Canela, Alvarez, Sentis, & Salleras, 1992). In the mid-1990s a series of studies clearly linked low literacy level to patient health behaviors. In a study of

patients at two urban public hospitals, one in Atlanta and the other in Los Angeles, Williams et al. (1995, p. 1677) assessed the functional health literacy among English-speaking and Spanish-speaking patients. They defined adequate functional health literacy as “the ability to comprehend quantitative information, which may differ from the ability to read a prose passage.” They found that up to 33 percent of patients presenting for acute care at these facilities could not adequately understand instructions for a common radiographic procedure written at a fourth-grade level, 24.3 to 58.2 percent of patients did not understand directions to take medication on an empty stomach, and more than 20 percent of patients incorrectly answered questions regarding information on a routinely used appointment slip.

Jolly, Scott, Feied, and Sanford (1993) and Powers (1988) assessed the readability of patient-directed print materials in university hospital emergency departments. They found that a significant number of the patients (more than 50 percent in Powers’s study) were not able to read well enough to understand standard discharge information, such as instructions on how to care for wounds or sprains.

Many Americans Are Low-Literate

The National Adult Literacy Survey (NALS) found that approximately 45 percent of the U.S. population (90 million people) has limited literacy (Kirsch, Junegeblut, Jenkins, & Kolstad, 1993). NALS made it possible, for the first time, to construct a detailed picture of the literacy skills of adults in the United States. This study assessed three types of literacy: prose, document, and quantitative. NALS sheds important light on the literacy of older Americans, high consumers of health care, as it indicates that low levels of prose, document, and quantitative literacy are a significant problem for a large portion of the older adult population in the United States (defined as 60 years and older). Among the population age

65 and older, 44 percent tested at the lowest literacy level, level 1 (roughly third to fifth grade level), and 32 percent tested in the second-lowest level, level II. When literacy levels were correlated with physical disabilities, similar results were revealed. For instance, of the population with long-term illness, 70 percent of the affected population performed at the lowest literacy levels.

Do Literacy and Education Go Hand in Hand?

Education level is often used as a proxy for literacy level, presuming the higher the level of education, the higher the literacy level. But as the International Adult Literacy Survey (IALS, 2003) Canadian report indicates, “The connection between educational attainment and literacy levels, while strong, is not exclusive. Many individuals—one third of the population in fact—do not fit the general pattern. But with respect to individuals, their actual literacy may be greater—or less—than their level of education might suggest” (para. 22).

Literacy Problems Among Minorities in the United States

English literacy levels among minorities in the United States are very low, as Table 1.1 shows (levels I and II are fifth-grade level and lower, and level I is below third-grade reading level ability).

What Are the Barriers to Health Literacy?

Among the most recognized barriers to health literacy are the following:

- Complexity of written health information in print and on the web
- Lack of health information in languages other than English
- Lack of cultural appropriateness of health information

- Inaccuracy or incompleteness of information in mass media
- Low-level reading abilities, especially among under-educated, elderly, and some segments of ethnic minority populations
- Lack of empowering content that targets behavior change as well as direct information (social marketing strategies)

Why Is Literacy So Important to Health Promotion?

Literacy is not just about reading and writing. It has powerful individual and social consequences and corollaries (Olson, 1994).

Table 1.1. English Literacy Levels Among Minorities in the United States

| Race/Ethnicity | Level I (%) | Level II (%) |
|--|-------------|--------------|
| Black | 46 | 34 |
| Asian/Pacific Islander | 33 | 23 |
| American Indians | 29 | 37 |
| Other | 49 | 21 |
| Hispanic (Mexicans) | 54 | 25 |
| Hispanic (Cubans) | 46 | 20 |
| Hispanic (Puerto Ricans) | 51 | 28 |
| Hispanic (Central and South Americans) | 53 | 25 |
| Hispanic (other) | 31 | 25 |

Note: Results of this survey were reported in five levels. Levels I and II were considered to have the lowest literacy.

Source: Kirsch et al. (1993).

Intuitively we understand that people who cannot read (those who are illiterate) or cannot read well (those who are low literate) are handicapped to a great degree in society. Literacy helps us get on in the world; it gives us access and privilege. If you have ever assisted someone who cannot read a train schedule, or overheard a patient asking his wife to read a prescription label for him, or struggled while traveling in a country where another language is mainly spoken, you know in an instant the profound impact literacy has on a person's life.

During the dramatic anthrax events of 2001, a Gallup poll found that individuals with less formal education were more likely to be worried about exposure to anthrax. Forty-four percent of Americans with a high school education or less were worried compared to 21 percent of those with college degree (Jones, 2001). (See the anthrax case study in Chapter 9.) These data suggest that people with higher education levels (and, more likely, higher functional literacy level) may be better able to judge the quality and reliability of information sources and weigh relative risk.

Research from many disciplines contributes to the understanding of literacy. Major contributors include linguists, philosophers, anthropologists, psychologists, cognitive scientists, reading researchers, and educators. Representative of these disciplines are the following: sociolinguistics and discourse analysis (Gumperz, 1982; Hymes, 1974; Labov, 1972, 1994; Stubbs, 1983; Tannen, 1982), social anthropologists (Achard & Kemmer, 2003), text analysts studying narratives (Propp, 1968; van Dijk, 1977), researchers of written and spoken language (Kroll & Vann, 1981; Scribner & Cole, 1981), cognitivists (Luria, 1976; Vygotsky, 1962), and literacy and reading experts (Britton & Graesser, 1996; Olson, 1980; Olson & Torrance, 2001; Orasanu, 1986). Among the central questions that scholars in these fields ask about literacy and language are:

- How do literacy and language influence how we think (cognition)?

- What is the relationship between spoken and written language?
- What happens to our literacy abilities over our lifetime?
- What are the skill differences between less and more literate individuals?
- What kinds of empowerment result from literacy or are a consequence of it?
- How do written, spoken, and visual texts get understood and used?

The consequences of literacy have been closely examined by studying both literate and nonliterate cultures (Goody & Watt, 1968; Havelock, 1973; McLuhan, 1964; Olson, 1977). We know that literacy affects rational thought and the cognitive processing of information (Bruner, 1966; Clanchy, 1979; Greenfield, 1972; Scribner & Cole, 1981; Stock, 1983). Researchers and philosophers over the past 200 years have associated literacy with social progress. Literacy provides a means to create social norms as well as the ability and tacit permission to question them.

Rao and Rao (2002, p. 32) capture this power: "Proper literacy comprises practices and reading and writing which enhance people's control over their lives and their capacity for making rational judgments and decisions by enabling them to identify, understand, and act to transform social relations and practices in which power is structured unequally." The social and political power of literacy can be seen clearly in an antialcohol literacy program developed in the state of Andhra Pradesh in India. A literacy program was established in a way that allowed the female participants to select their content focus. The women selected alcohol use, a serious issue facing their communities. As a result, the literacy program coalesced into a civic effort that successfully banned alcohol sales. The state,

later realizing the loss of income from tax on alcohol, eliminated the literacy program and eventually allowed alcohol to be sold again.

Characteristics of People as Language Users

To frame the subsequent discussion of health and health literacy, the following key characteristics of people as language users are important to keep in mind:

- People are meaning makers, no matter their skill. Speakers and readers try to make meaning from what they read, see, and hear, as the following joke circulated on the internet in 2005 shows:

Q: Is your appearance here this morning pursuant to a deposition notice which was sent to your attorney?

A: No, this is how I dress when I go to work.

- Literacy and language reflect and influence how we see the world and make meaning. The way we use language and how literate we are says much about how we interpret the world. Consider the profound yet subtle distinction the speakers of English and the Hopi language make in the following utterance:

English: "I am riding the horse."

Hopi: "The horse is running for me."

The two utterances demonstrate uniquely different views of the relationship between people and animals.

Using a more contemporary example, after 9/11, militaristic and scientific language mingled and percolated into everyday language, reshaping our vocabulary and worldview. New words entered the

public dialogue and consciousness. The noun *weapon* has been made into a verb, *weaponizing*, as in “weaponizing a substance,” and “dirty bombs” do not refer to sanitation. Terrorist groupings became “cells”; *spores* became a word used to describe what might be in the mail. By November 2001, U.S. postal workers were being called “unlikely foot soldiers in the war against terror” (Cannon, 2001, p. 18).

- Literacy is a means to create social norms as well as a means to question these norms. Literacy permits local knowledge to be generalized. Therefore, literacy is in part about power, and its goal includes social transformation. For example, literacy programs have been linked with women’s empowerment in microcredit programs. One such program is the Nepal Women’s Empowerment Project (WEP) in which literacy improvement among women was combined with microfinance education. Over 100,000 women (native citizens) were taught how to read and write, how to start small businesses and village banks, and how to manage small health or social projects. With their knowledge and skill, they went on to teach other women. After three years, the number of women deemed literate rose from 39,000 to 122,000; the number of small businesses rose from 19,000 to 86,000, yielding income of more than \$10 million; 1,000 village banks were founded; and 50,000 social projects were planned and carried out on self initiative (PACT Nepal, n.d.).

- People’s literacy skills vary greatly. There is tremendous variability in people’s literacy skills (reading, writing, numeracy, and speaking) and in their spoken language abilities. These skills can change over one’s lifetime. Variation in literacy abilities is related to many factors, including education, socioeconomic status, culture, speech community, health status (such as sight and hearing impairments), cognitive and mental capacities, and relevance and motivation.

- Literacy is dynamic; it evolves. Over a lifetime, we can acquire literacy abilities to meet life’s changing circumstances. Take,

for example, the high school dropout who learns to read when 33 years old and is able to get a job not obtainable beforehand; the midlife mother who returns to the workforce and learns how to do a sales presentation using PowerPoint; or the 70-year-old woman who learns to communicate in chatrooms on the internet and finds an arthritis support group.

Wrapping Up

It is understandable that deficits become most salient when experts of any type need to communicate with nonexperts. In this chapter, we have introduced a discussion of the consequences of low health literacy in the United States. Low health literacy is an important public health issue that, if addressed, will greatly contribute to the health, safety, and well-being of millions of people.

In the next chapter, we briefly review the history of health education and promotion over the past century in the United States. The growing emphasis on health literacy has evolved from a long history of both successful and unsuccessful strategies of health promotion and health education. This historical lens will help the reader as subsequent chapters develop our model of health literacy.

Exercises

1. Choose a health situation appropriate to your practice or profession. List the types of decisions your patients or the public are asked to make in regard to this situation. Now list the types of skills that they need in order to make these decisions.
2. Choose a print communication (brochure, handout, fact sheet, ad, patient worksheet) that you use with patients or the public. Make two lists: one of elements that you believe your patient or other recipient would find easy

to read and use, the other containing elements that would be hard to read and use. Explain how you would address the complexity.

3. Discuss the opportunities and obstacles to enhancing shared decision making among patients and publics.

