
Library outreach: overcoming health literacy challenges*

By Ruth Parker MD, FACP
rpark01@emory.edu
Professor

Emory University School of Medicine
Mailstop 1480/002/1AA
Atlanta, Georgia 30322

Gary L. Kreps, PhD
gkreps@gmu.edu
Eileen and Steve Mandell Endowed Chair in Health Communication and
Professor and Chair

Department of Communication
George Mason University
Thompson Hall 206
MSN 3D6
Fairfax, Virginia 22030

Objective: This paper examines the powerful influences of consumer health literacy on access to and use of relevant health information.

Method: The paper describes how widespread problems with health literacy significantly limit effective dissemination of relevant health information in society, especially to many vulnerable populations where health literacy challenges are especially pervasive.

Results: The paper examines strengths and weaknesses of different programs for addressing health literacy problems, including educational programs, message design programs, and strategic communication training and intervention programs.

Implications: The paper evaluates strategies that can be implemented throughout the modern health care system to address problems of health literacy by improving health information access, processing, and understanding. It concludes by examining several strategies that libraries can adopt to overcome many health literacy challenges.

We depend on relevant health information to promote our own health and the health of others; we need relevant health information to make the best decisions about avoiding health risks, detecting and diagnosing health problems, and seeking the best available health care services [1, 2]. Yet widespread problems with health literacy significantly limit effective dissemination and understanding of relevant health information in society, especially among many vulnerable populations where health literacy challenges are especially pervasive [3, 4].

According to a major report by the Institute of Medicine (IOM), *Health Literacy: A Prescription to End Confusion*, nearly half of all American adults, about ninety million people, have difficulty understanding and us-

ing health information, leading to a higher rate of hospitalization and use of emergency services among patients with limited health literacy [5]. Limited health literacy may lead to billions of dollars in avoidable health care costs; this is a direct challenge to the ability to communicate relevant health information to those who most need such information: health care consumers, providers, and caregivers.

Health literacy refers broadly to the ability to understand health information, including the use of reading, writing, listening, speaking, arithmetic, and conceptual knowledge [5]. Health literacy has been defined as the ability to obtain, process, and understand basic information and services needed to make appropriate decisions regarding health [6]. Addressing health literacy by enabling patients to understand and act in their own interest, is a final, yet neglected, pathway to improved quality care in our country [7]. Efforts to reduce disparities in health, decrease cost, and

* This paper is based on a presentation at the "Symposium on Community-based Health Information Outreach"; National Library of Medicine, Bethesda, Maryland; December 3, 2004.

enhance the quality of care will not succeed unless the health literacy needs of people are met at the same time [8]. It is the authors' contention that a great deal can be done throughout the modern health care system to address problems of health literacy by improving health information access, processing, and understanding. This paper will examine several strategies that libraries can adopt to help address and overcome many health literacy challenges.

RESPONDING TO HEALTH LITERACY PROBLEMS

There are many different paths for addressing health literacy problems. Each path has its own strengths and weaknesses, and it may take a combination of strategies to address the complexities of overcoming health literacy effectively. A review of interventions can help libraries develop integrated models for outreach to address health literacy challenges.

Health literacy educational programs

A traditional strategy for addressing health literacy problems has focused on developing educational programs to help increase the literacy levels of health care consumers. Schools, colleges, hospitals, clinics, and libraries are just some of the institutions that can offer educational programs to increase public health literacy levels. These programs can be offered as topical seminars, as credit or noncredit courses, and as a part of distance education programs.

The US kindergarten through twelfth grade educational system offers a site for interventions to improve general literacy and health literacy. The recent IOM report on health literacy reviewed current programs and opportunities in education and found that there are currently significant obstacles and barriers to successful health literacy in kindergarten through twelfth grade education programs. Adult education programs hold opportunities for implementation of programs to improve health literacy and provide promising models. For example, MedlinePlus has been linked to the Health & Literacy Special Collection <<http://www.worlded.org/us/health/lincs/>>, a Website designed to support adult basic literacy and health literacy education. The IOM report also notes that health providers receive little training and education to develop their skills in improving health literacy [5].

While educational programs to help consumers improve their reading, numeracy, writing, speaking, and listening skills can improve literacy levels, these programs have some limitations, too. One limitation is the long-term nature of these educational programs. Consumer education programs often take a long time to improve literacy and health literacy levels, and they are not very helpful to consumers at the moment when they most need relevant information to address current health problems. In addition, more than 300 published studies indicate that most patient and health information materials far exceed the reading ability of most US adults [5].

Another limitation to many consumer health literacy educational programs is that they focus solely on reading, writing, speaking, and listening skills and not on the larger set of communication strategies consumers need to get the most out of the modern health care system [9, 10]. Educational programs can help consumers develop the functional abilities to gather relevant health information, interpret health information, engage in meaningful deliberations with their health care providers, and explain their symptoms and health experiences clearly. Moreover, educational programs must be tailored to the needs of consumers and patients to learn how to negotiate and navigate the many complexities and bureaucracies of the modern health care system; to learn essential skills for self-management of chronic conditions; and to learn how to communicate about their health needs for acute, chronic, and preventive care. A good example of an educational program that provides training for functional health literacy is the Virginia Adult Education Health Literacy Toolkit <<http://www.aelweb.vcu.edu/publications/healthlit/sections/b/1/>>. Another variation of health literacy educational programs discussed later in this paper is strategic communication training, where health care system participants are taught to develop adaptive and culturally sensitive communication skills to overcome health literacy challenges.

Culture gives meaning to health communication and provides the context for understanding health information [5]. Health literacy education programs must be developed to reflect the unique contexts of language and culture. For example, to be effective, communication tools for health education programs targeted at Korean-American immigrants should employ language and examples that are familiar to members of this cultural group; this will make the programs easy to understand and memorable. Use of the same language and examples in health education programs for Chinese-American immigrants is not likely to work as well, because the messages designed for Korean-American immigrants are not likely to match the cultural expectations and experiences of Chinese-American immigrant audience.

Another major challenge faced by consumer literacy education programs is that they generally only address one of the multiple audiences affected by health literacy problems. Educational programs also need to be developed and implemented to help health care providers and caregivers cope with health literacy problems. Educational programs for doctors, nurses, and other health care providers can help train these professionals to communicate effectively with consumers who have low literacy, to seek feedback from consumers to determine how well they understand relevant health information, and to develop strategies for vividly explaining complex terms and procedures. Informal caregivers, such as family members, also need help through education to increase their understanding of relevant health information.

Message design programs

Another often-used health literacy intervention strategy involves the design and redesign of health communication materials (pamphlets, instruction guides, package inserts, Websites, and so on) to promote understanding. Typically, this involves translating complex terms and medical jargon into more easily understood terms, phrases, and simple sentences. Charts, diagrams, and photographs are often used to help explain complex health procedures and to illustrate anatomical and biological processes. State and federal government programs, such as the National Institutes of Health's "Plain Language Initiative," have been developed to encourage the design and production of documents, posters, pamphlets, and Websites that are easy to understand <<http://execsec.od.nih.gov/plainlang/>>: "The Plain Language Initiative requires the use of plain language in all new documents written for the public, other government entities and fellow workers. Writing that is clear and to the point helps improve communication between the government and the public" <<http://science-education.nih.gov/WebPages.nsf/WebPages/The+Plain+Language+Initiative>>. Similarly, the California Health Literacy Initiative Website provides information and support for the use of plain language in communicating with health care consumers <<http://cahealthliteracy.org/healthliteracylinks.html>>.

The use of plain language message design programs has some limitations. One potential problem is the static nature of message redesign. That is, once produced, plain language documents are often used with audiences with differing literacy levels; they cannot match the language use level of all audiences. Because health care consumers, providers, and caregivers are likely to represent a range of different health literacy abilities, it is best to employ the simplest possible use of plain language for documents. Research has demonstrated that simplifying written health information alone, while necessary, is not sufficient for ensuring that all people understand the information they need for taking care of their health. The IOM report on health literacy recommends engaging consumers in developing health communications and incorporating their insights into health messages.

A variation of the message design strategy for non-native speakers of English is to translate health information documents and materials into other languages. This process is tricky because the English language, especially technical language concerning complex medical topics, does not always translate very well into other languages, sometimes resulting in misrepresentations and misunderstanding. Furthermore, there are often different dialects of foreign languages, and translators must take the dialects and idioms used by nonnative speakers into account. Translating documents is also complicated by the sheer numbers of different languages used by participants in the modern health care system. For example, a Northern Virginia hospital chain, the Inova Health Care System,

recently estimated that it needed translation services for health care consumers speaking forty different languages. It is a tremendous and expensive challenge to translate health communication materials into a range of different languages, and meaning can be lost in translation. Yet language is important for both access to and quality of care, and promising approaches, such as the use of bilingual hospital employees as interpreters, can be used to improve access to health information for consumers who are not native English speakers [11].

Strategic communication training and intervention programs

Health information providers need to learn how to evaluate the literacy levels of those they interact with and to use this information to develop messages these audiences can understand. This also involves increasing providers' sensitivity to how anxious and ashamed many people are about having difficulty understanding health messages [2, 12]. Health information systems need to help create a culture where communication strategies are routinely adapted to match the literacy levels of unique audiences. Help should be routinely offered in interpreting complex health messages, as well as for completing important documents [2].

Practitioners should also consider using nonwritten materials to convey important information to patients with limited health literacy. Even patients who read well often prefer nonwritten materials, including straightforward picture books, videotapes, audiotapes, or multimedia presentations. When written materials are required, they should use plain language at the fifth-grade level or lower. Health educators stress that people of all literacy levels prefer materials that are simple and easy to understand. Because many standard patient education materials are written at a high school or college level, they are often inaccessible to patients.

During clinical encounters, health practitioners need to make their communication "fit" their patients' actual level of health literacy [12]. A few basic techniques are to use simple language, to slow down, and to include important family members in discussions. Both clinicians and health educators often inadvertently hinder communication by providing too much complex background information that has little to do with what patients need to know about how to care for themselves. Instead, more needs to be done to ensure real patient understanding, a key ingredient in adequate health literacy. Health educators advocate a "teach back" or "show me" approach. Providers can demonstrate to patients a desired skill (for example, checking a blood glucose level or using an inhaler) rather than asking patients to read about the skill. Then, they ask the patient to demonstrate the skill to ensure they have understood. To help make patients feel more comfortable about being "tested," they try asking the patient to teach back what was just explained so practitioners can judge their abilities as

teachers. For example, "Could you now tell me or show me what I just went over with you? I need to see how well I did explaining this to you. This is important so we both feel you'll know how to take care of yourself at home."

Some patients with health literacy problems may use "surrogate" readers to help them understand what they need to do. Surrogates may be family members, close friends, or sometimes a neighbor. Often these important caretakers are not present when the provider gives critical health education. An environment that promotes a culture of health literacy ensures that surrogate readers for patients with health literacy difficulties are included in conversations about health education and instructions for self-care.

To promote and provide the best possible care for patients requires real communication, not just "words." Providing high-quality care to patients with health literacy problems does require spending time on patient education. The "information-giving" time that patients value so much is shrinking in practice settings that increasingly seem to equate time with money. Adequately addressing the health literacy needs of all patients is a virtuous task, and one that will indeed require partnerships with patients (the real experts on health literacy) and all of those concerned with health.

IMPLICATIONS FOR LIBRARY OUTREACH

Consumers frequently ask public librarians health questions. Those who enter the library with health questions are motivated to learn more, and library staff are trained to help library users search for and obtain useful information. However, library staff members, like health professionals and health providers, lack adequate training in understanding the health literacy of library patrons. Library staff members need training and ongoing support and education so that they can provide health information requested by patrons. Local community libraries can work to identify their patrons' particular health information needs and the barriers that are preventing them from meeting those needs. The libraries can then develop approaches that are responsive to the identified cultural and content needs. The IOM report notes examples of partnerships. For example,

[T]he Santa Clara (California) Medical Center, Santa Clara County Library, and Plane Tree Health Library have partnered since 2001 to operate a center for health literacy on the Medical Center campus. The community learning center provides information on a variety of medical topics and conditions in English, Spanish, and Vietnamese in a variety of formats (print, audio, and video) with a focus on easy-to-read materials. The Medical Center provides space readily accessible to patients, the Plane Tree Library provides supervision and expertise in resource development, and the Santa Clara Library recruits adult literacy students to visit the Center and provide literacy support to patrons referred by health care providers. [5, p. 225]

Increasingly, consumers seek health information on

the Internet, and competing sources of Web-based health information present a daunting challenge to those who use the Internet. Recently, the American College of Physicians Foundation and the National Library of Medicine created the Information Prescription Project to enable physicians to provide their adult patients with MedlinePlus customized uniform resource locators (URLs) for health education materials that are authoritative, user-friendly, and commercial free <<http://foundation.acponline.org/healthcom/info.rx.htm>>. After initial pilot testing in two states, the project was launched on a national scale in 2004. Collaborative efforts like this one between librarians and practicing physicians offer opportunities to link "information giving" with "information seeking."

Health literacy is a complex issue, and improvements in health literacy require a variety of approaches. Health literacy not only involves the communication skills and abilities of health care consumers to understand spoken, written, and mass-mediated communication about health and health care, but it also involves the communication skills and predispositions of a broad range of health care providers and information sources and the support of the larger health care system in promoting effective health communication. Moreover, effective health communication is interactive and adaptive, utilizing many different channels of communication and operating across a number of different contexts. To address current problems of health literacy effectively, the multiple interdependent dimensions of this complex issue have to be addressed. This means developing sophisticated multi-dimensional approaches and creating interdisciplinary partnerships to address the many problems associated with health literacy in the modern health care system. Ninety million Americans have difficulty understanding and acting on health information. To treat this silent epidemic, efforts are needed to strengthen skills and coping strategies for consumers and providers. Partnerships between different health information specialists, health care providers, and consumers who desperately need relevant health information can help overcome the many problems related to health literacy. Library professionals have a unique opportunity to help overcome health literacy challenges by developing new and effective communication strategies for disseminating relevant health information to audiences with differing levels of health literacy.

REFERENCES

1. KREPS GL. The pervasive role of information in health and health care: implications for health communication policy. In: Anderson J, ed. Communication yearbook 11. Newbury Park, CA: Sage, 1988:238-76.
2. PARKER R. Health literacy: a challenge for American patients and their health care providers. *Health Promot Int* 2000 Dec 1;15(4):277-83.
3. CHANG BL, BAKKEN S, BROWN SS, HOUSTON TK, KREPS GL, KUKAFKA R, SAFRAN C, STAVRI PZ. Bridging the digital divide: reaching vulnerable populations. *J Am Med Inform Assoc* 2004 Nov-Dec;11(6):448-57.

4. KREPS GL. Enhancing access to relevant health information. In: Carveth R, Kretchmer SB, Schuler D, eds. *Proceedings of Shaping the Network Society: Patterns for Participation, Action and Change*; 16–19 May 2002. Seattle, WA: CPSR, 2002:149–52.
5. NIELSEN-BOHLMAN L, PANZER AM, KINDIG DA, EDS. *Health literacy: a prescription to end confusion*. Washington, DC: The National Academies Press, 2004.
6. NATIONAL LIBRARY OF MEDICINE. *Current bibliographies in medicine: health literacy*. [Web Document]. Bethesda, MD: National Library of Medicine, 2000. [accessed 10 Feb 2005]. <<http://www.nlm.nih.gov/pubs/cbm/hliteracy.html>>
7. FINEBERG HV. Foreword. In: Nielsen-Bohlman L, ed. *Health literacy: a prescription to end confusion*. Washington, DC: The National Academies Press, 2004:xi–xii.
8. KINDIG DA. Preface. In: Nielsen-Bohlman L, ed. *Health literacy: a prescription to end confusion*. Washington, DC: The National Academies Press, 2004:xiii–xiv.
9. CEGALA DJ. Patient communication skills training: a review with implications for cancer patients. *Patient Educ Couns* 2003 May;50(1):91–4.
10. JONES JA, KREPS GL, PHILLIPS GM. *Communicating with your doctor: getting the most out of health care*. Cresskill, NJ: Hampton Press, 1995.
11. MORSE A. *Language access: helping non-English speakers navigate health and human services*. Denver, CO: National Conference of State Legislatures' Children's Policy Initiative, 2003.
12. PARKER RM, DAVIS TC, WILLIAMS MV. Patients with limited health literacy. In: Bateman WB, Kramer EJ, eds. *Patient and family education in managed care and beyond: seizing the teachable moment*. New York, NY: Springer, 1999:63–71.

Received April 2005; accepted May 2005