

HEALTH LITERACY: CHALLENGES AND IMPLICATIONS FOR CONSUMER HEALTH LIBRARIANS

by Elizabeth Orban



In recent years libraries have experienced a bigger demand from the general public for accessible and reliable health information sources and services. Not only have public libraries been responding to the growing needs of America's health-conscious consumers, but many academic and hospital libraries have responded as well, opening their doors to worried patients and inquisitive community members in search of valuable, even life-saving, medical information. Extending health information services to the layperson involves unique challenges that all librarians must recognize and address if they are to effectively meet the diverse information needs of today's health consumer. Because consumers may rely on the health information they obtain from libraries to make important decisions regarding their personal well-being, it is imperative that the librarians responsible for selecting and disseminating consumer health information are mindful of the far-reaching implications of their services. This paper will explore some of the most important issues involved in providing patrons with consumer health information, and, more importantly, offer practical strategies for managing these issues.

One issue in particular warrants special consideration and is perhaps the biggest challenge that consumer health librarians now confront. Health literacy, defined 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," has received increased attention in recent years as a public policy issue impacting the health of millions of Americans (HHS, 2000). Alarming reports of pervasive health illiteracy and its adverse effects on health outcomes have inspired changes in the ways many health care professionals approach patient care and patient education. So too should librarians work to increase awareness of this issue in their own field and adapt to meet the special health information needs of the many patrons with inadequate health literacy skills. Furthermore, librarians have a professional obligation, albeit a daunting one, to promote health information literacy to all library users, so that

more Americans have "the ability to recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions" (MLA, 2003).

The role of the librarian in providing health information to the layperson has expanded in recent years. The concept of teaching health information literacy to library users is an even newer phenomenon. Both of these modern trends are due to the indisputable fact that patients are now expected to assume more responsibility for their own health care and therefore need to access information relevant to their personal health concerns. Some critics blame managed care or current office practices for this shift in patient responsibility, claiming shorter office visits leave less time for patients to ask their doctor pertinent questions (Chobot, 2000). As a result, patients turn to the library for answers to their questions.

Chronic disease is another significant factor that has "dramatically transformed the role of the patient." Over the past fifty years chronic disease has replaced acute disease as the dominant health problem in America. Chronic illnesses are the main reason people seek health services, and they account for 78% of all health expenditures (Holman, 2004). Furthermore, the management of chronic diseases has become increasingly complicated for patients. "Because the patient must usually engage in unending treatment, make behavior changes, and adjust to consequences of the disease, the patient inevitably becomes a principal caretaker" (Holman, 2004). Therefore, patients must have accurate information and the skills to make use of that information if they are to understand their illness, monitor symptoms, and manage their conditions. Again, librarians play an important role in providing much-needed information to people with chronic conditions. However, poor health literacy may actually be preventing many individuals from comprehending and acting on the information they receive. This is precisely why librarians must become more sensitive to

the current health literacy crisis and work to better serve the consumer health information needs of a diverse population.

The widespread deficiency in general literacy skills among Americans has been well documented in recent years, but the more specific problem of health literacy — or the lack thereof — has been slow to make its way into the headlines. The 1992 National Adult Literacy Survey (NALS) found that an estimated 40-44 million Americans, or approximately 22% of the adult population, are functionally illiterate. Another 50 million Americans, or roughly 26%, have only marginal literacy skills. All told, nearly 90 million people, or about half of the adult population, demonstrate basic deficiencies in reading, computational skills, or English (Kirsch et al., 1993).

Though the 1992 NALS survey measured only traditional literacy skills, that is, basic reading and writing proficiency, it led to a startling question about health literacy as well. If so many individuals are unable to perform the basic literacy functions necessary to meet the demands of everyday life, is it also likely that these individuals are incapable of performing the more complex task of comprehending medical information? To answer this question, the National Center for Education Statistics repeated its national literacy survey in 2003. Now called the National Assessment of Adult Literacy (NAAL), the new survey included for the first time a separate Health Literacy Component (HLC), consisting of 28 health-related questions aimed at measuring participants' knowledge and skills in locating and understanding medical information and services. It was the first ever national assessment designed specifically to measure health literacy, and the much-anticipated results were published in the summer of 2005 (White, 2004).

It seems likely that the 2005 NAAL findings will confirm what other recent reports have declared. In 2004, a landmark report by the Institute of Medicine (IOM) claimed, "Nearly half of all American adults — 90 million people — have difficulty understanding and using health information" (Institute of Medicine, 2004). The Agency for Healthcare Research and Quality (AHRQ) released a similar statement this year acknowledging, "For the 90 million Americans with limited literacy skills, it's tough to read the front page of a newspaper or a bus schedule, much less the complicated documents that go along with being a patient in our country today" (AHRQ, 2004). In spite of the growing number of reports such as these, many health care professionals are still unaware of the health illiteracy problem or are ill-prepared to effectively handle low-literacy patient (Parker, 2000).

Many library professionals are likely just as uninformed or uncomfortable about low-literacy library

patrons. Though professional organizations such as the Medical Library Association and its Consumer and Patient Health Information Section (CAPHIS) have begun to address health literacy issues in recent years, a 2004 survey of North Carolina public libraries found that public librarians are only "moderately comfortable" answering consumer health questions. While the librarians taking part in the survey expressed interest in receiving additional training for handling consumer health requests, the results of the survey indicated that "the interests and training needs of public librarians for assisting the public in accessing health information have not been addressed" (Linnan, 2004).

Addressing health illiteracy is an enormous and complicated endeavor. Fortunately there is a growing movement to increase awareness of the health literacy problem and decrease its harmful effects on society. Though the issue is receiving more exposure in the library and information science literature, most of the data to this point regarding health illiteracy and proposed strategies for dealing with it has appeared in the biomedical literature. Nevertheless, library and information professionals can certainly benefit from the same information used by physicians and other health care workers, and apply much of it to their own work environments.

One of the most challenging aspects of the health literacy problem for both librarians and physicians is knowing how to identify someone with poor health literacy. As one practitioner wrote, identifying patients with health literacy problems is difficult because "you can't tell by looking" (Parker, 1999). Though studies have indicated a higher rate of illiteracy and health illiteracy among specific groups of people — the elderly, the poor, ethnic minorities — health literacy problems affect people from all backgrounds, so no assumptions can or should be made about an individual's literacy skills based on age, race, or other superficial characteristic (Kirsch, 1993).

Likewise, no assumptions should be made about an individual's health literacy based on his educational achievement. The 1992 National Adult Literacy Survey reported that the average educational attainment of adults in the United States is above the twelfth grade level (Kirsch, 1993). However, the average reading level of adults in the United States is reported to be only between the eighth and ninth grade levels (Stedman, 1991). Furthermore, many adults may read four to five grade levels below their stated level of education (Davis, 1990). Clearly, education level does not necessarily translate to a similar reading level. Academic librarians can especially benefit from this information and should be careful not to assume that most college students easily comprehend twelfth grade health information sources. Even well-educated people with

seemingly strong reading skills may have trouble comprehending complex health information, because “literacy skills are context and setting specific.” That is, an individual may have adequate understanding in one content area because the material is familiar, but struggle to comprehend information in another content area if the vocabulary and concepts are unfamiliar (Parker, 2000).

Many people with low health literacy do not even recognize that they have a problem. Others are too ashamed to admit their inadequacy. Either of these circumstances further complicates the already difficult task of identifying low-literacy patrons. A pioneering study on the relationship between low health literacy and shame revealed that 67% of low-literacy patients had never revealed their problem to their spouse, and 19% never told anyone (Parikh, 1996). Undoubtedly, the “social stigma” associated with illiteracy creates feelings of inadequacy and poor self-esteem, compelling those who recognize their problem to remain silent. Therefore, library professionals should not expect low-literacy library users to disclose their special needs.

The Center for Health Care Strategies advises health care providers to create a “shame-free” environment so that low-literate patients can seek help without intimidation (CHCS, 1998). Librarians should strive to provide the same approachable service so that “patrons feel comfortable in a situation that may be perceived as intimidating, risky, confusing, and overwhelming” (RUSA, 2004). Approachability is not a unique requirement of consumer health reference services. In fact, it is one of many guidelines established for all reference and information services. The Reference and User Services Association (RUSA), a division of the American Library Association, has established “Guidelines for Behavioral Performance of Reference and Information Service Providers” as well as “Guidelines for Medical, Legal, and Business Responses.” Librarians providing consumer health information services should familiarize themselves with both of these documents and adhere to their directives when helping all patrons, especially those with special needs.

As patrons with special needs may be less capable of comprehending the medical information provided to them by a librarian, they may be more inclined to ask the librarian for help interpreting or clarifying the information. The RUSA guidelines allow librarians to “advise users regarding the relative merits of sources ... and make recommendations regarding library materials when appropriate” (RUSA, 2001). However, librarians must be careful not to overstep their professional and ethical bounds by providing too much assistance to special needs patrons. Though librarians are skilled in “identifying and providing information, they are not

practicing health professionals who interpret information and give advice” (CAPHIS, 1996). No matter how innocent the patron request might be, librarians must avoid professional malpractice and resist the temptation to practice medicine without a license. The National Network of Libraries of Medicine offers consumer health librarians some of the best practical advice for avoiding malpractice in their online manual, *Ethics and the Consumer Health Librarian*, available at www.nlm.nih.gov/scr/conhlth/ethics.htm.

Unfortunately, practical advice for assessing the literacy level of consumer health patrons is not so readily available. In fact, no such assessment instrument exists for use by librarians, with the possible exception of the well-conducted reference interview. But with the unpredictable nature of human interaction, the reference interview is often not as effective as librarians would like it to be when ascertaining the special needs of the patron. A more consistent means of evaluation would be welcome.

Though no “gold standard” exists for measuring health literacy, there are multiple instruments available to physicians for assessing patient literacy in the clinical setting (Parker, 2000). Regrettably, they are not feasible in the library environment. One of the most popular and accurate assessment methods used today is the Rapid Estimate of Adult Literacy in Medicine (REALM). This word recognition test measures a patient’s ability to read from a list of increasingly more difficult medical terms. It is simple to use and can be completed in five minutes or less (Parker, 2000). Despite the relative simplicity of administering REALM in a doctor’s office or research study, it would not be practical at the library reference desk. The idea of completing a short medical terminology quiz before receiving reference services would surely embarrass or offend many patrons. Health care providers also cite the potential for patient embarrassment, as well as apprehension regarding confidentiality, as obstacles to routine literacy screening. Thus, health care professionals would also appreciate a quicker, easier-to-use screening instrument.

One recent attempt to develop an alternative to existing literacy screenings led to a favorable outcome and promising implications. Doctor Lisa D. Chew and colleagues used three carefully chosen oral questions during the course of interviewing patients to detect the patients’ inadequate health literacy (Chew, 2004). While the use of this brief and less embarrassing method is promising for librarians, the questions and response choices must be made simple for both the patron to understand and the librarian to ask. Two of the three questions used in the Chew study were written at the college level, which could be too difficult for many patrons to understand. Simplifying the

questions would lead to more meaningful answers from patrons, and thus a more reliable measure of their literacy.

Health literacy research must move beyond assessing the problem of health illiteracy to offering feasible solutions. Some practical advice for librarians already exists in the literature. Again, much of this literature was written for health care providers, but librarians can benefit from it as well. First, in the absence of any true method for analyzing the literacy of library patrons, the next best strategy is to assess the readability of library materials — both in print and online — and provide information at multiple reading levels and in different formats. The goal should be to meet the needs of as many library users as possible, so this means allowing for diverse literacy levels and various learning styles. Providing patrons with several different information options allows them to make the best choice for their needs without the embarrassment of asking specifically for low-literacy materials.

Most written health materials are written at the tenth grade reading level or above. Studies have also found the reading level of most health-related web sites to be at the tenth grade level or higher (Schloman, 2004). This means most of these materials are too complex for a majority of the population. The National Work Group on Literacy and Health recommends health materials be written at a 5th grade readability level, which is actually still too difficult for about one-fourth of the population. Though there are conflicting opinions, most experts believe that all readers, regardless of their literacy level, appreciate written materials that are simple and attractive (CHCS, 1998). Including such easy-to-read consumer health materials in any library is a good idea, as is including something more advanced for those readers who want more in-depth information. Most people, even good readers, use visual clues to reinforce learning (CHCS, 1998), so non-print media can be a very effective way of providing health information to those with low functional literacy. Pictures, videotapes, audiotapes, or interactive multimedia may allow patrons to learn what they might not have learned with traditional print materials.

Assessing patron literacy levels and providing appropriate information materials is only part of the role librarians must play in providing consumer health information in today's complex world. There is a need for further research into the complicated issue of functional health illiteracy, so that librarians can become more aware of the problem and how to address it. By doing so, they can better serve the special needs of all health consumers and help enable them to make better choices about their own health care.

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