

Promoting Individual and Community Health at the Library



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Introduction

A library is a place that is a repository of information and gives every citizen equal access to it. That includes health information.

And mental health information. It's a community space.

It's a place of safety, a haven from the world.

—Neil Gaiman

THE INFORMATION AGE HAS USHERED IN A LEVEL OF EXPECTATION for volumes and quality of information unimaginable in any previous era. In spite of most Americans having smartphones and Internet access, recent decades have recorded increased usage of public libraries, with millions of people per year using their local libraries for health information. Many libraries have dramatically stepped up their provision of health information in order to meet these demands and patron expectations. This volume covers the strategies used by libraries to improve people's access to and use of health information, whether to address an individual's acute information need, to improve the community's ability to understand health information, or in some cases to lead programs and efforts to improve people's health.

In communities throughout the world, public libraries offer all types of support beyond access to books and information. From citizenship classes to early literacy initiatives to maker spaces to wide arrays of program provision, libraries provide not only resources and space; they are full of opportunities that support individual fulfillment and community progress. As longtime literacy providers and advocates, public libraries are expanding services to incorporate all types of literacies, such as

financial and digital literacy. Because they provide access to health information in a variety of ways, health literacy is yet another area where public libraries can offer support for individuals and communities.

Health Literacy

From their inception, public libraries have served as venues for all types of literacy activities and instruction. As educational organizations, they have a long history of supporting lifelong learning; libraries provide classes, tutoring, and individual training. Much of the programming in libraries is centered on literacy, such as storytime programs, book discussion groups, and summer reading programs. Many libraries also provide outreach to organizations such as Head Start and local day care centers, extending their influence and literacy training beyond the library's walls and into the community.

Literacy is not only restricted to a person's ability to read; there are other types of literacies that contribute to an individual's capacity to function. These can include information, digital, computer, technology, media, cultural, multicultural, visual, and financial literacy. Another type of literacy has a significant impact on individuals' well-being—health literacy. The unique aspects of health information contribute to the challenges related to health literacy, however. Medical science progresses rapidly, and health information can overwhelm even persons with advanced literacy skills. In addition, what has been learned often becomes outdated or forgotten, or is incomplete. Health information can be misrepresented or misunderstood, and is often provided in a stressful or unfamiliar situation, and so is difficult to retain.

Health Literacy Defined

Ratzan and Parker (2004) developed the definition of health literacy adopted for use by the U.S. Department of Health and Human Services for *Healthy People 2010*: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services to make appropriate health decisions" (Institute of Medicine, 2004, 4). This and other early definitions of health literacy set the stage for

studying the concept, but they have been characterized as somewhat limited in that they were focused on individual skills (Six-Means, 2017). Over time, the definition of health literacy has been extended to include health care personnel and expanded to include abilities, such as to communicate and use information (Centre for Literacy); in addition, shared responsibility for health literacy has been ascribed to clinicians, institutions, and health care systems (Koh and Rudd, 2015).

In 2012, a systematic review of the health literacy field was conducted in which researchers identified 17 definitions of health literacy and 12 conceptual frameworks (Sorensen et al., 2012). These were integrated to provide the following definition which points to the centrality of health information: “Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” (Sorensen et al., 2012). The U.S. Department of Health and Human Services (2017) now states: “The primary responsibility for improving health literacy lies with public health professionals and the healthcare and public health systems. We must work together to ensure that health information and services can be understood and used by all Americans. We must engage in skill building with healthcare consumers and health professionals. Adult educators can be productive partners in reaching adults with limited literacy skills.” This description of health literacy points to a responsibility for those who work in the information field, namely librarians, to embrace their role in health literacy promotion, not only in health care systems, but in the community as well (Six-Means, 2017).

Background

Health literacy requires a basic knowledge of health topics. People with limited health literacy often lack such knowledge or have misinformation about the body and the nature and causes of disease, and they may not understand the relationship between lifestyle factors (e.g., diet and exercise) and various health outcomes. Health literacy also requires or includes numeracy skills for things such as interpreting tests results,

calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels. In addition, choosing between health plans and comparing prescription drug coverage requires numeracy skills for calculating premiums, co-pays, and deductibles.

Although more than 90 million American adults have low health literacy, the health effects of low literacy and illiteracy have been referred to as “the silent epidemic” (Marcus, 2006, 339). Only 12 percent of adults have proficient health literacy, which means that approximately 9 out of 10 adults may lack the necessary skills to manage their health and prevent disease. Thirty million people (14 percent of adults) lack even basic health literacy. These adults are more likely to report their health as poor (42 percent), and are more likely to lack health insurance (28 percent) than adults with proficient health literacy (Kutner, Greenberg, Jin, and Paulsen, 2006).

According to the U.S. Department of Health and Human Services, health literacy is dependent not only on individual factors, but on systemic factors in health care as well. These include:

- Communication skills of lay persons and professionals
- Lay and professional knowledge of health topics
- Culture
- Demands of the health care and public health systems
- Demands of the situation/context

Low health literacy can affect people’s ability to navigate the health care system, such as locating providers or services and filling out complex forms. It may also make it difficult to share personal information (e.g., health history) with providers, to engage in self-care and chronic-disease management, and to apply the mathematical concepts that are needed to understand probability and risk. The population groups who are at higher risk for low health literacy include

- Older adults
- Racial and ethnic minorities
- People with less than a high school degree or GED certificate
- People with low income levels
- Nonnative speakers of English

- People with compromised health status
- Rural populations

Costs of Low Health Literacy

Nearly half of all Americans are estimated to be functionally illiterate in terms of dealing with health care issues (Dickenson et al., 2014). In the United States, the cost of not meeting health literacy needs is estimated to be between \$106 and \$238 billion annually, or between 7 and 17 percent of all personal health care expenditures (Vernon, Trujillo, Rosenbaum, and DeBuono, 2007). Low literacy has been linked to higher hospitalization rates and less frequent use of preventive services; both of these are associated with higher health care costs. The costs are not just monetary, however; low health literacy skills often lead to poor health consequences. Patients with low literacy are 1.5 to 3 times more likely to experience a poor outcome, as determined by morbidity measures, intermediate disease markers, health resource utilization, and general health status (DeWalt et al., 2004).

Elderly individuals with lower health literacy comprehension are more likely to have poorer mental and physical health. Inadequate health literacy in this population has also been linked to higher risk-adjusted rates of cardiovascular death and an increased risk of hospital admission as well (Baker et al., 2002; Baker, Parker, and Williams, 1998; Baker et al., 2007). Besides poor health outcomes, low literacy affects compliance and self-care capability. Numerous examples in the medical literature outline the negative effects of inadequate literacy. Low levels of the understanding of chronic diseases, such as diabetes and hypertension, have been linked to low literacy. In one study, 94 percent of patients with diabetes and adequate functional health literacy could identify the symptoms of hypoglycemia, compared to only 50 percent of patients with inadequate literacy (Williams, Baker, Parker, and Nurss, 1998). Findings such as these warrant attention, since individuals' misunderstanding or ignoring of early disease signs can result in delayed care, with the consequences of poorer health outcomes and increased costs.

Treatment can also be adversely affected. Among asthma patients, inadequate literacy has been strongly correlated with improper metered-dose inhaler utilization (Williams, Baker, Honig, Lee, and Nowlan, 1998).

Patients with low literacy are often unable to understand prescription drug warning labels as well (Davis, Wolf, and Bass, 2006). Preventive care is another area that can be adversely affected by low literacy levels. In Louisiana, a study of low-income women showed that 39 percent of those with a third-grade reading level did not know what a mammogram was for, as compared to only 12 percent of women with a reading level at or above the ninth grade level (Davis et al., 1996).

Inadequate literacy can produce negative effects at all levels of encounters in the patient-care process. With an increasing emphasis on patient-centered care, individuals with inadequate literacy levels will face increasing challenges. As the adverse consequences of low literacy with regard to health status become better known, the health care community is responding. A relatively easy and cost-effective response is to simplify print materials for patients (Lee, 1999; Wilson, 2000). Tailored educational approaches have also been found to help patients to learn and remember self-management skills in asthma treatment, and to improve outcomes for diabetes management (Paasche-Orlow et al., 2005; Rothman et al., 2004).

EMPOWERING PATRONS

A distraught mother comes to the circulation desk at a small, rural public library in New England. She is checking out books on autism; in fact, it looks like she has most of the books in the collection piled on the counter. She tells the clerk at the desk that she is trying to find a cure for her son's condition; she will do anything to help him. A few weeks later she returns, and optimistically reports that she will no longer need the books. She received an invitation to attend a weekend-long seminar in Utah, where a new cure for autism is being introduced. It is a relatively new therapy, but so far, it looks like it has a 100 percent success rate. The seminar will cost \$25,000, all expenses included. If she takes out a second mortgage, she should be able to swing it. She is worried, though, and before she borrows the money, she would like to know a little more about the new therapy.

The circulation clerk refers her to the reference librarian. When the mother sits down at the reference desk, she explains her quandary. When the librarian asks for more information, the mother hands her the

solicitation she received in the mail. The librarian then goes online to the National Library of Medicine's PubMed website. She explains a bit about the MEDLINE resource and the necessity for using authoritative health information sources, and performs a search on the reported therapy. When she finds no results, she tries finding synonyms, and performs more searches using a wider variety of keywords. She explains that if this therapy was effective, it is highly likely there would be some reports in the medical literature. The mother considers carefully, thanks the librarian, and says rather forlornly, "I guess I won't be making that trip." In the years that followed, it became clear that the solicitation was nothing more than blatant and unethical false advertising. The encounter between the reference librarian and the mother provided the necessary information to save not only money, but time, effort, and inestimable emotional duress.

Role of Librarians

A fundamental component of improving health literacy is the transmission of health information (Nutbeam, 2000). Thus, librarians have a central role to play in addressing this social challenge. No matter the type of setting where a patron may be seeking health information, the librarian's role is to make easily and readily understood information available (Martin and Wathen, 2008). Public libraries have been identified as logical partners in promoting health literacy efforts. Not only do public libraries provide free access and ensure confidentiality, they are also located in almost every neighborhood, and are generally well connected to other community resources. In 2009, approximately 28 million patrons used public library computers for locating information on a variety of health issues, such as specific diseases and medical conditions, medical procedures, diet and nutrition, and finding doctors and health support groups (Becker et al., 2010).

The 2014 Digital Inclusion Survey reports that 58 percent of public libraries help patrons find health information online, close to 60 percent help patrons find health insurance resources, and 48 percent help patrons understand specific health topics (Bertot et al., 2014). At the Libraries for the Future Building Partnerships conference, public libraries were

characterized as gateways to electronic access for the underserved. At that same conference, keynote speaker and literacy expert Rudd (2009) stated: “Libraries are the only public institution that says to its users: ‘we trust you.’ The importance of that philosophy in promoting health literacy—particularly among the underserved—cannot be underestimated.”

Organizations such as the American Library Association (ALA), the Public Library Association (PLA), and the Medical Library Association (MLA) also recognize the potential role librarians can play and are involved in efforts to promote health literacy (American Library Association, 2009; Deutsch, 2017; Hogan-Smith, 2004). The PLA used the opportunity of National Public Health Week in April 2017 to highlight public libraries’ work in advancing health and health literacy. The Health Information Literacy Research Project, an undertaking by the MLA, and funded by the National Library of Medicine, studied the health science librarian’s role as health literacy educator (Shipman and Funk, 2009). These advocacy and study efforts are appropriate steps and indicate recognition in both the medical and public library fields of the importance of engaging in health literacy efforts, and the need for librarians to become involved.

Public libraries already support health literacy in a number of ways, including the provision of free access to the Internet, consumer health collections, native language resources, reference assistance, and training for patrons and community members on how to find authoritative, high-quality health information. Organizations across the country are building coalitions and engaging in outreach activities to improve health literacy in their communities, since community-based educational outreach will be key to addressing this important issue (Pomerantz, Muhammad, Downey, and Kind, 2010; Nutbeam, 2008). Partnerships provide forums for reaching new and larger audiences, sharing resources, creating new tools, expanding services, and increasing funding opportunities (Libraries for the Future, 2009). Given the complexity of issues surrounding health literacy, these efforts will require collaboration not only across disciplines but across institutions as well. It is clear that a national, integrated effort is necessary to determine what strategies and approaches work for communicating health information to patients, no matter what their educational level, reading ability, culture, or language is (Baker, 1999).

Tools

Two federal agencies, the Agency for Healthcare Research and Quality and the Centers for Disease Control and Prevention (CDC), have extensive resources for promoting health literacy. The health literacy sections on both their websites provide information, tools, and links on research, practice, and evaluation. The CDC site also has a section on libraries and health literacy, a list of health literacy activities by state, and provides a weekly health literacy e-mail update. The National Library of Medicine's (NLM) consumer health site, MedlinePlus, also has numerous resources on the topic.

ACRONYMS IN THE HEALTH FIELD

As with most professions and specialties, the health care field is rife with acronyms, a veritable alphabet soup. Table 1.1 includes a sample of some of the agencies and organizations involved in health information and their accompanying abbreviations. It is by no means an exhaustive compilation, but includes organizations that have been referred to in this volume and those that might be referred to by library patrons, or encountered during reference transactions in the public library setting.

TABLE 1.1
Acronyms related to health agencies

ACRONYM	
ACA	Affordable Care Act (shortened from Patient Protection and Affordable Care Act)
AHIP	Academy of Health Information Professionals (MLA)
AHIP	America's Health Insurance Plans
AHRQ	Agency for Healthcare Research and Quality
AMA	American Medical Association
AMIA	American Medical Informatics Association
CAPHIS	Consumer and Patient Health Information Section (MLA)

(cont.)

TABLE 1.1 Acronyms related to health agencies (cont.)

CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services (previously known as Health Care Financing Administration)
DHS	Department of Homeland Security
DHHS	Department of Health and Human Services
DIMRC	Disaster Information Management Research Center (NLM)
FEMA	Federal Emergency Management Agency
IMLS	Institute for Museum and Library Services
IOM	Institute of Medicine (now National Academy of Medicine)
MLA	Medical Library Association
NACCHO	National Association of County and City Health Officials
NAM	National Academy of Medicine (formerly Institute of Medicine)
NCCIH	National Center for Complementary and Integrative Health (NIH)
NCHS	National Center for Health Statistics
NHIS	National Health Interview Survey
NIH	National Institutes of Health (for list of Institutes and Centers of the National Institutes of Health, see nih.gov)
NLM	National Library of Medicine
NN/LM	National Networks of Libraries of Medicine
ONC	Office of the National Coordinator for Health Information Technology
PHS	Public Health Service
WHO	World Health Organization

In a Nutshell

Since public libraries missions' have long been intertwined with literacy promotion, it makes sense for public librarians to become involved in collaborative efforts to improve health literacy. In the words of one health literacy expert, "Improving health literacy in a population involves more than the transmission of health information, although that remains a fundamental task. Helping people to develop confidence to act on that knowledge and the ability to work with and support others will best be achieved

through more personal forms of communication, and through community based educational outreach” (Nutbeam, 2008, 2077). Public libraries are the perfect setting for these empowering interactions to take place.

Besides literacy activities and initiatives, there are countless ways that public libraries are addressing local health challenges. The chapters that follow will address specific aspects of public libraries with regard to individual and community health promotion and efforts. Chapter 2 discusses the role of public libraries and consumer health from a historic perspective. Chapter 3 more specifically addresses health information provision in public libraries and highlights appropriate, trustworthy resources. Chapter 4 describes health programming in the library and offers some examples. Chapter 5 explores how the public library can reach out and engage with the broader community around health initiatives. Chapter 6 talks about future organizational opportunities for public libraries in the arena of community health and resilience. Chapter 7 addresses ethical and cultural sensitivity and discusses opportunities for incorporating and sustaining health initiatives through training and capacity-building.

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