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Health Literacy: A Survey of the Issues and Solutions

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Health literacy has been recognized as a pressing issue in providing good health care and holding down health care costs. This article presents various definitions of health literacy, enumerates the statistics and demographics of this significant global issue, provides a survey of the literature with links to the most authoritative Internet resources, and discusses the role the medical library community must take to address the subject of health literacy, especially as it relates to health care professionals. Selected fundamental online resources and literature on this vital topic are reviewed, with links to relevant sources.

KEYWORDS Consumer health information, health care costs, health literacy, medical jargon, medical libraries, medspeak

INTRODUCTION

Health literacy has been defined by many online sources. ^{1–3} The definition of health literacy has changed fairly radically over the years. Initially, it referred merely to the ability to read health information; however, the definition has expanded to include a much broader set of more subtle factors. The majority of web resources quote *Healthy People 2010* in defining health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make

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appropriate health decisions."⁴ These are the basic cognitive skills that all people need, for instance, to find their way to the right unit in a hospital or other health facility, to fill out medical and insurance forms accurately and completely, to understand specific medical instructions, and to communicate their history and health needs to health care providers. In the same report, the U.S. Department of Health and Human Services included improved consumer health literacy as an objective (Objective 11-2), and identified health literacy as an important component of health communication, medical product safety, and oral health.⁴

BACKGROUND

Health literacy is a relatively recent concept, first appearing in the early 1990s literature on health care. In the last few years, the topic of health literacy has been recognized as an important issue in delivering good health care, and, concomitantly, in stabilizing health care costs.

Recently, there has been a proliferation of online information on the issue of health literacy for many reasons, primary among these being the impact of health literacy on health care costs as well as its effect on patient care. This subject has captured both professional and public interest, since health literacy is considered to be an essential factor in the prevention of disease and the maintenance of good health on a broad scale. In fact, health literacy has now become a viable field of study.

At The Institute for Health Care Advancement's (IHA) 8th Annual Health Literacy Conference, held at the Hyatt Regency Irvine in Irvine, California, in May 2009, Dr. Rima Rudd, ScD, MSPH, of the Harvard School of Public Health, highlighted the emergence of the problem of health literacy. She indicated that there is an ever-widening gap between the literacy demands of our increasingly complex health system and the actual literacy skills of the population, leading to unfortunate consequences in health care inequalities that exist between those with strong and those with weaker skills. She stated that people must be full partners in health decisions in the management of chronic diseases and that this partnership is severely limited by the existence of health disparities. There are more than 1,500 peer-reviewed articles that testify to these disparities, resulting in differences in rates of participation in screening and disease prevention, participation in healthful activities, basic understanding of causes and treatment of diseases, and comprehension of medicines and regimens.⁵

At the same conference, Michael K. Paasche-Orlow, MD, of the Boston University School of Medicine, pointed out that "instruction on dealing with disparities in patients' health literacy needs to be incorporated into the agenda of medical schools. Currently...it is not addressed, so physicians are leaving patient education up to the nurses."⁵

Another IHA Conference speaker, Ariella Herman, PhD, founder of the UCLA/Johnson & Johnson Health Care Institute, stated: "As the field of health literacy matures, it becomes increasingly important to move beyond research and measurement to the development of specific interventions that can be put into place. The field needs to identify some best practices that can be adopted, analyzed, and improved." ⁵

Despite the progress in medical technology in such areas as improved diagnostic tools, surgical procedures, and imaging techniques, and despite the formulation, production, and improved delivery of new pharmaceuticals, unless the patient understands and can comply accurately with directions given by health care professionals, his or her health care will be adversely affected and the cost of medical care will exponentially increase. By improving the public's ability to understand the implications of all aspects of health care, it is hoped that the basic state of health of the general population can also be improved, and if public health is improved, costs of health care will be accordingly reduced.⁶

DEMOGRAPHIC STATISTICS

About one-third of the adult population in the United States has limited health literacy. Although minorities and those who are socioeconomically disadvantaged are disproportionately affected by low health literacy, it is incorrect to assume that they are the only ones with low health literacy skills. As a matter of fact, statistics prove that the majority of those with low health literacy skills in the United States are white, native-born Americans, so the latter group represents the largest segment of the population affected. However, information can overwhelm even people with advanced literacy skills when they are emotionally overwrought, feeling very ill, or when messages about their health are not clearly conveyed by health care professionals.

Limited health literacy can affect an individual's ability to

- Fill out complex medical history forms properly
- Locate appropriate providers and services
- Share personal information such as a detailed health history
- Take care of one's health and practice preventive medicine
- Manage a chronic disease
- Understand how to take medicines accurately and effectively

Low health literacy skills lead to:

- Poorer health knowledge
- Poorer health status
- Higher mortality

- More hospitalizations
- Higher health care costs

The U.S. Department of Education's National Center for Education Statistics conducted the National Assessment Adult Literacy Survey (NAAL) in 2003. This study is important because for the first time a national report was issued that included an evaluation of health literacy of the population of the United States focusing on measuring the skills needed to read, understand, and use health-related information. According to the NAAL study, the populations that struggle the most with health literacy include:

- Elderly (age 65+) Two-thirds of U.S. adults ages 60 and over have inadequate or marginal literacy skills, and 81% of patients age 60 and older at a public hospital could not read or understand basic materials such as prescription labels.
- Minority populations
- Immigrant populations
- Low income Approximately half of Medicare/Medicaid recipients read below the fifth-grade level
- People with chronic mental and/or physical health conditions⁷

Reasons for limited literacy skills include:

- Lack of educational opportunity people with a high school education or lower
- Learning disabilities
- Cognitive declines in older adults
- Use it or lose it Reading abilities are typically three to five grade levels below the last year of school completed. Therefore, people with a high school diploma typically read at a seventh or eighth grade reading level.

"Those with low health literacy incur medical expenses that are four times greater than patients with adequate health literacy because of:

- More medication and treatment errors
- Less compliance to treatment directives
- · Limited skills needed to successfully negotiate the health care system
- Lack of understanding about the value of preventive services (screenings, immunizations, annual physicals, and medical home)
- Limited understanding of their medical condition and its treatment
- Limited self-management skills for chronic conditions such as diabetes and asthma
- More chronic conditions and limited ability to manage them

- Greater use of treatment services due to being late in seeking care causing increased complications of acute and chronic conditions
- Greater hospitalizations
- Unnecessary emergency room visits
- Unnecessary physician visits
- Low utilization of preventative services such as mammograms, Pap tests
- If insured, unaware of services covered."8

In summary, people with low health literacy:

- Are often less likely to follow prescribed treatment and self-care plans.
- Fail to seek preventive care and are at higher (more than double) risk for hospitalization compared to adults with higher health literacy.
- Remain in the hospital nearly two days longer than adults with higher health literacy.
- Often require additional care that results in annual health care costs that are four times higher than for those with higher literacy skills.

Kutner et al. report that those with low literacy were very dependent on information they receive from family, friends, and co-workers if they sought any health advice at all; however, sometimes they did seek advice from one particular health care provider. In contrast, individuals with high health literacy levels sought information from health care providers among others, while those with intermediate or proficient levels did not rely on health care professionals as a main source of information but used a variety of both print and nonprint sources.⁹

HEALTH LITERACY: WHAT PROVIDERS NEED TO KNOW

A report released in October 2007 from the University of Connecticut, Storrs, states that the cost of low health literacy to the U.S. economy is in the range of \$106–236 billion annually. According to the report, *Low Health Literacy: Implications for National Health Policy*, the savings that could be achieved by improving health literacy translate into enough funds to insure every one of the more than 47 million persons who lacked coverage in the United States in 2006.¹⁰

Health literacy is not only costly to the health care system in this country, but it is also an increasing public health issue that impacts the health of its population. Although the problem is most prevalent among seniors, immigrants, and the poor, it can affect anyone regardless of age, education, and level of income. Some of the problem can be traced to health care providers failing to communicate important health information clearly but instead using medical jargon. Also, patients are often fearful about speaking up when they

do not understand the information communicated to them. The phrase "silent epidemic" can be used to describe patients too ashamed to confess that they are unable to read or understand health information.

Studies have shown that approximately 40–80% of the medical information patients receive is forgotten immediately, and nearly half of the information they retain is incorrect. People who understand and retain health care information will be healthier.

The National Patient Safety Foundation's (NPSF) Partnership for Clear Health Communication (NPSF PCHC) has found that only 50% of patients take their medications as directed, which may lead to issues of compliance, resulting in possible negative health outcomes, and even death. In a report titled *Health Literacy: A Prescription to End Confusion*, the Institute of Medicine stresses health literacy as "critical to successful healthcare."

The NPSF puts forth a program of "Ask Me 3." The program promotes three important questions patients should ask their health care providers in every interaction.

- What is my main problem?
- What should I do about this problem?
- Why is this important to me?¹⁴

STRATEGIES TO IMPROVE HEALTH COMMUNICATION

It is unrealistic to think that patients will significantly improve their health literacy skills in the context of a medical visit. Therefore, the focus must be on improving the communication of complex health information to low health literate populations by health care providers, practitioners, insurers, educators, administrators, pharmaceutical manufacturers, and others. There are a variety of different learning styles; therefore, improving health literacy should focus on more than one way for communicating health information.

Unlike *Healthy People 2010, Healthy People 2020 (HP 2020)*, released by the U.S. Department of Health and Human Services on December 2, 2010, has set relatively moderate goals. Still, there is a focus on health literacy as an important objective.

HP 2020 focuses on developing a "Health Information Technology (IT) and Health Communication" to support what would be called the "Healthy People Community," which is grounded in health literacy principles and which would provide an electronic communication infrastructure via Information Technology to promote shared learning. The objective is to achieve long, healthy lives while supporting a health improvement platform that would be available and accessible to all. However, when aiming for this objective, HP 2020 must address the "digital divide" that exists in the

population between those who are comfortable using technology and those who are reluctant to use it or who do not have access to a computer. 15

A 2005 survey by the Pew Internet & American Life Project reported that "thirty-two percent of American adults, or about 65 million people, do not use the Internet and not always by choice. Certain groups continue to lag in their Internet adoption, including Americans age 65 and older, African-Americans, and those with less education." Keeping this in mind, *HP* 2020 should have available appropriate products to promote health literacy in other formats for those who cannot or prefer not to access IT.

The Joint Commission is a nonprofit, independent organization that accredits and certifies more than 18,000 health care organizations and programs in the United States. In 2001, the Commission launched the Joint Commission's Public Policy Initiative to address issues for providing "safe, high-quality health care and, indeed, the health of the American people." A white paper issued in 2007 titled "What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety" sets forth recommendations for dealing with health literacy. "The risk of miscommunication and unsafe care is not solely the potential fate of those who cannot read. It is a risk for a large segment of the American population." Thus, it is important for the health care provider to understand each patient's degree of health literacy as well as the beliefs, values, and cultural mores and traditions that may influence how they share and receive health care information. ¹⁷ The white paper stresses effective communication as a priority in providing health care and addressing the health literacy of all patients. In the health care encounter, providers should apply communication techniques that increase the patients' understanding by using such methods as "plain language avoiding medical jargon, using the "teach back" and "show back" techniques to determine a patient's understanding. It is recommended that the provider should limit information "to two or three important points at a time" and consider the use of "drawings, models or devices to demonstrate points." 17

Verbal Communication

A number of studies have shown that those with low health literacy have difficulty in understanding health information delivered orally as well as through written communication. Also, patients often feel uncomfortable asking for clarification of information communicated by a health care provider or asking that the information be repeated. Thus, it is extremely important that verbal delivery of health information be presented in a clear and simple way. This is important for all patients but particularly for those with low health literacy. Health information should be free of jargon and complicated medical terminology. Plain language should be used in a patient-provider interaction and, at the least, medical terms should be explained in plain language. Also, important information and procedures

to be followed by the patient should not be communicated rapidly but rather should emphasize what is most essential. It is helpful to use visual materials along with verbal communication to aid in the understanding of health information. Some feel that health literacy can be improved by using what has been called the "teach-back" technique. Health care providers will ask the patients to repeat information that they have just been told, in their own words.

Written Communication

An abundance of documents provide details on various aspects of health information about specific conditions, treatment guidelines, the health care system, and health insurance coverage, to list just a few. Often these materials are difficult to understand because they are written at the college level, in small print, and have many complex medical terms. Documents given to patients should be written at a reading level appropriate to the audience. It is best to write using plain language, the active voice, short sentences, and a conversational manner. It is helpful to include a glossary in plain language to explain complex terms. The formatting of health information material should have sufficient white space and adequate margins that enhance and help reading. There should be headings that are clear and descriptive. Pictures and diagrams should be used to aid comprehension and recall and to promote patients' ability to follow the information in order to act in dealing with their own health issues. It is not too trite to use the saying, "a picture is worth a thousand words," to aid in delivering important health information to a patient.

The Center for Health Studies Readability Toolkit provides guidelines that can be useful when developing health information documents. These include:

- Write information at an appropriate reading level.
- Replace complicated medical or technical words with plain language.
- Use short sentences and short paragraphs.
- Write using the active voice.
- Use clear and descriptive headings.
- Use adequate white space and margins.
- Use pictures and diagrams that clarify written concepts.
- Focus materials on desired behaviors rather than on medical facts.
- Make information culturally sensitive and motivate consumers to take action.²⁰

Websites

Internet websites have become a popular way of distributing and accessing health information. Many consumers and patients are looking for medical information on the Internet. "Eight in ten Internet users have looked online for health information. Many e-patients say the Internet has had a significant impact on the way they care for themselves or for others."21 The advantage of disseminating health information via the Internet is that it can be updated at any time. However, the accuracy of the information can vary from one website to another, and there is no systematic program for evaluating content. Also, the average reading level on English-language websites is at the college reading level.²² Websites that provide heath information should follow similar guidelines put forth for written documents. However, visuals, pictures, and graphics should adhere to somewhat different guidelines. Some consumers of health information on the Internet may be unable to view graphics or videos clearly, so it is best to use a limited amount of text to accompany these visuals. The information on such websites should be presented in an organized way with no distractions such as backgrounds with complex patterns, and the links on each web page should be limited. The information should be available without users having to scroll down the page. It is a good idea to put the website through usability testing.

IMPROVING HEALTH CARE PROVIDERS' COMMUNICATION SKILLS

Health care providers with poor communication skills can put patients' health outcomes at risk. Institutions and organizations that train health care professionals need to incorporate health literacy training into all aspects of their training. Health literacy training should be integrated into the medical curriculum. The Centers for Disease Control and Prevention (CDC) addresses the problem of health literacy by asking the question "what needs to be done?" and puts forth this answer for the health care professional: "We can do much better in designing and presenting health information and services that people can use effectively. We can build our own health literacy skills and help others—laypersons, health professionals, and anyone else who communicates about health—build their skills too."23 Health care delivery has seen an increase in the use of pharmaceuticals. Approximately 80% of the adult population takes at least one medication on a weekly basis; about a third, at least five.²⁴ Given these numbers, it is not surprising that medication errors occur. There is research being conducted to improve drug labeling to assist patients in understanding and complying with prescription information. Labeling of medications should be accurate, and directions should avoid vague terminology. The labeling should also include what the medication is for, its benefits as well as its side effects, and when and how long to take it. All of the information should be in large font. Pharmacists need to be trained in counseling patients about their medications.

Health care and public health settings rely heavily on forms and printed instructions such as:

- Medical history forms
- Insurance forms
- Informed consent forms
- Child immunization records for school
- Test results
- Directions to the lab or pharmacy
- Hospital discharge and home care instructions
- Clinical research protocols and announcements

These forms need to be revised to ensure clarity and simplicity. Also, the forms should be available in multiple languages, and assistance with completing forms and scheduling follow-up care should be available.²⁵

WHAT MEDICAL LIBRARIANS ARE DOING TO ADDRESS HEALTH LITERACY

Medical and health sciences librarians are situated in a prime position to advocate for health literacy advancement and to assist health care professionals in better serving and communicating with patients possessing a broad spectrum of literacy skills. Academic and hospital librarians alike can find guidance and educational materials from the Medical Library Association (MLA). The mission of MLA is to "foster excellence in the professional achievement and leadership of health sciences library and information professionals to enhance the quality of health care, education, and research." As a part of that mission, MLA has focused on the quality of health care by developing a health information literacy web page full of resources for both health practitioners and information professionals as well as consumers (see Figure 1).

A section of the MLA Health Information Literacy web page for health and information professionals contains dynamic tutorials, one for health care providers and one for health sciences librarians. These consist of several written sections plus discussion forums, embedded URLs that link to external websites and resources, video clips, and quizzes that help users review the material and submit comments. There are also several toolkits, brochures, fact sheets, definitions, survey results, and resource compilations as well as a health literacy curriculum developed by MLA for librarians to use with health care professionals. PowerPoint slides are available that include a script, toolkit ideas, and evaluation forms.

The consumer resources listed at the bottom of the MLA Health Information Literacy page help users find a local public or health library using a



FIGURE 1 Medical Library Association's Health Literacy campaign logo.

MedlinePlus library-finder feature, locate health information for older adults at the very accessible Seniorhealth.gov website, and learn about understanding their own medical records; these resources generally guide users in accessing and evaluating online health information. These links guide health consumers to both MLA resources and external, MLA-recommended websites such as the Mayo Clinic, American Cancer Society, and CDC. Among MLA-produced resources, the "Deciphering Medspeak" initiative is appropriately included. It is a common practice for doctors, nurses, pharmacists, and other health care providers to use jargon that has been called "medspeak." To help with an understanding of this jargon, MLA has developed several Medspeak resources. The information provided is disease specific and in English, Spanish, and Plain language (see Figure 2).²⁸

In 2007, the University of Michigan Taubman Health Sciences Library received funding to address the issue of health literacy under a subcontract from National Network of Libraries of Medicine Greater Midwest Region, for the Michigan Health Literacy Awareness Training Program. The Michigan Health Literacy Awareness Training Program (MHLATP) is a collaborative project, which includes the University of Michigan's Taubman Health Sciences



FIGURE 2 Medical Library Association Deciphering Medspeak pamphlets for various diseases.

Library (THSL) and Washtenaw Literacy. The goal of MHLATP is to raise awareness among health professionals of the issue of low literacy and poor health literacy among their patients, and to provide communication techniques and resources to improve patient care. One of the major objectives of the subcontract was to develop a program providing resources for health literacy awareness to health providers. Classes were offered to health providers in a variety of settings, particularly in neighborhood-based health clinics.

In October 2009, to recognize Health Literacy Month, the University of Michigan Taubman Health Sciences Library organized a two-day forum with the aim of building a community network to improve health communication. ²⁹ On the evening of Thursday, October 22, 2009, THSL hosted a panel

discussion of literacy statistics and local programs aimed at improving health literacy and health communication.³⁰ The panel of speakers included the executive director of Michigan Washtenaw County Literacy, who discussed the issues and prevalence of illiteracy in Washtenaw County; a member from the Literacy Coalition of Washtenaw County, who spoke about the "Learning is a Family Thing" (LIFT) literacy program³¹; a faculty member of Health Behavior and Health Education in the University of Michigan School of Public Health, who discussed health literacy and its implications for public health³²; and a retired librarian from the University of Michigan Health Sciences Libraries, who discussed the Michigan Health Literacy Awareness Training Program's goals and accomplishments. A poster session followed the panel discussion and featured 18 community programs aimed at improving health literacy.³³ On Friday, October 23, 2009, Jean Shipman, director of the Tompkins-McCaw Library for the Health Sciences & Associate University Librarian, VCU Libraries, Virginia Commonwealth University Richmond, VA, taught a morning workshop on improving health literacy. She discussed research and development of the Medical Library Association's health information literacy curriculum and then taught the program that they created.²⁷

FUTURE STRATEGIES FOR HEALTH LIBRARY PROFESSIONALS

- Help to train all health care staff in the principles of health literacy and plain language.
- Create collections or repositories of materials (e.g., insurance forms and instructions, informed consent and other legal documents, aftercare and medication instruction, and patient education materials) in several languages and review the materials with members of the target population.
- Help to disseminate existing communication tools and resources for patients.

Journal of Healthcare Quality Editor Joshi Maulik was interviewed and videotaped saying, "Librarians can help to navigate and synthesize complex health care information and can help to engage clinicians and consumers."³⁴ Hospital librarians, who are often an untapped resource for health literacy and plain language training, must also be included in addressing the issue of health literacy.

CONCLUSION

Based on the numerous published papers and the ever-increasing emphasis on this topic in conferences, health literacy is an exceedingly important factor in preventive medicine, in maintaining adequate levels of public health, and in keeping health costs at their lowest possible levels. Vernon et al. report that savings in health care costs (\$106–238 billion) that could be achieved by improving health literacy could be used to insure every one of the 47 million people who lacked health insurance in 2006.³⁵ Medical librarians can play an important role in educating health providers about how to communicate clearly and effectively with their patients. They can also make strides in educating patrons directly about how to work in their own best interests in their interactions with physician and nurses and how to strive to be the best possible partners in achieving their own optimal health care, particularly in cases of chronic disease requiring constant medication and continuous care. If the low health literacy problem can be addressed in conjunction with the new health care reform program, this opportunity can result in both major savings and better health in the future.

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