MARKET WATCH

Health Literacy: A Policy Challenge For Advancing High-Quality Health Care

Creating a health-literate America may not be easy, but it is the right goal for health policy.

by Ruth M. Parker, Scott C. Ratzan, and Nicole Lurie

ABSTRACT: Health literacy, at the intersection of health and education, involves more than reading ability. Studies of health literacy abilities show that many Americans with the greatest health care needs have the least ability to comprehend information required to navigate and function in the U.S. health care system. This paper defines health literacy as an important policy issue and offers strategies for creating a health-literate America.

EDUCATION IS ESSENTIAL to a thriving society. Not only does it provide the basis for successful participation in our economy and democracy, but it is an essential determinant of health.[1] While policymakers frequently search for ways to improve both education and health, they rarely appreciate the relationship between the two. Most are also not aware of a silent epidemic pertinent to both policy spheres. Health literacy—the degree to which people have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions—is a policy issue at the intersection of health and education.[2]

Health literacy has many dimensions, including what it means to be able to read, understand, and communicate important medical and health information during different phases of life. Health literacy is central to multiple health system priorities, including quality, cost containment, safety, and patients' involvement in health care decisions.

Active, health-literate consumers can go online and get the latest information on sophisticated technological innovations; they create demand for the latest technology. Patients with low literacy sit on the other side of the digital divide and are not able to function as "informed" consumers. Recent work on understanding health disparities across education groups suggests that technological progress in health care will exacerbate disparities over time and that disparities will be larger for sicker, older, and more vulnerable groups.[3] Such forecasting bears ominous prediction. Health and health care in America are increasingly characterized by technological sophistication, and choice by "informed" consumers is of growing importance in the market. Patients who are better informed about their options and who understand the evidence behind certain approaches to care may have better health outcomes.[4] Those without adequate understanding—without adequate health literacy—cannot function successfully in a market designed for active, informed consumers. They are the ones most likely to be left behind.

Problems with health literacy are extremely common and costly; millions of Americans

Ruth Parker is faculty in the Department of Medicine, Emory University School of Medicine, in Atlanta. Scott Ratzan is vice-president, Government Affairs, Europe, at Johnson and Johnson, based in Belgium. Nicole Lurie is senior natural scientist and the Paul O'Neill Alcoa Professor at RAND in Arlington, Virginia.

struggle to read and understand the information needed to function in the health care system.[5] Many current health policy debates pertaining to Medicare and Medicaid, various patients' bills of rights, and privacy of health information are built on an assumption of adequate health literacy. How can elderly Medicare beneficiaries calculate their need for and the affordability of supplemental insurance if they cannot read and understand a bus schedule? Proposed patients' bills of rights would provide managed care enrollees with access to an external appeals process for disputed claims. Can patients with low health literacy skills take advantage of this and other rights created under this legislation?

There is a widening policy discussion related to health literacy. It is recognized as one of the nation's Healthy People 2010 objectives.[6] It is a vital part of the World Health Organization's (WHO's) new health promotion strategy.[7] Further, it is mentioned in a prominent European Commission health policy report.[8] The Institute of Medicine (IOM) listed health literacy as one of twenty priority areas in which quality improvement could transform health care in America.[9] The IOM recognized that sharing the same knowledge between clinicians and patients and their families is fundamental to successful self-management. It identified self-management and health literacy as a cross-cutting priority, representing an opportunity for boosting quality of care for all other designated priority areas.

Although health literacy is a salient issue for health policy today, it has been largely ignored in political dialogue.[10] In this paper we describe the problem of health literacy, focusing on the elderly with chronic health conditions, because of their high health care costs and implications for the Medicare program; discuss policy implications; and offer a blueprint for change.

Defining The Problem

The National Adult Literacy Survey (NALS) provides the most comprehensive portrait of Americans' abilities to successfully complete everyday tasks.[11] In 1993 NALS identified some forty-four million Americans—about one-fourth of the adult population—as having low functional literacy skills. These people cannot reliably enter background information on a Social Security application. Another fifty million adults have limited literacy skills, meaning they have difficulty using a bus schedule. In other words, about half of the adult U.S. population has deficiencies in reading or computational skills that inhibit full participation in what we might consider normal daily activities. These same Americans use the health care system.

The term "health literacy" was first used in a 1974 paper that discussed how health education affects the health care system, the educational system, and mass communication.[12] This initial discussion called for minimum standards for health literacy for all school grade levels, presenting an opportunity to link educational and health competencies. Although failures in health education have contributed to poor health literacy, the roots of these problems are not just in the history of our educational system. Advances in medical science, changes in the delivery of care, and increased consumerism have created a culture of high health literacy demands. At the same time, patients are increasingly encouraged to take more responsibility for their health. Their health literacy can be thought of as the currency needed to negotiate the system.[13] Unfortunately, there is a growing gap between the demand for skills and the actual skills of many Americans.

"Health Literacy" listings in the Current Bibliographies in Medicine, National Institutes of Health National Library of Medicine (NIH/NLM) number over 450 citations related to background and strategies. The NIH/NLM definition emphasizes the functional nature of health literacy.[14] It helped set the agenda and objectives for Healthy People 2010.[15] People with adequate health literacy can read and understand prescription bottle labels and warnings, appointment slips, informed consent documents, insurance forms, and other essential health-related materials required to successfully function as a patient.[16]

Healthy People 2010 describes health literacy as being increasingly vital for navigating a complex health system and for enabling people to better manage their own health.[17]

How Big Is The Problem?

The literature documents that problems with health literacy are common and are associated with poor outcomes.[18] Those with inadequate health literacy have less knowledge about their medical conditions and treatment, worse health status, and a higher rate of hospitalization than the rest of the population.[19]

In one large public hospital study, more than one-third of English-speaking patients and 61 percent of Spanish-speaking patients had inadequate or marginal health literacy.[20] This study used actual materials from common health tasks to define patients' health literacy. Forty-two percent did not understand directions on a pill bottle for taking medication on an empty stomach, 43 percent did not understand the rights and responsibilities section of a Medicaid application, and 60 percent could not understand a standard informed consent form.[21]

Literacy problems are especially common among the elderly; NALS reported that 44 percent of adults age sixty-five and older scored at the lowest of five skill levels.[22] NALS did not include health-related items, and it is unclear how many elderly people in the general population have inadequate health literacy. Among community-dwelling Medicare managed care patients in four cities, 34 percent of English-speaking and 54 percent of Spanish-speaking seniors had inadequate or marginal health literacy.[23] Although health literacy abilities and years of school completed were strongly associated, 17 percent of respondents with a high school education and 10 percent with more than that had inadequate health literacy. This is consistent with previous studies demonstrating that the number of years of education completed is not an accurate indicator of adults' literacy abilities.[24]

According to NALS, 75 percent of Americans reporting a long-term illness (of six months or more) had limited literacy.[25] This may mean that they know less about their conditions or how to handle them. A national survey of chronically ill people found that almost half did not understand services they were eligible for, and most did not know who provides needed services.[26]

There is a strong inverse relationship between increasing age and health literacy. Although there have been no longitudinal studies of individuals' health literacy skills, data suggest that these skills markedly decline with age.[27] The higher prevalence of health literacy problems among the elderly is important because they are also most likely to have chronic health conditions. Approximately 80 percent of all seniors have at least one chronic condition, and 50 percent have at least two.[28] On average, Medicare beneficiaries use 18.5 prescriptions annually.[29] Those with a chronic condition see eight different physicians yearly, on average.[30]

Since literacy problems are more common among the elderly, health literacy problems will continue to expand along with the elderly population. There were thirty-five million American age sixty-five and older in 2000; there will be forty million in 2010 and a projected seventy million in 2030.[31]

Health literacy is not solely related to immigration policy or language ability. Of the ninety million Americans with limited literacy, only 15 percent were born outside the country, and 5 percent described themselves as having a learning disability.[32] The majority of adults with poor literacy are white, native-born Americans. However, language differences, cultural barriers, and different educational opportunities place the growing populations of minorities at relatively higher risk for low literacy. In the Commonwealth Fund 2001 Health Care Quality Survey, only 57 percent of more than 6,000 racially and ethnically diverse adults said that they found it "very easy" to understand information from their doctor's office.[33]

The Cost

The nation's growing rate of spending on health has been well documented.[34] High health care costs are magnified for people with

poor health literacy. Inadequate health literacy was an independent risk factor for hospital admission among elderly managed care enrollees, even after demographics, socioeconomic status, health behavior, chronic diseases, and self-reported physical and mental health were adjusted for.[35] To date, only one economic study has been conducted on the overall costs of health literacy. The preliminary analysis, by the National Academy on an Aging Society, estimates that low health literacy costs the health care system $30–$73 billion annually (1998 dollars).[36] Sixty-three percent of the additional costs attributed to low health literacy may be borne by public programs.[37]

In 2000 nearly half of the U.S. population had a chronic condition. Direct medical costs for chronic conditions were $510 billion in that year. By 2020 this is projected to double to more than $1 trillion. In 2020 an estimated 157 million Americans will have at least one chronic condition, and sixty million will have two or more such conditions.[38] Those with chronic diseases have more health literacy demands yet often have fewer health literacy skills. A recent study of patients with diabetes found health literacy independently associated with worse blood sugar control and higher rates of complications such as retinopathy, blindness, and cerebrovascular disease.[39]

Unanswered Questions

Despite growing information on the magnitude and consequences of health literacy problems, more research needs to be done on how to easily detect and improve health literacy. To date there has been only a small research investment in searching for strategies to address this issue. Current efforts focus mostly on revising written information to a simpler level, and a few studies have demonstrated that more simply written materials improve knowledge.[40] Despite the obvious benefits of simplified written materials, though, a simply written pamphlet or consent document on its own does not adequately inform a patient. Nonreading solutions, including cartoons, pictographs with spoken explanations, and videos, also can increase comprehension and should be considered.[41]

The nature of the relationship between advancing age and declining health literacy skills requires further investigation. Longitudinal cohort studies are needed to understand the relationships between prior educational attainment and cognitive decline during aging, and solutions will depend on understanding the root causes. If cognitive decline is a large contributor, school-based educational solutions alone cannot bridge the gap.

What is the best way to communicate important health information to ensure adequate understanding? What actual content is required for patients with chronic illness to achieve self-management goals? How can multimedia technologies improve health literacy? How do screening and identifying patients with inadequate health literacy affect the patient-clinician relationships and health outcomes? In the current practice environment, time is equated with money, and practitioners are not reimbursed for educating patients. Whose responsibility is it to spend the extra time and effort to ensure that patients have the understanding they need to take care of themselves? Who will pay for this?

Implications For Policy

> A two-year-old is diagnosed with an ear infection and prescribed an antibiotic. Her mother understands that her child has an ear infection and knows she should take the prescribed medication twice a day. After looking at the label on the bottle and deciding that it does not tell how to take the medicine, she fills a teaspoon and pours the antiobiotic into her daughter's ear.

Health practitioners are becoming aware of just how commonly people struggle with health literacy. Other examples include difficulty monitoring multiple medications by elderly patients and overdosing a child with a fever reducer despite inclusion of an eyedropper to ensure proper dosage. Increased media attention and the work of professional societies, including the American Medical Association and the American College of Physicians–American Society of Internal Medicine Foundation, and voluntary health agencies such as

the American Cancer Society have helped to raise awareness. Both the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the National Committee for Quality Assurance (NCQA) have focused greater attention on health communication and developed guidelines about patients' understanding and the readability of patient materials. Congress and the U.S. Food and Drug Administration (FDA) have recognized for years the need to improve patients' understanding of prescription drugs. So far, that awareness has not extended to other areas of medical care and other parts of the federal legislative or regulatory apparatus.

■ **Link with quality improvement efforts.** In the effort to improve quality, one goal for health policy should be to ensure a health-literate America. What would a health-literate public look like? Informed patients have better outcomes; they are more concordant with the people who provide health services; they seek care earlier because they recognize warning signs; they read and comprehend instructions; they understand what their doctors advise them to do; and they are not afraid to ask questions when they do not understand. They are able to seek new information on the Internet, read the newspaper critically, and place new health studies in context. A high-quality health care system is characterized by appropriate use of drugs and services, not misuse, overuse, or underuse.

■ **Role of education improvements.** If the literacy of all Americans is improved, then education probably will eliminate most of patients' reading problems. This will require at least a generation, perhaps even longer. However, in addition to reading, health literacy requires understanding and solving health issues, so simply counting on education to solve the health literacy problem is not enough. Although education can improve general literacy, ensuring understanding of health and health care information is essential for any plan to improve health.

■ **Improvement across generations.** Health literacy must be addressed across the lifespan, and progress will be incremental. Research demonstrates that we retain much of what we learn as youth, which makes it logical to teach essential health literacy skills to youth and find ways to reinforce them across the lifespan. Because older people have more difficulty multitasking and learning new information, the process must start at younger ages.

As we improve the health literacy of new generations, we must simultaneously address the current health literacy problems of millions of Americans. Systemic changes in the way we deliver care are required to address the misinformation, miscommunication, and mistakes that characterize the health care experience of people with inadequate health literacy.

A Blueprint For Change

We estimate that at least one-third of Americans have major health literacy problems; many are elderly, with chronic conditions. Envisioning a health-literate America requires a blueprint for change. We will need to develop indicators and mechanisms by which all sectors—education, health systems, and providers—can be accountable. Health literacy is an issue of ethics and equity and is essential to reducing disparities. Although we strive to treat all patients equally, it is important to remember that not everyone has the same health literacy abilities. The following are policy-oriented strategies for improving health literacy.

■ **Research and measurement.** (1) Provide funding for much-needed multidisciplinary research on health literacy. This includes creating indicators as a tool for measuring and gauging progress in addressing this silent epidemic, as well as identifying measurement and reporting strategies. (2) Consider using existing tools, such as the Medicare Current Beneficiary Survey and National Health Interview Survey, to gather information on the dimensions of health literacy, including its implications on use of services and costs. Such measurement(s), if administered regularly, also could gauge progress toward the Healthy People 2010 objective to "improve the health literacy of persons with inadequate or marginal literacy skills." (3) Stimulate federal

funding of interventional and health communication science research aimed at bridging the gap in communication created by inadequate health literacy. (4) Use new technologies to develop non-reading solutions, recognizing that addressing health literacy goes beyond better-written communications. The Small Business Innovation Research (SBIR) program is one potential funding source to consider.

■ **Reducing health disparities.** (5) Incorporate health literacy improvements in existing and future activities related to the elimination of health disparities. Problems with health literacy can contribute to and be an underlying factor for socioeconomic health disparities. (6) Establish health literacy learning standards across the lifespan. These can be incorporated into school-based education.

■ **Engaging the federal government.** (7) Encourage federal funding of research in each of the IOM's twenty priority areas for improvement in health care quality to define the critical health literacy tasks for each. Work with target populations having low, marginal, and adequate health literacy to identify how best to communicate needed information to all populations. (8) Convene and educate stakeholders in HHS, the Department of Education, and other federal entities. As part of this awareness raising, federal agencies should be encouraged to introduce health literacy into appropriate aspects of their health-related activities. Health literacy should become a priority in the federal government's communication about health issues with the public. (9) Support the recently announced IOM initiative to map a national agenda and "system" solution to creating a health-literate America. (10) Encourage the Centers for Medicare and Medicaid Services (CMS) to conduct demonstration projects to further assess and address the impact of low health literacy among the beneficiaries of publicly funded programs, with particular emphasis on Medicare and Medicaid.

■ **Improving medical practice.** (11) Stimulate efforts to make health literacy a component of training for health professionals. Awareness of and assessment of health literacy should be part of provider systems and quality analysis. (12) Include health literacy in studies of preventive services. The U.S. Preventive Services Task Force should study whether health literacy screening should be recommended.

IMPROVING HEALTH LITERACY is a tool for improving health and health care in America. It is both a process and an outcome. Creating a truly health-literate America is a challenge requiring leadership, strategy, cooperation, and most importantly, a democracy with citizens who are well informed. It may not be easy, but it is the right goal for health policy.

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