

Health literacy: a challenge for American patients and their health care providers

RUTH PARKER

Emory University School of Medicine, 69 Butler Street SE, Atlanta, GA 30303, USA

SUMMARY

Health literacy skills are increasingly important for both health and health care. Unfortunately, many patients with the most extensive and complicated health care problems are at greatest risk for misunderstanding their diagnoses, medications and instructions on how to take care of their medical problems. Much health promotion and patient education

information has traditionally used printed materials written at reading levels at or above the 10th grade. Such material is not accessible to the millions of Americans with inadequate literacy. This paper gives an overview of the prevalence of poor health literacy skills in America and describes how poor health literacy affects their health care experience.

Key words: health education; health literacy; literacy; patient–provider communication

INTRODUCTION

The results of a national survey documenting that millions of Americans have inadequate literacy made headline news in 1993 (Kirsch *et al.*, 1993). Multiple studies in various health care settings have subsequently confirmed that these same people struggle as patients with health literacy demands. Yet most health care workers are unaware of the magnitude of the problem, and even fewer claim adequate skills for communicating with the many patients who have low literacy. Physicians routinely take for granted patients' ability to read and understand all types of health-related materials. In reality, many patients have difficulty communicating with their health care providers and following up with self-care instructions due to poor understanding of basic health vocabulary, limited background health knowledge, and trouble assimilating new information and concepts (Doak *et al.*, 1996). Instructions and warning labels about how to properly take medications, how to correctly prepare for diagnostic studies, and directions for follow-up appointments can be overwhelming to

many low-literate patients. This paper provides an overview of literacy and health literacy skills of Americans, how health literacy impacts patient–provider communication, the identification of patients with poor health literacy, and advice for improving communication with low-literate patients.

LITERACY AND HEALTH LITERACY IN AMERICA

The National Adult Literacy Survey [NALS, (Kirsch *et al.*, 1993)] found 40–44 million Americans, or about a quarter of the adult population, are functionally illiterate. This survey provided the most accurate and detailed portrait ever available of the condition of literacy in the USA. The survey assessed practical, everyday reading and numeracy skills required to function in everyday situations. Twenty-two percent of the 26 000 adults surveyed for the NALS scored in the lowest of five skill levels. They struggle with tasks such as determining the location of a meeting on a form and locating the expiration

date on a driver's license. Another 50 million Americans have only marginal literacy skills, as reflected by their score in the second of five skill levels. Level 2 tasks include locating an intersection on a street map, and identifying and entering background information on a social security application. Overall, almost half the American adult population has basic deficiencies in reading, computational skills, or English. Importantly, among the 90 million Americans with limited literacy skills, only 15% were born outside the country and 5% described themselves as having a learning disability. Inadequate literacy is especially common among the elderly, with almost half scoring in the lowest skill level. This has important implications for health providers, as the elderly are also most likely to have the greatest health-related literacy needs because of the high prevalence of chronic diseases in this age group.

The National Literacy Act of 1991 defines literacy as 'an individual's ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential' (Public Law 102-73, 1991). Americans are more educated than at any time in our history; the average educational attainment of adults is reported to be above the 12th grade level (Kirsch *et al.*, 1993). However, education level does not translate directly into a corresponding level of reading or literacy. Despite increasing education, average reading skills of US adults are only between the eighth and ninth grade levels (Stedman and Kaestle, 1991). Reading, writing and computational skills (i.e. literacy) actually better reflect functional ability than the number of years of formal school completed. Literacy experts also point out that literacy skills are context and setting specific. This means that an individual may have adequate literacy skills in one content area, but inadequate skills in a different content area or setting.

The impact of limited literacy on the health care experience is being documented in a growing body of literature. In 1999, the Council on Scientific Affairs of the American Medical Association (AMA) convened an expert panel to write a report on health literacy (Council on Scientific Affairs for the American Medical Association, 1999). The AMA subsequently adopted as policy several statements, including their recognition that limited patient literacy is a barrier to effective medical diagnosis and treatment, and

their encouragement of the allocation of federal and private funds for research on health literacy. The Department of Health and Human Services Healthy People 2010 Initiative which was recently released listed health literacy as one of the 450 national objectives (US Department of Health and Human Services, 2000). In February 2000 the National Library of Medicine posted a complete bibliography of medicine on the web to help define and build an evidence base for advancing health literacy programs by examining theories, strategies and tactics available in published literature (<http://www.nlm.nih.gov/pubs/cbm/hliteracy.html>). The search for that bibliography retrieved records for over 3600 citations. In the overview of the bibliography (Ratzan and Parker, 1999) we note that the first use of the term 'health literacy' was in a paper published in 1974 about health education as a policy issue affecting the health care system, the educational system and mass communication. The genesis of health literacy problems in America today is not only in our system of education. The roots of health literacy problems have grown as health practitioners and health care system providers expect patients to assume more responsibility for self-care at a time when the health system is increasingly fragmented, complex, specialized and technologically sophisticated. The National Library of Medicine bibliography defines health literacy 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. This definition assumes that a population with adequate health literacy can make more appropriate decisions for improving its health and well being'. The definition also stresses that health literacy is about both health and health care.

In the first published study of functional health literacy in America, over one-third of English-speaking patients and 61% of Spanish-speaking patients at two public hospitals had inadequate or marginal health literacy (Williams *et al.*, 1995). These patients struggled or were unable to read basic health materials. Forty-two percent of patients could not comprehend directions for taking medication on an empty stomach, 26% were unable to understand information on an appointment slip, 43% did not understand the rights and responsibilities section of a Medicaid application, and 60% did not understand a standard informed consent. A 2-year follow-up study of 958 patients from that public hospital

study found patients with inadequate literacy were nearly twice as likely to have been hospitalized during the previous year [31.5% versus 14.9% (Baker *et al.*, 1998)]. This relationship persisted after adjusting for health status and various socioeconomic indicators. A recent study of community-dwelling Medicare-managed care patients in four cities enhances the generalizability of the earlier public hospital research on health literacy (Gazmararian *et al.*, 1999). In this study conducted in four geographically diverse US cities, 34% of English-speaking and 54% of Spanish-speaking Medicare patients aged 65 years and older had inadequate or marginal health literacy. Importantly, reading ability among the elderly declined very dramatically with age, even after adjusting for education level and cognitive impairment. This study showed that health literacy problems are not confined to the public hospital setting; many independent, community-dwelling elderly people do not have the literacy skills necessary to function adequately in the health care environment.

Many smaller research studies reinforce these findings and document that low health literacy is associated with decreased medication adherence, knowledge of disease and self-care management skills (Williams *et al.*, 1998a; Williams *et al.*, 1998b; Kalichman *et al.*, 1999; Kim *et al.*, 1999). From these studies we know that for patients with diabetes, hypertension or asthma, low health literacy is common and strongly correlated with poorer knowledge of one's chronic condition(s). In addition, poorer knowledge may be correlated with increased medication errors and non-adherence.

The social stigma associated with illiteracy compounds the problem. People who have difficulty reading are often ashamed and hide their illiteracy from health care providers, friends and even close family members (Parikh *et al.*, 1996). Shame may prevent poor readers from asking for simpler materials or seeking help when they do not understand medication labels, medical forms or self-care instructions.

IMPACT OF HEALTH LITERACY ON PATIENT-PROVIDER COMMUNICATION

Patients' health literacy can be thought of as their currency for negotiating the health care system (Parker *et al.*, 1999). The increasing importance

of this currency is exemplified by the expansion in patient education requirements, which has paralyzed the exponential growth in medical technology. The following clinical example, initially cited in the American Medical Association's summary paper on health literacy, demonstrates the relevance of this to practicing clinicians (Council on Scientific Affairs for the American Medical Association, 1999). Twenty-five years ago patients newly diagnosed with asthma were instructed to take their theophylline regularly, and encouraged to be diligent about compliance with follow-up appointments. Today, practitioners ask patients to monitor their disease with a peak flow meter, select and correctly use multiple appropriate inhalers, sometimes augment therapy with tapering doses of oral steroids, and identify and avoid environmental triggers that exacerbate their asthma. Additionally, we expect patients to properly use, but not overuse, potential sites of care including the emergency room, their primary care physician and sub-specialists. The complexity of diagnosing and treating just one of the most common chronic medical conditions challenges many physicians. Yet, we expect patients to acquire necessary disease knowledge and complex self-management skills in busy practice settings that increasingly equate time with money.

Many patients have limited health vocabulary (Davis *et al.*, 1999). When compounded by physicians' facile use of medical terms, this often becomes a major source of miscommunication between patients and their providers. Careful studies show that patients commonly do not feel their physicians adequately explain illness or treatment plans in understandable terms (Mayeaux *et al.*, 1996). Many busy practitioners may realize that some misunderstanding exists between them and their patients, but hope that easily accessible health educational brochures will help patients clarify their understanding and answer any remaining questions. Unfortunately, there is a growing disparity between patients' reading abilities and their actual health literacy needs (Council on Scientific Affairs for the American Medical Association, 1999). Numerous studies now document how commonly many health materials, including patient education brochures, discharge instruction sheets, contraception instructions and informed consent documents are often written at levels far exceeding patients' reading abilities.

Patients with limited literacy, many of whom have poor background health knowledge and

vocabulary, obtain less information from health education materials (Doak *et al.*, 1996). Many may be overwhelmed with information, yet too uncomfortable to ask questions (Parker *et al.*, 1999). Health providers often give too much background information, rather than simple, essential information that helps the patient solve their problems. This inadequate communication may result in misinformation, misunderstandings and mistakes. Patients with poor health literacy report taking medications at the wrong dosage or frequency, and may not be aware of important treatment side effects or the need for follow-up testing (Baker *et al.*, 1996). Patients with inadequate health literacy who have chronic diseases, e.g. hypertension, diabetes or asthma have less understanding of their disease than patients with adequate literacy (Williams *et al.*, 1998a; Williams *et al.*, 1998b). Providers should not routinely assume that patients correctly understand their diagnoses and treatment plans.

Unfortunately for those with limited health literacy, as health care is becoming increasingly complex and health information is becoming more diffuse in the public domain, there is more reliance on written materials to educate and inform people about their health. This means that Americans need both functional and health literacy to make use of health information (Ratzan and Parker, 1999). Many managed care organizations use regular newsletters to communicate with patients about self-management issues regarding chronic diseases (Davis *et al.*, 1999). Adequate health literacy is essential for primary prevention and health promotion. Many public health messages and education materials about recommended disease prevention and screening are inaccessible to those with low literacy. For example, those with low literacy may not read and understand messages about the value of mammography or flu shots that may be found in magazines, on billboards or on clinic posters.

IDENTIFICATION OF PATIENTS WITH POOR HEALTH LITERACY

There is still a great need to raise awareness among practitioners that many patients have poor health literacy, and that the problem is often hidden (Parker *et al.*, 1999). Most people with limited literacy do not recognize or admit their reading difficulty; remarkably, two-thirds of those

who tested in the lowest skill level of NALS described themselves as being able to read 'well' or 'very well'. In a study of the relationship of shame and health literacy, shame was common among patients with low literacy who acknowledged they had trouble reading (Parikh *et al.*, 1996). Shame is a deeply harbored emotion, and it probably plays an important role in understanding how patients with low literacy feel. The social stigma associated with illiteracy creates feelings of inadequacy and poor self-esteem. The stigma of illiteracy in our society is probably one of the main reasons so many hide their inability to read. When asked to read in front of their physician, patients with low literacy might hide their problem by saying, 'I forgot my reading glasses', 'I'd like to discuss this with my family first', 'may I take the instructions home?' or 'I don't need to read this through now; I'll read it when I get home'. Providers need to be aware of just how commonly health literacy problems exist for their patients, and should not assume they can readily identify which patients have poor health literacy. A critical teaching message for practitioners is that you can not tell by looking.

The actual assessment of patients' reading ability can help health providers begin to find ways to more effectively communicate with their patients (Davis *et al.*, 1999). There are a few tests available for assessing patients' literacy in the office setting. The Rapid Estimate of Adult Literacy in Medicine [REALM (Davis *et al.*, 1993)] is a word recognition test, which measures a patient's ability to read from a list of progressively more difficult words until they encounter words they cannot correctly pronounce. The REALM was developed for use in the clinical setting, and is simple to use and can be completed in 5 min or less. The REALM is not valid in Spanish and does not assess patients' quantitative literacy skills, or numeracy. The Test of Functional Health Literacy in Adults (TOFHLA) was developed to test a patient's ability to read passages and phrases using real materials from the health care setting (Parker *et al.*, 1995). The TOFHLA was the first available tool for measuring functional health literacy, or patients' ability to perform health-related tasks requiring reading and computational skills. Reading passages on the TOFHLA were selected from instructions for preparation for an upper gastrointestinal series, the patient rights and responsibilities sections of a Medicaid application form, and a

standard hospital informed consent form. The numeracy items test a patient's ability to comprehend directions for taking medicines, monitoring blood glucose, obtaining financial assistance and keeping clinic appointments. The TOFHLA is a valid and reliable tool for measuring patients' health literacy, but it takes up to 22 min to administer. The short TOFHLA (S-TOFHLA) was subsequently developed (Baker *et al.*, 1999). Its maximum time for administration was reduced to 12 min, and the S-TOFHLA is a reliable and valid measure of functional health literacy.

There really is no 'gold standard' for measuring health literacy (Parker *et al.*, 1999). Patients who completed eight or fewer years of school very likely have inadequate health literacy, and those who completed education beyond the high school years are likely to have adequate functional health literacy. However, the NALS found that 16–20% of adults with high school diplomas scored in the lowest of five proficiency levels. For the many patients who completed nine–12 years of school, it is difficult to identify those with health literacy problems without actual testing. The S-TOFHLA measures patients' ability to read and understand actual health texts, while the REALM measures their ability to pronounce words in isolation. Published studies using the TOFHLA have shown its ability to independently predict patients' health status, knowledge of chronic disease and self-management skills, and use of health care services. Patients' REALM scores have been associated with the stage of presentation for prostate cancer patients, and women's knowledge and attitudes about mammography (Council on Scientific Affairs for the American Medical Association, 1999). Further studies are needed to determine relative advantages and disadvantages of the S-TOFHLA and REALM in various clinical and research settings.

Recognizing reading difficulties does not always require formal testing with a standardized instrument. You may identify patients with reading problems in a busy public hospital clinic setting by asking patients to read the label on a real pill bottle. Practitioners should also be suspicious when patients fill out intake forms incorrectly or return survey risk forms with all items checked identically. Most importantly, clinicians and support staff in health care settings should not routinely assume all patients have adequate health literacy.

ADVICE FOR IMPROVING COMMUNICATION WITH LOW-LITERATE PATIENTS

Those who discover that a substantial portion of their patients have health literacy problems will need to closely evaluate and probably revise a lot of the educational approach used in their clinical setting. The health care setting must become a 'shame-free environment' where patients of low literacy levels can seek help without feeling stigmatized. Staff need to be sensitized to how anxious and ashamed some patients are about being expected to correctly read and complete intake forms, informed consent documents, or complex instructions for diagnostic studies (Parker *et al.*, 1999). Creating a culture where help is routinely offered in completing important documents, and where surrogate readers for patients with limited health literacy are included when health education is communicated can help circumvent some of the problem.

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

During clinical encounters, health practitioners need to make their communication 'fit' their patients' actual health literacy (Parker *et al.*, 1999). A few simple techniques are to use simple language, slow down and include important family member(s) in discussions. Both clinicians and health educators often inadvertently hinder communication by providing too much complex background information that has little to do with what patients need to know about how to care for themselves. Instead, we need to do more to ensure real patient understanding, a key ingredient for adequate health literacy. Health educators advocate a 'teach back' or 'show me' approach. Providers can demonstrate to patients a desired skill (e.g. checking a blood glucose level or using an inhaler) rather than asking patients to read about the skill. Then ask the patient to

demonstrate the skill to assure they have correct understanding. To help make patients feel more comfortable about being 'tested', try asking the patient to teach back what was just explained so the practitioner can judge his/her ability as a teacher. For example, 'Could you now tell me or show me what I just went over with you? I need to see how well I did explaining this to you. This is important so we both feel like you'll know how to take care of yourself at home'.

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

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

Address for correspondence:

Ruth Parker
Emory University School of Medicine
69 Butler Street SE
Atlanta
GA 30303
USA

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