Approximately half of all Americans do not understand written and verbal health information well enough to take appropriate action. For chronic conditions requiring patients’ ongoing self-management, limited literacy may be a powerful barrier to achieving optimal outcomes. Because low literacy is associated with a number of psychosocial variables that also act as barriers to self-management, health literacy experts recommend that efforts to alleviate the burden introduced by low literacy be addressed not only by developing means of increasing patients’ understanding, but also by integrating such efforts into systems aiming to improve self-management support across the continuum of patient care. This article provides an overview of efforts to define, assess, and improve the quality of diabetes care provided to those with limited health literacy.

Low Health Literacy: Overview, Assessment, and Steps Toward Providing High-Quality Diabetes Care

Andrea Wallace, PhD, APRN-BC ADM

Although hypotheses about the link between literacy and health outcomes were published in the 1980s,1 the potential consequences of limited literacy in U.S. health care settings was brought to the attention of the larger clinical and health policy communities by a study published in 1995. In this landmark study, researchers revealed dramatic statistics: up to two-thirds of patients seen in public hospitals in the United States were unable to comprehend key health information such as how to take a medication or schedule a follow-up appointment.2 Hundreds of studies have since explored how patients’ ability to read and comprehend the written information encountered in health care settings is independently associated with a variety of poorer health outcomes.3

Because low literacy is more common among vulnerable populations (racial and ethnic minorities, elderly people, patients with chronic conditions, and those seeking care in public systems), it likely contributes to the disproportionate burden of disease-related problems among disadvantaged and vulnerable populations.3 In fact, when literacy is considered, the role of race in health disparities decreases dramatically.4,5

With an estimated 40% of adults in the United States having less-than-functional literacy,6 addressing health literacy has moved to the forefront of several policy agendas aimed at improving health care quality and outcomes.

Defining Health Literacy

Despite the growing literature on the topic, definitions of what constitutes literacy in health care settings continue to be developed and refined. One of the most commonly used definitions of literacy is that put forth by the U.S. Department of Education, which defines functional literacy as “the ability to use reading, writing, and computational skills at a level adequate to meet the needs of everyday situations.”7

But it is commonly recognized that literacy in health care settings, also called health literacy, encompasses many unique skills. Being functionally literate in health care settings not only requires an ability to read and understand terminology unique to health care settings but also to do so during what may be emotionally charged or physically challenging circumstances. Health care encounters often include complex instructions for taking medications, undergoing medical tests, and obtaining insurance reimbursement. The more context-specific skill set required to function in health care settings is reflected in the widely accepted definition of health literacy adopted by the Institute of Medicine (IOM): “the degree to which individuals have the capacity to obtain, process, and
understand basic health information and services needed to make appropriate health decisions.”

Building on its basic definition of health literacy, the IOM examines health literacy as capability in four primary domains: cultural and conceptual knowledge, speaking and listening skills, writing and reading skills, and numeracy. These domains are reflected in studies that have expanded on early work, largely based on patients’ reading ability, to document that numeracy (i.e., the ability to accurately manipulate numerical information) and listening skills are associated with literacy skills, as well as with engagement in health behaviors and disease-related outcomes.

Achieving optimal health outcomes for many conditions requires that patients are not only able to read and understand written and numerical information, but also able to take appropriate action. Researchers continue to elucidate concepts related to health literacy. One such example of how literacy can be further refined is by distinguishing between functional literacy skills (those needed to function effectively in everyday situations), interactive literacy skills (those needed to actively participate in everyday activities), and critical literacy skills (those needed to critically analyze information and exert control over life events).

This is particularly relevant to people with diabetes and their health care providers. For patients, successful diabetes self-management requires actively participating in a wide range of complex tasks that go beyond accurately interpreting written information to relaying the integration of a number of behaviors into the context of daily life. Recognizing that skills necessary to successfully manage diabetes draw on the more complex interactive and critical types of literacy suggests that health literacy in diabetes may be better served by adopting the definition of health literacy offered by the World Health Organization (WHO) and researcher Donald Nutbeam, which states that “health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health.”

We are only at the beginning of associating health literacy with the wide range of psychosocial and emotional factors implied by the WHO definition of health literacy. However, this line of reasoning is generally supported by our emerging understanding of how health literacy affects health outcomes for diseases such as diabetes, which require a high degree of self-management. Findings suggesting that health outcomes are influenced by the literacy of family members, that health literacy influences family support, and that literacy is associated with social isolation are just a few examples of the complex relationships currently being explored.

In response, expert clinical and health literacy researchers have recently called for the health literacy community to adopt an even more comprehensive definition of health literacy, which not only takes into account patients’ reading and numeracy skills, but also considers evidence of how a broad range of cognitive and psychosocial factors—such as confidence, engagement, problem-solving, and social support—are associated with patients’ ability to successfully engage in self-management behaviors. These experts propose that referring to health literacy as “health-learning capacity” may help stakeholders recognize the ever-broadening factors contributing to patients’ ability to act appropriately on health information and inspire researchers to draw on work from the diverse fields of education, cognitive science, and psychology to create increasingly informed, comprehensive, and innovative clinical interventions.

Assessing Health Literacy

According to the American Diabetes Association (ADA), assessing patients’ literacy is instrumental in developing a comprehensive plan of care and providing self-management education. However, because of its inherent complexity, there is currently no single measure that reflects the many constructs related to health literacy; measures are continually being developed and refined.

Although providing a comprehensive list of instruments assessing health literacy is beyond the scope of this article, one can gain a general understanding of commonly used health literacy assessments by placing them into three primary categories that measure patients’ ability to 1) read written words, 2) comprehend prose, and 3) comprehend and conduct numerical calculations. Many instruments incorporate one or more of these skills, measure skills particular to diabetes management, and are available in languages other than English. Instruments range from lengthy, comprehensive assessments that take close to 1 hour to complete to short, 1-item screeners (Table 1).

The choice of assessment is largely determined by its appropriateness for a population (e.g., availability in Spanish or diabetes-specific), utility (e.g., whether the assessment will be used for a research study or during routine care), information germane to the clinical setting or research question (e.g., the ability to calculate carbohydrates), and/or feasibility (e.g., the amount of time needed to complete the assessment).

Two examples of instruments that assess reading ability are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the diabetes-specific Literacy Assessment for Diabetes (LAD). The REALM is a 66-word screening instrument that quickly identifies patients who are unable to read and pronounce commonly used medical terms. Words pronounced correctly from the list are summed, giving a score range from 0 to 66. Although REALM does not assess reading comprehension, it has excellent concurrent validity with other literacy assessments (0.88–0.97) and high test-retest reliability (0.99). REALM has been successfully used in a wide variety of patient populations and takes approximately 3 minutes to administer and score. A shortened version of the REALM, the Rapid Assessment of Adult Literacy in Medicine–Revised (REALM-R), is also available and consists of only eight items. LAD is a diabetes-specific word recognition test that has three graded word lists ordered by difficulty (fourth-, sixth-, and sixteenth-grade reading levels) for the patient. It measures patients’ ability to pronounce terms related to health care and can be administered in 3 minutes or less.

The well-established Test of Functional Health Literacy in Adults (TOFHLA), which was used in the landmark 1995 study documenting the prevalence of health literacy, continues as a standard against which other health literacy assessments are measured. TOFHLA consists of...
reading passages related to common health care scenarios and multiple choice questions that assess reading comprehension (50 items) and numeracy (17 items). Because TOFHLA takes ~ 20–25 minutes to administer, the Short Test of Functional Health Literacy in Adults (S-TOFHLA)\(^2\) was developed. S-TOFHLA, which uses 36 items from the reading comprehension subsection of the full test, takes only 7 minutes to administer. S-TOFHLA retains much of the validity and reliability of the full version (e.g., it is highly correlated with tests used in general education). It is scored on a scale of 0–36, with scores of 23–36 indicating adequate literacy, 17–22 indicating marginal literacy, and 0–16 indicating inadequate literacy.

Because diabetes self-management often requires that patients accurately conduct numerical calculations, health literacy assessments that are grow-

<table>
<thead>
<tr>
<th>Name</th>
<th>Assessment</th>
<th>Time to Administer (minutes)</th>
<th>Language</th>
<th>Diabetes-Specific</th>
<th>Resources</th>
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</thead>
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<tr>
<td>REALM</td>
<td>Ability to read and pronounce health-related terms</td>
<td>3</td>
<td>English</td>
<td>No</td>
<td>Terry C. Davis, <a href="mailto:tDavis1@lsuhsc.edu">tDavis1@lsuhsc.edu</a></td>
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<td>REALM-R</td>
<td>Ability to read and pronounce health-related terms</td>
<td>&lt; 2</td>
<td>English</td>
<td>No</td>
<td>Terry C. Davis, <a href="mailto:tDavis1@lsuhsc.edu">tDavis1@lsuhsc.edu</a></td>
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<tr>
<td>SAHLSA</td>
<td>Ability to read and pronounce health-related terms</td>
<td>3–6</td>
<td>Spanish</td>
<td>No</td>
<td>Shou-Yih D. Lee, <a href="mailto:sylee@email.unc.edu">sylee@email.unc.edu</a></td>
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<td>LAD</td>
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<td>Charlotte Reese Nath, <a href="mailto:nathc@rcbhsc.wvu.edu">nathc@rcbhsc.wvu.edu</a></td>
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<td>TOFHLA</td>
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<td>20–25</td>
<td>English and Spanish</td>
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<tr>
<td>S-TOFHLA</td>
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<td>English and Spanish</td>
<td>No</td>
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<td>WRAT</td>
<td>Reading, spelling, and computation</td>
<td>20–30; 5 if only reading recognition subtest</td>
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<td></td>
<td>English and Spanish*</td>
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<td>DNT</td>
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<tr>
<td>NVS</td>
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<td>No</td>
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<td>SILS</td>
<td>Need for assistance with written information</td>
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</table>

\(^2\)Spanish translations are available by special request

†DNT15-Latino currently being validated

‡Asking the screening question in other languages may be appropriate, but the scale has not been validated in languages other than English.

SAHLSA, Short Assessment of Health Literacy for Spanish Adults.
Barriers to Assessing Health Literacy

There are many barriers to formally integrating health literacy assessments into clinical encounters, including time limitations and concerns about embarrassing patients. But a great deal of evidence suggests that the alternative—identifying patients with limited health literacy by using demographic risk factors alone—is ineffective. Self-reported health literacy is inaccurate, and, although variables such as years of education are associated with health literacy, they are not perfectly correlated and do not provide enough information to guide care.

That said, missed appointments, not following through on discussed plans, lack of questions, and inability to recall prescriptions are important clues that can be gleaned from routine clinical encounters and may indicate that a patient is having difficulty understanding health-related information. Experts also suggest that informal assessment may be accomplished by simply asking patients to read a prescription label. But incorporating technologies such as check-in kiosks and tablet PCs may help remove barriers to more formally assessing patients’ health literacy during routine clinical encounters.

Because of the high degree of shame associated with illiteracy, it is a subject that needs to be approached with sensitivity. However, data suggest that patients are generally supportive of measures that help inform their health care providers of their literacy status. When incorporated as part of a comprehensive health and social history, addressing the subject and taking appropriate action can be nonthreatening and rewarding for both clinicians and patients.

Improving Care for Those With Low Health Literacy: Focusing on Self-Management Needs and Skills

Although discussions about how health literacy ought to be defined and measured will continue to guide interventions in coming years, by examining how to best support self-management, we can identify areas ripe for present-day clinical innovations. These include meeting patients’ communication needs, developing patients’ skills, and systematically integrating the two in a manner that removes self-management barriers across the continuum of care.

Meeting the communication needs of patients with low health literacy

Clearly, patients must be able to understand what they are being instructed to do before they can do it. However, evidence suggests that health care encounters are laden with medical jargon, and, as a result, patients may understand as little as 50% of what is told to them during medical encounters. In a recent study of those with diabetes, two-thirds did not know their last A1C value and, of those who claimed they did, only 25% were able to accurately report the value.

Patients who rate their providers as being more thorough are more likely to know their A1C values and patients whose physicians assessed recall or comprehension are more likely to have lower A1Cs. But few clinicians do this during visits; physicians assess understanding only 20% of the time, suggesting that, at its most basic level, literacy influences health outcomes by posing a barrier to knowledge acquisition and that focusing on improved communication during health care encounters may result in improved outcomes for patients.

Research exploring optimal methods for communicating with patients with limited literacy skills is by no means conclusive, but health literacy experts agree that incorporating a few simple techniques to improve communication and patients’ understanding during clinical encounters is not only effective, but also feasible. These techniques include 1) asking open-ended questions, 2) limiting the number of new topics addressed and the amount of medical jargon used during clinical encounters, and 3) asking patients to restate information or to “teach back” information. Adopting these strategies allows health care providers to assess lapses in current understanding, uncover health beliefs, focus interventions, and appropriately tailor health messages.

An example of how to assess understanding through open-ended questioning is to ask patients about their understanding of diabetes, who else is involved in their care, examples of a typical day, and what medications they take, as well as how and when they take them. Research suggests that those with limited literacy may expect their involvement in health care decision-making to be limited to consenting to the recommendations offered by their health care provider.
Developing patient skills: numeracy and goal-setting

Although ensuring that patients understand health information serves as a foundation for diabetes self-management, understanding alone does not translate into successful self-management on the part of patients. Many, if not most, patients with diabetes face significant self-management challenges. However, low health literacy is associated with a number of factors negatively influencing patients’ ability to successfully translate knowledge into effective self-care, including lower self-efficacy (confidence), lower participation in decision-making, limited social support, depression, unemployment, lack of insurance, and low socioeconomic status.

These findings suggest that addressing the many psychosocial factors associated with self-management may be instrumental in improving the health outcomes for those with limited health literacy. Researchers have proposed that the health care community move beyond viewing health literacy as a risk factor to be “identified and appropriately managed” and instead view literacy as an asset to be developed that enables individuals “to exert greater control over their health and the range of personal, social, and environmental determinants of health.”

Research demonstrating that lower numeracy skills are associated with difficulty in performing a number of self-management tasks (e.g., correctly interpreting glucose meter readings and calculating carbohydrate intake and medication dosages) lead to worse glycemic control and are a source of racial health disparities. Because lower numeracy skills are associated with a host of negative outcomes, researchers and clinicians have begun to explore means of teaching numeracy skills to patients with diabetes.

One example is the Diabetes Literacy and Numeracy Education Toolkit (DLNET), developed by clinician-researchers at Vanderbilt University. For further information, readers are referred to an article in this issue (p. 238) by the Vanderbilt University team that developed DLNET.

For many patients with diabetes, integrating the numerous self-management behaviors (e.g., medication management, glucose testing, regular appointments, diet, and exercise) into their daily lives also requires significant behavior changes. The process of integrating behaviors into the context of daily life not only requires knowledge acquisition, but also skill in applying practical information, setting realistic goals, and problem solving. Therefore, patient goal-setting and follow-up support have emerged as two cornerstones of quality self-management support.

Because data suggest that goal-setting and follow-up support are not commonly reported by diabetic patients, it has been suggested that integrating these areas into routine care is an important area for improving the quality of diabetes care. However, because goal-setting and follow-up are reported significantly less often by patients with low literacy skills, these needs may be a prime area of focus for interventions aiming to improve outcomes for those with limited literacy.

A number of interventions aimed at activating patients, supporting behavior change, and providing follow-up support are reported in the literature. One such example is the Living With Diabetes Toolkit, which pairs a simple behavioral change counseling strategy focused on constructing “action plans”—small, immediate, measureable behavioral goals—with visually appealing materials written at a low literacy level.

When tested in a diverse sample of diabetic patients, the toolkit intervention resulted in improvements in a number of variables (e.g., self-efficacy, distress, activation, and knowledge) believed to contribute to improved self-management and thus to improved outcomes. In addition, patients reported a high degree of success achieving behavioral goals and a high level of satisfaction. The Living With Diabetes Toolkit is publicly available from the American College of Physicians’ Foundation at http://diabetes.acponline.org/clinician. Patient materials are available in both English and Spanish.

Creating a supportive system

Improving communication during health care encounters and developing patients’ skills are important steps toward providing high-quality care for all patients with diabetes. However, evidence suggests that progress toward improving diabetes outcomes for those with limited literacy is slow. For example, when notified of their patients’ limited health literacy, physicians successfully incorporated commu-
nication and management strategies recommended for patients with limited health literacy. But, although both physicians and patients felt screening was useful, these changes did not result in significant differences in patients' physiological outcomes, and physicians felt less satisfied with the overall quality of their visits. In a trial using DLNET, patients benefited from the materials and teaching strategy, but the differences in physiological outcomes between the intervention and control groups dissipated after 6 months.

On the surface, these results appear discouraging. However, what they likely suggest is that, for literacy-based interventions to affect patient outcomes, they need to be implemented as part of a system providing ongoing support for both people with diabetes and the clinicians caring for them. This is the primary reason for the diabetes self-management support requirements communicated in the ADA's National Standards for Diabetes Self-Management Education.

Success at achieving and sustaining improvement in diabetes outcomes for those with limited literacy may lie in recognizing and addressing the self-management barriers that exist throughout the continuum of patients' experiences. Low literacy is associated with many known self-management barriers that are unrelated to knowledge or skill acquisition, including lack of insurance, lack of transportation, and unemployment. Scarc resources pose significant self-management barriers for all patients, but the impact for those with limited literacy is likely to be more exaggerated; a seemingly minor change in pharmacy benefits can create an insurmountable barrier to accessing medications for a person who is unable to read. Adopting a comprehensive, coordinated approach that integrates a multidisciplinary team and community resources may help ameliorate many self-management barriers and improve health-related outcomes for those with limited literacy.

One example of system redesign is that offered by the popular Chronic Care Model (CCM), which has been applied to improve the overall quality of diabetes care delivered in primary care settings. Care modeled on the CCM includes providing not only self-management support to patients through goal-setting and routine follow-up, but also links to community resources and support to care providers through clinical information systems and decision support.

Modeling primary care services on the CCM improves diabetes outcomes overall, but data suggest that improvements for patients with limited literacy may be even greater in these systems that provide proactive, coordinated diabetes care, particularly those that help patients address access barriers such as insurance and transportation problems. The positive effect of proactive care modeled on the CCM may also be the result of better coordination of care across providers, reinforcement of messages, general awareness, and support from outside services. This coordination of care may be particularly helpful to patients with limited literacy who may struggle with communicating their comprehensive health histories in the setting of complex regimens and multiple provider visits. Additional details about the CCM and its implementation in clinical settings can be found online at http://www.improvingchroniccare.org.

A second, closely related effort based in part on the CCM is the adoption of the Patient-Centered Medical Home (PCMH) model by health care settings. The principles of the PCMH movement include finding sustainable and feasible means of providing ongoing access to a personal physician; a team of individuals at the practice-level who collectively take responsibility for the ongoing care of patients; a whole-person orientation that includes acute, chronic, preventive, and end-of-life care during all life stages; and care that is coordinated across the health care system and patients' community (e.g., family, public, and private community-based services).

Each of these principles, if realized, has important implications for meeting the needs of patients with limited literacy skills, particularly related to support for self-management needs and continued, personal follow-up, which are instrumental in efforts to improve the health outcomes of those with limited literacy. (For further discussion, readers are referred to the article on p. 228 of this issue by Erin E. Van Scoyoc, MD, MPH, and Darren A. DeWalt, MD, MPH.)

Although not specific to those with limited literacy, a number of demonstration projects sponsored by various stakeholder groups, including government agencies, payers, and providers, have reported early successes in improving health care for several conditions. Because limited literacy is more common among disadvantaged populations (e.g., those without insurance, racial and ethnic minorities, and those who are socially isolated), who are more likely to be without a medical home, widespread adoption of the PCMH model may be an important step to improving the quality of diabetes care delivered to those with limited literacy. Additional information about the PCMH model and movement can be found at http://www.pcpcc.net.

Conclusion

Limited literacy, when narrowly defined as the ability to read, is prevalent. When expanded to include the many skills related to successfully managing diabetes, literacy likely poses a barrier for >50% of patients seeking care in our health care settings. The prevalence of limited health literacy has important implications in terms of health disparities, patient safety, and health care costs. Numerous risk factors are associated with limited health literacy, but diabetes outcomes are influenced by health literacy through its effect on patient self-management. Although not well understood, there are a number of factors involved in this link, including ability to read prose and interpret numerical information, confidence and ability to act on health information, and problem-solving skills. As a result, interventions that aim to improve the outcomes of those with limited literacy are more likely to be successful if they are multifaceted, aim to help patients develop better oral and written communication strategies and key literacy and numeracy skills, and provide support for making behavior changes. In addition, because low health literacy exists in a context of other self-management challenges and access barriers, these efforts are more likely to succeed when carried out in the setting of a coordinated system supporting the self-management needs of patients across the continuum of care.

Next steps in improving the quality of care for those with limited
literacy are likely to include a general understanding about how to implement complex interventions aimed at developing patients’ skills into routine practice and the restructuring of care systems to better support the needs of busy providers trying to manage the complexities of diabetes care. Accurately screening all patients’ health literacy skills may not be feasible on the large scale, so adopting clear communication strategies, supporting self-management, and redesigning care systems may be best viewed as a means of improving the overall quality of diabetes care, not only for those with limited health literacy, but for all patients.

Acknowledgments
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Andrea Wallace, PhD, APRN-BC
ADM, is an assistant professor at the University of Iowa College of Nursing in Iowa City.