Have you ever noticed patients having difficulty filling out medical history forms? Have you ever wondered whether patients really understand the implications of their diagnosis of diabetes mellitus even when they say they do? Or have you ever been perplexed about why patients do not adhere to their insulin regimens after you have explained their specific plan to them more than once? These questions may reflect issues relating to health literacy.

By K. Aletha Maybank, MD, MPH, and Teré Dickson, MD
According to the Centers for Disease Control and Prevention, 20.8 million people, about 7% of the US population, have diabetes. Many are racial and ethnic minorities, a large proportion of whom do not speak English as their primary language. Blacks, Hispanics, American Indians, Alaska Natives, Asians and Pacific Islanders are 1.5 to 2.2 times as likely to have diabetes as whites.

Difficulties with health literacy among patients and the lack of awareness about the importance of health literacy among physicians are thought to be contributing factors leading to health disparities in diabetes.1-2

The National Academies’ Institute of Medicine defines health literacy as the ability to obtain, process and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment.3

Why is health literacy so important? It is one of the best indicators of health status. It is well documented that those with low literacy skills are less aware of ways to prevent disease and how to manage their medical conditions. Ultimately, this leads to poorer health outcomes and health status. Consequently, low literacy levels are associated with poor glycemic control, more frequent hospitalizations and a higher incidence of diabetes complications.4

In 2002, Dean Schillinger, MD, and colleagues found that Medicaid enrollees with low literacy skills were less likely to maintain tight control of their diabetes as compared with those with adequate literacy skills (20.4% versus 33%).5

The 1992 National Adult Literacy Survey found that almost 50% of people in the United States are functionally or marginally illiterate, equating to reading levels ranging from first to fifth grades. Numerous studies have documented that both printed and Web-based health information are written at the eighth grade level or higher, with reading levels much higher than what the average person understands.6

Conducted by the National Center for Education Statistics, the 2003 National Assessment of Adult Literacy (NAAL) was the first large-scale national effort to specifically assess health literacy. NAAL showed that an astounding 36% of Americans have only basic or below basic health literacy skills. This means that this population can read and understand only very simple documents and perform only one-step arithmetic problems.

An additional 5% of the population has literacy levels so low that they could not even be evaluated. Those with a higher likelihood of having limited health literacy skills are the elderly, racial and ethnic minorities (primarily blacks and Hispanics), high school dropouts, people with low incomes, the unemployed, recent immigrants who do not speak English, and those born in the United States who do not speak English at home.6

### Literacy and treatment adherence

Diabetes management can be complicated for anyone, no matter how educated or experienced one is. Adhering to treatment regimens, especially self-management, is crucial for controlling diabetes.

Patients being treated for diabetes probably have some of the greatest challenges related to health literacy. Counting carbohydrates, for example, requires patients to read food labels, to estimate the amount of carbohydrates in grams or ounces to determine serving sizes, and to apply math skills in multiplication and addition. In addition, interpreting values from a glucometer and relating these values to symptoms of hyperglycemia and hypoglycemia require an understanding of how diabetes works. Adhering to treatment regimens and preventing medication errors necessitates an ability to comprehend both physicians’ verbal instructions about medications and the written directions that accompany filled prescriptions.

All these components of diabetes management require proficiency in health literacy. For those who do not have above-average skills, this process can be especially daunting.

Additionally, patients’ confidence in controlling diabetes, known as self-efficacy, affects their willingness to change. Self-efficacy is especially important for patients being treated for prediabetes (previously known as impaired fasting glucose or impaired glucose tolerance) and for overweight patients undergoing preventive treatment for obesity. Initiating an exercise regimen with a dietary change can be challenging if a patient does not first understand what alterations he or she needs to make and how best to make them.

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**References:**
Low health literacy also creates a sense of shame and embarrassment. For many racial and ethnic minorities who already avoid the healthcare system because they have experienced mistrust and bias within it, this further affects their willingness to access care or exacerbates health disparities.

**Building effective communications**

Health literacy challenges can be difficult to identify because physicians cannot simply look at patients and know for sure whether they can read or write information provided to them? To begin with, physicians should relay health information to all patients in simple language and create a patient-friendly environment that is free from judgment.

The onus of responsibility, in part, rests on physicians to ensure that all patients walk away at least understanding the basics of their disease and its management, which can lead to greater patient self-confidence and involvement in the management of their diabetes.

To accomplish this, physicians must first honestly assess their current beliefs and practices concerning communication and health literacy. This may entail soliciting input from patients to understand how they feel about both the spoken and written health information they receive. Active listening is essential to gaining true understanding of patients’ needs.

Healthy People 2010, the national health promotion and disease prevention initiative, promotes interventions that improve health literacy for racial and ethnic minorities and it supports the development of materials that provide diabetes education at appropriate reading levels in a culturally appropriate manner. Fortunately, due to growing attention to health literacy and health disparities, many organizations created health literature at appropriate reading levels—6th grade and below—indicating those levels in sales and packaging information. Physicians should ascertain the reading levels of such materials prior to purchasing, displaying or handing them out in their practices.

While there is not much physicians

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**Check it out**

See “Building trust: DOs examine cultural competency in medicine,” in the May 2008 issue of The DO for information on the impact of culture on health outcomes and how physicians can strive to overcome cultural, language and communication barriers. For additional information visit www.do-online.org.
can do to directly improve the general literacy level of their patients, they can incorporate tools into their clinical practice that will help strengthen their patients’ understanding of their disease and self-management to gain better control of their diabetes.

As Johann Wolfgang von Goethe, one of the key figures of German literature once said: “Knowing is not enough; we must apply. Willing is not enough; we must do.”

**Tips to improve health literacy**

Following are 11 steps physicians can take to help improve health literacy:

- **Speak slowly when discussing a patient’s condition and your management of their healthcare.**

- **Use everyday language whenever possible, avoiding medical jargon.**

- **Use visual tools, such as videos, diagrams, models, photographs and drawings to illustrate your point.**

- **Provide small amounts of information at a time, and repeat what you have said at least once during the patient encounter.**

- **Use the “teach-back” method. Ask your patients to repeat your instructions in their own words.** When patients leave your office, hospital or emergency department, they should be able to tell you about the status of their diabetes. They should be able to explain any important issues that you are following—pertinent and current lab values such as A1c levels, abnormal urinalysis findings and blood pressure readings. They should also be clear about the additional tests they will need and where to get them; their insulin medication plan, whom to call if something is wrong; and the time and date of their next appointment.

- **For patients who speak languages you don’t speak fluently, always offer interpretation services via a phone-line or in-person interpreter. Do not assume that because someone is bilingual, he or she has the necessary literacy level to interpret medical information. Medical interpretation and translation services should always be certified.**

- **Encourage questions to create a patient-centered atmosphere. Welcome family and friends if the patient needs help understanding.**

- **Remind patients to bring all of their medications to their appointments to review problems with adherence, medication errors and interactions.**

- **Provide comprehensive diabetes education classes using materials culturally and linguistically appropriate for your patient population.**

- **Provide assistance with referrals for prevention services such as podiatry and retinopathy screening.**

- **Use reminders. If possible, follow up with a phone call after a new diagnosis or treatment change. Ask about self-management difficulties and remind patients of their appointments.**

**Resources worth noting**

For additional information regarding health literacy, check out the following resources:


**References**


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