

Low health literacy predicts poor adherence

Daniele Farrisi, MPH

Health literacy is a topic that has been gaining attention in HIV care as well as the healthcare field in general. More than just a buzz word, health literacy is emerging as an important factor in health disparities and adverse health outcomes.

In their *Healthy People 2010* report, the Department of Health and Human Services defined health literacy as “the degree to which individuals have capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹ Health literacy is not the same as prose literacy; it is more than just being able to read words on the page. A patient with adequate health literacy is expected to be able to interact with health information: put it in context, recognize important information, make informed decisions, and ultimately take action to improve or maintain health status.²

A patient’s level of prose literacy may serve as an indicator of his or her health literacy. However, the Institute of Medicine cautioned against relying too heavily on general prose literacy level as a proxy for health literacy level. They warn that many people who have adequate literacy skills in everyday contexts can lack the skills to effectively read and use health information.³ Information from the medical and scientific fields often contains terminology and subject matter that is unfamiliar to the average person. For this reason, even patients with high literacy skills in everyday situations often prefer to read health information that is presented at a more basic level.

Listed below are some examples of common health-related tasks that require a patient to draw upon his or her health literacy skills:

- Follow the instructions on a medicine label
- Calculate how many days worth of medication he or she has
- Fill-out registration forms
- Give his or her medical history
- Read an appointment slip
- Follow preparation instructions for a procedure
- Give informed consent
- Understand the nature of his or her diagnosis and corresponding treatment.

Consequences of low health literacy

Keeping in mind the tasks that require health literacy, it follows that low health literacy can have serious consequences. Patients who are unable to understand their medication instructions can have poor adherence to treatment. Low health literacy skills can make it very difficult for a patient to navigate the healthcare system, leading to missed appointments or worse, delayed entry into care. Patients with low health literacy are less likely to have a full understanding of their disease or treatment plan, which hinders their ability to give informed consent.⁴

Ultimately, patients lacking adequate health literacy skills often have poorer health status than patients who are able to effectively use health information. It has been shown that health literacy level is a stronger predictor of health status than education level, income, race/ethnicity, and even age.³

Patients with low health literacy report a lower level of understanding their health conditions and corresponding treatments than people with higher health literacy levels.³

Kalichman and his research group demonstrated this relationship between health literacy level and treatment knowledge specifically in HIV patients.⁶ His group showed that low health literacy is a predictor of poor adherence to highly active antiretroviral therapy (HAART).⁷ As such, HIV patients with low health literacy are more likely to have a detectable viral load and low CD4 count.⁸

Who has low health literacy?

The most recent National Assessment of Adult Literacy (NAAL), conducted by the U.S. Department of Education in 2003, contained a separate survey assessing participants' health literacy skills. Not only does this inclusion emphasize that health literacy is a topic of national importance, it also provides national data on the prevalence of poor health literacy and associated demographic factors. The NAAL report on health literacy found that 14% of the US adult population has below basic health literacy.⁴ People in this category had difficulty completing rudimentary tasks such as locating information in short texts and performing simple mathematical calculations.⁴

Although 14% may seem like a low prevalence of Americans with below basic health literacy, looking at the numbers based on certain demographic factors can paint a different picture. When the NAAL results were stratified by race/ethnicity, it was found that 41% of Hispanic adults, 25% of Native American adults, and 24% of African American adults have below basic health literacy.⁴ By age, those 65 years and older had the lowest health literacy scores.⁴ Differences in health literacy levels were also seen with respect to health insurance source. Recipients of Medicaid and Medicare had below basic health literacy prevalence of 30% and 27% respectively.⁴ Educational attainment was also found to have an association with health literacy level. 49% of adults with less than high school (or equivalent) education had below basic health literacy, compared to only 3% of adults who completed a four-year college degree or higher.⁴ No state-level health literacy data was available, but prose literacy data shows that residents of Southern states (including Arkansas, Louisiana, and Mississippi) have lower scores than the nation as a whole.³ Given the demographic factors associated with low health literacy, it is conceivable that some HIV treatment programs (particularly those in the public sector) may have prevalence of low health literacy well above the national average.

Clear health communication

An individual's health literacy is influenced by many societal factors, including the educational system and cultural aspects.³ Poor health literacy will not change without intervention both within and outside of the healthcare system. Within the healthcare system, the onus falls on providers to ensure that we communicate clearly with patients. Clear communication and consideration of health literacy level are part of the patient-centered model of care that is becoming a popular approach to medical care.³ All professionals who provide care to HIV-positive clients (doctors, nurses, case-managers, etc.) have the opportunity to improve communication by being aware of the barriers that low health literacy can create.

Even without expertise in the fields of health literacy and health education, care providers can take steps to make medical information more accessible and usable. When explaining information to a patient, it can facilitate understanding to use a variety of teaching methods (written, oral, visual) as preferred learning style varies by individual. Written materials are most effective when they are concise and employ everyday language.²

As experts in the field, healthcare professionals can easily fall into the trap of over-informing a patient. Although some patients may be interested to learn more about a subject, many will be overwhelmed by the extra information. Faced with an over abundance of information, patients with poor health literacy skills have difficulty discerning which points are most important and should be acted upon.²

To help providers and patients improve communication, the National Patient Safety Foundation developed the *Ask Me 3* tool, which reminds both parties of what information is most essential. *Ask Me 3* consists of the following three questions:

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?⁹

Patients are encouraged to ask these three questions, and providers are reminded to provide the answers in a way that the patient can understand.

How does a provider know that a patient understands the information given? Patients often do not speak up if they are confused or unsure of what to do. When a provider simply asks if the patient understands, the answer is often “Yes” regardless of whether or not it is true. A better way to get a sense of what the patient has understood is the “teach-back” method in which the client is asked to explain what has just been explained to him or her. Giving the patient the opportunity to repeat information in his or her own words allows the provider to confirm that he or she has communicated clearly or to try again in cases where the client does not recount the intended message.

Summary

Low health literacy can create significant barriers to effective care and treatment for HIV or any other health condition. Low health literacy is more commonly seen in traditionally marginalized populations: racial/ethnic minorities, the elderly, those with lower educational attainment. Regardless of a patient’s potential for low health literacy, clinicians should strive to make all health communication easily understood and easily acted upon. Care providers have the responsibility to ensure that each patient understands the actions to take in order to achieve his or her desired health outcome.❖

BIBLIOGRAPHY

1. U.S. Department of Health and Human Services. *Healthy People 2010*. Washington, DC: U.S. Government Printing Office; November, 2000.
2. Doak C, Doak L, Root J. *Teaching Patients with Low Literacy Skills*. 2nd ed. Philadelphia: J. B. Lippincott Company; 1996.
3. Neilsen-Bohlman L, Panzer A, Kindig D (eds.). *Health Literacy: A Prescription to End Confusion*. Washington, DC: The National Academies Press; 2004.
4. Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America’s Adults: Results from the 2003 National Assessment of Adult Literacy*. Washington, DC: U.S. Department of Education; 2006. NCES 2006-483. National Center for Education Statistics.
5. Williams MV, Davis T, Parker RM. The Role of Health Literacy in Patient-Physician Communication. *Journal of Family Medicine*. 2002; 34(5):383-9.
6. Kalichman SC, Cherry J, Cain D. Nurse-Delivered Antiretroviral Treatment Adherence Intervention for People with Low Literacy Skills and Living with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*. 2005; 16(5):3-15.
7. Kalichman SC, Ramachandran B, Catz S. Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy. *Journal of General Internal Medicine*. 1999; 14(5): 267-273.
8. Kalichman SC, Rompa D. Functional Health Literacy is Associated with Health Status and Health-Related Knowledge in People Living with HIV/AIDS. *Journal of Acquired Immune Deficiency Syndrome*. 2000; 25(4): 337-44.
9. Ask Me 3 [Internet]. Boston: National Patient Safety Foundation; [cited 2011 May 28]. Available from: <http://www.npsf.org/askme3/>.

Daniele Farrisi is Health Educator at the HIV Outpatient Program (HOP) Clinic of the LSU Interim Public Hospital in New Orleans.