Managing Managed Care: Health Literacy, HIV, and Outcomes

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Anyone who has had an encounter with our health care system in the past several years has probably been told to "come a little early for your appointment to complete the paperwork." On arrival, the patient has likely been subjected to an avalanche of paper to read and forms to complete and sign, all in the interest of providing optimal health care. Added to this is health information designed to educate and inform the patient about certain health issues, medication and treatment issues, diagnostic tests, outcomes, return appointments, and the like.

Do our patients really understand what they read? Do they adhere to our medical advice? Is the information that we give them understandable, and does that information result in better outcomes? Not necessarily, according to a 2004 report from the Institute of Medicine (IOM).

The IOM's estimates are sobering: 40 million Americans cannot read complex text at all, and another 90 million have difficulty in doing so.

This article uses the IOM report as a backdrop for a review of how health literacy affects HIV care, with specific examples from the literature.

WHAT IS HEALTH LITERACY?

The IOM report defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services in order to make appropriate health decisions."

The report includes many examples and vignettes to illustrate the point. One example from the ubiquitous privacy notices that we distribute to our patients: "Examples of such mandatory disclosures include notifying state or local health authorities regarding particular communicable diseases." Unfortunately, the problem of unfriendly, confusing written and verbal communication is found throughout our system of care. This leads to difficulty in navigating the health care system and can lead to poorer outcomes for patients with lower levels of literacy compared with patients who have higher levels of literacy.

In a comprehensive review of health literacy, Andrus and Roth write that our health care system places significant reading and comprehension demands on patients. These writers define literacy in overly complex terms 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 to develop one's knowledge and potential." They note that literacy describes a person's understanding of or knowledge about a particular topic (eg, "computer literacy"). In that context, "health literacy" is a group of skills that allow us to perform basic reading and numeric tasks for functioning in the health care environment and for acting on health care information. In short, health literacy helps persons navigate the health care system effectively.

Improving health literacy is a major public health goal for the 21st century, as health care becomes more complex and specialized. To date, trends suggest that patients with high blood pressure, diabetes, asthma, or HIV/AIDS who have limited health literacy skills have less knowledge of their illness and its management.

HEALTH LITERACY AND HIV: WHAT DO WE KNOW?

Although limited, a number of studies in the HIV literature show a causal relationship between limited health literacy and health outcomes.

HIV in General

Hicks and colleagues studied the association between health literacy and HIV/AIDS knowledge among patients seen at an inner-city, public hospital urgent care center (UCC). Using a prospective survey of patients offered an HIV test by their providers during a UCC visit, the investigators measured patients' health literacy level via the Rapid Estimate of Adult Literacy in Medicine (REALM) scale and assessed their HIV/AIDS knowledge with a 22-item questionnaire.

A total of 372 patients were enrolled. Among participants in this relatively young sample (55% younger than 40 years), 92 (25%) had a REALM score at or below a 6th-grade level and 122 (33%)
did not have a high school diploma. Mean HIV/AIDS knowledge scores differed significantly between patients with inadequate health literacy and those with marginal or adequate health literacy. In multivariate analyses, patients' REALM scores were positively associated with their HIV/AIDS knowledge even after adjusting for income, education, and risk perception. These findings demonstrate that HIV/AIDS knowledge is strongly associated with patients' health literacy in an inner-city population. These findings also reinforce the need for HIV prevention strategies to target populations with inadequate health literacy levels and to dispel misconceptions regarding HIV/AIDS that directly influence risk-taking behaviors and health care utilization.

**HIV Testing**

Barragán and colleagues found that patients with health literacy at a 6th-grade level or below were more likely to accept HIV testing than were patients with adequate health literacy. Furthermore, low health literacy was found to be associated with increased HIV testing after controlling for age and education.

Given the current dynamics of the HIV epidemic in the United States, which increasingly affects minority, inner-city populations, where low health literacy is frequently found, campaigns using low–health-literacy ads and brochures may actually increase the number of persons seeking HIV testing and counseling services. These data also suggest that new recommendations from the CDC for opt-out testing without written consent may be effective at increasing testing among the populations who need it most.

**Health Literacy and HIV Outcomes**

On the other hand, increasing the numbers of persons who are tested and who receive results is just the first step in the process. After patients with positive test results have been identified, low health literacy still represents a significant barrier to access to care and to understanding HIV infection and its treatment.

Kalichman and Rompa tested the hypothesis that persons with lower health literacy experience greater illness severity than persons with higher health literacy. A community-recruited sample of 339 HIV-infected men and women completed surveys and interviews that assessed functional health literacy, health status, AIDS-related disease and treatment knowledge, and health care perceptions and experiences. Medical records were available for chart abstraction of health status for a subsample of participants. Almost 25% of persons living with HIV/AIDS demonstrated difficulty in comprehending simple medical instructions and, therefore, lower health literacy. HIV-infected persons with lower health literacy had lower CD4+ cell counts and higher HIV RNA levels, were less likely to be taking antiretroviral medications, and reported more hospitalizations and poorer health than those with higher health literacy. In addition, after adjusting for number of years of formal education, lower health literacy was associated with poorer knowledge of one's HIV-related health status, poorer AIDS-related disease and treatment knowledge, and more negative health care perceptions and experiences.

The researchers concluded that health literacy is a significant factor in the health and treatment of persons living with HIV/AIDS and that interventions are needed to improve medical care and the health status of persons with HIV/AIDS who have lower health literacy.

**Treatment Adherence**

Kalichman and colleagues tested the significance of health literacy relative to other predictors of adherence to HIV/AIDS treatment. They studied a community sample of HIV-positive men (n = 138) and women (n = 44) who were on a triple-drug antiretroviral regimen: 60% were ethnic minorities, and 73% had received a diagnosis of AIDS.

Patients were assessed using a modification of the Test of Functional Health Literacy in Adults (TOFHLA), a comprehensive health and treatment interview that included 2-day recall of treatment adherence and reasons for nonadherence as well as measures of substance abuse, social support, emotional distress, and attitudes toward primary care providers.

Multiple logistic regression showed that education and health literacy were significant and independent predictors of 2-day treatment adherence after controlling for age, ethnicity, income, HIV symptoms, substance abuse, social support, emotional distress, and attitudes toward primary care providers. Persons with low literacy were more likely to miss treatment doses because of confusion, depression, and a desire to "cleanse the body" than were participants with higher health literacy.

The researchers concluded that interventions are needed to help persons of low health literacy adhere to antiretroviral therapies.

In a separate study, Kalichman and colleagues expanded literacy to a broader spectrum of health implications. In a group of 228 HIV-positive men and women recruited from AIDS service
organizations and HIV clinics, a lower health literacy score also related to misunderstanding the HIV transmission risk. Many participants believed that antiretrovirals could reduce the need to practice safe sex. This suggests that persons living with HIV or AIDS who understand less about their health also are at increased risk for transmitting the virus.

**Clinical Trials**

A study by Ives and colleagues \(^{12}\) examined the impact of an information booklet about HIV clinical trials on patients' knowledge and attitudes about HIV clinical trials. Fifty HIV-positive patients who attended the HIV clinic at a London hospital were randomized to receive either the standard trial information alone or the standard trial information plus a 16-page information booklet explaining the principles and procedures of HIV clinical trials. A questionnaire was used to assess the patients' attitudes regarding clinical trials at baseline and at 2 to 6 months after randomization. The researchers found that in both groups there was an increase in knowledge about clinical trials, but the increase was not significantly higher in one group than the other. The results indicate that although patients' knowledge and understanding of clinical trials improved, the recollection of the protocol details remained poor, possibly because of the material's high readability level and the patients' low-level reading skills.

Table 1 provides an example of a simplified consent form. Complex words or phrases in the original that have been simplified in the edited version are in bold type. The edited version could probably be further simplified by breaking the single paragraph into multiple paragraphs and/or bullet points. In any event, the simplified version is a remarkable improvement over the original.

**INTERVENTIONS TO IMPROVE HEALTH LITERACY**

The IOM report lists many suggestions for improving health literacy from a variety of sources. The IOM suggestions tend to be more global. Some of the more practical ones are abstracted in Table 2. The suggestions include reinforcing the message by having the patient "teach the educator." Important messages should be repeated periodically or at every visit. Also important is what we try to teach patients. Practical information about adherence and the significance of key laboratory parameters (eg, the desire for "high T-cell levels" and low viral levels) is more important than trying to teach the patient where and how HIV attaches itself to CD4+ cells. Also, brevity is critical. In the example in Table 1, the word count is reduced by half in the edited version and is more understandable. Patients with low literacy levels—and many patients with higher literacy levels—are unlikely to read a several-page, single-spaced document that uses complex words and phrases. More likely, they will sign it without ever understanding issues related to disclosure, privacy, or the like. Most documents used in health care probably could be limited to one side of one page and be either double-spaced or presented in bulleted format using simple language.

Finally, to be truly effective, health communication needs to involve the intended audience in the development of information/education products. Over the longer term, measures of the appropriateness/effectiveness of our health information can be used as quality measurement tools.

**SUMMARY**

In the United States, federal-level collaborative efforts have revolved around Healthy People 2010, \(^{13}\) which includes an objective to "improve the health literacy of persons with marginal or inadequate literacy skills."

The IOM report states that as long as consumer communication is marginalized within organizations and is an afterthought to the main agenda, health literacy will be ignored. Developing materials for consumers is a science. Unfortunately, there is not a single solution that fits everyone, and information is useful only if it is appropriate for the intended audience. Furthermore, sending a message is not enough; we need to be sure that our message has been properly conveyed. While the data linking health literacy to outcomes in HIV care are limited, the trends suggest that we can improve those outcomes through more effective communication with our patients.

**References:**


3. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health
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