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Raising Awareness: The Overlapping Epidemics of Low Health Literacy and HIV

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Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. vi). Health literacy includes measures of prose literacy, document literacy, and quantitative literacy (Kutner, Greenburg, Jin, & Paulsen, 2006). Unfortunately, according to the 2003 National Assessment on Adult Literacy, 88% of U.S. adults lack proficient health literacy (Kutner et al., 2006). While health-related studies commonly ask patients to indicate their highest levels of education, health literacy may actually be a better indicator of an individual’s ability to interpret health information; research has shown that the average person’s health literacy is even lower than the level predicted from their educational attainments (Kemp & Eagle, 2008). This means that a person may have more difficulty understanding health information than would be expected given his or her level of education. Overall, having low health literacy could affect the quality of care patients receive, as they may be unable to obtain, process, and/or understand the information they need to manage their health (Ratzan & Parker, 2000).

Health Literacy and Patient-Provider Communication

Low health literacy can negatively affect patient-provider communication. Studies have shown that patients with inadequate or marginal health literacy—compared to those with adequate health literacy—tend to report lower-quality interpersonal processes of care with their physicians (Schillinger, Bindman, Wang, Stewart, & Piette, 2004). These processes include the general clarity of conversations about health and the quality of explanations about their health care conditions (Schillinger et al., 2004). Patients with low health literacy also tend to have decreased participation in making decisions about their care (DeWalt,

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Boone, & Pignone, 2007; Mancuso & Rincon, 2006) and decreased satisfaction with the decision-making process (Schillinger et al., 2004). In fact, 45% of patients with low health literacy reported poor decision-making interactions with their physicians, as compared to only 26% of patients with adequate health literacy (Schillinger et al., 2004). All of these factors—clarity of health conversations, quality of health explanations, and level of patient participation in medical decision-making—are important contributors to effective patient-provider communication. Unfortunately, many providers may not be aware of their patients' health literacy needs or the extent to which health literacy can affect their patients' care (McCall & Wilson, 2015). Without this knowledge, providers will be ill equipped to adapt to their patients' needs and provide quality health care.

Health Literacy and Patient Preventive Care

In addition to affecting patients' relationships with their providers, low health literacy can also affect patients' health and their relationships with the health care system as a whole. Studies have found that individuals with low health literacy have a poorer understanding of their medical conditions, lower health statuses (Andrus & Roth, 2002; Parker et al., 1999), and worse health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). They are also less likely to use preventive health services (Andrus & Roth, 2002; Berkman et al., 2011). This may be because patients with low health literacy often feel a sense of shame seeking the care that they need due to anticipated discomfort, confusion, or embarrassment (Andrus & Roth, 2002). As a result, the health outcomes of these patients are often worse than for those with proficient health literacy (Berkman et al., 2011), most likely because they are less knowledgeable about how to prevent and manage disease.

Health Literacy and HIV Care

Several demographic groups most affected by low health literacy are also those disproportionately affected by HIV. These groups include adults who are low income, have lower levels of education attainment (Denning & DiNenno, 2010; Kutner et al., 2006), and are racial and ethnic minorities (Centers for Disease Control and Prevention, 2015; Kutner et al., 2006). Yet, despite the overlapping demographics between low health literacy and HIV, few studies have addressed the link between literacy levels and HIV prevention, diagnoses, and outcomes.

The negative effects of low health literacy are evident in HIV prevention and management, particularly for African Americans. Many studies have found that African Americans with low health literacy have limited knowledge of HIV transmission risks (Hicks, Barragán, Franco-Paredes, Williams, & del Rio, 2006; Kalichman et al., 2000). For low health literacy patients, poor patient-physician communication may negatively affect the ultimate quality of HIV prevention and care. These patients may be less likely to talk to their care providers about health problems and may feel less comfortable communicating their confusion or asking questions. This puts low health literacy patients at a disadvantage and prevents them from receiving the quality of care they need to properly prevent or manage HIV. A study conducted by Kalichman and colleagues (2000) found that lower health literacy patients with HIV infection were less likely to receive information from their care providers that they

could understand. Limited information is certainly a potential hindrance to a patient's ability to self-care for HIV and to engage in activities to prevent ongoing HIV transmission. In fact, in African Americans who have HIV, studies have shown that low health literacy was correlated with lower CD4+ T cell counts (Kalichman & Rompa, 2000). Additionally, low health literacy patients were less likely to receive antiretroviral therapy and were less likely to have undetectable viral loads, indicating the potential for worse health outcomes (Kalichman & Rompa, 2000).

Strategies for Improvement

There are multiple ways to improve the quality of health care for low health literacy patients. The Agency for Healthcare Research and Quality (AHRQ) recently published the *AHRQ Health Literacy Universal Precautions Toolkit*, which outlines strategies to help low health literacy patients manage their health (Brega et al., 2015). These include simplifying communication and making the health care environment easier for patients to navigate (Brega et al., 2015). They also proposed strategies to help health care workers ensure that patients understand health information. For example, the "teach back" method instructs health care providers to explain health information to patients and then ask the patient to re-explain the information back to the care provider (Brega et al., 2015). This ensures that the patient has understood and processed the right information and is a useful tool to facilitate productive conversations with low health literacy patients (McCall & Wilson, 2015). Additionally, health information could be made more accessible to low health literacy patients if written at a fifth grade reading level and using clear, large fonts and pictures to supplement the text (Sudore & Schillinger, 2009).

Changes such as these can improve the effectiveness of health information communicated to the public. They would also allow health care information (e.g., facts, recommendations, campaigns) to better target those who have low health literacy and, thus, have a greater need for supplemental information. Once written health materials are developed, tools such as the *Suitability Assessment of Materials* can be used with the target audience to assess readability and understandability of materials before they are distributed (Doak, Doak, Miller, & Wilder, 1994; U.S. Department of Health and Human Services, 2005).

Conclusion

According to the U.S. Department of Health and Human Services' (2010) National Action Plan to Improve Health Literacy, "everyone has the right to health information that helps them make informed decisions" (p. 1). In order to most effectively improve HIV prevention, care, and health outcomes for the most afflicted populations, HIV health information should be made more accessible to low literacy populations. Low health literacy is clearly a barrier to receiving the best possible health care, and its effects are particularly caustic in the case of HIV prevention and treatment. In battling the HIV epidemic in the United States, the correlations between those affected by low health literacy and HIV cannot be ignored. By improving the health care knowledge and experiences of low health literacy patients, these individuals can be empowered to better prevent and manage HIV, ultimately benefitting themselves and their communities.

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