Feature

Building Trust and Relationships Between Patients and Providers: An Essential Complement to Health Literacy in HIV Care

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*Health literacy is important for access to and quality of HIV care. While most models of health literacy acknowledge the importance of the patient–provider relationship to disease management, a more nuanced understanding of this relationship is needed. Thematic analysis from 28 focus groups with HIV-experienced patients (*n *= 135) and providers (*n *= 71) identified a long-term and trusting relationship as an essential part of HIV treatment over the continuum of HIV care. We found that trust and relationship building over time were important for patients with HIV as well as for their providers. An expanded definition of health literacy that includes gaining a patient's trust and engaging in a process of health education and information sharing over time could improve HIV care. Expanding clinical perspectives to include trust and the importance of the patient–provider relationship to a shared understanding of health literacy may improve patient experiences and engagement in care.*

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The ability of individuals to find, understand, and follow health-related information, known as health literacy, can have a substantial impact on health outcomes (Institute of Medicine Committee on Health Literacy, 2004). This may be particularly true for complex and chronic health conditions such as HIV. The U.S. Centers for Disease Control and Prevention has estimated that only 86% of people living with HIV (PLWH) in the United States have been diagnosed and know that they have the disease, and even fewer are linked to care, engaged in care, and prescribed life-saving antiretroviral therapy (Gardner & Young, 2014). They further estimated that only 30% of PLWH have achieved viral suppression, the main marker of controlled disease. Although many factors contribute to this situation, it is likely that health literacy plays an important role that is not yet fully understood.

The notion of health literacy has been defined in various ways, with early conceptualizations seeing it as a set of individual capabilities within the social context of a health care encounter. In 2004, the Institute of Medicine Committee on Health Literacy defined health literacy as, "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions" (2004, p. 32). Implementation of this clinical conceptualization of health literacy (Pleasant & Kuruvilla, 2008) focused largely on patients' deficiencies in capabilities to direct their own health, seeing the lack of health literacy as a risk for poor health. More recent public health models of health literacy have examined health literacy as an asset, and as an outcome of health-related education and communication efforts (Nutbeam, 2008), but the exact relationship has not been empirically demonstrated. Although health literacy is clearly an important factor in health outcomes, neither the clinical nor the public health definitions fully acknowledge the relational aspects of the concept.

For most people, health literacy is closely interconnected with socioeconomic status, education levels, age, and race/ethnicity (Kutner, Greenberg, & Baer, 2006; Paasche-Orlow & Wolf, 2007; Wawrzyniak, Ownby, McCoy, & Waldrop-Valverde, 2013). Many individuals with low health literacy are marginalized within society based on these characteristics, and may also be ashamed of their lack of literacy (von Wagner, Steptoe, Wolf, & Wardle, 2009). Because of the stigma associated with HIV, PLWH may be doubly concerned about revealing their lack of health literacy within the clinical setting. In one recent study, investigators found that a high perception of social stigma was a significant independent predictor of poor medication adherence for those individuals with low literacy (Waite, Paasche-Orlow, Rintamaki, Davis, & Wolf, 2008). And, for people of color, historical events may be another barrier to accessing health care. Relevant patient and provider communication varies with levels of health literacy as the person with low health literacy may not know what questions to ask or may not fully comprehend what providers are explaining to them. For this reason, the patient–provider relationship (Paasche-Orlow & Wolf, 2007) may be particularly important to ensuring that patients receive the