Doing What You're Told: It's Not That Simple

Inge B. Corless, PhD, RN, FNAP, FAAN*

Key words: *health literacy, HIV, professional care team member*

The expectation of health care practitioners is that patients will follow through on their recommendations—in effect, that patients will do as they've been told. Of concern to nurses and other providers is patient adherence to appointments and medications. While adherence to HIV medications has led to improved individual well-being, antiretroviral therapy (ART) also has been shown to reduce transmission to uninfected sexual partners (Cohen et al., 2011). Thus, lack of ART adherence is not only a danger to the patient's health, but it may have implications for the larger community.

Although members of patients' health care teams strive to educate them about the importance of adherence to ART and medical appointments, they encounter many challenges to providing such education, due, in part, to problems with health literacy. Health literacy is defined as, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman, Panzer, & Kinding, 2004, p.2). While an important issue in educating people living with HIV (PLWH) about their disease and treatments, health literacy is only one of the challenges confronting nurses attempting to inform their patients about HIV infection and the value of adhering to ART regimens.

The numerous challenges became evident in a recent multisite focus-group study in which we investigated the concept of health literacy with professional care team members (PCTM), nurses, social workers, pharmacists, and providers (physicians and nurse practitioners), as well as with separate groups of male and female HIV-infected patients (Corless et al., 2015). The same script of questions about health literacy was used with the PCTM focus groups held in Gabarone, Botswana, and in four U.S. cities (Boston, MA; New York, NY; San Francisco, CA; and Wilmington, DE). The principal investigators for each site participated in a 1.5-day training led by two investigators with expertise in qualitative methods to ensure consistency in the method used in the collection of data with various focus groups. Part of that training included having site principal investigators lead mock focus groups. Prior to collection of data, each site's institutional review board approved the research. Written informed consent was obtained from each participant prior to initiating this study. Recordings of data were transcribed verbatim and imported into Atlas Ti (Berlin, Germany), a software program for managing qualitative, textual data (Corless et al., 2015). A coding professional coded data and elicited themes. These codes were used together with reading the textual data repeatedly to identify the themes and expressions reported in the paper by Corless et al. (2015).

PCTM Focus Group Study Findings

The three major barriers related to health literacy identified by Corless et al. (2015) were: (a) individual barriers, (b) provider-related barriers, and (c) system-

*Inge B. Corless, PhD, RN, FNAP, FAAN, is a Professor, School of Nursing, MGH Institute of Health Professions, Boston, Massachusetts, USA. (*Correspondence to: icorless@mghihp.edu).*

JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE, Vol. 27, No. 2, March/April 2016, 117-120
http://dx.doi.org/10.1016/j.jana.2015.12.002

level barriers. A number of relevant subthemes were also identified, particularly for individual barriers. The discussion below highlights some of the individual- and systems-level barriers that inhibit a patient's attention to HIV education.

Individual Barriers

Individual challenges included physical needs, such as a medical issue or pain management, which can be a patient's top priority. PCTM focus groups also identified psychological challenges, including a patient's mental stability, as potential barriers to HIV education. Another individual challenge confronting the PCTM is the person newly diagnosed with HIV. Given that the patient is coping with and adjusting to a new diagnosis, s/he may not be able to hear anything more than the diagnosis. This response is similar to that of any patient confronting a new diagnosis with a life-threatening disease.

Participants in the PCTM focus groups also raised the issue of a lack of basic literacy skills (Corless et al., 2015). One gave the following example:

> … we have a patient and we went over, how do you get refills, what do you ask, what do you check the pharmacy for, how do you make sure you have everything you need. He happened to be illiterate but what we didn't realize was that–it took us three or four visits to realize, you have to go to the kiosk at the pharmacist first, put in your name, print out a ticket, get the ticket, and then sit in line and wait for your number to be called–to get your medication. And while he could talk to the pharmacist about everything, he didn't know how to use the kiosk. So for us he was saying, "Sure, sure, sure—I know how to do this." But then we realized he wasn't picking up his medications because of the kiosk issue … if we hadn't kept asking about that, and kept reassessing, we would not have known that he wasn't picking up his medications. (Corless et al., 2015, ¶22)

Incorrect information obtained from the Internet or elsewhere also was considered a barrier to HIV education. PLWH may or may not be able to discriminate between accurate and inaccurate information. Further, there may be behavior issues such as a lack of planning and poor organization skills, resulting in missed appointments. PLWH substance abuse was also noted to be a concern for PCTM attempting to teach patients about HIV. In addition to substance abuse, perhaps one of the most profound issues concerned socioeconomic factors. The need for housing was just one of such factors. As one PCTM stated:

> … for me, working in a health center and in a place where … most people live 300-400% below the poverty line, to me the biggest eye-opener was … that right now someone might not be focused on their HIV, their focus is … making sure the electricity doesn't go off, or that they have food on the table. (Corless et al., 2015, ¶33)

System-Level Barriers

Eligibility for funded care was a systems-level issue that also contained a socioeconomic subtheme. PCTM focus group participants noted that patients who were partially employed might have $8,000 in co-pays on a $20,000 salary. Another systems-level issue identified in the focus groups was that the literacy levels of written materials provided for PLWH were often complex and complicated by the fact that they might not be in the language of the recipient. The failure to communicate effectively with their intended recipients through written materials complicated the efforts and increased the challenges of PCTM in educating HIV-infected patients.

Overcoming Impediments to HIV Education

Given these sorts of barriers to providing education to PLWH, what options are there to address these issues, most of which are not new to clinicians and researchers? And unless support functions are developed and/or coordinated to address some of the concerns noted in this research, such as housing, food, and other types of psychosocial, behavioral, and financial issues, the PCTM will forever be playing catch-up in the challenges to helping patients to be informed about their diseases. Such support also has the potential to keep patients engaged in care and to continue involvement with the health care team.