Going the Extra Mile for Retention and Re-engagement in Care: Nurses Make a Difference

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It's never crowded along the extra mile.
Wayne Dyer (n.d.)

An estimated 942,000 persons in the United States with HIV are aware of their infection (Centers for Disease Control and Prevention [CDC], 2011). According to published studies, approximately 77% of persons diagnosed with HIV were linked to care within 3–4 months of diagnosis (Marks, Gardner, Craw, & Crepaz, 2011; Torian & Wiewel, 2011), and 51% were retained in ongoing care (Hall et al., 2011; Marks et al., 2011; Torian & Wiewel, 2011; Tripathi, Youmans, Gibson, & Duffus, 2011).

The trilogy of HIV outpatient care includes the following essential processes for optimal patient outcomes: (a) linkage to care, (b) retention in care, and, when necessary, (c) re-engagement in care. As important components of successful HIV management and prevention strategies, these processes are often discussed together. More effort is needed to ensure that patients who are successfully linked to care remain in care. Clinic and/or practice personnel from a multitude of disciplines can have a significant impact on achieving high patient linkage and retention rates.

Continuing engagement with regularly scheduled continuity visits is necessary for optimal treatment of all HIV-infected persons, including patients not yet taking antiretroviral therapy (ART; Cheever, 2007; Marks et al., 2011). Retention in HIV care is particularly critical for the provision of effective ART, suppression of viral load and cumulative HIV burden, evaluation of disease progression, and maintenance of good health for persons living with HIV (Mugavero et al., 2012). However, ongoing retention in HIV care is not always consistent, and some patients repeatedly cycle in and out of care (Christopoulos, Das, & Colfax, 2011). Identifying those patients or patient groups that are at greatest risk for not being retained in care is important to target available resources and efforts and thereby help avoid losing patients from care (Horstmann, Brown, Islam, Buck, & Agins, 2010).

Patients may not attend medical appointments for a variety of reasons. Commonly cited reasons include: conflicts with work schedules, limited financial resources for copays and automobile gas, lack of reliable child care or transportation, family illness, domestic violence, homelessness or unstable housing, stigma, fear of unintended disclosure, and comorbid conditions such as substance use and mental illness. Whereas retention and re-engagement in care are predominantly practice- or clinic-based components of HIV management and prevention strategies, HIV nurses can make a big difference through individual enterprise and by positively influencing their organizations' retention and re-engagement systems, mechanisms, and protocols. For a long time, nurses have been pursuing a variety of methods to assist HIV-infected patients to access health care (Andersen, Smereck, Hockman, Ross, & Ground, 1999; Andersen et al., 2007). The following suggestions and recommendations are based on nursing practice at the 1917 HIV Outpatient Clinic at the University of Alabama at Birmingham School of Medicine.

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Individual Nursing Approaches to Retention in Care

At our clinic, we use visual reminders extensively to remind patients and staff about the importance of engagement in care to improve health outcomes. We previously used handout flyers but found that patients were discarding them. Our visual messages consist mainly of nicely framed posters, which are placed in clinic examination rooms, the laboratory, and hallway. Patients can easily read them. Figure 1 provides an example of a visual message from the CDC that can be placed in your clinic or practice. Nurses are very creative. Additional posters can be developed to present and reinforce retention in care and re-engagement messages for use in other clinics or practices. A local clinic-sponsored contest (or even a national Association of Nurses in AIDS Care-sponsored contest) could be undertaken as an innovative way to develop new posters and other visual aids.

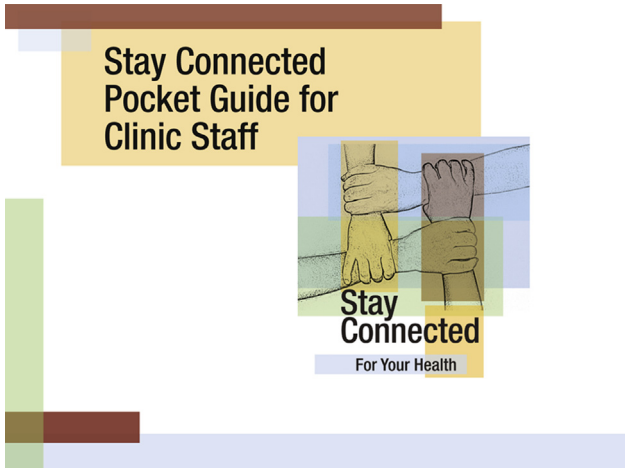

Figure 1. Stay connected for your health. Courtesy: Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA).

Nurses constantly interact with the electronic medical record (EMR). Our EMR provides nurses with a wealth of information about the patient's past and pending appointments, including appointments that were cancelled, not kept, or not even scheduled; 1917 Clinic nurses use this information when answering patient telephone calls. For example, using EMR when a patient calls for any reason (e.g., sick-call problem, laboratory results, prescription refill request, reschedule an appointment), a nurse might say: "I see that you haven't been here for a long time. You've missed four appointments. How can we help you come to clinic and make sure that you keep your appointments?" Nurses are facilitators; they make things happen. With respect to retention in care, it is critical for nurses to go the extra mile and speak candidly with patients whenever possible, not only complimenting them for coming to clinic but also rescheduling missed appointments. Having the EMR available to the nurse for all patient telephone interactions is extremely helpful.

The first clinic visit is crucial to retention in care. At the 1917 HIV Outpatient Clinic, every new patient and patients re-engaging in care after a gap of 12 months or longer must attend a new patient orientation (NPO) visit. During NPO, the patient is informed about our patient-centered medical home model of care and the members of his/her assigned team. In addition to the patient, the other members of the team include a primary provider (nurse practitioner or infectious diseases physician), a nurse, a social worker, and an attending physician. A member of the social work staff facilitates NPO visits. Patient expectations and clinic routines for the first provider visit are reviewed with the patient. Patients are highly encouraged to keep all appointments, to notify the clinic promptly if they will not be able to keep their scheduled appointments, and to call promptly after any missed visit to reschedule another appointment as soon as possible to prevent prolonged appointment intervals. New and re-engaging patients receive a patient folder, which contains the aforementioned and other important information. At the first provider visit, the assigned nurse introduces him/herself, explains to the patient the role of the nurse as the patient's principal clinic contact, and gives the patient one of his/her business cards. Even patients who are homeless demonstrate the ability to retain the business card in the patient folder or in a purse or wallet for easy reference. Patients are also informed how to contact other members of the team.

Nurses offer ongoing discussions about the need to remain in care and help patients identify problem-solving strategies to empower their patients to achieve