

Perspective

Retention in HIV Care: What the Clinician Needs to Know

Poor retention in HIV disease care is a common, modifiable risk factor associated with poor outcomes, including higher rates of antiretroviral therapy failure, increased HIV transmission risk behaviors, and worse survival. Predictors of poor retention include younger age, female sex, racial or ethnic minority status, low socioeconomic status, no usual source of health care, less advanced HIV disease, fewer non–HIV-related comorbidities, and greater unmet psychosocial needs. Thus far, there have been few published randomized trials of interventions to improve retention. The fact that most clinics are understaffed and underresourced in a flat funding environment raises serious questions about the translation, dissemination, and sustainability of interventions found to be successful in the research setting. Efforts to improve retention in care should incorporate informational, motivational, and behavioral skills components. Practical steps can be taken by clinics to improve retention. This article summarizes a lecture by Thomas P. Giordano, MD, MPH, at the 13th Annual Clinical Conference for the Ryan White HIV/AIDS Program held in Washington, DC, in August 2010.

Retention in HIV care is a modifiable risk factor that profoundly affects outcomes of HIV disease at the individual and population levels. It is clear that any test-and-treat strategy is not going to be effective unless strong attention is paid to linkage to and retention in care. As stated recently: “Significant barriers impede the efficient movement of a patient infected with HIV from diagnosis to care.... As with voluntary testing, a public health-systems research agenda will be needed to define efficient and effective means of entering and retaining patients in care.”¹

From the clinic perspective, retention also affects quality of care measures, including those used by the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) and HIVQUAL (a national project for HRSA grantees to build quality improvement). Retention in care will also impact the provider’s and the

clinic’s productivity and efficiency. Fortunately, HIV care clinicians can effect substantial changes in retention in care.

Magnitude of the Problem

Findings in several studies illustrate the extent of the problem in retaining patients in HIV care. The HCSUS (HIV Cost and Services Utilization Study), a landmark HIV health services study performed in the late 1990s, found that one-third to two-thirds of persons infected with HIV in the United States were not in regular care, with half of these persons knowing their HIV serostatus.² A Centers for Disease Control and Prevention (CDC) study showed that 17% to 40% of persons who knew their HIV serostatus were not in regular care.³ A study in British Columbia found that 69% of 554 nonaccidental deaths evaluated from 1997 to 2001 were HIV related; among the persons dying of HIV-related causes, the estimated median proportion of time receiving antiretroviral therapy before death was 20%, and more than 50% were not taking antiretroviral therapy at the time of death.⁴ The ARTAS (Antiretroviral Treatment Access Study) showed that 40% of patients newly diagnosed with HIV infection did not see an HIV care practitioner within

6 months of diagnosis, and approximately 50% did not see a practitioner during both the first and second 6-month intervals after diagnosis.⁵

Impact on Outcomes

Numerous studies describe the adverse impacts of poor retention in care on patient outcomes.^{6–14} In particular, poor retention in care is associated with the following outcomes:

- Decreased likelihood of receiving antiretroviral therapy
- Higher rates of antiretroviral therapy failure
- Increased HIV transmission risk behavior
- Increased hospitalization rates
- Worse survival

An example of poorer outcome associated with initial poor retention is provided by a study using nationwide Veterans Affairs data for patients who initiated antiretroviral therapy in the late 1990s.¹⁰ Only patients who had at least 1 visit and remained alive during the first year after receiving their antiretroviral therapy prescriptions were included in the analysis. Among 2619 such patients, 64% (n = 1685) had an HIV care visit in each of 4 quarters during the first year, 18% (n = 479) in each of 3 quarters, 11% (n = 286) in each of 2 quarters, and 6% (n = 169) in only 1 quarter. Patients with greater initial retention in care had the greatest survival over 5 years of follow-up, and patients with the worst initial retention had the poorest survival (Figure 1). After adjustment for other risk factors (age, race or ethnicity, baseline CD4+ cell count, antiretroviral therapy use, hepatitis C virus [HCV] coinfection, non–HIV-related comorbidities, excessive alcohol use, hard-drug use, and social instability), the hazard ratio (HR) for death compared with patients who had

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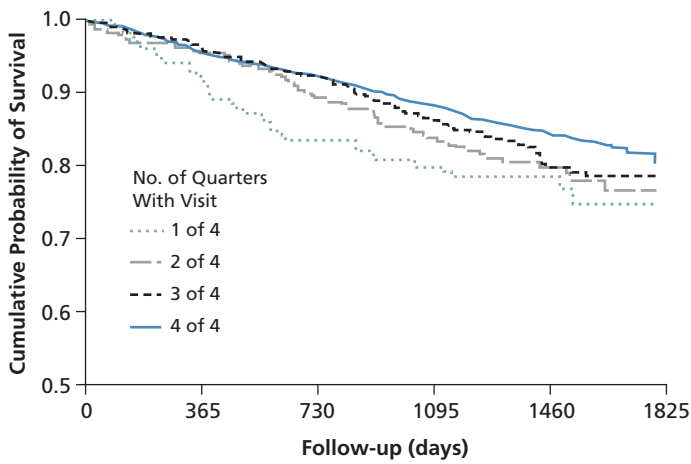


Figure 1. Cumulative probability of survival according to the number of quarters with an HIV care visit during the first year after receipt of an antiretroviral therapy prescription. Based on Veterans Affairs data for patients initiating antiretroviral therapy in the late 1990s. Adapted from Giordano et al.¹⁰

a visit in each quarter was 1.41 ($P < .01$) for those with visits in 3 quarters; 1.68 ($P < .001$) for those with visits in 2 quarters; and 1.94 ($P < .001$) for those with a visit in 1 quarter. Patients in the group with the worst retention had nearly twice the risk of death as those with the best initial retention in care.

Predictors of Poor Linkage and Retention

Predictors of poor linkage to and poor retention in HIV care include demographic, disease severity, psychosocial, and ancillary services use factors (Table 1). An example of difficulties in relinking with and staying in care is provided by a recent study of patients' accessing of antiretroviral therapy after release from prison in Texas. In Texas, HIV-infected inmates are released with a 10-day supply of antiretroviral drugs. Among 1215 HIV-infected persons released from prison between 2004 and 2007, the proportion with antiretroviral therapy prescriptions filled by 10 days was approximately 5%, increasing to only approximately 18% at 30 days, and 30% at 60 days.¹⁵

Retention in care is more likely when patients are engaged in the care process. As shown in the HRSA Special Projects of National Significance (SPNS) Outreach Initiative studies (a group of prospective, nonrandomized

intervention studies), baseline engagement in care predicts, but not completely, subsequent engagement in care. In this study, the proportions of patients engaged in care at 12 months were 75.9% among 290 engaged in care at baseline, 59.6% among 260 "somewhat" engaged in care at baseline (odds ratio [OR] compared with those engaged at baseline, 0.52; $P = .002$), and 52.9% among 68 not engaged at baseline (OR, 0.41; $P = .001$).¹⁶ Although persons presently in care were more likely to remain engaged in care, it is noteworthy that one-fourth of the patients "engaged" at baseline were poorly engaged at 12 months.

Interventions

The study of interventions to retain patients in care is a fairly young science in the HIV disease field and has lagged behind the study of interventions to improve medication adherence. Few randomized trials have been reported thus far, although there is a considerable amount of ongoing work in this area. Published studies include ARTAS, which was a randomized study of care linkage rather than retention. This study showed that 90-day intensive case management using a strength-based approach produced a 12% to 15% improvement in successful linkage to care.⁵ This approach also proved transferrable from the research setting to the clinic setting, and it may soon be promoted by the CDC as an evidence-based intervention for improving linkage.

The HRSA Ancillary Services Use studies, which used retrospective observational data, found that use of ancillary services reduced patients' unmet

needs and resulted in better retention in care.¹⁷ In addition to finding that baseline engagement in care predicts subsequent engagement, the HRSA SPNS Outreach Initiative studies found that factors associated with retention at 12-month follow-up (with analysis adjusted for race and most recent CD4+ cell count) were discontinued street-drug use, decreased structural barriers, decreased unmet needs, and no negative health beliefs about HIV disease and care.¹⁶

Ongoing studies in the area include evaluation of patient navigation and peer outreach approaches (used by some sites in the SPNS initiative). A major collaborative program sponsored by HRSA-HAB is under way in 5 states (Connecticut, New Jersey, Pennsylvania, Texas, and Virginia) and in-

Table 1. Predictors of Poor Linkage to and Retention in HIV Care

Demographic Characteristics
Younger age
Female sex
Racial or ethnic minority status
No insurance or public health insurance
Lower socioeconomic status
Rural residence
No usual source of health care
Disease Severity
Less advanced HIV disease
Fewer non-HIV-related comorbidities
Psychosocial Characteristics
Substance dependence
Low readiness to enter care
Less social support
Ancillary Services Use
Less use of ancillary services (eg, case management)
Greater unmet social services needs

cludes assessment of retention-in-care strategies, as do a number of current research projects funded by the National Institutes of Health. Perhaps most notable at present is a randomized, controlled intervention jointly sponsored by HRSA and CDC in 6 clinics in Baltimore, Birmingham, Boston, Houston, Miami, and New York City. This study, which is enrolling 300 patients per site, will compare retention outcomes using an intensive intervention, a limited intervention, or usual care. The intervention goes beyond a straightforward case-management approach to include skills building with motivational interviewing and a strength-based approach to add value to the services already available at the study clinics. The study is just completing enrollment, and results will be available in 2013.

Challenges in Retention

Challenges in assessing and improving retention in HIV care include measurement issues; patient-, provider-, and system-level issues; and staffing and resource issues. Currently, there is no single best way to measure and define retention. Methods include counting missed visits (eg, using an absolute count or a minimum number of missed visits), appointment adherence (proportion of scheduled visits that are kept), persistence or constancy (a minimum standard of visits per time period; eg, attending at least 1 visit every 90 days), and gaps in care (eg, no 6-, 9-, or 12-month gaps in visits).

The HRSA-HAB measure of retention requires at least 2 visits in a year, at least 90 days apart (Figure 2). In the figure, Patient A, for example, missed 1 of 5 scheduled visits and thus had appointment adherence of 80%, had 100% constancy, had no gap in care, and met the HRSA-HAB criterion. Patient D had only 1 missed visit (adherence 67%) but missed a scheduled visit in the second quarter and had no scheduled visits in the last 2 quarters; thus, this patient had low visit constancy and a gap in care and failed to meet the HRSA-HAB criterion. A method of measuring retention should be selected that best suits the objectives

and needs of the researcher, clinician, or clinic.¹⁸

At the patient level, challenges include:

- Changing retention-adherence behavior, in a manner similar to changing medication-adherence behavior
- Improving trust, including improving patient communication with the clinic and removing the stigma associated with requiring care for HIV infection
- Removing structural barriers and addressing unmet needs (eg, transportation, housing, child care, and financial needs)
- Reducing substance dependence

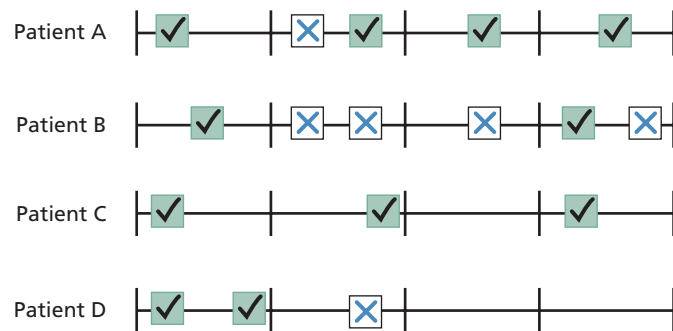
With regard to the effect of reducing structural barriers, a study conducted in Chicago randomly assigned hospitalized homeless persons to receive either immediately secured housing at the time of discharge or usual care including housing assistance. The study found a statistically significant improvement in the composite outcome of sur-

vival and CD4+ cell count greater than 200/ μ L in the housing-first group.¹⁹

Challenges at the practitioner and system levels include:

- Improving practitioner communication and decision making
- Improving appointment-scheduling systems (eg, considering open-access systems)
- Improving clinic access, for example, by extending clinic hours
- Improving processes for maintaining accurate contact information
- Defragmenting health insurance and health care processes
- Reorganizing health care delivery for HIV-infected patients to meet the demands of a population requiring care over decades
- Addressing staffing and resource limitations

Financial constraints limit our ability to address some of these challenges.



Patient	Number of Missed Visits	Appointment Adherence	Visit Constancy	Gap in Care?	Meets HRSA-HAB Criterion?
A	1 of 5	80%	100%	No	Yes
B	4 of 6	33%	50%	Yes	Yes
C	0 of 3	100%	75%	No	Yes
D	1 of 3	67%	25%	Yes	No

Figure 2. Examples of measuring retention in care. Top, quarterly tracking of attended appointments (checked boxes) and missed appointments (X). Bottom, various measures of the tracking results for Patients A through D. HRSA indicates Health Resources and Services Administration; HAB, HIV/AIDS Bureau. Adapted from Mugavero et al.¹⁸

Data from studies of interventions that have shown benefits highlight the fact that clinics are understaffed and under-resourced. For example, estimates from ARTAS were that each of the case managers involved could provide care for approximately 120 clients per year. In Houston, there are approximately 1500 new diagnoses of HIV infection annually, indicating the city's need for 10 to 15 new case managers per year. The SPNS outreach initiative had an average of 4.9 contact hours per new client per month for 12 months. Assuming a workload of 168 hours per month, each outreach worker could serve 34.3 clients.

At Thomas Street Health Center in Houston, Dr Giordano and colleagues care for approximately 300 patients with newly diagnosed HIV infection per year, indicating a need for an additional 9 dedicated outreach workers. The SPNS study found that their intervention was effective when there were at least 9 contacts within 90 days. At Thomas Street Health Center, approximately 1000 patients (of more than 4000 total) have poor retention; assuming 15 minutes per contact, taking care of this population would require 5 additional dedicated outreach workers. In the current, flat funding environment, the absence of necessary resources to implement interventions that have been shown to be successful raises serious questions about the translation, dissemination, and sustainability of intervention strategies.

What We Can Do Now

Neither patient admonishment nor information alone is successful in keeping patients in HIV care. One model for retention in care posits that information, motivation, and behavioral skills determine retention in care. The model was first developed to promote condom use²⁰ and later adapted for medication adherence; now it has been adapted for retention in care. In essence, people who know they have HIV infection know they should seek health care, but for many, this behavior will not be achieved without (1) support that motivates

them to seek and stay in care and (2) the behavioral skills that enable them to enter and navigate the health care system. Thus, steps toward improving retention can be made on 3 separate fronts: improving information, improving motivation, and improving behavioral skills.

Clinics can implement 10 measures immediately to some degree to improve retention in care: (1) Track no-show rates and rates of patients who leave care; the first step in improving retention is to measure it. (2) Examine processes of retention with the understanding that bringing patients back is much more difficult once they are completely out of care. (3) Work with personnel from hospital emergency departments and inpatient services, community-based organizations, public health agencies, jails and prisons, and other HIV care practitioners to identify patients poorly retained in care and to build and strengthen relinkage processes. (4) Build and strengthen outreach or peer-navigator programs. (5) Working with existing resources, highlight the importance of retention to staff and have staff members advocate with patients for retention.

Additional measures to implement include those focused on the patient: (6) Improve the patient's experience; good "customer service" likely leads to return visits. (7) Minimize unmet psychosocial needs by strengthening receipt of substance-use, mental health, case-management, and social services. (8) Minimize the time between scheduling appointments and the date of appointments. (9) Do a pilot trial of wider appointment availability and consider open appointment access if suitable. (10) Remember that patients generally know they should be in care. Corollaries to this recognition are: (a) reminders help but are likely not enough; (b) admonishment will not work and neither will encouragement alone; and (c) problem solve collaboratively with patients just as in attempts to improve medication adherence.

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