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.”

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.

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. 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. 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. 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.

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. 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
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.18

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

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

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
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.

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

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**Table 1. Examples of measuring retention in care.**

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

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**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 underresourced. 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 use 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.

Presented by Dr Giordano in August 2010. First draft prepared from transcripts by Matthew Stenger. Reviewed and edited by Dr Giordano in January 2011.

Financial Disclosure: Dr Giordano has no relevant financial affiliations to disclose.

References

11. Berg MB, Salien SA, Mimiaga MJ, Grasso C, Boswell S, Mayer KH. Nonadherence to medical appointments is associated with increased plasma HIV RNA and decreased CD4 cell counts in a community-


The following article in this issue is associated with CME credit:
Giordano TP. Retention in HIV care: what the clinician needs to know.
Top Antivir Med. 2011;19(1):12-16

Instructions
This journal-based continuing medical education (CME) activity provides a review of retention in HIV care. To complete the activity, the learner is instructed to:
• Read the article
• Review a selection of the references
• Reflect on how the information might be applied to the clinical practice
• Take the posttest
• Complete the CME claim form and send it to the IAS–USA office.

Learning Objectives
Upon completion of this activity, learners will be able to describe results of recent research on retention in HIV care and the potential clinical implications for their HIV-infected patients.

Accreditation Statement
The IAS–USA is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

The IAS–USA designates this journal-based CME activity for a maximum of 1.5 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Intended Audience
This activity is intended for physicians involved in the care of patients infected with HIV or other viruses. It is also relevant to nurse practitioners, physician assistants, nurses, and other health professionals who provide care for people with viral diseases.

Conflicts of Interest
IAS–USA policy requires that the IAS–USA resolve any real or apparent conflict of interest that may influence the development, content, or delivery of its educational activity prior to the activity’s being delivered to learners. The IAS–USA has several mechanisms for resolving conflicts of interest in educational activities. If the conflict of interest cannot be resolved through these mechanisms, the party will be removed from the activity.

Dr Giordano has no relevant financial affiliations to disclose.

Posttest Questions
Check the box next to the single best answer to each of the questions below. To earn CME credit, you must receive a passing score of 80% or more correct.

1. Which of the following new patients to your clinic is most likely to have a problem with retention in HIV care?
   - A. A 33-year-old, asymptomatic, antiretroviral therapy–naive man with a CD4+ cell count of 380/µL
   - B. An HIV-infected person who just was admitted to the hospital with cryptococcal meningitis
   - C. A person who is transferring care to your clinic and whose partner is HIV-infected

2. The Health Resources and Services Administration HIV/AIDS Bureau (HRSA-HAB) standard for retention in HIV care requires:
   - A. At least 1 visit each quarter-year
   - B. At least 3 visits per year, with the first and last visits at least 90 days apart
   - C. At least 2 visits per year, with the first and last visits at least 90 days apart
   - D. Fewer than 25% missed visits over 1 year

3. Which strategy will likely be the most effective in helping a homeless patient stay in care?
   - A. Educating the patient about the importance of HIV care and antiretroviral therapy
   - B. Assisting the patient in meeting his housing needs
   - C. Encouraging and motivating the patient to stay in HIV care
   - D. Withholding antiretroviral therapy until the patient makes at least 3 appointments in a row

4. A patient’s problem with retention in care is most likely to be solved by:
   - A. The physician
   - B. The patient
   - C. A case manager
   - D. A collaboration between the patient and care team

5. Which of the following is an example of a structural barrier to HIV care?
   - A. Side effects from antiretroviral therapy
   - B. Clinic hours limited to 2 days per week
   - C. Heavy “crack” cocaine use
   - D. Low trust in a health care practitioner

This CME activity is offered from March 25, 2011, to March 25, 2012. Participants who receive a passing score on the posttest and submit the registration and evaluation forms are eligible to receive credit. Physicians (MDs, DOs, and international equivalents) may receive CME credit for completing this activity. Nonphysician health care practitioners will receive a certificate of attendance.
To receive CME credit, please complete the posttest, participant information, and evaluation forms and return all to the IAS–USA.

### Participant Information

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<td>City</td>
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The amount of time (in hours) I spent on reading the article, reviewing the references, reflecting on how the information might be applied to the practice, and taking the posttest was:

- ☐ 1
- ☐ 1.5
- ☐ 2
- ☐ 3
- ☐ other ____

### Evaluation

Please complete the following evaluation form for the *Topics in Antiviral Medicine* article for which you are currently claiming CME credit:

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<thead>
<tr>
<th>Content and presentation of article</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
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Please list 3 specific measurable changes you will make in your practice based on the information presented in the article:

1. __________________________________________________________________________________________________________________
2. __________________________________________________________________________________________________________________
3. __________________________________________________________________________________________________________________

Which parts of this journal-based CME activity could have been improved?
_______________________________________________________________________________________________________________________
_______________________________________________________________________________________________________________________

Other comments (please feel free to comment on any aspect of *Topics in Antiviral Medicine*):
_______________________________________________________________________________________________________________________
_______________________________________________________________________________________________________________________

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