Introduction

Background

For persons living with HIV, the ability to remain retained in care plays a critical role in achieving good health outcomes. Despite tremendous advances in HIV treatment, a significant proportion of persons with HIV infection do not receive antiretroviral therapy, often due to poor engagement in long-term clinical care. Recent work has shown that poor retention in care serves as a major barrier for optimal HIV care and correlates with poor outcomes and increased transmission of HIV. In contrast, good retention in care correlates strongly with suppression of HIV RNA levels, improved health outcomes, and lower risk of transmission of HIV.

Definitions

The following definitions are important to understand when evaluating and addressing issues related to retention in care.

- **HIV Care Continuum**: The HIV care continuum is a term that identifies the spectrum of engagement in HIV clinical care (Figure 1).[1] The HIV care continuum spans the range from persons unaware of their HIV infection status to those fully engaged in HIV care. Testing for HIV is considered the entry point into the continuum and is crucial since the earlier an individual is diagnosed with HIV, the sooner they can be linked to HIV care for disease management and case coordination services. Early linkage to care and coordination of needed services has the potential to improve life expectancy, quality of life, and potentially reduce HIV transmission to others.

- **HIV Care Cascade**: The HIV care cascade quantitatively evaluates the HIV care continuum by estimating the number and proportion of individuals within each stage of the HIV care continuum; these quantitative estimates have been used to better understand weaknesses in the HIV care system. The initial model for the HIV care cascade in the United States, which was developed by Gardner and colleagues, showed significant fall-offs at every step of the care cascade, with fewer than 20% of the persons living with HIV in the United States having an undetectable HIV RNA (Figure 2).[2] Subsequently, the Centers for Disease Control and Prevention (CDC) performed its own analysis using similar cascade of care parameters; this analysis produced results similar to prior analysis by Gardner and colleagues (Figure 3).[3,4] Differences in the HIV care cascade occur with different racial/ethnic groups as shown in estimates from 2009 (Figure 4) and 2011 (Figure 5).[4,5]

- **Retention in Care**: In a general sense, retention in care is defined as a patient’s regular engagement with medical care at a health care facility after initial entry into the system. More formal definitions and measurements have utilized required follow-up at certain intervals to define retention in care; these definitions have typically conceptualized retention in care based on either appointments missed or medical visits attended at regularly defined
intervals.[6] In addition, some investigators have further categorized patients and their level of retention in care as regular users, sporadic users, and nonengagers.
Risk Factors for Decreased Retention in Care

Understanding patient variables associated with poor retention in care can assist medical providers in their efforts to identify risk factors, health behaviors, or social needs that can be modified to enhance the likelihood that an individual with HIV infection will engage in HIV care and subsequently move in a progressive direction along the care continuum. The ultimate goal of retention in care is to reach the point of viral suppression and obtain the highest quality of life possible. When gaps in linkage and retention in care are identified and remedied, patients maintain a better chance of remaining engaged in care. Presently, less than 50% of individuals infected with HIV in the United States are considered sufficiently retained in care. When patients are retained in care, approximately 90% receive antiretroviral therapy and 80% obtain complete viral suppression. Although it is difficult to predict the likelihood of an individual staying engaged and retained in a system of HIV care, investigators have identified certain variables associated with lower retention rates:

- **Non-White Race/Ethnicity**: Various studies have shown an association with decreased retention in care among blacks and non-white Hispanic, Asian, and Pacific Islander groups, when compared to patients who are white, as measured by the number of office visits missed.[8]
- **Heterosexual Orientation**: Compared with men who have sex with men (MSM), heterosexual males are more likely to have missed office visits within the first year of care; heterosexual women, however, have relatively high rates of retention.[8,11]
- **Young Age**: Individuals with HIV infection who are 24 years of age or younger have been shown to have lower rates of retention, receive fewer prescriptions for antiretroviral medication, and have poorer outcomes.[8] Young African-Americans are at particularly high risk of being lost to follow-up.[12]
- **Uninsured or Underinsured**: Patients who lack medical or prescription insurance, or have policies with poor coverage, are less likely to see medical providers or fill prescriptions, due to inability to pay for services. This can lead to patients dropping out of, or not engaging in care. Helping patients explore all opportunities for assistance in paying for medical services, such as sliding fee scales, or assisting them in applying for Medicaid, Medicare, or insurance through the Affordable Care Act, can maximize their health care coverage.[9]
- **Active Substance Use Disorder**: Alcohol or illicit drug use is reported in a large portion of patients infected with HIV. Data on injection drug use continues to suggest patients who actively use drugs have lower rates of retention in care and are more likely to miss office visits.[13,14] Persons with active use of alcohol and/or injection drugs who do not have access to substance abuse treatment, or choose not to engage in treatment, tend to have a more unstable lifestyle that increases the likelihood of missed appointments and dropping out of care. For persons with alcohol or opioid use disorder, the most important factor for improving retention in care is to receive medication-assisted treatment—a process that combines behavioral therapy with medications.[15,16] Medications with established benefit for opioid use disorder include buprenorphine, buprenorphine-naloxone, or methadone.[17,18]
- **Mental Illness**: Research has linked depressive symptoms to poor HIV outcomes and therefore engaging patients in medication treatment and/or counseling for their depression or untreated mental health conditions may improve symptoms and increase engagement in care.[14,17] At first glance, this appears to conflict with data indicating persons with an affective mental health disorder have higher rates of retention in care, but researchers postulate that this may be due to high rates of undiagnosed mental health disorders among persons with HIV infection, such that individuals diagnosed with mental illness and receiving care have better retention outcomes relative to those with undiagnosed and unmet mental health needs.[7]
- **Health Status Perception**: Individuals diagnosed with HIV infection who generally feel healthy may not appreciate the importance or relevance of seeing a medical professional on a regular basis. Medical care providers need to educate patients on the importance of routine follow up, including laboratory monitoring, vaccines, evaluation for other diseases associated
with HIV, and identify any other social or medical needs.

- **Fear and Stigma**: Fear and stigma are common feelings for individuals recently diagnosed with HIV infection. Persons living with HIV infection often are vulnerable to racial, social and economic disparities and can experience fear and stigma and therefore have difficulty remaining in care. Though the clearly described relationship between retention in care and survival is partly mediated by adherence to effective antiretroviral therapy, patients who do not remain in care also cannot receive treatment for medical and psychiatric comorbid conditions or benefit from the careful clinical monitoring necessary when taking antiretroviral therapy. Individuals with poor retention in care, due to stigma or fear or other factors, have been shown to have difficulty achieving a comparable CD4 cell count, plasma HIV concentration, and survival benefits to those patients who are retained in care.[19]

- **Unmet Needs**: Patients who lack certain support services such as case management, mental health counseling, and transportation assistance may also lack the ability to stay engaged in medical care.[20]

- **Place of Residence**: CDC surveillance data has identified that living in a non-metropolitan location, with population size less than 500,00 people, correlates with lower retention in care rates, possibly due to geographical and environmental difficulties accessing care (Figure 6).[21] In addition, rates of retention are lower in the West and South compared to the Northeast and Midwest.[22]
Evaluation of Retention in Care

Definitions Used in Evaluation of Retention in Care

Retention in HIV care is a crucial step in maximizing individual patient outcomes. Clinicians providing HIV medical care and their clinic administrators have a challenge when considering how to evaluate patient engagement and measure retention in care. Four definitions have been proposed to better evaluate, quantify and measure retention in care for persons with HIV infection as outlined below:

- **Missed Visits**: the number of missed appointments (no shows) during an observation period.
- **Appointment Adherence**: the number of completed visits divided by the number of total scheduled visits.
- **Appointment Constancy**: the proportion of time intervals with at least one completed visit during an observation period.
- **Gaps in Care**: the time interval between completed clinic visits, usually based on a predetermined threshold of 3, 4, or 6 months. A time frame of 6 months is typically used, as this threshold has been determined by clinical expert consensus to allow for patients who are well controlled clinically and stable on their current regimen.

Performance Measures for Retention in Care

In November 2013, the Human Resources and Services Administration HIV/AIDS Bureau (HRSA HAB) established revised performance measures to provide an indication of an organization’s performance in relation to a specified process or outcome. HRSA HAB evaluates performance measures across programs to document areas of strength and identify areas for improvement in order to help guide, shape and enhance the delivery and quality of care. One such performance measure, “HIV medical visit frequency”, may assist HIV providers when evaluating if a patient is retained in care. The “HIV medical visit frequency” defines the minimum clinic appointment schedule needed for an individual with HIV infection to be considered retained in care as at least one medical visit in each 6-month period of a 24-month measurement period, with a minimum of 60 days between medical visits. For the purpose of this performance measure, the time frame of 6 months was determined by clinical expert consensus to allow for patients who are well controlled clinically and stable on their current regimen. It is important to note that patients can and should be seen at more frequent intervals as dictated by their current health status. The Institute of Medicine (IOM) has defined retention in care as at least 2 medical visits every 12 months, with a minimum of 90 days between visits.

Estimates of Retention in Care

Early cascade of care models generated by Gardner and by the Centers for Disease Control and Prevention (CDC) estimated that among all persons living with HIV infection in the United States, only 40 to 41% are retained in care, but that among those HIV-infected persons already linked to care, 66 to 67% are retained in care. In a study involving 530 patients with HIV infection already linked to a university-based HIV clinic, 59% were identified as being consistently retained in care (defined as consistent attendance across 4 consecutive 6-month periods). A separate and different study analyzed retention among veterans for 1 year after starting antiretroviral therapy and found only 64% of the individuals diagnosed with HIV infection had visits in each quarter in the year after starting antiretroviral therapy. In a more recent study, investigators utilized several accepted retention measures and estimated a rate of retention in care of 71 to 75% among clients with HIV infection in 12 HIV clinics in the United States. Using 2011 retention in care data from an estimated 512,911 clients with HIV infection at Ryan White clinics, investigators reported rates of retention and viral suppression that were significantly higher than prior national estimates.
Limitations of Measuring Retention in Care

As made clear in the performance measures, there is no gold standard for measuring retention in care.[23] When using the above measures, one should always consider the advantages and limitations of each, especially in the context of applying the measure to a desired application, whether for clinical, administrative, or research purposes.[23,28] Retention in care measures should be aligned with national and international guidelines and should incorporate data sources including state surveillance systems, clinic medical records, and administrative databases; the integration of various data sources can enhance monitoring of retention in care efforts. Several more recent studies have shown that earlier reports probably overestimated the proportion of persons out of care by not taking into account the migration of individuals with HIV infection who were receiving ongoing medical care in a region or city outside of their prior jurisdiction.[29,30,31,32,33] For example, a pilot study conducted by the Massachusetts Department of Public Health found that only 25% of persons characterized as being out-of-care by the absence of laboratory test results were actually disengaged from care; the majority had moved or engaged in care elsewhere.[32] Similarly, in Washington, a clinic-based surveillance-informed re-linkage intervention found that 79% of patients who were characterized as out of care had moved, transferred care, or were in a long-term correctional facility (and thus were not out of care).[33] Further, a collaborative analysis across 6 states in the Northwestern United States reached analogous findings: 72% of patients described as out of care were not disengaged from care but rather had moved, died, or were erroneously identified as being out of care.[34] Taken together, these studies emphasize the need for revised surveillance techniques to allow for better estimates of retention in care.[35]
Impact of Poor Retention in Care

Impact on Clinical Outcomes

Although investigators have identified certain variables associated with decreased retention in HIV care, clinicians also need to clearly understand the overall consequences of failed retention in care. Until recently, little was known about the impact of poor retention in HIV care on health outcomes, such as behaviors associated with increased risk of HIV transmission, time to initiation of antiretroviral therapy, and mortality rate. Several studies have measured the impact of poor retention on mortality. One study demonstrated that patients who missed a visit in the first year after establishing initial outpatient HIV treatment had approximately twice the long-term mortality rate, when compared with those who attended all scheduled appointments.[9] Even when patients meet the overall retention indicators, missed clinic visits have been shown to be independently associated with all-cause mortality.[36] A retrospective study performed in South Carolina examined data from persons newly diagnosed with HIV from January 1, 2004 through December 31, 2009 and found that poor rates of retention were associated with lower rates of virologic suppression and increased risk of mortality (Figure 7).[8] In another study conducted in the Veterans Affairs patient population, investigators reported that patients who attended an appointment in only one quarter over the span of a year had almost twice the mortality rate compared to patients who attended a visit in all four quarters of the year.[19]

Impact on HIV Transmission

In addition to increased mortality rates, persons with HIV infection who do not consistently demonstrate adherence with regularly scheduled appointments (and are not adequately ‘retained’ in HIV care) consistently have worse clinical and behavioral outcomes when compared to patients who are optimally engaged in care. For example, in one study, patients who attended 3 or more office visits over a 6-month span were twice as likely to have abstained from having unprotected sex in the preceding month with a partner who is HIV-negative or whose HIV status is unknown.[37] Several studies have also identified that patients who are linked and retained in care are more likely to initiate antiretroviral therapy, achieve viral suppression, and avoid viral rebound compared to individuals who had suboptimal retention in care.[38,39,40] It is the responsibility of the HIV care provider to identify important risk factors that may predispose a patient for poor retention and take appropriate measures to help reduce the negative outcomes. These findings have important public health implications: in 2009, individuals who were diagnosed with HIV infection but not retained in care were responsible for 61.3% of all HIV transmissions within the United States (Figure 8).[41] The individuals with HIV and not retained in care are estimated to transmit HIV at a rate of 5.3 transmissions per 100 person-years, compared with 0.4 transmissions per 100 person-years by those individuals engaged in care with viral suppression.[41]
Strategies for Improving Retention and Re-Engagement in Care

Multiple studies have demonstrated that providing comprehensive and easy-to-access services (e.g. case management, mental health support, transportation, drug treatment programs, etc.) can enhance retention in care. In addition, decreasing structural barriers in the clinic setting, utilizing interventions that assist patients in developing positive relationships with their health care professionals, providing basic HIV education, and dispelling negative health beliefs about HIV can improve patient outcomes.

In a randomized study performed at six HIV clinics in the United States, investigators reported improved retention with enhanced contact with an interventionist when compared with standard of care practices; the enhanced contact with the interventionist consisted of brief face-to-face meetings at medical appointments, reminder calls for appointments, and check-in calls for missed appointments. In another randomized trial (Project Hope), investigators explored different strategies for engaging hospitalized persons with HIV infection and substance use into HIV medical care; they found that providing patient navigators and financial incentives had the greatest impact on engagement in care and subsequent rates of virologic suppression.

A recent systematic review evaluated interventions to increase engagement in care and confirmed the myriad of strategies that are being implemented across the country; this review found that only a small percentage of the interventions have led to a significant improvement in retention in care. Notably, the most successful programs have involved education and enhanced patient contact, clinic-based substance abuse treatment, or technology-based decision support tools to alert providers to poor patient outcomes.

Data to Care

In recent years, several groups have utilized a new public health strategy that uses HIV surveillance laboratory data to identify persons diagnosed with HIV infection who are not in care (based on absence of laboratory monitoring data), with a subsequent goal to link or relink these identified individuals to medical to care. This approach is now commonly referred to as Data to Care and has been recommended by the CDC. The Data to Care programs for linkage and re-engagement now incorporate three models:

- **Health Department Model**: Health department-initiated linkage and re-engagement outreach
- **Healthcare Provider Model**: Healthcare provider-initiated linkage and re-engagement outreach
- **Combination Health Department/Healthcare Provider Model**: A combination of both approaches

Guidelines from the International Association of Physicians in AIDS Care

The International Association of Physicians in AIDS Care (IAPAC) has published evidenced-based guidelines for improving entry into and retention in care for individuals with HIV infection. These recommended interventions are based on randomized, controlled trials or observational studies that had at least one measured biological or behavioral end point. The recommendations are graded for overall quality and strength and consist of five major components related to entry and retention in care:

- **Systematic Monitoring of Entry into HIV Care**: These guidelines recommend that systematic monitoring of entry into HIV care should occur for all individuals diagnosed with HIV infection. Within a service area, rapid HIV testing programs, public health departments, and medical clinics should coordinate the monitoring of patients who are entering HIV care. Integrating databases, medical records, and surveillance data among service providers involved in HIV care may enhance monitoring of initial entry into HIV care. The authors also noted that improved patient survival has been observed when entry into
care occurs with an HIV provider with clinical competence in prescribing antiretroviral therapy.

- **Systematic Monitoring of Retention in HIV Care:** Though monitoring retention in care is routinely recommended, specific monitoring, including retention measures and desired visit frequency can vary among jurisdictions and should be standardized with national guidelines (II A). Many retention measures (e.g., visit adherence, gaps in care, visits per interval of time, etc.) and data sources (e.g., public health surveillance, medical records, administrative databases, etc.) can be applied in accordance with local resources and standards of care. As well, the integration of data sources may enhance monitoring of retention in care.[19, 23]

- **Strength-Based Case Management:** For individuals with a new diagnosis of HIV infection, a brief strength-based case management intervention should be available (II B). Citing data from the Antiretroviral Treatment and Access Study, utilizing multiple, strength-based case management sessions (defined as up to 5 sessions in a 3-month period) can lead to a significantly higher proportion of patients attending an HIV clinic appointment at least once in a 6-month period, as compared to patients who were passively referred to local points of care following a new HIV diagnosis (78% versus 60%).[44] Case-managed individuals also attended HIV clinic appointments at least twice in a 12-month period more often than individuals not case-managed (64% versus 49%). Strength-based case management sessions entailed trained social workers identifying patient strengths and assets in order to facilitate successful linkage to and retention in care. Obviously, the effect of strength-based case management can be reduced if there is limited availability of resources in a service area.

- **Intensive Outreach for Recently Diagnosed:** For individuals with HIV infection who are not engaged in medical care within 6 months of a new HIV diagnosis, intensive outreach may be considered (III C). Maintaining individuals newly diagnosed with HIV in routine care has been shown to improve chances of achieving an undetectable viral load by 12 months of follow-up. Intensive case finding, with re-enrollment into care, should focus on vulnerable populations considered at risk for receiving fewer services, including women, youth, and individuals with a history of mental illness or substance use. A dose-response relationship has been described between increasing numbers of quarterly medical visits and decreasing patient mortality.[19] Additionally, optimal care (at least four clinic visits, one per quarter, in a calendar year) is associated with better mean increases in CD4 count and better mean decreases in HIV viral load.[8]

- **Peer or Paraprofessional Patient Navigators:** The guidelines recommend considering using peer or paraprofessional patient navigators to help facilitate interactions with health care (III C). Patient navigation is based primarily on peer-based programs developed for patients with cancer. Navigators are trained to assist patients in their interactions with the complex U.S. health care and social service systems in order to ensure that patients get the assistance they need. The U.S. Special Projects of National Significance Outreach Initiative is one program that has demonstrated positive outcomes with use of HIV patient navigators. This program enrolled 1,100 patients with inconsistent engagement in care and demonstrated that, after 6 months of patient navigation assistance, the proportion of patients with at least 2 visits in the previous 6 months increased from 64% at baseline to 87% at 6 months and 79% at 12 months. Furthermore, the proportion of participants receiving patient navigation assistance who had undetectable HIV viral loads increased 40% after 12 months in care, as compared to baseline.[17]
Summary Points

- The Continuum of HIV Care offers providers a context to help identify where their patients fall in the spectrum of engagement in clinical care.
- The Cascade of HIV Care helps providers to understand how larger groups or populations are engaged at each step of this cascade in order to identify, monitor, and ensure that more patients are tested, linked, retained, placed on antiretroviral therapy, and virologically suppressed.
- Earlier models estimated less than 50% of individuals infected with HIV in the United States are considered sufficiently retained in care; estimates of retention are significantly higher when these data take into account persons who move or transfer care to a new city or region.
- When patients are retained in care, 90% receive antiretroviral therapy and 80% achieve complete viral suppression.
- Persons diagnosed with HIV infection but not retained in care are responsible for approximately 60% of all HIV transmissions.
- Regardless of how retention in care is ‘measured’ in a patient population, providers should attempt to identify how well their clinic is performing at retaining patients and explore ways to improve their system.
- It should be a goal of all HIV clinicians to identify risk factors for decreased retention in care, and develop strategies to increase engagement and achieve viral suppression.
- Providers should examine simple, low-cost ways of improving retention in care by partnering with local/regional stakeholders, engaging with case-management opportunities, and using various outreach and peer-navigation support.
- Partnerships between clinics and health departments can utilize Data-to-Care as a tool for identifying persons not retained in care and to provide support for re-engagement in care.
Citations


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Figures

Figure 1 Model for HIV Care Continuum

This graphic represents the continuum of engagement in HIV care, as represented by the Health Resources and Services Administration.

Figure 2 Model of Stage of Engagement in HIV Care

This graphic represents a model generated by Gardner and colleagues. Abbreviations: ART = antiretroviral therapy

Figure 3 Estimated Percentage of Persons Living with HIV Infection Along the HIV Care Continuum — United States, 2011

This graphic represents HIV care cascade estimates from the CDC for 2011; the CDC used data from the National HIV Surveillance System and the Medical Monitoring Project for these estimates.

**Figure 4 HIV Care Cascade, by Race, 2009**

This graph shows the percentages for individuals in the United States engaged in as estimated by the Centers for Disease Control and Prevention for selected stages of the HIV cascade during 2009. Abbreviations: ART= antiretroviral therapy

Figure 5 HIV Care Cascade, by Race, 2011

This graph shows the percentages for individuals in the United States engaged in as estimated by the Centers for Disease Control and Prevention for selected stages of the HIV cascade during 2011.

Figure 6 Retention in HIV Medical Care and Viral Suppression, by Population Category of Residence at Diagnosis

Data shown are for People Aged ≥13 Years With HIV Infection Diagnosed by Year-End 2011 and Alive at Year-End 2012.

Figure 7 Association of Retention and Mortality

This retrospective study analyzed data from 2197 persons in South Carolina newly diagnosed with HIV infection from January 1, 2004 through December 31, 2009. The subjects were followed over 2 years and data analyzed for 6 month intervals (total of 4 intervals). Optimal = 4 visits in 4 intervals Suboptimal = 3 visits in 4 intervals Sporadic = 1-2 visits in 4 intervals Drop-Out = No visits in 4 intervals

Figure 8 Estimated HIV Transmission at Each Step of the HIV Care Continuum, United States 2009

Figure 9 Project Hope: Effect of Patient Navigation with or without Financial Incentives on Viral Suppression

This study was conducted from July 2012 through January 2014 and investigators enrolled 814 patients with HIV infection and substance use who were hospitalized to determine the impact of different strategies on subsequent engagement in HIV care and treatment. Patients were randomized to one of three groups: patient navigation alone, patient navigation plus financial incentives, or treatment as usual.

Figure 10 Data to Care Health Department Model for Linkage and Re-Engagement

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.

Data to Care Health Department Model

1. Health Department (HD)
   Generate list of clients identified by HIV surveillance as “not in care”

2. HIV surveillance and prevention staff may check additional sources to confirm “not in care” status and gather information needed for follow-up.

3. Healthcare providers and HD staff communicate about care status of patients on not in care list.

4. Patients contacted by HIV prevention or linkage staff for linkage or re-engagement assistance.

5. Patient care visit scheduled.

Health Care Provider

Patient
Figure 11 Data to Care Healthcare Provider Model for Linkage and Re-Engagement

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.

Data to Care Health Care Provider Model

1. Health Department (HD)
   - Generate list of clients identified by HIV surveillance as "not in care"

2. HIV surveillance and prevention staff may check additional sources to confirm "not in care" status and gather information needed for follow-up.

3. Healthcare providers and HD staff communicate about care status of patients on not in care list

4. Patients contacted by healthcare provider for linkage or re-engagement assistance

5. Patient care visit scheduled

Patient
Figure 12 Data to Care Combination of Health Department and Health Care Provider Models for Linkage and Re-Engagement

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.

Data to Care Combination Health Department/Health Care Provider Model

1. Health Department (HD)
   - Generate list of clients identified by HIV surveillance as "not in care"

2. HIV surveillance and prevention staff may check additional sources to confirm "not in care" status and gather information needed for follow-up.

3. Healthcare providers and HD staff communicate about care status of patients on "not in care" list

4. Patients contacted by HIV prevention or linkage staff for linkage or re-engagement assistance

5. Patients contacted by healthcare provider for linkage or re-engagement assistance

Patient care visit scheduled