Retaining HIV-Infected Patients in Care: Where Are We? Where Do We Go from Here?

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Retaining human immunodeficiency virus (HIV)–infected patients in medical care at regular intervals has been shown to be linked to positive health outcomes. This article examines the available literature and research on retention and engagement in care of HIV-infected patients. We identify the extent of the problem of keeping patients engaged in care, as well as analyze which groups of patients are likely to be lost to follow-up. A review of different ways to measure patient retention is considered, as well as some preliminary data that suggest successful ways to re-engage patients in care. The need to ensure that HIV-infected patients are retained in care is a pressing public health issue and one that affects multiple populations. Further research and exchange of information are needed to keep patients in continuous care and to ensure that all patients are provided with regular, high-quality care that achieves both desired patient and population health outcomes.

WHAT IS PATIENT RETENTION?

In published studies, patient retention is conceptualized and measured in 3 different ways: appointments missed, medical visits at regularly defined intervals, and a combination of those methods focusing on use of the health care system. Patient retention is most frequently studied as missed appointments, missed visit rates, and the percentage of patients who miss appointments over a defined period [9–11]. Missed appointments are defined as those not cancelled or rescheduled; missed appointment rates are the proportion of total appointments that are missed and are also referred to as a missed visit proportion, which has been used with a threshold of 25% to compare association with independent variables [12].

The single major inconsistency in these measures has been which appointments are included. Some studies include only primary care but not subspecialty appointments [13]. Some include only appointments with a doctor or a nurse but not others such as phlebotomy [9], thus raising questions of what kind of visit should be used to measure retention and how to compare studies.
Like the measurement of missed appointments, retention rates require decisions about which types of visits to include. These measures are conceptualized as the number of patients with an expected minimum number of visits in a defined period. For example, a “retained patient” has at least 1 medical appointment every 6 months [14–16].

One group of researchers developed an alternative approach to assessing retention by creating 3 categories that classify persons living with HIV infection by their use of health services [17, 18]. “Regular users” complete medical appointments at least every 6 months, are not “no shows” for any scheduled primary care appointments, and both reschedule and complete any cancelled primary care appointments. “Sporadic users” complete at least 1 appointment per year, are “no shows” for at least 2 primary medical appointments per year, and use an HIV urgent care clinic at least once a year. “Nonengagers” complete initial visits but do not return. Primary medical care appointments include HIV follow-up, subspecialty, nursing, and phlebotomy appointments.

These 3 ways of measuring patient retention are useful in different ways. Generation of a list of patients who missed an appointment on a particular day is easy. Staff can then act quickly to re-engage patients in care. Because missed appointments cost both time and revenue [19], minimizing them is a priority from a clinic perspective. From a patient health perspective, consideration of missed appointments alone is not adequate. Without assessing whether patients who miss appointments return to care and when they return, the ongoing health and engagement of a patient with the health care system is not captured.

Assessing longitudinal engagement of patients with the health care system involves setting a standard for an expected number of HIV care visits to occur at defined periods. Although measuring patient retention this way better addresses the heart of the issue (keeping people in care), it is more challenging to measure than missed appointments. Measuring patient retention requires maintaining a case list and tracking whether patients on that list attend clinic during specific periods. In addition, a detrimental time lag may occur by the time a patient is identified as having fallen out of care or is no longer within the reach of the health care system. This approach allows for a more systematic look at the group of patients who are not retained, so that resources can be better targeted to engaging them. Finally, setting a minimum standard for how often patients should be seen will inevitably not be often enough for some patients and too often for others.

Categorizing patients into regular users, sporadic users, and nonengagers promotes the notion that patients participate along a continuum of engagement with the health care system [18]. This approach presents similar advantages and drawbacks as measuring patient retention with a defined number of visits in a given period; yet, it also potentially allows for different interventions targeting people on the basis of their location on the continuum. Ultimately, the conceptualization and investigation of patient retention should be based on which measures best capture the essence of an established provider-patient relationship, which patients fall out of care, and the types of interventions that will be targeted to maintain ongoing engagement in care.

WHAT DATA ARE THERE?

The extent of the problem. Studies have quantified retention of HIV-infected patients by using all 3 aforementioned measurement methods. Missed appointment rates are consistently 25%–35%, despite differences in the type of appointments included [9, 11, 20]. Although the percentage of patients in a particular clinic population who have missed at least 1 appointment in a defined period spans a larger range (25%–44%), comparing studies is difficult because their durations vary [13, 21–23]. Although missed appointments are common, their extent varies among different populations.
Three studies published in 2003 measured patient retention rates by using roughly the same definition of 1 medical visit every 6 months over a 2-year period [14–16]. A wide range was found in the retention rates (18%–61%). In New York, self-reported data from ambulatory care clinics in 2007 revealed that retention rates were 20%–100%, with a mean rate of 72% (New York State Department of Health, unpublished data). Although several studies have used the continuum engagement model, only one has reported the distribution of a clinic population by using these categories. That study found that 25% were regular users, 32% were sporadic users, and 43% were nonengagers [17].

**About which patients are we concerned?** Identifying which patients are at greatest risk for not being retained is important to target intervention efforts to those groups. In the HIV literature, demographic characteristics found through multivariate analysis to be associated with missed appointments include race (specifically, African American) [9–11, 24], younger age [9–11, 25], heterosexual orientation [11], less education [25], lack of health insurance [13], and lower household income [11]. Clinical characteristics associated with missed appointments have included higher CD4 cell count [9, 20, 21], absence of an AIDS diagnosis [11, 21], and detectable viral load or AIDS-defining CD4 cell count [26]. Although these studies of clinical characteristics may seem contradictory, they actually reflect expected health care seeking behaviors. Patients may not attend their appointments because they do not feel sick, but they also may not attend because they feel sick. Which comes first and causes the other—the missed appointment or the worse health—is not clear.

Other characteristics associated with missed appointments include either a history of or current injection drug use [10, 20, 21, 24, 27], lower perceived social support [9], less engagement with the health care provider [28], and shorter duration of follow-up since baseline [21]. Although fewer studies have identified patient characteristics associated with low retention rates, existing data are consistent with the characteristics of patients more likely to miss appointments. In addition, self-paying patients [14, 16], unemployed patients [17], and patients with psychiatric illness [15] visit a clinic less regularly for care.

Patients may not attend clinic because of conflicts with work schedules, lack of child care or transportation, family illness, and hospitalization [29]. A study of HIV-infected women found that the 3 most common reasons for missing appointments were forgetting appointments, conflicting appointments, or feeling too sick to attend [13]. In a study involving HIV-infected patients in New York City, patients missed appointments for no specific reason, because they forgot, or for unexpected social reasons [30]. These studies are consistent with those involving HIV-uninfected patients [19, 31–33]. Characteristics associated with retention will necessarily vary between clinics and become important when prioritizing interventions for improvement.

Using qualitative research methods, Mallinson et al [18] explored the process through which HIV-infected patients become engaged users of health care. Becoming a regular user involved decreasing structural and practical barriers to care [27], such as confronting stigma and obstacles, including a lack of transportation, food, and clothing, and developing health literacy and a connectedness with others, including friends, family, partners, or primary care providers.

**What have been the health costs of not retaining patients in care?** Published studies consistently report that missed appointments are associated with worse health outcomes (Tables 1 and 2), including failure to suppress viral load [10, 36, 38], and clinically significant drug resistance [37]. At Johns Hopkins University HIV Clinic, patients who missed <25% of their appointments, compared with patients who missed ≥25% of their appointments, were more likely to be receiving HAART, to have suppressed viral loads, to have a positive change in CD4 cell count since baseline, to have fewer hospital admissions, and to have fewer emergency department visits (R. D. Moore, personal communication). Other studies showed a positive association between missing appointments and poor adherence to antiretroviral therapy [23] and that the number of missed appointments significantly predicted presence of an AIDS-defining CD4 cell count, independent of HAART use [26].

Giordano et al [34] revealed a relationship between retention in care and survival among newly identified HIV-infected patients at hospitals and clinics run by the United States Department of Veterans Affairs. Patients were categorized by the number of quarters of the year in which they had a primary care visit after their initial visit. A dose-response relationship was found for visits, significantly affecting CD4 cell count, viral load, and survival. Another recent study showed that missed HIV primary care appointments during the initial year of clinic enrollment leads to higher mortality rates, compared with not missing any appointments [12].

Patient retention is associated with public health benefits. A

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<th>Table 1. Individual and Public Health Outcomes Associated with Patient Retention</th>
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<td>Outcome</td>
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<tr>
<td>Increased access to highly active antiretroviral therapy</td>
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<td>Improved treatment adherence</td>
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<td>Viral load suppression</td>
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<td>Improved immune function</td>
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<td>Less drug resistance</td>
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<td>Reduced health care costs associated with reductions in hospitalization and emergency department use</td>
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<td>Reduction in risky sexual behavior</td>
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<td>Improved population survival rates</td>
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recent longitudinal study showed that patients who had received medical care for HIV infection at least 3 times in the preceding 6 months were significantly less likely to engage in unprotected vaginal or anal intercourse with HIV-uninfected or unknown status partners in the preceding month, suggesting that regular medical care may reduce HIV transmission [35].

What has been successful in bringing people to care? Limited published data address the effectiveness of specific interventions to improve retention among persons living with HIV infection (Table 3). Multipronged approach interventions have had a positive impact on the number of patients who reschedule appointments after missing one [41]. These include reminder calls before appointments, updating patients’ phone numbers and addresses at each appointment, attempting to reach patients through emergency contacts and community agencies, and phone calls by peer educators after 3 consecutive missed appointments.

A care coordination model linking patients with an individual who can help with navigation of the health care system has been shown to reduce structural barriers and to increase the number of patients with ≥2 appointments during a 6-month period [43]. Several other studies revealed the positive impact of supportive service programs on patient retention, including case management, mental health, substance use, transportation, advocacy, drug assistance programs, food and nutrition, and complementary medicine services [14–16]. One study found that clinics with <4 providers and those offering mental health services have fewer missed appointments [42]. Other studies suggest that supportive services help specific populations, such as substance users, those with psychiatric illnesses [44], and at-risk youth, to stay in care [40]. In addition, increased frequency of contact with clinicians, peers, and paraprofessionals in or outside the medical office results in fewer gaps in care during the first 12 months of follow-up [39]. These preliminary studies suggest that navigators and supportive services help the most vulnerable populations to stay in care [39]. More data are needed, however, to better understand how clinic characteristics influence patient retention.

What can we learn from other diseases? Extensive literature exists about interventions to reduce the number of missed appointments in the HIV-uninfected population. Reminders for missed appointments, the intervention most studied, have shown mixed results [45–48]. Strategies that have increased clinic visits include exit interviews confirming that the patient understood the information discussed during the visit [49], patient orientation to the clinic [50, 51], open access scheduling system [52], contracting with patients [50], improving social support [53], and case management involvement [54]. Studies to date have not addressed the question of which interventions work best for which specific populations.

Studies assessing missed appointments among patients with diabetes have found that changes in processes of care are most likely to be effective interventions (eg, improving patient education or enhancing the nurse’s role in delivering care) [55]. Appointment reminders have minimal impact [55, 56]. Griffin has found that the “focus of the research should move away from appointment reminders towards interventions targeting the delivery of health care and the health professional-patient relationship which are more likely to be stronger predictors of default” [57, p S21]. These recommendations suggest that quality improvement methods may be ideally suited for study of patient retention strategies through their focus on systems and processes of care.

WHERE ARE WE NOW?

Retention of HIV-infected patients in care deserves serious attention by both providers and public health agencies. Research consistently suggests that health outcomes, including viral load suppression, in patients in regular care are better than outcomes in patients not in regular care [12]. Improving patient retention at programmatic and policy levels will require a better understanding of factors beyond demographic characteristics that contribute to patients falling out of care, followed by an assessment of factors that can be addressed. Some factors, such as active substance use, may benefit from treatment referrals or behavioral interventions. Others, such as transportation and housing, can be addressed through service provision, whereas chronic conditions, such as mental health disorders, may or may not respond to treatment. Incarceration and relocation cannot be addressed by health care providers directly. More importantly, resources are needed to fund and support efforts assessing whether patient retention is the most basic predictor of outcomes and to identify appropriate interventions.

Longitudinal studies are urgently needed to assess sporadic users of health care, how these patients are reconnected with care, and variables that affect their retention in care. Researchers testing quality improvement interventions to keep people connected to care need to publish and share their work. Consistent, meaningful measurement of retention will require making decisions about whether to focus on missed appointments or other standardized measures that capture continuity of care.

Currently, most patient retention studies in the HIV literature report retention rates at a single facility. However, this approach may not identify that a person is in continuous care but accessing care at different clinics. The likelihood that patients will seek care from multiple providers is high in urban areas where supply is plentiful and in rural areas where primary care is often supplemented by HIV treatment experts. Therefore, perspective of continuity changes, depending on the position from which measurement occurs.

Continuity of care is generally defined as the extent to which services are coordinated as an uninterrupted succession of
<table>
<thead>
<tr>
<th>Study (year)</th>
<th>Study population</th>
<th>Study duration</th>
<th>Measurement definitions</th>
<th>Health outcome</th>
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<tr>
<td>Berg et al [26] (2005)</td>
<td>995 Patients with HIV infection at an urban community health center in Boston, MA</td>
<td>1 August 2002–31 July 2003</td>
<td>Number of missed appointments</td>
<td>Number of missed appointments is significant predictor in logistic regression analysis of having an AIDS-defining CD4 cell count (OR, 1.14; ( P &lt; .05 )) and detectable plasma HIV RNA (OR, 1.10; ( P &lt; .05 )).</td>
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<td>Giordano et al [22] (2003)</td>
<td>354 Patients entering care at an academically affiliated, public HIV specialty clinic in Houston, TX</td>
<td>New patients in 1998</td>
<td>Missed appointments was defined as missing &gt;2 primary care appointments in 6 months</td>
<td>In multivariate analysis, missed appointments were generally associated with not receiving HAART (OR, 5.85; 95% CI, 3.46–9.90; ( P &lt; .001 )); when patients lost to follow-up were excluded from analysis, the effect of missed appointments remained in predicting which patients did not receive HAART (OR, 2.70; 95% CI, 1.43–5.07; ( P = .002 )).</td>
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<td>Giordano et al [34] (2007)</td>
<td>2619 HIV-infected male veterans having a primary care visit at any US Department of Veterans Affairs hospital or clinic from 1 January 1997 through 31 December 1998, including only patients whose first HAART prescription was after 1 January 1997</td>
<td>Follow-up until either death or 31 December 2002, whichever came first (mean duration of follow-up, &gt;4 years)</td>
<td>Patients grouped by how many quarters of the year they had HIV-related appointments after their index visit (range, 1–4)</td>
<td>Kaplan Meier results show higher mortality rate among patients with visits in only 1 quarter of the year, compared with patients with visits in all 4 quarters (( P = .02 )); the magnitude of change for CD4 cell count and plasma HIV concentration was greater for patients with visits in all 4 quarters, compared with patients with visits in 0–3 quarters; median CD4 cell count change was an increase of ( 92.0 \times 10^6 ) cells/L for all patients, ranging from ( 100 \times 10^6 ) cells/L for patients with visits in 4 quarters to ( 48.5 \times 10^6 ) cells/L for patients with visits in 1 quarter (( P &lt; .001 )); median plasma HIV concentration change was a decrease of ( 1.29 \log_{10} \text{copies/mL} ) for all patients, ranging from ( -1.47 \log_{10} \text{copies/mL} ) for patients with visits in 4 quarters to ( -0.22 \log_{10} \text{copies/mL} ) for patients with visits in one quarter (( P &lt; .001 )).</td>
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<td>Lucas et al [10] (1999)</td>
<td>273 Protease inhibitor–naive patients at an urban HIV clinic in Baltimore, MD</td>
<td>Treatment-naive patients initiated HAART from March 1996 through February 1998</td>
<td>Percentage of missed appointments; patients receiving HAART seen every 4–6 weeks, then every 3 months thereafter; appointments included were psychiatry, dermatology, gynecology, neurology, and gastroenterology</td>
<td>Logistic regression analysis associated missed clinic appointments and suppression of HIV RNA level to &lt;500 copies/mL at 7–14 months (OR, 0.27; 95% CI, 0.16–0.47; ( P &lt; .001 )).</td>
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### Metsch et al. [35] (2008)

- **Patients**: 316 Patients from 4 US cities (Atlanta, GA; Baltimore, MD; Los Angeles, CA; and Miami, FL) with a recent diagnosis of HIV infection
- **Year**: 2000–2001
- **At least 3 appointments in the previous 6 months**
- **Patients who had received medical care for HIV infection at least 3 times in the previous 6 months had reduced odds of engaging in risky behavior associated with transmission, compared with patients with <3 visits in that time, according to the multiple logistic regression model (OR, 0.53; 95% CI, 0.30–0.94; \(P = .029\)).**

### Mugavero et al. [12] (2009)

- **Patients**: 543 Patients with an initial HIV primary care visit from 1 January 2000 through 31 December 2005 at a clinic in Birmingham, AL
- **Deaths tracked through 1 August 2007**
- **No show visits (missed visits not cancelled or rescheduled) during the first year after establishing outpatient care**
- **Kaplan Meier survival analysis showed better survival for those with no missed appointments (1.0 deaths per 100 person-years) during the first year after an initial visit, compared with those with at least 1 missed visit (2.3 deaths per 100 person-years), where \(P = .02\).**

### Rastegar et al. [36] (2003)

- **Patients**: 123 Patients not previously treated with HAART who were initiated HAART at a primary care practice in Baltimore, MD
- **7–14 months during 1997–1999**
- **Percentage of missed appointments**
- **Patients with an undetectable viral load missed fewer appointments than did patients with a detectable viral load (22.1% vs 38.3%; \(P < .001\)); multivariate analysis by logistic regression associates missed appointments with treatment failure (OR, 0.66; 95% CI, 0.52–0.83; \(P < .001\)).**

### Sethi et al. [37] (2003)

- **Patients**: 195 Patients with viral loads of <500 copies/mL at an outpatient center in Baltimore, MD, who were receiving HAART
- **February 2000–February 2001**
- **Missing a scheduled clinic visit and viral load analyzed as a time-dependent covariate**
- **Individuals with missed visits in the previous 30 days were more likely to have viral rebound with clinically significant resistance (multivariate adjusted HR, 2.40; 95% CI, 1.13–5.09; \(P = .023\)).**

### Valdez et al. [38] (1999)

- **Patients**: 366 Patients at a university-affiliated HIV clinic in Cleveland, OH
- **Patients seen from June 1995 through December 1997**
- **Number of missed clinic visits**
- **In multivariate analysis controlling for sex, early protease inhibitor start date, nadir CD4 cell count, and peak plasma HIV RNA levels, missing <2 clinic visits in the year was predictive of virological success (defined as plasma HIV RNA level <400 copies/mL at last clinic visit; OR, 0.2; 95% CI, 0.08–0.47; \(P < .001\)).**

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**NOTE.** CI, confidence interval; HR, hazard ratio; OR, odds ratio;
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<thead>
<tr>
<th>Study (year)</th>
<th>Study population</th>
<th>Duration</th>
<th>Measurement definition</th>
<th>Intervention</th>
<th>Outcome</th>
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<tr>
<td>Ashman et al (2002)</td>
<td>29,153 HIV-infected adults and youth (age, &gt;12 years) who received at least 1 service at a safety net-funded agency within a HRSA Client Demonstrator Project</td>
<td>1997–1998</td>
<td>Retained patient received ≥1 medical visit during each of the four 6-month periods</td>
<td>Ancillary services including mental health counseling and treatment, substance abuse counseling and treatment, case management, housing assistance, food bank, emergency financial assistance, transportation, buddy or companion service, advocacy, day or respite care</td>
<td>When controlling for race, age, sex, insurance status, primary health care source, CD4 cell count, and psychiatric illness or substance use, the following ancillary services were associated with increased retention rates: mental health care (OR, 1.46; 95% CI, 1.36–1.57), substance treatment (OR, 1.49; 95% CI, 1.30–1.72), transportation (OR, 1.18; 95% CI, 1.09–1.26)</td>
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<td>Cabral et al (2007)</td>
<td>773 HIV-infected individuals participating in an outreach initiative funded by HRSA</td>
<td>Intake to 12 months of follow-up (2004–2006)</td>
<td>Outcome variable was the time from study intake to first 4-month gap in HIV primary care</td>
<td>Range of outreach programs: appointment reminders and/or rescheduling, service coordination, relationship building, concrete services (food, transportation), counseling, information about the program, HIV education, accompanying clients to appointments</td>
<td>The number of program contacts with individual patients was correlated with patient retention; major finding: ≥9 program contacts in the first 3 months in the program significantly reduced the risk of a 4-month gap in HIV primary care (HR, 0.45; 95% CI, 0.26–0.78); patients ≥9 contacts had a 50% greater likelihood of not having a 4-month gap in care, compared with those with 0–8 contacts</td>
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<td>Harris et al (2003)</td>
<td>1426 Youth and young adults at risk for HIV infection in a prevention program (2.6% were already HIV infected)</td>
<td>January 1994–June 1998</td>
<td>Retention was defined as the number of days between a client’s first and the last visit during the 4-year period</td>
<td>Outreach contacts, case management contacts, and mental health counseling</td>
<td>Longer retention was associated in multivariate analysis with ≥2 outreach contacts reporting adjusted HRs for both male patients (0.64; 95% CI, 0.57–0.73; P &lt; .001) and female patients (0.72; 95% CI, 0.61–0.85; P = .002) at 301, 14, and 28 days; for case management at ≥3 visits for both male patients (0.57; 95% CI, 0.46–0.69; P &lt; .001) at 676, 15, and 15 days and female patients (0.54; 95% CI, 0.34–0.84; P = .013) at 534, 21, and 33 days; and for receipt of mental care services for male patients (0.66; 95% CI, 0.54–0.80; P &lt; .001) at 767, 6, and 21 days</td>
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<tr>
<td>Study Authors/Year</td>
<td>Sample Size/Population/Study Period</td>
<td>Description/Variables Assessed</td>
<td>Impact</td>
<td>Services Found to be Positively Associated with Retention</td>
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<td>Lo et al [16] (2002)</td>
<td>999 HIV-infected individuals receiving health care at a community health center 1997–1998 (2-year study)</td>
<td>Retention was defined as a dichotomous variable; a retained patient received primary care at least once every 6 months</td>
<td>Impact of ancillary services on retention was assessed; ancillary services included mental health care, case management, HIV/AIDS Drug Assistance Program, food and nutrition, complementary services (acupuncture, chiropractic, massage therapy), housing, transportation, legal, translation, and substance abuse treatment</td>
<td>Services found to be positively associated with retention: mental health care (70.5% of those receiving mental health care were retained, and only 57.1% of those not receiving mental health care were retained; $P &lt; .005$); case management (63.8% vs 57.8%; $P &lt; .05$); HIV/AIDS Drug Assistance Program (69.1% vs 58.8%; $P &lt; .05$); food and nutrition (73.6% vs 57.0%; $P &lt; .005$); complementary services (73.3% vs 58.8%; $P &lt; .005$); housing (72.9% vs 60.0%; $P &lt; .05$)</td>
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<td>Sendzik et al [41] (2004)</td>
<td>Study of 1 HIV clinic serving a population of at least 800 HIV-infected patients August 2002–July 2003</td>
<td>Looked at missed appointments</td>
<td>Multipronged approach: clerks phoned patients before their appointments, making 3 attempts, updated patients' phone numbers and addresses at each visit and reached out to no-show patients through emergency contacts and community agencies</td>
<td>Before the intervention, 52% of patients who missed appointments rescheduled, and after the intervention, 60% rescheduled; the number of monthly medical visits increased from 335 to 402 (increase of 20%)</td>
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<td>Sherer et al [14] (2002)</td>
<td>2647 HIV-infected adults (age, ≥ 19 years) January 1997–December 1998</td>
<td>Retention was defined as having at least 1 visit every 6-month period in the study (4 study periods)</td>
<td>Assessed impact of 4 supportive services: case management, transportation, mental health, and chemical dependency</td>
<td>All 4 services were found to be positively associated with retention; patients receiving case management were 16% more likely than patients not receiving case management to be retained ($P &lt; .001$), patients receiving transportation were 15% more likely to be retained ($P &lt; .001$), patients receiving mental health services were 18% more likely to be retained ($P &lt; .001$), data was not reported for the second year, and patients receiving treatment for chemical dependency were significantly more likely to be retained ($P = .036$) after 1 year</td>
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<td>Wohler-Torres et al [42] (2002)</td>
<td>Survey of 138 HIV treatment facilities; survey completed by clinic administrators</td>
<td>Percentage of HIV-infected patients missing a scheduled appointment on any given date</td>
<td>Size of clinic (number of providers) and availability of mental health services in the clinic</td>
<td>Clinics with &lt; 4 providers had fewer missed appointments (OR, 0.3), and clinics with mental health services available had fewer missed appointments (OR, 0.3)</td>
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**NOTE.** CI, confidence interval; HR, hazard ratio; HRSA, Health Resources and Services Administration; OR, odds ratio.
events concordant with the patient’s clinical requirements [58, 59] and one in which both the provider and the patient expect an enduring relationship [60]. In US HIV ambulatory care clinics, this relationship extends to the multidisciplinary provider team [61]. To measure continuity, the numerator would require greater specificity to measure whether visits are occurring with a specific provider or team; the denominator would likely extend for a period >12 months, to effectively assess longstanding care relationships.

At the community or state level, retention extends beyond the clinic to assuring that HIV-infected patients are adequately connected to a regular source of care that permits routine monitoring of immune status and access to treatment. Whether or not a patient is seen in the same clinic may not be important, as long as the patient is able to receive regular, coordinated care. In addition to patients’ voluntary decisions to seek care from multiple providers, they may relocate or become hospitalized or incarcerated—situations in which they would by most current measures be considered as not retained. In rural areas, care may be comanaged intentionally by primary care physicians and experienced HIV providers with fewer visits to one or the other, depending on clinical need. With access to more comprehensive information systems that include data from multiple providers in 1 state or from a large payor system, such as Medicaid, public health officials can identify whether patients are still connected to care in the larger system to determine whether they require special efforts to be reconnected. Cross-matching of databases between correctional systems, public health agencies, and other providers, such as the Veterans Health Administration hospitals, would potentially identify whether patients are continuously receiving care.

Currently available technology and the will to collaborate among different providers afford the opportunity to maximize available information to determine whether patients infected with HIV are connected to a regular source of care. Public health agencies can play a critical role by using this information, championing quality care, facilitating provider collaboration, and setting regional standards that define retention and continuity.

CONCLUSIONS

Exciting work is being conducted in the field of patient retention. Although significant literature exists describing both the demographic characteristics of patients more likely to fall out of care and the health consequences of falling out of care, much more work is needed. Research, particularly implementation research, is needed to understand the process of falling out of care and effective strategies for bringing patients back to care in a real-time context. Additional studies and exchange of information about patient retention at the health care system level are needed that embrace the concept of continuous care and demonstrate its link to improving public health outcomes. Keeping HIV-infected patients connected to care should be a major health care and public health priority. Improving patient retention will reduce morbidity, comorbidities, and transmission, ultimately leading to better patient and population health.

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