Published in final edited form as:

AIDS Patient Care STDS. 2007 September ; 21(9): 691–701. doi:10.1089/apc.2006.0205.

Retention Challenges for a Community-Based HIV Primary Care Clinic and Implications for Intervention

Sharon Coleman, M.S., M.P.H.¹, Ulrike Boehmer, Ph.D.⁴, Fumihido Kanaya, M.S., CPH², Christine Grasso, M.P.H.², Judy Tan, B.A.^{2,5}, and Judith Bradford, Ph.D.^{2,3}

¹Boston University School of Public Health, Boston, Massachusetts

²Fenway Community Health, The Fenway Institute, Boston, Massachusetts

³Community Health Research Initiative, Virginia Commonwealth University, Richmond, Virginia

⁴Department of Health Policy and Management, Boston University, Boston, Massachusetts

⁵Department of Social Psychology, University of Connecticut, Storrs, Connecticut

Abstract

The present study sought to elucidate factors involved in loss to follow-up (LTF) among HIV-infected patients who had been receiving medical care at Fenway Community Health (FCH) located in Boston, Massachusetts. FCH provided care to 1143 HIV-infected patients in 2005, predominantly Caucasian men who have sex with men (MSM). Two approaches were used to address the research question. First, 495 patients were identified that had been LTF from 2001–2005. One hundred seventy-nine eligible patients completed a questionnaire to determine reasons for discontinuing care, representing a 51% response rate. Second, a cohort study was performed using the medical record data of 896 HIV-infected patients who were receiving medical care in the year 2000. Patients' utilization of primary medical care was followed until January 1, 2005 and predictors of LTF were examined using Cox proportional hazards regression modeling. Survey respondents reported that the greatest perceived barriers to care at FCH were personal/cultural, structural, and financial in nature. Twenty-two percent reported sporadic care elsewhere with gaps in care of 6 months or more, and 8% reported no regular provider for HIV. Significant predictors of LTF from regression analysis included: minority race/ethnicity, use of safety-net insurance, appointment nonadherence and no medical social work visits. To improve engagement and retention in care, organizations may use patient surveys for organizational self-assessment to effect operational changes that minimize barriers to care. A risk assessment tool based on evidence-based methods can be implemented to identify high-risk patients for innovative outreach interventions. The primary study limitation is the underrepresentation of minority and traditionally underserved populations.

Introduction

Engaging and Retaining HIV-infected patients in HIV primary care has been a persistent challenge to healthcare systems. Continuity of medical care is a prerequisite for ongoing provision of life-prolonging therapies, which include antiretroviral medications and opportunistic infection prophylaxis.¹ The Centers for Disease Control and Prevention estimates that one third of all people who know their HIV status are not receiving care; while the HIV Cost and Services Utilization Study, based on a national probability sample, concluded that many Americans with diagnosed or undiagnosed HIV infection are not receiving medical care at least as often as every 6 months.^{2,3} The frequency of primary care evaluation depends on the stage of HIV disease and on the medications a patient is taking. Asymptomatic patients with normal CD4 cell counts and low viral loads require monitoring at least once every 6 months and patients with low CD4 cell counts, high viral loads, or taking anti-viral medication require visits more frequently, every 3–4 months.^{4,5}

Factors that influence a patient to disengage from care frequently result in patterns of episodic utilization that may compromise the patient's health status and increase their psychosocial vulnerability. When specifically examining highly active antiretroviral therapy (HAART) outcomes, studies have found that missed appointment rates were the most significant factor related to treatment failure.⁶ More recently, nonadherence to medical appointments has also been associated with increased plasma HIV RNA and decreased CD4 cell counts.⁷ In 1998, the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) investigated the relationship between a patient's receipt of ancillary services and their entry into and retention in HIV primary medical care.⁸ The outcomes suggested that receipt of ancillary services such as case management, mental health and substance abuse treatment, transportation, and housing assistance is associated with primary care entry and retention among Ryan White Comprehensive AIDS Resources Emergency (CARE) Act patients. Past literature is illustrative of the fact that ancillary services, especially case management were shown to have a positive influence on access to primary care, reducing unmet needs, and higher use of HIV medication.^{9–11}

To evaluate specific targeted outreach strategies, HRSA funded an initiative to test and evaluate interventions designed to engage people in HIV care, turn sporadic users into regular users, and promote retention in care among under-served populations living with HIV.¹² This 5-year initiative began in 2001 and The Fenway Institute (TFI) of Fenway Community Health (FCH) was one of 10 grantees funded under the project. Beyond implementing enhanced out-reach, TFI looked specifically at why approximately 125 or 10% of annual HIV-infected patients, are lost to follow up (LTF) each year at FCH.

This paper contributes new information to the literature by using several approaches to find out which patients have continuity of medical care after establishing a primary care relationship. Despite an annual increase of new HIV-infected patients seeking care at FCH, why are approximately 125 patients discontinuing care at FCH each year and can we develop an evidence-based risk assessment tool assisting providers to recognize patients that may be tenuously connected to care? Examining this primary research question could lead to

important contributions to policy and practice. Some patients may be retained in care by using enhanced outreach methods.

Service setting

Located in Boston, Massachusetts, FCH is a federally qualified community health center (FQHC) serving 11,000 patients in 2005, of which 1,143 were HIV-infected. The primary mission of community health centers is to provide primary and preventive healthcare for underserved and vulnerable populations including the uninsured and underinsured. They are often referred to as “safety net” providers. In keeping with its mission, FCH became federally qualified in 2002. As a FQHC, target populations are distinctly different from the population originally served in the first generation of HIV—primarily Caucasian, men who have sex with men. As the HIV/AIDS epidemic in the United States now disproportionately affects racial and ethnic minorities¹³ FCH desires to meet the needs of the changing epidemic. Despite its extensive array of health care and related services, FCH has not had sufficient resources to maintain continuing contact with patients who do not return for their medical appointments. Without the resources to conduct extensive follow-up efforts, providers do not know whether these patients are receiving care elsewhere or not at all. The present study was conceptualized to facilitate organizational self-analysis and to minimize barriers to HIV care.

Materials and Methods

Study design

Two approaches were used to answer our research question: (1) a patient survey was given to LTF patients to determine reasons for discontinuing care at FCH and (2) a retrospective cohort design: data available in the electronic medical record was analyzed to develop a statistical model. This model of predictor variables could help identify individuals who may be at higher risk of dropping out of care. Identification of specific factors that contribute to retention and attrition will provide insight to guide interventions to ensure fully effective service planning. The Institutional Review Board (IRB) of FCH approved both aspects of the study design.

Survey sample

An initial population of 495 HIV-infected individuals who had been receiving medical care at FCH was selected as potential survey respondents due to their inactive medical utilization status. The population was identified from the clinic's electronic medical record system (Centricity®). A patient was defined as inactive if they had not received an HIV primary medical care visit for 1 year or longer. We examined a cohort who had been lost to follow-up over the course of 4 years that included calendar years 2001, 2002, 2003, and 2004. Eligible survey participants were 18 or older, HIV-infected, were not incarcerated during the interview period, contact information was up to date, and they were determined to be inactive patients at FCH.

Survey methods

There were two methods of survey data collection implemented to minimize nonresponse bias. The first method was the use of a telephone questionnaire and the second was a mail questionnaire. Each questionnaire inquired about patient demographics, reasons for discontinuing care at FCH, health care that they are receiving now for HIV treatment and perceived barriers to care. Specific prescreening questions were embedded into the survey to identify sporadic or nonusers of care who may have been interested in enrolling into an out-reach intervention called Health System Navigation (HSN).

HSN is an innovative model for assisting HIV-infected individuals to become engaged and retained in HIV medical care. Peer and near-peer outreach workers perform the service, which has been described as an emerging model of care coordination within HIV care.¹⁴ Inclusion criteria for HSN included: HIV-infected and one of the following: (1) began HIV medical care less than 6 months ago, (2) does not have a regular HIV care provider, (3) has switched providers 2 or more times in the past 2 years, (4) has gone 6 months or more without seeing an HIV provider in the past year, (5) missed or rescheduled 1 or more of every 3 HIV appointments in the last year, (6) self-reported life issues (i.e., lack of housing, depression, problems with providers, drug use) interfering with HIV medical care once or more in the past year.

Each eligible survey participant was mailed an introductory letter stating the purpose of the project. Several days after the initial mailing, telephone attempts, using contact information from patient registration, were made. The protocol consisted of 10 attempts to each valid phone number. This phase of the study began in January 2005. By March 2005, the disposition of many calls was not in service, disconnected, or a wrong number. For these individuals we began more extensive attempts at locating accurate contact information. We requested Registry of Motor Vehicle license abstracts for former patients who were difficult to reach by telephone. The license abstracts gave us address information for individuals who may have moved since they stopped receiving care at FCH. Updated abstracts were received on 80% of the population. Methods to secure a valid telephone number were initiated at this time and included using 411, online search methods, and postal forwarding addresses. A search of the Social Security Death Index was performed intermittently throughout the project to determine if anyone was deceased. In addition, criminal offender record information searches were performed to determine if an individual was incarcerated during the project period.

The second method of data collection was a mail survey. In April 2005, the mail survey was implemented to enhance response rates. Using Dillman's Total Survey Design¹⁵ approach we sent the mail survey to all individuals who had not yet taken a telephone survey. A total of 247 individuals were sent the mail survey.

Medical record methods

The second approach used to address our research question was to conduct a retrospective cohort analysis using information available in medical records. Medical records are considered one of the best approaches to obtaining valid information on utilization

patterns.¹⁶ These data allowed us to devise a statistical model to predict factors that are associated with LTF. Electronic medical record data have significant advantages by facilitating data extraction on large samples, and the ability to control for sampling bias by contributing information from subjects who may not regularly access healthcare. All data had been stored in the electronic medical record system (Centricity®) as a function of routine service provision. Centricity® is an Oracle-based relational database software system, built specifically for patients' medical record management. An analysis dataset was created by extracting data from Centricity® using Seagate Crystal Report Professional 9.0, removing patient identifiers, and then converting and importing data into Microsoft Access (Microsoft, Inc., Redmond, WA) and SAS (SAS Institute Inc., Cary, NC) data formats for further data management.

Study analysis was based on 5 years of data collected from patients who received primary HIV medical care at FCH. The source population included 896 patients that were actively receiving HIV medical care in the calendar year 2000. A patient's use of primary medical care was then followed until January 1, 2005. The outcome variable of interest was LTF as measured by time in care. Anyone who did not continue care past December 31, 2003 was defined as having the event of interest; 326 patients were determined to be LTF during the defined period. This cohort was further refined to censor competing risks which included death within a year of last appointment or moving out of the catchment area leaving 212 patients. This step was performed because we were primarily interested in factors that may predict LTF that could be impacted by clinicians and/or outreach interventions. Patients who remained in care past December 31, 2003 were defined as active.

Independent variables in the analysis were those previously suggested to be associated with nonadherence to medication or regular HIV care. Demographic information included gender, age, insurance status, and race-ethnicity based on self-report at registration. Racial-ethnic group was coded as black, white, Hispanic, Asian, or undetermined. Insurance information was categorized into four groups: private/commercial insurance, Medicaid, Medicare, and health care "safety net" programs including the HIV Drug Assistance Program, Ryan White funding, and the free care pool, which are programs for uninsured or underinsured HIV positive individuals to access primary care and medication assistance. Other variables extracted from the medical record included the use of medical social work services and the use of acupuncture detoxification and maintenance (ADAM), which were constructed into binary (yes/no) variables. A missed appointment rate was calculated by creating a ratio between cancelled and no show appointments and scheduled appointments. Each patient visit is recorded into Centricity® by patient services staff, and all appointments are classified by the appointment status into "scheduled," "arrived," "cancelled," and "no show." Length of time in care may vary for individuals who were lost to follow-up; we control for this by creating a ratio versus absolute accounting of missed appointments. A ratio of no show to arrived appointments was also calculated. Comorbidities included substance abuse, smoking, and hepatitis diagnosis. Disease severity was determined by examining the most recent CD4 cell count, the most recent HIV RNA, and time since diagnosis, which subtracted HIV onset date from first appointment date in 2000.

Dummy variables were created to create more clinically meaningful interpretation in the regression model. Race-ethnicity was dichotomized to white versus racial minority and insurance status to safety net funding versus all other forms of insurance. The missed appointment rate was analyzed for the entire cohort and the 25th percentile was chosen as a cut-off point for analysis. Therefore we created a missed appointment rate variable of greater than 20% and 20% or less missed to scheduled appointments.

Statistical analysis

All analyses were performed in SAS version 8.2. Descriptive statistics were used to describe the patient survey results and a comparison to nonresponders was performed. Bivariate analysis used χ^2 statistics or t tests to compare differences between the active cohort and the LTF cohort in the retrospective cohort analysis. Wilcoxon nonparametric testing was used for data that did not follow a normal distribution. Survival analysis using Cox proportional hazards modeling was used to examine predictors of attrition.¹⁷ This model was used due to its ability to account for time to event and censored observations. Censored observations include individuals who did not have the event (LTF) over the course of follow-up, and individuals with competing risks (death, moving). Survival analysis is often used in longitudinal studies where subjects have differing contributions of time in the study and the hazard ratio is interpreted like a risk ratio. Variables that were significant at the $p < 0.05$ level in the bivariate analysis were considered as candidates for the multivariate analysis as we wished to create the most parsimonious model. With survival analysis, we examined the relationship between our dependent variable, length of time in care, and the independent variables meeting criteria for inclusion. A χ^2 p value < 0.05 was considered statistically significant in the multivariate analysis.

Results

Survey results

Overall, survey attempts demonstrated that 69 (14%) of the 495 patients that discontinued care at FCH were deceased. Another 15% were ineligible secondary to incarceration or unobtainable contact information leaving a final sample size of 352. One hundred seventy-nine surveys were completed which represents a Council of American Survey Research Organization (CASRO) response rate of 51%.

Thirty percent of those surveyed reported relocation as the only reason for discontinuing care at FCH, 22% reported sporadic care elsewhere with gaps in care 6 months and 8% reported no regular provider for HIV. Other perceived barriers contributing to LTF included: personal/cultural (poor engagement with provider, clinic atmosphere, concerns of stigma), structural (transportation/parking issues), and financial. The patient responses to the question, "Did any of the following problems lead to your decision to discontinue at FCH?" are presented in Table 1.

Patient demographics are presented in Table 2. Of note, 26% of the original sample had a criminal history and 10% had a history of incarceration. Nonresponders were defined as individuals who were believed to have accurate contact information, and were not

incarcerated or deceased. We examined nonresponse bias by comparing non-responders to responders on the following variables: gender, race/ethnicity, and age. There was no significant difference in nonresponders except for age. The mean age of the nonresponders was 41.7 and the mean age of the responders was 44.4, $p < 0.001$. Of the respondents interviewed, 14% were eligible for the HSN intervention (more respondents were sporadic users of care but were located outside of the metropolitan Boston area and therefore ineligible for the intervention).

Medical record results

Bivariate analyses of patient characteristics as derived from chart review are shown in Table 3. When comparing the LTF cohort to those who remained active in care from 2000 to 2004, we note significant differences in age, race/ethnicity, insurance status, missed appointment rate and use of medical social work. The LTF cohort tended to be younger, minority individuals with no/minimal health insurance and using safety net funding such as Ryan White. The missed appointment rate of 42% in the LTF group is significantly higher than the active group while the 26% missed appointment rate is consistent with the reported rate in the study by Berg et al.⁷

The LTF cohort was less likely to have used medical social work as a support service (33.5% of the population used this service versus 41.8% of the active group). Examining health status (Table 4), the time since onset of HIV was shorter in the LTF group, the most recent CD4 count was more likely to be < 200 cells/mm³ and the most recent plasma HIV RNA was detectable. Comorbidities were not different between groups. Survival analysis was used to determine the predictive ability of age, racial minority status, use of the safety net care pool, medical social work utilization, and appointment nonadherence in LTF. As noted in Table 5, all variables were significant predictors of becoming LTF except for age at intake. Time since HIV onset was not included in the model due to the number of missing observations. The risk of discontinuing care could be calculated by applying the regression model as follows:

$$h(t) = h_0(t) * e^{(\beta_1 X_1 + \beta_2 X_2 + \dots + \beta_k X_k)}$$

The above formula allows us to predict the risk of discontinuing HIV medical care based on any of the significant covariates. For example, a black male with Ryan White funding for HIV medical care, who missed more than 1 out of 5 scheduled medical appointments:

$$\text{Risk} = \text{Exp} (0.46 * \text{Racial minority} + .52 * \text{Safety net funding} + \text{Missed more than 1 out of 5 appointments} * 1.73)$$

Code racial minority as 1, safety net payment source as 1, more than 20% missed appointment rate as 1.

Therefore

Risk=Exp (2.71) or this individual would be 15 times more likely to discontinue care.

Discussion

Continuity of medical care is critical for ongoing provision of life-prolonging treatment including antiretroviral medication and opportunistic infection prophylaxis. This is one of the first known studies to interview a LTF HIV-infected population and broadens the findings of Samet et al.¹⁸ by interviewing patients who had discontinued care. Samet and colleagues found that hospital site, no high school education, no history of victimization, jail time in the last 10 years and higher CD4 cell counts were all associated with discontinuation of care. Unlike, the present study, they did not ask patients directly why they discontinued care and their patient sample reflected more traditionally underserved populations.

Our survey results corroborate the Institute of Medicine's model of barriers to health care.¹⁹ Most respondents reported reasons that were personal-cultural barriers, such as poor provider engagement and concerns of stigma. Structural barriers included parking, transportation, and appointment time issues, while financial barriers included worrying about how to pay for HIV medical care. Exploring provider engagement issues among others reported is recommended as there is a growing trend in skills building in doctor-patient communication. There is an increasing body of literature that explores the association between HIV-infected patients' level of trust in systems of care and their provider and their use of health services. Trust has been associated with more clinic visits, use of antiretroviral medications, fewer emergency room visits, and better health outcomes. Patients who are more engaged with their health care provider have reported greater adherence to medication regimens and provider advice.^{20,21} The survey also demonstrated the need for sustaining enhanced outreach interventions such as HSN to facilitate regular care and ancillary service use. We noted that 10% of the LTF population had a history of incarceration. This should also be taken into consideration with outreach interventions to ensure that individuals engage in care after reentry. Survey results do have limitations due to the inherent issues of interpretation of self-report data. The sample size represents only a portion of all patients that were LTF so we cannot rule out nonresponse bias in the sample. Nonresponders were no different from responders when comparing gender and race/ethnicity but the nonresponders were more likely to be younger. We were not able to compare the groups on other characteristics. Nonetheless, direct patient feedback indicated areas for organizational self-analysis to effect operational changes that minimize barriers to care.

The retrospective analysis of electronic chart data revealed a model for determining factors that predict LTF in a cohort of HIV-infected patients. Individuals who were racial minorities, used safety net payment sources, missed greater than 20% of scheduled appointments (or had 1 of 3 no-shows) and had no medical social work visits were at greatest risk of attrition. Of note, a detectable viral load and a CD4 count less than 200 were also significant in the regression model. For simplification toward a risk assessment tool and because care must be taken in making causal inferences with HIV markers—patients' may

have poorer health status secondary to appointment nonadherence, we focused on the four factors noted above and not HIV markers for risk assessment. It was notable that virologic outcome data in the LTF group demonstrated that 42% of this group potentially experienced treatment success. In comparison to other studies of underserved populations, this rate may be relatively high. When subanalysis was carried out, however, minorities and those with safety net funding did not fare as well. Despite the relative amount of treatment success, it has been documented that viral suppression is hard to maintain and that missed appointment rates are the most important risk factor for treatment failure.⁶ The present rate of viral suppression (42%) in the LTF group has been demonstrated to be significantly associated with medication adherence rate less than 90%. A study by Paterson et al.,²² found that patients with adherence of 95% or greater had superior virologic outcomes (78% with an undetectable viral load), a greater increase in CD4 cell count, and a lower hospitalization rate than did patients with lower levels of adherence. It is also important to note that CD4 cell counts in the LTF group closely approximate those found in the Targeted HIV Outreach and Intervention Initiative, a study of underserved persons targeted for supportive outreach services; 24.8% of the outreach population presented with CD4 counts less than 200 cells/mm³ in comparison to 21.2% of our LTF population.²³

We are not able to determine whether patients who were LTF at our clinic followed up with care elsewhere, however, the survey results demonstrated that 22% reported only sporadic care elsewhere and 8% reported having no regular provider for HIV. Forty-five percent of survey respondents met prescreener eligibility criteria for HSN but were residing outside of metropolitan Boston and, therefore, ineligible. The medical record results complement studies on appointment nonadherence and HIV health status and suggest that appointment nonadherence leading to attrition may also lead to disease progression and failure to maintain viral suppression. Patient retention and continuity in HIV care is imperative for optimal health and it is more cost effective for the health care system. Targeting patients at highest risk for discontinuation of care is a potential strategy for implementing interventions that would address this population. Given that FCH is broadening its target populations for outreach and health care, it is timely to institute procedures that serve to enhance retention in care. Primary care teams are key to FCH's case management and retention efforts. The implementation of HSN or a similar patient navigation approach may strengthen existing retention efforts even further by targeting the hardest to reach populations. There is an emerging body of literature examining the use of patient navigation in cancer care and a call for studies to document its effectiveness. This model may be useful if adapted for HIV interventions, as similar barriers impede the delivery of and retention in HIV primary care.

A limitation of the current study is the generalization of results. The population evaluated came from a community based urban medical center in Boston and the HIV-infected population may not be reflective of populations at other urban medical centers. The population had substantial representation of Caucasian MSM and 46% had private health insurance. Survey respondents were 96% male and had relatively high socioeconomic status so competing needs such as childcare were not demonstrated.

Another limitation is the lack of data on other potential predictive variables such as mental illness diagnoses and use of mental health care. Despite these limitations, this study can

serve as a model for other HIV clinics that may develop similar patient surveys and risk assessment tools. Furthermore, it provides an evidence-based tool to identify high-risk patients that may benefit from enhanced outreach to remain engaged in HIV primary care. This will be imperative as the epidemic's disproportionate impact on racial and ethnic minorities continues.

Acknowledgments

This research was supported by grant number H97HA00191-05-07 from the Health Resources and Services Administration. This grant was funded through the HIV/AIDS Bureau's Special Projects of National Significance. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the views of the funding agencies or the U.S. government. The authors wish to thank Eugenia Handler for her assistance on this endeavor.

References

1. Aday LA. A health services research perspective on the use of ancillary services to retain persons living with HIV/AIDS in primary care. *AIDS Care*. 2002; 14(Suppl 1):S133–136. [PubMed: 12204147]
2. Bozzette SAB, Duan SH, Frankel N, et al. The care of HIV-infected adults in the United States. HIV Cost and Services Utilization Study Consortium. *N Engl J Med*. 1998; 339:1897–1904. [PubMed: 9862946]
3. Fleming, PL.; Byers, RH.; Sweeney, PA.; Daniels, D.; Karon, JM.; Janssen, RS. HIV Prevalence in the United States, 2000; 9th Conference on Retroviruses and Opportunistic Infections; Seattle, WA. 2002.
4. DHHS. Panel on Clinical Practices for Treatment of HIV Infection Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents. 2005
5. Aberg JA, Gallant JE, Anderson J, et al. Primary care guidelines for the management of persons infected with human immunodeficiency virus: Recommendations of the HIV Medicine Association of the Infectious Diseases Society of America. *Clin Infect Dis*. 2004; 39:609–629. [PubMed: 15356773]
6. Rastegar DA, Fingerhood MI, Jasinski DR. Highly active antiretroviral therapy outcomes in a primary care clinic. *AIDS Care*. 2003; 15:231–237. [PubMed: 12856344]
7. Berg MB, Safren 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-based HIV primary care clinic. *AIDS Care*. 2005; 17:902–907. [PubMed: 16120506]
8. Conviser R, Pounds MB. Background for the studies on ancillary services and primary care use. *AIDS Care*. 2002; 14(Suppl 1):S7–14. [PubMed: 12204138]
9. Friedmann PD, D'Aunno TA, Jin L, Alexander JA. Medical and psychosocial services in drug abuse treatment: Do stronger linkages promote client utilization? *Health Serv Res*. 2000; 35:443–465. [PubMed: 10857471]
10. Lo W, MacGovern T, Bradford J. Association of ancillary services with primary care utilization and retention for patients with HIV/AIDS. *AIDS Care*. 2002; 14(Suppl 1):S45–57. [PubMed: 12204141]
11. Katz MH, Cunningham WE, Fleishman JA, et al. Effect of case management on unmet needs and utilization of medical care and medications among HIV-infected persons. *Ann Intern Med*. 2001; 135(8 Pt 1):557–565. [PubMed: 11601927]
12. HRSA. FY 2001 Program Guidance: New Competitive Initiative for Targeted HIV Outreach and Intervention Model Development and Evaluation for Underserved HIV-Positive Populations Not in Care. 2001
13. HIV/AIDS Policy Fact Sheet. 2006
14. Vargas RB, We C. Evolving trends in medical care-coordination for patients with HIV and AIDS. *Curr HIV/AIDS Rep*. 2006; 3:139–143. [PubMed: 16970841]

15. Dillman, DA. Mail and Telephone Surveys: The Total Design Method. Baltimore: John Wiley and Sons Inc.; 1978.
16. Mkanta WN, Uphold CR. Theoretical and methodological issues in conducting research related to health care utilization among individuals with HIV infection. *AIDS Patient Care STDs*. 2006; 20:293–303. [PubMed: 16623628]
17. Therneau, T.; Grambsch, P. Modeling Survival Data: Extending the Cox Model. New York: Springer-Verlag; 2000.
18. Samet JH, Freedberg KA, Savetsky JB, Sullivan LM, Padmanabhan L, Stein MD. Discontinuation from HIV medical care: Squandering treatment opportunities. *J Health Care Poor Underserved*. 2003; 14:244–255. [PubMed: 12739303]
19. Millman, M. Committee on Monitoring Access to Personal Health Care Services IoM Access to Health Care in America. Washington, D.C.: National Academy Press; 1993.
20. Whetten K, Leserman J, Whetten R, et al. Exploring Lack of trust in care providers and the government as a barrier to health service use. *Am J Public Health*. 2006; 96:716–721. [PubMed: 16507725]
21. Bakken S, Holzemer WL. Relationships Between perception of engagement with health care provider and demographic. *AIDS Patient Care STDs*. 2000; 14:189. [PubMed: 10806637]
22. Paterson DL, Swindells S, Mohr J, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med*. 2000; 133:21–30. [PubMed: 10877736]
23. Cunningham WE, Sohler NL, Tobias C, et al. Health services utilization for people with HIV infection: Comparison of a population targeted for outreach with the U.S. population in care. *Med Care*. 2006; 44:1038–1047. [PubMed: 17063136]

Table 1
Patient Reasons for Discontinuation of Care

	<i>All respondents</i> n = 179	<i>Respondents</i> <i>excluding</i> <i>“Movers”</i> n = 126
Were you dissatisfied with your primary provider?	30%	43%
Were you dissatisfied with the manner in which you were checked in by reception staff?	17%	24%
Did you move to a different area?	46%	23% ^a
Did you have trouble with parking?	11%	16%
Did you have trouble with transportation?	10%	14%
Did you have trouble getting an appointment at a time you could make it?	10%	14%
Were you afraid that other people might find out that you had HIV if you went for care at Fenway?	9%	13%
Were you worried about how you would pay for your HIV medical care?	8%	11%
Did you have problems with billing?	8%	11%
Did your primary provider leave Fenway Community Health?	8%	11%
Were you dissatisfied with your mental health provider?	7%	10%
Were you worried about what other people might think about your sexual orientation if you went for care at Fenway?	5%	6%
Did you have a problem finding providers who speak your language?	1%	0%
Did you have any other problems with Fenway Community Health?	37%	53%
Specify: _____		

Note: Responses are > 100% due to participants ability to choose more than one response.

^a Some individuals selected moving and another reason for leaving. They may have moved within the catchment area, therefore they were kept in this analysis.

Table 2
Survey Respondents Self-Reported Characteristics

<i>Variable</i>	<i>n</i>	<i>%</i>
Gender		
Male	170	95.5
Female	7	3.9
Transgender	4	2.3
Race/ethnicity		
White	138	77.1
Black	19	10.6
Latino/a	17	9.6
Asian/Pacific Islander	2	1.1
More than one race	13	7.3
Sexual orientation		
Gay	146	82.5
Straight	13	7.3
Lesbian	4	2.3
Bisexual	11	6.2
Prefer not to identify	3	1.7
Education		
High School	52	29.2
> High School	126	70.8
Insurance Status at FCH		
Private	90	50.8
Medicaid	44	24.9
Medicare	32	18.1
No insurance	16	9.0
Veteran student	6	3.4
Income		
200% FPL	54	32.5
> 200% FPL	112	67.5
CORI check on $n = 495$		
Criminal history	128	25.9
History of incarceration	49	9.9

Table 3
Patient Characteristics from Electronic Medical Record

<i>Variable</i>	<i>Overall sample n = 896</i>	<i>Active cohort n = 570</i>	<i>LTF Cohort with LTF secondary to moving/death removed n = 212</i>	<i>Significance</i>
Age in years—Mean (SD)	39.7 (7.7)	40.3 (7.7)	38.6 (7.8)	$p < 0.01$
Gender <i>n</i> (%)				
Female	29 (3.2)	17 (3.0)	8 (3.8)	ns
Male	867 (96.8)	553 (97.0)	204 (96.2)	ns
TG	8 (1.0)	3 (0.53)	4 (1.9)	$p = 0.09$
Race/ethnicity <i>n</i> (%)				
Black	87 (9.7)	50 (8.8)	27 (12.9)	$p = 0.09$
Latino/a	69 (7.7)	37 (6.5)	22 (10.5)	$p = 0.07$
Asian	11 (1.2)	7 (1.2)	3 (1.4)	ns
Undetermined	14 (1.6)	1 (0.2)	9 (4.3)	ns
White	711 (79.5)	474 (83.2)	149 (71.0)	$p < 0.001$
Insurance <i>n</i> (%)				
Private	501 (56.3)	348 (61.1)	97 (45.8)	$p < 0.001$
Medicare	164 (18.5)	110 (19.3)	33 (16.1)	ns
Masshealth	129 (14.5)	73 (12.8)	38 (18.5)	$p = 0.07$
Ryan White, other safety net	88 (10.0)	36 (6.3)	34 (16.6)	$p < 0.001$
Missed Appt. Rate (%)				
Missed/Scheduled	31	26	42	< 0.001
No Show/Arrived	12.5	12	36	< 0.001
Ancillary Services <i>n</i> (%)				
Medical social work	340 (38.0)	238 (41.8)	71 (33.5)	$p = 0.04$
ADAM	70 (7.8)	52 (9.1)	13 (6.1)	ns

TG, transgender; ADAM, Acupuncture Detoxification and Maintenance Program; ns, not significant; LTF, lost to follow-up.

Table 4
Health Status from Electronic Medical Record

<i>Variable</i>	<i>Overall sample n = 896</i>	<i>Active cohort n = 570</i>	<i>LTF cohort with LTF secondary to moving/death removed n = 212</i>	<i>p value</i>
Comorbidity N (%)				
Substance Abuse	342 (38.2)	223 (39.1)	80 (37.7)	ns
Smoking	145 (16.2)	89 (15.6)	32 (15.1)	ns
Hepatitis	200 (22.3)	128 (22.5)	49 (23.1)	ns
Disease Severity				
Time since diagnosis (yrs)				$p < 0.0001$
Median (range) $n = 651$	2.5 (0–16.5)	2.7 (0–16.5)	1.0 (0–15.1)	
Recent CD4 cell count (Mean)	534	565	468	$p < 0.0001$
Recent HIV RNA	20245 Mean 75 Median (50–500,000)	12,387 Mean 75 Median (50–500,000)	28,385 Mean 1000 Median (50–500,000)	$p = 0.016$
Recent CD4 < 200 n (%)	117 (13.1)	45 (7.9)	45 (21.2)	$p < 0.0001$
Recent CD4 200–350 n (%)	164 (18.3)	104 (18.3)	43 (20.30)	ns
Recent CD4 350 n (%)	615 (68.6)	421 (73.9)	124 (58.5)	$p < 0.0001$
Recent HIV RNA n (%)				
Undetectable	497 (55.5)	358 (62.8)	89 (42.0)	$p < 0.0001$
Stratification by race and pay source		Minority 63 (17.6) Safety net 18 (5.0)	Minority 21 (23.6) Safety net 16 (18.0)	
Detectable	399 (44.5)	212 (37.2)	123 (58.0)	$p < 0.0001$

ns, not significant.

Table 5
Multivariate Regression Analyses Predicting Patient Attrition

<i>Regression variables</i>	<i>β</i>	<i>HR</i>	<i>95% Confidence Interval</i>	<i>p</i>
Greater than 20% missed appointments	1.73	5.66	(3.14–10.18)	< 0.0001
Safety net for medical care	0.52	1.69	(1.15–2.49)	< 0.01
Racial minority	0.46	1.56	(1.17–2.13)	< 0.004
Medical social work	−0.55	0.58	(0.43–0.77)	< 0.001
CD4 count <200	0.58	1.79	(1.26–2.52)	< 0.002
Detectable HIV RNA	0.49	1.63	(1.23–2.17)	< 0.001
Age at intake	−0.009	0.09	(0.97–1.01)	ns

HR, hazard ratio; ns, not significant.