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Sorting Through the Lost and Found: Are Patient Perceptions of Engagement in Care Consistent with Standard Continuum of Care Measures?

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Abstract

Background—Indicators for determining one's status on the HIV care continuum are often measured using clinical and surveillance data but do not typically assess patient perspectives. We assessed patient-reported care status along the care continuum and whether it differed from medical records and surveillance data.

Methods—Between June 2013–October 2014, a convenience sample of clinic-attending HIV-infected persons was surveyed regarding care-seeking behaviors and self-perceived status along the care continuum. Participant responses were matched to DC Department of Health surveillance data and clinic records. Participants' care patterns were classified using HRSA-defined care status:

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in care (IC); sporadic care (SC), or out-of-care (OOC). Semi-structured qualitative interviews were analyzed using an open coding process to elucidate relevant themes regarding participants' perceptions of engagement in care.

Results—Of 169 participants, most were male (64%), black (72%), and a mean age of 50.7 years. Using self-reported visit patterns, 115 (68%) were consistent with being IC, 33 (20%) SC, and 21 (12%) OOC. Among OOC participants, 52% perceived themselves to be fully engaged in HIV care. In the prior year, among OOC participants, 71% reported having a non-HIV related medical visit and 90% reported current antiretroviral use. Qualitatively, most SC and OOC persons did not see their HIV providers regularly because they felt healthy.

Conclusions—Participants' perceptions of HIV care engagement differed from actual care receipt as measured by surveillance and clinical records. Measures of care engagement may need to be reconsidered as persons not receiving regular HIV care may be accessing other health care and HIV medications elsewhere.

Keywords

HIV; engagement in care; continuum of care; self-perceived; surveillance; clinic records

INTRODUCTION

According to the HIV continuum of care, in order for HIV-infected persons to take full advantage of HIV care and treatment and achieve viral suppression, they must be engaged and retained in HIV care and receiving antiretroviral (ARV) therapy. At an individual level, engagement and retention in care have been shown to improve immunological outcomes, decrease HIV-associated morbidity, and prolong survival. Patients who delay entry into care or miss visits within the first year of diagnosis have higher mortality.¹⁻⁴ Once engaged in care, those persons who are able to sustain engagement in care have higher rates of viral suppression.⁵ At a population level, when a person is fully engaged in care their risk of transmitting virus to others is also significantly decreased due to both decreased risk taking behaviors and decreased biological risk of transmission from being virally suppressed.⁶⁻¹⁰ Thus, the central tenet of prevention approaches such as treatment as prevention, which aims to treat infected persons with the goal of achieving individual and public health benefit, cannot be met if we are unable to fully engage HIV infected persons in care.^{10,11}

Despite unequivocal evidence in support of HIV care engagement, it remains one of the most difficult steps of the HIV care continuum to achieve and maintain. While HIV routine testing scale-up has resulted in earlier diagnosis and with the majority of persons successfully linking to care, the ability to remain in care, adhere to medication regimens, and achieve viral suppression has not been as successful.⁶ The US Centers for Disease Control and Prevention (CDC) estimates that as few as 40% of HIV-positive people are engaged in care with only 30% achieving viral suppression.^{12,13} Persons who tend to be poorly engaged in care are often young, racial or ethnic minorities, have co-morbid conditions such as mental health disorders, and inject drugs or abuse other illicit substances.¹⁴⁻¹⁸ HIV-infected persons who are poorly engaged or fall out of care have higher rates of complications and increased hospitalizations and deaths, resulting in an undue economic burden.^{19,20}

Additionally, they are often engaging in high risk behaviors such as injection drug use and unprotected sex, thereby decreasing medication adherence and increasing the risk of transmission to sexual partners.^{7,8,21}

Given the relatively low rates of care engagement in the US, the National HIV AIDS Strategy (NHAS) calls for increasing access to care and improving clinical outcomes by increasing the proportion of persons who are retained in care and virally suppressed.²² In Washington, DC a city with a 2.4% HIV prevalence and continuum of care outcomes similar to those nationally, multiple efforts are underway to address the NHAS goals which include efforts to identify persons who are HIV positive but out of care, to identify barriers to care, and to improve clinical outcomes. Since 2009, Washington, DC has been one of two intervention cities participating in the Testing and Linkage to Care Plus study which aims to look at the feasibility of implementing a population-based test and treat approach and includes city-wide initiatives aimed at testing, linkage to care, and retention in care coupled with financial incentives.²³ Additionally, an essential District of Columbia Department of Health (DCDOH) led effort is the conduct of a city-wide Recapture Blitz by the District of Columbia Department of Health (DC DOH). First conducted in 2008, the goal of the Recapture Blitz is to identify persons who are out of care based on review of both clinical and surveillance records and attempt to re-engage these persons into HIV care.²⁴ In past years, the Recapture Blitz has successfully identified and re-linked to care hundreds of HIV-infected persons who had fallen out of care.²⁴

Determining who is truly out of care for programs such as the Recapture Blitz is a complex process. HIV infection is a lifelong chronic illness and as such engagement in care is often a dynamic state with HIV positive persons sometimes cycling in and out of care, at times referred to as “churn”.^{25–30} Previous research has found that persons tend to cycle in and out of care due to a combination of structural, cultural, and individual-level barriers. Structural barriers that prevent HIV-infected persons from receiving optimal care include unstable housing, unemployment, lack of insurance, and transportation.^{15,31–33} Moreover, clinic-level barriers such as limited clinic hours, poor patient-provider relationships, language, or cultural barriers also prevent HIV-infected persons from fully benefiting from HIV care and treatment.^{31,34–36} Given the disproportionate impact of HIV on socioeconomically disadvantaged populations, competing priorities related to the daily responsibilities of life can also present a significant barrier to engagement and retention in care.^{37,38}

Furthermore, there is no agreed upon gold standard for measuring engagement and retention in care.^{39–41} The Health Resources Services Administration HIV/AIDS Bureau (HRSA HAB) was one of the first federal agencies to propose a standard measure for HIV engagement in care which suggested that persons should have evidence of at least two HIV related clinic visits at least 90 days apart within a 12 month period.⁴² While other alternative measures have been defined, these measures vary with respect to the data sources (missed vs. kept visits), required visit frequency (60 vs. 90 days apart), and observation period (12 vs. 24 months) necessary to be considered engaged in care.^{41,43–45} In addition, these measures are variable with respect to the source of data as some rely on clinic-based data and others use population-based data from cohorts or public health and laboratory surveillance.^{5,39,43,46}

As researchers attempt to refine the measurement of engagement in care indicators, an often overlooked perspective is that of the patients themselves. While previous studies have used patient self-report of CD4 and viral load measures, and elicited reasons for poor care engagement, few studies have explicitly asked patients their perceptions as to their level of engagement in care and status along the care continuum.^{21,26,27,47,48} Thus, we conducted a mixed methods study to compare self-reported care status and perceptions regarding engagement in care with HIV surveillance and medical records, and to assess barriers and facilitators to care engagement among HIV-infected persons at differing stages along the care continuum.

METHODS

Study population

Participant recruitment—Participants were recruited for the study using several approaches (Figure 1). This study was conducted in conjunction with the 2013 DC DOH Recapture Blitz. During the Recapture Blitz, seven Ryan White-funded clinics provided lists of patients who had not received clinical care in the prior 6 to 12 months to surveillance staff at the DC DOH. The DC DOH surveillance staff matched the clinics' lists to surveillance databases and returned data to each clinic regarding which patients appeared to be out of care, were receiving care elsewhere, or were otherwise ineligible for recapture. For the purposes of this study, two of the seven Ryan White clinics, and one non-Ryan White funded private hospital-based clinic submitted out of care lists to the DC DOH. Among the three participating clinics, 769 patient names were submitted of whom 312 persons were determined to be out of care and required re-engagement. As clinic staff contacted persons determined to be out of care to re-engage them into care, they were recruited to participate in this study.

In order to have a comparison population, a convenience sample of persons receiving HIV care at the three clinics was simultaneously recruited for our study. Additionally, study fliers were distributed at a local emergency department, throughout the community, at local venues, by community based organizations, and on local websites. Eligible participants had to be 18 years of age or older, self-reported HIV positive, and if they were recruited at a clinic, it could not be their first visit to that provider. All participants were screened for eligibility, at which time they were asked to describe their HIV clinic visit patterns. If determined to be eligible, their self-reported visit patterns were categorized and informed consent obtained. Surveys were administered by research staff at the clinical site or at a community based organization.

Engagement in care definitions—Participants were determined to be in one of three categories of engagement in care based on HRSA HAB definitions using self-reported care patterns: in care, sporadic care, or out of care. Persons "in care" (IC) were defined as those who self-reported an HIV visit pattern consistent with the HRSA HAB definition of at least 2 visits at least 90 days apart in a 12 month period. Persons in "sporadic care" (SC) were defined as those persons who self-reported an HIV visit pattern other than that meeting the HRSA HAB definition of engagement in care. For example, these persons may have had

more than two visits less than 90 days apart or may have had only one HIV related visit in a 12 month period. Persons who were “out of care” (OOC) were defined as those persons who reported not having had an HIV related medical visit in at least 6 months.

Data sources

Quantitative data for this study were obtained from three different sources. First, an interviewer-administered structured survey was conducted, which included questions regarding participant demographics, general health care and HIV care seeking behaviors, HIV treatment history, engagement with providers, attitudes about coming to clinic, and self-perceived status along the care continuum. Second, participants provided consent to have data abstracted from their clinic medical records; this included CD4 counts, percentages, viral loads, kept and missed visits, and ARV history for the 12-month period of interest. Third, participants also provided consent to have their DC DOH surveillance data abstracted. Surveillance data including demographics, CD4 count, percentage, viral loads for the 12 month period of interest for each participant were abstracted. Data from participant surveys, medical records, and DC DOH surveillance data were linked for each participant.

In order to elicit additional in-depth information regarding participant perspectives on engagement in care, a subsample of participants were asked to participate in semi-structured, qualitative interviews. Every other participant, regardless of care status, was asked to participate in a qualitative interview. A separate informed consent was obtained for these interviews. All interviews were audio-recorded and transcribed.

Participants were remunerated \$25 for participating in the survey, and \$25 for participating in the qualitative interview and received compensation for their travel in the form of metro cards. All study procedures were reviewed and approved by the George Washington University and DC DOH Institutional Review Boards.

Analytic methods

As described above, participant survey responses, medical record data, and HIV surveillance data were linked. Descriptive statistics were used to summarize participant demographics and care patterns, and bivariate tests were conducted to compare differences across the three categories of engagement in care. These tests included Chi-square tests for categorical outcomes, F tests in analysis of variance (ANOVA) for normally distributed continuous outcomes, and Wilcoxon Rank-sum tests for non-normally distributed continuous variables. Surveillance and medical record data were used to corroborate self-reported care status using the following variables from these data sources: kept visits from medical records and CD4 and viral load test dates from DOH surveillance records. To further triangulate the data from clinics and the DC DOH with that of self-report, participants were asked to indicate where they considered themselves to be along the HIV care continuum: options included “aware of their HIV status”, “receiving some medical care but not HIV care”, “using HIV care intermittently (i.e. every once in a while when needed)”, “entered into HIV care but never went back”, and “fully engaged in HIV primary care”. All statistical analyses were conducted using SAS version 9.3.

Qualitative data from participant interviews were analyzed using an open coding process to uncover relevant patterns, categories, and themes in the data. Data from qualitative interviews were coded by three experienced qualitative researchers on the project team. Initial codes were developed based on the study conceptual framework and subsequent codes were selected as they emerged from the interviews. The qualitative analysis utilized a constant comparative coding scheme that identified and characterized emergent and relevant domains elucidated during the interview and identified through the overall objectives of the project. The data analysis procedure included a computer-assisted qualitative data analysis approach using ATLAS.ti 7. A conceptually clustered matrix was developed to show the relationship between the perspectives of the three care groups.⁴⁹

RESULTS

Survey Participant Demographics

One hundred sixty-nine HIV positive persons participated in the survey. Participants were mostly non-Hispanic black (71.9%), 88.8 were DC residents, 63.8% were male and the mean age was 50.7 years old (range 25–72) (Table 1). The vast majority of participants were insured (92.3%), most were unemployed (61.5%), and almost a third (31.4%) had completed some college. The most common comorbidities reported in addition to HIV infection included mental health diagnoses (47.3%), hepatitis C infection (29.0%), and cardiovascular disease (27.8%). The majority of participants (n=115, 68.0%) described self-reported visit patterns consistent with being in care as per the HRSA HAB definition, while 33 (19.5%) were categorized as being in sporadic care and 21 (12.4%) were out of care. The only statistically significant difference in demographics across the three care groups was with respect to age and race/ethnicity; participants in the sporadic care group were significantly younger (mean age 46.2 vs. 51.7 (IC) vs. 52 (OOC); $p=0.006$) and less likely to be non-Hispanic black (36.4% SC vs. 75.4 (IC) vs. 81.0 (OOC); $p=0.047$).

Participant Healthcare Seeking Behaviors and HIV Care Patterns

With respect to their health care seeking patterns, according to participant self-report, the median length of time since HIV diagnosis was 16 years, with most participants reporting being linked to care within 3 months of diagnosis (71.0%) (Table 2). Although most participants reported not receiving assistance with linkage into HIV care (52.7%), among those who did, counselors, social workers, and case managers were most frequently reported as assisting (25.4%). When asked about the longest gap in time without HIV care, overall 31.0% of participants reported being out of care for more than 12 months. Across the three care groups, as expected, a high proportion of out of care participants reported gaps greater than 12 months; gaps differed significantly across the three care groups (45.0% (OOC) vs. 29.6% (IC) vs. 27.3% (SC); $p=0.003$). Although not statistically different, the mean number of missed visits was almost three times higher for the sporadic care group compared to the in care group (2.2 vs. 0.8 visits, respectively) and most participants, regardless of care group, had seen a provider for non-HIV related medical care (range: 71.4% – 80.0%) in the prior 12 months. Participants, in general, expressed agreement with the importance of notifying the clinic of missed visits, not skipping appointments, and the need to come in for visits even when feeling well.

A majority of participants (94.1%) had been prescribed antiretrovirals (ARVs) at some point in time since diagnosis. A high proportion of OOC participants reported being currently on ARVs, which differed significantly from the IC and SC groups (90.0% vs. 99.1% (IC) vs. 93.1% (SC); $p=0.041$). Among the OOC participants on ARVs, more than two-thirds self-reported being 100% adherent in the prior 7 days (72.2%). Given that out of care persons reportedly had not seen their HIV provider in 12 months, those who were currently taking ARVs reported getting them from their healthcare provider's office (33.3%) or a community clinic or health center (27.8%); other commonly reported sources included pharmacies.

Among the 163 of the 169 (96.4%) participants with available medical record data, the mean of the last recorded CD4 count in the 12 month period was 609.4 cells/microliter and most (91.2%) were virally suppressed (i.e. VL <200 copies/ml) with a median VL test result of <20 copies/ml. Medical record data found VL tests and CD4 tests on nine out of care participants despite their self-reports of being out of care during the 12-month period of interest. However, regardless of care status, the last recorded CD4 and VL measures did not differ significantly across the three self-reported groups.

Linkage of participant survey data to medical records and surveillance data identified discrepancies in self-reported care patterns (Table 2). Among participants with available medical record data, more people were considered out of care compared to self-report (16.6% medical record vs. 12.4% self-report). Similarly, among the 159 participants with available surveillance records, more people were considered out of care (32.1% surveillance vs. 12.4% self-report) and fewer participants were considered to be in care compared to self-report (51.6% surveillance vs. 68.1% self-report).

Participants' Self-perceived Status along the HIV Care Continuum

Irrespective of one's self-reported care group, most participants perceived themselves to be fully engaged in HIV primary care (94%, 95% and 52% of IC, SC, and OOC participants, respectively) (Figure 2). Thirty eight percent of out of care participants perceived themselves as accessing HIV care intermittently compared to 4% and 5% of in care and sporadic care participants; 5% perceived themselves as receiving only non-HIV related medical care and 5% were aware of their HIV status but recognized that they were not actively receiving HIV care.

Qualitative Findings Regarding HIV Care Engagement

In-depth interviews were conducted among 62 participants ($n=40$ IC, $n=10$ SC, and $n=12$ OOC participants). The median age of interviewees was 52 years, 57% were male, 77% were black and the median length of time since diagnosis was 16 years. Sporadic care interviewees were younger (median age 42 yrs. vs. 52 (IC) and 53 (OOC), fewer were black (50% vs. 75% (IC) and 83% OOC), and they had been more recently diagnosed with HIV (median 11 vs. 15 (IC) and 19 years OOC). Major themes elicited through structural coding revealed both distinct similarities and differences according to self-reported care status with respect to the patient provider relationship, perceived care engagement, and facilitators and barriers to care. Table 3 shows select data that characterize the participants' perspectives. Participants in all three groups generally reported favorable experiences regarding medical

providers and the clinics where they received services. Some described having unsatisfactory experiences with providers initially and described a pattern of seeking care with multiple providers until they established care with their current provider. Participants detailed specific characteristics of their HIV care delivery from the ease of being able to get appointments without long wait times to the receipt of comprehensive medical care and services in one visit. They also expressed the importance of feeling engaged with their providers, having the sense that the provider was empathetic and listened to their concerns, and being able to talk to him/her about HIV as well as other issues.

With respect to patient perceptions of care engagement, in care participants' discussions demonstrated strong self-efficacy and motivation to take care of oneself. Among in care participants, having symptoms or not feeling well served as a motivator for accessing care from their HIV care provider. In contrast, among the sporadic care and out of care participants, feeling good or not being sick was attributed to not scheduling appointments or having extended periods of time between visits to their HIV provider. Out of care participants often perceived themselves to be engaged in other care or admitted to missing their HIV visits because they wanted a break. The range of barriers and facilitators of engagement in care were fairly consistent across the groups and included drugs use, stigmatization, transportation, unemployment and lack of insurance.

DISCUSSION

This mixed methods study identified distinct differences between patient perceptions of care engagement compared to standard predefined measures of engagement in care. Although our sample was relatively small, the demographics of our participants were consistent with those of the HIV-infected population in Washington, DC, with a predominantly Black epidemic, high rates of insurance coverage, and an aging cohort of HIV-infected persons.⁵⁰ Different from previous studies of out of care cohorts, other than younger age, we did not identify any significant demographic differences when comparing our out of care cohort with those optimally or sporadically engaged in care. Reported time to linkage to care was also high (71%), and consistent with DC public health HIV surveillance data which estimate that linkage occurs within 3 months of diagnosis for 69% of persons. However, given the long length of time since diagnosis among our study participants, these linkages would have occurred prior to the initiation of local and national efforts around engagement in care. Despite successes in linkage gaps in care were common with almost one third of participants having a gap in care of greater than 12 months.⁵⁰

Many participants had co-occurring conditions and were seeking other non-HIV care in lieu of or in addition to their HIV care. This health care utilization pattern may help explain why such a large number of persons reportedly out of care continued to access and take ARVs as they were able to obtain medications through different providers and pharmacies. This implies that HIV-infected persons marginally or disengaged in care may be able to access HIV care and medications without being seen at regular intervals or from care sites outside of their HIV provider's clinical setting. These findings are congruent with those published previously both domestically and abroad. In New York City and San Francisco, researchers have found that while surveillance data suggested that persons may be out of care, when

contacted, many people thought to be out of care were receiving other types of medical care.^{27,37} Similarly, in a study conducted by Tweya et al in Malawi, more than half of HIV-infected patients initially thought to be out of care were found to be accessing ARVs through other clinics, friends, and other sources.⁵¹ Qualitative work with DC HIV providers also suggests that some clinicians will prescribe bridge medications for patients who are unable to attend a clinical visit due to travel, lack of transportation, or lack of insurance (Castel, unpublished data). Although the receipt of medications was based on participant self-report, clinical parameters from medical record data among those sporadically engaged in care supported their assertions that they may have truly been taking their medications. Nonetheless, while our findings suggest that there may not be as large a gap in treatment as once suspected among marginally engaged HIV-infected persons, this is still a high-risk group that needs to be seen by their healthcare providers so that they can be monitored for medication side effects, drug resistance, complications, and receive secondary prevention messages.^{1,52}

By linking medical records and surveillance data, we were able to further validate participants' self-reported care patterns. Applying the HRSA HAB measure, both data sources found that more persons were out of care compared to self-report, with surveillance data identifying the highest percentage of persons as out of care (32.1%). Assessing the accuracy of each data source is however difficult. Interventions using surveillance data to contact persons never linked to care or who have been lost to follow-up have found that 33% to 37% of persons thought to be out of care were in fact in care.^{37,48} In DC, the 2009 Recapture Blitz determined that 57% of people previously thought to be out of care were receiving care elsewhere.²⁴ When using only one data source such as clinic records, retention may be underestimated, particularly if multiple care sites are being utilized. Sohler et al have also found poor agreement between self-reported HIV care utilization and medical record data with persons overestimating the number of outpatient visits and use of medications. Their findings, coupled with the findings from our study suggest that we cannot rely solely on self-report.^{26,47} Given that there is no gold standard, the use of a combination of data sources may be more effective in not only identifying out of care persons but in measuring continuum of care outcomes.^{53–55} Further analysis of these measures for our study population will be conducted to compare variability across these measures and to further delineate and understand the dynamic nature of HIV care engagement.⁵⁶

Participants' perceived status along the HIV care continuum was also inconsistent with their care seeking behaviors. Strikingly, while participants across all care groups expressed an understanding of the importance of care engagement and the need for regular HIV primary care visits, care patterns among patients in sporadic care and out of care reflected a disconnect between participants' self-reported status with an overwhelming majority of participants perceiving themselves to be fully engaged in their HIV care.

Triangulation of the self-reported data using qualitative approaches allowed us to further understand patients' perceptions of engagement in care and the care continuum. These data identified known barriers to care, including lack of insurance, transportation, and drug use.^{29,57} Many persons engaged in HIV care soon after their initial diagnosis but disengaged

or entered into a cycle of sporadic care simply because they felt well, a previously identified reason for poor engagement.³⁷ Our data are in contrast to previous studies in which reasons for poor engagement have stemmed from poor or tenuous patient provider relationships or insurmountable structural barriers that prohibit persons from fully engaging in care. Instead, we found there was a (mis) perception that since they were doing well, patients did not need see the importance of continuing to see their HIV provider regularly.^{57–59} Surprisingly, many persons did not equate their lack of care engagement with the fact that they would be considered out of care by their clinics. This perspective has been described among a cohort of persons out of care in San Francisco who also did not perceive themselves to be out of care and were not intentionally disengaged in care.²⁷ Both the quantitative and qualitative data from our study highlight the need for provider communication that emphasizes treatment goals, the chronicity of HIV treatment, and the need for regular HIV visits despite being clinically stable. Given the trusting and reciprocal patient-provider relationships reflected in our interviews, this type of education would likely be well-received by patients.

There are several limitations worth noting from our study. First, we were only able to access a small sample of out of care participants and thus had to employ a complex recruitment strategy whereby participants were recruited from a variety of settings ranging from clinics to community-based outreach. Despite using these multiple approaches, identifying and recruiting persons who were out of care proved difficult and highlights the need for innovative approaches to sampling out of care populations.⁶⁰ Further, the persons identified as out of care were clinically doing well and similar to those in care and may not be representative of all HIV-infected out of care persons. Among those persons who did participate in the study, our survey findings may be subject to selection and social desirability bias as we recruited a convenience sample of patients attending clinics for the in care and sporadic care groups, relied on patient self-report which may have led to an overestimation of engagement, and were unable to obtain medical records on all participants. Additionally, there may have been additional sampling bias among those persons who were approached and agreed to participate in the in-depth interviews. However, by triangulating survey data with medical record, surveillance data, and qualitative data we were able to identify perceived and important differences regarding patient perceptions of care engagement.

This study focusing on patient perceptions of the care continuum adds to the growing body of literature on how best to measure engagement in care and should prompt us to reconsider whether the many standard measures being used are truly reflective of the actual patient experience and care being received. Instead of trying to fit patients' care patterns into neatly circumscribed measures of care engagement, we need to take into account varying perspectives to include the dynamic nature of patient engagement. Now that the DHHS guidelines have recently recommended that patients who are virally suppressed can be monitored less frequently, it may be time to rethink our definitions of engagement in care among those persons who perceive themselves to be clinically stable.⁶¹ Similarly, just as there is no gold standard for measuring engagement in care with clinic or surveillance data, our findings emphasize the need for a comprehensive and multi-faceted approach to measuring care engagement which takes into consideration the individual perspective in addition to that of the provider and system.²⁷ A collaborative and comprehensive approach

in which health departments work with clinics to identify which patients are out of care or marginally engaged in care coupled with healthcare providers working with patients to understand the nature of HIV care engagement and preempt significant gaps in care receipt may result in an overall improvement in care engagement and retention and ultimately increase rates of achieving and sustaining viral suppression.

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Figure 1. Participant Recruitment Flow Diagram, N=169

Shows the recruitment strategy used to identify potential participants and assign them to one of the HRSA defined care categories: in care, sporadic and out of care. It also shows the number and proportion of participants for whom we were able to obtain survey, health department surveillance data, medical record, and in-depth interview data.

Figure 2. Self-Perceived Status along the HIV Care Continuum¹

Illustrates participants' self-perceived status along the HIV care continuum. Categories of care were determined by participant self-reported visit patterns.

¹Categories of care were determined by participant self-reported visit patterns.

Table 1Demographics of Study Participants Stratified by Self-Reported Care Status^f

Characteristic	IC N=115 No. (%)	SC N=33 No. (%)	OOC N=21 No. (%)	Total N=169 No. (%)	p-value
Age (mean, range)	51.7 (25–72)	46.2 (25–66)	52.0 (46–70)	50.7 (25–72)	0.006
Race/ethnicity (n=89)					0.047
Black non-Hispanic	43 (75.4)	4 (36.4)	17 (81.0)	64 (71.9)	
White non-Hispanic	7 (12.3)	3 (27.3)	4 (19.0)	14 (15.7)	
Hispanic	3 (5.3)	2 (18.2)	0 (0)	5 (5.6)	
Multiracial	4 (7.0)	2 (18.2)	0 (0)	6 (6.7)	
DC resident	103 (89.6)	30 (90.9)	17 (81.0)	150 (88.8)	0.448
Gender (n=105)					
Female	26 (37.7)	4 (26.7)	8 (38.1)	38 (36.2)	0.709
Male	43 (62.3)	11 (73.3)	13 (61.9)	67 (63.8)	
Insured in past 12 months	106 (93.0)	31 (93.9)	18 (85.7)	155 (92.3)	0.479
Homeless/Unstably housed	28 (24.3)	7 (21.2)	8 (38.1)	43 (25.4)	0.340
Education					0.526
Less than high school	18 (15.7)	8 (24.2)	4 (19.1)	30 (17.7)	
High school/GED	35 (30.4)	11 (33.3)	8 (38.1)	54 (32.0)	
Some college	42 (36.5)	5 (15.2)	6 (28.6)	53 (31.4)	
college	10 (8.7)	5 (15.2)	2 (9.5)	17 (10.0)	
Advanced degree	10 (8.7)	4 (12.1)	1 (4.8)	15 (8.9)	
Employment status					0.622
Unemployed	74 (64.4)	16 (48.5)	14 (66.7)	104 (61.5)	
Part-time or less	17 (14.8)	8 (24.2)	3 (14.3)	28 (16.6)	
Full-time	22 (19.1)	9 (27.3)	4 (19.0)	35 (20.7)	
Homemaker	2 (1.7)	0 (0)	0 (0)	2 (1.2)	
Relationship status (n=167)					0.308
Legally married	10 (8.7)	3 (9.1)	2 (10.5)	15 (9.0)	
Committed relationship	24 (20.9)	5 (15.2)	5 (26.3)	34 (20.4)	
Open relationship	1 (0.9)	0 (0)	0 (0)	1 (0.6)	

Characteristic	IC N=115 No. (%)	SC N=33 No. (%)	OOC N=21 No. (%)	Total N=169 No. (%)	p-value
Single	62 (54.9)	20 (60.6)	5 (26.3)	87 (52.1)	
Widowed/divorced/separated	18 (15.6)	5 (15.2)	7 (36.8)	30 (17.9)	
Comorbidities					
Mental health	56 (48.7)	15 (45.5)	9 (42.9)	80 (47.3)	0.860
Hepatitis C	34 (29.6)	8 (24.2)	7 (33.3)	49 (29.0)	0.751
Cardiovascular disease	36 (31.3)	5 (15.2)	6 (28.6)	47 (27.8)	0.188
Diabetes	18 (15.7)	2 (6.1)	3 (14.3)	23 (13.6)	0.424

I IC: in care, SC: sporadic care; OOC: out of care

Table 2

HIV Care Patterns by Self-Reported Care Group^a

Characteristic	IC N=115 No. (%)	SC N=33 No. (%)	OOC N=21 No. (%)	Total N=169 No. (%)	p-value
Time since HIV diagnosis (yrs.) Median (IQR)	16.2 (10.9–23.2)	14.1 (8.1–19.8)	17.7 (8.0–22.1)	16.0 (10.0–22.3)	0.332
Linked to HIV care 3 mo.	81 (70.4)	26 (78.8)	13 (61.9)	120 (71.0)	0.400
Person(s) who helped entry into HIV care					
No one/no help	64 (55.7)	14 (42.4)	11 (52.4)	89 (52.7)	0.407
Counselor/Social worker/Case manager	28 (24.3)	10 (30.3)	5 (23.8)	43 (25.4)	0.774
Family member/friend	13 (11.3)	5 (15.2)	6 (28.6)	24 (14.2)	0.112
Others ²	19 (16.5)	8 (24.2)	2 (9.5)	29 (17.2)	0.357
Longest period without HIV medical care (n=168)					0.003
< 6 months	67 (58.3)	13 (39.4)	4 (20.0)	84 (50.0)	
6–12 months	14 (12.2)	11 (33.3)	7 (35.0)	32 (19.0)	
> 12 months	34 (29.6)	9 (27.3)	9 (45.0)	52 (31.0)	
Number of missed visits (n=148) Mean (range)	0.8 (0–10)	2.2 (0–10)	N/A	1.2 (0–10)	
Seen a provider for any non-HIV related visits in past 12 months	92 (80.0)	25 (75.8)	15 (71.4)	132 (78.1)	0.639
Attitudes towards coming to clinic (probability of agreement)					
When I have to miss my HIV medical appointment, there's no need to let the clinic know.	5 (4.3)	3 (9.1)	4 (19.0)	12 (7.1)	0.039
It is OK to skip my HIV medical appointments every now and then.	6 (5.2)	2 (6.1)	0	8 (4.7)	0.738
I need to come in for my HIV medical appointments even when I am feeling well.	112 (97.4)	33 (100.0)	19 (90.5)	164 (97.0)	0.168
Ever on ARVs (n=168)	109 (95.6)	29 (87.9)	20 (95.2)	158 (94.1)	0.266
Currently on ARVs ³ (n=158)	108 (99.1)	27 (93.1)	18 (90.0)	153 (96.8)	0.041
Self-reported ARV adherence past 7 days (all pills)	89 (82.4)	17 (63.0)	13 (72.2)	119 (77.8)	0.164
Location where received last ARV prescription (n=153)					0.149
Healthcare provider office	69 (63.9)	14 (51.9)	6 (33.3)	89 (58.2)	
Community clinic or health center	15 (13.9)	6 (22.2)	5 (27.8)	26 (17.0)	

Characteristic	IC N=115 No. (%)	SC N=33 No. (%)	OOC N=21 No. (%)	Total N=169 No. (%)	p-value
Commercial storefront clinic	7 (6.5)	1 (3.7)	3 (16.7)	11 (7.2)	
Pharmacy	17 (15.7)	6 (22.2)	4 (22.2)	27 (17.6)	
Hospital/ED/urgent care	0	0	0	0	
Surveillance reported care status (n=159)					-
Medical record care status (n=163)	82 (51.6)	26 (16.4)	51 (32.1)	159 (100.0)	-
	111 (68.1)	25 (15.3)	27 (16.6)	163 (100.0)	
Last recorded CD4⁴ (N=124) Mean (Range)	N=101 618.0 (2–1,507)	N=20 558.2 (4–1,432)	N=3 632(184–1210)	N=124 609.4 (2–1,507)	0.759
Last recorded VL^{4,5} (n=129) Median (IQR)	N=106 19 (19–30)	N=22 19 (19–60)	N=9 19 (19–20)	N=137 19 (19–30)	0.599
Proportion virally suppressed at last recorded VL (VL <200 copies/ml)^{4,5} (n=137)	N=106 96 (90.6)	N=22 20 (90.9)	N=9 9 (100.0)	N=137 125 (91.2)	1.000

¹ IC: in care, SC: sporadic care; OOC: out of care

² Other persons who assisted with linkage included physicians, other medical staff, colleague, support group, and therapist.

³ Denominator is among those ever on antiretrovirals (ARVs).

⁴ Data source for these variables was from the medical record. These values reflect the last CD4 or viral load recorded during the 12-month period of interest or the 12-month period the participant reported being out of care.

⁵ For all viral load values less than 20 copies/ml, the value of 19 copies/ml was assigned.

Table 3**Key In-Depth Interview Findings and Sample Quotes on Engagement in Care by Self-Reported Care Group**

Domain	In care (N=40)	Sporadic Care (N=10)	Out of care (N=12)
Attitudes about clinic and patient provider relationship	<p>1009: I like my doctor and the rest of the staff here-the nurses and everyone that I've come in contact with has always been nice. I don't feel that they are judging me.</p> <p>3009: And what I liked about Clinic X is when I called there I could always get somebody, or if they weren't available they would either call back ... and my appointments wouldn't be a month long, you know, um if I needed to make another one.</p> <p>3025: It's pretty open, we talk about a lot of things as far my medical care to social life to employment to housing and things like that. They usually ask me how I'm doing and a lot of time they don't only inform me of my HIV status but of my overall health.</p>	<p>1003: I've been seeing Dr. X since 1994 ... he's got a lot of experience, number one. He and I get along very well. He understands me, I understand him...</p> <p>1005: I always had good experiences with the doctors...I had this really good doctor ...I was just like really close to her, and then she-her practice moved.... And I remember saying that I don't wanna go to any more doctors, because I felt like she left me...</p> <p>3013: I asked my gay friends for a doctor. So I assumed a gay doctor would be gay-friendly but that's not always the case...</p>	<p>1060: Oh, like I said, everyone, they don't treat you like you have leprosy. They treat you like you, you know like you are another patient.... they don't treat you any differently than they would anybody else.</p> <p>1057: I think with [Clinic X] it is a one-stop shop. I am able to deal with my HIV status, I'm able to deal with my mental health status, And they also have some addiction services there where I can have some outpatient...interactions with some counselors.</p> <p>1058: It was because of him that I accepted the diagnosis as well as I did. Because he was just that intimately involved in his presentation of the illness to me. It made all the difference in the world ... They take their time; they give a full discussion of what's going on, what their plans are.</p>
Perceptions of care engagement	<p>3008: Yes. A lot of people come for different reasons. Some people come to get something to eat. Some people come to get gift cards. Some people come to save their lives. I am one of those who come to save our lives.</p> <p>3017: I did miss appointments but I never stopped treatment. I knew it was in my best interest to always continue care.</p> <p>3025: Yeah cause I like to stay healthy and I don't like getting sick... So I just went ahead and stayed continuous on the HIV care.</p>	<p>1003: I don't automatically go to the doctor when I'm feeling well, other than as part of a regular series of checkups that I need to have lab tests done....My HIV problem is basically solved. I'm taking medications and I will probably take them the rest of my life, and I will probably never get sick.</p> <p>1055: Well, I wasn't doing too good, but I'm doing great now. You know, I am going to the doctor, I am seeing who I need to see, I am talking to who I need to talk to ...you know, get things done that I need done for me.</p> <p>1005: I took like [medication] maybe for a year and .. I remember saying, your count is fine, I'm thinking this is what was told, you really don't need the medication right now but we're gonna keep you on it anyway...So I'm thinking I'm healthy, I'm fine, I don't need it....And I've been healthy and fine up until a year, year and a half ago.</p>	<p>1057: That doesn't apply...Because I do...I go to a life support group on Monday, Living Well on Tuesday, mood disorder at Clinic X on Wednesday, totally plugged in.</p> <p>1058: I didn't miss appointments. I just didn't schedule as many appointment as I should have scheduled...The main reason was because I have just felt so well. At the last visit the numbers were very positive, they were good. I believe at undetectable level, and I just continued to take the medications and do what I need to do to maintain that level.</p> <p>1059: ...Except I take my HIV medicine... I am very, very strict with that ...I do go to the doctor more often, only now and then I forget.</p> <p>1060: At this point, you know the biggest worry I think for most people that have the diagnosis is like where on this spectrum is my health? There is the spectrum of I am alive and kicking and happy and healthy, and dead. Where am I on that spectrum?</p> <p>1069: Because I was doing very, very well. I felt healthy and I got kind of tired of taking medication constantly.....Nothing other than I just wanted a break.</p> <p>B2084: I haven't really been off of them because they had put in like a couple of refills on them so I basically have had them; I just haven't been going to my doctor.</p>
Barriers to care engagement	<p>3009: The drug use made it hard because I didn't think that. ... all the drugs I was doing and drinking ... I didn't think that would mix with the medicine... So I had to give up one of them, or give up the medicine.</p> <p>1009: It's stupid, but it's maybe the fear of running into someone</p>	<p>1005: ...I had-my children were younger then, so now they're-they're adults now. ... They were younger, so I was trying to make sure I took care of them.</p> <p>1055: Well, it was, like I was doing heroin, and I didn't want the doctors to know I was doing drugs so that was my lack of not coming and everything, and ... I was taking my money and spending it on heroin,</p>	<p>1057: The main thing was when I lost my job, lack of insurance ... there have been times when I wasn't able to get my meds right away. I had to kind of rustle up a few dollars to get me meds so that has been an issue. And I would say active addiction kept me away, and depression.</p>

Domain	In care (N=40)	Sporadic Care (N=10)	Out of care (N=12)
	<p>that sees that I'm coming to get care, and then people realize that I am HIV-positive.</p> <p>3025: If anything probably transportation, I just would have to reschedule and usually I would reschedule it for the next week or something like that but nothing more than 2.</p>	<p>instead of taking it and paying for my appointments ...</p> <p>3013: Worries? ... I remember thinking I just don't wanna take that many pills so I'm just not gonna take them ...I didn't want HIV to be an all-consuming thing ...it's just that I wanna ignore it as much as possible.</p> <p>...Generally this is what I would do, if I knew my insurance was ending I would try to get as much medication as possible before the end and kinda just space out. I would take it every other day or once every 3 days.</p>	<p>1060: If it [clinic] was closer, it would make it a lot easier, it will make it a lot [more]accessible. However, I don't want it in my own backyard. And the reason being I get my medication in a different state is because you don't know that that pharmacist might know somebody you know... and we all know of HIPAA, but you know, people are human, so.</p> <p>2064: Yeah, every time I get high, I don't go to the doctor....You use until you don't use it no more, you put nothing aside.</p>
Facilitators of care engagement	<p>1009: I guess my health insurance would be the most important. As long as I have that, it makes getting treatment easier and more affordable... The location is very convenient to access it via the metro, or just locally I could drive here, you know, myself.</p> <p>3025:If I ever had to reschedule, even if I was sick, I went in there or if I wasn't feeling well I still put on my clothes and make myself go. I wanted to be healthy, I wanted to be out in society, in the environment and be normal.</p> <p>3017: It could be better and I again I learned to navigate the system so I know that if I don't get the assistance I need in 1 place I can look somewhere else. And I'm lucky that I have both insurances, they're not the best but other people are not as lucky.</p>	<p>3021: I think the location is good because of something like the metro, um, I think the hours are good too for people who are working also.</p> <p>1003: Support means you need help that you can't get on your own and....I'm in full control of all the resources that I need. There's nothing that I am prevented from getting that I need to get in order to have HIV care...</p>	<p>1057: [The clinic] has support groups that I attend on a regular basis.... And they provide information ...just all that I need to know to kind of help me, to lessen the effects of stigmatization] ... Accessibility. I mean, I think that is the biggest thing. Probably transportation. If I didn't live a few blocks away, that would be an issue. ... I think the community needs to know that there are some success stories and there is a better way for them.</p> <p>1058: If you receive detailed information from your physicians, from your pharmacist. I don't know of anything else that could be done that would force the patient or make the patients or perhaps it could encourage them, I don't know. It hasn't encouraged me, it perhaps it could encourage somebody.</p>