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Comparing Different Measures of Retention in Care among a Cohort of Adolescents and Young Adults Living with Behaviorally-Acquired HIV

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Abstract

Young people living with HIV (YLWH) have some of the lowest rates of retention in HIV care, putting them at risk for negative health outcomes. To better understand retention in care in this age group, we conducted a retrospective cohort analysis of YLWH initiating care at a multidisciplinary, adolescent-focused HIV clinic ($N = 344$). Retention was calculated using a variety of definitions, and relationships between different definitions were assessed. During the one-year study period, on average YLWH missed two scheduled appointments, and attended 80% of appointments, usually at least once every three months. About one-quarter experienced a six-month gap in care and about two-thirds met the Health Resources and Services Administration's retention criteria. Although most retention definitions were significantly correlated, not all were. Researchers, clinicians, and policymakers should consider the impact of varying definitions of retention, in order to optimally measure this outcome in YLWH, a key vulnerable population.

Keywords

adolescents; HIV; retention in care; loss to care; intermittent care

Introduction

The "HIV care continuum" describes five progressive stages of engagement in HIV care: 1) diagnosis, 2) linkage to care, 3) retention in care, 4) receiving antiretroviral therapy (ART), and 5) achieving viral suppression (1). This framework provides a useful tool for promoting

public health by systematically analyzing particular phases of vulnerability to suboptimal engagement and highlighting possible points of intervention. However, it is increasingly apparent that a sequential stage-based model does not perfectly describe how patients actually engage in HIV care over time. Recently, the HIV care continuum has been reconceptualized, adding complexity to the notion of retention by defining it not as a step between linkage and ART initiation, but as a dynamic, “churning” process that impacts many different stages of care (2, 3). For instance, a patient could be prescribed ART and even achieve viral suppression, and then fall out of care and require re-linkage. The complexity of the concept of retention has led to a wide variety of definitions in the literature. Mugavero and colleagues (4) brought clarity to the measurement issue in their excellent review, summarizing five common definitions of HIV care retention (Table 1). They highlighted how the varying frameworks might be most appropriate for different goals. For instance, the number of missed visits could be most important for an administrator seeking to improve clinic efficiency, while the appointment adherence ratio, which examines the proportion of completed visits among all visits scheduled, might be more useful for characterizing the engagement of a specific patient in care.

A consistent finding is that adolescents and young adults living with HIV have the lowest rates of retention in care of any demographic population of people living with HIV. CDC data indicate that about one-third of 13 to 24 years olds are retained in care, whereas about one-half of adults older than 35 years old are retained in care (5). Researchers estimate that youth living with HIV (YLWH), ranging from 13 to 24 years old, miss approximately one-third of scheduled visits (6). Furthermore, of the youth who initiate ART, 57% are later lost to care (7). Young adults (e.g., those aged 19–24 years) may be at even higher risk for loss to care in contrast to adolescents (e.g., those ages 13–18 years). For instance, in an HIV clinic in Washington, D.C., retention in care was less likely among young adult men who have sex with men (YMSM), 41%, compared with adolescent YMSM, 53% (8). Therefore, for YLWH especially, rather than a set of sequential treatment stages, the HIV care continuum may resemble repeated episodes of linkage to care followed by periods of disengagement and then re-linkage. Poor retention in care may partially explain why YLWH have lower rates of viral suppression than adults and higher rates of virologic rebound (9). CDC data indicate that about one-quarter of 13 to 24 year olds are virally suppressed, whereas about one-half of adults over 35 are virally suppressed (5).

The literature on understanding and promoting retention is complicated by authors using differing definitions of retention. For example, research identifying psychosocial predictors of retention yields mixed findings, possibly due to different approaches to operationalizing retention. For example, Magnus and colleagues found that Black YMSM with depression self-reported fewer missed visits (10), whereas Outlaw and colleagues found that global measures of emotional distress and mental health symptoms in a sample of ethnic minority YLWH were not related to a strict, dichotomous definition of “optimal,” retention in care defined as attendance at least one appointment in all four quarters of the year (11). In addition, within a single study with adults living with HIV, patients who reported their subsistence needs (e.g., food, shelter) competed with their need for healthcare were more likely to have missed visits, but did not have lower visit constancy (12). Contradictory

results like these suggest choosing a particular definition of retention could impact the conclusions researchers draw from different samples.

The present study aimed to achieve a deep understanding of the varying definitions of retention in care and the relationships between these definitions. We examined retention in care rates for YLWH receiving care at a single multidisciplinary adolescent HIV clinic, using a variety of established definitions for retention in care. Then, we tested whether retention variables were significantly correlated with one another to assess the comparability between definitions.

Methods

Study Design

We conducted a retrospective cohort analysis of YLWH initiating care at Children's Hospital of Philadelphia (CHOP) Adolescent Initiative HIV clinic between January 2002 and June 2015. For each patient, we examined only their first year in care at the clinic, covering the period beginning at their initial visit through 12 months later. Data were abstracted from a research registry containing all clinical and laboratory visits during the study period. Details on how the medical records were abstracted and other major findings from this sample can be found in previous articles (13, 14, 15).

Participants and Setting

The Adolescent Initiative clinic consists of a multidisciplinary research and clinical team providing care to YLWH, aged 12 to 26 years. Patients are seen for visits approximately every three months, and services include medical assessments, viral load measurement, screening for sexually transmitted infections, ART adherence counseling, and intensive medical case management. All patients in the clinic are provided with Ryan White medical case management which consists of regular phone calls, reminders and extra clinic visits on the same day or a different day from a medical visit with the medical case manager to address psychosocial needs and care coordination. Patients are discussed weekly at a multidisciplinary team meeting and contacted for follow-up and support based on team recommendations. Further, patients who are "lost to care" (defined as no visits for > 6 months) are discussed quarterly to develop intensive outreach and re-linkage to care plans. Additionally, medical case managers will make home or community-based visits on an as needed basis. The clinic is located in Philadelphia, which may decrease some barriers to retention since most patients lived within a few miles of the clinic and had access to reliable, affordable public transportation. The clinic's registry contains data from all individuals ($N=436$) receiving care during the study period. The study was approved by the CHOP Institutional Review Board, with a waiver of informed consent.

Measures

Retention.—The traditional measure of retention in care is a dichotomous categorization of "retained" or "lost to care" over a discrete time period. Reviews show that researchers use a wide variety of time periods to categorize loss to care, ranging from no appointments attended for two weeks to no appointments attended for 12 months (16). All five measures

defined by Mugavero and colleagues (4) were analyzed in this study, including missed visits, appointment adherence ratio, visit constancy, gaps in care, and the Medical Visits Performance Measure (MVPM). The definition for each measure is detailed in Table 1. For this study, visit constancy was defined as the number of three-month periods with at least one appointment attended, based on Mugavero's example, ranging from one to four (4). A gap in care was defined as attending no appointments for six months, based on research demonstrating most patients achieve viral suppression within six months of initiating ART (17). All retention variables were calculated for the time period starting at the first baseline visit with this clinic through 12 months later.

We also measured several demographic variables, including age, sex assigned at birth, gender identity, race, and ethnicity. In addition, variables related to client's HIV diagnosis and health care were included in this study. Specifically, the age at HIV diagnosis, the mode of HIV transmission, whether patients were on ART at baseline, absolute CD4 cell count, and quantitative HIV RNA (viral load) were all assessed.

Data Analysis

We calculated descriptive statistics for each retention measure, including medians and interquartile ranges (IQRs) for continuous measures and frequencies and proportions for binary measures. We conducted correlation analyses to better understand the interrelations between each retention measure and between year of initial visit and retention, using Spearman Rank-Order Correlations, due to expected non-normal distributions (18).

Results

For the current analysis, we excluded $n = 24$ patients who had already been receiving care at this clinic before the coding period began in 2002, and $n = 13$ patients who had their initial visit to the clinic fewer than 12 months before the end of coding in 2015. In addition, we excluded $n = 11$ patients who living with perinatally acquired HIV because these patients presumably had established care early in life and thus could be expected to have different retention patterns and visit schedules than youth living with behaviorally acquired HIV with recently diagnosed infection. We also excluded patients ($n = 44$) who transferred care or closed their cases for unknown reasons within the first year of care ($n = 19$ patients transitioned to adult care, $n = 9$ chose to seek care at another health care center, $n = 8$ relocated, and $n = 8$ had closed cases in the clinic for unknown reasons). Therefore, the total sample used in these analyses is $N = 344$.

The participants included in these analyses were predominately Black (86.6%) and cisgender male (82.8%), and were 19.02 years old ($SD = 2.17$), on average at time of first visit in the study period. The average age at HIV diagnosis was 19.53 years old ($SD = 5.25$). Most patients reported they contracted HIV from male-male sexual activity (79.9%) or heterosexual sex (25.6%). Most patients had public insurance (26.7%) or were uninsured (43.3%). All baseline characteristics are reported in Table 2.

The median number of visits scheduled for patients in the year after initiating treatment was 9 (IQR = 7–12). In the first year, the median number of missed visits was two, the median

appointment adherence ratio was 0.78, and the median visit constancy was 1.00. About 24% of participants had at least one six-month gap in care and about 65% of patients met the MVPM criteria (Table 3) for retention. Many retention measures were significantly positively or negatively correlated with one another (Table 4). However, missed visits was only significantly negatively associated with adherence ratio and visit constancy, but not gaps in care or MVPM. In addition, appointment adherence ratio was not significantly correlated with MVPM. All significant Spearman rank-order correlations were in the logical direction (e.g., appointment adherence ratio was negatively correlated with gaps in care; visit constancy was positively correlated with meeting the MVPM criteria). Bivariate spearman rank-order correlational analyses also indicated missed visits and appointment adherence ratios were significantly correlated with the year of entry into care at this clinic. Specifically, the number of missed visits increased over time, $\rho = .40$, $p < .001$, and the appointment adherence ratios decreased over time, $\rho = -.38$, $p < .001$ (see figure). During this time period, year of entry was also positively correlated with the number of appointments scheduled, $\rho = .25$, $p < .001$, increasing from a median of 7 appointments scheduled in 2002 to 11 appointments scheduled in 2014.

Discussion

This study represents an empirical application of several well-established definitions of retention in care (4, 19, 20, 21). Our data are unique, as the other research teams to operationalize different retention definitions in a single North American sample all focused on adult populations [22, 23, 24, 25]. In this study of predominantly African-American YLWH, a population both disproportionally affected by HIV and at increased risk for poor retention and treatment outcomes, all five retention definitions were utilized. Overall, the sample in this study appeared to have stronger retention than national averages, at least in their first year of care at this clinic. The participants in this study tended to miss about two of their scheduled appointments over one year. Participants in this study tended to attend at least one appointment in each of the four quarters of the year and about one-quarter of participants experienced a six-month gap in care. As opposed to published data showing YLWH miss about one-third of their appointments (6), the median appointment adherence ratio in this study was almost 80%. In contrast to the CDC's estimate that 31% of 13–24 years olds meet the MVPM criteria (5), the current sample doubled that rate at 64.5%. Clinic practices such as medical case management, multidisciplinary care, and intensive outreach and re-linkage may have promoted stronger retention at this site.

Two definitions, missed visits and appointment adherence ratios, suggested retention may have worsened over time. There were several changes in the clinic's practices during the study period that may explain the increase in missed visits and decreased appointment adherence ratio. Specifically, in 2009 the clinic moved to electronic medical records, which may have led to better tracking of missed visits, which could also impact the calculation of appointment adherence ratios. Furthermore, the HRSA quality measures and new universal ART treatment guidelines could have led to increasing the frequency of scheduled visits at the clinic, resulting in more missed visits and lower appointment adherence ratios.

Retention definitions were mostly significantly positively correlated with one another in this sample of YLWH, similar to previous findings in adults living with HIV [23, 24]. However, each definition had different qualities, such as being dichotomous, count, or continuous variables. Furthermore, not all retention definitions were significantly correlated, despite sufficient variability and sample size to find relationships. There are important practical differences between retention definitions that could impact the conclusions drawn regarding each specific operationalization. For example, a YLWH who has advanced HIV or intense psychosocial and socioeconomic needs may be scheduled for visits every month at the clinic. If they attend only one-quarter of these visits (three out of 12), visit constancy, gaps in care, and MVPMM measures would suggest strong retention in care; however adherence ratio and missed visits measures would suggest poor retention. For example, in this cohort, missing more visits was not significantly related to meeting the HRSA's MVPMM definition. Some definitions of retention may be more applicable to improving clinic efficiency or reducing healthcare costs versus ensuring quality medical care or improving health outcomes. This suggests that although a high frequency of missed visits within a clinic could impact the work flow of practitioners and lengthen wait times for appointments, patients within the clinic could still be accessing services sufficiently for their own health care needs. The only definition that was significantly correlated with each other retention definition was visit constancy, defined in this study as the proportion of 3-month intervals with at least 1 completed clinic visit over a 12-month observation period. In addition to its convergent validity with every other operationalization, this definition conveys how regularly patients access health care throughout the year, rather than simply describing the quantity of visits, and produces a range of values from 0 to 1.00 that could result in higher statistical power than dichotomous definitions such as gaps in care and MVPMM.

In order to better understand treatment retention and associated risk and protective factors, it is important that researchers, clinicians and policymakers consider the differential operationalization of retention definitions. Furthermore, it may be necessary to move beyond the concept of retention, and investigate treatment engagement more broadly. The term "engagement" rather than retention provides a more expansive perspective on how patients sustain their involvement in HIV care. This term could be used to describe a wide range of activities, including linkage with care, medication adherence, following recommendations, enacting positive health behaviors, attending appointments, and maintaining communication and collaboration with a treatment team.

Limitations

This study had a few limitations in addition to the strengths delineated above. First, excluding the patients who transitioned to adult care, chose to seek care at another health care center, relocated, and had closed cases in the clinic for unknown reasons ($n = 44$) may have inflated the retention rates in this study. In addition, this study was conducted at a single site in an urban, academic medical setting, with medical case management, multidisciplinary care, and intensive outreach and re-linkage as part of care, which limits generalizability to other populations. Finally, the dataset was created based on electronic medical records which could contain errors, such as having appointments which were scheduled, but never entered in the system.

Conclusion

In sum, this study examined retention based on a variety of definitions in a predominantly African-American sample of YLWH receiving care from a single multidisciplinary adolescent HIV clinic in an urban setting. Each definition of retention led to a slightly different understanding of how patients attended their medical visits and engaged in care. Further research is needed in larger samples to confirm the most appropriate retention definitions and meaningful predictors for YLWH in this vulnerable population who have distinct needs and health outcomes.

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Figure 1.

Statistically significant relationships between year of entry and retention definitions.

Multiple Measures of HIV Treatment Retention during Initial 12 Months of Treatment at Clinic

Table 1.

Retention Measures	Definitions ¹
Missed Visits	Number of missed visits over a 12-month observation period.
Appointment Adherence Ratio	Proportion capturing the number of completed visits in the numerator and the number of total scheduled (completed plus missed visits) visits in the denominator over a 12-month observation period.
Visit Constancy	Proportion of 3-month intervals with at least 1 completed clinic visit over a 12-month observation period.
Gaps in Care	Whether the time interval between completed clinic visits exceeds a 6-month threshold, during a 12-month observation period.
Medical Visits Performance Measure ²	Whether a patient had 2 completed clinic visits separated by 3 more months during a 12-month observation period.

¹ Definitions were described by Mugavero and colleagues (4)

² Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) measure

Table 2.

Baseline Characteristics of Sample (N =344)

Variable	M or Median	SD or IQR	n	%	Missing n (%)
Demographic Characteristics					
Age at Initial Visit, years	19.02	2.17	--	--	0 (0.0)
Year of First Visit	2009	2006–2012	--	--	0 (0.0)
Assigned Male Sex at Birth	--	--	293	85.2	0 (0.0)
Gender Identity					
Cisgender male	--	--	285	82.8	0 (0.0)
Cisgender female	--	--	51	14.8	0 (0.0)
Transgender female	--	--	8	2.3	0 (0.0)
Race					
Black	--	--	298	86.6	0 (0.0)
White	--	--	16	4.7	0 (0.0)
Asian/Pacific Islander	--	--	1	0.3	0 (0.0)
American Indian/Native	--	--	1	0.3	0 (0.0)
Bi-racial/Multi-racial	--	--	3	.9	0 (0.0)
Other	--	--	25	7.3	0 (0.0)
Hispanic Ethnicity	--	--	12	3.5	1 (0.3)
HIV Characteristics at Initial Visit					
Age at HIV Diagnosis, years	17.96	2.15	--	--	1 (0.3)
Time Since HIV Diagnosis					
<3 Months	--	--	268	77.9	1 (0.3)
3–6 Months	--	--	23	6.7	1 (0.3)
6–12 Months	--	--	21	6.1	1 (0.3)
>12 Months	--	--	31	9.0	1 (0.3)
Mode of HIV Transmission					
MSM Activity	--	--	275	79.9	0 (0.0)
Heterosexual Activity	--	--	88	25.6	0 (0.0)
IV Drug Use	--	--	2	0.6	0 (0.0)
Viral Suppression	--	--	35	10.2	28 (8.3)

Variable	<i>M</i> or Median	<i>SD</i> or <i>IQR</i>	<i>n</i>	%	Missing <i>n</i> (%)
CD4 Count	444	305–611	--	--	103 (29.9)
Viral Load	15,373	3,063–64,110	--	--	26 (7.6)

MSM = men who have sex with men; no transgender males received care at clinical site in study period. CD4 count and viral load are presented as median and IQR due to extreme skewness. Percentages for mode of transmission sum to >100% because participants could have reported multiple modes of transmission. *M* = mean; *SD* = standard deviation; *IQR* = interquartile range.

Table 3.

Descriptive Retention Statistics

Retention Measures	Descriptive Statistics	
	<u>Median</u>	<u>Interquartile Range</u>
Missed Visits	2.00	1.00–4.00
Appointment Adherence Ratio	0.78	0.56–0.92
Visit Constancy	1.00	0.75–1.00
	<u>Count</u>	<u>Percentage</u>
Gaps in Care	84	24.4
Medical Visits Performance Measure	222	64.5

All measures were calculated based on the period beginning at the initial visit to this clinic through 12 months. Visit constancy was calculated using 3 month periods. Gaps in care were defined as no completed appointments over 6 months.

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Table 4.

Spearman Rank-Order Correlations (ρ)

	AAR	Visit Constancy	Gaps in Care	MVPM
Missed Visits	-.91**	-.14**	.07	.07
AAR	--	.39**	-.31**	.02
Visit Constancy	--	--	-.75**	.15**
Gaps in Care	--	--	--	-.23**

All measures were calculated based on the period beginning at the initial visit to this clinic through 12 months. AAR = Appointment Adherence Ratio; MVPM = Medical Visits Performance Measure.

† $p < .10$,
* $p < .05$,
** $p < .01$,
*** $p < .001$