

Factors Associated With Retention Among Non-Perinatally HIV-Infected Youth in the HIV Research Network

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Background. The transmission of human immunodeficiency virus (HIV) among youth through high-risk behaviors continues to increase. Retention in Care is associated with positive clinical outcomes and a decrease in HIV transmission risk behaviors. We evaluated the clinical and demographic characteristics of non-perinatally HIV (nPHIV)-infected youth associated with retention 1 year after initiating care and in the 2 years thereafter. We also assessed the impact retention in year 1 had on retention in years 2 and 3.

Methods. This was a retrospective analysis of treatment-naïve nPHIV-infected 12- to 24-year-old youth presenting for care in 16 US HIV clinical sites within the HIV Research Network between 2002 and 2008. Multivariate logistic regression identified factors associated with retention.

Results. Of 1160 nPHIV-infected youth, 44.6% were retained in care during the first year, and 22.4% were retained in all 3 years. Retention in the first year was associated with starting antiretroviral therapy in the first year (adjusted odds ratio [AOR], 3.47 [95% confidence interval (CI), 2.57–4.67]), Hispanic ethnicity (AOR, 1.66 [95% CI, 1.08–2.56]), men who have sex with men (AOR, 1.59 [95% CI, 1.07–2.36]), and receiving care at a pediatric site (AOR, 5.37 [95% CI, 3.20–9.01]). Retention in years 2 and 3 was associated with being retained 1 year after initiating care (AOR, 7.44 [95% CI, 5.11–10.83]).

Conclusion. A high proportion of newly enrolled nPHIV-infected youth were not retained for 1 year, and only 1 in 4 were retained for 3 years. Patients who were Hispanic, were men who have sex with men, or were seen at pediatric clinics were more likely to be retained in care. Interventions that target those at risk of being lost to follow up are essential for this high-risk population.

Key words. adolescents; HIV Research Network; retention; youth.

The incidence of human immunodeficiency virus type 1 (HIV-1) is increasing in adolescents and young adults. Recent US Centers for Disease Control and Prevention estimates showed that youth aged 13 to 24 years account for 26% of new HIV infections in the United States [1]. Sexual acquisition is the predominant mode of infection for non-perinatally HIV (nPHIV)-infected youth [2]. Access to care and integration into the care system are particularly problematic for nPHIV-infected youth. nPHIV-infected youth face barriers to care such as fear of disclosure and

stigmatization caused by HIV infection or sexual orientation that may influence their acceptance of diagnosis and adherence to treatment [3].

Early establishment and retention in HIV care can help to achieve antiretroviral therapy (ART) adherence, improve clinical outcomes, decrease HIV transmission risk behaviors, and reduce the mortality rate [4–9]. The Health Resources and Services Administration HIV/AIDS Bureau [10] and the National Quality Forum [11] both view retention as a marker of quality HIV care. In general,

younger age has been associated with poor retention [5, 12, 13]. Even after attending a clinic, barriers including a lack of transportation to appointments, poor health literacy, and perceived lack of a youth-friendly clinic atmosphere [14] can derail retention. Understanding the retention patterns of newly enrolled nPHIV-infected youth and the clinical and demographic characteristics associated with retention are essential for developing intervention strategies to ensure that at-risk youth are receiving consistent care.

Multiple methods have been used to measure retention in care among youth; there is no gold standard [15]. However, the National Quality Forum has recommended several measures of retention [16, 17]. Using these recommended measures, we analyzed the retention patterns of treatment-naïve nPHIV-infected youth enrolled in the HIV Research Network (HIVRN) 1 year after initiating care and in the second and third years after enrollment. We also identified clinical and demographic characteristics associated with retention in each time period.

METHODS

Study Setting and Participants

We conducted a retrospective study of retention in care among nPHIV-infected youth between the ages of 12 and 24 years followed at outpatient HIV clinical sites in the HIVRN [18]. We structured the analysis to exclude those aged 25 years or older, because 25 years is the age at which most patients treated at pediatric sites must switch to adult providers/clinics. Therefore, they were excluded to avoid being considered not retained. The HIVRN is a consortium of clinics that provide primary and subspecialty care to HIV-infected children, youth, and adults [18]. To ensure consistency over time, 2 sites ($n = 50$ nPHIV-infected patients) that did not contribute data during the entire study period were excluded. The remaining 16 sites, 4 pediatric and 12 adult, were geographically distributed in the Northeast (6), the South (5), the West (4), and the Midwest (1).

Data Collection

Data were abstracted from the medical records at each site from January 1, 2002, through December 31, 2011. Data were sent to a coordinating center and combined across sites to produce a uniform database, as previously described [18]. Abstracted data included CD4 cell count, insurance status, age, sex, self-identified race/ethnicity, HIV acquisition risk, clinic type (pediatric or adult), clinic utilization (outpatient HIV provider visits), and ART prescription. The study was approved by the Institutional Review Board of Johns Hopkins University and each participating institution.

Eligibility

To be included in the study, patients must have enrolled in HIV care at HIVRN clinic sites between 2002 and 2008. Patients had to have acquired infected through sex, injection drug use (IDU), or both; to have been between 12 and 24 years old at the time of enrollment; to have had at least 1 CD4 cell count recorded during the first year of enrollment; and to have had an outpatient visit in the first 4 months of care. Patients infected perinatally or through blood transfusion ($n = 47$) were excluded. To ensure that we excluded those who had received HIV care before enrollment, we excluded patients who were on ART before enrollment ($n = 200$) and those whose first recorded viral load was either below the limit of detection of the assay being used or was $<2.6 \log_{10}$ HIV-1 RNA copies/mL ($n = 172$). Patients were also excluded if they transferred care to a non-HIVRN site ($n = 63$) or died ($n = 27$) during the study period.

Outcome Measures

We examined 2 time frames for measuring retention in HIV care: the 360-day period after enrollment and the subsequent 2-year period (ie, combined years 2 and 3 after enrollment). Retention 1 year after initiating care was defined as having had at least 1 medical visit in each 4-month period of the year of study. Because having 1 visit in the first 4 months after enrollment was an inclusion criterion, this retention measure, in effect, reflects whether the patient had visits in each of the remaining quarters. Retention in years 2 and 3 was defined as having had at least 1 medical visit within each 6-month period of the overall 24-month measurement period, with a minimum of 60 days between visits [16]. The observation periods began on the enrollment date for each person. There was no necessary relationship between retention in year 1 and retention in years 2 and 3. For example, a patient could not be retained in year 1 but be retained in years 2 and 3.

Demographic and Clinical Variables

Age was categorized as 12 to 16, 17 to 20, or 21 to 24 years for descriptive analyses. Race/ethnicity was categorized as non-Hispanic, white, non-Hispanic black, Hispanic, or other. HIV transmission risk factors were grouped as men who have sex with men (MSM), patients who obtained HIV through heterosexual transmission (HET), IDU, or other/unknown. Patients with both sexual and IDU acquisition risk were categorized as IDUs. HIV acquisition risk was self-reported. Insurance status was categorized as insured or uninsured. Patients supported by Ryan White funding were considered uninsured. ART was defined as concomitant use of ≥ 3 antiretroviral drugs from either ≥ 2 classes or 3 nucleoside reverse

transcriptase inhibitors. The relevant guidelines for ART initiation for a given year were used [19]. Patients were considered to be on ART if they initiated treatment after enrollment within the first year or if they were prescribed treatment in year 2 after initiating care. The CD4 cell count was classified as <200, 200 to 350, 351 to 500, or >500 cells/ μ L.

Variables included CD4 cell count, ART prescription, insurance status, and age. For the analysis of retention in the first year after enrollment, values for these variables reflected status at the first outpatient visit after enrollment. For the analysis of retention in years 2 and 3, time-dependent variables reflected values during the beginning of year 2 in care. If patients did not have values for insurance status ($n = 455$) or CD4 cell count ($n = 381$) during year 2, the values at enrollment were used when examining retention in years 2 and 3. Patients older than 24 years during year 2 ($n = 211$) were excluded from the study of retention in years 2 and 3.

Statistical Analyses

The chi-squared test was used to compare differences in demographic and clinical characteristics between those who were retained and not retained during the first year of care and for the 2 years thereafter. A P value of <.05 was considered significant.

We estimated 2 multivariate logistic regression models, one for each dependent variable. Both models included clinical and demographic factors thought to potentially affect retention. The model for retention in years 2 to 3 also included a variable indicating whether the patient had been retained in year 1 [12]. Age was entered as a continuous variable. (Sensitivity analyses categorizing age as 12–16, 17–20, or 21–24 years produced similar results.) All regression models included indicators for each HIVRN site and for year of first outpatient visit. For all analyses, we used robust standard errors clustered on site. Statistical analyses were performed using Stata 13 (Stata Corp, College Station, TX).

RESULTS

Between 2002 and 2008, 1160 nPHIV-infected youth aged 12 to 24 years who were enrolled in care at 1 of 16 HIVRN sites met eligibility criteria for this analysis. The median age at the time of enrollment into care was 21 years (interquartile range [IQR], 20–23 years). The median CD4 cell count at enrollment was 399 cells/ μ L (IQR, 265–550 cells/ μ L). The majority of the study participants were male (74.3%), black (60.6%) or Hispanic (19.1%), had an MSM-related HIV acquisition risk (57.7%), were insured

(54.5%), and were enrolled at an adult clinic (91.3%). Forty-one percent started ART during the first year after initiation of care (Table 1).

Retention in the First Year

Among the study participants, 517 (44.6%) youth were retained during their first year of care (Table 1). In multivariate analysis, Hispanic ethnicity (adjusted odds ratio [AOR], 1.66 [95% confidence interval (CI), 1.08–2.56]) and MSM-related HIV transmission (AOR, 1.59 [95% CI, 1.07–2.36]) compared with HET risk were significantly associated with retention in the first year. Starting ART within 1 year after initiating care (AOR, 3.47 [95% CI, 2.57–4.67]) and being enrolled in care at a pediatric site (AOR, 5.37 [95% CI, 3.20–9.01]) were also independently associated with being retained in the first year after initiating care. IDUs had worse retention than participants in the other HIV risk groups (AOR, 0.43 [95% CI, 0.19–0.99]) (Table 2).

Retention in Years 2 and 3

Among those younger than 25 years in the second year ($n = 949$), 26.6% were retained during the second and third years of care (Table 1). Of those who were younger than 25 years throughout the eligibility period, only 22.4% were retained during all 3 years of care. Among those retained in year 1 who were younger than 25 years during the study period, 49.3% were retained in years 2 and 3; among those not retained in year 1, 8.7%, reentered care and were subsequently retained in years 2 and 3.

In multivariate analysis, retention in year 1 was strongly associated with retention in years 2 and 3 (AOR, 7.44 [95% CI, 5.11–10.83]). Receiving care at a pediatric site (AOR, 4.02 [95% CI, 2.28–7.09]), being on ART during the second year after initiating care (AOR, 2.84 [95% CI, 1.97–4.10]), and having a CD4 cell count in the second year of either 351 to 500 cells/ μ L (AOR, 2.39 [95% CI, 1.18–4.84]) or >500 cells/ μ L (AOR, 2.15 [95% CI, 1.06–4.35]) were significantly associated with being retained in years 2 and 3 (Table 3). A separate multivariate analysis (data not shown) was conducted in which retention in year 1 was not included. The analysis had consistent findings with the multivariate analysis in year 1, except the Hispanic ethnicity and IDU risk group factors were not statistically significant.

DISCUSSION

Among our sample of nPHIV-infected youth, more than 50% were not retained 1 year after initiating care, and only 22.4% of those younger than 25 years during the entire study period were retained in all 3 years after initiating

Table 1. Clinical and Demographic Characteristics of nPHIV-Infected Youth (12–24 Years Old) at Presentation Into Care, Retention in Year 1, and Retention in Years 2 and 3

Variable	Overall n (%) (N = 1160)	n (%) Retained in Year 1 (N = 517 [44.6%])	P	n (%) Retained in Years 2 and 3 (N = 252 [26.6%])	P
Retention in year 1			—		<.001
Not retained	—	—		46 (8.7)	
Retained	—	—		206 (49.3)	
Age			.182		.325
12–16 y	38 (3.3)	21 (55.3)		4 (28.6)	
17–20 y	407 (35.1)	190 (46.7)		81 (29.9)	
21–24 y	715 (61.6)	306 (42.8)		167 (25.2)	
Sex			.233		.251
Male	862 (74.3)	393 (45.6)		193 (27.5)	
Female	298 (25.7)	124 (41.6)		59 (23.8)	
Race/ethnicity			.008		.002
Non-Hispanic white	183 (15.8)	65 (35.5)		24 (18.6)	
Non-Hispanic black	703 (60.6)	330 (46.9)		179 (30.1)	
Hispanic	221 (19.1)	105 (47.5)		44 (24.7)	
Other/unknown	53 (4.6)	17 (32.1)		5 (10.4)	
Risk group			<.001		.046
HET	390 (33.6)	166 (42.6)		82 (25.1)	
MSM	669 (57.7)	325 (48.6)		159 (29.1)	
IDU	44 (3.8)	9 (20.4)		4 (12.5)	
Other/unknown	57 (4.9)	17 (29.8)		7 (15.9)	
Insurance status			.743		.094
Insured	631 (54.5)	284 (45.0)		146 (28.8)	
Uninsured	529 (45.6)	233 (44.0)		106 (24.0)	
CD4 cell count			.007		.033
< 200	185 (16.0)	99 (53.5)		14 (15.6)	
200–350/μL	264 (22.8)	126 (47.7)		56 (24.8)	
351–500/μL	355 (30.6)	154 (43.4)		88 (30.9)	
>500/μL	356 (30.7)	138 (38.8)		94 (27.0)	
ART use			<.001		<.001
Not on ART	685 (59.1)	231 (33.7)		127 (19.0)	
On ART	475 (41.0)	286 (60.2)		125 (44.6)	
Site of care			<.001		<.001
Adult	1059 (91.3)	441 (41.6)		193 (22.7)	
Pediatric	101 (8.7)	76 (75.3)		59 (59.0)	

care. Being Hispanic, initiating ART in the first year, having an HIV risk factor of MSM and receiving initial care at a pediatric site were associated with a higher probability of retention in the first year after initiating care. IDUs had worse retention than MSM or HET. Subsequent retention, in the second and third years after initiating care was associated with initiation of care at pediatric sites and with being on ART and having a CD4 cell count of ≥ 351 cells/ μL in the second year. Finally, patients who were successfully retained in the first year after initiating care were significantly more likely to remain retained during the following 2 years.

Our study was strengthened by focusing specifically on youth and using current measures recommended to evaluate retention. Many previous studies assessed a combination of adults and adolescents, which limits the ability to assess youth-specific retention, or were single-site studies, which limits the generalizability of their findings [5, 20–22]. Previous studies of retention also used various measures of retention, which makes it difficult to compare across studies, age groups, and different affected populations.

A recent comprehensive meta-analysis of adult and adolescent retention studies reported a retention rate of 59% in studies that defined retention as having ≥ 3 visits over a course of 12 months [23]. Similarly, a study of retention patterns of HIV patients (13 years old or older) living in New York and initiating care 3 months after diagnosis showed that youth (aged 13–24 years) were at a greater risk for not being retained than adults older than 50 years [21]. Other studies have reported retention rates of 44.2% and 70% among youth 1 to 2 years after initiating care [20, 22]. Compared with these studies, we report an even lower level of retention among our cohort of nPHIV-infected youth during a comparable time period. Even among those who were retained in the first year, the attrition rate in subsequent years was significant. Our finding that only 22.4% of the youth were retained in care for more than 3 years is significantly lower than that found among adults over a similar time period [24] and highlights the fact that continuity of care is a pressing issue among newly enrolled infected youth.

Table 2. Logistic Regression Analysis of Retention in Year 1^a

Variable (N = 1160)	Retention in Year 1 (Univariate Odds Ratio [95% CI])	Retention in Year 1 (Multivariate AOR [95% CI])
Age		
12–24 y	1.09 (0.96–1.23)	0.96 (0.83–1.1)
Sex		
Male	1.00 (ref)	1.00 (ref)
Female	0.85 (0.65–1.11)	0.99 (0.64–1.53)
Race/ethnicity		
Non-Hispanic white	1.00 (ref)	1.00 (ref)
Non-Hispanic black	1.61 (1.15–2.25)	1.28 (0.88–1.85)
Hispanic	1.64 (1.10–2.46)	1.66 (1.08–2.56)
Other	0.86 (0.45–1.64)	0.81 (0.40–1.63)
Risk group		
HET	1.00 (ref)	1.00 (ref)
MSM	1.27 (0.99–1.64)	1.59 (1.07–2.36)
IDU	0.35 (0.16–0.74)	0.43 (0.19–0.99)
Other/unknown	0.57 (0.31–1.05)	0.56 (0.28–1.09)
Insurance status		
Insured	1.00 (ref)	1.00 (ref)
Uninsured	0.96 (0.76–1.21)	0.98 (0.75–1.27)
CD4 cell count		
<200/μL	1.00 (ref)	1.00 (ref)
200–350/μL	0.79 (0.54–1.16)	0.88 (0.58–1.32)
351–500/μL	0.67 (0.47–0.95)	1.18 (0.78–1.78)
>500/μL	0.55 (0.38–0.79)	1.19 (0.77–1.85)
ART use		
Not on ART	1.00 (ref)	1.00 (ref)
On ART	2.97 (2.33–3.79)	3.47 (2.57–4.67)
Site of care		
Adult	1.00 (ref)	1.00 (ref)
Pediatric	4.26 (2.67–6.80)	5.37 (3.20–9.01)

Abbreviation: ref, reference group.

^aEntries in bold type are significant at a *P* value of <.05.

Retention in the first year after initiation of care is highly associated with subsequent retention in the 2 years thereafter. This study is among the first to explore how early retention may impact retention in later years of care for youth [4–6, 20–26]. The first year serves as a crucial checkpoint, especially for youth, given their developmental stage with concrete thinking and limited support [27]. Despite increased attention to the importance of maintaining retention in care, youth continue to be at risk for suboptimal care patterns and poor clinical outcomes [28]. How youth initially engage in the health care system, evidenced by their early retention, may represent a critical point at which interventions and outreach initiatives should be emphasized.

Receiving care at a pediatric site was associated with a greater probability of retention than receiving care at an adult site. This may reflect differences in culture, treatment practices, and potentially the way youth engaged in care at the respective sites. Barriers to entering adult care for youth with a chronic illness include fear of new providers and increased independence [29]. In addition, nPHIV-infected youth face many age-specific medical and psychosocial concerns [30] that may not be fully addressed at adult sites. A recent set of studies evaluating “youth-friendly” clinics showed that common elements include adolescent-

only spaces, staff trained to work specifically with youth, and having flexible hours, all of which may play crucial roles in linking and retaining youth in care [31, 32]. Innovative interventions, such as having youth-specific support groups, the presence of providers with experience with HIV and youth, and peer outreach and navigation hold promise for addressing the issues that youth face in being retained in care [33]. Our study did not investigate specific characteristics among the pediatric and adult HIVRN sites. Additional work should evaluate characteristics among clinic sites that increase retention patterns and positive clinical outcomes in youth.

Black youth did not have significantly worse retention than white youth. In fact, similar to adult Hispanic patients, Hispanic youth were more likely than white youth to be retained in the first year of care [34]. Additional research must be done to clarify retention patterns among Hispanic patients and to explore the potential impact of culturally relevant interventions on retention.

Retention in the first year after initiation of care was significantly associated with the initiation of ART in the first year. Retention in years 2 and 3 was also significantly associated with being on ART in year 2. Two studies of HIV-infected adults in Africa also reported poor retention

Table 3. Logistic Regression Analysis of Retention in Years 2 and 3

Variable (N = 949)	Retained in Years 2 and 3 (Univariate OR [95% CI])	Retained in Years 2 and 3 (Multivariate AOR [95% CI])
Retention in year 1		
Not retained	1.00 (ref)	1.00 (ref)
Retained	10.25 (7.16–14.66)^a	7.44 (5.11–10.83)
Age		
12–24 y	1.13 (0.96–1.32)	0.86 (0.70–1.06)
Sex		
Male	1.00 (ref)	1.00 (ref)
Female	0.82 (0.59–1.15)	0.74 (0.40–1.36)
Race/ethnicity		
Non-Hispanic white	1.00 (ref)	1.00 (ref)
Non-Hispanic black	1.89 (1.17–3.04)	1.37 (0.78–2.42)
Hispanic	1.44 (0.82–2.51)	1.25 (0.65–2.39)
Other	0.51 (0.18–1.42)	0.38 (0.12–1.21)
Risk group		
HET	1.00 (ref)	1.00 (ref)
MSM	1.23 (0.90–1.68)	1.04 (0.59–1.84)
IDU	0.43 (0.14–1.25)	0.75 (0.21–2.68)
Other/unknown	0.56 (0.24–1.32)	0.58 (0.20–1.63)
Insurance		
Insured	1.00 (ref)	1.00 (ref)
Uninsured	0.78 (0.58–1.04)	0.76 (0.53–1.09)
CD4 cell count		
<200/μL	1.00 (ref)	1.00 (ref)
200–350/μL	1.79 (0.94–3.41)	1.52 (0.74–3.14)
351–500/μL	2.42 (1.30–4.52)	2.39 (1.18–4.84)
>500/μL	2.01 (1.08–3.72)	2.15 (1.06–4.35)
ART use		
Not on ART	1.00 (ref)	1.00 (ref)
On ART	3.44 (2.54–4.67)	2.84 (1.97–4.10)
Site of care		
Adult	1.00 (ref)	1.00 (ref)
Pediatric	4.89 (3.18–7.52)	4.02 (2.28–7.09)

Abbreviation: ref, reference group.

^aEntries in bold type are significant at a *P* value of <.05.

among patients who were not eligible for ART [35, 36]. Patients in pre-ART care, in addition to not experiencing any symptoms, may not perceive a benefit to coming in for care because little therapy is offered during this stage of HIV care [36]. Also, compared with adults, nPHIV-infected youth in the HIVRN who were eligible for treatment were found to be less likely to initiate treatment [37].

More than half of the sample (59.1%) were not on ART during the first year of care. Similar findings were reported in a study among treatment-eligible nPHIV-infected patients younger than 25 years, in which 69% initiated ART compared with 79% of treatment-eligible adults [37]. During much of the study period, guidelines suggested initiating ART at a CD4 cell level of 350 cells/μL. The rates of ART initiation were 81%, 63%, 30%, and 15% for youth with CD4 cell counts of <200, 200 to 350, 351 to 500, and >500 cells/μL, respectively. In multivariate analysis in the first year, youth were less likely to initiate ART the higher their CD4 count, whereas in the second and third years, youth with a CD4 cell count of >500 cells/μL (AOR, 0.27 [95% CI, 0.15–0.51]) were less likely to initiate therapy (results not shown). Current guidelines strongly

recommend ART initiation at higher CD4 cell counts; concerns for youth in particular include poor medical adherence and adverse-effect tolerability with resultant evolution of viral resistance [38–40], which may lead to delays in ART initiation [37]. The association of ART initiation with retention provides additional support for ART initiation in youth early in the course of clinical management.

This study had several limitations. Although this was a multisite HIVRN study, which allows for greater generalizability than a single-site study, it is not nationally representative. Retention rates may differ among providers with a smaller volume of HIV patients and in communities with a different mix of HIV patients. In addition, we did not have data on substance use, mental health issues, socioeconomic status, homelessness, education, or employment status, which have been shown to be associated with poor retention [32]. Furthermore, the sample in the 12- to 16-year age group was small, with only 6 of 38 patients younger than 15 years meeting our inclusion criteria. Evaluating outcomes such as viral suppression was beyond the scope of our analysis, but future research should analyze the clinical outcomes associated with retention. Finally, it is

possible that we did not exclude all the patients who died, and other patients classified as lost to follow-up may have actually transferred to a different care provider.

In summary, the high proportions of newly enrolled nPHIV-infected youth in the HIVRN cohort who were not retained in care at 1 year and in years 2 and 3 are alarming. Specific subgroups of youth, such as those being followed at adult sites, IDUs, and those not on ART, are at considerable risk for not being retained. In addition, our data underscore the importance of optimizing retention in the first year of care, as it has a significant association with subsequent retention. Additional studies are needed to evaluate the efficacies of services and initiatives designed to address the unique needs of youth early in care because of the significance that early retention has in building habits of consistent utilization.

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