



# Predicting Retention in HIV Primary Care: Is There a Missed Visits Continuum Based on Patient Characteristics?

Emma Sophia Kay<sup>1,2</sup> · Ashley Lacombe-Duncan<sup>1</sup> · Rogério M. Pinto<sup>1</sup>

Published online: 15 April 2019  
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## Abstract

Missing 3 + scheduled HIV primary care visits over a 1-year period increases mortality risk for people living with HIV (PLWH). We used electronic health data from PLWH ( $\geq 18$  years old) at a southeastern US HIV clinic in 2016 to examine differences across patient-level characteristics and number of missed visits (1–2 vs. 0, 3+ vs. 0, 3+ vs. 1–2). In multivariable multinomial logistic regression analyses, poverty, lack of Ryan White HIV/AIDS Program support services, being uninsured, not having a high school degree, and being younger were significantly associated with 1–2 or 3+ missed visits (vs. 0 missed). Only poverty remained predictive of missing 3+ versus 1–2 visits (RR = 2.70, 95% CI 1.49–4.88). Patients at risk for missing 3+ visits present similar characteristics to patients who miss 1–2 visits. Interventions aimed at poverty reduction and increased access to education, health insurance, and support services may improve retention and, therefore, decrease mortality risk.

**Keywords** HIV continuum of care · Retention in care · Missed visits · Risk ratio

## Resumen

No acudir a más de tres visitas programadas de VIH en atención primaria durante un período de un año, aumenta el riesgo de mortalidad para las personas que viven con VIH (PLWH). Utilizamos datos electrónicos de salud de 2016 de PLWH ( $\geq 18$  años de edad) en una clínica de VIH del sureste de EE. UU, para examinar las diferencias entre características del paciente y número de visitas perdidas (1–2 vs. 0, 3+ vs. 0, 3+ vs. 1–2). En los análisis multivariados de regresión logística multinomial, la pobreza, la falta del programa de servicios de apoyo Ryan White HIV/AIDS, la carencia de seguro médico, carencia de estudios secundarios, y ser joven, resulta tener una asociación significativa con una dos o más de tres visitas perdidas (vs. 0 perdidas). Solo la pobreza es predictiva de perder más de 3 en comparación con 1–2 visitas (RR = 2,70; IC del 95% = 1,49–4,88). Los pacientes en riesgo de perder más de three visitas presentan características similares a los pacientes que no acuden a 1–2 visitas. Intervenciones dirigidas a la reducción de la pobreza, mayor acceso a la educación y a un seguro médico, así como acceso a servicios de apoyo, pueden mejorar la retención y, por tanto, disminuir el riesgo de mortalidad.

## Introduction

Retention in HIV care is one of five key steps in the HIV Continuum of Care (“Care Continuum”), a progression from initial diagnosis to viral suppression, and currently the prevailing clinical indicator of HIV health [1]. Poor retention (infrequent

or high number of missed HIV care visits) is associated with suboptimal patient-level outcomes (e.g., viral non-suppression) and population-level outcomes (increased HIV transmission) [2]. The Centers for Disease Control and Prevention (CDC) report that under half (48%) of people living with HIV (PLWH) in the US are retained in care [3]. This statistic is based on the Institute of Medicine (IOM)’s indicator, which defines retention as at least two attended primary care visits separated by more than 90 days during a 12-month period [4]. Retention has gained much less attention than other care continuum outcomes, particularly adherence to antiretroviral treatment (ART) [5, 6]. For example, a recently published systematic review of studies focused on predictors of retention

✉ Emma Sophia Kay  
esophkay@umich.edu

<sup>1</sup> University of Michigan, Ann Arbor, MI, USA

<sup>2</sup> School of Social Work, University of Michigan, 1080 S University Ave, Ann Arbor, MI 48109, USA

included only 30 studies [7], compared to a systematic review of studies focused on predictors of antiretroviral therapy which included 207 studies [8]. This paper aims to narrow this gap by assessing risk ratios (RRs) for missed visits in a population of 1159 patients living in the southeast US.

### Metrics for Retention in Care

There are several recognized metrics for retention in care. Indicators based on missed (“no show”) scheduled visits have particular clinical relevance, as research indicates that missing scheduled visits is independently associated with mortality [9–11]. In a seminal study, even when PLWH were classified as retained by the IOM’s indicator, PLWH who missed three or more scheduled visits had nearly four times the mortality risk of PLWH who did not miss any scheduled visits [10]. Moreover, retention indicators based on multiple visits (e.g., the IOM indicator) can underestimate retention for people who have been living with HIV for longer and/or are on established treatment regimens, but, who, nonetheless, may require fewer medical visits than PLWH who are newer to care [12]. For this sub-population of PLWH with established treatment regimens, the missed visit indicator may be a more appropriate performance measure of retention in care, as it does not depend on a particular visit schedule that may vary across patients presenting diverse biopsychosocial characteristics, as follows.

### Factors That Influence Retention

There are several known correlates of retention. These include sociodemographic factors (black or African American race [2, 13], female gender [13, 14], younger age [11], individual clinical and health factors [having previously missed visits [15], substance use [16], depression [17], and structural factors [lower income [13], unemployment [18]. However, we do not know the extent to which patients who miss three or more visits differ from those who miss fewer than three. Therefore, this study aimed to identify factors associated with poor retention in care and to examine the extent to which such factors predicted the actual number of missed scheduled HIV primary care visits. Given the nearly fourfold increase in mortality risk associated with missing 3+ scheduled visits, we examined whether patients who missed 3+ scheduled visits were uniquely different from patients who missed fewer scheduled visits (i.e., 1–2 or 0 missed visits).

## Methods

### Data Source and Sample

#### Data Source

We obtained de-identified, patient-level medical records data from a large, urban, academically affiliated HIV/AIDS clinic in the southeastern United States. The clinic receives funding from Ryan White HIV/AIDS Program (RWHAP) parts B and C and provides medical as well as social services onsite, such case management, dental care, psychiatric care, and nutritional counseling. For all patients, the clinic maintains an electronic medical record (EMR) system that includes demographic, administrative, and clinical data. The clinic does not treat minors; thus, only adults ( $\geq 18$  years old) were included in the study sample.

#### Sample

We used data from 1159 adults living with HIV who received HIV primary care services at the clinic in 2016. A primary care visit was defined as one that would address routine medical care and thus scheduled in advance (emergency or walk-in visits or specialty care appointments not included). All patients at the clinic receive an automated telephone call to remind them of upcoming primary care appointments.

The sample included only those patients who attended at least one scheduled HIV primary care appointment at the clinic in 2015, the year prior to the study’s observation window. Anchoring the sample to patients with previous clinic attendance in 2015 meant that patients more established in care were included; as previously mentioned, we considered the missed visits retention measure, the focus of the study, the most appropriate retention measure for this subpopulation of PLWH. PLWH who died in 2016 were excluded ( $n = 35$ ) due to having an incomplete observation window.

#### Outcome

Retention (specifically, lack of retention) was measured by number of missed HIV primary care visits, categorized as 0, 1–2, or 3+ visits. A *missed* visit is one that was *not* cancelled by the patient or provider at any point prior to the scheduled visit. Number of visits was captured for the 12-month observation window, January 1, 2016 and December 31, 2016.

#### Predictors

Certain patient-reported demographic measures were hypothesized to be correlated with lack of retention (i.e.,

increased number missed visits) based on known correlates of retention in the literature discussed above [2, 11, 13, 15–18]. These demographic measures included a continuous variable, age, and categorical variables for biologic sex (reference category: female), race [black or African American, white (reference category), other], highest education obtained [less than high school (reference category), high school or GED, college, some college, college or higher].

Socioeconomic measures: RWHAP support services [yes, no (reference category)]; primary healthcare payer type [RWHAP, public insurance, private insurance, none (reference category)], and poverty [below federal poverty level (FPL)/at or above FPL (reference category)]. The poverty measure was based on self-reported monthly income, and it was created using the 2016 Poverty Guidelines for the 48 Contiguous States and the District of Columbia [19]. We did not have information on patients' marital status or household size; therefore, we used the most conservative poverty guideline (i.e., a one-person household), and provided monthly income values too.

## Statistical Analysis

Descriptive cross-sectional statistics for independent and dependent variables, including means, standard deviation, frequencies, and percentages, were conducted (Table 1). Bivariate (Table 2) and multivariable (Table 3) multinomial logistic regressions were conducted to compare factors associated with missing 1–2 versus 0 visits, 3+ versus 0 visits, and 3+ versus 1–2 visits using RRs. A risk ratio (RR) describes the relative risk of experiencing a health event between two or more groups:  $RR = 1$  means that all groups have equal risk of experiencing the event;  $RR < 1$  means that the reference group has a higher risk of experiencing the event; and  $RR > 1$  means that the reference group has a lower risk of experiencing the event [20].

A significance level ( $\alpha$ ) of  $p < 0.05$  was used. All analyses were conducted using Stata 15.

## Results

Sociodemographic characteristics are presented in Table 1. The range of scheduled HIV primary care visits was between 1 and 11 [mean = 3.01; standard deviation (SD) = 1.43], and the range of missed HIV primary visits was between 0 and 8 (mean = 0.71; SD = 1.13). The percentage of missed visits ranged from 0 to 100%, with a mean of 16% missed visits (SD = 23%). Patients had a mean age of 44 and were predominantly male (72.0%) and black or African American (77.4%), had a high school education (52.4%), had private health insurance (56.9%), and did not miss any scheduled visits (100% retention–60.5%). The mean monthly income

**Table 1** Retention of 1159 patients in primary HIV care at a south-eastern US HIV/AIDS clinic in 2016

Characteristic	Mean (SD); median/ range or frequency (%)
Scheduled visits in 2016	3.01 (1.43); 3 1–11
Retention: missed visits (continuous)	0.71 (1.13); 0 0–8
Percent missed	16% (23%); 0% 0–100%
Missed visits (categorical)	
0	701 (60.5)
1–2	362 (31.2)
3+	96 (8.3)
Primary payer type	
Private	659 (56.9)
Public	379 (32.7)
RWHAP	44 (3.8)
None	77 (6.6)
Ryan white HIV/AIDS program support services	
Yes	525 (45.3)
No	634 (54.7)
Highest education level obtained	
Less than high school	264 (22.8)
High school	607 (52.4)
Some college	190 (16.4)
College or higher	98 (8.5)
Sex	
Male	835 (72.0)
Female	324 (28.0)
Race	
Black/African American	897 (77.4)
White	221 (19.1)
Other	41 (3.5)
Poverty	
Below federal poverty level	699 (60.3)
At or above federal poverty level	460 (39.7)
Monthly income (US dollars)	\$963.77 (\$804.86); 781 \$0–\$5,572
Age (years)	44 (12.5); 45 20–83

was \$804.86. More than half (60.3%) of PLWH lived below the federal poverty level, and less than half (45.3%) received support services from the RWHAP.

Bivariate multinomial logistic regression analyses revealed significant RRs for missed visits (Table 2). The only factor associated with missing 3+ versus 1–2 visits was poverty. Compared to PLWH living at or above the federal poverty level, PLWH living below the federal poverty level had over twice the risk of missing 3+ versus 1–2 visits ( $RR = 2.45$ , 95% CI 1.39–4.32). Factors associated with

**Table 2** Bivariate RRs for missed visits with 95% confidence intervals (CIs)

Characteristic	Missing 1–2 versus 0 visits		Missing 3+ versus 0 visits		Missing 3+ versus 1–2 visits	
	RR (95% CI)	<i>p</i>	RR (95% CI)	<i>p</i>	RR (95% CI)	<i>p</i>
Primary payer type						
Uninsured (no RWHAP)						
Referent						
Private insurance	0.43 (0.26–0.71)	<b>0.001</b>	2.74 (1.27–5.91)	<b>0.01</b>	1.17 (0.54–2.54)	0.69
Public insurance	0.57 (0.33–0.96)	<b>0.03</b>	1.94 (0.88–4.30)	0.10	1.10 (0.49–2.45)	0.82
RWHAP	0.54 (0.24–1.22)	0.14	1.51 (0.46–4.99)	0.50	0.82 (0.24–2.85)	0.76
RWHAP support services						
Yes						
Referent						
No	1.31 (1.01–1.69)	<b>0.04</b>	1.41 (0.91–2.18)	0.12	0.93 (0.58–1.47)	0.74
Highest education level obtained						
< High school						
Referent						
High school/GED	0.70 (0.51–0.96)	<b>0.03</b>	1.0 (0.61–1.68)	0.97	0.71 (0.42–1.20)	0.20
Some college	0.60 (0.40–0.90)	<b>0.01</b>	3.15 (1.31–7.57)	<b>0.01</b>	1.90 (0.77–4.68)	0.16
≥ College	0.23 (0.12–0.43)	<b>&lt; 0.001</b>	4.73 (1.38–16.20)	<b>0.01</b>	1.09 (0.29–4.06)	0.90
Sex						
Female						
Referent						
Male	1.02 (0.77–1.35)	0.91	0.89 (0.55–1.45)	0.65	0.91 (0.55–1.52)	0.72
Race						
White						
Referent						
Black/African American	1.49 (1.06–2.09)	<b>0.02</b>	0.60 (0.33–1.09)	0.09	0.89 (0.47–1.69)	0.73
Other	0.88 (0.40–1.91)	0.74	0.21 (0.03–1.59)	0.13	2.46 (0.29–20.82)	0.41
Poverty						
At or above FPL						
Referent						
Below FPL	1.57 (1.21–2.05)	<b>0.001</b>	3.86 (2.24–6.65)	<b>&lt; 0.001</b>	2.45 (1.39–4.32)	<b>0.002</b>
Age (in years)	0.97 (0.96–0.98)	<b>&lt; 0.001</b>	1.04 (1.02–1.06)	<b>&lt; 0.001</b>	1.01 (0.99–1.03)	0.25

Bold values are statistically significant ( $p < 0.05$ )

RWHAP ryan white HIV/AIDS program, FPL federal poverty level

missing any visits (either 1–2 or 3+) were younger age, poverty, being uninsured (as opposed to having private or public insurance), and not having at least a high school degree.

There were also several factors associated with missing 1–2 compared to 0 visits: not receiving RWHAP support services (RR = 1.31, 95% CI 1.01–1.69) being black or African American as compared to white (RR = 1.49, 95% CI 1.06–2.09), and not having public or private insurance as compared to being uninsured (patients with private insurance had 0.43 times the risk of missing 1–2 versus 0 visits [95% CI 0.26–0.71]; patients with public insurance had 0.57 times the risk [95% CI 0.33–0.96].

In the full multivariable model, several socioeconomic and demographic characteristics remained significantly associated with missing either 1–2 or 3+ visits (vs. 0 missed visits–100% retention), including poverty, lack of RWHAP

support services, not having at least a high school degree, and being younger. Compared with uninsured patients, patients with private insurance had half the risk of missing 1–2 versus 0 visits (RR = 0.48, 95% CI 0.28–0.83). As in the bivariate model, only poverty remained predictive of missing 3+ versus 1–2 visits (RR = 2.70, 95% CI 1.49–4.88). In a separate multivariable model (not shown), we confirmed that patients' number of scheduled visits was not significantly associated with number of missed visits.

## Discussion

Findings suggest that patients at risk for missing 3+ visits present similar characteristics of those patients who miss 1–2 visits, and thus underscore that poverty reduction,

**Table 3** Multivariable RRs for missed visits with 95% CIs

Characteristic	Missing 1–2 versus 0 visits		Missing 3+ versus 0 visits		Missing 3+ versus 1–2 visits	
	RR (95% CI)	<i>p</i>	RR (95% CI)	<i>p</i>	RR (95% CI)	<i>p</i>
Primary payer type						
Uninsured (no RWHAP)						
Referent						
Private insurance	0.48 (0.28–0.83)	<b>0.01</b>	0.46 (0.20–1.06)	0.07	1.04 (0.46–2.36)	0.92
Public insurance	0.67 (0.37–1.19)	0.17	0.61 (0.25–1.47)	0.27	1.09 (0.46–2.62)	0.84
RWHAP	0.70 (0.30–1.64)	0.41	0.99 (0.28–3.57)	0.99	0.70 (0.19–2.54)	0.59
RWHAP support services						
Yes						
Referent						
No	1.48 (1.12–1.96)	<b>0.006</b>	1.83 (1.12–2.97)	<b>0.02</b>	0.81 (0.49–1.34)	0.42
Highest education level obtained						
< High school						
Referent						
High school/GED	0.71 (0.51–0.98)	<b>0.04</b>	1.05 (0.62–1.81)	0.85	0.67 (0.39–1.16)	0.15
Some college	0.58 (0.40–0.89)	<b>0.01</b>	0.32 (0.13–0.80)	<b>0.02</b>	1.81 (0.72–4.56)	0.21
≥ college	0.30 (0.16–0.58)	<b>&lt;0.001</b>	0.39 (0.11–1.42)	0.15	0.76 (0.19–2.99)	0.70
Sex						
Female						
Referent						
Male	1.03 (0.76–1.40)	0.86	1.15 (0.68–1.93)	0.60	0.89 (0.52–1.53)	0.68
Race						
White						
Referent						
Black/African American	1.22 (0.85–1.74)	0.28	1.27 (0.68–2.39)	0.46	0.96 (0.50–1.84)	0.89
Other	0.60 (0.25–1.42)	0.24	0.19 (0.02–1.66)	0.08	3.10 (0.34–28.12)	0.32
Poverty						
At or above FPL						
Referent						
Below FPL	1.37 (1.03–1.82)	<b>0.03</b>	3.69 (2.07–6.57)	<b>&lt;0.001</b>	2.70 (1.49–4.88)	<b>0.001</b>
Age (in years)	0.97 (0.96–0.98)	<b>&lt;0.001</b>	0.96 (0.94–0.97)	<b>&lt;0.001</b>	1.01 (0.99–1.03)	0.20

Bold values are statistically significant ( $p < 0.05$ )

RWHAP ryan white HIV/AIDS program, FPL federal poverty level

increased access to education, and increased access to health insurance and RWHAP support services are interventions with potential to improve HIV care retention, and ultimately mortality risk, by decreasing number of missed visits [9–11]. These interventions are supported by our findings showing that PLWH who achieved 100% retention (no missed visits) were more likely to live above the federal poverty level, have more years of formal education, and receive RWHAP support services. Certain characteristics were associated with poorer retention, such as being younger, and not having at least a high school degree.

Our most noteworthy finding suggests that patients at risk for missing 3+ visits, and who may have been at higher mortality risk according to the literature [10], were not so different from patients who missed 1–2 visits, in either the bivariate or multivariable models. This finding is

particularly relevant in terms of its potential to inform clinical interventions aimed at increasing retention, as patients at risk for missing any visits may benefit. For example, a multisite randomized controlled trial tested an “enhanced personal contact” intervention (PLWH received initial face-to-face meeting with interventionist and social support and appointment reminders throughout the year), and it helped to improve number of visits consistent across race, age, sex, insurance, and baseline clinical differences [21]. Interventions like this one may be useful to all patients at risk for missed visits.

Black or African American identity was associated with poor retention (missed visits) in previous studies [2, 13]. However, it did not retain significance in our current multivariate model. A sensitivity analysis (results not shown) revealed that the inclusion of the education variable

attenuated the effect of race, which demonstrates the importance of increasing access to education as an upstream determinant of retention in care. For example, evidence-based programs that maintain engagement of youth in high school (e.g., alternative schooling, attendance monitoring) [22], as well as those that increase access to higher education (e.g., financial aid programs), [23] may increase later retention in care. Research suggests that providing culture- and age-appropriate HIV health education to PLWH using web- and app-based technology may increase ART adherence and retention among older [24] and younger [25] PLWH. Pictograph adherence counseling has also been shown to increase ART adherence among adult PLWH with marginal health literacy (defined as scoring between 85 and 90% correct on the Test of Functional Health Literacy scale) in a randomized trial [26].

RWHAP support services were significantly associated with good retention. This finding corresponds with previous studies, showing that the RWHAP-related services, such as case management and transportation assistance, are good predictors of retention in HIV care [27–30]. Health insurance remained unassociated with missed visits in the multivariable model. This finding further highlights the importance of having RWHAP. Poverty remained associated with poor retention even though several socioeconomic status variables, including healthcare type and education level, were included. It is likely that an unmeasured variable associated with poverty, perhaps reduced access protective factors such as social capital, affected retention [31]. Previous research suggests that these and other unmet needs may reduce the impact of interventions aimed at improving retention [31, 32].

### Limitations

Our sample included categories for biologic sex rather than gender; therefore, we were unable to account for transgender individuals. The analytic sample was anchored to PLWH who had at least one attended visit in the previous year, so PLWH without clinic attendance in 2015 were excluded from analysis. Our sampling strategy was intended to include PLWH who were more active in care during the observation window. We submit that it may have contributed to a smaller percentage of PLWH who missed 3+ visits. We measured attendance over a 1-year time period and could not capture temporal trends; future research is needed to assess visit attendance over time. The demographics and socioeconomic variables used in the sample represent but a few characteristics. Our definition of poverty likely underestimates the rate of poverty within the sample since we did not have information about household size and, therefore, used the most conservative poverty guideline of a one-person household. Also, more research is needed to identify the aspects of the

RWHAP that facilitate visit attendance, as we were unable to identify which specific RWHAP support services that patients received. Clearly, there is a need for research to advance this area of inquiry. Our sample represents patients in one HIV/AIDS clinic in one southeastern state; therefore, the findings may not be generalizable to PLWH at other clinics or in other states/regions.

### Conclusion

Based on our findings that PLWH who missed 3+ visits were not unique from PLWH who missed 1–2 visits, we recommend that interventions aimed at improving visit attendance identify PLWH with any missed visits. PLWH who had any missed visits were more likely to have certain characteristics, including living below the federal poverty level, younger age, lack of a high school degree, and lack of RWHAP support services. These findings underscore the importance of increased access to education, increased access to health insurance and supplementary support services, and poverty reduction strategies to increase HIV care retention among PLWH. Though PLWH experiencing poverty would likely benefit from these efforts the most, it is also important to consider the accessibility of support services, especially for disadvantaged or marginalized PLWH. A social justice perspective, which would consider HIV primary care visit attendance an indicator of resource availability and accessibility as well as clinical health, is needed.

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