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An Interrupted Continuum of Care? What are the Risk Factors and Comorbidities Related to Long-Term Engagement and Retention in HIV Care?

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Abstract

Despite the importance of continuous care, a large proportion of persons with HIV are not engaged or retained in care at any one time, leading to poor outcomes. Identifying the risk factors associated with lack of engagement and retention in HIV care is needed in order to target patients for interventions. While both engagement and retention in care have been studied using multiple measures, the observation period for the majority of studies is less than one year, few studies have examined both initial engagement and retention, and the effect of comorbidities has typically not been included. This study extends the literature by examining how comorbidities, in addition to demographics, HIV clinical indicators and transmission risk factors, were associated with engagement and retention in a cohort study of 485 HIV-infected persons seen for an initial HIV visit at an urban safety-net hospital. Using the electronic medical record, demographic, risk factor, health status and comorbidity data were gathered at the time of initial visits. To measure engagement and retention, appointment data were obtained for a 24-month period following the initial visit. Key findings were that unknown HIV transmission risk factor and being homeless at initial visit were associated with both lack of engagement and retention. Conversely being diagnosed with a psychiatric disorder was predictive of retention. Our findings have important implications for program structure, including the integration of care, as well as regarding key components to be addressed holistically in early clinic visits.

Keywords: HIV; Safety net providers; Continuity of care; Care models

Introduction

Widespread access to combination antiretroviral therapy (cART) has transformed HIV into a chronic, manageable disease, drastically lowering HIV-related morbidity and mortality [1-4].Yet recent estimates suggest that little over half of those diagnosed with HIV may be engaged in and retained in care at any one time [5-9]. Studies have shown that HIV-infected persons who are not consistently engaged in care have only intermittent access to cART or to other medical and psychiatric services, and consequently have poorer outcomes including greater numbers of hospitalizations and increased mortality [1,2,6,10,11] Moreover, from a public health perspective, individuals without regular access to cART may continue to transmit HIV in the community due to ongoing viremia [1,11,12]. Therefore, identifying the risk factors associated with inability to initially engage in as well as stay in HIV care is needed in order to target patients for interventions that can ultimately lead to improved clinical status, lower mortality, and reduced transmission of disease [6,9,13,14].

Studies of participation in HIV care are complicated with patients often demonstrating care patterns that include cycling in and out of care over time [15]. The literature contains a range of measures of engagement and retention [16,17]; however, the observation period for the majority of studies is less than one year, a small interval for assessing retention in care for a disease that requires chronic lifetime management [9]. Moreover, only a small number of studies have examined both initial engagement and ongoing retention in HIV care simultaneously [6,8]. In addition, while many studies of engagement and retention have included HIV clinical indicators and transmission risk factors, comorbidities have typically not been included. The current study extends the literature by examining how comorbidities, in addition to demographics, HIV clinical indicators and transmission risk factors, are associated with engagement and retention in a single clinic cohort study of HIV-infected persons seen for care at an urban safety-net hospital over a 24 month-period. Information available from single sites allows for more detailed knowledge of patients and of the care received [19], including comorbid health conditions frequently present in HIV-infected persons. In this study, we first examined demographic, clinical, and comorbidity characteristics of patients who successfully engaged in care delivery compared to those who failed to initially engage. We expected that patients who were never engaged in care would have unique factors affecting their probability of engagement. Moreover, these factors would be different from those associated with patients who had been initially engaged in care to

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experience an interruption in the future. Hence in a second step, we identified which of these characteristics were associated with longer-term retention in care.

Methods

Data source and study sample

We conducted a retrospective cohort study of patients new to care at the HIV clinic of a large urban medical center located in the northeast U.S. Data on demographic and clinical characteristics of patients were drawn from electronic medical records (EMR) collected at the medical center. Patients were eligible for inclusion in the study if they were HIV-positive and were seen for an initial visit for HIV primary care with a physician in the clinic between April 1, 2007 and September 1, 2010. Patients were identified as new to care if they had no prior visits to the clinic or had not had a visit with a physician to the clinic in the three years prior to the initial visit. The window of observation on each patient was 24 months, beginning at the date of the initial visit. The patient cohort consisted of 485 individual patients. HIV care in this study was operationalized as attendance at HIV primary care visits, a commonly used method in prior studies [2,4,17]. As described below, we then used different measures of time and number of appointments kept to define engagement and retention in care.

Definitions of outcome variables

For our initial analyses, the outcome variable was engaged in care. In our cohort, we observed different overall utilization patterns within the first three months of initiating care, and we therefore created the engaged in care variable according to utilization during the first three months of care. We coded patients as engaged if they had at least one follow-up visit with a physician in the first three months of their observation period in addition to the initial physician visit. Patients who did not return for care within three months of the initial visit were coded as not engaged.

The second outcome variable was retention in care. We applied one definition used in previous literature to create the retention in care variable, defining a gap in care (not retained) as 180 days or more occurring between two primary care visits [20]. If there was a period of time during the 24-month observation period in which a patient had more than 180 days between two visits, that patient was recorded to have a significant interruption or a "gap" in care.

Covariates

Covariates included several demographic variables: age, gender, race/ethnicity, housing status, and self-reported HIV transmission risk category. Transmission risk categories included heterosexual, men who have sex with men (MSM), intravenous drug use (IDU, including MSM IDU), other risk, and unknown risk. Clinical covariates consisted of three HIV-related variables: CD4 cell count, detectable viral load (VL) (>200), and whether the patient indicated being on cART at the initial visit. In terms of comorbid conditions, we included indicator variables for comorbidities frequently present in HIV-infected persons: the presence of an AIDS-defining illness (ADI); sexually transmitted infections (STI); psychiatric conditions including depression, mood and anxiety disorders and cognitive impairment; substance abuse disorders and hepatitis (A, B or C). Other specific health conditions included as an any other comorbidity variable included cancer, cardiovascular disease, diabetes, pulmonary disease and renal disease. All covariates were based on data available at the index HIV primary care visit.

Statistical analysis

In order to determine factors associated with engagement in care, we conducted bivariate analyses using chi-square tests or t-tests for continuous variables. Next, we used multivariable logistic regression analysis, controlling for all characteristics simultaneously, to predict engagement in care. Our second analysis focused on identifying those characteristics that predicted retention in care. Using "no six month gaps in care" as the outcome variable measuring retention in care, we repeated the bivariate and multivariable analyses. We compared patients who had no gaps in care to those who had at least one gap in care in the bivariate models, and performed logistic regression to predict the probability of retention in care. We also conducted sensitivity analyses using several different gap-in-care models. All analyses were performed using the statistical software Stata (Version 12). The study was approved by the Boston University Medical Center Institutional Review Board.

Results

Description of the study sample

Among the 485 patients studied, the majority were male (58%) and persons of color, including 55% Black and 21% Latino/a. The sample had a mean age of 42. The cohort were housed at the time of enrollment (82%) although 17% indicated being homeless. The most common HIV risk category was heterosexual transmission (48%), followed by 22% identifying as men who have sex with men (MSM) and 18% injection drug use (IDU). Notably, the transmission risk factor of 8% of patients was unknown at the time of initial visit. In terms of comorbidities commonly considered "related" to HIV, 5% were documented to have an AIDS-defining illness (ADI), 11% a sexually transmitted infection (STI), 8% hepatitis (A, B or C), 12% a psychiatric disorder, and 11% a substance use disorder. In addition, 18% were documented as having at least one additional health condition, as defined above. Most patients were not on cART at their first visit (62%). Only 20% had an undetectable viral load at initial visit and 12% had a CD4 count below 200 ml/copy at that time. Additionally, the CD4 counts and VLs were unknown for over 40% of the overall sample.

Engagement in care

Overall, 397 (82% of the full cohort) established care according to our measure of engagement. Table 1 presents the results of bivariate analyses comparing the 397 engaged patients with the 88 patients (18%) who were not engaged within three months after the initial visit. The two groups did not vary significantly on age, gender, or race. However, there was a significant difference in housing status: among those not engaged in care, 30% were homeless compared to 14% of engaged patients ($p<0.01$). HIV transmission risk factor also differed statistically between the two groups, notably for the categories heterosexual (51% engaged compared to 35% not engaged), IDU (17% engaged compared to 23% not engaged), and unknown (7% engaged compared to 15% not engaged) ($p=0.01$). Among the HIV-related clinical variables, the groups differed according to whether they were on cART and the presence of detectable VL at initial visit. The not engaged group had both a higher proportion of individuals on cART (48% compared to 35%, $p=0.03$) and with undetectable VL (31% compared to 18%, $p<0.01$). In terms of comorbidities, patients with a history of ADIs at

'Characteristic	Not Engaged (n=88)		Engaged (n=397)		p-value*
	n	%	n	%	
Female	37	42%	165	42%	0.93
Male	51	58%	232	58%	
White	24	27%	78	20%	0.27
Other/ Unknown Race	2	2%	10	3%	
Black	41	47%	226	57%	
Hispanic	21	24%	83	21%	
Housing	61	69%	339	85%	<0.01
Homeless	26	30%	56	14%	
Unknown Housing	1	1%	2	1%	
Heterosexual	31	35%	204	51%	0.01
Other Risk	5	6%	11	3%	
Unknown Risk	13	15%	26	7%	
MSM	19	22%	90	23%	
IDU (incl MSM IDU)	20	23%	66	17%	
Mean age	40.5	NA	42.4	NA	0.13
On ART Baseline	42	48%	140	35%	0.03
VL undetectable	27	31%	72	18%	0.01
VL detectable	23	26%	153	39%	
VL unknown at first visit	38	43%	172	43%	
CD4 over 200	40	45%	166	42%	0.80
CD4<200	11	13%	49	12%	
CD4 unknown at first visit	37	42%	182	46%	
ADI	9	10%	16	4%	0.02
Hepatitis A, B, or C	11	13%	26	7%	0.06
Other Medical Comorbidity	16	16%	72	18%	0.62
Psychiatric Disorder	12	14%	47	12%	0.64
STI	14	16%	39	10%	0.10
Substance Use Disorder	10	11%	44	11%	0.94
*P-value calculated using either $\chi 2$ test or, for variables with expected cell counts ≤ 5, Fisher's Exact test. The exception was age, a continuous measure, where a student's t-test was used to calculate the p-value. The n column for mean age is the mean age for that patient group.					

Table 1: Characteristics of Patients Engaged and Not Engaged in Care (n=485).

baseline were less likely to engage in care than patients without ADIs (10% compared to 4%, p=0.02).

Table 2 presents the results of the logistic regression in which ***engaged in care*** is the outcome variable. Older age was associated with higher odds (1.03) of engagement (95% CI, 1.01-1.06; p=0.02). Persons with a detectable VL were more than twice as likely (2.64) to be engaged in care (95% CI, 1.18—5.94; p=0.02) than those with an undetectable VL. Persons with an unknown transmission risk category had substantially lower odds of engagement: (0.43) (95% CI, 0.19-1.01; p=0.05) relative to those whose transmission risk was heterosexual. Homelessness was also associated with lower odds (0.49) of engagement (95% CI, 0.26-0.92; p=0.03). Among comorbidities, only the presence of an ADI was associated with engagement, as persons with ADIs were less likely (0.37) to be engaged in care (95% CI, 0.13-1.01; p=0.05).

Retention in care

Table 3 presents results for bivariate analyses comparing individuals who were retained (no gap in care) with those who were not retained (had any gap in care). In terms of retention, 27% of the sample (n=130) was fully retained over the 24-month period of review, while 73% (n=355) had at least one gap in care. The retained and not retained groups were significantly different in terms of housing status, transmission risk factor, presence of a psychiatric disorder, and CD4 count and VL at initial visit. Persons who were homeless were more likely to have a gap in care (20% of not retained compared to 9% of retained, p=0.001), and persons with an unknown transmission risk factor were also more likely not to be retained (10% compared to 2% of retained, p=0.01). Persons whose viral load was unknown at the initial visit were more likely to be retained (52% compared to 40%, p=0.03), as were persons with an unknown CD4 count (55% compared to 41%, p=0.01). Finally, having a psychiatric disorder documented in the EMR was associated with retention (17% compared to 10%, p=0.05).

In Table 4, we present the results of the multivariable logistic regression with the outcome of ***retention*** (no gap in care). Housing status, transmission risk factor and psychiatric diagnosis were statistically significant. Individuals who were homeless had less than half the odds (0.43) of being retained in care than those who were housed (95% CI, 0.21-0.89; p=0.02) and persons with an unknown transmission risk factor (0.18; 95% CI, 0.05-0.64; p=0.01) were far less likely to be retained in care compared to those with heterosexual risk. Persons diagnosed with a psychiatric disorder were almost three times more likely (2.65) to be retained in care compared to those without a psychiatric disorder (95% CI, 1.27-5.51; p=0.01). Results of sensitivity analysis using different gap-in-care models yielded similar results to those reported in Tables 3 and 4.

Characteristic	Engaged			
	OR	p-value	95% CI	
Female	1.00	Ref.		
Male	1.05	0.86	0.58	1.90
White	1.00	Ref.		
Other/Unknown Race	1.59	0.59	0.30	8.48
Black	1.25	0.52	0.63	2.49
Hispanic	1.18	0.67	0.56	2.50
Housing	1.00	Ref.		
Homeless	0.49	0.03	0.26	0.92
Unknown Housing	0.43	0.53	0.03	5.88
Heterosexual	1.00	Ref.		
Other Risk	0.33	0.08	0.09	1.12
Unknown Risk	0.43	0.05	0.19	1.01
MSM	0.85	0.69	0.38	1.90
IDU (incl MSM IDU)	0.63	0.24	0.29	1.37
On ART Baseline	0.96	0.90	0.53	1.76
Age	1.03	0.02	1.01	1.06
VL undetectable	1.00	Ref.		
VL detectable	2.64	0.02	1.18	5.94
VL unknown at first visit	1.10	0.87	0.37	3.24
CD4 over 200	1.00	Ref.		
CD4<200	0.76	0.52	0.33	1.75
CD4 unknown at first visit	1.77	0.27	0.65	4.80
ADI	0.37	0.05	0.13	1.01
Medical Comorbidities 1+	1.05	0.89	0.49	2.25
Hepatitis A, B, or C	0.56	0.23	0.22	1.45
Psychiatric Disorder	0.83	0.67	0.36	1.94
STI	0.66	0.30	0.31	1.44
Substance Use Disorder	2.13	0.14	0.78	5.82

Table 2: Predictors of Engagement in Care (n=485).

Characteristic	Retained (n=130)		Not Retained (n=355)		p-value*
	n	%	*n*	%	
Female	56	43%	146	41%	0.70
Male	74	57%	209	59%	
White	23	18%	79	22%	0.62
Other/Unknown Race	2	2%	10	3%	
Black	75	58%	192	54%	
Hispanic	30	23%	74	21%	
Housing	117	90%	283	80%	0.01
Homeless	12	9%	70	20%	
Unknown Housing	1	1%	2	1%	
Heterosexual	71	55%	164	46%	0.01
Other Risk	2	2%	14	4%	
Unknown Risk	3	2%	36	10%	
MSM	35	27%	74	21%	
IDU (incl MSM IDU)	19	15%	67	19%	
Mean age	41.1	NA	42.1	NA	0.36
On ART Baseline	49	38%	133	37%	0.94
VL undetectable	19	15%	80	23%	0.03
VL detectable	43	33%	133	37%	
VL unknown at first visit	68	52%	142	40%	
CD4 over 200	40	31%	166	47%	0.01
CD4<200	18	14%	42	12%	
CD4 unknown at first visit	72	55%	147	41%	
ADI	7	5%	18	5%	0.89
Hepatitis A, B, or C	31	9%	6	5%	0.13
Medical Comorbidities 1+	62	17%	24	18%	0.80
Psychiatric Disorder	22	17%	37	10%	0.05
STI	16	12%	37	10%	0.56
Substance Use Disorder	11	8%	43	12%	0.26

* P-value calculated using either $\chi 2$ test or, for variables with expected cell counts ≤ 5, Fisher's Exact test. The exception was age, a continuous measure, where a student's t-test was used to calculate the p-value. The n column for mean age is the mean age for that patient group.

Table 3: Characteristics of Patients Retained and Not Retained in Care (n=485).

Discussion

In this study, we examined both early engagement (two visits within the first three months) and long-term retention (no care gap of greater than 180 days over 24 months) in care among patients initiating care at an HIV clinic within a safety net urban medical center. While the large majority of patients initially engaged in care based on our definition of engagement, we found that having an unknown HIV transmission risk and having an AIDS-defining illness documented at baseline were associated with lack of engagement. When we examined retention over 24 months after the initial visit, however, just over one-quarter of patients had been fully retained. In terms of retention, housing status and HIV transmission risk factor were significant, with homeless persons and persons for whom HIV transmission risk factor was unknown less likely to be retained. Conversely, being diagnosed with a psychiatric disorder was predictive of retention over 24-month observation period.

As expected with the overall life instability that can be intrinsic to homelessness and has been shown in other reports to be negatively associated with participation in HIV care [21-24] patients identified in this study as being homeless were less likely to be successfully retained in care. The lack of engagement and retention associated with an unknown HIV transmission risk factor raises the question of whether not endorsing transmission risk that may actually be a surrogate for some other factor that is creating barriers to engagement and retention. This highlights that more intensively exploring risk group with patients at initial visit, while potentially off-putting for some, could also serve to identify areas for intervention.

The higher level of engagement among patients with detectable VL at baseline was unexpected, as detectable VL is typically indicative of not being on cART and thus not being engaged in care. However, our finding raises the possibility that if a patient has an undetectable viral load at baseline and thus is likely already on cART, he/she may be presumably transitioning care from another clinical site, which is widely known to create high potential for disruption in continuity of care [19,25,26] While these patients may ultimately choose to return to care at the prior site, there is also the implicit risk that they may not return to care at the prior site or effectively engage at a new care site, illustrating the vulnerable time period of care transitions as an important yet not previously highlighted aspect of the HIV care continuum. However, our findings may simply be reflective of the high proportion of patients with unknown VL at baseline, many of whom could actually have a detectable VL. Either way, our findings point out the importance of intervening with all patients arriving for initial care, including those transitioning care, whether or not their VL is detectable and ensuring that all patients are maintained in care over time.

We also found that having a psychiatric diagnosis was protective in terms of retention in care. This may be due in part to the need

	Retention			
Variable	OR	p-value	95% CI	
n=485				
Female	1.00	Ref.		
Male	0.84	0.51	0.50	1.41
White	1.00	Ref.		
Other/Unknown	0.55	0.47	0.11	2.81
Black	1.32	0.40	0.69	2.50
Hispanic	1.41	0.34	0.70	2.84
Housing	1.00	Ref.		
Homeless	0.43	0.02	0.21	0.89
Unknown Housing	1.18	0.90	0.08	16.37
Heterosexual	1.00	Ref.		
Other Risk	0.23	0.07	0.05	1.13
Unknown Risk	0.18	0.01	0.05	0.64
MSM	1.26	0.48	0.66	2.44
IDU (incl MSM IDU)	1.10	0.79	0.55	2.23
Age	1.30	0.30	0.79	2.16
On ART Baseline	0.99	0.26	0.97	1.01
VL undetectable	1.00	Ref.		
VL detectable	1.20	0.62	0.57	2.52
VL unknown at first visit	1.12	0.82	0.43	2.89
CD4 over 200	1.00	Ref.		
CD4<200	1.67	0.16	0.81	3.41
CD4 unknown at first visit	2.09	0.07	0.94	4.65
ADI	1.36	0.56	0.49	3.83
Medical Comorbidities 1+	0.91	0.78	0.48	1.74
Hepatitis A, B, or C	0.75	0.59	0.26	2.13
Psychiatric Disorder	2.65	0.01	1.27	5.51
STI	1.11	0.77	0.55	2.24
Substance Use Disorder	0.54	0.20	0.22	1.37

Table 4: Predictors of Retention in Care (n=485).

for individuals with psychiatric disorders to maintain connection to services in order to maintain their mental health, as well as to the ability of the multidisciplinary medical home model in this clinic (co-located primary care, case management, mental health treatment, and support services) to address their needs. A medical home that includes integrated behavioral health services may be one of the strongest impetuses for patients to continue to return to care.

This study has several limitations. First, it is based on data from a single institution and therefore may not be generalizable. However, the single institution evaluated is of interest as a large urban safety net medical center and the findings may be relevant to other safety net institutions. Second, in order to make comparisons between groups, it was necessary to use only the data available at the baseline visit which meant that a large proportion of CD4 and VL data were unknown, and some comorbidities may not become apparent until follow-up visits. Third, in using any sample drawn from a health care setting there may be selection bias. Our sample was selected from patients who made an initial clinic visit and this may have underestimated the challenges faced by individuals who cannot even make that initial visit. Finally, as the electronic medical record is from a single institution, it does not allow us to track other locations where patients might receive care. This could lead us to believe that some patients have dropped out of care when they actually have changed their location of care.

Despite these limitations, important knowledge can be gained from this study. We found specific factors that can be identified at an initial clinic visit that are associated with a lack of engagement in care and as well as a lack of retention over time. These findings have important implications for the content of an initial HIV visit and the development of care models, such as the importance of probing related to transmission risk factor, the strength of co-location of mental health and general health care. This investigation has also identified a potentially risky time point on the HIV care continuum, the period of transitions between care sites that has not been previously well-explored. Yet our findings may indicate the need for a special focus when patients are experiencing care disruption in order to assure successful engagement in care. Developing a system at the initial patient visit to thoroughly identify and mitigate factors that put patients at greatest risk for poor engagement and/or retention in care may be an important step, and is consistent with the imperative for the development of the medical home espoused by the Affordable Care Act (ACA) of 2012. The medical home model with the use of a multi-disciplinary team dedicated to addressing behavioral health and case management issues integrated into a primary care clinic has the potential to provide enhanced intake and address needs that may otherwise lead to poor outcomes for individuals at the highest risk. This is also is consistent with findings regarding the value of integrated care for high-risk populations, particularly those with limited social stability [27-30]. Patients with complex psychiatric and social issues may not always view their medical care as a key priority in an otherwise extremely complicated life, particularly if they are feeling well. Having behavioral health care and case management as core services within an HIV clinic may mean that patients are more likely to receive care for both their medical and mental health issues and may motivate such patients to consistently "come home" to effectively address these potentially destabilizing issues, while simultaneously receiving HIV-specific medical services vital for their long term physical health and well-being.

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