Clinic-Level Factors Associated With Retention in Care Among People Living With Human Immunodeficiency Virus in a Multisite US Cohort, 2010–2016

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Background. Retention in care (RIC) leads to reduced HIV transmission and mortality. Few studies have investigated clinic services and RIC among people living with HIV (PLWH) in the United States. We conducted a multisite retrospective cohort study to identify clinic services associated with RIC from 2010–2016 in the United States.

Methods. PLWH with ≥1 HIV primary care visit from 2010–2016 at 7 sites in the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) were included. Clinic-level factors evaluated via site survey included patients per provider/trainee, navigation, RIC posters/brochures, laboratory test timing, flexible scheduling, appointment reminder methods, and stigma support services. RIC was defined as ≥2 encounters per year, ≥90 days apart, observed until death, administrative censoring (31 December 2016), or loss to follow-up (censoring at first 12-month interval without a visit with no future visits). Poisson regression with robust error variance, clustered by site adjusting for calendar year, age, sex, race/ethnicity, and HIV transmission risk factor, estimated risk ratios (RRs) and 95% confidence intervals (CIs) for RIC.

Results. Among 21 046 PLWH contributing 103 348 person-years, 67% of person-years were retained. Availability of text appointment reminders (RR, 1.13; 95% CI, 1.03–1.24) and stigma support services (RR, 1.11; 95% CI, 1.04–1.19) were associated with better RIC. Disparities persisted for age, sex, and race.

Conclusions. Availability of text appointment reminders and stigma support services was associated with higher rates of RIC, indicating that these may be feasible and effective approaches for improving RIC.

Keywords. HIV; retention; clinic; stigma support; text reminders.

It is estimated that almost 1 million people are living with human immunodeficiency virus (HIV) in the United States currently [1]. Due to the availability of effective combination antiretroviral therapy (ART), people living with HIV (PLWH) are living longer and experiencing higher-quality lives [1]. In 2019, the US Department of Health and Human Services proposed the "Ending the HIV Epidemic (EtHE): A Plan for America" initiative, which has a primary pillar to rapidly treat PLWH, as early treatment is an effective strategy for prevention of HIV transmission [2, 3]. Furthermore, retention in HIV care (RIC) has been shown to increase the effectiveness of ART [4]. To achieve

the EtHE goals, HIV care providers are realigning practice with a comprehensive model in which clinics offer services to reduce barriers to engagement in care and RIC [5].

Previous studies have evaluated clinic-level interventions to improve RIC and found that clinic services such as substance abuse treatment, mental health treatment, transportation services, peer navigation, and housing assistance were associated with better RIC [6–9]. Enhanced quality and duration of contact with patients have also been found to increase RIC [6]. One systematic review found that interventions encouraging patient self-management led to better HIV outcomes and another found overwhelming evidence that text appointment reminders improved HIV outcomes [7, 8]. However, most previous studies assessing the impact of interventions on RIC were conducted at a single site. Additionally, previous studies did not examine how availability of services affected RIC for everyone attending the clinic.

The Centers for AIDS Research (CFAR) are national centers of excellence for HIV care and research located at academic

and research institutions throughout the United States [10]. The CFAR Network of Integrated Clinical Systems (CNICS) harmonizes data from CFAR HIV clinics to address long-term HIV clinical outcomes, such as RIC, in the contemporary ART era [10]. We conducted a retrospective cohort study to identify clinic-level interventions associated with better RIC at 7 CNICS sites from 2010 to 2016. We sought to address limitations of previous studies by assessing the effect of several different clinic-level factors on RIC for everyone attending the clinic.

METHODS

Study Population

We conducted a retrospective cohort study using data from seven CNICS sites. CNICS collects longitudinal data from a national network of centers of excellence for HIV care to improve knowledge on relationships between patient and treatment factors and HIV outcomes [9]. The 7 sites involved in this study were the University of California, San Diego (UCSD); University of Alabama at Birmingham (UAB); University of Washington (UW), University of California, San Francisco; John Hopkins University (JHU); University of North Carolina, Chapel Hill (UNC); and Fenway Health/Harvard University.

We included PLWH with at least 1 attended HIV primary care visit between 2010 and 2016 who were 18 years of age or older at first visit during the study at the participating site. Follow-up began on the first clinic visit after 1 January 2010 and continued until date of death, loss to follow-up (LTFU), or the end of the study period (31 December 2016). We defined LTFU as no visit within 12 months after the last completed HIV healthcare provider visit in an attempt to exclude person-years from PLWH who may have moved or had begun attending another clinic during the study.

Data Collection and Study Definitions

Individual-level data were collected as part of routine clinical care from the electronic health record. We gathered clinic-level data through surveys requesting information on site-level characteristics and services available during each year of the study. Our study outcome was RIC defined as 2 or more encounters per year, 90 days or more apart, observed until death, end of the study period, or LTFU [11, 12].

We evaluated the following site-level factors: patients per provider/trainee, availability of peer navigation, RIC posters/brochures, laboratory test timing, flexible scheduling, appointment reminder types, and stigma support services. These variables were updated by year and applied to every person included in the study attending that clinic. We modeled patient per provider/trainee as a continuous variable by dividing patients seen by the total number of providers and trainees who could prescribe ART at each clinic, and additionally divided this number by 10 to scale the variable and make regression model coefficients more interpretable. Other exposures were included in

models as dichotomous variables (ie, presence vs absence of the site-level factor). Peer navigation was defined as the presence of individuals with a common cultural background who work with patients to identify unmet needs and available resources. The presence of RIC posters/brochures was defined as clinic-wide messaging regarding the importance of RIC in the form of posters and brochures. Laboratory test timing was modeled with 2 binary variables: testing available the same day as the appointment and testing available prior to the appointment. E-mail, personal call, and text appointment reminders were coded as separate dichotomous variables. We did not specify how the e-mail, call, or text appointment reminders were conducted. The survey simply asked whether or not these services were available. Stigma support services were defined as the presence of intensive HIV education and advocacy regarding support to address stigma at outreach visits.

Individual-level variables were measured at clinic enrollment and included sex assigned at birth (male or female), race/ethnicity (white non-Hispanic, black non-Hispanic, Hispanic, or other/unknown), and HIV transmission risk factors (men who have sex with men [MSM], heterosexual sex, injection drug use [IDU], and other/unknown). If someone had multiple risk factors, we coded the person as having whichever risk factor was most likely to transmit HIV, ordered as IDU, MSM, heterosexual sex, and other/unknown. We also included age and calendar year modeled with restricted cubic splines with 4 knots to relax linear distribution assumptions and to allow model flexibility. We displayed regression model point estimates from the splines for age compared with the mean age, 45 years, for ease of interpretation. We chose individual-level and site-level covariates to be included in the multivariable model a priori based on a literature review and consultation with specialists in the care of PLWH.

Statistical Analysis

We described individual-level characteristics as the frequency and percentage of the population for categorical variables and as median and interquartile range (IQR) for continuous variables. The availability of site-level services was analyzed in person-years, as site-level services changed by year. Modified Poisson regression with robust error variance was used to estimate risk ratios (RRs) and 95% confidence intervals (CIs) for RIC, and associations were considered significant if the P value was less than .05. We accounted for clustering by site using generalized estimating equations, which account for variance due to clustering at the individual level, nested within the site level [13]. To control for confounding, we adjusted for individual-level factors. For site-level factors, the lack of service availability was the referent category. To improve statistical stability, the largest subgroup was used as the referent for all individual-level factors. We also used Levin's formula for those who did not have the site-level factor that was found to be associated with worse

retention in care to determine what percentage of person-years not RIC could be attributed to not being exposed to the site-level factor [14]. Therefore, we could estimate what percentage of people we should expect to have better RIC if this factor was implemented.

Because varying definitions of LTFU can alter estimates of the relationship between the exposure and RIC, we decided a priori to include a sensitivity analysis to determine how our results may change when a different definition of LTFU was used [15]. In our primary analysis, we used the retrospective definition of LTFU in which PLWH were censored after their first 12-month interval without a visit if there were no future visits; in our sensitivity analysis, we used a prospective LTFU definition in which PLWH were censored at their first 12-month interval without a visit, regardless of later visits in the study period. Stata Software, version 14.0 (StataCorp), was used for all analyses.

RESULTS

Population Characteristics

This study included 21 046 PLWH who were followed for a total of 103 348 person-years. The median follow-up time per PLWH was 7 person-years (IQR, 5–7 years). During the follow-up, 4262 individuals died; the median yearly mortality rate was 11 per 1000 individuals (IQR, 6–12 years). Baseline individual-level demographic characteristics are listed in Table 1. Of note, the largest groups in each category, and therefore the referent category for the regression analyses, were as follows: males (81.4%), non-Hispanic whites (43.8%), and MSM (56.9%). The median age was 43 years (IQR, 34–50 years). The sites contributing the most PLWH were UCSD (20.9%) and UAB (20.3%); the site with the fewest PLWH was Fenway Health/Harvard University (8.0%).

Site-level variables were summarized by person-years among the individuals at the relevant sites (Table 2). The median number of patients per providers/trainees prescribing ART was 50.3. The most common site-level factors were navigation to services (73.0%) and flexible scheduling of appointments (67.5%). The least common site-level factors were text appointment reminders (10.3%), testing available prior to the appointment (13.9%), and personal call appointment reminders (29.9%).

Retention in Care

Of the total 103 348 person-years of follow-up, 66.7% met the definition of RIC. Results from our modified Poisson regression models are presented in Table 3. In the adjusted model, clustering on site and controlling for both individual-level characteristics and site-level factors, younger age was associated with worse RIC, with those aged 20 (RR, .83; 95% CI, .80–.88), 30 (RR, .88; 95% CI, .85–.90), and 40 (RR, .94; 95% CI, .93–.95) years faring worse than those aged 45 years. Older age was

Table 1. Individual-level Characteristics of People Living With Human Immunodeficiency Virus Seen at CNICS Sites From 2010 to 2016

Individual-level Characteristics	Total (%) or Median (IQR)
Total	21 046
Age, years	43 (34–50)
Sex	
Male	17 140 (81.4)
Female	3906 (18.6)
Race/ethnicity	
White, non-Hispanic	9220 (43.8)
Black, non-Hispanic	7807 (37.1)
Hispanic	2948 (14.0)
Other/unknown	1071 (5.1)
Risk	
MSM	11 976 (56.9)
Heterosexual	5103 (24.3)
IDU	3207 (15.2)
Other/unknown	760 (3.6)
Site	
University of California, San Diego	4400 (20.9)
University of Alabama at Birmingham	4277 (20.3)
University of Washington	3054 (14.5)
University of California, San Francisco	2900 (13.8)
John Hopkins University	2578 (12.3)
University of North Carolina, Chapel Hill	2148 (10.2)
Fenway Health/Harvard University	1689 (8.0)

N = 21 046.

Abbreviations: CNICS, Centers for AIDS Research Network of Integrated Clinical Systems; IDU, injection drug use; IQR, interquartile range; MSM, men who have sex with men.

significantly associated with better RIC, with those aged 50 (RR, 1.07; 95% CI, 1.06–1.08) and 60 (RR, 1.15; 95% CI, 1.13–1.17) years faring better than those aged 45 years. Hispanic PLWH were more likely to be retained than non-Hispanic whites (RR, 1.09; 95% CI, 1.05–1.13).

Site-level factors independently associated with better RIC were text appointment reminders (RR, 1.13; 95% CI, 1.03–1.24) and stigma support services (RR, 1.11; 95% CI, 1.04–1.19). Our model suggests that the percentages of not RIC that can be attributed to not having text appointment reminders and stigma support services are 21.2% and 9.3%, respectively. Availability of e-mail appointment reminders compared with not providing e-mail appointment reminders were independently associated with worse RIC (RR, .96; 95% CI, .94–.99). One site-level variable, financial services, was removed from the final model due to collinearity with personal call appointment reminders in the model.

Sensitivity Analysis

When using a prospective follow-up definition, the number of person-years included in our modified Poisson regression was 62 412 person-years, which accounts for 60.4% of the person-years from the initial analysis. The adjusted RRs from the modified Poisson regression using the prospective follow-up definition can be found in Table 4. All factors had very similar

Table 2. Site-Level Characteristics in Person-years

Site- level Factor	Total (%) or Median (IQR)
Patients per providers/trainees	50.3 (37.5–88.9)
Navigation to services	75 395 (73.0)
RIC posters and brochures	50 555 (48.9)
Testing same day as appointment	74 538 (72.1)
Testing prior to appointment	14 326 (13.9)
Flexible scheduling	69 799 (67.5)
E-mail appointment reminders	40 760 (39.4)
Personal call appointment reminders	30 680 (29.9)
Text appointment reminders	10 670 (10.3)
Financial services	40 989 (39.7)
Stigma support services	60 910 (58.9)

N = 103 348.
Abbreviations: IQR, interquartile range; RIC, retention in care.

magnitude and the same direction of association in the sensitivity analysis as in the initial analysis. Financial services were still dropped from the model due to collinearity.

DISCUSSION

Our study utilized data from 7 CNICS clinics to assess how the availability of services and clinic-level factors affected RIC among PLWH in the United States from 2010 to 2016. We found that text appointment reminders and stigma support services were associated with better RIC compared with not offering text appointment reminders and stigma support services, while e-mail appointment reminders were associated with worse RIC compared with no e-mail appointment reminder.

Throughout the study period, 66.7% person-years met the definition of RIC. However, this was higher than the 49% who were retained overall in the United States [1]. This finding may be a result of our study population being enrolled in care at centers of excellence, which may have increased resources compared with other HIV clinics. Nonmodifiable demographic characteristics associated with better RIC were older age, female sex, and Hispanic race/ethnicity (compared with white race/ethnicity). Older age, female sex, and Hispanic race/ethnicity

Table 3. Risk Ratios for Retention in Care from Modified Poisson Regression Models Clustering on Site

Individual- and Site-level Factors	Unadjusted RR (95% CI)	Adjusted RR (95% CI)
Age (years)		
20	.85 (.81–.88)	.83 (.80–.88)
30	.89 (.87–.91)	.88 (.85–.90)
40	.95 (.94–.96)	.94 (.93–.95)
45	Ref	Ref
50	1.06 (1.05–1.07)	1.07 (1.06–1.08)
60	1.14 (1.12–1.16)	1.15 (1.13–1.17)
Sex		
Male	Ref	Ref
Female	1.04 (1.00–1.07)	1.03 (1.02–1.05)
Race/ethnicity		
White, non-Hispanic	Ref	Ref
Black, non-Hispanic	1.01 (.97–1.06)	1.00 (.97–1.04)
Hispanic	1.02 (.97–1.06)	1.09 (1.05–1.13)
Other/unknown	.93 (.88–.97)	.98 (.95–1.01)
Risk		
MSM	Ref	Ref
Heterosexual	1.03 (1.00–1.08)	.98 (.95–1.02)
IDU	1.00 (.95–1.06)	.97 (.92–1.02)
Other/unknown	.95 (.90–1.01)	.94 (.90–.98)
Site-level factors		
Patients per providers/trainees[a]	1.00 (1.00–1.01)	.99 (.97–1.01)
Navigation to services	.99 (.94–1.04)	.95 (.87–1.04)
RIC posters and brochures	1.03 (.98–1.08)	1.05 (.96–1.15)
Testing same day as appointment	1.03 (.94–1.12)	.84 (.69–1.02)
Testing prior to appointment	.94 (.90–.98)	1.00 (.84–1.19)
Flexible scheduling	.95 (.91–1.00)	.94 (.86–1.01)
E-mail appointment reminders	.97 (.90–1.03)	.96 (.94–.99)
Personal call appointment reminders	.99 (.91–1.07)	1.00 (.90–1.10)
Text appointment reminders	1.09 (1.05–1.12)	1.13 (1.03–1.24)
Financial services	.98 (.92–1.05)	…[b]
Stigma support services	1.02 (.94–1.09)	1.11 (1.04–1.19)

All models adjusted for all variables listed in the table as well as year of study.

Abbreviations: CI, confidence interval; IDU, injection drug use; MSM, men who have sex with men; Ref, reference group; RIC, retention in care; RR, risk ratio.

[a]Interpreted as the RR associated with a 10-patient increase per provider/trainee.

[b]Removed from the model due to collinearity with personal call appointment reminders.

have been associated with better RIC in previous studies [16, 17]. The apparent trend among Hispanics is consistent with the Hispanic Paradox, which posits that even with a higher prevalence of demographic factors generally associated with worse health outcomes, Hispanic individuals tend to have better health outcomes in the United States [18].

In our study, site-level factors associated with better RIC were text appointment reminders and stigma support services. A qualitative study in 51 PLWH from 3 HIV clinics in Philadelphia determined that appointment reminders are needed to improve RIC [19]. However, the type of reminder was not specified. We found that text appointment reminders were associated with better RIC, while e-mail reminders were associated with worse RIC; this could have occurred if the PLWH included in this study had better text than e-mail access. If a clinic

relies on e-mail reminders, but individuals do not have regular e-mail access, they may miss the reminder and be less likely to attend a visit. Text messaging may be more broadly available, making it a more beneficial reminder approach. A literature review conducted in 2018 found overwhelming evidence of the effectiveness of text messaging in health services [8]. However, text message appointment reminders were one of the least common services, offered at only 2 clinics included in our study. One clinic's text reminder was an opt-in service and the other was opt-out. They both used one-way texting to remind the patient 7–10 days before their appointment; 1 clinic additionally provided a reminder at the time the appointment was booked, and the other provided an additional reminder 1 day before the appointment. Other sites did not have this service due to a lack of resources or electronic medical record system that could

Table 4. Adjusted Risk Ratios for Retention in Care From the Modified Poisson Regression Models Using Person-time Apportioned With a Retrospective Loss to Follow-up Definition in the Primary Analysis and a Prospective Loss to Follow-up Definition in the Sensitivity Analysis

Individual- and Site-level Factors	RR (95% CI)	
	Retrospective Loss to Follow-up	Prospective Loss to Follow-up
Age (years)		
20	.83 (.80–.88)	.82 (.78–.86)
30	.88 (.85–.90)	.87 (.85–.89)
40	.94 (.93–.95)	.95 (.94–.96)
45	Ref	Ref
50	1.07 (1.06–1.08)	1.05 (1.04–1.07)
60	1.15 (1.13–1.17)	1.11 (1.09–1.13)
Sex		
Male	Ref	Ref
Female	1.03 (1.02–1.05)	1.01 (1.00–1.03)
Race/ethnicity		
White, non-Hispanic	Ref	Ref
Black, non-Hispanic	1.00 (.97–1.04)	1.01 (.97–1.04)
Hispanic	1.09 (1.05–1.13)	1.09 (1.05–1.13)
Other/unknown	.98 (.95–1.01)	.99 (.96–1.02)
Risk		
MSM	Ref	Ref
Heterosexual	.98 (.95–1.02)	1.00 (.97–1.03)
IDU	.97 (.92–1.02)	.99 (.94–1.03)
Other/unknown	.94 (.90–.98)	.96 (.93–1.00)
Site-level factors		
Patients per providers/trainees[a]	.99 (.97–1.01)	.98 (.96–1.00)
Navigation to services	.95 (.87–1.04)	1.01 (.95–1.07)
RIC posters and brochures	1.05 (.96–1.15)	1.06 (.97–1.15)
Testing same day as appointment	.84 (.69–1.02)	.87 (.74–1.01)
Testing prior to appointment	1.00 (.84–1.19)	1.02 (.89–1.17)
Flexible scheduling	.94 (.86–1.01)	.99 (.93–1.05)
E-mail appointment reminders	.96 (.94–.99)	.99 (.98–.99)
Personal call appointment reminders	1.00 (.90–1.10)	.96 (.88–1.04)
Text appointment reminders	1.13 (1.03–1.24)	1.16 (1.03–1.30)
Financial services	…[b]	…[b]
Stigma support services	1.11 (1.04–1.19)	1.08 (1.03–1.13)

All models adjusted for all variables listed as well as year of study.

Abbreviations: CI, confidence interval; IDU, injection drug use; MSM, men who have sex with men; Ref, reference group; RIC, retention in care; RR, risk ratio.

[a]Interpreted as the RR associated with a 10-patient increase per provider/trainee.

[b]Removed due to collinearity with personal call appointment reminders.

assist with sending text reminders. If text messaging appointment reminders were implemented in sites that do not have this service, 21.2% of those not having RIC would be expected to have RIC. Research on ART adherence found that 2-way texts are more effective than a reminder that does not require a response [20]. Future studies of text appointment reminders should evaluate reminder frequencies and 1-way versus 2-way text reminders.

Stigma support services were measured through a fairly broad question in the survey; each of the 4 clinics offering stigma support services likely differs in how stigma is addressed. Stigma support services included counseling through trained on-site social workers and mental health providers. Experiencing stigma has been associated with worse RIC in previous studies; therefore, addressing stigma should improve RIC [21, 22]. In another CNICS study, mental health services appeared to improve RIC, and stigma support could be considered to be a type of mental health support [9]. Similar to our study, a clinical trial including 1838 participants, from several US sites, found that personal telephone contact increases RIC [6]. A second analysis using the same cohort found that patients with common behavioral health needs who received personal telephone contact had better RIC as well; however, this was only true for those who successfully received the telephone contact [23]. The stigma support services included in our study increased meaningful contact with patients (although not by personal telephone contact), which could also explain improved RIC. Adding stigma support services at sites not providing these services could improve RIC by 9.3%.

Notably, higher volume clinics tended to have worse RIC, but in our study this variable was not significantly associated with RIC, which could be due to a similar number of patients per provider at each clinic, low power to detect the effect of small differences, and possible within-clinic variability, as this was an aggregate measure.

In our sensitivity analysis utilizing a prospective LTFU definition, 39.6% of the person-years from the initial analysis were lost, suggesting a substantial proportion of our study population left care for at least 1 year but then returned. However, the findings from this analysis were nearly identical to those of the initial analysis. This indicates that using a retrospective LTFU definition does not appear to bias RIC inferences in these clinical populations, and future studies should utilize a retrospective definition, when possible, in order to use all data available.

There were multiple limitations to this study. First, the outcome may have been misclassified as not retained if the individual attended another clinic (ie, were silent transfers) outside of the CNICS network; although it is possible that this misclassification would be nondifferential (and thus bias our results toward the null), we are not certain that this is the case [24]. Second, the survey did not collect specific information

on what was included in stigma support services or amount of individual patient uptake of site-level services. Different sites may have stigma support services of differing intensity and they may be available to a different proportion of the clinic population due to resources and staffing issues. Therefore, there may be measurement error due to a heterogeneous implementation of site-level services and variation in individual access/usage of services. Third, our inferences may be influenced by residual confounding by site, as although we accounted for clustering within site, we were unable to adjust for site without removing variables of interest from the model due to collinearity between site-level variables and sites. Fourth, there are numerous approaches to measuring RIC. The method employed is consistent with national quality indicators but tends to generate a higher estimate of retention than other RIC measures [25]. Last, our results may not be generalizable to rural clinics, as the sites in this study were all in relatively urban settings. However, our findings are likely more generalizable than previous single-site studies, as there were 7 sites included from diverse regions across the United States.

Our study also benefits from a large sample size and a long duration of follow-up (including up to 7 years of follow-up for each individual). We also assessed multiple site-level factors, whereas previous prospective studies typically focused on a single site-level intervention or, at most, a few site-level interventions related to RIC.

Conclusions

In conclusion, text appointment reminders and stigma support services were associated with better RIC, although text messaging was one of the least common services offered. Use of e-mail appointment reminders was associated with worse RIC, possibly due to lower access to e-mail. Demographic disparities persisted by sex, race/ethnicity, and age even after accounting for clinic-level factors. These results indicate that text messaging appointment reminders and stigma support services could be implemented at HIV clinics to improve RIC, as these clinic-level factors appeared to be effective in improving RIC in this multisite US cohort.

Notes

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