

Engagement in Outpatient Care for Persons Living with HIV in the United States

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Abstract

Prior studies that have assessed engagement within the various stages of care for persons living with HIV (PLWH) studied patients receiving care in HIV medical care facilities. These data are not representative of care received throughout the United States, as not all PLWH receive care in HIV clinics. This study evaluated engagement in outpatient care and healthcare utilization for PLWH, beyond facilities that specialize in HIV. Cross-sectional data were from the 2009–2010 National Hospital Ambulatory Medical Care Survey. Levels of care included receiving any care, receiving HIV-related care, established in care, engaged in care, and prescribed antiretroviral therapy (ARV). Factors associated with ARV prescription were determined by logistic regression. We analyzed data for ~2.6 million outpatient clinic visits for PLWH. Of these, 90% were receiving HIV-related care, 86% were established in care, 75% were engaged in care, and 65% were prescribed ARV. In stratified analysis, the proportion of PLWH who were engaged in care varied by race/ethnicity ($p < 0.001$) and ARV prescription varied significantly across the three age groups ($p = 0.004$). Clinic visits within the past year did not differ for those prescribed ARV vs. not prescribed ARV [median, IQR = 3.3 visits (1.8–5.6) vs. 3.6 visits (1.3–5.9); $p = 0.7$]. Seeing a physician was associated with ARV prescription (OR = 0.27, 95% CI = 0.15–0.51), whereas routine engagement in care was not associated with ARV prescription (OR = 0.99, 95% CI = 0.96–1.03). Given that non-ARV-treated PLWH utilized outpatient care services at rates similar to ARV-treated PLWH, these routine clinic visits are missed opportunities for increasing ARV prescription in untreated patients.

Introduction

IN 2013, THE DEPARTMENT OF HEALTH and Human Services (DHHS) Panel on Antiretroviral Guidelines for Adults and Adolescents recommended that antiretroviral therapy (ARV) be initiated in all persons living with HIV (PLWH) in order to reduce the risk of disease progression and HIV transmission.¹ The goal of ARV therapy is to inhibit HIV replication and achieve viral load (VL) suppression. Viral suppression is also an integral component of preventing HIV transmission to uninfected individuals.² However, approximately 25% of PLWH in the United States achieve viral load suppression³; lack of access and poor engagement in routine outpatient HIV medical care are cited as barriers to achieving this outcome.^{4,5}

The *HIV cascade* has recently emerged in the scientific literature to illustrate how patients engage in the many stages of the HIV care spectrum.⁶ HIV treatment requires routine care and monitoring, however, PLWH often discontinue care at different stages, which precludes them from achieving an

undetectable VL. Recent estimates from the National HIV Surveillance System of the Centers for Disease Control and Prevention (CDC) indicate that there are approximately 1.15 million PLWH in the United States, of which 940,000 (82%) have diagnosed infection and of which only 287,000 (25%) have undetectable VL.⁷ Other studies that have applied the cascade to various patient populations report greater engagement in care, with viral suppression rates as high as 70%.^{8,9} However, the CDC surveillance system and other studies were restricted to patients receiving care in HIV specialty clinics. Such clinics may not be representative of nonspecialty facilities that provide care to PLWH in the United States; as such, the generalizability of these findings beyond specialty care settings is uncertain.

The HIV cascade not only reveals gaps in continuity of care, but also illustrates the health inequities inherent in our healthcare system. Certain subgroups of PLWH, particularly racial/ethnic minorities, males, and those younger in age, demonstrate lower engagement in the various stages of HIV care and are also less likely to achieve viral suppression.⁷

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Our primary objective for this study was to estimate engagement in outpatient care for PLWH who received services from a broad range of facilities, beyond those that specialize in HIV. Our secondary objectives were to document differences in engagement in care between groups by age, sex, and race/ethnicity and to identify determinants of ARV coverage among established patients visiting their usual source of care. Lastly, we also examined the relationship between ARV coverage, healthcare utilization, and clinic visit disposition.

Materials and Methods

Study design

Cross-sectional data from the 2009 and 2010 National Hospital Ambulatory Medical Care Survey (NHAMCS) were used to conduct this study. The NHAMCS is a nationwide probability sample survey conducted by the CDC. Survey data are available to the public and provide national representations of annual hospital clinic visit records. The purpose of NHAMCS is to provide a population-level estimation of the utilization of outpatient services in the United States. The data are collected through chart reviews conducted by trained clinic personnel. The University of North Carolina Institutional Review Board (IRB) reviewed the study protocol and determined that this research was not considered Human Subjects Research, therefore, IRB approval was not needed.

To identify PLWH within the NHAMCS dataset, we selected patient records containing at least one of three *International Classification of Diseases*, Ninth Revision, Clinical Modification (ICD-9-CM) codes: 042 (HIV disease), V08 (asymptomatic HIV infection), or 079.53 (HIV-2 illness). We excluded nonadult patients (age < 18 years of age at time of clinic visit). Approximately 1.1% of the patient records that met the age criteria had at least one of the three HIV disease codes.

Outcomes

Healthcare utilization was calculated as the number of clinic visits within the past year. The number of clinic visits was collected through chart review and was exclusive to one clinic. Levels of care included “receiving any care” (≥ 1 clinic visit for a PLWH), “receiving HIV care” (≥ 1 clinic visit with a primary ICD-9-CM code for HIV), “established in care” (patient previously seen within the clinic), and “engaged in care” (≥ 2 clinic visits in the past year). “Prescribed ARV” was defined as the documentation of ≥ 1 ARV medication in the clinic visit record. The dataset provides data on up to eight medications that were prescribed (ordered, supplied, administered, or continued) during the clinic visit. Medications were identified using 5-digit codes located within the CDC’s Ambulatory Care Drug Database System.¹⁰

“Visit disposition” at the completion of the clinic visit was classified as return to the clinic, refer to other physician, or refer to the emergency department (ED) or hospital for admission, other, or no disposition documented. We calculated the proportions of visits that were engaged in the various levels of care using appropriate denominators for each level.⁷ The total number of visits meeting study criteria was used as the denominator to calculate the proportion receiving HIV care and the proportion established in care, whereas the number of visits for PLWH established in care was used as

the denominator to calculate the proportion engaged in care and the proportion prescribed ARV.

Covariates

Additional covariates included patient demographics [patient age at time of clinic visit (years), race/ethnicity, sex, insurance status] and visit characteristics (clinic geographic region in the United States, total number of visits to the clinic in the past year, and patient comorbidities). Comorbidities were measured using additional clinic visit diagnoses, and included chronic renal failure, depression, hypertension, ischemic heart disease, hyperlipidemia, and diabetes.

Analyses

Statistical analyses were performed using standard survey analysis methodology. Domain analysis is used for proper estimation of variance based on the selected subpopulation. National estimates of outpatient clinic visits were computed using survey weights for each observation. We also compared patient demographics and comorbidities between patients with and without ARV coverage, while accounting for the stratifying and clustering effects of the principal sampling units (PSUs). For categorical variables, the survey chi-square tests were applied; for continuous variables, tests based on the survey linear regression were used. Furthermore, we built a survey logistic regression model predicting ARV prescription based on important patient characteristics such as age, sex, race/ethnicity, and geography. Additional visit characteristics will also be included as covariates if they are found to be significantly associated with ARV in the bivariate analyses. All analyses were performed with SAS version 9.2 (SAS Institute, Cary, NC) using procedures SURVEYFREQ, SURVEYMEANS, and SURVEYLOGISTIC, where appropriate.

Results

Using weighted observations, approximately 2.6 million outpatient clinic visits for PLWH met study inclusion criteria. Overall, engagement in care decreased across the progressing levels of care, as illustrated in Fig. 1. Of PLWH with ≥ 1 clinic visits, 90% were receiving HIV-related care, 86% were established in care, 75% were engaged in care, and 65% were prescribed ARV.

The remaining results pertain to PLWH who were established in care. In stratified analysis, which is presented in Table 1, engagement in the various levels of care did not vary significantly by sex. We found significant differences by race/ethnicity in the proportion of PLWH engaged in care ($p < 0.001$) and ARV prescription varied significantly across the three age groups ($p = 0.004$).

Differences in patient demographics and comorbidities, by ARV status, are presented in Table 2. Physicians more frequently provided care for untreated PLWH than treated PLWH (91% vs. 77%; $p < 0.01$). The number of clinic visits within the past year did not differ for visits prescribed ARV compared to those not prescribed ARV [median, interquartile range (IQR) 3.3 visits (1.8–5.6) vs. 3.6 visits (1.3–5.9); $p = 0.7$].

Seeing a physician, compared to a nonphysician, at the time of clinic visit was the only factor that was significantly associated with ARV prescription (OR = 0.27, 95% CI = 0.15–0.51).

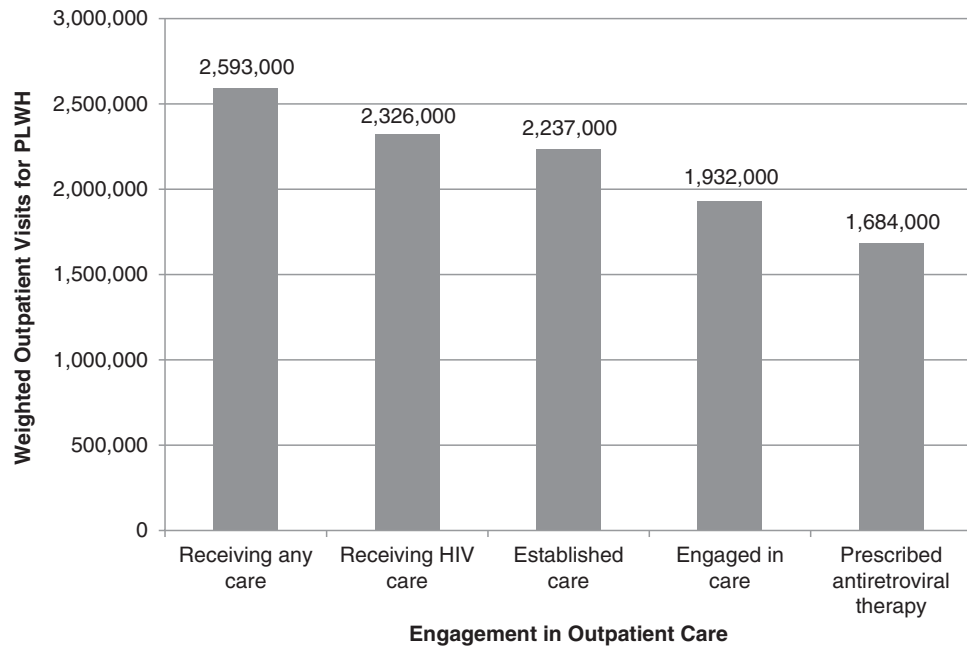


FIG. 1. Levels of engagement in outpatient care for persons living with HIV infection (PLWH) in the United States from 2009 to 2010.

An increasing number of clinic visits within the past year was not associated with ARV prescription (OR=0.99, 95% CI=0.96–1.03), nor was visit with the primary care physician/provider (OR = 1.18, 95% CI=0.58–2.39). Full regression analyses are presented in Table 3. The majority of PLWH were instructed to return to the clinic at a specified time (98%).

Discussion

We estimated the levels of engagement in care for PLWH in a broad setting of outpatient clinics in the United States. Mapping the HIV care cascade in PLWH helps to ascertain points for subsequent health interventions. As expected, engagement declined with progressive levels of care; of those in outpatient care, only 65% were prescribed ARV. Given that non-ARV-treated PLWH utilized outpatient care services at rates similar to ARV-treated PLWH, these routine clinic

visits are missed opportunities for promoting ARV use in untreated patients. Of note, our study is representative only of PLWH with diagnosed HIV infection already in care. Diagnosis is still the first step in the cascade; yet between 18% and 20% of HIV infections remain undiagnosed.^{7,11} This underscores the need for routine HIV testing for patients in all healthcare settings.^{12,13}

Overall, our findings are consistent with prior studies evaluating the continuum of care for PLWH that was conducted during the same period of time.¹³ Hall *et al.*⁷ used 2009 data from the CDC’s National HIV Surveillance System, a primary source for HIV epidemiologic data in the United States, and the Medical Monitoring Project (MMP), a nationwide surveillance project to gather clinical and behavioral information for PLWH. However, the MMP is restricted to outpatient HIV specialty medical care facilities, whereas the NHAMCS is representative of hospital outpatient departments. Per their

TABLE 1. ENGAGEMENT IN LEVELS OF OUTPATIENT CARE FOR PERSONS LIVING WITH HIV

	Age group (years)				Sex			Race/ethnicity				
	18–29	30–49	≥50	p-value ^a	Male	Female	p-value ^a	White	Black	Hispanic	Other	p-value ^a
Receiving HIV-related care, % ^b	84.9	89.2	92.3	0.360	91.0	85.7	0.102	90.5	86.5	94.1	81.3	0.237
Established in care among PLWH receiving HIV care, % ^b	78.7	86.5	89.0	0.217	87.6	82.5	0.187	88.5	84.1	87.5	80.8	0.702
Engaged in care among PLWH established in care, % ^c	75.8	83.0	94.6	0.133	86.4	86.1	0.960	90.5	86.6	80.6	100	<0.001
Prescribed ARV among PLWH established in care, % ^c	57.4	82.7	71.3	0.004	78.6	65.0	0.274	81.0	67.1	80.2	83.3	0.092

^ap-values are obtained from chi-square tests.

^bNumber of visits meeting study criteria was used as the denominator.

^cNumber of visits for PLWH established in care was used as the denominator. PLWH, persons living with HIV; ARV, antiretroviral.

TABLE 2. CHARACTERISTICS FOR PERSONS LIVING WITH HIV ESTABLISHED IN CARE, WITH AND WITHOUT ANTIRETROVIRAL THERAPY

Characteristic	Total	With antiretroviral therapy	Without antiretroviral therapy	p-value ^a
Population total (1,000) (95% CI)	2,237 (758–3,718)	1,684 (496–2,872)	553 (227–879)	<0.001
Patient demographics				
Mean age (years) (95% CI)	44.4 (42.3–46.5)	44.7 (43.1–46.3)	43.4 (38.6–48.2)	0.514
Age (years) (%)	—	—	—	0.004
18–29	12.9%	9.8%	22.1%	
30–49	50.2%	55.1%	35.0%	
≥50	36.9%	35.1%	42.9%	
Sex (%)	—	—	—	0.274
Male	75.7%	79.0%	65.6%	
Female	24.3%	30.0%	34.4%	
Race/ethnicity (%)	—	—	—	0.092
White	31.0%	33.4%	23.8%	
Black/African American	40.0%	35.7%	53.2%	
Hispanic	27.5%	29.3%	22.0%	
Other	1.5%	1.6%	1.0%	
Geographic region (%)	—	—	—	NA ^b
Northeast	21.4%	21.2%	22.0%	
Midwest	0.2%	0.2%	0	
West	14.1%	13.4%	16.5%	
South	64.3%	65.2%	61.5%	
Insurance status (%)	—	—	—	0.605
Private	20.8%	20.3%	22.2%	
Medicare	22.4%	25.0%	14.5%	
Medicaid	40.7%	38.0%	48.9%	
Uninsured (self-pay, charity care)	3.3%	2.8%	4.6%	
Other (other, unknown, worker's compensation)	12.8%	13.9%	9.8%	
Patient comorbidities				
Hypertension (%)	30.1%	30.4%	29.1%	0.904
Ischemic heart disease (%)	1.0%	0.2%	3.6%	0.002
Hyperlipidemia (%)	19.8%	20.6%	17.2%	0.663
Chronic renal failure (%)	2.9%	1.6%	6.7%	0.142
Depression (%)	31.8%	33.3%	27.5%	0.256
Diabetes (%)	9.3%	8.3%	12.4%	0.450
Visit characteristics				
Patient's primary care physician/provider (%)	—	—	—	0.407
Yes	38.8%	40.1%	35.0%	
No	59.1%	58.6%	60.4%	
Unknown	2.1%	1.3%	4.6%	
Health care professional seen (%)	—	—	—	
Physician	80.5%	77.0%	91.3%	<0.001
RN/LPN	79.7%	79.5%	80.3%	0.917
Nurse practitioner/midwife	13.7%	14.2%	12.4%	0.705
Physician assistant	5.3%	6.9%	0.2%	0.134
Other	32.2%	31.5%	34.2%	0.689

^ap-values are obtained from chi-square tests.

^bNo test available because of too few unweighted observations in at least one cell.

analysis, only one-third of all PLWH were retained in care (defined as having ≥ 1 medical care visit in a 4-month period). They estimated that the majority (89%) of those retained in care were prescribed ARV.

This high coverage of ARV is consistent when compared to other studies that have studied HIV specialty medical care facilities.^{4,8} It has also been demonstrated that clinics with highly integrated healthcare systems (such as the VA system) can attain even greater engagement at each of the stages of care, when compared to these national estimates.¹⁴

In contrast, our study revealed that engagement in care was lower in comparison to previous studies. We found that only 72% of those receiving HIV-related medical care were prescribed ARV, a finding that is similar to estimates modeled by Gardner *et al.*⁶ Although this finding is likely attributed to our broader scope of outpatient facilities, it may also be a reflection of low ARV treatment utilization in nonspecialty clinics. Historically, the predominant source of HIV care has been in HIV/infectious diseases specialty clinics.^{15–17} Given the numerous advances to combination ARV, HIV has now

TABLE 3. FACTORS ASSOCIATED WITH ANTIRETROVIRAL THERAPY PRESCRIPTION FOR PERSONS LIVING WITH HIV ESTABLISHED IN OUTPATIENT CARE

Covariate	Adjusted OR (95% CI)	p-value
Age	1.01 (0.97, 1.06)	0.636
Sex	—	
Female	1	
Male	1.68 (0.43, 6.60)	0.459
Race	—	
White	1 (ref)	
Black/African American	0.63 (0.25, 1.61)	0.480
Hispanic	0.97 (0.56, 1.69)	0.938
Other	1.32 (0.10, 17.27)	0.758
Insurance	—	
Private insurance	1 (ref)	
Medicare	1.56 (0.49, 4.92)	0.321
Medicaid	1.09 (0.47, 2.52)	0.626
Uninsured	0.45 (0.05, 4.09)	0.277
Other/unknown	0.97 (0.22, 4.37)	0.940
Number of past visits	0.99 (0.96, 1.03)	0.685
Primary care physician/provider	—	
No	1 (ref)	
Yes	1.18 (0.58, 2.39)	0.398
Provider seen (physician)	0.27 (0.15, 0.51)	<0.001
Nonphysician	1 (ref)	
Physicians	0.27 (0.15, 0.51)	<0.001

evolved into a chronic disease that can be managed in the outpatient care setting.¹⁸ Nevertheless, there is still the need for specialty training for any provider caring for PLWH, particularly primary care providers practicing in nonspecialty settings.¹⁹ Providers need to be well equipped to manage treatment-related complications, such as drug toxicities, drug resistance, waning adherence, and the yet unknown sequelae of long-term therapy.¹⁸

We compared levels of care by select demographics and found no differences by sex for any of the levels of engagement. We found significant differences by race/ethnicity in the proportion of PLWH who were engaged in care. Prescription of ARV was lowest for blacks, but this finding was not statistically significant. Although there were no differences in the proportions of PLWH receiving HIV care or established in care across the age groups, younger adults were less likely to be engaged in care or to be prescribed ARV compared to older adults. This age disparity has been reported elsewhere.^{7,8,20,21} According to CDC HIV surveillance data, younger adults aged 15–29 years accounted for only 10% of those living with diagnosed infection in the United States, but accounted for 35% of all new infections occurring in 2010 (16,000 estimated new infections).²² These age differences in engagement and ARV coverage are likely a reflection of lower rates of adherence in younger adults with HIV infection.²³ These findings highlight the need for age-appropriate interventions to not only prevent HIV transmission in younger adults, but also to improve care retention and treatment utilization.²⁴ As expected, the majority of HIV infections occurred in the southern region of the United States.²⁵ It has also been demonstrated that engagement and

retention in care vary widely by state and location in the United States, underscoring the need to evaluate geographic and localized gaps in the continuum of care.²⁶

Prior studies have shown that lack of continuous engagement in care is associated with noninitiation of ARV.^{8,27} In contrast, the number of visits in the past year was not significantly associated with ARV prescription in our study. This implies that routine clinic visits may be missed opportunities to promote ARV use for PLWH, particularly those seeking care in nonspecialty clinics. In light of recent DHHS treatment recommendations, outpatient providers are encouraged to initiate patients on ARV when they come in to receive HIV medical care. This reinforces the need for outpatient providers to receive the necessary training and expertise to best manage these patients.

This study is subject to some limitations related to the nature of the NHAMCS and limitations of cross-sectional studies. Within the NHAMCS, it is not possible to differentiate HIV/infectious diseases specialty clinics from nonspecialty clinics. This possibility of confounding is limited since PLWH should receive the same standard of medical care regardless of the medical facility. The data presented in these surveys represent national, population-level estimates rather than patient-level estimates. Each weighted observation represents a clinic visit, rather than a patient; it is possible that a single patient represents multiple clinic visits leading to possible selection bias. The complex multistage sampling design reduces the likelihood that an individual patient is sampled more than once during the 4-week sampling period. This was a cross-sectional study. Patients were not followed longitudinally, thus long-term outcomes were not available. However, data regarding clinic disposition were available.

Our analysis of HIV care may not be directly comparable to other standard retention definitions that have been applied in cohort studies.²⁸ Rather, our measures of healthcare utilization were based on patients previously receiving care at the clinic, the number of documented clinic visits in the past year, and documentation of any antiretroviral medications at the time of the clinic visit. Objective laboratory markers, such as CD4⁺ and HIV-1 RNA, were not collected as part of the survey design; therefore it was not possible to determine ARV eligibility based on CD4⁺ or the effectiveness of ARV based on HIV VL. Data from this study were from 2009–2010 and might not capture the current landscape for ARV coverage. Treatment guideline recommendations now endorse ARV in all PLWH, regardless of CD4⁺ count. Limited research is available to determine how this change in guideline recommendations will shift clinical practices.

In the changing landscape of ARV treatment guidelines, more research is needed to understand factors deciding when a PLWH is prescribed ARV. Given that non-ARV-treated PLWH utilized outpatient care services at rates similar to ARV-treated PLWH, these routine clinic visits are missed opportunities for increasing ARV prescription in untreated patients.

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Author Disclosure Statement

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