Outcomes Along the HIV Care Continuum Among Undocumented Immigrants in Clinical Care

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Abstract

HIV-infected undocumented immigrants face unique barriers to care yet little is known about their clinical outcomes. We performed a retrospective cohort study of HIV-infected adults in clinical care from 2006 to 2014 at a large academic medical center in a setting where medical insurance is available to HIV-infected undocumented immigrants. Undocumented status was assessed based on Social Security number and insurance status and verified through medical chart review. Using Poisson regression models, we compared undocumented and documented patients with respect to retention in care (≥ 2 HIV-related laboratory tests ≥ 90 days apart), antiretroviral therapy (ART) prescription (≥ 3 active antiretroviral agents prescribed in a year), and viral suppression (HIV RNA < 200 copies/ml for the last measured viral load) for each year in care. Of 7,551 patients included in the analysis, we classified 173 (2.3%) as undocumented. For each year of the analysis, higher proportions of undocumented patients were retained in care, prescribed ART, and virally suppressed. In adjusted models, undocumented status was associated with increased probability of retention in care [risk ratio (RR) 1.05, confidence interval (95% CI) 1.01–1.09], ART prescription (RR 1.05, 95% CI 1.01–1.08), and viral suppression (RR 1.13, 95% CI 1.08–1.19) compared to documented status. Undocumented patients achieved clinical outcomes at modestly higher rates than documented patients, despite entering care with more advanced disease. In a setting where insurance is available to undocumented patients, similar outcomes along the HIV care continuum may be achieved regardless of immigration status.

Keywords: immigrants, undocumented immigrants, HIV care continuum, retention in care, viral suppression

Introduction

THE NATIONAL HIV/AIDS STRATEGY for the United States calls for focusing prevention and treatment efforts on populations at high risk.¹ An estimated 11.7 million undocumented immigrants live in the United States, with many residing in areas with high HIV prevalence.^{2,3} The few studies published on HIV-infected undocumented immigrants indicate that they enter care with more advanced disease compared to documented patients⁴ and also face unique barriers to remaining engaged in care, including stigma, high levels of acculturation stress, and fear of deportation.^{5–8} They may therefore be at risk of poor clinical outcomes.

The HIV care continuum is a framework used to outline the sequential steps necessary for both the individual and public health to fully benefit from antiretroviral therapy (ART).⁹ Engagement and retention in HIV care are considered crucial steps in maximizing patient outcomes, yet approximately half

of all HIV-infected persons in the United States are not retained in care.¹⁰ Compared to U.S. citizens and permanent residents, undocumented immigrants living with HIV in the United States are more likely to have characteristics associated with poorer retention in care, including foreign-born status, younger age, lower income, and higher levels of experienced stigma.^{11–14} These same characteristics and others such as lack of health insurance, lower levels of educational attainment, and low CD4 count before starting ART have been identified as predictors of virologic failure.^{15–18}

Limited data have been published on the clinical outcomes of HIV-infected undocumented immigrants. One study from a single HIV clinic in Texas that examined outcomes 1 year after entry into care found that undocumented Hispanics achieved rates of retention in care and viral suppression that were similar to other groups of patients.⁴ However, these findings may not be generalizable to settings with immigrants from more diverse backgrounds or beyond the first year in

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care. To better understand potential disparities in HIV clinical outcomes, we compared rates of retention in care, receipt of ART, and viral suppression between undocumented immigrants and documented individuals in a large diverse clinical population of HIV-infected patients in a setting with high HIV prevalence and a substantial number of undocumented immigrants.

Methods

Research design

We conducted a retrospective cohort study of HIV-infected patients receiving care in a large academic medical center from 2006 to 2014.

Setting

An estimated 867,000 undocumented immigrants reside in New York State (NY). Although ineligible for most public benefits, they can obtain coverage for emergency conditions requiring hospitalization through Emergency Medicaid. In addition, HIV-infected undocumented immigrants who are NY residents with incomes below 435% of the federal poverty line can obtain health insurance and prescription medication coverage through the state's AIDS Drug Assistance Program (ADAP).

The Bronx—one of New York City's five boroughs—is the poorest urban county in the United States, has an HIV prevalence of 2.0%, and is home to approximately 476,000 immigrants, including an estimated 113,000 who are undocumented.¹⁹ Montefiore Medical Center (MMC), the largest healthcare provider in the Bronx, is an integrated healthcare delivery system with four acute care hospitals and over 50 ambulatory care sites. All sites share an electronic medical record (EMR) that was implemented in 1997 and includes patient problem lists, visit and billing history, and laboratory test results. Outpatient HIV care at MMC is provided at a large infectious diseases clinic, 10 community-based primary care clinics, 3 substance abuse treatment programs, and an adolescent clinic. These clinics are funded by the Ryan White Program and are required to report data to the NY State Department of Health's AIDS Institute Reporting System (AIRS), including demographic characteristics, HIV risk factor history, substance use, laboratory tests, and medication utilization.

Population

We included all HIV-infected persons at least 18 years old who had at least one outpatient visit at MMC between January 1, 2006 and December 31, 2014 and had data available from AIRS. As we have done previously, we defined patients as HIV-infected if they had a positive HIV-1 or HIV-2 Western blot, a positive Multispot HIV 1/2 test, a detectable HIV viral load, or at least three undetectable HIV-1 viral loads ordered concurrently with a CD4 count.²⁰

Data sources

We extracted sociodemographic information, Social Security number (SSN), insurance status, laboratory data, prescription data, and diagnosis codes [*International Classification of Disease, 9th Revision, Clinical Modification (ICD-9-CM)*] from the MMC EMR. We obtained additional

data on demographic characteristics, HIV diagnosis date, and HIV risk factors from AIRS. Fact and date of death were obtained through a match with the National Death Index (National Center for Health Statistics, Hyattsville, MD). Additional information on immigration status and country of origin were obtained by manually reviewing medical records of patients classified as undocumented (see Independent variable of interest—immigration status section).

Independent variable of interest—immigration status

We defined *undocumented* patients as those who (1) had a missing SSN or invalid SSN in the EMR and (2) had insurance status as no insurance, self-pay, Emergency Medicaid, or ADAP.²¹ We considered an SSN invalid if it began with 000 or 666, contained 00 as the fifth and sixth digits, or ended with 0000.⁴ Patients who did not meet these criteria were defined as *documented*. For patients classified as undocumented, a single author (J.R.) manually reviewed medical records to verify immigration status and obtain data on country of origin, examining notes written by physicians, nurses, and social workers for explicit mention of undocumented immigration status, or indications of ineligibility for services because of immigration status.

Outcome variables

Because all of the patients in this study population had data in AIRS, which is principally populated from outpatient data, we considered all patients to be initially linked to care. For each year that patients were in care (defined as any evidence of a healthcare encounter in that particular year), we then examined the proportion of patients engaged in subsequent steps of the HIV continuum of care (i.e., the number retained in care among those in care, the number prescribed ART among those retained in care, and the number achieving viral suppression among those receiving ART).

We classified individuals as *retained in care* if they had ≥ 2 HIV-related laboratory tests (CD4 count or viral load) ≥ 90 days apart during each calendar year. This measure has demonstrated high correlation with the Health Resources and Services Administration (HRSA) definition for retention in care of ≥ 2 HIV primary care visits ≥ 90 days apart in a calendar year.²² We excluded the initial year of care from the retention in care denominator if the patient entered care in the final quarter of a calendar year; similarly, we excluded the year of death from the retention in care denominator if the patient died in the first quarter of a calendar year. We used indicators recommended by the Department of Health and Human Services for *ART prescription* (prescription of ≥ 1 regimen of ≥ 3 active ARV agents in a year) and *viral suppression* (HIV RNA measurement of < 200 copies/ μ L for the last measured viral load during each calendar year).²³

Other variables

Other variables extracted from data sources included age, date of HIV diagnosis, date of entry to care, clinic setting (infectious diseases clinic, community-based primary care clinic, other), HIV risk factor [heterosexual, men who have sex with men, injection drug use (IDU), other], CD4⁺ T-cell counts, HIV RNA measurements, diagnoses of comorbid depression, psychotic disorder, or substance use disorder (based

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF STUDY PATIENTS AT ENTRY TO OUTPATIENT HIV CARE, BY IMMIGRATION STATUS, 2006–2014 (N=7551)

	<i>Undocumented</i> (N = 173)	<i>Documented</i> (N = 7,378)	p
Demographic characteristics			
Year entered care, <i>n</i> (%)			
Before 2000	12 (6.9)	2,011 (27.3)	<.0001
2000–2005	42 (24.3)	1,982 (26.9)	
2006–2009	55 (31.8)	1,784 (24.2)	
2009–2014	64 (37.0)	1,601 (21.7)	
Facility, <i>n</i> (%)			
Community-based primary care clinic	41 (23.7)	1,317 (17.9)	.03
Infectious diseases clinic	115 (66.5)	4,888 (66.3)	
Other ^a	17 (9.3)	1,173 (15.9)	
Mean age at entry to care, years (SD)	37.8 (11.4)	40.6 (10.9)	<.001
Female, <i>n</i> (%)	55 (31.8)	3,187 (43.2)	<.01
Race/ethnicity, <i>n</i> (%)			
White non-Hispanic	4 (2.4)	313 (4.3)	.02
Black non-Hispanic	65 (39.2)	3,255 (45.2)	
Hispanic	89 (53.6)	3,489 (48.4)	
Other	8 (4.8)	148 (2.1)	
Clinical characteristics			
Comorbidities, <i>n</i> (%)			
Depression	15 (8.7)	718 (9.7)	.64
Psychotic disorder	8 (4.6)	414 (5.6)	.57
Substance use disorder	6 (3.5)	612 (8.3)	.02
Any mental health disorder	20 (11.6)	1,168 (15.8)	.12
HIV risk factor, <i>n</i> (%)			
IDU ^b	5 (2.9)	1,326 (18.0)	.0001
MSM	37 (21.4)	1,268 (17.2)	
Heterosexual	100 (57.8)	3,594 (48.8)	
Other	12 (6.9)	466 (6.3)	
Unknown	19 (11.0)	724 (9.8)	
Incident HIV diagnoses, <i>n</i> (%)	62 (35.8)	1,625 (22.0)	<.0001
Median baseline CD4 count, cells/mm ³ (IQR)	299 (150–450)	341 (164–560)	.01
Baseline CD4 count, cells/mm ³			
<200	59 (34.1)	2,187 (29.6)	.02
200–349	39 (22.5)	1,567 (21.2)	
350–500	40 (23.1)	1,333 (18.1)	
>500	35 (20.2)	2,291 (31.0)	

^aIncludes substance abuse treatment programs and the adolescent HIV clinic.

^bIncludes individuals who identified IDU and MSM as primary HIV risk factor.

IDU, injection drug use; IQR, interquartile range; MSM, men who have sex with men.

on ICD-9-CM codes),²⁴ and date of death. To determine whether patients were newly diagnosed with HIV, we compared the first date indicating HIV-infected status in the EMR (e.g., date of positive HIV Western blot, Multispot test, or detectable HIV viral load) with the date of HIV diagnosis reported in AIRS. Individuals diagnosed with HIV while in care at MMC or within 1 month before entry to care at MMC were considered newly diagnosed with HIV, that is, incident cases; the remaining were considered prevalent cases.

Data analyses

We first compared baseline characteristics of undocumented and documented patients using the chi-squared test for categorical variables and the Student *t*-test or Mann–Whitney test for continuous variables. We next examined outcomes for each step along the HIV care continuum over each year in care. For each individual, we assessed retention in care, ART prescription and viral suppression for every year in care. Patients

were followed for up to 9 years. For each of these outcomes, we assessed trends over time, as well as differences in trends between undocumented and documented patients, using a Poisson regression model that included immigration status, calendar year, and an interaction term for these two variables.

We determined risk ratios (RRs) and 95% confidence intervals (95% CIs) of outcomes by immigration status with bivariate and multivariable Poisson regression models. We included the following variables in multivariable models based on review of the literature: patient sex, age, race/ethnicity, year of entry to care, clinic site, HIV risk factor, diagnosis of substance use, and first CD4 count and viral load of each year of the analysis. Given potential clinical and epidemiologic differences among newly diagnosed patients and patients transferring care from an outside institution, we included incident versus prevalent HIV diagnosis at entry to care as a variable in the model as well. We assessed interaction between immigration status and relevant baseline variables at a statistical significance of $p < .05$. To account for within-individual

correlation of repeated outcomes across years, we used a Generalized Estimating Equation (GEE) with unstructured working correlation.

A sensitivity analysis repeated all of the above analyses comparing undocumented patients whose immigration status had been confirmed by chart review with documented patients. All statistical tests were two sided with statistical significance set at $p < .05$. Analyses were conducted using SAS v9.4 (Cary, NC).

Ethical considerations

To determine immigration status, we queried the EMR for patients who met the SSN and insurance criteria described above. A single investigator reviewed SSN data. SSN was used only for this purpose and only for this specific study. This study was approved by the institutional review board of the Albert Einstein College of Medicine and adhered to the tenets of the Declaration of Helsinki.

Results

A total of 7,551 eligible patients were followed for a median of 5 years [interquartile range (IQR) 2–9]. Mean age was 40.6 years (SD 10.7). Most patients were Hispanic (47%) or Black non-Hispanic (44%), and 57% were male. We classified 173 (2.3%) as undocumented.

Demographic and clinical characteristics of documented and undocumented patients at entry to care are shown in Table 1. Compared to documented patients, undocumented patients were younger (mean age in years: 37.8 vs. 40.6, $p < .001$), less likely to have a substance abuse diagnosis (3.5% vs. 8.3%, $p = .02$), less likely to report IDU as their primary HIV risk factor (2.9% vs. 18.2%, $p < .0001$), and less likely to have been diagnosed with HIV before entry to care at MMC (64.2% vs. 78.0%, $p < .0001$). Median CD4 count was lower for undocumented than documented patients [in cells/mm³: 299 (IQR 150–450) vs. 341 (IQR 164–560), $p < .01$]. Data on country of origin were available from the medical

records of 101 of 173 undocumented patients (58%). Of these, 37% were from Central America, including Mexico, 27% from the Caribbean, 22% from sub-Saharan Africa, and 10% from South America.

Figure 1 presents proportions of documented and undocumented individuals retained in care, prescribed ART, and achieving viral suppression for each year from 2006 to 2014. Proportions for each care continuum outcome increased over time overall and within each group defined by immigration status (all $p < .05$). When we compared documented and undocumented patients with respect to increases over time in rates of retention in care, ART prescription, and viral suppression, we found no significant differences.

In bivariate regression models, compared to documented status, undocumented immigration status was associated with increased probability of retention in care (RR = 1.11, 95% CI 1.06–1.18), ART prescription (RR 1.07, 95% CI 1.03–1.11), and viral suppression (RR 1.15, 95% CI 1.10–1.21). After adjustment in full multivariable models, these associations remained significant; compared to documented patients, undocumented patients were more likely to be retained in care (RR = 1.05, 95% CI 1.01–1.09), prescribed ART (RR 1.05, 95% CI 1.01–1.08), and achieve viral suppression (RR 1.13, 95% CI 1.08–1.19). Other demographic and clinical factors were associated with care continuum outcomes in expected directions (Table 2).

In sensitivity analyses, we compared undocumented individuals whose immigration status had been confirmed by chart review ($n = 101$) to documented individuals with respect to retention in care, ART prescription, and viral suppression. Results obtained from bivariate and multivariable regression models did not substantially differ from models that included all 173 patients classified as undocumented.

Discussion

Beyond the linguistic, financial, and cultural barriers they frequently encounter because of their foreign-born status,²⁵

FIG. 1. Proportion of patients retained in care[§], prescribed ART,[¶] and virally suppressed[^] by immigration status, 2006–2014. [§]Defined as ≥ 2 HIV-related laboratory tests (CD4 count or viral load) ≥ 90 days apart. [¶]Defined as ≥ 3 active ARV agents prescribed in a year. [^]Defined as HIV RNA < 200 copies/ml on last measurement of year. ART, anti-retroviral therapy.

TABLE 2. MODELED ASSOCIATIONS BETWEEN PATIENT CHARACTERISTICS AND OUTCOMES ALONG THE HIV CARE CONTINUUM, 2006–2014

	<i>Retention in care^a</i> <i>Risk ratio (95% CI)</i>	<i>ART prescription^b</i> <i>Risk ratio (95% CI)</i>	<i>Viral suppression^c</i> <i>Risk ratio (95% CI)</i>
Immigration status			
Documented	Reference		
Undocumented	1.05 (1.01–1.10)	1.05 (1.01–1.08)	1.13 (1.08–1.19)
Year of entry into care			
2010–2013	Reference		
2006–2009	1.04 (1.02–1.08)	0.94 (0.92–0.96)	0.96 (0.93–0.99)
2000–2005	1.05 (1.03–1.08)	0.96 (0.94–0.97)	0.95 (0.92–0.98)
<2000	1.07 (1.04–1.09)	0.97 (0.95–0.99)	0.96 (0.93–0.99)
Sex			
Male	Reference		
Female	1.02 (1.00–1.03)	0.98 (0.96–0.99)	0.98 (0.96–1.00)
Race			
Hispanic	Reference		
Black	0.97 (0.96–0.97)	0.99 (0.97–1.00)	0.98 (0.96–0.997)
White	0.96 (0.93–0.99)	0.97 (0.93–1.004)	1.05 (0.99–1.10)
Other	0.98 (0.93–1.02)	1.01 (0.96–1.05)	1.04 (0.97–1.12)
10-year increase in age	1.03 (1.026–1.038)	1.05 (1.04–1.06)	1.08 (1.07–1.09)
Diagnosis category			
Prevalent case	Reference		
Incident case	0.99 (0.97–1.01)	0.97 (0.95–0.99)	0.97 (0.95–1.00)
Clinic			
Infectious Diseases Clinic	Reference		
Community Primary Care	0.98 (0.96–0.99)	1.02 (0.999–1.03)	1.09 (1.07–1.12)
Other ^d	0.99 (0.97–1.02)	0.87 (0.85–0.90)	0.99 (0.95–1.03)
HIV risk factor			
Heterosexual	Reference		
IDU	0.98 (0.97–1.00)	0.96 (0.94–0.98)	0.95 (0.92–0.98)
MSM	1.00 (0.98–1.02)	1.01 (0.98–1.03)	1.06 (1.03–1.09)
Other	0.93 (0.90–0.96)	0.99 (0.96–1.02)	0.94 (0.89–0.99)
Unknown	0.89 (0.86–0.92)	0.97 (0.94–1.00)	0.96 (0.91–0.99)
Substance use diagnosis			
No	Reference		
Yes	0.98 (0.95–1.00)	0.99 (0.96–1.02)	0.96 (0.92–1.01)
CD4 count (cells/ μ l)			
>500	Reference	Reference	
350–500	0.99 (0.97–0.99)	1.02 (1.00–1.03)	0.93 (0.91–0.94)
200–349	0.96 (0.95–0.97)	1.07 (1.05–1.08)	0.84 (0.82–0.86)
<200	0.91 (0.90–0.93)	1.11 (1.10–1.13)	0.70 (0.68–0.72)

^aDefined as ≥ 2 HIV-related laboratory tests (CD4 count or viral load) ≥ 90 days apart.

^bART prescription, defined as ≥ 3 active ARV agents prescribed in a year.

^cDefined as HIV RNA <200 copies/ml on last measurement of year.

^dIncludes substance abuse treatment programs and the adolescent AIDS program ART, antiretroviral therapy; IDU, injection drug user.

undocumented immigrants face several unique impediments to healthcare, including limited access to health insurance, stigma, high levels of acculturation stress, and fear of deportation.^{6–8,26} We found that undocumented immigrants entered care with more advanced disease compared to documented persons, a result that may be explained by barriers in initially accessing care. Once engaged in care, however, we found that undocumented patients achieved rates of retention in care, ART prescription, and viral suppression that were as good as or better than documented patients. Our results are similar to those reported in other studies of undocumented and documented HIV-infected immigrants^{4,27,28} and suggest that if barriers to accessing care are overcome, HIV-infected undocumented immigrants can succeed in clinical care.

Several factors may have contributed to the ability of undocumented patients in our cohort to successfully achieve outcomes along the HIV care continuum. We observed low rates of substance use disorders among undocumented patients, a finding similar to other studies of undocumented immigrants.^{29,30} This may be indicative of other health-promoting behaviors that facilitate engagement in care. Other unmeasured characteristics among undocumented immigrants, for example, social and community support, may also promote retention in care and adherence to medications.³¹ Access to insurance very likely contributed to continued engagement of undocumented patients in HIV care as well. In our cohort, many undocumented patients obtained medical insurance through NY State ADAP, eliminating a major

barrier to healthcare. ADAP is federally funded through the Ryan White Program and is available to HIV-infected patients meeting state eligibility criteria, including undocumented immigrants. NY State's ADAP is one of the most generous in the country, and one of the only programs that provides both insurance and prescription medication benefits to all of its clients.³²

We are aware of only one other published study examining clinical outcomes of HIV-infected undocumented immigrants.⁴ Our findings, which are in agreement with their results, add to the limited literature on HIV-infected undocumented immigrants in several respects. First, our analysis included 9 years of follow-up data, allowing us to assess outcomes beyond the first year of care and to provide a more comprehensive assessment of retention in care, ART prescription, and viral suppression. Second, our study was not limited to undocumented Hispanics, as nearly half of the undocumented patients in our cohort were from sub-Saharan Africa or the Caribbean. Our results are therefore more generalizable to the broader undocumented population in the United States. Finally, Poon, *et al.* defined undocumented immigrants using only missing or invalid SSN, an approach that may have misclassified persons who were missing SSN for other reasons. We believe that the potential for information bias is reduced in our study, both because of the combined use of SSN and insurance data and because we found similar results when restricting analyses only to patients whose immigration status was confirmed.

Only 2.3% of our cohort was undocumented, while the undocumented population of the Bronx is estimated to be between 8% and 9%.¹⁹ This discrepancy may be due to a few factors. In New York City, foreign-born persons are diagnosed with HIV at a lower rate than nonforeign born,³³ and thus, the prevalence of HIV may be lower in the undocumented population than the general population. It is also possible that a substantial proportion of HIV-infected undocumented persons are not diagnosed or linked to care, an idea supported by our finding that they present to care later than documented individuals. Our cohort was limited to persons who were already linked to care, and further studies are needed in this population on earlier outcomes in the HIV care continuum.

Several limitations of this study are worth noting. The cohort we studied was restricted to patients from a single health system who are HIV infected and live in a state where specific insurance is available to undocumented immigrants, characteristics that may limit the generalizability of our findings. It is also possible that some patients transferred care or were getting additional care elsewhere. Because our analysis was retrospective, we were unable to examine additional factors (e.g., income and education level) that may influence clinical outcomes. Moreover, some of the variables we examined, including substance use and HIV risk factor, could have been subject to social desirability bias and thus our findings may not accurately reflect the prevalence of these behaviors in the HIV-infected undocumented immigrant population. This bias is particularly relevant given the substantial stigma undocumented immigrants face and the potential fear of disclosure they may experience when interacting with the healthcare system. Finally, we were not able to definitively determine immigration status for every patient in the cohort, and use of SSN and insurance to classify immigration status may have misclassified some individuals.

In conclusion, in our cohort, HIV-infected undocumented immigrants in the Bronx achieved retention in care, ART prescription, and viral suppression at rates that were modestly higher than documented persons, despite entering care with more advanced disease. Our findings suggest that programs providing insurance and prescription medications to HIV-infected undocumented immigrants may promote achievement of desired outcomes on the HIV continuum of care. As health policy goals turn toward ending the HIV epidemic, expanding the provision of such services to all HIV-infected undocumented immigrants in areas where they are currently unavailable has the potential to improve the public health.

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Author Disclosure Statement

Dr. Cunningham's husband is an employee of Quest Diagnostics and they own stock and stock options in Quest Diagnostics. All other authors report no competing financial interests.

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