Published in final edited form as:

AIDS Care. 2017 December ; 29(12): 1491–1498. doi:10.1080/09540121.2017.1307921.

Emerging from the database shadows: characterizing undocumented immigrants in a large cohort of HIV-infected persons

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Abstract

Little is known about how HIV affects undocumented immigrants despite social and structural factors that may place them at risk of poor HIV outcomes. Our understanding of the clinical epidemiology of HIV-infected undocumented immigrants is limited by the challenges of determining immigration status in large data sets. We developed an algorithm to predict undocumented immigration status using social security number (SSN) and insurance data. We retrospectively applied this algorithm to a cohort of HIV-infected adults receiving care at a large urban healthcare system who attended at least one HIV-related outpatient visit between January 1997 and December 2013, classifying patients as “screened undocumented” or “documented”. We then reviewed the medical records of screened undocumented patients, classifying those whose records contained evidence of undocumented immigration status as “undocumented per medical chart” (charted undocumented). Bivariate measures of association were used to identify demographic and clinical characteristics associated with undocumented immigrant status. Of 7,593 patients, 205 (2.7%) were classified as undocumented by the algorithm. Compared to documented patients, undocumented patients were younger at entry to care (mean 38.5 years vs. 40.6 years, $p<0.05$), less likely to be female (33.2% vs. 43.1%, $p<0.01$), less likely to report injection drug use as their primary HIV risk factor (3.4% vs. 18.0%, $p<0.001$), and had lower median CD4 count at entry to care (288 cells/mm³ vs. 339 cells/mm³, $p<0.01$). After medical record review, we re-classified 104 patients (50.7%) as charted undocumented. Demographic and clinical characteristics of charted undocumented did not differ substantially from screened

undocumented. Our algorithm allowed us to identify and clinically characterize undocumented immigrants within an HIV-infected population, though it overestimated the prevalence of patients who were undocumented.

Keywords

undocumented immigrants; immigrants; HIV; electronic health records; disparities

INTRODUCTION

An estimated 11.7 million undocumented immigrants live in the United States (US) (Passel & Cohn, 2014). Social and structural factors, including restricted access to health services (Fuentes-Afflick & Hessol, 2009; Munro, Jarvis, Munoz, D'Souza, & Graves, 2013), negative experiences of medical care (Chandler, Malone, Thompson, & Rehm, 2012; Ortega et al., 2007), and low socioeconomic status (Passel & Cohn, 2009), may place this population at risk of poor health outcomes. Little is known about undocumented immigrants living with HIV. Qualitative studies suggest that they face unique barriers to engaging in care (Dang, Giordano, & Kim, 2012; Kang, Rapkin, Springer, & Kim, 2003). One study of undocumented Hispanic patients from a single HIV clinic in Texas found that, compared to other groups, they were less likely to report injection drug use [IDU] and entered care with more advanced disease (Poon, Dang, Davila, Hartman, & Giordano, 2013). However, the population of HIV-infected undocumented immigrants has not been well-characterized in a large heterogeneous sample.

An understanding of HIV epidemiology in undocumented immigrants has been limited by difficulty in accurately identifying this population. Of the limited number of original research studies published on undocumented immigrants, many have utilized self-report to establish immigration status (Dang et al., 2012; Hadley, Galea, Nandi, Nandi, & Lopez, 2008; Montealegre, Risser, Selwyn, McCurdy, & Sabin, 2012; Nandi, Galea, Lopez, Nandi, & Strongarone 2008; Prentice, Pebley, & Sastry, 2005). Such an approach is not feasible for investigations utilizing clinical, epidemiologic or administrative datasets, as data on immigration status are not routinely collected in these settings. No standardized method exists for determining immigration status using information available in these datasets, and methods previously used to estimate immigration status are problematic for the following reasons. The use of missing or invalid Social Security number (SSN) (Castro-Echeverry et al., 2013; Poon et al., 2013) to identify undocumented immigrants likely overestimates this population, as SSN data may be missing for many reasons other than being undocumented. Inferring undocumented status from utilization of Emergency Medicaid (Reed, Westfall, Bublitz, Battaglia, & Fickenscher, 2005) – insurance available to undocumented immigrants in some states for emergency inpatient care – may also misclassify individuals as undocumented, and is not generalizable to outpatient settings. Predictive models employing country of birth, years of residence in US, employment status, and/or income (Hall & Stringfield, 2014; Pourat, Wallace, Hadler, & Ponce, 2014) may improve estimates of the undocumented population, but include information that is not typically collected in clinical

or administrative settings. Thus, more generalizable and accurate approaches for defining undocumented immigration status are needed.

The National HIV/AIDS Strategy calls for focusing prevention and treatment efforts on high-risk populations (White House, 2015). To fully appreciate how undocumented immigrant status may be associated with HIV outcomes, we must first be able to accurately identify these individuals. Therefore, we aimed to develop and evaluate a method for identifying undocumented immigrants in a database of HIV-infected patients from a large, multi-site healthcare system and to describe their demographic and clinical characteristics at entry into care.

METHODS

Setting

An estimated 850,000 undocumented immigrants reside in New York State (NY) (Migration Policy Institute, 2016). Though ineligible for most public benefits, they can obtain payment for emergency conditions requiring hospitalization through Emergency Medicaid. Additionally, HIV-infected undocumented immigrants who are NY residents with incomes below 435% of the federal poverty line can obtain insurance 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 US (U.S. Census Bureau, 2014), has an HIV prevalence of 2.0% (New York City Department of Mental Health and Hygiene, 2015) and is home to an estimated 114,000 undocumented immigrants (Fiscal Policy Institute, 2006). This study was conducted at an academic medical center and integrated healthcare delivery system that is the largest healthcare provider in the Bronx, with four acute care hospitals and over 50 ambulatory care sites. All sites share an electronic medical record (EMR) that was introduced in 1997 and includes patient problem lists, visit and billing history, and laboratory test results. Outpatient HIV care is provided at clinics that receive funding from the NY Ryan White Program and are therefore required to report data to the NY State AIDS Institute Reporting System (AIRS). Reported data include demographic characteristics, HIV risk factors, substance use, laboratory tests, and medication utilization. Immigration status is not reported to or collected in AIRS.

Population

We included all HIV-infected persons at least 18 years old who entered care between January 1, 1997 and December 31, 2013 and had data available from AIRS. 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 3 undetectable HIV-1 viral loads ordered concurrently with a CD4 count (Hanna, Felsen, Ginsberg, Zingman, & Beil, 2016).

Data source

We extracted sociodemographic information, SSN, insurance status, laboratory data, and billing information (*International Classification of Disease, 9th Revision, Clinical*

Modification [ICD-9-CM] from the EMR. We obtained additional data on demographic characteristics, HIV diagnosis date and HIV risk factors from AIRS. Electronic data from the EMR and AIRS underwent data quality assurance and were then combined in a centralized location. To obtain further evidence of undocumented status and identify region of origin, we manually reviewed patient charts, examining notes written by physicians, nurses and social workers.

Determination of undocumented status

To determine undocumented status, we first screened patients who met inclusion criteria to identify those with: 1) missing or invalid SSN and 2) insurance status recorded as no insurance, self-pay, Emergency Medicaid, or ADAP. We classified patients meeting these criteria as *screened undocumented* and all others as *documented* (Figure 1). Subsequently, one author manually reviewed medical records of all screened undocumented patients, examining text for evidence of undocumented status. Immigration status is not routinely collected by administrators or clinicians at study sites; however, individual clinicians may inquire about and record undocumented status as part of the provision of medical services. Patients whose records contained explicit mention of undocumented status or indications of ineligibility for services because of immigration status were re-classified as *undocumented per medical chart (charted undocumented)*. We re-categorized the remainder as *misclassified* if records contained evidence of US citizenship or legal immigration status, or having *unknown status* if insufficient data were available to determine immigration status.

Other variables

Other variables extracted from data sources included age, region of origin, date of HIV diagnosis, date of entry to care, duration of known HIV diagnosis, HIV risk factor (heterosexual, men who have sex with men [MSM], IDU, other), CD4 count, HIV viral load, and diagnoses of comorbid depression, psychotic disorder or substance use disorder (based on ICD-9-CM diagnosis codes) (Elixhauser, Steiner, Harris, & Coffey, 1998). We limited collection of region of origin to charted undocumented patients given the proportion of screened undocumented who were misclassified or missing data on region of origin. Individuals diagnosed with HIV while in care, or within 1 month prior to entry to care, were considered incident HIV cases; the remainder were considered prevalent cases.

Data analyses

To examine whether characteristics differed between groups of patients whose medical records were reviewed, we compared charted undocumented patients, misclassified patients and those with unknown status using ANOVA or Kruskal-Wallis tests for continuous variables and Chi-square or Fisher's exact tests for categorical variables. To examine differences in characteristics between groups identified by the algorithm, we compared screened undocumented with documented patients using the same tests for categorical variables and the Student t-test or Mann-Whitney test for continuous variables. We then repeated this analysis, comparing charted undocumented with documented patients. All statistical tests were two-sided with statistical significance set at $p < 0.05$. Analyses were conducted using SAS v9.4 (Cary, NC).

Ethical considerations

In order to determine undocumented status, we queried the EMR for patients who met the SSN and insurance criteria described above. SSN was used only for this purpose and only for this specific study. Medical records were reviewed by a single investigator. After medical record review, SSN and all other identifying information were deleted from the dataset. This study was approved by the institutional review board of the medical center.

RESULTS

Of the 7,593 HIV-infected patients with available data, 3,254 (42.9%) were female and 3,056 (40.2%) were incident HIV cases. Mean age at entry to care was 40.6 years (SD 10.7) while median duration of known HIV diagnosis was 1.2 years (IQR 0–8.3). Using SSN and insurance data, we classified 205 patients (2.7%) as screened undocumented. After medical record review of these 205 patients, we categorized 104 (50.7%) as charted undocumented, 50 (24.4%) as misclassified, and 51 (24.9%) as having unknown status. Demographic and clinical characteristics of charted undocumented did not differ significantly from the 50 misclassified and 51 patients with unknown status (data not shown).

Screened undocumented versus documented patients

Demographic and clinical characteristics at entry to care for screened undocumented, charted undocumented, and documented patients are shown in Table 1. Screened undocumented, compared to documented patients, were younger (mean age 38.5 years [SD 11.5] vs. 40.6 years [SD 10.7], $p<0.05$) and less likely to be female (31.7% vs. 43.1%, $p<0.01$) or report IDU as their primary HIV risk factor (2.9% vs. 18%, $p<0.001$). Median CD4 count was lower for screened undocumented than documented patients (in cells/mm³: 288 vs. 399, $p<0.01$).

Charted undocumented versus documented patients

Charted undocumented, compared to documented patients, were younger (mean age 37.9 years [SD 11.3] vs. 40.6 years [SD 10.7], $p<0.01$) and less likely to be female (33.2% vs. 43.1%, $p<0.05$) or report IDU as their primary HIV risk factor (3.4% vs. 18.0%, $p<0.001$). Median CD4 count was lower for charted undocumented than documented patients (in cells/mm³: 288 vs. 399 $p<0.05$).

Data on region of origin were available for 102 of 104 charted undocumented and are presented in Figure 2. Most patients were from Central America (37.3%), the Caribbean (26.5%) or Sub-Saharan Africa (21.6%).

DISCUSSION

We developed and assessed a screening algorithm using SSN and insurance status to determine undocumented status in a large, diverse administrative dataset of HIV-infected patients. Although the algorithm overestimated the number of persons who were undocumented, characteristics of screened undocumented and charted undocumented patients were similar, demonstrating that our algorithm can feasibly be used to provide

important epidemiologic data on HIV-infected undocumented immigrants from administrative datasets. Characterizing this population has important public health implications.

We found substantial differences in available demographic and clinical characteristics of undocumented immigrants compared to those who were documented. Undocumented immigrants in our study were younger, less likely to be female or to report IDU as their primary HIV risk factor. These results are similar to those reported in a study of HIV-infected undocumented Hispanics in Texas (Poon et al., 2013) and in studies of HIV-infected immigrants in general (Carten, Castillo-Mancilla, Allshouse, & Johnson, 2013; Crawford, Caldwell, Bush, Browning, & Thornton, 2012). The low proportion of undocumented patients in our cohort reporting IDU is consistent with studies describing lower rates of substance use in immigrant populations compared to U.S.-born persons (Ojeda, Patterson, & Strathdee, 2008; Vega, Sribney, & Achara-Abrahams, 2003). Rates of substance use among immigrants rise with increasing acculturation and duration of residence in the U.S. (Borges et al., 2016; Ortega, Rosenheck, Alegria, & Desai, 2000). Compared to documented immigrants, undocumented immigrants have a lower median duration of residence in the U.S. (Passel & Cohn, 2009) and have lower levels of acculturation (Arbona et al., 2010), and may therefore be less likely to have substance use disorders. Other potential reasons for the low proportion of undocumented patients reporting IDU include under-reporting secondary to social desirability (Maldonado, Rodriguez, Torres, Flores, & Lovato, 2013), and a study sample that may not be fully representative of the broader population of HIV-infected undocumented immigrants.

Compared to documented persons, undocumented patients in this study entered care with more advanced disease as indicated by lower median CD4 count, findings consistent with prior studies of HIV-infected immigrants (Prosser, Tang, & Hall, 2012), including undocumented immigrants (Poon et al., 2013). Studies of HIV-infected foreign-born persons indicate that most were infected after arrival in the U.S. (Wiewel, Torian, Hanna, Bocour, & Shepard, 2015), suggesting that delays in HIV diagnosis for undocumented immigrants may result from barriers to entering care. Barriers to healthcare for undocumented immigrants that may lead to underutilization of healthcare can be organized into predisposing factors, structural factors, and available resources (Leclerc, Jensen, & Biddlecom, 1994). These include negative experiences of medical care, stigma, fear of deportation, restricted access to health services and lack of a regular healthcare provider (Chandler et al., 2012; Fuentes-Afflick & Hessol, 2009; Munro et al., 2013; Rhodes et al., 2015). In addition to these barriers, HIV-infected undocumented immigrants may also face an additional layer of stigma from their own communities secondary to their HIV status (Dang et al., 2012).

Previous studies examining HIV among undocumented immigrants in the U.S. have largely focused on the Latino population. We found that over 20% of undocumented HIV-infected immigrants in our study were from sub-Saharan Africa, even though Africans make up only 10% of foreign-born persons in the Bronx (New York City Department of City Planning, 2013). We are not aware of published data describing race and ethnicity of undocumented immigrants in the Bronx. It is unclear whether the observed overrepresentation may be due to high rates of HIV infection among African-born immigrants in New York City (Wiewel et

al., 2015), or whether, compared to other undocumented groups, African immigrants more successfully navigated the healthcare system.

An estimated 8% of the population in the Bronx are undocumented immigrants (Fiscal Policy Institute, 2007); however, fewer than 3% of patients in this cohort were classified as screened undocumented. This discrepancy may be due to several reasons. First, although no data on the prevalence of HIV among undocumented immigrants have been published, it may be lower than that of the general population. This hypothesis is supported by data from a study of HIV diagnosis rates in New York City that found lower annual rates of HIV diagnosis among foreign-born persons compared to individuals born in the US (Wiewel, Torian, Nasrallah, Hanna, & Shepard, 2013). Second, we limited our analysis to patients with data in AIRS – comprised overwhelmingly of patients with at least one HIV-related outpatient visit – and thus did not capture HIV-infected undocumented immigrants who have never been diagnosed or linked to care. Third, it is possible that undocumented patients in the Bronx may disproportionately seek care at other clinics and hospitals, i.e. the safety-net public hospital system in New York City. Finally, our algorithm did not capture undocumented immigrants who may have procured SSNs or purchased private health insurance.

The use of medical records to ascertain undocumented status in a large dataset is a novel approach and adds to the robustness of the algorithm used. We observed few differences in the characteristics of screened and charted undocumented patients, indicating that our algorithm can provide important, clinically- and epidemiologically-relevant information on HIV-infected undocumented immigrants. Nonetheless, we recognize several limitations to this method. Nearly one-quarter of individuals screened by our algorithm were incorrectly classified as undocumented, and this may have occurred for several reasons. Because SSN and insurance information may be missing from clinical or administrative records for a number of reasons, use of these variables may have resulted in misclassification. Moreover, immigration status may shift over time, thus patients may have entered care as undocumented immigrants but subsequently obtained legal status. The retrospective, cross-sectional design of this study did not allow us to measure immigration status at multiple points in time. An additional 25% of patients had no indication of immigration status in their medical charts. While clinicians may record immigration status as an important and relevant element of undocumented patients' healthcare, these data are not routinely collected, nor are there institutional guidelines with respect to how immigration status should be recorded in the confidential medical record. Moreover, because these assessments are not standardized, it is possible that providers may have incorrectly identified some patients as undocumented.

The misclassification of immigration status among a sizeable proportion of screened undocumented patients suggests it should be used selectively. Despite the utility of this algorithm for determining characteristics of undocumented immigrants in the aggregate, it should not be used to predict individual patients' documentation status, given the possibility of misclassification as well as risk of further stigmatizing both undocumented and documented HIV-infected patients. Overall, while our algorithm contributes to the very limited knowledge on HIV-infected undocumented immigrants, investigators utilizing this

methodology must exercise caution when using this method to determine immigration status in clinical or administrative datasets.

This study has several additional limitations. First, because we restricted our analysis to patients that attended at least one HIV-related outpatient visit as noted above, the findings may not be generalizable to the broader population of HIV-infected individuals who have not linked to care. Similarly, the cohort 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 the algorithm used. Finally, because data on country of origin were not available for the entire cohort, we were unable to compare undocumented immigrants to all immigrants. It is possible that some of the observed differences between undocumented immigrants and others were due to factors associated with being an immigrant rather than being undocumented.

In conclusion, we developed an algorithm that allowed us to characterize undocumented immigrants within an HIV-infected population. Understanding the clinical epidemiology of HIV-infected undocumented immigrants is of high importance, yet classifying this group remains difficult. The legal and ethical challenges of implementing a more systematic method for assessing immigration status justifies the need to develop algorithms such as ours to identify these high-need and high-risk individuals. As public health goals turn towards ending the HIV epidemic, comprehending its impact on undocumented immigrants will be essential to improve the health care of this specific population and society at large.

Acknowledgments

This work was supported in part by the National Center for Research Resources under Grants UL1RR025750, KL2RR025749 and TL1RR025748, the National Institute on Drug Abuse under Grants K24DA036955 and R25DA023021, and the National Institute of Mental Health under Grants K23MH106386 and K23MH102118. The authors would like to acknowledge Mindy Ginsberg and Martin Packer for their assistance in obtaining and organizing the data.

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^a SSN: social security number

^b ADAP: AIDS Drug Assistance Program

Figure 1.
Flowchart showing ascertainment of undocumented status.

Figure 2.
Geographic region of origin for *charted undocumented* (N=104).

Table 1

Demographic and clinical characteristics of HIV-infected adults at entry to care, by immigration status (N=7593).

	Screened undocumented ^d (N=205)	Charted undocumented ^b (N=104)	Documented (N=7388)
Female gender, n (%)	68 (33.2) **	33 (31.7) *	3186 (43.1)
Mean age, y (SD)	38.5 (11.1) *	37.9 (11.3) **	40.6 (10.7)
Comorbidities			
Depression diagnosis ^e , n (%)	18 (8.8)	12 (11.5)	716 (9.7)
Psychotic disorder diagnosis ^e , n (%)	9 (4.4)	6 (5.8)	415 (5.6)
Substance use disorder diagnosis ^e , n (%)	8 (3.9) *	5 (4.8)	615 (8.3)
HIV Risk Factor, n (%)			
Injection drug use ^f	7 (3.4) **	3 (2.9) **	1326 (18.0)
Men who have sex with men	47 (22.9)	23 (22.1)	1270 (17.8)
Heterosexual contact	114 (55.6)	61 (58.7)	3597 (48.7)
Other	12 (5.9)	8 (7.7)	467 (6.3)
Unknown	25 (12.2)	9 (8.7)	728 (9.9)
Median duration of HIV infection, y (IQR)	0.1 (0–2.8) **	0.1 (0–4.2) **	1.3 (0–8.4)
Incident HIV diagnosis at entry to care, n (%)	117 (57.1)	50 (48.1)	2939 (39.8)
Median CD4 count, cells/mm ³ (IQR)	288 (140–450) **	288 (150–433) *	339 (162–555)
Prevalent cases ^g with suppressed viral load, n (%)	27 (30.7)	18 (33.3)	1076 (24.2)

^aIdentified by algorithm using social security number and insurance status; statistical associations reported for *screened undocumented* compared to *documented*

^bIdentified by manual medical record review; statistical associations reported for *confirmed undocumented* compared to *documented*

* p<0.05

** p<0.01

^cDefined by *International Classification of Disease, 9th Revision, Clinical Modification* (ICD-9-CM) codes 300.4, 301.12, 309.0, 309.1, 311 (*ref. 20*)

^dDefined by ICD-9-CM codes 295.00–298.9, 299.10, 299.11

^eDefined by ICD-9-CM codes 291.0–291.3, 291.5, 291.8–89, 291.9, 292.0, 292.82–292.9, 303.0–303.93, 304.0–304.93, 305.0–305.03, 305.2–305.93, 648.3–648.34

^fIncludes those who identified men who have sex with men *and* injection drug use as risk factors

$N=88$ for screened undocumented, $N=54$ for confirmed undocumented, $N=4449$ for documented

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