

Undocumented African Immigrants' Experiences of HIV Testing and Linkage to Care

Jonathan Ross, MD, MS,¹ Matthew J. Akiyama, MD, MSc,¹ Deepika Slawek, MD,¹ Jennifer Stella, MD,² Kim Nichols, MPH, ScM,³ Mulusew Bekele, BA, BS,³ Chinazo O. Cunningham, MD, MS,¹ and Oni J. Blackstock, MD, MHS⁴

Abstract

In the United States, undocumented African immigrants living with HIV enter care late, potentially leading to adverse individual and population health outcomes, yet little is known about the specific experiences of HIV diagnosis and linkage to care among this population. We conducted individual, semi-structured interviews with adults who were undocumented African immigrants living with HIV in New York City. Interviews explored perspectives regarding individual, social, institutional, and societal barriers and facilitators of HIV testing and linkage to care. Of 14 participants from 9 different African countries, 9 were women and the median age was 44 years (interquartile range: 42–50). Participants described fear of discovery by immigration authorities as a substantial barrier to HIV testing and linking to initial medical appointments. Actual and perceived structural barriers to both testing and care linkage included difficulty obtaining health insurance and a belief that undocumented immigrants are ineligible for any health services. Participants also expressed reluctance to be tested because of HIV-related stigma within the immigrant communities that they heavily relied on. After diagnosis, however, participants overwhelmingly described a positive role of health and social service providers in facilitating linkage to HIV care. Concerns about immigration status and HIV-related stigma are significant barriers to HIV testing and linkage to care among undocumented African immigrants. Multilevel efforts to reduce stigma and increase awareness of available services could enhance rates of HIV testing and care linkage in this population.

Keywords: HIV, African immigrants, undocumented immigrants, HIV testing, linkage to care

Introduction

IMMIGRATION FROM SUB-SAHARAN Africa to the United States more than doubled from 2010 to 2015. Immigrants from sub-Saharan Africa to the United States (hereafter, African immigrants) are disproportionately affected by HIV, with diagnosis rates three to six times that of the general US population.^{1,2} In New York City (NYC), an epicenter of the US HIV epidemic, African immigrants constitute ~4% of the foreign-born population but account for 15% of new HIV diagnoses among persons born outside the United States.² Undocumented African immigrants, like other groups with unauthorized immigration status in the United States, are often exposed to unique stressors that may limit their access to health services, including fear of deportation, marginalization, stigma regarding immigration status, and limited

access to social services and health insurance.^{3–6} Therefore, compared to those with legal immigration status, they may be at even greater risk of adverse HIV-related outcomes.

HIV testing, diagnosis, and linkage to care are the first steps in the HIV care continuum, the framework used to outline the sequential steps necessary for both the individual and public health to fully benefit from HIV care and antiretroviral therapy.⁷ Although no studies have specifically reported on care continuum outcomes among undocumented African immigrants, data on the more general population of African immigrants in the United States indicate that they are less likely than nonimmigrants to be tested for HIV,⁸ and among persons diagnosed with HIV are more likely to initiate care later than other immigrant and nonimmigrant groups.^{9–11} Identified barriers to HIV testing among African immigrants include sociocultural factors such as low English

¹Division of General Internal Medicine, Montefiore Medical Center/Albert Einstein College of Medicine, Bronx, New York.

²Division of Hospital Medicine, Zuckerberg San Francisco General/University of California, San Francisco, San Francisco, California.

³African Services Committee, New York, New York.

⁴New York City Department of Health and Mental Hygiene, New York, New York.

proficiency and HIV-related stigma, and structural factors such as lack of regular access to care.^{8,12–14} Limited data exist describing barriers to linkage to HIV care among African immigrants diagnosed with HIV; however, a study of social service providers in NYC highlighted immigration-related fears, competing stressors, and cultural beliefs as potential barriers to care linkage for immigrants in general.¹⁵

More restrictive immigration policies recently implemented by the US federal government have highlighted the potential health-related vulnerabilities of undocumented immigrants in the United States. While prior studies have explored barriers to HIV testing and receipt of HIV care among African immigrants living in the United States, to our knowledge, no studies have exclusively focused on those who have undocumented immigration status, nor explored in depth how their immigration status influences HIV testing and subsequent linkage to care. Therefore, we conducted a qualitative study to better understand individual, social, and structural factors influencing HIV testing and linkage to HIV care among undocumented African immigrants in NYC.

Methods

We conducted individual, semi-structured interviews of undocumented African immigrants living with HIV. The study was approved by the Institutional Review Board of the Albert Einstein College of Medicine.

Setting and participants

We conducted this study in NYC, where the HIV prevalence is 1.3% and the foreign-born population is >3 million persons, of whom an estimated 613,000 are undocumented.^{16,17} Given difficulties in identifying and engaging undocumented immigrants in research studies, we recruited a convenience sample of undocumented African immigrants living with HIV from a community-based organization (CBO) in NYC that provides legal, social, and health services to ~5000 predominantly immigrant clientele.

Participants

We recruited participants passively using recruitment flyers and by active referrals from staff at the CBO. We included clients who were (1) 18 years of age or older, (2) living with HIV by self-report, (3) born in Africa, (4) reported undocumented immigration status at the time of initial HIV diagnosis (if diagnosed in the United States) or at the time of initial linkage to care in the United States (if diagnosed before immigration), and (5) fluent in English or French. Participants were compensated with a \$25 gift card and an additional \$5.50 for transportation costs. Data were collected from March to September 2017.

Data collection

To avoid written documentation linking undocumented participants to this research study, we did not collect any identifying information and received a waiver for collecting written informed consent. After obtaining verbal informed consent, face-to-face semi-structured interviews were conducted by one of two internal medicine physicians experienced in conducting qualitative research, in English or French in a private room at the CBO. All interviews were

audio-recorded, professionally transcribed and translated to English if necessary.

An interview guide informed by the socio-ecological model (SEM)¹⁸ was developed to elicit participants' experiences with HIV testing and linkage to US-based care. According to the SEM, individual experiences, social networks, institutions, and society are all important domains affecting individual behaviors. Therefore, interview questions addressed these domains as they may relate to African immigrants' experiences of HIV testing and linkage to care, exploring individual feelings, social networks such as family or the immigrant community, institutional settings including hospitals and CBOs, and elements at the societal level such as immigration policy and laws. Guides were iteratively refined to clarify and further explore emerging themes.

Analysis

We analyzed data in an iterative process using a thematic analysis to describe barriers and facilitators of HIV testing and linkage to care. Three investigators (J.R., M.A., and D.S.) developed a coding scheme guided by the individual, social, institutional, and societal domains of the SEM to categorize common themes that emerged upon reading of the first three transcripts. Discrepancies in initial coding were discussed and resolved by consensus to develop a final coding scheme; all transcripts were then independently coded by at least two coders using DeDoose software (Hermosa Beach, CA). The coding team subsequently discussed content by code, examining relationships between codes, and using the constant comparative method to identify, refine, and consolidate emergent themes until saturation was achieved.

Results

Participant characteristics

Of 14 participants, 9 were female and the median age was 44 [interquartile range (IQR): 42–50] (Table 1). Immigrants came from nine different countries in West, Central and Eastern Africa, and had been living in the United States for as little as 1 month to as long as 20 years. Participants were diagnosed with HIV in the late 1990s ($n=5$), 2000–2010 ($n=6$), or 2011–2016 ($n=3$). Most ($n=11$) participants were

TABLE 1. PARTICIPANT CHARACTERISTICS (N=14)

Characteristic	N
Women, n (%)	9 (64)
Median age, years (IQR)	44 (42–50)
Language of interview	
French	3 (21)
English	11 (79)
Region of origin in Africa	
West Africa, n (%)	8 (57)
East or Central Africa, n (%)	6 (43)
Place of HIV diagnosis	
United States, n (%)	11 (79)
Africa, n (%)	3 (21)
Median years since immigration (IQR)	14 (1–20)
Median years since HIV diagnosis, years (IQR)	16 (12–18)

IQR, interquartile range.

diagnosed after immigration to the United States, typically either during prenatal evaluation or after presenting with symptoms of advanced AIDS, and all reported provider-initiated (rather than self-initiated) HIV testing. Median time since HIV diagnosis was 16 years (IQR: 12–18). Three interviews were conducted in French and the remainder in English. All participants were receiving HIV care at the time of the interviews.

Analysis revealed four major themes affecting participants' behaviors with respect to HIV testing and seeking care after diagnosis: (1) concerns or worries about participants' undocumented immigration status, (2) difficulties obtaining health insurance, (3) anticipated and experienced social isolation, and (4) social and health service providers as allies.

Concerns or worries about participants' undocumented immigration status

A common barrier to not getting tested for HIV, or seeking HIV care after diagnosis, was a climate of fear surrounding immigration-related consequences of accessing health care. Participants viewed a potential HIV diagnosis through the lens of their precarious immigration status, worrying that contact with the health care system could ultimately lead to deportation. A 44-year-old woman from Tanzania who was diagnosed with HIV during pregnancy, recalling her thoughts before her diagnosis, stated, "If I go in and get tested and if they find out that I am positive, then next thing, they're just going to ship me out...They're going to just send me back home to die." Even after diagnosis, participants recalled worrying that their new HIV status would be grounds for deportation. The same participant stated, "I thought...they would send me back because now I am positive. ... What if the police stop me? What if the hospital reports me?" Several participants specifically mentioned the restriction on travel to the United States for persons living with HIV (in place from 1989 to 2010¹⁹) as a factor influencing their fears.

On a more concrete level, participants reported uncertainty regarding eligibility for health services because of their immigration status, perceptions that were sometimes reinforced by their social networks. A 48-year-old woman from Zimbabwe recounted being told by her American partner that, "I need to go pack my bags and go back home, because there's no way I can get help because, you know, I was illegal here, I was an immigrant." Moreover, some participants described the compounded stress of trying to navigate a foreign health care system while also dealing with poor health. For example: "So, finally I am not only an illegal immigrant...but I'm also sick. So, if there was not someone to help me get the papers and then treat me, frankly, it was going to be difficult" (58-year-old Congolese man).

Difficulties obtaining health insurance

Lack of health insurance and uncertainty about navigating the process of obtaining health insurance were identified as major barriers to HIV testing and linkage to HIV care. Describing the undocumented African immigrant community, one participant stated, "Most people don't even have health insurance or even have money to do a HIV initial test" (47-year-old man from Ivory Coast). Participants felt that their marginalized status and limited employment prospects prevented them from accessing preventive health care. For ex-

ample, describing her situation at the time of her diagnosis, a 48-year-old Zimbabwean woman said, "I am an immigrant, I don't have any money, and then, I was just doing all these jobs—odd jobs for babysitting or housecleaning, so, I did not have any health insurance." Even after diagnosis, lack of insurance remained a significant barrier to linking to HIV care. A 49-year-old woman from Tanzania described receiving a prescription for antiretroviral therapy and not being able to fill it: "The guy give me prescription. I tried to go different pharmacists. [They] say, 'No, we can't give you. You have to find insurance.' I don't have insurance. I don't know about [it]... So, I said, 'Okay, let me die.'"

Figuring out how to obtain insurance, or how to access health care without insurance, led to substantial anxiety. Describing the process, a 28-year-old Nigerian man stated, "And on top of that, you need to also have...medical insurance, so they can get access to medication...Because if you don't get those things, you'll be stressed out. HIV doesn't kill anybody. Because of stress, you can die." Often, these issues were foreign to immigrants who had not needed to worry about insurance before immigration. This same participant continued, "The first question I was asked was as follows: Do I have health insurance? And back in my country, we have never heard of you going to hospital and you being asked for health insurance, either public hospital or private hospital...I was shocked probably I would be denied, um, healthcare service."

Anticipated and experienced social isolation

Another major theme was an overwhelming sense of social isolation. Participants described an enormous amount of HIV stigma in Africa and in the immigrant community in the United States that had shaped their and their community's viewpoints on HIV. The anticipation of social isolation led to a high degree of reluctance to get tested, to subsequently seek out HIV care, or even acknowledge HIV in any way. This was especially notable because, for undocumented immigrants without access to many services, the immigrant community served as a primary support system. For example, a participant recounted a prior HIV testing experience where she was unable to complete the test because the fear of a positive diagnosis was too great: "I entered the room, I was scared. Said, 'Uh, let me go.' I run away. I scared. Because you know people, if they know you have this disease, they run away from you. Even your family" (49-year-old Tanzanian woman). Similarly, another participant stated, "So, there is that fear of 'What if somebody knows or what if I talk about it? Are they going to think I am sick? Is my family going to abandon me? Are they going to kill me?' You know? So, people don't even talk about it. So, most people don't even get tested" (44-year-old Tanzanian woman). This fear of rejection from community members carried over after diagnosis. This same participant described what would happen if her family discovered her new HIV status: "But, my family...If there was an island out of the universe, they would drop me there and forget about me." This participant stated that in over a decade since her diagnosis, she had not disclosed her HIV status to a single person in her family.

Beyond anticipation of isolation affecting health care seeking behaviors, participants described devastating experiences that left them feeling as if they had nowhere to turn.

These included loss of community, employment, and housing. For example, a 48-year-old Zambian woman explained, “We came here without working papers and looking for jobs to work for little jobs as nannies, housekeepers...So, what would happen is, those that turn out HIV-positive, if they really know, they find out that you are HIV-positive they’ll find a way to make you lose your job. And what they’ll do is, they’ll find, they will call your boss, tell them that you’re HIV-positive.” She recounted how she was hospitalized while working as a live-in nanny and diagnosed with HIV and then told not to return to work: “[And then] I had nowhere to live, and I had to go sleep in the shelter. And I couldn’t go back home. When I called my home and told my husband who I was married to, that day when he found out I had HIV he told me not to come back.”

Social and health service providers as allies

While undocumented immigration status, difficulty accessing health insurance, and social isolation were the main barriers described by participants, a major facilitator of linkage to care for this population was service providers, including health care providers, social workers and CBOs. An important element these actors provided were tangible, concrete services to help undocumented immigrants get connected to care, including help in accessing health insurance, accompaniment to appointments, and providing food assistance. A participant summarized how after being referred to the CBO “they helped me to—find a doctor, the hospital, the clinic, everything” (48-year-old Zimbabwean woman).

Perhaps more importantly, participants described these settings as safe spaces where they felt comfortable disclosing their HIV status and where they did not fear immigration authorities or rejection from their community. For example, a 37-year-old Nigerian woman explained, “When I’m talking to my doctor, when I’m talking to the social workers, they are accommodating and they are always ready to assist. So, I think that makes it easier.” Another participant, describing the CBO, stated simply, “At least you have somewhere where...you are not alone” (55-year-old Tanzanian woman).

Discussion

In this qualitative study of undocumented African immigrants in NYC, participants identified fear of immigration authorities, a lack of understanding about their eligibility for health care, and the high degree of social stigma in African immigrant communities as major barriers to HIV testing. Social and health service providers were characterized by participants as facilitators of linkage to care; these key providers were able to assist undocumented Africans in overcoming these barriers. This study, to our knowledge the first to explicitly examine undocumented African immigrants’ experiences with HIV testing and linkage to care, contributes to the very limited literature on immigration status as a barrier to HIV care for undocumented African immigrants. Our findings demonstrate that the experiences of HIV testing and subsequent linkage to care of undocumented African immigrants are shaped by factors across individual, community, institutional, and policy levels, and suggest that approaches directed at all of these domains are important in facilitating

HIV testing and linkage to appropriate HIV care for this vulnerable population.

At the societal and policy level, we found that fear of deportation and uncertainty regarding eligibility for insurance and health services both before and after HIV diagnosis led to participants delaying HIV testing and having difficulties linking to care after diagnosis. These findings were consistent across time, with similar barriers reported among participants who had recently entered HIV care and those who had been diagnosed even two decades prior. HIV prevention and testing messages that directly address immigration-related concerns, and policies that reduce structural barriers related to immigration status, may be an important intervention to decrease disparities in these early steps in HIV care.

Within social networks, participants described a high level of stigma that influenced decisions to test for HIV and to link to care after diagnosis. Participants described anticipated and actual rejection from family members, roommates, and employers, a finding particularly striking because these individuals often serve as the only social support available to undocumented immigrants ineligible for most social services. We observed consistency in descriptions of stigma among participants from different regions of Africa and who entered HIV care at different time points over the past two decades. Many previous investigations have documented high levels of HIV-related stigma in the African immigrant community,^{20–23} potentially driven by lower levels of both HIV knowledge and lower levels of risk perception compared to US-born persons.^{8,21,24} Undocumented immigrants, who have less access to preventive health services and lower levels of educational attainment than persons with legal immigration status,^{25,26} may depend to a higher degree on informal social support networks where HIV-related stigma is high. Therefore, their HIV-related health-seeking behaviors may be more negatively impacted by this stigma, and they may be less likely to be tested for HIV. While numerous interventions have been directed at individual-level HIV-related stigma, culturally tailored, community-based programs aimed at reducing stigma within social networks and normalizing HIV testing (e.g., bundling HIV testing together with screening for other conditions²⁷) could potentially increase voluntary HIV testing among undocumented African immigrants.

Analysis at the institutional level revealed that after HIV diagnosis, participants in this study reported substantial practical and emotional support provided by health and social service providers, including navigating the complex health care system, assistance in obtaining health insurance, food and housing, reassurance about their HIV diagnosis, and facilitating support groups with other African immigrants living with HIV. Although no studies have directly compared rates of linkage to HIV care among US- and foreign-born persons of African descent, once engaged in HIV care, immigrants living with HIV, including undocumented immigrants, achieve clinical outcomes equal to or better than US-born persons.^{9,28} These findings suggest that the services provided by CBOs and health care providers are effective at addressing some of the individual, social, and societal barriers faced by undocumented African immigrants living with HIV, and that similar efforts in more proximal stages of the HIV care continuum could reduce HIV-related disparities in this population.

Prior studies of African immigrants living with HIV in the United States and of service providers delivering care to this population described fear of deportation, dual stigma from HIV and immigration status, lack of insurance, and lack of English proficiency as barriers to accessing HIV-related services.^{15,20,21,29} However, these studies were limited in that they did not focus primarily on undocumented immigrants and they examined the more distal steps in the HIV care continuum (i.e., retention in care and adherence to treatment). For example, in a study of African women living with HIV, Ojikutu, et al. described how a subset of participants with undocumented status experienced stigma and economic distress, focusing on how these contributed to poor mental health rather than HIV outcomes.²⁰ Foley explored structural barriers to consistent engagement in HIV care for African women from both a service provider and patient perspective, but did not focus on HIV testing.²¹ Other studies of African immigrants at risk for or living with HIV have only peripherally examined the role of immigration status.^{8,14,22,23,30,31} By exploring the fears, uncertainties, and structural factors undocumented African immigrants experience surrounding HIV testing and linkage to care, particularly as these relate to their immigration status and social networks, our study provides important insights into barriers to engagement in the earliest steps in the HIV care continuum.

Many participants were diagnosed with HIV over a decade before interviews were conducted for this study, when the climate surrounding both HIV and immigration were substantially different than today. These participants potentially faced additional barriers to HIV testing and linkage to care that may not exist today, including the requirement for written consent for HIV testing³² and delays in reporting results, though these were mentioned by few participants. Before 2010, persons living with HIV were banned from traveling or immigrating to the United States, likely contributing to the stigma and fear of deportation faced by undocumented African immigrants.³³ Over the past two decades, as immigration to the United States has grown by nearly 50%,²⁷ anti-immigrant policies and rhetoric have increased substantially.^{34,35} Thus, while some structural barriers to HIV testing and linkage to care may no longer be in place, participants' experiences may be even more salient today.

This study has several limitations. First, we interviewed a convenience sample of undocumented African immigrants living with HIV receiving care at a single CBO in a state with a relatively high degree of social service benefits. Therefore, our findings may not be representative of undocumented African immigrants who do not receive services at CBOs or who live in other geographic regions. Second, given the fear and stigma surrounding both HIV and immigration, we faced substantial challenges in recruiting participants to this study. Although thematic saturation was reached in the course of interviews, the relatively small sample size did not allow comparisons of subgroups of participants defined by gender, age, place of HIV diagnosis, or region of origin. Third, for many participants, the long interval between diagnosis and data collection may have led to recall bias. Finally, interviews were conducted by two physicians in English and French, rather than participants' native African languages, potentially resulting in some social desirability bias and inability to capture some of the more nuanced elements of participants' experiences.

In conclusion, in this qualitative study of undocumented Africans living with HIV, participants reported barriers to HIV testing and linkage to care within multiple domains, including fear of deportation and uncertainty about eligibility for health services, difficulties obtaining health insurance, and anticipated and experienced social isolation. After diagnosis, social and health services providers were able to address some of these barriers, facilitating access to HIV care. These findings suggest a framework for developing interventions to promote HIV testing and facilitate linkage to care for undocumented African immigrants that incorporates individual, social, institutional, and societal levels of influence. Utilizing such an approach to increase awareness of eligibility for HIV testing and care, decrease HIV-related stigma, and address immigration-related concerns could potentially mitigate late HIV diagnosis and late entry to care for this population.

Acknowledgments

This study received support from the National Institute of Mental Health (K23 MH114752), National Institute of Drug Abuse (K99 DA040311 and K24 DA036955), the Lawrence S. Linn Research Grant from the Society of General Internal Medicine, and the Einstein-Rockefeller-CUNY Center for AIDS Research (P30-AI124414), which is supported by the following NIH Co-Funding and Participating Institutes and Centers: NIAID, NCI, NICHD, NHBL, NIDA, NIMH, NIA, FIC, and OAR.

Author Disclosure Statement

Dr. C.O.C.'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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Address correspondence to:
Jonathan Ross, MD, MS
Division of General Internal Medicine
Montefiore Medical Center/
Albert Einstein College of Medicine
3300 Kossuth Avenue
Bronx, NY 10463

E-mail: joross@montefiore.org