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Barriers to HIV Testing in Black Immigrants to the U.S.

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Abstract

Background—Late HIV testing is common among immigrants from sub-Saharan Africa and the Caribbean. Since 2010, HIV testing is no longer a required component of immigrant screening examinations or mandatory for immigrants seeking long term residence in the US. Thus, barriers to HIV testing must be addressed.

Methods—Five hundred and fifty-five (555) immigrants completed a barriers-to-HIV testing scale. Univariate and multivariate linear regression were performed to examine predictors of barriers.

Results—In multivariate analysis, primary language other than English ($\beta=2.9$, $p=.04$), lower education ($\beta=5.8$, $p=.03$), low income [= below \$20K/year] ($\beta=4.6$, $p=.01$), no regular provider ($\beta=5.2$, $p=.002$) and recent immigration ($\beta=5.7$, $p=.0008$) were independently associated with greater barriers. Barriers due to health care access, privacy, fatalism, and anticipated stigma were greater for recent versus longer term immigrants.

Discussion—Immigrants from sub-Saharan Africa and the Caribbean face significant barriers to HIV testing. Interventions to improve access and timely entry into care are needed.

Keywords

HIV; HIV testing; Black immigrants; health care access

Nearly one-third of HIV diagnoses in the United States occur late (AIDS diagnosis made less than 12 months from HIV diagnosis).¹ Late HIV diagnosis leads to delayed entry into medical care, preventable morbidity and mortality, and increased risk of transmission to sexual partners.^{2–4} Although significant efforts have been undertaken to decrease late HIV testing, certain groups remain at high risk. Among Black individuals, immigrants, most of whom emigrate from higher-prevalence regions in sub-Saharan Africa and the Caribbean, tend to be diagnosed with more advanced infection than native born individuals, suggesting a long lag time between initial infection and diagnosis.^{5,6} Late diagnosis in this population

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may be due to the timing of immigration (i.e., infection occurred pre-immigration and HIV testing was either not obtained until arrival in the U.S. or was obtained earlier but when access to care was limited) or to barriers to accessing HIV testing in the U.S.⁷

Though little attention has been focused on HIV in non-U.S. born Black individuals, this subpopulation has a higher rate of HIV infection than native born Blacks (81.4 vs. 78.9 per 100,000). Differences by nativity among women are pronounced; the HIV diagnosis rate among foreign born Black females in 2010 was 1.6 times the rate noted in native born women (78.8 vs. 48.6 per 100,000).⁶ Seventy-four percent of HIV cases in Black immigrants have been attributed to heterosexual exposure.⁶ Surveillance data from several jurisdictions around the country are also particularly striking. In Massachusetts, 51% of new HIV cases in 2008–2010 among Black individuals were in immigrants.⁸ Washington State and New York State also have a disproportionately high proportion of immigrants among new cases of HIV in Black individuals (46% and 24%, respectively).^{9,10}

In general, immigrants face numerous barriers to health care access, including lack of health insurance, provider linguistic discordance and fear of deportation.^{11–14} The vast majority of immigrants are members of racial and ethnic minority groups; thus, perceived and anticipated discrimination have been identified as deterrents to accessing health services.^{15,16} As a result of these barriers, common screening tests are underutilized by immigrants.^{17–20} Limited research, most of which has focused on the Latino population, has been conducted to identify specific barriers to HIV testing. In addition to the barriers that have been described for other screening tests, HIV-related stigma and low HIV knowledge have been noted.^{21–24}

Longer duration living in the U.S. has been found to attenuate some, but not all, access health care access barriers faced by immigrants.^{18,25} Recent immigrants are less likely to have a primary care doctor and undergo screening tests when compared to more established immigrants.^{26–31} HIV testing may represent a unique intervention which, prior to January 2010, recent immigrants were afforded better access to than longer-term immigrants. Prior to 2010, according to U.S. immigration law, HIV testing was offered as a component of the medical screening examination required for most immigrants, and HIV testing was mandatory for all those seeking long-term residence in the U.S.³² Therefore, recent immigrants may have tested for HIV early during their residence in the U.S. Research has noted that many immigrants to the U.S. were tested because that law was in place.²⁴ Removal of the law may inadvertently serve as a barrier to HIV testing and lead to late diagnosis, particularly for recent immigrants.³³ In light of this policy change, understanding barriers to HIV testing and developing appropriate interventions are critical to ensuring that immigrants living with HIV are tested and engage in care in a timely manner. This study focused on the experiences of Black immigrants because the access challenges experienced by this high-risk group have not received attention in research studies. Information gleaned from our study will inform the development of interventions that encourage universal testing in this vulnerable population.

Methods

Study population and recruitment

Recruitment for this study was part of a cross-sectional study comparing self-reported rates of HIV testing between US born (African- Americans) and non-US born Black individuals.²⁴ Between June 2010 and November 2011 we recruited participants from four counties in Massachusetts with relatively large African-American, Caribbean and African immigrant populations (Suffolk, Essex, Plymouth, and Middlesex). Eligible participants were 18–64 years of age, self-identified as Black, and sexually active. HIV-positive participants were included in this study. The analysis described in this paper only includes data obtained from study participants who indicated that they were born outside of the US or its territories.

Convenience sampling was used for this study because we did not have an existing sampling frame from which to select a systematic random sample of participants.³⁴ Our recruitment strategy was based on formative research conducted in conjunction with the Multicultural AIDS Coalition, a community-based organization serving immigrants in Massachusetts. Research assistants from the target populations were also hired to assist with recruitment and survey administration. Venues within each of the four counties were purposefully selected to increase recruitment of immigrants. Recruitment outreach was conducted at selected venues at various times to decrease systematic selection bias. Forty-one recruitment events were held during the survey period. Recruitment outreach took place during or at national celebration events, health fairs, ethnic grocery stores, shopping centers, night clubs/bars, community health centers, and churches. In addition, recruitment was conducted in conjunction with a community-based mobile health van. During recruitment each potential participant who entered the venue or who walked past the recruitment table who appeared to be Black was approached by a research assistant and offered to participate in the study. Participants who were interested were screened for eligibility. The number of participants approached and the number who agreed to participate were documented. Those who met inclusion criteria were asked to provide spoken informed consent after reviewing a consent statement that was available in six languages: English, Haitian Creole, Cape Verdean Creole, French, Spanish, and Arabic.

This study was approved by the Partners Health Care Institutional Review Board.

Data collection

The survey instrument was developed in English and translated into the five additional languages by certified translators. Surveys were back-translated and discrepancies were resolved by a committee comprised of bilingual reviewers and the research team. Surveys were self-administered and completed by respondents via paper/pencil. Average survey completion time was 30 minutes. No identifying information was collected. Participants were offered \$20 remuneration.

Measures

The survey was designed to determine HIV risk and HIV testing patterns in U.S. born and non-U.S. born Black individuals. Survey development and design are described elsewhere.²⁴ Demographics, HIV knowledge, stigma, sexual and drug using risk behavior, health care access, HIV testing history and barriers to HIV testing were collected. This study utilized a barriers-to-HIV-testing scale developed by Awad *et al.*, which was validated and subsequently used to assess barriers in Black and Latino populations.^{35,36} The barriers scale comprises 32 Likert-scale items addressing potential barriers or facilitating factors that may influence HIV testing behaviors. Six domains of interest are covered by the scale: access to health care services, concern for privacy, fatalism, perception of risk, social norms, and anticipated stigma (the fear that one will personally experience stigma if one tests positive).

Key informants from immigrant communities reviewed the scale and found that several items applicable to the immigrant experience were missing from the scale: (1) I can't afford treatment so why get tested (health care access); (2) I am not sick, so there is no reason to test (perception of risk); (3) I would be deported (fears or anticipated stigma). These items were added and a pilot survey was conducted (20 immigrants). The barriers-to-testing scale demonstrated good reliability in this group and in the entire survey cohort (Cronbach alpha .70).

Dependent and independent variables

The main outcome variable was the total barriers-to-HIV-testing scale score which was calculated by summing up responses for the 32 Likert scale items. Similarly, secondary response variables were calculated for each of the six subdomains. Greater overall and subscale scores represent greater perceived barriers. Age, gender, marital status, highest educational level attained, total household income, primary language(s), housing status, employment status, country of origin, immigration status, and year of immigration were collected. To assess sexual risk behavior, participants were asked whether they had had vaginal or anal intercourse in the past three months and whether their sexual partners were male, female or both. Risk associated with drug use was ascertained by asking participants whether they had ever used cocaine, heroin, or crystal meth. Health care access was assessed by asking the patients if they had a primary care provider. Duration in the U.S. was calculated by subtracting the survey date from the date of entry to the U.S. To assess for any potential nonlinearity between total barriers and duration of stay in the U.S., we examined generalized additive models (GAM) using plots of penalized splines.^{37,38} We also use the *local regression* (or, LOESS) procedure to generate a scatter plot overlaid on the loess plot.³⁹ The cubic splines as well as the scatter plot revealed a non-increasing or decreasing trend over the range of U.S. duration of stay except at the highest duration (longer than 40 years) where a decreasing trend was evident. Therefore, we dichotomized duration in U.S. to shorter than 10 years (recent) and 10 years or longer (longer-term). This stratification is consistent with other studies.^{40–42}

Data analysis

Descriptive statistics, means and standard deviations and inter-quartile ranges (IQRs) were calculated for continuous variables and percentages for categorical variables.

We compared immigrants residing in the U.S. for periods shorter than 10 vs. periods 10 years or longer in duration using a two-sample t-test. The chi-squared test was used to compare categorical variables and a two-sample t-test (with pooled or unequal variance as indicated) to compare continuous variables. We used multivariate analysis of covariance (ANCOVA) to compare the two groups adjusting for participant characteristics. Univariate and ANCOVA were used to examine predictors of barriers to testing. Variables that attained statistical significance at $p < .05$ in univariate models were included in multivariable adjusted model resulting in an ANCOVA model with the following variables: immigration status, primary language, housing status, educational attainment, employment status, annual household income, presence of primary health care provider, and duration of residence. We also evaluated for effect modification by age and gender by incorporating interaction terms in the multivariable adjusted ANCOVA models. Residual analysis using a histogram of the residuals and normal quantile-plot showed that the residuals did not exhibit any departure from normality, thus indicating that the fit had accounted for most of the variation in barriers score. Results were summarized using β regression coefficients from the ANCOVA model. For each one year increase in duration of stay in the U.S., the barriers changed by the value of β estimate. A p-value of $< .05$ was considered statistically significant. In addition, summary statistics for the barriers-to-HIV-testing scale and the six sub-domains were compared for recent *versus* longer-term immigrants. Statistical analysis was conducted using the SAS version 9.3.⁴³

Results

Participant characteristics

Approximately 80% of those approached agreed to participate in the survey. The study sample characteristics are showed in Table 1. Less than 10% of survey responses were excluded for missing data on region of origin or duration in the U.S. Five hundred and fifty-five (555) participants were included in this study. Sixty percent (60%) were from sub-Saharan Africa. In total, 55 different countries of origin were represented. Forty-percent (40%) were recent immigrants, while 60.0% had lived in the U.S. for more than 10 years. The mean age of participants was 38.7 (± 12.1) years. Fifty-four percent (54%) were male. The majority of participants were single (55.4%). Only 2.0% reported their immigration status as undocumented. Languages other than English were identified as primary for 58.9% of participants. Most were renting their primary residence (74.8%). Eighty-nine percent of participants had completed high school or a higher level degree. Nearly one-half (48.7%) were unemployed. Thirty-six percent reported household incomes of less than \$20,000 per year. The majority of participants had a primary care doctor (72.5%).

Variables associated with barriers to HIV testing

Univariate and multivariate regression analysis results are displayed in Table 2. A positive β estimate indicates greater barriers associated with the factor in the model, whereas a negative β estimate indicates fewer barriers. Univariate analysis revealed that refugee immigration status, primary language other than English, renting, lower educational attainment, unemployment, household income of less than \$20,000 per year, not having a health care provider, and shorter duration of residence were significantly associated with

barriers to HIV testing (all p-values <.05). In the multivariable adjusted linear regression model permanent resident status ($\beta=-4.2$), having an active visa ($\beta=-7.4$), lower educational attainment ($\beta=8.6$), income less than \$20K ($\beta=4.6$), not having a primary health care provider ($\beta=4.5$), and duration of residence less than 10 years ($\beta=5.7$) were associated with overall barriers to HIV testing, (all p-values <.05). Duration in the U.S. was the most important variable in the multivariable adjusted model, accounting for up to 6% of the total variability in barriers to HIV testing. We did not observe any effect modification by age or by gender (p>.05 for all p-values).

Barriers to HIV testing by duration of residence

To explore differences in barriers to HIV testing by duration of residence we calculated unadjusted summary statistics for the barriers-to-HIV-testing scale and the six sub-domains by duration of residence (Table 3). Recent immigrants reported significantly higher barriers to HIV testing than longer-term immigrants (mean score 83.5 vs. 76.3, respectively, p<.0001). Median scores for subdomains measuring barriers due to health care access (19.0 vs. 16.0, p<.0001), privacy (19.0 vs. 17.0, p<.0001), fatalism (6.0 vs. 4.0, p=.0006), and anticipated stigma (24.0 vs. 23.0, p=.0002) were significantly higher for recent immigrants.

Discussion

This study identified several variables that are associated with barriers to HIV testing. Primary language other than English, lower educational attainment, and low income have previously been associated with barriers to accessing health care services among immigrants in the U.S. and in Canada.⁴⁴⁻⁴⁶ Not surprisingly, we found that these factors are associated with barriers to HIV testing. In addition, not having a primary care provider (or a regular source of care) was also found to be independently associated with barriers to HIV testing. For immigrants as well as other populations, not having a regular source of care has been found to limit access to preventive as well as other health care services.^{47,48} As the availability of routine opt-out HIV testing in primary care settings expands, access to a regular source of primary care will become increasingly important to improving access to this service.^{49,50} Legal status, particularly undocumented status, is a well-documented barrier to health care access and utilization for immigrants.⁵¹⁻⁵⁴ We did not find that association in this study. However, the number of undocumented immigrants included in our sample was low and potentially limited statistical power to detect important barriers.

This study also found that barriers to HIV testing were notably higher for recent immigrants than for longer-term immigrants. This is of particular concern given the removal of HIV testing from the medical screening process that recent immigrants may undergo to obtain entry into the U.S. and to obtain longer-term residency status. Prior research indicates that greater length of stay may be associated with acculturation and an increase in resources that facilitate access to health care. These resources include proficiency in the country's official language, documented immigrant status, insurance coverage, and ability to navigate the health care system. In general, the longer an individual resides in his or her new country, the more s/he may adapt economically, culturally, and socially, which translates into increased health care access.⁵⁵ It is unclear whether or not this holds true for Black immigrants or for

HIV testing. However, studies have demonstrated increased access to health care services for Black immigrants over time.^{56,57} Similarly, this study found that barriers to HIV testing were lower in longer-term immigrants.

Barriers in four subdomains—health care access, privacy, anticipated stigma, and fatalism—were higher for more recent immigrants in our unadjusted exploratory analysis. Barriers to health care access (measured by health insurance coverage or presence of a regular source of care) among recent immigrants have been well-documented in the medical literature.^{18,26–28} In this study, as in others, HIV testing is associated with having a health care provider or regular source of care.⁵⁸ Privacy and confidentiality concerns have challenged efforts to scale-up HIV testing since the beginning of the epidemic.⁵⁹ More recently, expansion of HIV testing in non-traditional settings has slowly been implemented in part due to privacy concerns.^{60,61} Concerns regarding privacy and anticipated stigma are interrelated. Fear of deportation may fuel resistance to disclose results to the U.S. government. Reluctance to disclose results may also be due to medical mistrust, a well-documented theme underlying failure to access services, and poor linkage and retention in care among native Black individuals living with HIV as well as other diseases.^{62–65} Interventions such as computer-assisted HIV testing and self-testing (in-home HIV testing) have been explored as options to overcome privacy issues and mitigate some aspects of anticipated stigma and mistrust.^{66–68}

Fatalism, the belief in a lack of personal power or control over destiny or fate, constitutes a major barrier to participation in positive health behaviors and can adversely affect health outcomes.⁶⁹ A large body of literature describes the negative impact that fatalism can have on access to screening, preventive services and health care interventions.^{70–72} Disadvantaged groups, such as immigrants, who have historically received substandard medical care either in their home country or here in U.S. may also have a more fatalistic perspective regarding health.⁷³ Immigrants residing in the U.S. for longer periods may benefit from increased access to health care and experience diminished fatalistic beliefs over time.

This study has several limitations. Data were obtained *via* convenience sampling, which inherently entails bias and may not be generalizable to the entire population. It is possible that participants who chose to take our survey experienced different barriers than those who declined participation, creating bias in our estimates of barriers to HIV testing. All of our measures were self-reported, potentially leading to recall bias. We asked respondents to tell us their immigration status, and only 2% of the sample reported being undocumented, which is likely an underestimate. It is likely that respondents were unwilling to report their actual immigration status or that those who were undocumented were unwilling to participate. The survey and consent were not available in all languages native to Black immigrants, including Swahili. Offering the survey in all languages would have been cost-prohibitive. In addition, during recruitment, research assistants subjectively assessed potential participants and approached those who they perceived to be Black. Therefore, they may have failed to approach eligible participants. Health centers were included as recruitment sites which may have biased study participants to include those who had better access to health care. The barriers-to-HIV-testing scale also did not measure barriers to health care services unique to minority populations, such as racism and discrimination, which may pose barriers to HIV

testing acceptance in immigrants. Furthermore, though the barriers scale that was used has been validated in a population described as African American and presumed to be primarily U.S. born, the tool has not been specifically validated in populations from sub-Saharan Africa or the Caribbean.³⁶

HIV testing is the first step toward receiving timely clinical care and treatment. We found that Black immigrants, particularly recent immigrants, face significant barriers to HIV testing and are at risk for late presentation and suboptimal outcomes. Our findings provide a critical step in the process of understanding the barriers faced by this vulnerable population. Immigrants represent a significant proportion of all Black individuals living with HIV, particularly in certain jurisdictions around the U.S. Therefore, if racial and ethnic disparities in HIV incidence, morbidity, and mortality are to be eliminated, barriers to accessing HIV related services for Black immigrants must be addressed. Interventions that address barriers to HIV testing and timely entry into care for those testing positive should be developed for all high-risk immigrants, particularly those who have recently entered the U.S.

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Notes

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Table 1**BASELINE CHARACTERISTICS OF RESPONDENTS**

	Total, n=555
Age, years (SD)	38.7 (\pm 12.1)
Gender (%)	
Male	301 (54.4)
Female	252 (45.6)
Marital Status (%)	
Single	303 (55.4)
Married	244 (44.6)
Immigration Status (%)	
Resident	225 (40.5)
Active visa	32 (5.8)
Undocumented	11 (2.0)
Refugee	59 (11.0)
US Citizen	212 (39.3)
Primary Language (%)	
English	228 (41.1)
Other	327 (58.9)
Housing (%)	
Own	126 (22.7)
Rent	415 (74.8)
Homeless	14 (2.5)
Education (%)	
< High school	59 (10.7)
High school	494 (89.3)
Employment (%)	
Employed	285 (51.4)
Unemployed	270 (48.7)
Income (%)	
<\$20K	163 (35.8)
>=\$20K	292 (64.2)
Sex (vaginal/anal), 3 mos (%)	
Yes	323 (74.8)
No	109 (25.2)
Male to Male Sexual Contact	
Yes	6 (2.0)
No	295 (98.0)
Drug Use, 3 mos (%)	
Yes	19 (3.4)
No	536 (96.6)
Primary Health Provider (%)	

	Total, n=555
Yes	396 (72.5)
No	150 (27.5)
Region of Origin (%)	
Africa	333 (60.0)
Caribbean	222 (40.0)
Duration of Residence (%)	
<10 years	220 (39.6)
>10 years	335 (60.3)

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Table 2**ASSOCIATIONS BETWEEN RESPONDENT CHARACTERISTICS AND BARRIERS TO HIV TESTING:
UNIVARIATE AND MULTIVARIATE ANALYSIS**

	Univariate β (se) ^a	p value	Multivariate β (se) ^a	p value
Age 10, years	-0.5 (0.6)	.7477	-	-
Gender (ref. male)				
Female	0.7 (1.4)	.2880	-	-
Marital status (ref. married)				
Single	-1.9 (1.4)	.2733	-	-
Immigration (ref. US citizen)				
Permanent resident	-0.4 (1.5)	.9288	-4.2 (1.6)	.0088
Refugee	6.2 (2.4)	.009	-2.2 (2.8)	.43
Undocumented	2.7 (5.0)	.3300	2.2 (5.3)	.68
Active visa	-4.0 (3.1)	.1577	-7.4 (3.0)	.015
Primary language spoken in home (ref. English)				
Language other than English	5.2 (1.4)	.0002	2.6 (1.4)	.07
Housing status (ref. own)				
Rent	5.1 (1.6)	.002	1.0 (1.7)	.81
Homeless	6.3 (4.5)	.0253	-1.3 (5.3)	.58
Educational status (ref. high school or greater)				
<High School	12.5 (2.2)	<.0001	8.6 (2.6)	.0009
Employment (ref. employed)				
Unemployed	7.4 (1.3)	<.0001	1.7 (1.6)	.30
Income (ref. >\$120K)				
<\$20K	9.1 (1.5)	<.0001	4.5 (1.8)	.0128
No provider (ref. have provider)	7.4 (1.5)	<.0001	5.3 (1.7)	.0016
Duration of residence (ref. >10 years)				
<10 years	7.2 (1.6)	<.001	5.7 (1.7)	.0006
Region (ref. Caribbean)				
African	-1.6 (1.4)	.0666	-	-

^aFor each one year increase in duration of stay in the US, barriers changed by the value of β estimate.

Table 3
BARRIERS TO HIV TESTING AND SIX SUB DOMAINS BY DURATION OF RESIDENCE IN THE US

	Total (n=555)		<10 years (n=220)		>10 years (n=335)		p-value
	Median	IQR	Median	IQR	Median	IQR	
Overall Score	77.0	66.0–88.0	83.5	72.5–109.5	76.3	66.0–104.0	<.0001
Domains							
Health care access	16.0	12.0–21.0	19.0	13.0–29.0	16.0	12.0–28.0	<.0001
Privacy	17.0	15.0–20.0	19.0	16.0–23.0	17.0	14.0–23.0	<.0001
Fatalism	5.0	3.0–7.0	6.0	3.0–11.0	4.0	3.0–10.0	.0006
Perception of Risk	8.0	7.0–11.0	9.0	7.0–12.0	8.0	7.0–12.0	.88
Societal Norms	8.0	6.0–9.0	8.0	7.0–11.0	8.0	7.0–12.0	.56
Anticipated Stigma	23.0	18.0–27.0	24.0	20.0–35.5	23.0	16.0–33.0	.0002