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To cite this article: Sarah Moore Oliphant & Linda Plitt Donaldson (2019) A Community-Based Participatory Approach to Understanding HIV/AIDS in the Ethiopian Community, *Social Work in Public Health*, 34:7, 557-569, DOI: [10.1080/19371918.2019.1635944](https://doi.org/10.1080/19371918.2019.1635944)

To link to this article: <https://doi.org/10.1080/19371918.2019.1635944>



Published online: 02 Jul 2019.



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A Community-Based Participatory Approach to Understanding HIV/AIDS in the Ethiopian Community

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ABSTRACT

The rate of HIV/AIDS in Washington, D.C remains at epidemic levels and is most prevalent in the black community, with foreign-born blacks accounting for an increasing proportion of HIV infections in the Washington DC area. The Ethiopian community is among the subgroups that are especially impacted by HIV/AIDS. Yet, seldom does research on the epidemiology of HIV/AIDS break data into diverse subgroups, accounting for the distinct needs based on cultural or ethnic differences. This paper reports on the qualitative findings from a community participatory action research study that involved interviewing 60 Ethiopian-immigrants and nine community-based providers about their attitudes toward HIV/AIDS, and to elicit their ideas about how to improve HIV/AIDS prevention, promotion, and treatment approaches targeting the Ethiopian community. Findings show that stigma remains the largest barrier to accessing HIV/AIDS treatment among Ethiopians in the Washington, D.C. area. Therefore, strategies to reduce HIV/AIDS must address stigmatizing beliefs and be met with cultural sensitivity when developing community prevention and treatment outreach programs designed to reduce HIV/AIDS among Ethiopians.

KEYWORDS

Ethiopian; HIV; AIDS; immigrant; stigma

Introduction

In Washington, D.C., 1.9% of the population (13,003 people) is living with HIV/AIDS (DC Department of Health, 2018). Although the number of new HIV infections has declined from 2013 to 2017 (District of Columbia Department of Health, 2018), a 1.9% prevalence rate shows that HIV/AIDS remains at epidemic levels. This epidemic reaches across race and gender, but it is most prevalent in the black community (District of Columbia Department of Health, 2018). The uniform risk category of “black” is misleading because it only accounts for the race and does not consider the cultural and ethnic differences that distinguish foreign-born blacks from US-born blacks. (Demeke et al., 2018; Koku et al., 2016). This paper uses the categories “black”, “African American”, “foreign-born blacks,” and “Black/African American”, depending on the source of the data. The terminology to describe individuals comprising this racial group is one of the challenges in addressing the needs of diverse populations in HIV/AIDS education and treatment.

Foreign-born blacks account for an increasing proportion of HIV infections in the Washington DC area (Koku et al., 2016). Yet, the category of foreign-born black is still too broad; diverse subgroups have distinct needs regarding intervention and policy responses (Wafula & Snipes, 2014). One such subgroup is Ethiopian immigrants. People from Ethiopia represent the second highest category of foreign-born blacks in the United States, and Washington, D.C., and its surrounding communities host the highest concentration of Ethiopian immigrants in the country (Migration Policy Institute, 2014). Among African-born immigrants in the United States, Ethiopian immigrants had the highest rates (14.8%) of HIV diagnosis from 2008–2014 (Demeke et al., 2018).

Despite these HIV rates, very little is known about the knowledge, attitudes, and behaviors of Ethiopians in the DC Metro area. The purpose of this study was to gain an understanding of the knowledge, attitudes, and behaviors related to HIV/AIDS within the Ethiopian community living in the Washington, DC Metropolitan area in order to inform next steps in developing HIV prevention, intervention, and treatment strategies that are culturally appropriate for the Ethiopian population. This paper presents the findings from the qualitative interviews with 60 members of the Ethiopian community, and nine interviews with staff from institutions which participated in the study. The authors conclude with recommendations for next steps in responding to the strategies and concerns raised by study participants.

Literature review

The containment of HIV/AIDS in the U.S. has been a public health priority which has seen recent incremental success. For example, according to the HIV Surveillance Report (Centers for Disease Control and Prevention, 2018), between the years of 2012–2016 the rate of diagnosis of HIV infection decreased in the United States overall. However, it is imperative to note that HIV still disproportionately affects members of the black community (Hall et al., 2017). Even though HIV infection among Blacks/African Americans decreased between 2012–2016, they still had the highest rate (41.1) of any other race/ethnic group (Centers for Disease Control and Prevention, 2018). There remains a gap in understanding and addressing the HIV health crisis in the United States, and in particular the particular needs of those who are disproportionately affected.

The very classification of “black” addresses race broadly and does not account for the heterogeneity of the U.S. black population, including cultural and ethnic differences, particularly when it comes to foreign-born blacks and US-born blacks. (Demeke et al., 2018; Koku et al., 2016; Ndikum-Moffor, Faseru, Filippi, Wei, & Engelman, 2015). The use of a single category of *Black/African American* results in the under-estimation of HIV prevalence in the African immigrant population and makes the allocation of resources more difficult (Koku et al., 2016).

Wafula and Snipes (2014) explain

... as researchers begin to separate black African immigrants from African-Americans in regard to both data collection and data analysis, researchers are uncovering differences between these two groups in regard to several health outcomes such as factors dependent on gender and ethnicity. (p. 697)

The growing numbers within these broad categories give even more reason for a closer examination. Using U.S. Census data, the Pew Research Center reports that 3.8 million black immigrants live in the United States; this is 8.7% of the country’s black population. Much of this growth in black immigration comes in particular from African immigration. The foreign-born black population is comprised of 36% Africans; this has risen from 24% in 2000. Nigeria and Ethiopia are the African countries with the highest numbers of US immigrants, respectively. Further, the foreign-born black immigrant population comprises a growing proportion of urban centers. For example, 15% of the black population living in the Washington DC area are immigrants (Anderson, 2015). Wafula and Snipes (2014) suggest that even the category of foreign-born black is too broad as culturally specific interventions and policy responses are particularly important to appropriately address sensitive and stigmatizing health concerns. The classification of foreign-born black ignores the culture, language, and even migration experiences which contribute to attitudes and behaviors among diverse subgroups (Nnaji & Metzger, 2014).

Given the high rates of HIV/AIDS among the black population in the U.S., and the complicated picture of the broad category of “black,” it is imperative to examine the subgroups within this population. Several states reported that a significant number of their black population with HIV were foreign-born (Demeke et al., 2018). Additionally, the diagnosis timeline for HIV has been shown to be different for different subgroups of the black population. Foreign-born black adults had higher late-stage HIV diagnosis than either U.S.-born black adults or Caribbean-born black adults

(Demeke et al., 2018). Women had the most striking difference of all: the diagnosis rate of HIV among African-born women was 5.3 times the rate of U.S.-born black women (Demeke et al., 2018). Broken down even further, African-born immigrants and refugees have HIV infection rates six times higher than any other minority group in the U.S. (Blanas, Nichols, Bekele, Lugg, Kerani & Horowitz, 2013; Connor et al., 2016; Ojikutu et al., 2013). Studies conducted in specific urban centers including New York City and Washington, DC found that HIV diagnosis rates were highest among African-born persons (Wiewel, Torian, Hanna, Bocour, & Shepard, 2015; Willis et al., 2015).

Knowledge, attitudes, and behaviors

The literature demonstrates contradictory data regarding African-born immigrants' knowledge about HIV transmission and risk factors (Akinsulure-Smith, 2014; Bova, Nnaji, Woyah, & Duah, 2016; Rosenthal, Scott, Kellela, & Zikarge, 2003). For example, possessing knowledge about HIV transmission does not necessarily translate into a reduction of HIV risk behavior among African-born immigrants (Akinsulure-Smith, 2014; Beyene, 2000; Rosenthal et al., 2003). Mitha, Yirsalign, Cherner, McCutchan, and Langford (2009) reported that Ethiopian immigrant men in San Diego knew about HIV risk factors and recognized the severity of the disease, but did not recognize their personal risk of infection. It is other factors such as stigma, fear of isolation, complex family situations, immigration concerns, cultural norms, religious beliefs, and gender expectations are driving African-born immigrants' attitudes and behaviors surrounding HIV (De Jesus, Carrete, Maine, & Nalls, 2015; De Jesus, Taylor, Maine, & Nalls, 2016; Kwakwa et al., 2017; Lindkvist, Johansson, & Hylander, 2015; Rosenthal et al., 2003).

Stigma

Earnshaw, Bogart, Dovidio, and Williams (2013) suggest "Societal stigma related to race/ethnicity ultimately contributes to and maintains racial/ethnic HIV disparities through its manifestations at the structural and individual levels" (p. 225). Such structural stigma manifestations are evident in the findings of Wafula & Snipes' (2014) literature review on the barriers black immigrants face in accessing the U.S. healthcare system. They found barriers to include "low literacy among black immigrants regarding the U.S. healthcare system, language barriers, stigma regarding illnesses such as HIV/AIDs, and lack of insurance" (Wafula & Snipes, 2014, p. 690). They also reported that most of the studies they reviewed suggest that ethnicity is a significant factor regarding healthcare access (Wafula & Snipes, 2014). Wafula and Snipes (2014) concluded, "we recommend that healthcare institutions, physicians, nurses, and other healthcare professionals address issues regarding cultural bias pertaining to the race and/or ethnicity of all patients, particularly in regard to African- and Caribbean-born blacks ... " (p. 693).

Gender

De Jesus et al. (2015) found that East African immigrant women were aware of Western public health messages including "Everyone should get tested for HIV" (p.606). Despite this, their behavior was not consistent with this message, and instead, they acted in accordance with their cultural and religious beliefs which were that HIV testing implies immoral behavior and brings shame upon self and family.

Worthington, Este, Strain, and Huffey (2013) conducted a qualitative, community-based study to understand the influence of gender on community perceptions of HIV/AIDS service needs among African immigrant men and women in Calgary, Canada. Participants indicated that family problems including under-employment, alcoholism, isolation lead to HIV risk behaviors. Strong gender norms in their cultures were reported including it being typical for men but not women to have multiple concurrent sexual partners. Additionally, participants discussed gender role reversal after immigration.

In their African home countries, men typically worked, and women cared for home and children. When men could not find jobs in Canada, and women were working instead, this led to disruption including sometimes spousal abuse. Further gendered cultural norms surrounding HIV were evidenced in De Jesus et al. (2016) study which found that East African women ascribe HIV risk to conditions of poverty and survival, instead of individual risk factors.

Immigration issues

The complexity of the immigration process adds to the challenges for HIV prevention and treatment. Ojikutu et al. (2013) found that of a sample in Massachusetts, foreign-born blacks were less likely than U.S.-born blacks to report that they had been recently tested for HIV; further, of the foreign-born blacks who were tested, they reported they received testing for immigration reasons, not for perceived risk concerns. However, the lift of the HIV entry ban in 2010 eliminated an important access point for HIV testing of foreign born (Kwakwa et al., 2017). Othieno (2007) reported that among a study of African immigrants living with HIV, the top reasons for not seeking or dropping out of care were:

fatalistic views about HIV, which respondents called a “disease with no cure” or “death sentence”; fear of isolation; fear of deportation; lack of knowledge of the care system and HIV-related services; and employment issues, including fear of termination by an employer (p.176)

De Jesus et al. (2016) similarly found that fears regarding immigration, lack of confidentiality of HIV testing results, and concerns about losing employment or housing were barriers to HIV testing for East African immigrants in Washington, DC.

There is a growing body of literature that addresses African-born, black immigrant communities and HIV/AIDS and emphasizes the need for culturally appropriate HIV-prevention programs and policies among these vulnerable populations with a focus on the importance of disaggregating HIV surveillance data on blacks by country of birth and ethnicity (Blanas, et al. 2013; Demeke et al., 2018; De Jesus et al., 2016; Koku et al., 2016; McMahon & Ward, 2012; Myles et al., 2015; Wiewel et al., 2015; Willis et al., 2015). This article will report on a study that engaged with Ethiopian immigrants and social service workers, health-care providers, and religious leaders who serve Ethiopian immigrants in Washington, DC to understand the knowledge, attitudes, and behaviors of the Ethiopian community toward HIV/AIDS. Ethiopian community members and first-line service providers echo the literature’s concerns with stigma, immigration concerns, and cultural barriers and then offer concrete suggestions for ways to better serve this specific, at-risk population.

Methodology

This study used a non-experimental mixed-methods research design to collect information through individual interviews and one focus group. This study reports on the qualitative findings from those interviews.

The original design sought to interview four populations including: (1) 60 individual Ethiopian people who live in the D.C. area; (2) nine religious leaders in the Ethiopian community; (3) four social service providers who have early contact with the immigrant community; and (4) 10 senior staff from health-care clinics that serve low-income communities. In the end, we were able to collect data from 60 Ethiopian individuals, but only one religious leader, one social service agency, and three health clinics. (Six staff participated in interviews from the three health clinics.) Researchers also conducted one focus group with three staff members who worked at social service and health-care agencies. To conduct this study, a research team at the Catholic University of America, National Catholic School of Social Service partnered with a community-based group called Holistic HIV Service Network (HHSN). HHSN was established by an Ethiopian team of individuals with more than 7 years of experience working on HIV/AIDS prevention, support, counseling, and global level

advocacy for the rights of people living with HIV and AIDS. This study was approved by the Catholic University of American Institutional Review Board.

Data collection and analysis

This study reports on the qualitative findings from 60 interviews with individual members of the Ethiopian community, nine interviews with staff, and one focus group with staff working in diverse contexts of the HIV/AIDS field. To recruit participants from the Ethiopian community, members of HHSN worked with the CUA team to arrange data collection efforts at various community locations where Ethiopians gather, including coffee shops and churches. At these locations, someone from the HHSN team would approach an Ethiopian person, tell them about our study and invite them to participate. If the individual agreed, the HHSN partner would connect them to a student or faculty member who would undertake the consenting process and complete the interview. To recruit participants from agencies who work HIV/AIDS patients, CUA faculty and graduate students called them to invite participation in the study and conducted follow-up interviews with those who agreed. Two CUA faculty members conducted the focus group that consisted of four staff people; a graduate student took notes to capture focus group responses.

With consultation from the HHSN community partners, researchers created a series of open-ended questions related to barriers and incentives for HIV testing, growing knowledge and awareness, and addressing stigma within the Ethiopian community. The responses to each question were noted by the interviewer, and then, after the interview, researchers wrote up detailed responses in a word document. To analyze the data, separate documents were made for each qualitative question with all 60 answers embedded within each document. The CO-PIs in the study individually coded the answers to each question and then met to compare and collapse codes and identify themes.

Findings

This section reports on the profile and findings from the interviews with individual Ethiopian people and interviews with health and community service providers. This section highlights the themes that emerged in regard to attitudes, treatment, testing, and prevention, including strategies for change.

Profile of Ethiopians who participated in the individual interviews

Table 1 gives a snapshot of the 60 adults who participated in the study. All participants were over 18, originally from Ethiopia and could read, speak, and understand English. While most participants (68%) spoke Amharic at home, five participants spoke both English and Amharic at home, and 13 participants reported speaking another primary language at home. The average age of participants was 38, and participant ages ranged from 26 to 64. Sixty-five percent (65%) of participants were men and 35% were women, and the majority (96%) of participants were Christian. In addition, most participants were either married (58%) or single (27%), but 15% reported being either separated, divorced, or widowed. The participants were a very educated group, with 42% having completed an undergraduate degree and 28% graduate degrees. More than half (55%) had been in the United States for more than 5 years, and 68% reported full-time employment, while 27% reported working part-time, working informally, or otherwise employed. All but one participant reported being heterosexual.

Changes in attitudes since immigrating to the U.S. from Ethiopian

Many individual participants (28) responded that their attitudes regarding HIV/AIDS had not changed since immigrating to the U.S. Those whose attitudes had changed talked about the differences in the experience of HIV/AIDS in the U.S. versus in Ethiopia. They reported that there is more HIV/AIDS education in the US as well as better access to testing and treatment, and greater

Table 1. Profile of participants ($N = 60$).

Primary language used at home	%	<i>N</i>	How long in the United States	%	<i>N</i>
Amharic	68	41	5 years or less	43	26
English	2	1	More than 5 years	55	33
Both	8	5	Prefer not to answer	2	1
Other	22	13	Education status		
Age ($\mu = 38$)			High school diploma	13	8
26 to 32 years old	25	15	Some college	12	7
33 to 40 years old	35	21	Bachelor's degree	42	25
41 to 50 years old	30	18	Graduate degree	28	17
51 to 64 years old	10	6	Other	5	3
Gender			How long in the United States		
Men	65	39	5 years or less	43	26
Women	35	21	More than 5 years	55	33
Religion			Prefer not to answer	2	1
Christian	96	58	Employment Status		
Muslim	2	1	Full Time	68	41
Atheist	2	1	Part Time	12	11
Marital Status			Unemployed	12	7
Single	27	16	Work informally or Otherwise employed	8	5
Married	58	35	Sexual Orientation		
Separated/divorced	13	8	Heterosexual	98	59
Widowed	2	1	Bi-sexual	2	1

awareness. One participant explained, "There is no change in my attitude ... I am surprised that people don't talk as much [about HIV/AIDS] herePeople in Ethiopia are more aware than people here." Among the participants there were conflicting views on the prevalence of HIV; some participants thought the prevalence was higher in the U.S.; others thought prevalence was higher in Ethiopia. Several participants also reported on the cultural differences between Ethiopian and American culture, especially in terms of the busier lifestyle in the US and higher levels of sexual freedom.

Importance of HIV testing

The overwhelming majority of individual participants (55) thought it was important to get tested for HIV. They cited many reasons including knowing your status for your own personal health (14), protecting others (23) including potential partners or marriage partners, family, and the larger community. In response to this question about testing, one participant said, "I live not for me only ... I live for others. I have to care about others."

Others answers focused on the importance of testing in order to get treatment (4) and to make future life plans (3) such as continuing education. Another perspective that was captured in the interviews was the idea that it is important for others to get tested, but that it does not apply to themselves. For example, one participant said, "I don't think it's important for me to get tested for HIV/AIDS because my wife is in Ethiopia and I am in the United States and I am not sexually active. I would only have sexual contact with my wife. But for other people, yes, I do think it's important for them to get tested."

To encourage HIV testing among Ethiopians, individual participants spoke of educating community members about the benefits of knowing your status and helping people understand that there is hope for those with a positive diagnosis. They reiterated educating people on where to go to get tested, what it costs, information on the possibilities and side effects. They suggested education about medical coverage options as well as misconceptions about HIV/AIDS treatment. They suggested sharing this information in Ethiopian markets and festivals – and in Ethiopian languages – and using Ethiopian media, Ethiopian business owners, and Ethiopian religious leaders to share the information.

Other ways to encourage HIV testing in the Ethiopian community include offering free, confidential testing, offering incentives for testing, requiring testing before marriage, offering testing at

churches and workplaces, providing testing at every medical visit – no matter the complaint, just making it part of the “standard procedure.” Another suggestion was to test Ethiopian immigrants when they first arrive in the US – at their first visit to the clinic.

Attention to the cultural differences was also a point brought up in the individual interviews. Participants mentioned the differences between individualistic American and communal Ethiopian cultures. Some participants noted the challenges this can pose when trying to encourage testing in the U.S. One participant, however, suggested tapping into the Ethiopian culture in a creative way, “Ethiopians have very beautiful ceremonies, such as coffee ceremonies, which people love to participate in. So, create community events around ceremonies people enjoy, invite people personally, and have free testing at these ceremonies. Make it special, have people dress up in traditional dress. People really enjoy these things and will come and get tested.”

Barriers to HIV testing

The primary reason that people do not test for HIV is fear (51 participants). Participants reported being afraid, having fear, being scared. These fears included various categories including fear of death and fear of the stigma associated with HIV. One participant said, “They are afraid of stigma in Ethiopian community ... They might not get the services. Also they might be afraid of discrimination in their families.”

Participants provided more details about what they meant by fear. This could be fear of isolation and discrimination if they were positive, fear of stigma and loss of immigration status if they were found positive. It also includes fear of the HIV/AIDS test results. Participants even expressed fear about the stigma of getting the testing done. One participant said, “ ... If people see you getting tested, they’ll just assume it’s because you’ve been having sex and that why you need tested. Another participant referred to the stigma in stark language, “People think of HIV/AIDS as it is a curse. Having HIV is not only a health issue, but being cursed by the almighty god.”

Multiple participants raised a concern about confidentiality, particularly within the Ethiopian community. One participant said people want to go somewhere [for testing or treatment] with professionals, but they do not want to go to an Ethiopian. As one participant explained, “The DMV [DC-Maryland-Virginia] community is small and limited, people don’t seek treatment because they don’t want to talk to someone who could leak their business to others.” Another participant said, “You don’t want to talk to people in your own community.” Because the Ethiopian community is small, people want to protect their participation in that community. They are far from home and do not want to be rejected from the immigrant community they have in the US.

Others said they would just rather not know or that they did not think HIV/AIDS was a possibility for them. Another reason given for why people do not get tested is because they don’t have medical coverage or could not afford the testing. Additionally, participants said that, culturally, Ethiopians do not go to the doctor for check-ups like Americans. They only go to the doctor if they are sick or have symptoms. Many participants also cited was a lack of knowledge about testing and treatment as a barrier to testing. Cost of testing was also cited as a barrier. These themes were captured by one participant, “No access to testing. People don’t get treated because they believe that HIV/AIDS is not treatable, and that there is no point to getting treated.”

Similarly, institutional partner/provider study participants reported that the barriers they see are stigma, concerns about confidentiality, access to care issues such as health insurance, financial barriers, and a lack of service providers who speak Amharic. They also spoke of cultural barriers including late diagnosis because it is not part of the Ethiopian culture to seek testing and treatment early. Another cultural barrier is that in the Ethiopian community, HIV/AIDS is viewed as a death sentence. They cited traditional standards of sexual behavior and sexual identity as an issue and a barrier to getting tested and receiving care. They also reported a lack of knowledge about HIV/AIDS as a barrier to receiving needed care.

Institutional partners explained that stigma delays testing and treatment, and does not allow for discussion and education about transmission and prevention. Two partners mentioned that they

think HIV/AIDS is more prominent in the Ethiopian community than is known at this time. Another issue that was highlighted was the conflict of traditional, conservative viewpoints related to sexual health and behavior, which contributes to the stigma, and therefore reluctance to seek testing and treatment.

Other challenges that institutional partners mentioned included the false beliefs among the community that people with HIV do not live very long. Another problem was that community members may not have some of the risk factors typically associated with HIV/AIDS such as men having sex with men (MSM) or drug use so they think testing and treatment do not apply to them. Issues of community members not trusting the government, concern about legal status, and worry about health insurance were also mentioned.

Where to receive sexual health services

Individual Participants said if they needed sexual health services they would go to the doctor (19), clinic (5), hospital (3), internet (3), street (1), and the Bible (1). Seven participants said they *did not know* where they would go for sexual health services. Further, it is important to note that many of the responses seemed theoretical in nature – like they knew they should say a health-care professional – but there really was not a clear definite place in their mind that they could go tomorrow. For example, one participant responded, “Never thought of it; maybe primary doctor would have suggestion.” Another important issue that was raised with this question was concerns with the healthcare system and prohibitive costs, as well as entry points to accessing the system. One participant explained, “I honestly don’t know. It’s because of a lack of awareness of healthcare system in the US ... In the US everything is expensive to pay off. For example, if I want information on healthcare, I could google it. I would then leave my phone number for more information ... and maybe they would call you backbut it’s all just a lot of money to get care.”

Preventing HIV/AIDS in the Ethiopian community in the U.S

Most individual participants stressed the importance of helping prevent HIV in the Ethiopian community in the United States (58). The reasons and explanations given for the importance can be categorized into several major themes. First, individual participants reported that there was a need for understanding, knowledge or awareness about HIV/AIDS among the Ethiopian community in the US. This includes prevention and protection of education. There was a dichotomy in understanding among the individual participants regarding the prevalence of HIV/AIDS in the US. Several reported that the US had a high prevalence of HIV/AIDS, while others thought Ethiopia had a higher prevalence and that it is less important in the US. “I think preventing HIV is more of a concern in Ethiopia than in America.”

Repeatedly, individual participants mentioned the cultural differences – that the US has a more permissive culture especially surrounding sexual behaviors and drugs and alcohol. They reported that new customs, systems including a single life/disconnected from community, stress and busy work schedules add to the barriers in reaching out for help. Several of the individual participants also talked about how important HIV prevention is for the community in terms of quality of life, allowing people to get education and jobs, and for the young people who are the future. There was a focus not only on the safety and life-saving importance of HIV/AIDS prevention personally, but also on the broader effects. One participant said, “It is good for the economy to have people who are healthy so they can work.” Another mentioned the importance of creating jobs for women other than prostitution.

HIV/AIDS awareness and treatment promotion

When asked where the Ethiopian community gets information about HIV/AIDS, the most common response can be captured in the category of either *nowhere or not sure* (19). Participants expressed this in various ways:

- “In the US I have no idea where the Ethiopians can get HIV/AIDS information.”
- “Nowhere. They don’t have the information they need.”
- “I don’t know. I really don’t know ... ”
- “I don’t think that the Ethiopian community here gets information here about HIV/AIDS. I’ve never seen any information here.”
- “There is no outlet to get information. No responsible grassroots organization that publicizes this issue. There should be announcements/leaflets during Ethiopian sport occasions. Restaurants who serve Ethiopians. Media/radio to announce and advertise about protection. Add awareness to the community.”

Others said they do get information from churches (12), a doctor or health center (11) or a community center (11). Other sources of information that participants mentioned were friends and word of mouth, school, the internet, television/radio/magazines, and newspapers. Four participants said they got their information/education about HIV/AIDS in Ethiopia and brought that with them to the United States.

Increasing knowledge about HIV/AIDS in the Ethiopian community

Individual participants emphasized education as the key action to increase knowledge about HIV/AIDS in the Ethiopian community.

- Increase awareness about how HIV/AIDS is transmitted, how transmission can be prevented, sexual education, use of condoms, safe needle practices, sanitization, and spill clean up
- Attention to “Mythbusting” around the false idea that “There is no HIV in US”; educate about prevalence rates
- Design leaflet or flyer to share in spaces where Ethiopians gather
- Educate about testing, confidentiality of testing
- Offer free testing, free treatment
- Offer counseling and encouragement. Several participants talked about decreasing the ostracism associated with HIV/AIDS through education. One participant talked about sharing the message: “Being HIV positive is not a death sentence; they can continue to live a normal life.”

Participants suggested various creative approaches to sharing information and awareness. These ideas included educating through art, music, theatre. They suggested sharing information on billboards and buses, hair salons, schools, colleges, cafes & restaurants. They recommended getting Ethiopian media (magazines, newspapers, radio, TV) and Ethiopian sporting events and festivals involved in sharing information. Participants advised creating a 1–800 hotline in order to provide confidentiality, designing an APP for smartphones, and using social media and other online sources.

Who conducts this education and awareness matters according to the individual participants interviewed. They suggested that there is a need for an organization to lead this effort in the Ethiopian community; others suggested that possibly the churches and mosques could be used as a platform from which to launch education. Individual participants highlighted the importance of education and services in Amharic, online resources in Amharic. Participants recommended recruiting people to share their personal experiences about getting tested, living with HIV. Famous Ethiopians or leaders in the community would be good people to do this or even to publicly get tested and make that process a public statement.

Finally, individual participants talked about seeking community. Participants wanted to know about other Ethiopians who have experienced HIV/AIDS and wanted to bring people together around this cause. They said there was a need to see other Ethiopians speak out and reduce the ostracism surrounding HIV/AIDS. One participant said that there was a need for “Building a stronger Ethiopian community not just for HIV and AIDS, but for other issues as well.”

Similar to the individual interview data, the institutional partner interviews yielded an emphasis on education. They suggested:

- Providing education in places where Ethiopians live their lives (nightclubs, churches, restaurants, etc.)
- Using media and radio to spread education about HIV/AIDS
- Educating regarding confidentiality
- Providing culturally sensitive education programs
- They also emphasized services and improved access to care including
- Have counseling and testing options readily available
- Streamline infected people into treatment and health facilities
- Provide more outreach
- Focus on culturally competent services. For example, have providers of same ethnicity, same gender as the clients. Having women talk to women, or peers of the same sexual orientation, would improve service.
- Provide not only HIV tests, but high-quality tests.
- Do not require showing legal documents to receive any testing or services
- Streamline services (testing, linking to care, assisting with insurance)

Strategies for changing attitudes about HIV/AIDS

Among individual participants, two key themes emerged regarding strategies for changing attitudes. First, participants emphasized the need to educate people, including messages such as:

- AIDS is treatable, preventable, and normal. But that prevention does not have to do with eating well, touching or hugging a person who is infected.
- Teach about how HIV/AIDS is transmitted.
- Life can be successful. One participant said, “Education through entertainment. Showing people who are successful and living with HIV. We have to show people they can live productive lives with HIV and AIDS and that having health challenges does not mean that people are not successful. We need to share more examples of celebrities and people who are well known who have HIV and are successful like Magic Johnson.”
- Provide more information about medication and treatment.
- Dispel myths that immigrants cannot come to the US if they are tested HIV/AIDS positive.

The second key theme is to treat people who are infected well. One participant summarized this theme, “Showing love. For the people who have already disclosed, treat them well. Let them know it is okay. Make them comfortable. Get them to encourage others to get help, to know it is okay.” And once again, participants suggested appealing to the Ethiopian faith communities to lead out in education and “to care for the people who are sick with HIV/AIDS.”

The institutional partners/providers, like the individuals interviewed, emphasized the importance of education and awareness. Their suggestions regarding advertising and awareness campaigns included using media, advertising in airports for when people arrive in the country, and educating in places where people worship, eat, and play. They also suggested drawing upon strategies that have been successful with other populations to reach MSM.

Other suggestions included teaching about patient rights and confidentiality, what it means to get an HIV diagnosis, and the importance of testing. They recommended pairing education with an already existing service or opportunity; for example, if there is a scheduled conference, add an HIV/AIDS component. One provider gave insight into the broader context, “Look first to the big picture. Do something about the fact that there is a general and pervasive negative perception of immigrants. We must improve immigrants’ access to quality health care.”

Another challenge they addressed was that there is a need for culturally competent insiders, and yet, when professionals are from within the Ethiopian community, then there is the tension and worry about confidentiality. They said it seems like the community wants fluent Amharic speakers who are not Ethiopian as providers. They also want someone who is intimately familiar with the culture.

The providers in interviews highlighted the importance of working with agencies that are already in the community including churches and Ethiopian community leaders. They emphasized being in places where Ethiopians spend their lives and their time. The providers in interviews highlighted the importance of working with agencies that are already in the community including churches and Ethiopian community leaders. They emphasized being in places where Ethiopians spend their lives and their time.

Discussion and social work implications

The qualitative findings from this study speak to the profound role of stigma in the Ethiopian community that creates barriers to testing, treatment, and prevention activities. The qualitative interviews revealed that in the Ethiopian community, HIV/AIDS is associated with fear of death, fear of depression, fear of shame and isolation and not being treated “normal.” When participants and providers were asked specifically about what keeps members of the Ethiopian community from getting tested or treated, they continued to speak of the fear of isolation and discrimination and stigma. The participants were also concerned with the issue of confidentiality in testing and treatment if their provider was Ethiopian, citing the small, close-knit Ethiopian community and worries that others would find out. Again, speaking to the stigma issues surrounding HIV/AIDS, one participant said, “People are more afraid of what others will say about them than they are of HIV itself.”

Several participants suggested the importance of identifying leaders and people from within the Ethiopian community talking openly about the issue to lessen the taboo around HIV/AIDS. One participant said, “I really believe that if we had people from within the Ethiopian community who also have HIV/AIDS volunteer to share their stories, then we could help more people change their opinions on it.” Participants suggested calling on Ethiopian business leaders, religious leaders, and celebrities to use their voices and platforms to address this issue.

Another theme from the interviews regarding stigma and attitudes around HIV/AIDS in the Ethiopian community was that how we treat people with HIV/AIDS matters. In order to change attitudes and help the Ethiopian community be more accepting of people with HIV/AIDS, it is important to treat people who are infected with dignity and respect, and to offer hope to them. Participants suggested visits and support for those who are infected to combat isolation. One participant said, “For example, encourage them that they can manage, giving them hope and strong messages we can make their hope strong.”

Another important finding from this study was the importance of developing culturally appropriate outreach, education, and treatment programs. The qualitative interviews with Ethiopian individuals and providers emphasized the need for more education, adding that education could encourage HIV testing in the Ethiopian community. Education could include where to go for testing, the cost of testing, the benefits of knowing one’s status, and what treatment possibilities exist. Participants recommended a number of strategies to encourage HIV testing that could be tested through research such as offering free access to testing, offering incentives, requiring testing before marriage, offering testing at churches, testing at every medical visit regardless of presenting problem – making it part of the standard procedure, offering workplace testing, and testing at the first medical clinic visit when immigrants arrive in the US.

For most participants, “culturally appropriate” services meant services provided in Amharic, using Ethiopian festivals and gathering places for outreach and testing efforts. However, they also expressed concerns about confidentiality in receiving or access these services due to the stigma in the community and fear of confidentiality being violated. This is a challenging dilemma that could be

more easily overcome if stigma were reduced. In addition to addressing stigma, culturally appropriate education and outreach services should also address the lack of knowledge about testing and treatment, lack of access to testing, the cost and time constraints, and concerns about immigration status.

Social workers play an important and sometimes leading role in HIV/AIDS outreach, education, prevention, and services in the United States, staffing community-based social service agencies and public and private not-for-profit health clinics. As a profession that embraces collaborative practice, social workers have an important role in working in partnership with the Ethiopian community to design prevention and service interventions that are culturally appropriate. Sometimes, the concept of “culturally appropriate” services gets translated into services provided by members of the community who are impacted by the problem. Yet, in this case, the stigma around HIV/AIDS among the Ethiopian community is so powerful, that services and promotion activities provided by one’s countrymen can serve as a barrier to testing, treatment, and even engaging in a conversation around HIV/AIDS. To overcome this stigma in local communities, it is critical for social workers to engage with religious leaders and prominent members of the Ethiopian community to normalize a universal practice of getting tested for HIV/AIDS, holding sacred issues of confidentiality and privacy, and educating about living with HIV/AIDS and even recovering from it as treatment and technology advance and become more widely available.

In addition to much of this agency and community-based practice, social workers need to continue to advocate to make these services available, accessible, and affordable to the people they serve through policy practice, including advocacy. Social workers should also contribute to the research literature on best practice methods to promote, prevent, and treat HIV/AIDS in the Ethiopian community.

Disclosure statement

No potential conflict of interest was reported by the authors.

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