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Experiences of and responses to HIV among African and Caribbean communities in Toronto, Canada

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African and Caribbean communities in Canada and other developed countries are disproportionately affected by HIV/AIDS. This qualitative study of African and Caribbean communities in Toronto sought to understand HIV-related stigma, discrimination, denial and fear, and the effects of multiple intersecting factors that influence responses to the disease, prevention practices and access to treatment and support services. Semi-structured interviews were conducted with 30 HIV-positive men and women and focus groups were conducted with 74 men and women whose HIV status was negative or unknown. We identified a range of issues faced by African and Caribbean people that may increase the risk for HIV infection, create obstacles to testing and treatment and lead to isolation of HIV-positive people. Our findings suggest the need for greater sensitivity and knowledge on the part of healthcare providers; more culturally specific support services; community development; greater community awareness; and expanded efforts to tackle housing, poverty, racism and settlement issues.

Keywords: stigma; people from Africa and the Caribbean; HIV; treatment barriers; sociocultural factors

Introduction

Since the late 1990s, service providers and members of African and Caribbean communities have sought to determine the prevalence of HIV infection within African and Caribbean communities in Ontario and to develop appropriate responses (Handa & Negash, 2003; HIV Endemic Task Force, 2001). These efforts led to the emergence of the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) in 2005, which is a coalition of organizations, service-providers, policy-makers, researchers and unaffiliated individuals working on HIV prevention, and access to care, treatment and support for African and Caribbean communities in Ontario. In 2004, ACCHO, together with researchers at the University of Toronto, initiated a study to understand HIV-related stigma, the mechanisms by which it is perpetuated and issues related to prevention, testing, treatment and support. The study included in-depth interviews with HIV-positive African and Caribbean people in Toronto about their experiences living with the disease, and focus groups with community members at large about experiences, perceptions and responses to HIV/AIDS.

The rationale for the study, and our approach, was motivated by a number of issues related to understanding and interpreting the social context of HIV, especially in relation to marginalized African and Caribbean communities in Toronto.

First, recent research has emphasized the importance of placing health “in a broader context” in order to address HIV among African diasporic communities (Burns & Fenton, 2006). This paper reports on the first major study to examine a range of social, structural and cultural issues that influence experiences of and responses to HIV in African and Caribbean communities in Canada. The overarching research objective was to investigate HIV-related stigma, denial, fear and discrimination among African and Caribbean communities in Toronto, both within the context of their own communities as well as the wider Canadian society.

Second, epidemiological data demonstrate the seriousness of HIV among these communities in Canada. In the province of Ontario, people born in Africa or the Caribbean constituted 2.6% of the population in 2001 (Statistics Canada, cited in Public Health Agency of Canada, 2005). However, in 2003, approximately 12% of people living with HIV in

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Ontario were from Africa and the Caribbean. From 1999 to 2003 the number of African and Caribbean people in Ontario infected with HIV increased by over 80% (Remis, Swantee, Schiedel, Fikre, & Liu, 2006).

Third, research studies have identified stigma as a barrier to accessing HIV testing, treatment and care both within African communities (Anderson & Doyal, 2004; Dodds et al., 2004; Foley, 2005) and other communities (Chesney & Smith, 1999; Herek, Capitanio, & Widaman, 2003). Also, service providers in Toronto report that HIV-positive people from the Caribbean and sub-Saharan Africa often fail to seek out the services they need because of the stigma associated with the infection (Ontario Advisory Committee on HIV/AIDS, 2002). In concrete terms, stigma may be associated with the high rates of undiagnosed HIV infection and late diagnosis identified among African migrants in the UK (Burns & Fenton, 2006; Burns, Fakoya, Copas, & French, 2001; Erwin et al., 2002; Fenton et al., 2002; Sinka, Mortimer, Evans, & Morgan, 2003). Similarly, people from Africa and the Caribbean may delay accessing treatment once diagnosed, partly due to distrust of pharmaceuticals, hospitals and medical care systems (Erwin & Peters, 1999).

Fourth, African and Caribbean communities in Canada face unique health and social challenges related to poverty, unemployment, immigration and settlement issues, and systemic racism in schools, the criminal justice system, workplaces and elsewhere (HIV Endemic Task Force, 2001). Some fear that publicity around rates of infection may fuel racism and its effects such as difficulties accessing services, housing and employment (Tharao & Remis, 2002). HIV-positive people may face a dual exclusion: both from the mainstream society on the basis of their race, ethnocultural or immigration status and also from "personal networks of social and emotional support on the basis of HIV status" (Dodds et al., 2004: 9). These conditions provide fertile ground for denial, silence and barriers to prevention, treatment and support activities within Toronto's African and Caribbean communities.

The overall aim of the study was to understand the role of denial, fear, stigma and discrimination associated with HIV/AIDS among people from sub-Saharan African and Caribbean communities in Toronto. Below, we present and discuss participants' views on particular issues or challenges faced by African and Caribbean HIV-positive people in Toronto and factors impacting on responses to HIV/AIDS within Toronto's African and Caribbean communities.

Methods

Research participants were recruited from three Caribbean (Guyanese, Jamaican and Trinidadian) and three East African (Ethiopian, Kenyan and Somali) communities, chosen based on their relatively high HIV-prevalence rates and sizeable populations in Toronto. Men and women over the age of 16 who reside in Toronto were invited to participate in the research if they or a parent was born in one of the six listed countries. Those who self-identified as HIV-positive participated in individual interviews and those who did not were recruited into focus groups. Twelve focus groups were held, one with women and one with men from each of the six communities.

Data were gathered from November 2004 to May 2006. Promotion of and recruitment to the study took place through posters and postcards placed at AIDS service organizations (ASOs), hospitals, health centers and clinics, and through referrals from physicians, service providers and community agencies.

The individual interviews ranged in length from 45 to 120 minutes and focus groups from 90 to 120 minutes. Topic guides were used in individual interviews and focus groups to ensure consistency in subjects covered, to allow interviewers and moderators to pursue issues in further detail as they arose and to allow participants the opportunity to tell their own stories. Topics for interviews included discovery and response to the HIV diagnosis, the short- and long-term impacts of learning the diagnosis, disclosure experiences and experiences accessing health and support services. Focus groups discussed the importance of HIV relative to other issues facing their communities in Toronto, community views of HIV-positive people, perceptions of stigma, denial, discrimination and fear and related impacts on access to HIV prevention, testing, treatment and support.

The research team comprised researchers from diverse disciplines, service-providers, educators and policy makers, many from African and Caribbean communities. The research team worked with a Community Advisory Committee (CAC) drawn from community-based ASOs and Community Health Centres in Toronto with considerable expertise in working with African, Caribbean and Black communities. The CAC advised on community needs, recruitment of participants, research instruments, interpretation of study results, dissemination of findings and future actions. The University of Toronto HIV Research Ethics Board approved the study protocol.

In-depth interviews were conducted by an experienced and ethnoculturally diverse team (the study coordinator and data analyst and three part-time

interviewers). Participants were given an option to choose an interviewer (according to gender and/or ethnocultural background) with whom they were likely to feel comfortable. The interviewers and one co-investigator moderated the focus groups. Interviewers received training on interview techniques, including techniques for probing and active listening. These were conducted by consultants and members of the research team with experience doing in-depth interviews with HIV-positive people and with members of African and Caribbean communities. All interviews and focus groups were audio-recorded and transcribed verbatim for coding with computer-assisted qualitative data analysis software.

The study took a pragmatic approach to grounded theory methodology (Melia, 1997, cited in Barbour, 2001). Coding was carried out with themes reflected in the initial research objectives, such as discrimination, denial, stigma and fear, and emergent themes such as gossip, silence and racialization. Emergent issues were identified through: (1) systematic reading of some transcripts by research team members followed by group meetings to discuss salient themes and possible interpretations of respondent comments, and (2) discussion of coding schemes and issues identified within thematic codes at research team meetings. As a result of these discussions, new codes were developed and existing codes were combined or redefined. Analysts approached the data with the view that participants' comments reflect a complex and layered mixture of social and cultural norms, individual experiences and disposition, the social context of the interview/focus group, as well as multiple rhetorical and linguistic features of speech. Furthermore, we understood, and it was re-affirmed throughout the research process, that researching and talking about HIV is political: there is a politics of blame, intersecting with racism, poverty, unemployment, immigration status and sexual and gendered identities.

Results

The study recruited a sample of 104 people, or close to three-quarters of the original maximum target of 144 people. Recruitment was terminated when the study had achieved a broadly diverse sample and when interviews no longer yielded new information, perspectives and themes. Table 1 illustrates the basic demographic characteristics of the sample. Thirty people living with HIV were interviewed, including 15 women and 15 men. Nine were from East Africa and 21 from the Caribbean. The age range of our sample was 17 to 54 years, with the majority between 34 and 45 years of age. The mean time since HIV diagnosis

was 7.6 years (range 1 month to 25 years). Twenty-seven (90%) were diagnosed in Canada. All were born outside Canada and most (87%) had legal residence status in Canada. The mean number of years since immigration to Canada was 16.6 years (range 3 weeks to 41 years).

In addition to the interviews with HIV-positive people, a further 74 community members whose HIV status was negative or unknown participated in 12 focus groups. Groups varied in size from 3 to 9 participants with a mean of 6.2. The majority of the participants were between 24 and 45 years old. Four participants (5%) were born in Canada. For the remainder, the mean number of years since immigrating to Canada was 13.2 years (range 3 months to 38 years).

Participants discussed a number of issues, from which the research team identified several key themes discussed below.

Canada versus "back home"

Some participants noted that there was a lack of information about HIV in Canada compared to "back home". An Ethiopian woman said that "I came from back home two years ago and everybody knows that there is AIDS. But now I think the problem is the people that live here and vacation back home because they don't have no idea about AIDS ... you don't hear about AIDS in Canada." Other participants observed that media coverage of HIV/AIDS in Canada focuses on the African context much more than the local context. In the words of one Kenyan woman, "Whenever people talk about AIDS it's all about Africa. So of course when you come here from an African country, you assume because they don't talk too much about it, there is no AIDS [here]."

Many focus group participants described not knowing any HIV-positive person, while also stressing that anyone who is HIV-positive would not disclose to others, feeding the perception that HIV is not present within their communities. Most HIV-positive participants confirmed reticence to disclose their status. Foley (2005) noted a similar contradiction among members of African immigrant communities in Philadelphia who commented on a "lack of evidence" that HIV is a problem within their communities, yet acknowledging that no one with HIV would disclose for fear of stigma and social isolation.

Several focus group participants also felt it would be "better not to know" one's HIV status because the stress of knowing would lead to physical decline. A few participants had close relatives back home who had died of AIDS and many knew of acquaintances

Table 1. Characteristics of the Stigma Study sample.

	Interviews with HIV-positive people <i>n</i> = 30	Focus group participants (HIV status unknown) <i>n</i> = 74	Total participants <i>n</i> = 104
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Community			
African	9 (30.0)	43 (58.1)	52 (50.0)
Caribbean	21 (70.0)	31 (41.9)	52 (50.0)
Gender			
Female	15 (50.0)	42 (56.8)	57 (54.8)
Male	15 (50.0)	32 (43.2)	47 (45.2)
Age			
Less than 35 years	6 (20.0)	28 (37.8)	34 (32.7)
35 year and older	24 (80.0)	46 (62.2)	70 (67.3)
Highest education			
Primary	0 (0.0)	4 (5.4)	4 (3.8)
High school	8 (26.7)	16 (21.6)	24 (23.1)
Post-secondary	15 (50.0)	47 (63.5)	62 (59.6)
Not provided	7 (23.3)	7 (9.5)	14 (13.5)
Years since immigrated to Canada			
Less than 10 years	10 (33.3)	25 (33.8)	35 (33.7)
10 years or longer	20 (66.7)	36 (48.6)	56 (53.8)
Not provided	0 (0.0)	9 (12.2)	9 (8.7)
Born in Canada	0 (0.0)	4 (5.4)	4 (3.8)

and community members who had died. The association of HIV with rapid decline and death is strong, with terms such as “dead and walking” used to describe community perceptions of HIV-positive people. This also makes it difficult for HIV-positive people to disclose to families back home that they are not able to see and reassure that they are healthy.

Community gossip

Experiences or fears of gossip and ridicule figured prominently in HIV-positive participants' accounts of living with HIV. Many took extreme precautionary measures to maintain confidentiality and disclosed to few people, if any. The fear of being seen by someone in their community and becoming a subject of community gossip was the most common barrier to accessing health and support services mentioned by HIV-positive participants. In some cases, friends', neighbours', co-workers' and acquaintances' responses involved exclusionary actions such as verbal harassment and breaking off contact. Such responses have particularly damaging consequences for those who are separated from family and rely on social support networks forged among smaller communities of common language and ethnocultural background.

Cultural silences

The complexities and nuances of silence in African and Caribbean communities was a recurring theme in the study. Both African and Caribbean participants reported that, for the most part, sex, sexuality and physical or psychological health issues were rarely discussed in their homes or communities. Community members are socialized to be “tough” through emotional stoicism and prohibitions against “speaking your business” or “airing dirty laundry”. This silence and secrecy can result in a tendency, noted particularly among men, not to seek medical care until a health condition is acute or at an “end stage”. It also impedes access to information about HIV or sexual health, discourages people from seeking treatment and contributes to ongoing denial of HIV as affecting African and Caribbean communities in Canada.

Perception that HIV is a “gay disease”

Caribbean participants discussed the belief that HIV is a “gay disease”, and the simultaneous denial of homosexuality, as components of HIV denial in their communities. A Jamaican woman stated with an ironic tone, “You associate HIV with homosexuality and coming from a Jamaican background, there are

no gay people in Jamaica, right? ... So therefore it follows that Jamaican people can't have HIV because there are no gays." Even if homosexuality is admitted, there is a sense that gay men are to be blamed if they become infected, indicating attitudes that continue to distance HIV from community life. A Jamaican man stated, "In a sense, the community don't care. First of all AIDS is a gay man disease. That's what they say ... It's not talked about. And when you do talk about it, you hear, 'Well, if people were doing what they were supposed to do, they wouldn't get HIV' You know? 'And they're nasty' 'And they must be gay.'"

Religious beliefs and norms

There is an assumption that HIV does not infect people who are following their religion. Somali women discussed a perception that Muslim women do not get HIV: "Muslim woman, she's allowed to touch only her husband ... So they [will] say 'you are Muslim, how come you get this disease?' They might make fun of you." A Kenyan woman states, "Back in Kenya, you find every Sunday everyone is in church, and your parents are church-going people. So when you're in the church you raise your children very well and they're not supposed to get into trouble." Both African and Caribbean participants spoke of religious prohibitions against condom use as being a major obstacle to tackling HIV/AIDS within their communities.

Issues of race and racism

Focus group participants described reluctance to access health services for fear of encountering a racist perception that African or Caribbean people are carriers of HIV and other diseases. HIV-positive participants discussed experiences of discriminatory treatment by health-care and other service providers. For example, a Kenyan woman related that the nurse at an HIV clinic "made a very sarcastic statement. She said she always tells her daughters that everybody from Africa is HIV-positive." Some participants stressed the need for more health and support services offered by African or Caribbean professionals and through organizations with a higher proportion of Black staff, executive and clientele, to address problems such as cultural misunderstanding, language barriers, racism and discriminatory treatment. An HIV-positive Ethiopian woman described how she felt better after meeting other Ethiopian women with HIV, "For me, it's good to talk about what's going on with your people, with your language. It makes me better."

Social determinants of health

Focus group participants indicated that, compared to HIV, other issues seem to be more important for Black Canadians on a daily basis, including inter-generational conflict, problems encountered by Black youth in the school system, unemployment, racism and immigration and settlement issues. A Trinidadian woman commented, "I think the Black community feels it's under siege ... And if you don't have to deal with [HIV] then why?" HIV-positive participants also discussed how they experience multiple forms of stigma, which cannot be unlinked. When asked about HIV stigma and discrimination, for example, an HIV-positive Jamaican woman replied, "We live with it everyday. It's not just HIV."

Participants also suggested that economic disadvantage puts their communities at greater risk for HIV infection. For example, a Kenyan man observed that Kenyans usually come to Canada as young single men or women with limited financial means. He suggested that to secure housing and survive financially, people enter into relationships with partners they do not know well. A Trinidadian woman made a similar point, "When the kids and them can't find a job, they're on the street, that's where [HIV] interacts."

Immigration

The immigration process affects how African and Caribbean people experience and respond to HIV in Canada. Participants describe the vulnerability of being an immigrant and dealing with issues such as unemployment and lack of family support networks. This can make it harder to live with a diagnosis of HIV because of heightened fear of the loss of support with disclosure or because they cannot disclose to family members who live far away. People may not present for testing or seek treatment and support services if they don't have legal residence status in Canada. While Canada has a universal healthcare system, Ontario and some other provinces have waiting periods prior to eligibility, and immigrants and refugees may be unable to access care because they lack identification documents or a fixed address or because they are awaiting decisions on their immigration status (Caulford & Vali, 2006). Immigrants often fear approaching health and support services. An HIV-positive Trinidadian man explains that some people "may feel that if you go to these services, they would have to disclose their [immigration] status and they may not get services or even they might call immigration [on] them. That's how people think."

Gender issues

Women in the focus groups discussed issues affecting women's sexual health, including violence, difficulties negotiating condom use with partners and the pressure of familial or cultural expectations regarding marriage and reproduction. Several HIV-positive women indicated encountering problems with male partners after HIV diagnosis. Four women described verbal, psychological or physical abuse, which either followed or was aggravated by disclosure of their HIV status to their partners. Two of the women described difficulties accessing HIV-related support services because of opposition from their partners. Both HIV-positive women and women in focus groups suggested that heterosexual men are more prone to denying their own or their partner's HIV status.

A further difficulty that women encounter is that their sexual lives are often not acknowledged (Reid & Walker, 2005). There is a widespread tendency to view women as either "promiscuous" (at risk for HIV infection) or "virtuous" (not at risk). This binary does not reflect the reality of women's lives. The consequences described by our female participants include fear of moral judgment being passed against them if they seek information about HIV or request testing, or a tendency on the part of healthcare providers to assume that women are not at risk.

Discussion

Our participants identified a number of factors that may negatively affect HIV-prevention efforts, timely diagnosis of infection and access to treatment and care within African and Caribbean communities in Toronto. HIV is seen to contravene cultural and religious norms regarding gender and sexuality. Some focus group participants spoke of how fear of encountering racist attitudes and the pathologizing of Black bodies as repositories of HIV and other diseases, creates a fear of approaching health services. In general, HIV-positive participants spoke highly of the healthcare they receive but they also encountered discriminatory attitudes from some healthcare and service providers. Participants frequently spoke of a struggle to find a foothold in Canada; they often face unemployment, discrimination and social isolation. Community networks are crucial for survival and the fear of being ostracized because of HIV status is great. Distrust of the medical system and official institutions and tendencies to avoid seeking medical care until problems are severe, deter accessing health and social services. Also, fear of HIV is influenced by experiences back home where treatment is less available or unaffordable.

This qualitative study suggests the need for multi-faceted responses to address cultural, social and structural components that impact the health and prevalence of HIV among African and Caribbean communities in Canada. Efforts are needed to counter the gossip and social exclusion faced by HIV-positive people within African and Caribbean communities in Toronto. Service providers working with people whose social networks, income, housing and immigration situations may be precarious, need to assure people that their anonymity and privacy are protected. Our findings indicate the need for greater sensitivity on the part of service providers and also the need for more services delivered by and for African and Caribbean people. Focus group participants emphasized the need for "spokespersons" such as celebrities or religious leaders to draw attention to HIV in their communities and also emphasized the need for community development measures to provide venues or forums for discussion and action. They indicate that information about HIV is not reaching their communities, perhaps because the distribution channels, language, images and cultural appropriateness of the messages are not geared to Black Canadian audiences. In response, ACCHO has implemented a number of initiatives within the framework of the provincial African and Caribbean strategy on HIV/AIDS (HIV Endemic Task Force, 2003). Examples to date include: a three-phase province-wide communication campaign to address stigma, promote safer sex and encourage HIV testing; resources and workshops to improve service providers' capacity to work with African and Caribbean communities; and forums with service providers and community members in Toronto to identify specific actions, strategies and responsibilities to address stigma.

This study describes major issues that impact HIV/AIDS experiences and responses within African and Caribbean communities in Toronto including: making sense of HIV in the context of Canada versus "back home", community gossip, cultural silences, the perception that HIV is a gay disease, religious beliefs and norms, issues of race and racism, social determinants of health, immigration and gender issues. These are similar to research findings pertaining to African migrants in other contexts, emphasizing that strategies and policies to reduce the impact of HIV must attempt to identify and address the specific needs and experiences of diasporic populations such as racism and language barriers, immigration and legal status, distrust of health systems and institutions, socioeconomic disadvantage and cultural articulations of HIV stigma (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007; Foley, 2005). These findings may also be situated within a body of research in Canada investigating the social determinants of health (Raphael, 2004).

Despite the many obstacles they face, HIV-positive participants in this study demonstrated impressive resourcefulness in coping with diagnosis. Many took on advocacy and peer counseling roles and organized and participated in support groups. HIV-prevention efforts among African and Caribbean communities in Canada must attend to the experiences of and responses to HIV within those communities. This study is part of a broad community effort to reduce infections and improve the quality of life for Africans and Caribbeans living with HIV in Canada.

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