

**HIV/AIDS
STIGMA,
DENIAL,
FEAR AND
DISCRIMINATION**

**EXPERIENCES
AND RESPONSES OF PEOPLE
FROM AFRICAN AND CARIBBEAN
COMMUNITIES IN TORONTO**



HIV/AIDS STIGMA, DENIAL, FEAR AND DISCRIMINATION:
EXPERIENCES AND RESPONSES OF PEOPLE FROM AFRICAN AND CARIBBEAN COMMUNITIES IN TORONTO

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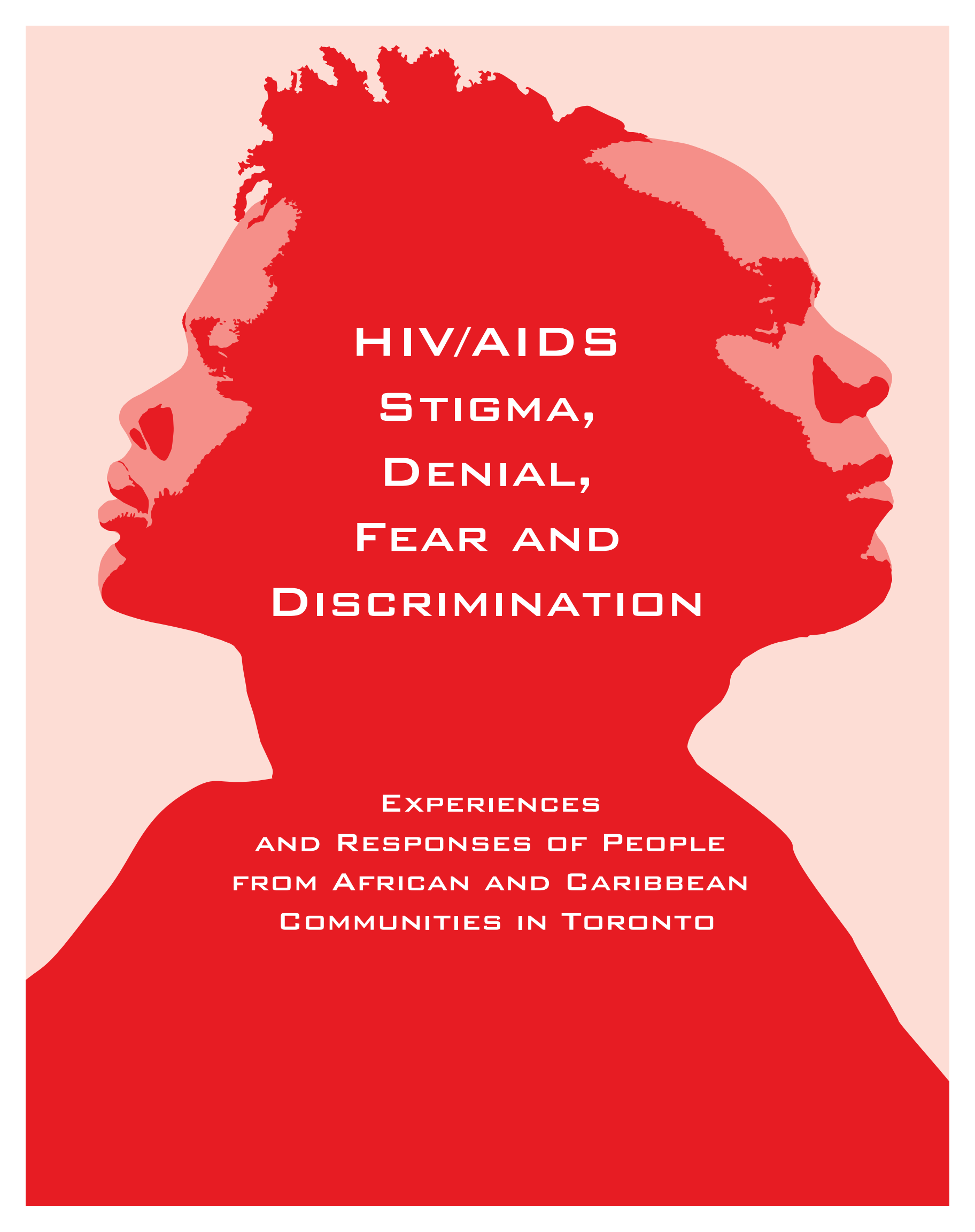
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EXECUTIVE SUMMARY

This report discusses the results of the study entitled *HIV/AIDS Stigma, Denial, Fear and Discrimination: Experiences and Responses of People from African and Caribbean Communities in Toronto*. The study was a joint effort between the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) and the HIV Social, Behavioural and Epidemiological Studies Unit at the University of Toronto. The research was funded by the Ontario HIV Treatment Network and took place between 2004 and 2006.

African and Caribbean people are overrepresented among HIV infections in Canada. It is estimated that, between 1999 and 2003, the number of African and Caribbean people in Ontario infected with HIV increased by over 80% (Remis, 2006). In 2003, approximately 12% of people living with HIV in Ontario were from Africa and the Caribbean. This qualitative study explores the experiences of HIV positive people in Toronto from Africa and the Caribbean, as well as the perspectives and experiences of members of these communities at large. The study sought to understand HIV-related stigma, discrimination, denial and fear and how these impact on responses to HIV, including testing, treatment and support.

Men and women over the age of 16 from three African (Ethiopian, Kenyan, and Somali) and three Caribbean (Guyanese, Jamaican, and Trinidadian) communities were invited to participate in the study. People who were HIV positive participated in private in-depth interviews. Other members of the communities participated in focus group discussions. In-depth interviews were conducted with 15 HIV positive men and 15 HIV positive women and focus groups were conducted with 32 men and 42 women from the communities at large. A total of 12 focus groups were held, one with women and one with men from each of the six communities.

The study found that there are a range of cultural and structural issues that may increase risk for infection, create obstacles to testing and treatment, and lead to isolation and stigma experienced by HIV positive people. Participants discussed religious beliefs and norms, homophobia or the denial of homosexuality within communities, and silence about health and sexuality as issues affecting responses to HIV within African and Caribbean communities. Gossip and fear within communities leads to isolation of HIV positive people and discourages many from seeking testing, treatment or support services. The racialization of HIV as a Black or African disease by mainstream cultural media and institutions has a detrimental impact on willingness to approach health or support services and on HIV knowledge and awareness. Participants spoke about how HIV stigma intersects with other forms of stigma and discrimination, and suggest that its impact is especially heavy on gay men, women, and poor people.

While describing the damaging effects of stigma, HIV positive participants' narratives also conveyed a sense of emotional resolve and resourcefulness in devising strategies for adapting to a diagnosis of HIV and managing the fear and stigma associated with it. For example, HIV positive participants described careful decision-making and negotiations around disclosing their diagnosis to family and friends, accessing support services, and maintaining social, cultural and community connections.

It is hoped that this report will be used to foster discussion and action to address HIV/AIDS within African and Caribbean communities in Toronto. Recommendations made by participants included: the need for greater sensitivity and knowledge on the part of health care providers; more ethnoculturally-appropriate support services; community development measures; education campaigns and greater community awareness; and expanded efforts to tackle housing, poverty, institutional racism, and settlement issues to improve the overall health of African and Caribbean communities in Toronto.



INTRODUCTION



INTRODUCTION

I. ABOUT THE STUDY

What are the day-to-day experiences of African and Caribbean people living with HIV? How do their families, friends and communities treat them? What are their concerns about access to treatment, support and care? How do social and environmental conditions affect their health outcomes? What do community members at large (those who are not HIV positive or whose status is unknown) think about HIV and the people who are infected? What particular difficulties do African and Caribbean people living with HIV face in Canada, and, most important, what is the impact of HIV-related stigma, fear, denial and discrimination on both their lives, and the lives of community members at large?

In pursuit of answers to these questions, the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), in partnership with researchers in the HIV Social, Behavioural and Epidemiological Studies Unit, Department of Public Health Sciences, University of Toronto, initiated a two-year research study to talk with, and hear from, the people and communities who are directly affected. With funding from the Ontario HIV Treatment Network (OHTN), from 2004 to 2006, the research team conducted face-to-face, confidential interviews with African and Caribbean people living with HIV, and focus group discussions with other members of these communities.

The study, referred to herein as the Stigma Study, aimed to explore the experiences of people living with HIV in three African and three Caribbean communities in Toronto. People from Ethiopian, Kenyan, Somali, Guyanese, Jamaican and Trinidadian backgrounds were recruited to participate in the study. These communities were chosen because of rising rates of HIV transmission within them and because of their large populations in Toronto. There is a growing body of evidence to suggest that, in Ontario, HIV prevalence is much higher among people from sub-Saharan Africa and the Caribbean than among other persons at risk through heterosexual intercourse (Remis, 2003).

II. ABOUT THIS REPORT

This report discusses HIV positive participants' views and experiences of what it is like for them to live with the disease. It represents their experiences in accessing HIV prevention, treatment, care, and support, and the negotiations that they undertake to live a 'normal' life and to be accepted within their families, communities, and society. The report also includes perceptions, opinions and commentaries about HIV/AIDS from community members at large. It reflects their fears, not just about HIV/AIDS, but also about trying to educate themselves and find employment in Canada, raise their children, and maintain their cultural connections.

This report provides an overview of the context, scope, and objectives of the research project; explains the methods, recruitment strategies, data collection and analysis; discusses the research



results; and identifies recommendations made by participants. The report is meant to be read, considered, distributed and acted upon in many ways at multiple sites. It is intended to be of benefit to people living with HIV/AIDS, as well as physicians, policy makers, service-providers, family members and friends of those living with HIV/AIDS, and the general public. It provides insight about stigma and its effects, and encourages critical reflection on developing a supportive environment for addressing HIV.

Given the extensive amount of data collected over one and a half years, this report focuses on key findings. We want the report to capture the most urgent recommendations, and we anticipate that what we are unable to address in this report will be attended to in other forums and publications.

The report reflects both the experiences of people living with HIV and the perspectives of members of the community at large who are not HIV positive or who do not know their HIV status. We paid particular attention to what these two groups of participants had to say about stigma, denial, fear and discrimination, and how these are experienced in their day-to-day lives. We also identified a number of other recurring themes such as immigration, community involvement, family life, and gender and sexuality, all of which have an impact on how communities and individuals view stigma, denial, fear and discrimination.

Finally, the stories and perspectives that people shared with us were examined for recommendations to address HIV stigma and discrimination, and for directions for future action-oriented research. It is our hope that the compelling excerpts taken from participants' narratives, the discussions, and the recommendations will be used by AIDS service organizations, physicians, counsellors, social workers, policy-makers, individuals and community groups to improve services and care for African and Caribbean people living with HIV, to develop programs and policies to address the effects of stigma and discrimination, and to improve the overall health and quality of life of African and Caribbean communities in Toronto.

III. ABOUT THE AFRICAN AND CARIBBEAN COUNCIL ON HIV/AIDS IN ONTARIO (ACCHO)

ACCHO is a coalition of organizations, service providers, policy-makers, researchers and unaffiliated individuals working on HIV prevention, and access to care, treatment and support among African and Caribbean communities in Ontario. The idea behind ACCHO started to take shape in the mid-1990s, when service providers working with African and Caribbean communities became concerned with increasing demand for their services. They formed a working group to strategize about an appropriate response from AIDS service organizations and governments. Through their advocacy, the provincial AIDS Bureau commissioned a study by Dr. Robert Remis to determine prevalence of HIV among African and Caribbean communities. That study, which was published in 1999, confirmed what the service providers were noticing in their everyday work – that increasing numbers of African and Caribbean people in Ontario were becoming infected with HIV, to the extent that African and Caribbean communities were being disproportionately affected by



the disease. (A summary of Dr. Remis' findings is presented in the next section of this report.) The working group reorganized itself as the HIV Endemic Task Force to develop a strategy to address issues related to HIV/AIDS faced by African and Caribbean people in Ontario (HIV Endemic Task Force, 2001). After a process of research, consultation and community mobilization, the Strategy was developed and completed in 2003. In 2005, the Strategy was launched and the HIV Endemic Task Force became ACCHO.

ACCHO has 21 members, and the terms of reference mandate that a majority of members must be African or Caribbean in origin.

ACCHO's work encompasses four main areas, namely (a) coordinating and supporting the implementation, monitoring, renewal/revision, and evaluation of the Strategy, (b) advising and advocating on HIV/AIDS issues affecting African and Caribbean communities, (c) promoting greater involvement of African and Caribbean people in the response to HIV/AIDS, (d) and assisting organizations to strengthen their capacity to respond to HIV/AIDS among African and Caribbean communities. This work is implemented through three strategic directions – community development, Strategy coordination, and research.

IV. LITERATURE REVIEW AND BACKGROUND

As of 2001, 1.5% of the Canadian population was born in a country where HIV is endemic (i.e. in Africa and the Caribbean). However, in 2002, the Public Health Agency of Canada estimated that 7-10% of prevalent HIV infections and 6-12 % of new infections in Canada were among persons from countries where HIV is endemic (Public Health Agency of Canada, 2005). HIV endemic countries are considered to be those in which the prevalence of HIV infection in the general population is 1% or greater and where heterosexual transmission accounts for more than half of the infections. While the list of countries meeting HIV endemic criteria is currently being updated, the regions that have been most affected are sub-Saharan Africa and the Caribbean.

In 2001, the HIV Endemic Task Force published the *Complete Report of the Community Forum, For Us, By Us, About Us: An Opportunity for African and Caribbean Communities to Address the Issue of HIV/AIDS Related Stigma and Denial*. This document evolved from a forum attended by African and Caribbean communities and service providers to “break the silence” about HIV/AIDS and address the barriers that prevent people from taking advantage of testing, early care, and treatment. At this forum Dr. Robert Remis presented findings from his situation report, *The HIV/AIDS Epidemic among Persons from HIV-Endemic Countries in Ontario, 1981-98* (Remis and Whittingham, 1999). These findings, as well as an update to 2002 (Remis, 2003) are presented below. Because complete data are not available, the figures are based on mathematical modeling and therefore represent plausible estimates of the number of HIV-infected persons.



HIV prevalence among African and Caribbean populations in Ontario (number of cases):

	1998	2002
Caribbean	1,491	1,366
African	855	1,261
Total	2,346	2,627

Within the Caribbean population in Ontario, four countries accounted for 87% of HIV infections in 1998 and 86% of infections in 2002 as follows:

	1998		2002	
Jamaica	544	(36%)	494	(36%)
Guyana	311	(21%)	261	(19%)
Trinidad	295	(20%)	277	(20%)
Haiti	141	(10%)	147	(11%)

Within the African population in Ontario, five countries accounted for 72% of HIV infections in 1998 and 66% of infections in 2002 as follows:

	1998		2002	
Ethiopia	158	(19%)	366	(29%)
Somalia	138	(16%)	127	(10%)
S. Africa	133	(16%)	114	(9%)
Uganda	96	(11%)	131	(10%)
Kenya	91	(11%)	88	(7%)

Although the above numbers may not seem high, the prevalence is of concern relative to the size of African and Caribbean populations in Ontario. In 2002, estimates suggest that 11% of HIV-infected people in Ontario were from Africa or the Caribbean compared to 2.6% of the province's population who were from Africa or the Caribbean. Compared to other heterosexual people in Ontario, infection rates were 15-fold higher among Caribbean people and 30-fold higher among African people (Remis, 2003).

In addition to research focusing on the prevalence of HIV within African and Caribbean communities in Canada, and in Ontario, other research has attempted to understand social issues related to HIV within African and Caribbean communities. *The HIV Endemic Task Force: Report on Phase Two of Community Consultation* reports on focus groups with service providers in Toronto and



Ottawa, interviews and focus groups with HIV positive African and Caribbean people in these two communities and Kitchener, and interviews with Caribbean youth in Toronto (Handa and Negash, 2003). The findings indicated a range of issues facing African and Caribbean people living with HIV, including stigma and racism, and difficulties related to income, employment, immigration, housing, and access to information, testing and treatment.

An earlier report entitled *Many Voices: HIV/AIDS in the Context of Culture – Report for the English-speaking Caribbean Communities* (Baxter, Brabazon, Gunter and Willms, 1993) explored HIV/AIDS in the context of Caribbean cultural values with respect to family, community, sexuality, and gender roles; it examined sexual risk, injection drug use, blame, condom use, and general attitudes towards HIV/AIDS. It was part of a larger study of ethnocultural communities in Canada and their needs related to HIV/AIDS. Data for the Caribbean community were gathered through interviews and focus groups with members of the English-speaking Caribbean communities in Toronto. The study suggested the need for culturally-specific strategies and responses, approaches that address a range of social issues that impact on the life and health of Caribbean communities, and linkages and coordination between community based organizations and social service agencies in programming and service delivery.

Silent Voices of the HIV/AIDS Epidemic: African and Caribbean Women in Toronto 2002-2004 reports on a study of the experiences of African and Caribbean women in Toronto (Tharao, Massaquoi and Teclom, 2006). The methodology involved interviews with service providers and focus groups and interviews with women from African and Caribbean communities. The study concluded that it is necessary to address socio-cultural and economic factors, including unemployment, gender-based violence, and racism in addition to cultural beliefs and practices. In other words, individual behaviour and risk cannot be addressed in isolation from these other intersecting factors (see also Tharao and Massaquoi, 2001).

Although previous studies significantly informed its goals and objectives, the Stigma Study is unique in its comprehensive examination of the experiences of African and Caribbean people living with HIV, as well as its exploration of the opinions and perceptions of community members at large. The Stigma Study situates these experiences and perspectives in the context of what it means to be Black/African in Canada. For example, how is living with HIV/AIDS here in Canada different from “back home”? How are stigma, discrimination, denial and fear experienced as people cross borders? How can local and international perspectives inform educational campaigns to address HIV-related stigma in Toronto?

Unlike the general trend in other studies about HIV, the Stigma Study did not focus on sexual behaviour and other risk factors. This is not to say that these factors are not evident in the data collected. However, the study sought to go beyond the focus on sexual practice, drug use and other factors known to increase risk, to capture the essence of what it means to *live* with HIV/AIDS on a daily basis, and what it means to belong to communities whose members are perceived as carriers of the disease. This work explores social, structural, economic and political dimensions of HIV/AIDS stigma and discrimination, similar to frameworks put forth by Aggleton, Wood and Malcolm (2005); Dodds, et al., (2004); and Parker and Aggleton, (2002).



As such, rather than using a structured questionnaire, the study used a grounded theory approach, allowing participants the space to tell their stories about how they cope with the disease and with other difficulties in their relationships and living circumstances. It simultaneously explored wider community views and perceptions, informed by the belief that strategies to address stigma and discrimination should be a collective effort.

In the Canadian context where the reality of racism is often denied in favour of a national investment in diversity and multiculturalism, this study is unique in its exploration of race, culture, power and social inequalities with respect to HIV-related stigma and discrimination. By attempting to address multi-dimensional challenges associated with HIV stigma and discrimination, the study contributes to a greater understanding of these issues as they are experienced by African and Caribbean people in Canada. The study, and the recommendations that came out of it, also have international implications for research, programs and policy in this area given that participants continue to maintain strong ties to their home countries, and that the experiences they shared are shaped by global issues such as immigration, employment and relationships across borders.

However, the study is not without limitations. First, the number of study participants (N= 104) fell short of the intended total number of 144. The reasons for this are discussed in the Recruitment section of this report. Second, the findings may not be generalizable given the small and non-random samples for each of the communities. However, the data collected provide a rich depth of information, not just about what it means to live with HIV/AIDS stigma, discrimination and fear, but also useful insights about the range of complex and intersecting social problems experienced by marginalized communities, as well as important lessons about coping mechanisms, and recommendations for policy, educational initiatives, care and services.

V. UNDERSTANDING STIGMA

In general, stigma is understood as “a multi-dimensional concept of which the essence focuses on deviance from an accepted standard or convention” (Goffman, 1963). It is an attribute, which in the eyes of society serves to reduce the person who possesses it. The term “stigma” originates from the Greek language and refers to a tattoo mark branded on the skin of an individual as a result of some incriminating action, identifying the person as someone to be avoided (Crawford, 1996, cited in Visser, Makin and Lehobye, 2006). Stigmatization takes place in specific contexts of culture and power; it has a history which influences its appearance and the form it takes, and it is used by individuals, communities and the state to produce and reproduce social inequality.

HIV/AIDS-related stigma refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the groups and communities with whom they are associated (Herek, 1999). Closely connected is the concept of discrimination, referring to the unfair and unjust treatment of an individual based on her or his real or perceived HIV status (UNAIDS, 2003).



There are different kinds of stigma that can be identified at different levels and examined for the particular impacts that they have on people living with HIV. For example, at an individual level, *experienced stigma* involves the perceptions that individuals with the stigmatized attribute have about the attitudes and reactions they expect and experience from others, thereby leading them to discredit themselves (Visser, Makin and Lehobye, 2006). At another level, *enacted stigma* refers to the stigmatization and discrimination actually experienced by the infected person on an interpersonal level (*Ibid*). It also is believed that the perception of community beliefs and shared ideas and discourses about HIV/AIDS, described as *perceived community stigma*, can have a negative impact on people living with HIV, especially if they rely on community supports and networks (*Ibid*).

World-wide, stigmatization and discriminatory attitudes towards people living with HIV are known to discourage them from effectively managing the disease. According to reports by service providers, people from Africa and the Caribbean often fail to seek out the services that they need because of the risk of being stigmatized. This is substantiated by studies of African women living with HIV in London, United Kingdom (Anderson and Doyal, 2004) and Philadelphia, USA (Foley, 2005). A study of HIV/AIDS stigma in Jamaica reports that some people become suicidal when they first receive their diagnosis, and suicidal tendencies are often rooted in the fear of isolation and discrimination that will come as a result of having others find out about the disease, more so than from the potential death associated with it (White and Carr, 2005).

HIV within African and Caribbean communities in Canada is difficult to address because it is compounded by stigma that already exists due to racism. This is evident in a belief, held among the non-African population, that HIV originated in Africa and is being brought here by African immigrants (Calzavara et al., 2000; UNAIDS, 2000). Due to stigma and denial, many people from immigrant communities may be discouraged from taking advantage of testing, early care and treatment (Handa and Negash, 2003; Manson-Singer et al., 1996; Myers et al., 2001). Instead, many are diagnosed late in the course of HIV progression when the illness can no longer be concealed (HIV Endemic Task Force, 2001). Caribbean and African communities in Toronto are often small and located in specific geographic areas, creating a sense that “everyone knows everyone” and that news about HIV illness will travel “back home.” This perceived lack of personal privacy may contribute to the denial of HIV and the fear of disclosure (HIV Endemic Task Force, 2001).



STUDY OBJECTIVES

The over all goal of the study was to understand the impacts of stigma, denial, fear and discrimination related to HIV within African and Caribbean communities in Toronto. With that in mind, our objectives were specifically to:

1. Describe HIV-related fear, denial and experiences of stigma and discrimination reported among persons diagnosed with HIV and those not diagnosed, within the context of their own communities as well as the wider Canadian society;
2. Describe participants' perceptions and understanding of societal and community responses to HIV/AIDS and in particular the role of stigma and discrimination;
3. Understand the role of social structures (e.g. family, economic, and cultural institutions) in creating and perpetuating HIV/AIDS related fear, denial and discrimination; and,
4. Explore other related issues identified through narratives and group discussions.

COMMUNITY ADVISORY COMMITTEE

A Community Advisory Committee (CAC) was established to assist the Research Team with meeting the objectives. Four members sat on the CAC and were drawn from community-based organizations including Women's Health in Women's Hands, The Black Coalition for AIDS Prevention (Black CAP), Centre Francophone de Toronto, People to People Aid Organization (which serves the Ethiopian community), and African Community Health Services (ACHES). The primary functions of the CAC were to:

- Provide advice on recruitment strategies and assist with recruitment
- Identify specific community needs
- Review research instruments
- Contribute to the interpretation of study results
- Advise on and assist with dissemination of findings
- Advise on future actions



METHODS



METHODS

I. DATA COLLECTION

Two approaches were used to meet the study objectives. Confidential face-to-face interviews were conducted with people living with HIV and moderated focus group discussions were held with community members at large. The study protocol was reviewed and received approval from the University of Toronto HIV Research Ethics Board. Interviews and focus groups were tape-recorded and transcribed in full.

Three interviewers were hired and trained to conduct interviews and facilitate focus group discussions along with the study's Research Coordinator and Data Analyst. Occasionally members of the Research Team and other community members facilitated focus groups. Interviews and focus groups took place at the University of Toronto, AIDS service organizations, community health centres, and other community agencies. Two of the focus groups took place in private homes.

1. INTERVIEWS WITH HIV POSITIVE PEOPLE

Individual interviews lasted between 45 and 120 minutes. An effort was made to provide participants with a choice of interviewer. Of those who expressed a preference, 7 of 30 chose a female interviewer and 8 participants wanted assurance that they would not be interviewed by someone from their country or region (e.g. Caribbean) of origin. Apart from 3 participants who only would consent to be interviewed over the telephone, all others were interviewed in person in a private setting at the location of their preference.

Participants living with HIV were asked a range of questions related to their identity and background and personal experiences living with HIV. The interview topic guide included questions and suggested probes related to how the participants learned their diagnosis, what they did after receiving test results, the short and long-term impacts of learning their diagnosis, their experiences disclosing their HIV status, and their experiences accessing health and support services. Participants also were asked directly about their thoughts on HIV-related stigma, denial, fear and discrimination. Finally, they were asked what advice they would give to a newly diagnosed HIV positive person from their community, and what recommendations they would make on how to address HIV/AIDS in general.

2. FOCUS GROUPS WITH COMMUNITY MEMBERS AT LARGE

Focus groups were approximately two hours in length. Focus groups were held separately for men and women according to country of origin (e.g. Guyanese women; Guyanese men; Kenyan women; Kenyan men, et cetera). Focus groups were moderated by someone of the same gender, and in most cases moderators were from Africa or the Caribbean. Topics discussed included what communities



participants saw themselves as belonging to; issues of concern to their communities; personal thoughts and community perceptions about HIV/AIDS; stigma, denial, discrimination and fear related to HIV/AIDS and how these impact on individuals and communities; suggestions or advice they would give to a newly diagnosed HIV positive community member, and recommendations on how to address HIV/AIDS.

Probes and follow-up questions were used in interviews and focus groups to find out how stigma and discrimination overlap and intersect with a number of challenges related to racism, unemployment, isolation, social exclusion and language barriers faced by these individuals and their communities. Therefore, stigma and discrimination were examined at the individual, interpersonal and community level, to better understand how community members grapple with these complexities in the face of a host of social challenges.

II. STUDY SAMPLE

Men and women over the age of 16 were invited to participate in the study if they resided in Toronto or the Greater Toronto Area and were members of the Ethiopian, Guyanese, Jamaican, Kenyan, Somali or Trinidadian communities. We interviewed 30 people living with HIV/AIDS, and conducted 12 focus groups with 74 community members at large. Table 1 (see page 15) presents a breakdown of the sample by gender, country of origin, age, education, and number of years in Canada.

1. HIV POSITIVE PARTICIPANTS

Thirty HIV positive participants were interviewed between November 2004 and May 2006. Fifteen were women and 15 were men. Nine were from Africa and 21 were from the Caribbean. The majority of participants were between 35 and 44 years of age. The youngest participant was 17 years old, and the oldest was in his mid-fifties. The average time since diagnosis was 7 years. Five participants had been diagnosed between 2004 and 2006. A further 7 were diagnosed between 2000 and 2003. Nine were diagnosed between 1995 and 1999, 6 were diagnosed between 1990 and 1994, and 3 were diagnosed prior to 1990.

All HIV positive participants were born outside Canada. Their length of time in Canada ranged from 6 weeks to 40 years, with an average of 17 years. Nine participants did not have landed status in Canada at the time of their HIV diagnosis. Of these, 5 now have permanent residence or citizenship, 2 are pursuing refugee claims, 1 has a work permit and is unsure if he wants to immigrate, and 1 has been in Canada for 11 years but is afraid to seek legal status for fear of being deported.

Fourteen of the HIV positive participants, 5 men and 9 women, had children. Two of the women had HIV positive children.



One third of the HIV positive participants were currently or formerly active in AIDS service organizations in a paid or volunteer capacity, or combination of both. Three of the 30 participants were employed full-time at the time of their interviews and 4 were looking for employment. Two participants were completing high school and 2 were doing post-secondary training programs, after which they hoped to find employment. Another participant was trying to complete his education but had difficulty finishing his program due to recurring depression. Many participants were not able to work for health reasons. Four mentioned being told that they could not work in their desired occupation because of their HIV status (2 were told they could not work in health care, 1 believes he can no longer work as a cook, and 1 was told she could not work in child care). Two of the participants spoke about being on long-term disability from their previous employment, and one reported that he was living on his retirement savings. One participant decided to quit her job rather than apply for long-term disability through her employer because she was afraid that people would find out her diagnosis. The most frequent income source identified by participants was the Ontario Disability Support Plan (ODSP).

2. OTHER COMMUNITY MEMBERS

Twelve focus groups were held with 74 participants. Groups ranged in size from 3 to 9 participants, with an average of 6. Forty-two women and 32 men participated in focus groups. Forty-three were of African origin and 31 were of Caribbean origin. The majority of participants (62%) were between the ages of 25 and 44. Over half of the participants (54%) had been in Canada for 15 years or less, and 4 had been born in Canada. The majority of participants had post-secondary education. There were 2 groups in which the majority of participants did not have post-secondary education: the Trinidadian women's group in which 3 out of 8 participants listed post-secondary education and the Somali women's group in which no participant listed education beyond high school.



TABLE 1: STUDY SAMPLE

	HIV Positive (n=30)			General Community (n=74)			Total (N=104)
	Female	Male	Total	Female	Male	Total	
COUNTRY OF ORIGIN							
Africa	6	3	9	24	19	43	52
Ethiopia	2	1	3	9	6	15	18
Kenya	4	1	5	6	5	11	16
Somalia	-	1	1	9	8	17	18
Caribbean	9	12	21	18	13	31	52
Guyana	2	1	3	4	5	9	12
Jamaica	5	4	9	6	5	11	20
Trinidad	2	6	8	8	3	11	19
Other (Barbados)	-	1	1	-	-	-	1
AGE							
16-24	2	-	2	-	5	5	7
25-34	3	1	4	15	8	23	27
35-44	8	9	17	13	10	23	40
45-54	2	5	7	5	4	9	16
55-64	-	-	-	7	5	12	12
65 and +	-	-	-	2	-	2	2
HIGHEST LEVEL OF EDUCATION							
Primary	-	-	-	4	-	4	4
High School	3	5	8	11	5	16	24
Post-secondary	7	8	15	17	21	38	53
Post-graduate	-	-	-	5	4	9	9
Not provided	5	2	7	5	2	7	14
YEARS IN CANADA							
<1	1	2	3	-	3	3	6
1-4	2	1	3	10	3	13	16
5-9	3	1	4	5	4	9	13
10-15	4	3	7	9	6	15	22
16-25	2	4	6	8	4	12	18
>25	3	4	7	4	5	9	16
Born in Canada	-	-	-	4	-	4	4
Not provided	-	-	-	2	7	9	9
TOTAL	15	15	30	42	32	74	104



III. RECRUITMENT

The study employed a number of different recruitment strategies to reach African and Caribbean people living with HIV and community members at large. These strategies included:

- Postcards and posters placed at AIDS service organizations, HIV and sexually transmitted infection (STI) clinics, hospitals, birth control clinics, community health centres, and other community based organizations and associations
- Word-of-mouth (for example, referrals from participants, doctors, service-providers)
- Community information forums and HIV-related events
- Direct contact with service-providers, doctors and organizations that provide a number of services to African and Caribbean populations (for example, employment training, immigration and settlement services and shelters)

Three hospitals with HIV/AIDS clinics were targeted as recruitment sites. Stigma Study staff completed ethics approval applications geared toward each hospital's specific requirements, after which staff were limited to placing posters and postcards in two of the three clinics. The third hospital clinic did not want posters and postcards publicly displayed, though clinic staff did agree to inform eligible patients about the study. We estimate that only 4 participants were recruited from hospitals. The low numbers of recruits from these sites means that the sample of people living with HIV/AIDS is biased toward those who frequent AIDS service organizations and who may be more comfortable discussing their experiences in a research interview setting.

Two recruitment strategies proved to be most effective: (1) direct contact with people living with HIV/AIDS who participate in support groups, and (2) direct referral from front line workers in AIDS service organizations. To a lesser extent, people with HIV/AIDS who were told about the study by their doctors came forward to participate. Overall, only a few doctors agreed to tell their patients about the study out of concern that the patient would feel obligated to participate.

Community members at large were recruited through organizations that deliver a range of social services such as settlement and immigration, and family counseling (for example, Jamaican Canadian Association; Trinidad and Tobago Association; Ethiopian Association; Kenyan Community Organization of Ontario; Midaynta; health care/drop in centres). Front line workers in some of these organizations assisted in arranging some of the focus groups. We were also assisted by individuals who had an interest in the study or personal concerns about HIV/AIDS in their communities. At least two focus group participants had lost family members as a result of AIDS, and many others expressed interest in participating in the discussion as a means of learning more about the illness.



IV. DATA ANALYSIS

After tape-recorded interviews were transcribed, they were coded for content and themes using QSR N6 computer-assisted qualitative data analysis software. Study staff and Research Team members met on a regular basis to discuss the transcripts in light of emerging themes, narrative content and possible ways of interpreting the data in a broader context. To understand how people made sense of stigma, fear, denial and discrimination, we paid specific attention to the way that people define themselves through factors such as culture and religion, and to what they said about the social context in which their lives were unfolding.

The next section provides detailed information about the core themes that emerged from the data, and quotations to illustrate these themes, as well as recommendations that emerged from individual interviews and focus group discussions.



RESULTS



RESULTS

I. PERCEPTIONS OF THE IMPORTANCE OF HIV IN RELATION TO OTHER ISSUES FACING AFRICAN AND CARIBBEAN COMMUNITIES IN TORONTO

Participants discussed their personal views on the importance of HIV within their communities, and assessed community perspectives. They articulated complex and layered assessments about why HIV is an important issue as well as reasons why it may be seen as less important.

Women in several focus groups expressed concerns about HIV related to difficulties negotiating condom use within heterosexual relationships. Participants, particularly in the women's focus groups, also stressed concern for how youth may be at risk within their communities.

Participants also suggested that economic disadvantage puts their communities at greater risk for infection. For example, participants in both of the Kenyan focus groups and the Somali men's group talked about unemployment and inadequate income as factors that make people vulnerable to HIV. A Kenyan man observed that Kenyans usually come to Canada as young single men or women. Their savings are quickly depleted because of the high cost of living and they face difficulties finding employment. He suggested that to survive financially, people enter into relationships with partners they do not know well.

Research participants pointed to a link between social issues facing their communities and HIV infection. Major issues mentioned included: police profiling, unemployment, lack of affordable housing, a breakdown in family structure and discipline, immigration and settlement issues and problems in the education system.

Because when the kids and them can't find a job, they're on the street, and they mix together. And that's where [HIV] interacts.

(Trinidadian woman, focus group)

Language barriers may make it difficult for people to access medical care and diagnosis. Somali women, for example, discussed how the need to have someone act as an interpreter in medical consultations undermines the presumed confidentiality of medical care in Canada, and deters some members of their community from going to the doctor.

Some participants said that HIV is not viewed as an important issue within their communities in Toronto because there is not enough direct experience combined with insufficient knowledge and information. For example Ethiopian women suggested they did not have enough knowledge to judge its importance.



I don't know the figure, but if there is a problem [with HIV] I think we need to educate the people.

(Ethiopian woman, focus group)

While a small number of the focus group participants had direct experience with a friend, family member or acquaintance with HIV/AIDS, most participants did not know of anyone who was HIV positive in Toronto, while at the same time acknowledging that if anyone in their community became HIV positive, they would not tell other people.

I haven't seen a Somali person who's HIV positive. That creates something of a myth. Like, everybody's talking about HIV, but practically, I haven't seen anyone who's HIV positive. So what are they talking about? ..anybody in the community who gets this [positive HIV] test would go underground. That is their right to be that way, but that creates a problem of no practicality, just theory. So that is why a lot of people in the community believe it doesn't happen to Somalis.

(Somali man, focus group)

Participants in the Guyanese women's focus group felt that HIV/AIDS was an important issue, but at the same time felt that for the "average" person in the community, other issues would be viewed as more important. Similarly, Somali men said they did not have any direct experience with HIV to judge its importance, and suggested that it pales in comparison to other issues such as unemployment. The broad range of pressing issues facing African and Caribbean communities in Canada can make it difficult to give priority to HIV:

I think the Black community feels it's under siege so that HIV is like one more thing on top of, you know? And if you don't have to deal with it, why?

(Trinidadian woman, focus group)

Some participants in the Jamaican and Kenyan men's focus groups felt that HIV is an important issue facing their communities back home but not as important here in Canada. Many participants also characterized as predominant the view that HIV is an issue that affects "other people" such as gay people or people from other ethnocultural backgrounds. A Trinidadian participant interviewed a few weeks after being diagnosed with HIV said that he considered his diagnosis to be a rare case of heterosexual transmission of HIV. Somali men explained that HIV is seen as something that does not affect Somalis as a cultural group.



Participants in the Jamaican and Kenyan women's groups pointed out that because media coverage tends to focus on Africa, and because treatment is available in Canada, HIV does not seem like a local, Toronto-based issue.

It's hard to tell who has AIDS here so you almost don't care who you talk to, who you socialize with, how far you go. I mean, people do know their limits, but not everybody.

(Kenyan woman, focus group)

We just hear about Africa. You know? Oprah going over to save the kids and stuff like that. But it doesn't seem to be very local. You know, it is talked about but it doesn't seem to be connected to my community where I live that strongly.

(Jamaican woman, focus group)

HIV positive participants frequently commented that many in their communities did not have enough knowledge about HIV. Most had very little knowledge about HIV themselves before learning their diagnoses. Some participants worry that others in their community may be infected and not know it, and recounted instances of trying to educate people within their social networks about HIV. Many HIV positive participants observed that HIV is not an issue that is discussed either within their communities or in the larger context of Canadian society.

[In Ethiopia] everyday the radio, the TV, they talk about it and people [are] dying everyday. But here they think there is not HIV because they never talk about it. ...The TV, the mass media is more powerful here. If they talk about HIV maybe people [will say] 'oh, still here in Canada.' But when they come from Ethiopia they think there is not HIV here. That fools a lot of young people.

(HIV positive Ethiopian woman, individual interview)



II. KEY THEMES

1. STIGMA

Participants discussed stigmatizing attitudes toward HIV positive people within their communities based on a range of assumptions about the infection. These include the assumption that it is a “gay disease” or one that results from promiscuity, and the association of HIV with contagion and death. They also spoke about HIV-related stigma faced by African and Caribbean communities originating from outside the community in the wider population, which views HIV as a Black or African disease.

Caribbean participants, in particular, spoke about the connection between the view that HIV is a “gay disease” and negative attitudes toward homosexuality within the community:

In a sense the community doesn't care. They don't care. First of all, AIDS is a gay man disease. That's what they say. ...It's not talked about. And, 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.'

(HIV positive Jamaican man, individual interview)

Regardless of whether their HIV status is known, some Caribbean male participants discussed feeling strongly stigmatized on the basis of presumed homosexuality.

Stigma would mean that once a person look at me they would just characterize me as gay and it is a committed cardinal sin. So that's one of the stigma that will be attached to me being HIV or at least gay. ...Because they don't know about my HIV status. So it was in relation to being gay.

(HIV positive Jamaican man, individual interview)

Focus group participants also stated that there is a tendency to label an HIV positive man as “battyman,” a derogatory label for gay men.



The key association to AIDS and the Caribbean or the Black, you know, macho thing, you know, like, battyman, and that whole kind of stuff is very much alive, you know, so anybody who has AIDS in the community, I mean, maybe he would have got it from a blood transfusion or maybe some other way, but without even knowing, you're stigmatized. That's how the community looks at it, and that is a big, big problem.

(Trinidadian man, focus group)

HIV is strongly associated with promiscuity according to African and Caribbean participants.

Everybody in the community, they know I'm HIV positive and they talk bad about me. You know, they even call me names. They don't know me, they don't know anything about me, but still, because they found I'm HIV positive, they think I'm a bitch lady.

(HIV positive Kenyan woman, individual interview)

One participant suggests that HIV stigma may impact more heavily on women because it is assumed that HIV results from promiscuity, and female promiscuity is viewed more negatively.

I find because there's a tendency to kind of glamorize male promiscuity, men who are affected with it are not as stigmatized as women because women the promiscuity is more demonized. ... So, I mean, both would experience stigma. But I think it's way more heavily against the woman.

(Jamaican man, focus group)

Focus group participants describe a tendency to associate HIV with extra-marital sex and prostitution. Ethiopian women describe a saying that "after 6 p.m., there is not AIDS," meaning that HIV is not transmitted in the evening when people are at home with their spouses. A Kenyan man describes a tendency to associate HIV with commercial sex workers:

The commercial sex workers, how do we view them as a community? As spoiled and outcasts. So when you get the disease AIDS, you have been interacting with those outcasts. So you're also an outcast. So if somebody has HIV, he keeps it to himself.

(Kenyan man, focus group)

Participants in several focus groups addressed the strong tendency to assume that if someone is HIV positive it is their own "fault." Blame or innocence is assigned to HIV positive people, depending on how they became infected, and depending on the person's social status.



If the person contracted it outside of medical use, again, you become a scorn. ...If it's through blood transfusion, you get a lot of public sympathy and you can live with the dignity of that.

(Jamaican man, focus group)

There also is the perception that HIV comes from outsiders.

It ties on a lot of things. Because if a person gets it, we don't think they got it from another Ethiopian person. Automatically it goes to 'oh, she or he has been associating with outsiders.'

(Ethiopian woman, focus group)

A Somali man stated that there is an assumption that HIV infection only happens to those who deviate from their culture and therefore it is their fault. Somali women described how people would make fun of an HIV positive woman because it is assumed that HIV is only transmitted through extra-marital sex and a Muslim woman is not supposed to behave that way. Thus, an additional component of HIV-related stigma could involve the assumption that HIV positive people have transgressed their culture or religion. In fact, focus group discussions contain many references to HIV as being brought into participants' countries of origin by other racial, ethnic or national groups.

Kenyan women suggested that there is a feeling that HIV positive people bring shame on their families. It is assumed that they are "immoral" and have been "brought up badly." The shame extends to the parents so that they may not want to socialize with other people who will think they are also to blame.

Back in Kenya, I think almost three-quarters of the country is in church on Sundays. So, you find every Sunday, everyone is in church. And your parents are church-going people. So, like, when you're in the church you raise your children very well, and they're not supposed to get into trouble and stuff like that. So, for them it's a shame if their child, like, something happens outside the moral code.

(Kenyan woman, focus group)

Participants suggested that HIV positive people may be "shunned" or "exiled" from the community. To disclose to the community would be "another death sentence." A Jamaican focus group participant says that if a person acquires HIV through means other than blood transfusion, there is an expectation that the person would "just disappear from among us." A Somali man explained that someone who is HIV positive might decide that it is better to keep quiet to maintain his or her status in the community than to seek medical treatment:



There are two [types of] treatment. There's medical treatment and there's human treatment, community treatment. So I might think that, yeah, I have this thing, and I'll die anyway from it, so I'll wait my day and just stay the way I am, you know. And for the remainder of my days I'll be a respectable member of the community.

(Somali man, focus group)

Both African and Caribbean participants reported that people within their communities are watched for signs of physical illness, such as getting too thin, or going to frequent medical appointments. They are then suspected of hiding an illness such as HIV or tuberculosis. If a person is known to be HIV positive, it is also assumed that the person is already dead, or in the words of a Somali focus group participant, “dead and walking.” An HIV positive Ethiopian man describes what happened after he told his friend he was HIV positive:

After two or three days when I see him he's changed, you know, he thinks I'm finished. Whatever plan I tell him I'm gonna do in life, he doesn't accept it. I have a goal to fulfill in my life but I see in his attitude, you know?...from my experience, people think I'm finished, you know?

(HIV positive Ethiopian man, individual interview)

HIV stigma also intersects with other forms of stigma and discrimination. Participants spoke about stigma in relation to HIV, but not just HIV.

We live with it every day. It's not just HIV. Those are stuff we have everyday. First of all, I'm Black. Second of all, I'm a woman. Third of all, I was a single Mom for a while. So, hello! I'm on social assistance. Right there I cover all the grounds for you. So, it's like racism, you can't hide from it.

(HIV positive Jamaican woman, individual interview)

[I face] the usual stereotypes. I'm a criminal, I'm a drug user, I've got AIDS...I'm Jamaican so I'm a criminal, right? Or a drug dealer or a pimp, or whatever people think I'm supposed to be.

(HIV positive Jamaican man, individual interview)

Both participants living with HIV and community members at large spoke often about how HIV and racism intersect. They discussed the way that African and Caribbean people are constructed as carriers of disease in general and HIV in particular. This issue will be discussed in further sections of the report.

Participants in several Caribbean and African focus groups also suggested that poverty and availability of resources impact strongly on the extent to which HIV positive people experience stigma. People who have the resources may be able to seek private medical care and not have to



disclose their illness to anyone. Those who are seen in public clinics that are known to treat HIV are those who cannot afford to hide their status. Stigma may also be greater in countries with fewer resources because the burden that HIV places on families and communities is greater.

You have to think about the economics. Perhaps here you have a health care system that will take care of you, but it only goes so far, you have to pay for the special medicine to take care of that. Whereas in Jamaica, it's not that viable that you can just go and take this income that you need to support your family or the extended family and buy medicine to cure some ailment. ... So I think economics is always an important element that you have to keep in mind. Not just the culturally construed stereotypes or biases.

(Jamaican man, focus group)

Kenyan women also discussed the economic hardship posed when an HIV positive family member cannot work, requires greater resources for food and health care, and may have children who need to be cared for by the extended family. This burden may create a situation in which judgment is passed against an HIV positive family member. Thus, participants suggest that there are economic in addition to attitudinal factors when considering the nature of HIV-related stigma, who it affects, and why.

2. DENIAL

Some participants suggest that there is a gender dynamic to denial. A Kenyan woman and a Jamaican woman both suggest that there is a tendency among heterosexual men to deny that they are HIV positive.

For a lot of them, they're in denial. Especially the men, they're in denial. They don't come out of the house. They don't want anyone to know their status. They tend to think, 'Okay, I'm a guy, I don't need help. I want to be macho. It's only gay guys that have HIV.'

(HIV positive Jamaican woman, individual interview)

Four HIV positive women in the sample mentioned denial on the part of male partners at the time of their diagnosis. For example, a Kenyan woman said that her husband denied that HIV was real when she was diagnosed early in her pregnancy:

I disclosed it to him and he seemed to be supportive in the beginning but he had this myth that HIV doesn't really exist, it's something that is made up, or I should try to maybe block it out of my mind and forget that I have it, and just continue living normally.

(HIV positive Kenyan woman, individual interview)



Participants spoke of a reluctance to discuss sexuality in general, as well as a denial of homosexuality, both of which create difficulties discussing sexual health and prevention practices.

...people don't actually discuss [HIV] openly. Again also in the African cultures, sex is not something to be discussed openly, so it's difficult to have people to discuss HIV.

(HIV positive Kenyan woman, individual interview)

The denial within the community is that they don't realize that there are so many men that are gay. Or, you know what? I don't even like to use that term. They are sleeping with men. They don't identify themselves as gay or bisexual, and they can't. They can't. You know what I mean? They can't. A lot of these men really like men. A lot of them like both. But they won't say, 'I am bisexual.' They can't.

(HIV positive Jamaican man, individual interview)

Several participants spoke about an initial period after diagnosis when the diagnosis seemed “too immense” to deal with, while also emphasizing that once they did access treatment and support they felt much better.

Denial is the clinical term for it. But the feeling is of an awareness, but it is something that you want to slide under the rug, temporarily, you know that kind of way? Because you're just not ready to deal with something so immense in your life, so big as far as HIV denial is concerned.

(HIV positive Trinidadian man, individual interview)

I did not access services when I found out that I was positive, but maybe I would have been doing much better now. It may have saved me a lot of pain because my doctor connected me with a counsellor, but I didn't show up for no appointments because I didn't want to go there at that time. I was in denial. Anybody that found out right now should get help as soon as possible. It could be much better for them.

(HIV positive Guyanese woman, individual interview)

According to some participants, there is not an open and adequate response to HIV/AIDS within their communities.



What saddens me is that I feel that HIV/AIDS is so controllable. And yet, because there's this huge silence around it, it's just going to get larger and larger and larger. And it's killing our people and we won't own it. At least the gay community, the white gay community, owned it and they were able to control it. But we don't even want to touch it, and that's going to be to the detriment of all of us.

(Jamaican woman, focus group)

This is attributed in part to the tendency within the wider Canadian society to view HIV as a Black or African disease.

I think part of the denial around HIV, the reason why the mainstream Black community doesn't want to deal with it, is because AIDS has been portrayed as something from Africa. And like, well, they don't want the community, the mainstream world, the European white world, to pin this on Black people. So there's a sort of [view that] it's homosexual and it's from sin. It's not from Africa.

(Trinidadian woman, focus group)

Focus group participants described a double barrier to discussing HIV – there is an assumption that HIV is only transmitted homosexually, while the existence of homosexuality within the community is simultaneously denied.

Some people are living in denial in the sense that [they don't know that] you're heterosexual, yeah you can get it.

(Jamaican man, focus group)

You associate HIV with homosexuality. And, coming from a Jamaican background, there are no gay people in Jamaica. Right? At all. There are no gays. So therefore, it follows that Jamaican people can't have HIV because there are no gays. Right?

(Jamaican woman, focus group)

Common forms of denial mentioned in African groups included the view that HIV is something that happens to “others.” For example, according to Somali men and women, HIV is viewed as something that practicing Muslims do not get. Somali men proposed that HIV is an “un-Somali disease.”

However, some participants suggest that perceptions are changing in their countries of origin. Ethiopian and Somali women believe that responses to HIV in Canada are inadequate compared to responses in their home countries. The lack of visibility of HIV in the Canadian context perpetuates



the view that HIV does not exist within the community, or, according to another Jamaican participant, “*For me it’s basically out of sight out of mind type of thing, you know? I don’t see it here.*”

3. DISCRIMINATION

Participants discussed discrimination in relation to racism, homophobia and gossip, harassment and ostracism of HIV positive people.

RACISM

Many participants discussed how the association of HIV with Africa or the Caribbean stigmatizes the community, is deeply felt as a form of discrimination and contributes to denial of HIV within the community.

Sometimes people feel like maybe because they’re Black or African they’re being discriminated and being pinpointed, you know, this is where the disease came from, this is who are affected, because everything seems to be focusing on that. So I think also there could be that discrimination based on the origin of HIV. I think that’s what causes a lot of fear and denial too I could say.

(HIV positive Kenyan woman, individual interview)

The nurse at the [HIV] clinic, she made a very sarcastic statement. She said she always tells her daughters that everybody from Africa is HIV positive. ...You know, that is not helping us. We don’t need rejection like that.

(HIV positive Kenyan woman, individual interview)

The portrayal of HIV as affecting only Black/African people, and the general perception that they are carriers of disease, was a major theme discussed by focus group participants. Somali women, for example, expressed anger about this widespread attitude that they have encountered in Canada. One participant recalled how a doctor explained why he had to check her blood immediately after her baby was born in a Toronto hospital: “*you’re from Africa, you might have HIV.*”

Some participants also drew a link between experiences of racism and risk of HIV. A Jamaican participant described how he feels HIV is related to poverty, racism and discrimination:



But discrimination is a lot of Black youths, you're Black or either homeless or you have low self-esteem. You do things that you shouldn't do. HIV comes right in. You steal. I mean, you have sex for money, and the sex you have is unsafe. And what are the things that cause you to do that? You know, I remember one guy said to me, 'Man, every minute police stop me. Every minute police stops me for nothing, because of how I dress. Me have no other clothes. Me no live nowhere. You know? Weh mi fi do? Weh mi fi do?' God know. So a lot of these things, you know? Discrimination.

(HIV positive Jamaican man, individual interview)

HOMOPHOBIA

Gay and bisexual participants mentioned strong homophobic attitudes in Caribbean cultures. As a result, according to one participant, people do not want to be seen with men whom they perceive to be gay, and Black gay men are not safe in certain parts of Toronto unless they can “pass as straight.” There is a belief that the community does not care about HIV because it is seen as a gay disease; therefore people who are HIV positive are to blame for their own situation. One participant mentioned that discrimination is more strongly related to being gay than to being HIV positive. Some participants described reduced family support because they are gay. Being gay and HIV positive can result in extreme levels of exclusion or isolation.

Being homosexual you're the bottom of the barrel. You add AIDS on to that, you're underneath the damn barrel. Like, you can be the bottom of the barrel, and then there's the underside of the bottom of the barrel. And then you're just totally shunned. ...[the Trinidadian community] don't accept it, they don't understand it. Canadian Black people, they're more open, I guess you grow up with it, it's a different culture. But when you're from the West Indies? It's not something you're supposed to see or talk about.

(HIV positive Trinidadian man, individual interview)

GOSSIP, HARASSMENT AND OSTRACISM

Participants mentioned gossip, verbal harassment or ridicule, and ostracism as frequent community responses to HIV. People used the words “scorned” and “shunned” to describe community responses, and described HIV as a “taboo.” Participants discussed what happens when a person’s HIV status is disclosed noting that: “they talk down,” “the talk goes around,” and “the name goes around the community.” As a result, people living with HIV have particular fears about disclosure and knowing whom to trust.



[African and Caribbean people] are afraid to come out and say that they have [HIV], or to speak to somebody who they can trust because they really can't trust anyone.

(HIV positive Jamaican man, individual interview)

Gossip enforces a silence around HIV. One Ethiopian man explained how gossip creates a situation in which people will not disclose their status to anyone, HIV remains invisible, and HIV positive people of similar cultural background are isolated from each other.

Especially in our community, once the thing comes out, everybody will know ...When there is a gathering, celebration, you know, people talk, talk, talk. Then it will spread and then nobody's gonna want to talk to me or do anything. ...Even though I know there are many people who are HIV positive. But no talk. Everybody in their own environment they live.

(HIV positive Ethiopian man, individual interview)

Gossip and ostracism have a particularly damaging impact on those who are already separated from their families through immigration or who are dealing with settlement issues.

I don't want to hear, because when I hear the stories [they tell about me], who suffers? It's me, right? So I don't want to suffer anymore. I miss my kids, I miss my parents, and I'm all alone in this country. What I have to do, I have to focus on my life. You know, it's not like everyday I have to get painful things. I'm not ready for that anymore.

(HIV positive Kenyan woman, individual interview)

4. FEAR

People living with HIV discussed the enormous fear they felt on a daily basis, related to physical health, income security and social wellbeing. Participants living with HIV spoke in particular about fear regarding the social consequences if or when others find out their diagnosis, specifically, fear of being judged, rejected and gossiped about.

Fear holds me all the time, you know? I don't want to be judged, I don't want to be outcast. You know? That's really tough.

(HIV positive Ethiopian man, individual interview)



Many feared losing the most important relationships in their lives and concealed their HIV status from people in their immediate support system. Some women mentioned being very afraid to disclose to partners.

I didn't know how I was going to approach my husband, of course, being of African descent, having to tell him, you know, such news of HIV. In Africa it's like a death sentence, as far as they're concerned and, you know, you're viewed as a moral disgrace, having HIV, 'Oh, you must have been maybe loose,' or maybe engaging in certain behaviours that are not acceptable, whatever. So I was in fear, like it was really, really very hard.

(HIV positive Kenyan woman, individual interview)

As a consequence of fear, many participants curtail relationships or social interaction in general.

I'm scared to go places that people don't really know me because then sometimes I'm thinking, they're looking at me, they probably know that I am [HIV positive]. I just don't want to think because of the way I've been treated. Like, it scares me. So I don't tend to go anywhere really.

(HIV positive Jamaican woman, individual interview)

Fear of being seen and having their HIV status disclosed caused many people to avoid seeking health and support services. Many will not approach AIDS service organizations because they are afraid of being seen by a member of their community. This may lead to a particular avoidance of services geared specifically to African and Caribbean communities.

Participants living with HIV stressed that people from their communities need to be very careful to whom they disclose their HIV status, in part because there is less anonymity in smaller ethnocultural communities. Many have experienced disclosure of their HIV status by third parties: one participant had her status disclosed within her community by a hospital staff person, and one by a relative who worked with an AIDS service organization. One man found out that his doctor told another of his patients who knew the participant. Three people had their HIV status disclosed by friends within their social networks, including one by a friend who works in a "medical field."

The fears of HIV positive participants are understandable in light of some of the reported consequences of diagnosis and disclosure. For example, a Jamaican woman was forced to move out of her apartment and live in a shelter for a year after a neighbour found out her HIV status:



From then it was like everything changed. She wouldn't talk to me anymore and then I heard my name all over the place. It was so bad. ...I would go through the back entrance [to my apartment building], so nobody would see me. And they would just bother me, bother me, bother me, making threats, uttering bad things. You know, it was terrible. ...All of a sudden I became an evil person...Very quickly it spread. And this was a Black community too.

(HIV positive Jamaican woman, individual interview)

One lady, I knew her from back home, ... I don't know why I told her about my situation, my status. I was wrong. I made a very big mistake. Because she told everyone in the community. ...everybody in the community, they know I'm HIV positive and they talk bad about me. You know, they even call me names.

(HIV positive Kenyan woman, individual interview)

I called this friend, and I said, 'Dear God. I just found out I am HIV positive.' Within a week, the whole community know, within a week. ... And everybody who knows you or just know of you, or know your face, have something to say. You know? And when you are on recovery and you would go out, or whatever, and somebody talks to you, somebody [else] say, 'Run like hell. He has AIDS.'

(HIV positive Jamaican man, individual interview)

Fear and avoidance are the predominant reactions to HIV, according to many focus group participants. People are often even afraid to discuss HIV. Fear is related to images and notions of suffering, shame and death, contagion, being dependent on others to take care of you, being rejected and feeling alone. A Jamaican woman expressed a common theme when she said that if she found out she was HIV positive, she would be in fear of other people's reactions more than the illness itself.

A Trinidadian man felt that the community is not in denial about HIV, but in fear of being infected, which is manifested as a hyper-vigilance around signs of illness such as coughing or getting thin. This watchfulness was mentioned several times by both African and Caribbean focus groups.

The fact that treatment for HIV is not widely available or affordable in countries of origin impacts on fear of HIV and its transmission in Canada. An elder Somali woman who participated in a focus group expressed her view that as soon as you are told you are HIV positive, you fall into the category of the dead.



A few participants, including a nurse who occasionally works with HIV positive patients, expressed fears about the possibility of transmission of HIV through casual contact with an infected person. They stated that they would avoid such a person. This is the case even though they describe themselves as being educated about HIV. Participants felt that fear often aligns itself with discrimination. Discrimination is not intentional but caused by fear, which leads to avoidance. A Trinidadian man, for example, spoke about knowing “several examples” in the Trinidadian community of people who were isolated after disclosure of HIV positive status due to fear of infection on the part of other community members.

III. ADDITIONAL THEMES

1. IMMIGRATION

Participants living with HIV reported a range of difficulties related to distance from family and lack of family support. Most participants do not have the financial resources to either sponsor family to come to Canada, or to visit family abroad. Until or unless they are able to meet their family members face-to-face, many participants keep their diagnosis to themselves.

It's tough without your family. I have nobody. Like I think sometimes now if something happened to me, what would happen with my kid? I don't like talk it too much because it makes me feel like cry because I really love my family so much. And I'm thinking I hope God will help me to bring them here to be with me.

(HIV positive Kenyan woman, individual interview)

Participants are uncertain about immigration law and policy regarding HIV and whether HIV positive people will be accepted as legal residents in Canada. In the meantime, they may go without health care, social assistance benefits or regular employment. Attempting to gain legal status may be expensive and there is a perception that some lawyers or immigration tribunals are not sensitive to what participants will face if sent back to their respective countries of origin.

The immigration law here in Canada changes like every six months. So even if you apply for something, within six months they can change it. Then that's it. That's your bad luck. I'm not even going to [apply for legal residence status] because the fact that even if you go and say, 'you know, if I go to Jamaica I'm going to die because they don't have any resources.' That's a good point to take to them but they don't care really.

(HIV positive Jamaican woman, individual interview)



Immigration puts an additional stress on families in terms of separation and reunification. Some of the HIV positive participants in the study had to leave children behind when they immigrated to Canada, or were reunited with children after many years. Others were reunited with their parents who came to Canada before them. One participant in this study is looking after four children on her own after her husband was deported. The pressures these processes put on families may make people feel that there is a degree of fragility to relationships, which is further complicated by the stresses of dealing with HIV.

There is an additional pressure in that some have come to Canada to work and send money to families back home and an HIV diagnosis causes concern about being able to fulfill that role.

I didn't want [my parents] to lose hope in me too. Maybe if they think, 'oh she's sick' and then 'who is going to help us?' They have other children, but still they will think like that, so I said no, I didn't want to hurt them [by disclosing my HIV status].

(HIV positive Kenyan woman, individual interview)

2. COMMUNITY INVOLVEMENT

Some participants described a stronger sense of community in their countries of origin compared to Canada, and discussed how community belonging impacts on their health and well-being.

Back home it's different. Maybe they don't understand AIDS and HIV, but back home you have somebody that cares, you know? Here I don't know about for other people, but for me I have nobody. I really don't. And it hurts sometimes because when I really just wanna lash out, I have nowhere to turn and lashing out on myself just doesn't work anymore because abusing myself, it doesn't do me anything well, you know?

(HIV positive Trinidadian woman, individual interview)

Society's influence changes when you decide to create a new habitat in a different part of the world. If I was raised in Jamaica, who knows if I was infected, but I know that I could have family that would love me. ...The community takes care of one another. There is love there. Now I'm not saying that people don't reject people in the family. There are isolated instances. But I find that the larger your community, the more safety you feel. You know what I mean? The healthier you'll become.

(HIV positive Jamaican woman, individual interview)



There was much discussion by HIV positive participants about the search for support networks or attempts to maintain existing support networks. HIV positive participants exercised extreme caution around disclosure and developed strategies around how, when and where to access support services so as not to jeopardize their ability to maintain community involvement.

While responses from family are not always supportive, family members may try to hide a person's diagnosis out of shame. Friends, in contrast, may be more likely to gossip. However, new immigrants often have to rely on friends for many things, which may increase the risk of having one's status become publicly known.

[My family members] didn't tell anybody. No. They can't say anything to anybody because people are going to laugh, you know? They're going to feel ashamed also. So it's between me and [them].

(HIV positive Guyanese woman, individual interview)

Because we live at the edge, we need support [from] whatever we have, you know? I don't have family so my friend is my family, people who I know is my family. So if that guy tell him he's HIV positive, nobody wants with him to do anything.

(HIV positive Ethiopian man, individual interview)

African and Caribbean people living with HIV negotiate means for support, belonging and cultural continuity within a context in which experiences of poverty, immigration and racism, heighten the fear of exclusion from the community.

3. PARENTING AND HIV

Eight of the HIV positive women, and one HIV positive man in the study are parenting children on their own. Several of the women discussed concerns about who will look after their children if they are unable to do so. The women also discussed wanting to ensure that their children grow up with a sense of security and well-being. An HIV positive man did not want to risk damaging his relationship with his child, which he described as one bright spot in his life. For these reasons, participants prefer not to disclose their HIV status to their children. Some participants felt pressured to disclose to their children by people who work in health care settings, partners, or people in the community who threaten to tell their children.

Two of the women also each had an HIV positive child. In these cases the child knew her own status and that of her mother, but other children in the family were not told. One of the women describes



avoiding telling her teenage son in particular because of existing tension in their relationship and the fear that he might use it against her.

Some women lack childcare when they need medical attention or are ill. For example, one participant was unable to be admitted to hospital because there was no one to look after her daughter. Lack of other family in Canada, and/or estrangement from partners and other family members subsequent to disclosing their HIV status, puts a significant burden on HIV positive women who have primary responsibility for raising their children while also attending to their own health issues.

4. GENDER AND SEXUALITY

CHANGE IN INTIMATE RELATIONSHIPS AFTER DIAGNOSIS

Being diagnosed with HIV had a particularly negative impact on intimate relationships of women in the study. While three women mentioned that their male partners remained with them and were supportive after their diagnosis, four women described verbal, psychological or physical abuse, which either followed or was aggravated by the disclosure of their HIV status to their male partners. In two of these cases women described difficulties accessing HIV-related support services because of opposition from their partners, and having to relocate to shelters with their children for a period of time to ensure their own safety.

Two other women mentioned that their male partners left them when they learned their HIV status. Both women were pregnant at the time. In one of these cases the participant said she had known her diagnosis and disclosed to her partner prior to the pregnancy but he did not believe her until she became pregnant and a doctor explained the diagnosis to him. He left her at that point. Another woman decided to end the relationship with her partner because he did not believe her HIV test results.

Four male participants had partners at the time of their HIV diagnoses. All four had male partners and all remained with their partners, at least for a few years. One nursed his partner who died a few years after they both learned they were HIV positive. Another man remained with his partner for several years in a relationship he described as 'toxic.' He believes that this partner infected him. Another currently has a partner who tested positive after the participant learned his diagnosis. He feels that the diagnosis has brought them closer.

I wondered if he would think that I gave it to him or if he's wondering if he gave it to me. I still think about that sometimes, which one of us infected the other person. We're trying not to let it be an issue. It has happened already so we're just trying to get past it. We're trying not to point fingers or to pinpoint blame on anyone.

(HIV positive Jamaican man, individual interview)



Four participants currently have HIV positive partners, two women and two men. The two men have male partners; one was with his partner at the time of diagnosis and the other met his partner after diagnosis. One of the women met her current partner while volunteering at an AIDS service organization, while the other was with her partner at the time of her diagnosis.

For some participants, a positive HIV diagnosis is viewed as an end to significant relationships in their lives. This may be because a partner leaves the relationship after disclosure, as happened with a few of the women in our sample. A Trinidadian woman ended a relationship with a man she wanted to marry because she could not bring herself to disclose her HIV status to him. After learning his diagnosis, a Somali man broke off an engagement he had arranged through correspondence. He describes the impact this had on his life:

It was devastating because it was the end of a life of having children and wife or something like that. So I think you can understand what weight it has when you want to be a family man, and it ended up being one of the worst diseases of this century.

(HIV positive Somali man, individual interview)

Some participants hesitate to pursue any relationships once they learn their diagnosis:

You don't want to get in that. Because you meet somebody, what are you going to tell them, 'I'm HIV positive?' Nobody's going to want to be with you unless it's another HIV positive person. Right?

(HIV positive Jamaican woman, individual interview)

Others describe searching for ways to meet HIV positive partners. One participant who is active in AIDS services organizations describes organizing singles events for HIV positive people. Unfortunately this option is not available to others who may be afraid to approach any organization for fear of having their status disclosed.

CONDOM USE AND SAFE SEX

Female participants in the Caribbean and African focus groups discussed difficulties they face negotiating condom use with men. An HIV positive woman describes the difficulty of using condoms with her husband:



How we was brought up, if you're married, you don't use condoms, you don't practice safe sex. It's your husband, your husband or wife. You can't do these things. You know, it's my husband, why should I? And like men, they will say, 'Oh, maybe you're sleeping around. Or maybe you're doing something you're not supposed to be doing.'

(HIV positive Guyanese woman, individual interview)

Women in the Jamaican focus group also discussed marriage as a factor that increases vulnerability to HIV infection because there is no “safe sex” in marriage. Similarly, Kenyan women discussed how difficult it is for married women to say no to sex without a condom. Caribbean women spoke about vulnerability and lack of control that women experience over their own bodies. The possibility of rape was mentioned, as well as partners who “cheat” or men who sleep with men as well as their wives or girlfriends.

Young Ethiopian men discussed the pressure and the desire to fit into a specific masculine identity in Canada, which “promotes sexuality” but which does not lend itself to sex education.

It rejects sex education basically, it promotes sexuality, and the sexual education is perceived as uncool, it's not cool, it's not, you know what I mean? Sitting in a room like this and talking about things like that, 'yo, no, forget that man, you know, let's go do something, let's go, let's go, let's go play ball man, let's go ahead and do something.' You know what I mean? And it has sort of been inscripted within us.

(Ethiopian man, focus group)

Participants in Somali and Ethiopian men's focus groups spoke about difficulty having any discussion of condoms within their communities, particularly among older members of the community:

It's against their ethic, it's against everything they believe in, it's like having a plastic on the body and having sexual intercourse, they don't want to do that. And some people, like, they're not even gonna give you a chance to explain it to them. So that's kind of a big problem.

(Ethiopian man, focus group)

COMMUNITY NORMS AND SEXUALITY

As with HIV positive participants, focus group discussants from Caribbean backgrounds talked about strong homophobic attitudes in their communities. For example, a participant told someone



at a telephone help line in Trinidad that she was a lesbian and was advised that, “people like you leave Trinidad.” Because of homophobia she avoids the Caribbean community and minimizes contact with her family.

Some interview narratives contained accounts of how communities monitor sexuality and about the pressure to be discernibly heterosexual.

I used to live in [name of neighbourhood], I never talk to nobody. I was just in and out, you know, in and out. Only old people would say good-morning. And because I don't talk to people because I was afraid, I would hear, 'oh, I think he's a battyman, you know? You see how him stosh [arrogant]. An him nuh talk to people? I've never seen him with a woman yet. Him a battyman.' And I was hip like everybody else. You name it I would wear it. But I was put down. So can you just imagine if somebody found out I was HIV positive?

(HIV positive Jamaican man, individual interview)

Much of the HIV-related stigma described earlier in this report ties into community norms of respectability and the assumption that HIV is transmitted through promiscuity and deviant sexuality.

5. RELIGION AND CULTURE

HIV positive participants describe a lack of discussion within their communities about personal issues or emotional/health issues.

We were brought up to be tough. You guys, [in Canada] you're more open. You can tell people stuff. ...But in my culture, you don't come up and tell people. You don't do that.

(HIV positive Jamaican woman, individual interview)

I've come from a culture where it's our culture not to speak your business to people, so you don't address issues and you don't know how to address issues. ...Ten years ago I would not have been sitting here talking to you like this because that was not me, that's not who I am. You know, that's my business and I would deal with my business in the best way that I can. But today I could do this because I've run the full gamut and I understand about dealing with issues and all those things. But there are some people who would still be in that same mindset coming from the islands.

(HIV positive Trinidadian man, individual interview)



Participants in African and Caribbean focus groups also discussed cultural barriers to discussing health and sexuality.

The way we are raised is to keep secret, don't talk to anyone except best friends. You're not supposed to talk to your community or tell about your sickness. We need to learn to open up and seek information.

(Ethiopian woman, focus group)

I guess there's the whole culture if you're West Indian you don't talk your business. And so, I mean, never talked really about sex. Even with your girlfriend. I mean, I just didn't. You know, we didn't talk about those things.

(Jamaican woman, focus group)

Participants also mentioned views on health, illness and mortality, which are more spiritual and less medical. Somali women explained that everything, including HIV, comes from God. Participants in African focus groups mentioned that some people feel that you have to “live your life naturally” and not worry because death can come in many ways or is in the hands of God. One participant said that God knows when you will die; if one listens to doctors, one may be misled. A Kenyan man explained that causes of death are not necessarily thought about at length because people die of many illnesses. The fact that death is common and random means that people may worry less about protecting themselves against a single individual risk factor.

Some Trinidadian and Guyanese participants mentioned a tendency within the community to wait until illnesses are very advanced before seeking medical attention, particularly among men. An Ethiopian woman also felt that men in her community avoid seeking medical care.

Churches and mosques are settings in which HIV positive people do not feel safe to disclose, despite the importance of religion for many. A few participants experienced discriminatory attitudes in church settings, while others have found churches or faith groups that are open and accepting. With few exceptions, participants identify themselves as religious, or as having a spiritual outlook, often deepened by their experiences living with HIV.

African and Caribbean focus group participants described their communities as very religious. The African groups in particular discussed the impact of religion on views of HIV positive people and HIV prevention. They spoke of a need to involve faith leaders in HIV education, but at the same time, they felt that it would be inappropriate or not possible for these leaders to talk about condom use as this would contravene religious teachings.

Somali men and women shared the assumption that HIV does not affect Muslim populations to the same extent as non-Muslim groups because their religion prohibits sex outside of marriage. Kenyan women also discussed how, amongst a church-going population, there is a “moral code”



that guides sexual behaviour. In both groups, those who become HIV positive are assumed to have ignored the limits on sex or violated the moral code, resulting in shame on themselves, their parents, and their families.

6. EXPERIENCES WITH TREATMENT AND SUPPORT SERVICES

HIV TESTING

Nine of 30 participants were diagnosed with HIV when they were seriously ill with symptoms. Two of these participants, both of whom were diagnosed in 2002, feel that they should have been diagnosed earlier as they spent several months seeking a diagnosis, and one was misdiagnosed with another life-threatening illness.

Six other participants sought HIV testing themselves: four of these were gay or bisexual men who requested testing after learning the status of a current or former partner. One Somali man decided to be tested before getting married and a Kenyan woman requested testing from her doctor because she was “not feeling right”.

The remaining fifteen participants learned of their HIV status in various ways. Two were diagnosed as a result of testing done during their pregnancies, two were diagnosed after applying for insurance, and one participant found out he was HIV positive when he applied to participate in a drug trial. Two Kenyan participants found out they were HIV positive through immigration testing after coming to Canada. One participant was tested while receiving treatment for another sexually transmitted infection. One participant’s doctor advised him to be tested after his partner was hospitalized and diagnosed with HIV. One participant was receiving regular HIV tests because of intravenous drug use. Three participants said that their physicians requisitioned the tests although they did not feel unwell at the time.

A few focus group participants discussed experiences with HIV testing in Toronto. Those who had negative experiences may have been more likely to share their experiences in the group discussions. One participant felt she received rude treatment when she tried to book an appointment for anonymous testing, while another says she was treated well. Three other participants mentioned doctors discouraging them from being tested because they did not feel they were at risk and a fourth describes encountering judgmental attitudes from her doctor when requesting testing and not receiving the information she had hoped for about how the virus is transmitted.

HEALTH CARE

Most HIV positive participants find that the health care they receive in Toronto is of a very high quality. Several mentioned that it took them a while to find a doctor who was helpful. Physicians are a key source of information and support for participants who avoid AIDS service organizations



because they are afraid of disclosure in the community. For some, their physicians are the only people who know their diagnosis.

However, a few difficulties with physicians were mentioned, such as not taking the time to adequately discuss medications or provide education about the virus, not acknowledging or addressing emotional or psychological difficulties, or being overly negative about the participant's future prognosis. Some participants did not receive counselling about HIV when their diagnosis was disclosed. One participant reported that her family physician ignored her HIV status and did not requisition any CD4 or viral load testing, nor did he refer her to a specialist. She received treatment only after she was hospitalized with pneumonia.

Two participants talked about the difficulty of being questioned about their HIV status when seeking medical care for other symptoms or conditions. For example, one participant was repeatedly asked to allow medical students to question her about how and when she became HIV positive when she went to appointments to monitor another chronic illness. She likened this to having her "wounds reopened."

While the majority of participants say that the health care they receive is excellent, some participants had experienced demeaning treatment by health care staff. Examples they gave included instances of staff laughing at them, behaving as though they are afraid to go near them, refusing them treatment on the basis of their HIV status, or disclosing their confidential information to people in the community.

One participant felt that there is a "cultural gap" in that physicians do not understand the background of the people they are treating. She suggested that it would be better to have more African and Caribbean doctors treating HIV in Toronto. Another participant specifically sought a family physician of African background after two other general practitioners refused to take her as a patient because she was HIV positive.

Two participants stress that a major impediment they face is lack of housing. While they receive good health care, their ability to rest, look after their health, and take medications, is hampered by living in shelters.

SUPPORT SERVICES

Most participants in this study were active clients and/or volunteers with AIDS service organizations, either currently or in the past. One participant from Kenya feels that the groups she has attended, together with information made available through support services, has helped her to put HIV in a context she feels comfortable with:



I've come a long way and I feel more comfortable now having to live with it, you know, not having that fear. I think I've eliminated that fear of having to live with it because I know it's okay, I know there is stuff out there for me that can make me well, that I feel like I live a normal life, interacting with people, you know, I don't feel any less, I don't feel any less. Now I've gained more confidence and I'm just living a normal life like everybody else.

(HIV positive Kenyan woman, individual interview)

Participants explain the importance of seeing other people in their situation for helping to put HIV in context and starting to feel hopeful about the future.

...the turn around point was when I went to the first discussion group with people like me and having the same fears and the same worries and it made me understand that I'm not alone.

(HIV positive Guyanese man, individual interview)

An HIV positive participant from Somalia explains how he had no idea what to expect regarding his diagnosis for many years until he finally went to an AIDS service organization in Toronto and met other HIV positive people for the first time. A young woman with a strong desire to have children found that meeting other HIV positive women with children was crucial in helping her come to terms with her diagnosis.

Because of stigma and discrimination, AIDS service organizations come to form an alternate community for many HIV positive participants.

If it wasn't for [name of AIDS service organization], a place that I could come, I don't know what I would do. ...I like to go out and do things, but when you go out people hear rumours, nobody talks to you.

(HIV positive Jamaican man, individual interview)

I don't know what community I belong to. Because I'm HIV positive I say that [name of AIDS service organization] is my community, that's where I go usually, or [name of another organization]

(HIV positive Ethiopian man, individual interview)



When I'm down and everything, I just call [name of AIDS service organization], talk to somebody, or [name of another organization], and I feel better. And I'm back to me again.

(HIV positive Jamaican woman, individual interview)

Some HIV positive participants mention that they will never work outside the HIV/AIDS community again because they do not feel safe elsewhere. AIDS service organizations provide a safe space for many to continue with employment or volunteer work after diagnosis. Through an AIDS service organization, one participant from Kenya was able to enter the work force and subsequently move into higher-level positions. She talks about how difficult it was to stay home alone and how bad she felt about not sending money back home to her family. Volunteering helps some participants take their mind off difficulties and they describe how rewarding it can be to be there for someone going through something similar to them.

I want to give love and positive things for people like me. Because I [have experience] in all these problems, in HIV, in homelessness, in everything.

(HIV positive Ethiopian woman, individual interview)

For HIV positive people, the risk of being seen by someone in their community is the most frequently mentioned barrier to accessing support services. Many HIV positive participants delayed accessing services for fear that someone they knew would see them and disclose their HIV status.

I came here about four or five years ago, and I was afraid because I see so much Black people. And I was like, 'Oh my God, Black people! My business is going to be on the street.'

(HIV positive Jamaican man, individual interview)

However, the most common advice HIV positive participants had for other people in their communities who test positive is to access support services, stressing in particular the usefulness of AIDS service organizations for peer support, a sense of community and opportunities for volunteering and employment.

Some participants living with HIV will only access services in anonymous ways. One participant uses the telephone, mail, or has a third party pick things up for her. She will not enter a building with a sign identifying it as an AIDS service organization. Her primary fear is that her daughter will learn that her mother is HIV positive. Another participant uses the Internet at the library. She will not use the Internet at home or keep any printed materials for fear of her son finding out. She does not use AIDS service organizations, stating that "you never know who you're going to meet."



People living with HIV expressed the need to be around other people of similar ethno-cultural background or racial identity and look for services and support offered by and for communities defined in this sense.

If I meet three, four people from my community who are HIV positive, maybe we developed, we listen each other, know how they have been, or how I have been, or whom to talk to, you know? But there is no such thing. So that's really hard. I find it very hard.

(HIV positive Ethiopian man, individual interview)

I think there is a cultural gap too because if you're treating people of a different ethnic group, you need to understand where they're coming from, their needs and all that. And if you don't have people that are from within that group, you know, being this is a multicultural society, it might be difficult also to deliver the services to these people because maybe you don't understand them all that much, their upbringing and all that. ...So I think if there are more African or Caribbean doctors that are involved in this, maybe it could make it much better.

(HIV positive Kenyan woman, individual interview)

Participants mentioned, for example, that agencies staffed by members of, and providing services specifically to, African and Caribbean communities may better understand issues such as the need for strict anonymity, and the importance of removing barriers to access such as locality of residence (Greater Toronto Area versus surrounding cities) and immigration status. Advice given about issues such as disclosure to children and “coming out” about sexual identity may not be appropriate across all ethno-cultural groups or social backgrounds. Two female participants mentioned that some women feel culturally out of place in settings with predominantly white gay male clientele and may avoid those organizations.

Several participants described avoiding services because of discriminatory or racist attitudes or behaviour.

Once in a blue I might go to [name of AIDS service organization]. I don't use them really. I've been there a couple of times. I remember when I was really facing a hardship. I mean a real hardship. And I looked at how people looked at me, you know? And it's not like you're making a big thing out of nothing, but it's just the way people look at you like 'Well, you're a fucking Black. What are you doing here?' You know?

(HIV positive Jamaican man, individual interview)



I know when I have a problem I can go to [name of AIDS service organization] and talk to them and I know it stays with them. But with the other [organizations], no. And then [name of clinic], they laugh and they smile at you. But deep down inside, they're all pretenders. It's all plastic smile. I don't want to [go] to a clinic [that] when I go there you laugh with me, and then when I turn my back, you're laughing at me.

(HIV positive Jamaican woman, individual interview)

A Guyanese man observed that people from his community are not likely to approach AIDS service organizations in the first place and if they do, they would not want to be approached by another person from their country.

It's the way the culture is. You're embarrassed if you have a gay person in your family. Now you're even more embarrassed to have someone with HIV. So this is part of the reason why I notice people from [Guyana] don't even go to places like [name of AIDS service organization]. They're embarrassed. Because I even see one or two and they kind of, you know? And I would love to go up and talk to them, and make them feel better, but I mean, if I wanted to avoid someone too I wouldn't want them to speak to me. So it's a lot of shame and taboo and fear.

(HIV positive Guyanese man, individual interview)

Several participants also talked about the need to maintain a “normal” identity in the sense that they are not seen as diminished or victimized by HIV. There are concerns around “patronizing” and “condescending” treatment from service providers, which angered many participants leading them to distance themselves from services.

[AIDS service organizations have] been a great help to me, but I will not go back as a client. I will volunteer, but I will not go back as a client. Again, I don't feel like a victim and I get this overwhelming repeatedly feeling and experience that I'm being treated like this indigent. And I don't feel that way about my life, you know? ...People do not need to be patronized because they're HIV positive. They know what they want, and they'll tell you what they want.

(HIV positive Trinidadian man, individual interview)

Other difficulties experienced by HIV positive participants included pressure to disclose to children, and a lack of services outside of the central Toronto area.



One participant emphasized the reasons why many HIV positive people who are relative newcomers in Canada may not come forward and access treatment and support services. They may not know whom to talk to because of being in a “strange land,” they may have been separated from family for a number of years, the family may not know their sexual orientation, and the person may not trust the health care system and the immigration system.

Because some of them may feel that if you go to these services, they would somehow have to disclose their status, and they may not get services, or even they might call immigration on them. That’s how people think, you know?

(HIV positive Trinidadian man, individual interview)

IV. PARTICIPANTS’ RECOMMENDATIONS

1. RECOMMENDATIONS BY PEOPLE LIVING WITH HIV

The most common recommendation made by HIV positive study participants is for more education. They often reported that they themselves had little or no knowledge about HIV before their diagnosis. Some felt they were not the type of people, or did not do the type of things, that would put someone at risk. Most began to learn about HIV after they were diagnosed.

For my part, when I heard the word HIV or AIDS, I always think of these people who live on the street, like whores and people, prostitutes and people who have sex with ten people at the same time. Or like different people every ten minutes, or whatever. I never thought it can happen being married.

(HIV positive Guyanese woman, individual interview)

They discussed the general lack of knowledge within the community and the difficulties this creates for them. For example, the community needs to understand that people can live productive lives with HIV and stop treating them as though they are “finished” or “dead.” One participant indicated that if the people around him simply had more understanding, his life would improve immensely.

Important lessons for the community members to understand include:

- An awareness of how HIV is transmitted
- HIV is not a “gay disease”
- It is not limited to people who are “promiscuous” or “bad”
- HIV positive people survive and go on to live a quality life after diagnosis



Raising awareness of HIV requires more media coverage and visibility, more accessible prevention work, and more discussions about HIV. Participants identified schools, hospitals, community centers and advertising campaigns as important sites for education. One participant felt strongly that the taboo around discussing HIV has to be broken:

First thing, you need to be talking about it more often. A lot of people don't speak about it. It's a taboo subject, and you're not supposed to speak about it. Don't even mention it. Don't even think about it. We need to speak about it more often. We need to educate the kids in school now because a lot of kids in school think that HIV is a gay disease still because that's what their parents are making them believe, that you got to be gay to have HIV, and you have to be a bad person to get HIV. You must have been a whore, because good people don't get HIV. So for me, more education in the schools, in the community centres, in the hospitals. ... [Right now] you have to go to an immune deficiency section [at a hospital] to find out about HIV. You know, put up posters, let people know, hand out condoms, you know, make a difference.

(HIV positive Jamaican woman, individual interview)

Another participant said that the only way to tackle fear is through education, so that people do not fear those who have HIV, and people with HIV are not afraid to access services in case they may be seen and gossiped about.

Other comments centred on practical problems that need improvement such as lack of housing, unemployment, and immigration barriers that make it difficult for people already living here to get status and health coverage. Some suggestions were made about services, including the need for more diversity in the executive, staff, programming, and clientele of AIDS service organizations, more services available outside of central Toronto, better attitudes from health practitioners and the need to be vigilant in hospitals around confidentiality concerns. Several participants mentioned that Caribbean communities need to address homophobia to a greater extent by, for example, rejecting gay-bashing music, and improved sensitivity and knowledge on the part of community leaders such as faith leaders. Support groups and peer counseling are seen as excellent spaces for people to talk about what they are feeling and experiencing and to learn from others.

2. RECOMMENDATIONS BY OTHER COMMUNITY MEMBERS

EDUCATION

Participants spoke at length about the need for more education. For example, Trinidadian women



identified two types of education that are needed: (1) HIV prevention, and (2) education about what it is like to be HIV positive and how not to fear and isolate HIV positive people. Others indicated that there is a great deal of general information that is not well understood. For instance, Kenyan and Ethiopian women mentioned that there is a widespread impression that if a person looks healthy, they are not HIV positive. A Kenyan man said that people need to know that there are things that can be done if they receive a positive diagnosis, otherwise they will feel it is better not to know.

Some participants felt that education needs to include doctors. Some women in the focus groups reported difficulty getting HIV testing when they requested it from doctors who either do not think they are at risk, or display judgmental attitudes when women request testing. Ethiopian women felt that doctors in their community need to play a leadership role in educating their community and need to take the time to educate their patients.

Overall, different types of education about HIV/AIDS need to come from both inside and outside of the community. Specifically, the outside community should provide financial support and medical information necessary to develop educational campaigns and stop portraying Black community members as carriers of HIV.

CHANGE MISPERCEPTION THAT HIV IS A “GAY DISEASE”

Caribbean participants talk about how there is still a strong perception that HIV is a “gay disease.”

I think a big part is that it is not seen as something that Black women have. It still is a ‘gay disease.’ Right? So, until we change that perception, then it’s going to be really hard, because it’s not targeting an audience that people think it applies to, right?

(Jamaican woman, focus group)

NEED FOR SPOKESPEOPLE

Participants in many of the groups talked about the need for spokespeople. These include people who are HIV positive, as well as celebrities willing to promote condom use and testing. Participants desired an HIV positive spokesperson, preferably someone from their community, who would be willing to put a “human face” on the disease and make it more real. On the other hand, they wanted a very specific representative: someone deemed respectable, or, in other words, not infected through sex or drug-related activities. A “suitable” representative would raise awareness and garner sympathy, according to a Somali male participant, while someone deemed unsuitable or promiscuous would attract scorn.



INVOLVE FAITH AND COMMUNITY LEADERS

Kenyan women felt that people are more likely to listen to and respect church leaders than politicians. A clergyman willing to disclose his positive HIV status, for example, would have a great impact, raising awareness and challenging stigma. One Jamaican man felt that churches are important sites of mobilization because they are both a source of discriminatory practices (for example, labeling HIV as a curse from God), and of assistance and stewardship. Somali men also felt that mosques should be involved in education. Some participants argued that community organizations also had a role to play in providing culturally appropriate services and education. Guyanese women felt that there was a generational issue to how HIV is taken up within their churches, with young people more open to discussing a range of topics including HIV/AIDS. Participants identify an assumption that if you are a “good Christian” or a “good Muslim” then HIV/AIDS is not an issue that concerns you and on that basis it is not necessary for faith groups to discuss it. As one Guyanese man states, there is an assumption that HIV is “for the sinners.” However, given the importance of faith and religion within the communities studied, it is emphasized that much could be accomplished by faith leaders and activities within faith groups.

ADDRESS SOCIAL ISSUES

Participants felt that part of combating HIV and its effects on their communities would be to address the social determinants of health. For example, Trinidadian women felt that employment opportunities must be made available for youth. Trinidadian men discussed the need to tackle issues around youth and schooling because “we have already lost a generation.” Kenyan men and women discussed the lack of affordable housing in Toronto, unemployment and poverty as risk factors. Several of the African groups conveyed the extent to which many members of their communities are living lives of isolation in Canada and how this creates a larger health crisis within their communities.



DISCUSSION



DISCUSSION

The data collected for this study provide important insights into HIV stigma, discrimination, denial and fear as they are understood and experienced at the level of the individual, the family, the community, and the society. The conclusions that we drew are both analytical and practical, and fully informed by what participants had to say about their own lives even as we summarized people's words to reflect the demands of a report format.

African and Caribbean participants told us that HIV stigma and discrimination are produced and reproduced in broader social processes and structures, cultural and religious beliefs, and in everyday interactions. The intersecting sites of discriminatory attitudes and practices have profound effects on people who live with HIV, and who are forced to negotiate a host of relationships and services to maintain safety and confidentiality.

Caribbean participants described the personal impact of homophobic attitudes within their communities and how these relate to stigmatization and discrimination against those who are, or are assumed to be, infected. Participants described mechanisms that are used to monitor sexual practices in general and to condemn same sex relationships in particular. These negative attitudes are sanctioned by cultural practices and social institutions such as family and church, and demonstrate how cultural and social norms about gender are constructed and policed.

Participants commented on the state's involvement in perpetuating discrimination through punitive immigration practices that limit access to employment and medical care, perpetuate the fear of deportation, and force people living with HIV to be even more careful about disclosure. Some participants live in hiding and are acutely fearful that if their HIV or immigration status were revealed the loss of relationships, treatment, care, and support would be great. They took extra precaution, for example, by calling ahead before going to medical appointments or to use services, to minimize the risk of being spotted by a member of their community. These precautions shed further light on why people living with HIV in marginalized communities may be reluctant to take part in research studies.

While HIV positive participants faced many challenges in their daily lives, they also demonstrated great resourcefulness in the face of these challenges. They devised strategies to cope with and adapt to their situations, which were reflected in their stories about how they made choices around disclosure of their HIV status, participation in family and community life, and accessing health and support services. Many spoke about HIV as giving them a different outlook on life, one that is more positive and that often led them to consider or reconsider issues around spirituality, community, and what it is that gives quality, purpose and meaning to life.

The Stigma Study is groundbreaking in its contribution to the development of frameworks for understanding how stigma, viewed and experienced by African and Caribbean people in Toronto, is situated in larger structures of inequality and dynamic social processes. Participants in the study repeatedly discussed HIV in relation to other pressing issues facing their communities including:



unemployment, family breakdown and intergenerational conflict, racism, racial profiling, poverty, and language barriers. Although some focus group participants did not rank HIV high on the list of issues facing their communities, this is not an indication of its relative lack of importance. Participants made connections, for example, between unemployment and the increased risk of infection for youth who may become disillusioned and pessimistic about the future. Drawing connections between the possibility of HIV infection and social exclusion suggests that it is futile to undertake HIV/AIDS prevention programs without addressing larger problems that keep African and Caribbean populations at the margins of Canadian society.

The Stigma Study further provides insights into how gender, race and poverty intersect with HIV/AIDS related stigma, denial, fear and discrimination. An understanding of these multiple issues is not limited to local experiences, but is situated in global processes such as crossing borders in search of better opportunities, safety and security; the isolation of living in a foreign place; the loneliness from missing loved ones, the difficulty of trying to establish new relationships and networks, and the decision to shield family ‘back home’ from an HIV positive diagnosis received in Toronto.

African and Caribbean people have local concerns associated with negotiating daily life in Toronto, but they also worry about the material effects of a positive diagnosis on loved ones in their home countries who depend on them. Some HIV positive participants opted to keep their diagnosis a secret from family members until they could tell them face-to-face. They believed that, by seeing that they are healthy and living a “normal” life, in-person disclosure would alleviate many concerns that loved ones may have. The pressures on these participants are many, and the networks for support are small and must be negotiated. All of these concerns place limits on the overall quality of life and pursuit of opportunities that can make life better over time for African and Caribbean people in Toronto.

It is difficult to fully appreciate the challenges facing these communities and to develop comprehensive strategies to address their needs without a full understanding of the complexities of the issues. We hope that this report will provide resources and act as a guide for identifying the specific ways that Caribbean and African people talk about the daily conditions of their lives; the issues that they face, the strategies that they use to cope, and how best to implement the recommendations that they made.



**APPENDIX A:
STIGMA &
DISCRIMINATION**



APPENDIX A: STIGMA & DISCRIMINATION

(UNAIDS FACT SHEET) [HTTP://USAFORAFRICA.ORG/PDF/STIGMA.PDF](http://usaforafrica.org/pdf/stigma.pdf)

All over the world, the AIDS epidemic is having a profound impact, bringing out both the best and the worst in people. It triggers the best when individuals group together in solidarity to combat government, community and individual denial, and to offer support and care to people living with HIV and AIDS. It brings out the worst when individuals are stigmatized and ostracized by their loved ones, their family and their communities, and discriminated against individually as well as institutionally.

AN OVERVIEW OF HIV/AIDS-RELATED STIGMA AND DISCRIMINATION

- Stigma and discrimination around HIV and AIDS continue to fuel the global AIDS epidemic. ‘Live and let live’, the World AIDS Campaign for 2003, explores how both individuals and organizations can help reduce stigma and discrimination.
- The campaign is working to tackle stigma and discrimination in a number of settings including: education, faith based organizations, health care settings, legal systems, the media, parliamentarians and the workplace.

WHAT IS HIV/AIDS-RELATED STIGMA AND DISCRIMINATION?

- HIV/AIDS-related stigma can be described as a ‘process of devaluation’ of people either living with or associated with HIV/AIDS. This stigma often stems from the underlying stigmatisation of sex and intravenous drug use – two of the primary routes of HIV infection.
- Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Stigma and discrimination breach fundamental human rights and can occur at a number of different levels including: political, economic, social, psychological and institutional.
- When stigma exists people often prefer to ignore their real or possible HIV status. This can lead to the risk of faster disease progression for themselves and also to the risk of them spreading HIV to others.

THE NATURE OF STIGMA AND DISCRIMINATION

- HIV/AIDS-related stigma builds upon, and reinforces, existing prejudices. It also plays into, and strengthens, existing social inequalities - especially those of gender, sexuality and race.
- HIV/AIDS-related stigma and discrimination play a key role in producing and reproducing relations of power and control. They cause some groups to be devalued and others to feel that they are superior. Ultimately, stigma creates and is reinforced by social inequality.



STIGMA, DISCRIMINATION AND HUMAN RIGHTS

- Prejudiced and stigmatizing thoughts frequently lead people to do, or not do, something that denies services or entitlements to another person. For example, they may prevent health services being used by a person living with HIV/AIDS, or terminate their employment on the grounds of their HIV status. This is discrimination.
- Discrimination occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group.

TACKLING STIGMA AND DISCRIMINATION AS A RIGHTS ISSUE

- The human rights framework provides access to existing procedural, institutional and other monitoring mechanisms for enforcing the rights of people living with HIV and AIDS, and for countering and redressing discriminatory action.
- Appropriate reporting and enforcement mechanisms ranging from legal aid services to hotlines for reporting acts of discrimination and violence can provide powerful and rapid means of mitigating the worst affects of HIV/AIDS-related discrimination.

THE WIDER IMPACT

- Stigma and discrimination can lead to depression, lack of self-worth and despair for people living with HIV. But people living with the disease are not the only ones at risk from this fear and prejudice.
- Negative attitudes about HIV also create a climate in which people become more afraid of the stigma and discrimination associated with the disease than of the disease itself. When fear and discrimination prevail, people may choose to ignore the possibility that they may already be, or could become, HIV-positive – even if they know they have taken risks. And people may decide not to take actions to protect themselves for fear that in doing so they are associating themselves with HIV and having been ‘at risk’. All of this helps to create an environment in which the disease can more easily spread.
- The World AIDS Campaign seeks to break the cycle of stigma and discrimination by:
 - Highlighting the harm of stigma and discrimination
 - Promoting the benefits of tackling stigma and discrimination
 - Using education to challenge ignorance, fear and denial
 - Promoting hope and the contribution of people living with HIV and AIDS
- One of the most effective ways to break the cycle of stigma and discrimination is through ensuring people living with HIV can contribute to society. The best way to do this is to provide treatment to keep people healthier longer.



- The World Health Organization (WHO) and UNAIDS are spearheading a bold initiative to roll out antiretroviral treatment to 3 million people, in areas of most need, by the end of 2005. In addition a growing number of countries are setting up national comprehensive prevention and care programmes. These initiatives can help lift the pall of suspicion and secrecy that accompanies the epidemic.
- Only by confronting stigma and discrimination will the fight against HIV/AIDS be won.

Live and let live. Help us fight fear, shame, ignorance and injustice worldwide.



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