Silent Voices of the HIV/AIDS Epidemic:

African and Caribbean Women in Toronto 2002 - 2004

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acknowledgements

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introduction

Research around the world shows that African and Caribbean women bear the greatest burden of HIV/AIDS (UNAIDS, 2005). This is in part due to having limited and inaccurate knowledge around HIV/AIDS modes of transmission and prevention. This research study has illustrated that there are also many other factors that influence African and Caribbean women's access to HIV/AIDS information and related services. These include, but are not limited to:

• lower economic status, specifically poverty

• cultural and religious stigma and discrimination related to HIV/AIDS

• religious beliefs perpetrating myths about AIDS, such as AIDS being a punishment from God for being immoral or sinful

• gender discrimination against women that has led to rigid gender roles that tolerates unequal treatment of women and has not supported women's rights to their bodies (right to say no to sex, right to ask for protection/testing, etc.)

• the attitudes and norms of African and Caribbean cultures; i.e. patriarchy; code of silence around sex; contraception uncommonly used; homosexuality as a taboo behaviour

• stress of settlement process (housing, education, employment, immigration issues, language training) reduces time available for healthcare needs

• immigrant status: no status/OHIP; fear of being deported if HIV-positive

• experiences of racism and cultural discrimination by others (especially service providers) leading to mistrust of system

The prevalence of HIV/AIDS in African and Caribbean communities in Ontario has grown by 85% in the last 5 years and 22-59% of these infections occurred after settlement in Ontario (Remis, 2004).

Though African and Caribbean people only make up approximately 4% of Ontario's population, with 76% of them living in Toronto (Statistics Canada, 2001), 20% of AIDS diagnoses in 2001 and 2002 were attributed to the women of these communities (Remis, 2004). Furthermore, between 1994 and 1996, 70% of mother-to-child HIV transmissions were attributed to African and Caribbean women (Remis, 1999).

While these statistics indicate a growing problem, there is very little documentation of the context within which transmission is occurring, the factors that facilitate or reduce transmission, and the factors that foster the ability to cope with HIV for people who are already infected. In addition, African and Caribbean women and their communities have played a very limited role in the efforts mounted to deal with the HIV/AIDS epidemic in their new host country. This has left service providers struggling to understand the forces that are driving the epidemic.

The lack of evidence upon which to base programs and services and the need to engage women and their communities in prevention, support, and care activities gave rise and impetus to this study. Research shows that individual risk is influenced by societal factors and that there is a need to address underlying factors that create an overall climate in which risk-taking behaviours are encouraged, maintained, and prove difficult to change (UNAIDS, 1998).

purpose

This report is a compendium of the original report/study entitled, "Silent Voices of the HIV/AIDS epidemic: African and Caribbean Women in Toronto" that is available through Women's Health in Women's Hands Community Health Centre.

The study was the result of a community-based research project that sought to engage African and Caribbean women living in Toronto in a discussion about HIV and AIDS. As well, there was an exploration of the experiences of service providers working with these populations.

This study explored the factors that facilitated HIV transmission or enabled risk reduction and/or the ability to cope with HIV/AIDS once infected. Economic, social, political, cultural and religious factors were examined to determine their role in either limiting or enabling women to protect themselves from HIV infection or cope with the disease once infected. Experiences of service providers working with African and Caribbean women were also explored to provide an in-depth understanding of the barriers, challenges, and gaps in services. The research participants also proposed ways in which services could be improved to better meet the HIV/AIDS needs of African and Caribbean women. This study has also provided many insights illustrating how the unfolding of the epidemic and mounted responses in countries of origin influence women's response to HIV/AIDS in Toronto.

Objectives

- To determine the level of awareness and knowledge of HIV/AIDS amongst African and Caribbean women

- To determine factors that influenced access to HIV/AIDS information and services amongst African and Caribbean women

- To identify and document the type of HIV/AIDS services available for African and Caribbean women

- To determine the level of knowledge, awareness, and utilization of HIV/AIDS services by African and Caribbean women

- To identify the major issues and barriers faced by service providers who were providing HIV/AIDS services for African and Caribbean women

- To use research methodologies which supported the involvement and participation of the target groups throughout the research process

research methodology

The data presented in this report was collected through semi-structured, in-depth interviews with service providers and key women from the African and Caribbean communities and through focus group discussions with general women from the two populations.

These methodological approaches were selected based on the fact that they would privilege the voices and experiences of African and Caribbean women to facilitate a better understanding of what HIV/AIDS means to them, the factors that influence their responses, and ways in which service providers engaged women to ensure better and more effective services. The methods used were qualitative and interpretative in nature and drew largely on the tradition of feminism, antiracism and participatory research fields. It was framed within a theoretical framework that allowed for an in- depth exploration of issues concerning multiple oppressions such as gender, culture, race, sexual orientation and how such oppressions influenced individual choices. Throughout, a practice-based research model that integrated feminist, anti-racist and participatory research strategies and respected principles of empowerment emerged. From this grounded approach, individual experiences were examined in relation to socio-cultural, economic, religious and related barriers at the individual, community and systemic levels.

This practice-based research model helped facilitate involvement of community leaders as collab-orators who had expert knowledge about, and experience within their communities as well as organizations providing health care and/or HIV/AIDS services. They formed an expert/advisory group that provided input and fully participated in the implementation and interpretation of the results.

Participants were recruited through network/snowball sampling strategy, followed by purposive sampling strategy to ensure a sample that would maximize variation in respondents.

Service Provider Interviews

Individual, in-depth interviews were conducted separately with 20 service providers. Criteria for participation included experience in providing services for African and Caribbean women in the Greater Toronto Area (GTA). Providers who met the criteria were drawn from a broad range of settings as indicated in Table I below:

Type of Agency/Institution Setting	Number of Participants
Black AIDS Service Organizations	3
Mainstream AIDS Service Organizations	3
Community Health Centres	4
Faith-Based Network	1
HIV Clinics in teaching hospitals	2
Triage Clinic in a hospital	1
Employment Skills Development Agencies	1
Youth Health Clinics	2
Women's Shelters	2
Department of Public Health	1
Total Number of participants	**20**

Table I: Institutional settings from which research participants were drawn

Key informant interviews

Individual, in-depth interviews were conducted separately with 31 key women from the African and Caribbean communities. These key informants were women who immigrated from Africa or the Caribbean and settled in Canada. They included graduate students, executive directors, managers, lawyers, practicing medical doctor, nurses, social workers, counselors/case workers, educators, and outreach workers. These women had an in-depth understanding of the values, beliefs, norms and practices inherent to the African and/or Caribbean culture(s) and tradition(s), the issues and barriers faced by African and Caribbean women in their efforts to settle in a new environment, and the relationship of these variables to sexual behaviors and, ultimately, to HIV/AIDS. The information that was shared by key informants was based on their lived experiences and their encounters with other African and Caribbean women in various settings.

See Tables II and III for distribution of the key informants based on country of origin:

Key Informants' Country of Origin	Number of participants Interviewed
1. Somalia	3
2. Ethiopia	2
3. Zimbabwe	2
4. Ghana	2
5. Kenya	1
6. Uganda	1
7. Eritrea	1
8. Mali	1
9. Republic of Congo (former Zaire)	1
10. Nigeria	1
Total Number of women Interviewed	**15**

Table II - Distribution based on Country of Origin: African Women

Key informants' Country of Origin	Number of participants Interviewed
1. Jamaica	7
2. Guyana	1
3. Antigua	1
4. Trinidad	1
5. Dominican Republic	1
6. St. Lucia	1
7. Grenada	1
8. Black Canadian	1
Total Number of women Interviewed	**16**

Table III - Distribution based on Country of Origin: Caribbean Women

Focus Group Participants

The women who participated in the focus groups were comprised of 17 African women and 6 Caribbean women. All of the women had immigrated to Canada, lived in the GTA, and were over 16 years old. They had varying immigrant status, e.g., citizens, refugees, undocumented women, landed immigrants. They also came from varying socioeconomic backgrounds. The African women focus group included seven HIV positive women.

results: an introduction

The data obtained in this study illustrated the importance of broadening the HIV/AIDS response to the communities of African and Caribbean women. The response must evaluate individual behaviours under the scope of how economics, culture, religion, gender, race and other social factors impact upon these women's everyday realities. This study demonstrated the major role that these factors play in determining African and Caribbean women's response to HIV/AIDS by influencing their ability to protect themselves from infection and/or cope with the impacts of the disease once infected.

The data from the key informants, the focus group participants, and the service providers has been synthesized to reveal the similar opinions that were shared from start to finish. The discussion that follows expresses the participants' thoughts and experiences with African and Caribbean women through their roles as health-professionals, as community workers, and as community members including women living with HIV/AIDS. It combines a report of the collected qualitative data with direct quotes from different participants to give voice to the silence that surrounds the HIV/AIDS response among women and their communities.

Research participants described African and Caribbean women as a diverse and complex group with multiple shifting identities based on gender, ethnicity/culture, religion, education, socio-economic status, age, and class. These identities constantly shifted based on numerous factors that included status/type of employment, reasons for migrating, length of time and residency status in Canada, marital status, and the ability to communicate in the Canadian official languages. Undoubtedly, many of the factors identified intersected/intertwined and influenced each other and the women's responses to HIV/AIDS.

Level of Awareness & Knowledge around HIV/AIDS

Accurate knowledge, information, and an understanding of one's own risk was limited to women living with HIV/AIDS, their caregivers and those involved as professionals or volunteers in the HIV/AIDS field. These women were also cognizant of the threat of HIV/AIDS in their communities that was largely due to a general lack of awareness among community members.

> "I do think that professionals working in this field respond differently from the general population and I see…some agencies, not a lot, sort of trying to mobilize their communities in terms of providing appropriate sex education…but I think in terms of the general population because again people don't think it affects their lives, they almost don't think anyone is infected with AIDS"
>
> *Caribbean Key Informant- Jamaican Woman 6*

Outside of this sub-population, there was generally limited awareness or knowledge about HIV/AIDS.

HIV/AIDS perceived as happening 'back home' or in a distant place

Many African and Caribbean women are aware of the devastating effects of the HIV/AIDS epidemic in their countries of origin, particularly those who have originated from Sub-Saharan Africa. As a result, many respondents reported that women from their communities perceived HIV to be an epidemic that was affecting particular countries/towns in sub-Saharan Africa and/or the Caribbean but not their communities here in Toronto. This limited women's involvement in efforts to fight the epidemic in Toronto.

> "HIV has always been someone else's problem. In developing countries it's different because families are affected, whether it is extended families or immediate family members. But here because that is not happening, you rarely would see or know someone who is HIV positive, or someone who is suffering from full blown AIDS. You know that its there but you really don't see it. So if you don't see it, then its really not there. It is not happening to people here, it is happening to those living in Africa"
>
> *African Key Informant - Kenyan woman 1*

HIV/AIDS perceived as a punishment & as happening to 'others'

Negative views about HIV/AIDS prevailed in African and Caribbean communities in Toronto, just like in their countries of origin. HIV/AIDS was seen from a moralistic perspective and as a consequence of one's actions such as punishment from God for immoral/questionable high-risk sexual behaviours (especially homosexuality) that are not accepted culturally or religiously.

> "Overwhelmingly women talked about HIV becoming who you are, and if you're a good person you don't get HIV, if you go to church you don't get HIV."
>
> *AIDS Service Organization Provider 5*

> "I think there is still the assumption that this is a gay disease, and I think that is a huge risk for women, that women need to understand and they need more clear information that everyone is at risk, really."
>
> *Caribbean Key Informant - Jamaican woman 2*

Invincibility to and invisibility of HIV/AIDS

Participants expressed that there was a sense of invulnerability and invincibility among women whom weren't HIV positive. As a result, they haven't sought information or services that deal with HIV/AIDS because they believed it didn't affect people like them. HIV/AIDS was not seen as a threat or a priority.

> "The bottom line is it hasn't made an impact in this community…nobody talks about HIV. The only time it comes up in a conversation is if someone has seen a movie or an ad. I don't know of anyone in the community that has died of HIV or AIDS, so it's a conversation more than a reality. It's not happening".
>
> *Caribbean Key Informant - Guyanese Woman 2*

Many of the women from these communities perceive that they are safe as long as they are in a stable heterosexual relationship (e.g., boyfriend, husband). Also, HIV/AIDS was thought to more likely affect young women.

Women who are HIV-positive endure feelings of shame, fear, and blame. They often deal with the disease alone, since they are always fearful of the consequences of being identified. Their communities' negative views of HIV/AIDS influences their decisions to disclose their HIV status and how they interact with service providers. Confidentiality regarding their status is the principal concern.

> "When you go out and tell a friend, you ask yourself is this person going to hurt me? For this person to know are they going to bring me down?"
>
> *African women focus group participant*

factors influencing the spread of HIV/AIDS and the response to HIV/AIDS

Income & Poverty

Generally, these women struggle with obtaining gainful employment (even after many years in Canada) that will cover minimal costs of living for themselves and their families. Many of their families also provide economic support to relatives in their countries of origin. Both the women and men in these communities experience significant levels of unemployment, underemployment, and many people often have (one or more) low-salaried jobs. To support their families, women have often taken any available jobs, including those that pay low wages. This impacts strongly on their responses to HIV/AIDS.

General response to HIV/AIDS: there are higher priorities & not enough time/money

Since generating income to survive was the top priority, and the women were also the primary caregivers in their families, there was virtually no time to invest in any health-related issues. More immediate issues and needs such as finding employment, affordable housing, feeding their family, etc, took precedence over any issues related to HIV/AIDS.

> "The majority of us are poor and even if we are working…we are just working for survival…the majority of black women…that I know are working 1½ jobs plus caring for homes, parents, families, husbands and anybody else. HIV/AIDS is really low in their list of priorities as a whole because they are working 50-60 hours per week. They are unable to supervise their kids' homework and you know they are doing everything, you know that HIV/AIDS gets dismissed. It's the easiest thing to dismiss."
>
> *Caribbean Key informant - Jamaican woman 6*

Poverty & African/Caribbean women living with HIV/AIDS

Most African and Caribbean women living with HIV/AIDS were unemployed, a factor that made living in poverty seem inevitable. Poverty exacerbated their ability to cope with the impacts of the epidemic.

The ever-present fear of being identified as HIV-positive and the subsequent stigma also prevented them from accessing food banks located within AIDS service organizations even when they may not have had enough money to pay for the proper foods/diet required to enhance their medication's effectiveness.

Settlement & Immigration Issues

Being diagnosed as HIV-positive during the immigration process added an overwhelming burden to an already stressful time. There was concern that being HIV-positive would jeopardize the chances of being allowed to stay in Canada, so some women tried to avoid being tested.

Undocumented women/women without residency status

Women without residency status or undocumented women were more common among the Caribbean population. Since they were not legally allowed to work and did not qualify for health coverage, they could not afford to pay for treatment and other medical related expenses that are normally covered through OHIP, so, they often did not attempt to access services.

Difficulties attaining recognition for the educational qualifications & experience they received in their countries of origin

Many women were forced to accept jobs below their skill level and salary expectations because they could not get their academic and/or professional credentials recognized in Canada and/or they didn't have Canadian experience. This generated feelings of frustration and skepticism about the Canadian system which affected their trust of the health care system.

"I came here with high hopes with my three nursing degrees. I have the psych nursing and the general nursing, but I have to start all over again. Even to the point that I was told to go in and get my OACs, and not even my OACs but my Ontario Secondary School Diploma, because if you start from there at least you can get a clerical job."

African Key informant -Ghanaian woman 1

Cultural values, beliefs, norms, & practices

Numerous cultural norms, values and practices increased the risk of HIV/AIDS infection among African and Caribbean women.

Influence of culture in daily life

Though they were living in Toronto, which is different from their countries of origin, these women maintained close ties with their cultures of origin, often retaining their traditional beliefs, values, norms and practices. Their cultures were seen as an overarching umbrella that influenced every aspect of their lives: the food they ate, their identity, their sexual and reproductive rights, and extended to their roles and behaviours within the institution of marriage.

Patriarchal nature of African & Caribbean cultures

African and Caribbean cultures were seen as inherently patriarchal, where women were conditioned or expected to defer to male authority and privilege, even at the risk of their own health. Women were supposed to be innocent, sexually inexperienced, and to leave all matters of sexuality to their male partners. In these cultures, males are the heads of the household and retained the right to make decisions on all family matters, including those involving sexual intimacy.

Code of silence around discussions of sex and sexuality issues

Participants expressed that there was a "code of silence" around sexual matters in their cultures. Any discussions about sexuality were considered to be taboo. As well, heterosexuality was seen as the only acceptable cultural norm. HIV/AIDS was treated with the same silence as all other sexual related matters, even amid suspected sexual indiscretions.

"HIV is associated with sex. So in my culture, sex is a taboo, people don't really talk about their sexual life no matter what, it is not normal."

African Key Informant - Somali woman 1

This "code of silence" limited parents' ability to talk with their children about sex and sexuality. Young people were left to learn from sources that were not always credible or did not always provide relevant or accurate information. They learned about sex and sexuality from peers, older siblings, TV, music, magazines, schools, by hearing others having sex in the house, etc.

> "Not from parents, that's for sure. I remember when I had to…teach my sister how to use a tampon. Parents just don't deal with those kinds of things. You also learn from older girls and from little stories that you hear and you hear all the crap in with the truth. You have to kind of muddle through to determine what in fact is real and that, of course, increases the risk, because you don't know."
>
> *Caribbean Key Informant - Jamaican woman 1*

In Africa, many cultures taught young girls about sex and sexuality through traditional means, with grandmothers and aunts playing a big role in initiation ceremonies and practices. This was usually done in preparation for marriage. Among other cultures, there was an expectation that girls would not learn about sex until they married and then the husband would take over the decision making in all matters related to sexuality.

> "Girls are not expected to learn anything about sex until they get married. Why would you teach something that would encourage deviant behavior? Parents…usually keep their fingers crossed that by the time my child, especially if it's a girl, is sexually active or thinking about sex, it's time for her to get married…[then what] they learn [about sex] within the confines of marriage is dictated by the male partner."
>
> *African Key Informant - Kenyan Woman 1*

Double standard regarding multiple sexual partners for men

Having multiple sexual partners was considered to be a common practice for men in both African and Caribbean cultures. It was seen as an expression of male virility, privilege and power and it was considered to be an inherent, unspoken right for males. Many African women expressed the opinion that even though they knew their partners were cheating, their culture did not allow for confrontation. These women were being exposed to their partners' unsafe sexual practices without being able to do anything about it.

> "Many married African women have a lot of suspicions in their marital relationship, because you don't have the sincerity of your husband and you don't really have too much control…you don't know [if] your husband is getting protection because we are not really open to our husband to talk with them…it's not like you don't know they go…so if you are married to an African man…you know that they go out with anybody they want."
>
> *African women focus group participant.*

Furthermore, if a woman questioned her partner, she risked being perceived as distrustful or being accused of cheating herself.

> "[It] is not acceptable to even hint that you do not trust your partner. When we look at that, it's part of the way that women are brought up…and part of that is sex, the issue of trust, you're not even supposed to bring it up."
>
> *African Key Informant - Kenyan Woman 1*

Condom Use

It was considered unconventional for these populations to use condoms, whether as a means of HIV prevention or as a contraceptive method. The withdrawal method and use of the "pill" was cited as being the most commonly used contraceptive methods.

> "Pull-out method and use of birth control pill are the most commonly used methods of contraception not condoms."
>
> *Caribbean Key Informant - Trinidadian Woman 1*

Men were not expected to use condoms with their long-term partners (e.g., wives or girlfriends), despite silent consciousness by both parties that some of the men were also having sex outside these relationships. As a result, women felt uncomfortable initiating discussions about condom use since they would then be accused of being unfaithful or not trusting their partner.

> "Rarely do condoms feature even as a contraception method. I think there is a lot of discomfort around it. Sometimes the view is that there is a lack of trust even though that is not an issue when the condom is introduced."
>
> *African Key Informant - Kenyan Woman 1*

Reasons given for not using condoms included: they are uncomfortable, they hurt, one person doesn't like them, partner is not infected, sex won't feel as good, black men can't find a condom that fits, the woman needs to get pregnant, condoms cause low sexual performance.

> "This idea that men like to ride bareback and that black men don't like to use condoms. I know that a lot of black men say that they like to feel the skin"
>
> *Caribbean - Jamaican Woman 6*

Polygamy

In Africa, many cultures allowed polygamy, which is a cultural and religious practice that permits a man to have more than one wife. While polygamy is illegal in Canada, research participants indicated that, to some extent, it was still practiced secretly in some of their communities. As well, it was believed that some African men had a partner in Toronto and another partner in their country of origin or that some men had several wives here, but they lived in different places with the man visiting them on a regular basis.

Traditional rituals & therapies/treatments

There is still some practice of female genital mutilation among African communities and douching among Caribbean women; these practices can put women at increased risk of HIV infection.

Traditional medicine was often sought out to deal with illness while western medicine was used as a last resort, which could reduce women's likelihood to seek HIV-related medical services in Toronto.

In summary, African and Caribbean women were at further risk of HIV/AIDS infection due to a combination of their cultures' practices that included limited discussions about sex and sexuality, men's ability to dictate the nuances of sexual relationships, the toleration of multiple sexual partners among men, and limited condom use.

Religious beliefs, values, & practices

Religion plays a very important role in African and Caribbean women's lives. It gives them hope and comfort, while also influencing many other aspects of their daily lives and activities.

It was deemed that the women tended to incorporate their religious faith into their lives more than men. The subgroup of Islamic and fundamental Christian women felt that their religious beliefs dictated their reproductive rights, their sexual behaviour within marriage and also provided definitions of what makes a good woman and a good mother.

> "[Religion] does dictate our womanhood though, how to be a good Christian woman, the manager of her household first of all, God, man and then you…It does dictate that and things related to working…it does dictate who you are as a women."
>
> *Caribbean Key Informant - Jamaican woman 6*

> "We've found that…women seem to be more religious. This is the observation we've made: more women attend religious services than men. The woman might be an ardent believer and the husband is not. So the women may think that fidelity within the marriage is okay, so they are less prone to involve themselves in extra-marital sexual relationships, where as the husband who is not very religious finds that its okay to go outside to other women. So we found the…women, inasmuch as they are following their belief system ardently are still becoming infected with HIV."
>
> *Faith Based AIDS Service Provider 1*

From a religious perspective, HIV/AIDS was seen as a punishment from God for immoral/inappropriate behaviour (sexual or otherwise).

Homophobia

Most of the people in these communities believed that their religions prohibit homosexuality as an immoral behaviour that was punishable. This resulted in ingrained homophobia.

> "A homosexual man will not be accepted by his family, he's cursed. Because most Ethiopians are very religious and follow the Orthodox religion…these kinds of things are not acceptable."
>
> *African Key Informant - Ethiopian woman 2*

Religion & Sex

Religious doctrine prohibited sex before marriage and advocated faithfulness to one's spouse after the bond of matrimony. Consequently, women adhering to these practices did not see the need for condom use and felt protected from HIV/AIDS, since they trusted that their partners were also following the same religious directives. As discussed earlier, however, this contradicts with the cultural practice of silently permitting men to have multiple sexual partners at any time.

Many of the religious institutions that these women followed, particularly the Islamic and more fundamental Christian denominations, frowned upon the use of condoms and even considered it sinful. This connects with the belief that sex is only acceptable within the confines of marriage. As a result, the use of any prophylactics, including condoms, often made the women of these communities feel guilty and uncomfortable.

Role of church

Among the Christian women, church was considered to be a very important place for socializing, bonding and sharing struggles. Women worried that their churches would likely judge and reject someone who had HIV/AIDS, therefore, they were less likely to disclose their HIV-positive status, since it could eliminate an important, weekly, support network that they depended on for other things.

> "Church is where people find comfort and that is the only place where you can get women from my community."
>
> *African Key Informant - Ghanaian woman 2*

Generally, the faith systems of these communities called upon women to be submissive to their partners. This limited the ability of women to confront their husbands even when they were aware that the men were not monogamous. The intersection of religious and cultural beliefs intensify African and Caribbean women's inability to negotiate safer sex, their inability to negotiate their roles with their partners, and their inability to seek support within their communities around issues of sex and/or HIV/AIDS.

Gender

By and large, the cultural and religious beliefs/practices of these communities perpetuated gender inequality as an acceptable norm. According to most of the research participants, these gender inequalities translated into power imbalances. A woman's primary role in her relationship was to honour and trust her husband.

"When I think about issues for that particular community, I'm forced to go a few steps backwards and examine inequalities, for example, that exist between men and women in those communities…the difficulties that women have in terms of being equal partners in protecting themselves and in being hard enough to take control over their own bodies and their health…There are a lot of inequalities that exist…It's not necessarily about HIV only, but it's much bigger issues."

Community Health Centre Provider 1

Physical & sexual violence against women

Research participants identified this as an area of concern for the women in their communities. It had direct bearing on women's ability to negotiate condom use or cope once infected. As well, forced sex, rape, and incest could directly lead to infection.

Single-mother families

It was common to find single-mother families among these populations, which often left women juggling so many responsibilities that there was little time left to think about HIV/AIDS and related services.

Race

Many research participants felt that most of the systems that women were expected to navigate through were inherently racist. From their overall experiences and observations, they had the impression that the Canadian public and government did not care about African and Caribbean communities or their HIV/AIDS-related issues. As a result, some women were reluctant to access services for fear of being stereotyped and discriminated against.

"Racism within the different systems, particularly the health care system, determines women's health. Racism influences access to…things such as education, jobs…all that Canadian society has to offer. Issues of poverty that are connected to access, issues of health that are connected to access, issues that are often overlooked and those connections are generally not made. I think that racism is a big determinant of health. Above issues come before thinking about HIV/AIDS and certainly these issues would sort of rank up there and HIV/AIDS would be something in the distance."

Caribbean Key Informant - Jamaican woman 2

Homophobia

As mentioned earlier, homophobia is fueled by religious and cultural beliefs, values and norms of African and Caribbean communities to the extent that people might react violently to the revelation that someone in their community is engaging in a same sex relationship. Fearful of the implications of their sexual orientation, many queer men and women (lesbian, gay, bisexual and transgendered) choose to keep their sexual identity a secret. Some have girlfriends or boyfriends or get married in order to avoid being labeled or stigmatized. Combined with limited condom use, homophobia further increases the risk of HIV/AIDS infection particularly among women whose partners may be having sex with other men.

Individual behavioural risk factors

Culture, religion and gender intersected to create unique conditions that increased the risk of contracting HIV/AIDS and/or the ability to cope with HIV and its impacts once infected. Furthermore, the cultural and religious systems which these women lived by often clashed with the practices and values of Toronto's western culture. The navigation between these two worlds sometimes lead to individual behaviours that could expose these women to contracting and spreading HIV/AIDS.

Sex without condoms

As discussed earlier, unprotected sex was a common practice. Often, the withdrawal method was used to prevent pregnancy and was sometimes believed to guard against sexually transmitted infections.

Sex with men who secretly/openly had multiple partners (male or female)

Participants expressed that heterosexual women would have unprotected sex with their partner whether or not they knew he was not being monogamous. If there was suspicion that the male partner wasn't monogamous, it was rarely thought that his other partners might be male, since heterosexuality was the only culturally accepted norm.

Sex in rushed & secretive circumstances

Many women had to deny that they were having sex due to cultural taboos, such as in the case of premarital sex. Hence, sex would sometimes have to be hurried and under unsafe/uncomfortable conditions to avoid suspicion from others (e.g. in parks, cars, motels, or at home while everyone was out). This type of sex was generally not supportive of women's choices and limited opportunities for dialogue or to negotiate condom use.

Choosing not to get tested for HIV

For fear of being stigmatized, most of the women from these communities preferred not to know their HIV status as they felt it would be too hard to deal with the impacts of being HIV-positive and were particularly concerned about its effects on their personal relationships.

> "I would not go for testing, I know a lot but I wouldn't go to be tested. Because there is…I think that if I test positive now, I can't handle it, I have so many other problems to handle. It's like, okay, maybe I'll wait. May be I will feel differently soon but now I wouldn't go. I have too many problems right now to deal with."
>
> *African Women Focus Group Participant*

Denial of HIV status & choosing not to disclose to sexual partners

Some women in these communities denied their HIV-positive status or chose not to disclose it in fear of being rejected. They feared the impact of disclosure on their lives with their partner, their family, and their community.

> "I recently had a problem with women disclosing to persons that they wanted to get into relationships with. They wonder how to tell the guy, how he's going to react, should they tell the men, negotiating sex. The problem is that these women want to meet men and they want to continue doing what they do, but having sex they're very scared."
>
> *AIDS Service Organization Provider 2*

Douching

Caribbean women identified douching as a common hygienic practice that was also used to remove signs of sexual intercourse, especially among young women who were still living at home with their parents. However, most doctors suggest that women do not douche as it dries the natural lubricants of the vaginal lining, resulting in dryness and increased friction during intercourse that may tear the vaginal lining or condoms, thereby increasing risk of acquiring HIV and other sexually transmitted infections.

Drug use

Recreational use of illegal drugs/substances, particularly marijuana among Caribbean women, might cause women to sell sex or exchange sex for drugs to sustain a drug problem or it may reduce the inhibitions of the users, thereby influencing their ability to negotiate the conditions of their sexual relations.

Involvement in sex trade

Sex was sometimes used as a source of income in order to have money to meet basic needs like groceries and child-care.

HIV/AIDS-related service provision

Level of knowledge, awareness, & use of HIV/AIDS services

African and Caribbean women who participated in the study indicated that the majority of women from their communities had limited, if any, information about available services. Participants felt that although women needed to be informed of these services, there were very few agency efforts to reach their communities. There was general agreement that their communities were largely unaware of available services related to HIV/AIDS.

> "I don't think that there is any concrete knowledge on a wide scale…[Among] ethno-specific agencies that women do tend to use [for services such as] parent drop-in programs…seeing a counsellor , going to a food bank, or going to a prenatal program...HIV is outside of those programs-it is not seen as an integral part of those programs and I think that is the challenge. I think we, as service providers need to take HIV education into every aspect of programming…just like we know that diabetes is a very big part of our community it is an epidemic and they have posters in different places…by talking about it and seeing information on it, it becomes a normalized part of our life. I think HIV education has to become a normalized part of our life."
>
> *Caribbean Key Informant - Guyanese Woman 2*

Again, the most informed women were those who worked or volunteered in the field or those who were directly affected by HIV (themselves or through family). Those participating in the school system were also thought to be better informed about services.
Women affected by HIV highlighted the gaps in service delivery around cultural appropriateness, linguistic access, and provider knowledge.

Women who had already been tested for HIV were concerned about being tested without any pre/post test counseling or information about available services. They felt this expressed a limited/lack of competency and compassion from the agencies testing and diagnosing this group of women with HIV/AIDS.

Types of HIV/AIDS services available

Information on available services was drawn from interviews with 20 service providers at 17 agencies whose clientele include African and Caribbean women. Models of service delivery differed among agencies and included those that were dedicated to provide HIV/AIDS services only (ASOs), stand alone HIV projects/units/departments within larger agencies/institutions, and fully integrated HIV/AIDS services within a broader health strategy that was found in some community health centres.

Most of the HIV/AIDS services were targeted to people living with HIV/AIDS and also facilitated access to services that were not HIV specific, but impacted on women's ability to cope with HIV/AIDS. Examples of these services are access to food and clothing banks, legal/immigration aid, assistance with housing and employment, and access to medication for undocumented/women without residency status.

A few of the agencies had developed an elaborate and effective referral system with a network of organizations that facilitated HIV-positive women's ability to meet basic needs and cope with HIV/AIDS. There was a constant attempt to tailor referrals to best meet their clients' needs.

Research participants also felt that the location and structure of services was not conducive to access by their communities. Many agencies were located downtown or too obvious as AIDS Service Organizations, which deterred access by threatening the women's anonymity.

barriers & issues in service provision

Service provision for African and Caribbean women was complicated due to the consideration of all the factors discussed throughout this report. These social and individual factors added challenges to the access and use of information and services available. As discussed earlier, factors such as poverty, culture, and religion often co-existed with other issues such as immigration status, housing issues, discrimination, issues within family, etc, to make service provision even more challenging.

> "People were overwhelmed by basic needs issues so they were having trouble maintaining housing, finding housing, feeding their children, employment and paying immigration lawyers so they are leaving [their appointment] with a lot of family depression around their HIV."
>
> *Public health Provider 1*

Service providers indicated that the number and complexity of issues that women brought into service provision overwhelmed them. Women who were being diagnosed with HIV/AIDS or those already living with the virus were trying to deal with their emotional and psychological state, while struggling with poverty, immigration, housing, etc. Some were dealing with multiple diagnoses in their family; some got diagnosed during pregnancy and had to make immediate decisions about treatment; others were abandoned by their partners upon positive diagnosis, etc. Treatment adherence was also affected when providers dealt solely with medical needs and neglected to address or acknowledge these women's other basic needs.

> "I think in particular around women with HIV and when you're dealing with immigration issues and women with kids and you don't live in the downtown core, I think a lot of ASOs think that this is just too complicated to deal with. There are just so many issues that we can't possibly meet them all. Most of the service providers are just overwhelmed with the issues and we don't really know where to begin."
>
> *AIDS Service Organization Provider 5*

All the research respondents agreed that African and Caribbean women were juggling too many priorities to even think about HIV/AIDS. For most women, meeting basic needs took first priority, which left little time to care for themselves by accessing HIV/AIDS information and services.

> "There is also the reality of women's lives that, a lot of times, it's just not a priority-they have other things to do in life.   And when they do access information or our services; HIV may not be top of the list. However, we have found that women come in to us, it might be about something else about immigration or it might be about housing or childcare, there are other things that take precedence over HIV…health issues are pushed to the bottom in the lives of marginalized women, they are just trying to survive and women who do not have [immediate] health concerns [are not] going to the doctor."
>
> *AIDS Service Organization Provider 3*

Low income & limited time to access services

As many of these women earned low wages, it was crucial to their families' well-being that they maintained their incomes. Accessing services quickly lost its appeal if it meant the woman's income might be reduced and/or she might be taken away from household obligations.

An appointment often required taking time off from work so there was enough time to travel and be at the appointment. Many of these women worked outside the standard business hours of 9am to 5pm. As well, most of the agencies in this study were located in the downtown core, which was not typically where these women lived and/or worked. Transportation also costs money, whether it is paying for public transit, parking, or a taxi.

Accessing services for women with children also mean having to pay for childcare. Some women brought their children to appointments; however, this was often a distraction to both the mother and the service provider. As well, depending on the age/maturity of the child, there was the looming concern of compromising the woman's need for confidentiality.

Immigrant status

Many women who were going through the immigration process feared the implications that an HIV-positive diagnosis would have on their case. This prevented them from either getting tested or from disclosing their HIV-positive status within any health-care setting. The health-care institutions in their countries of origin were constantly under suspicion of corruption, hence when these women came to Canada, many continued to question the trustworthiness of the health-care institutions here.

> "Even if you've got an illness, you're going to try to hide it…you don't want to jeopardize your [immigration] status. You have a suspicion of institutions because back home institutions are really corrupt. You don't want to go into an agency because you are afraid that if you admit that you have health concerns that there is going to be an immigration car outside waiting for you."
>
> *Caribbean Key Informant - Guyanese Woman 2*

Some of the service providers interviewed who were members of the African or Caribbean communities recognized the negative implications of testing for HIV during the immigration process. It was seen as a means of preventing those infected, their families, or those they wanted to sponsor from getting into the country. This impression of the Canadian immigration system promoted these communities' perception of being ignored and discriminated against. Immigrants and refugees are the only groups who have to go through mandatory HIV testing to apply and qualify for permanent status in Canada. Other Canadians are tested based on informed consent.

Lack of health coverage

Caribbean women were more often without residency status, which made access to suitable health care problematic. Women living with HIV/AIDS can usually access free medical services through Community Health Centres; however, access to ongoing treatment, specialized health services provided by HIV primary-care specialists, and laboratory tests is usually more challenging to obtain without health coverage.

Most pharmaceutical companies had compassionate drug access programs that facilitated access to free HIV medication for women who were in-between immigration application processes or for those awaiting health coverage after approval of their immigration application. However, treatment plans for these women were usually patchy and unsustainable on a long-term basis and they did not provide optimal virological outcomes.

"I have one case that I call my central call case…this is a person who was disqualified from permanent residency status on the basis of HIV infection…I've been working with [this] case for 7.5 years. She's been in Canada for 10 years and she works full time and we cannot get permanent residency status for her. I won't take any more referrals for this kind of case, I'm not prepared to do it…This person is very compromised; has had intermittent medication, so we haven't been able to have an integrated medication plan sustained enough to provide optimal virological outcomes. One of the conflicting aspects of medication acquisition is that if you can't acquire it consistently with continuity, you may not be helping the person that much. So I got lots of money for this person (thousands of dollars for consultations) and I have written the equivalent of a 120 single-spaced letters to 14 pharmaceutical companies and things like that. If you're very aggressive you can get maybe one third of the highly recommended cocktail…you may be able to put together a really flaky cocktail. Not a cocktail that anyone may necessarily prescribe.

I don't take cases of people who don't have health coverage any more…you have to set boundaries. And you have to learn where you can be successful in your battles as far as resource acquisitions is concerned…It can be difficulty psychologically. And

As well, access through these programs could not be used for prolonged periods of time to cover medication for women who were rejected by immigration, who would not be getting residency status, or whose sponsorship had broken down.

Based on the efforts involved and the time it took to put together a basic treatment and care plan, some providers eventually opted not to accept more women without health coverage.

Confidentiality & Anonymity

Client concern about confidentiality stood out as a principal area that requires attention if proper service provision is to be achieved. As discussed earlier, there are strong cultural and religious stigmas related to HIV/AIDS in African and Caribbean communities. Anonymity and confidentiality are of utmost importance and most women will refuse to have them compromised under any circumstance. This will continue to be a recurring theme in the discussion that follows.

Culture

Among African and Caribbean cultures, health issues were considered to be personal and private matters. There was very limited dialogue within the community around sexual matters due to this "code of silence" and HIV/AIDS was associated with the same discomfort and silence. Accordingly, the ethno-cultural organizations of these communities sometimes chose not to offer HIV/AIDS education/services to their members for fear of how it might be interpreted within their cultural context. This further complicated women's attempts to access services and discouraged them from speaking out among their own.

The complexity of African and Caribbean women's sexual relationships defies simplistic solutions that were usually proposed as a means of facilitating prevention for those at risk or coping strategies for those already infected. Service providers need to consider that strategies such as bringing home condoms and/or information pamphlets, suggesting a woman ask her partner to come in for testing, or offering help through support groups cannot always be used in these communities.

Fear of HIV-related stigma & discrimination

As studies have shown worldwide, the experience of stigma and discrimination related to HIV/AIDS keeps people from accessing HIV/AIDS services. This study found this to be very true among African and Caribbean women in Toronto. Women expected that they would experience stigma and discrimination and were willing to do anything to avoid it. The fear of being ostracized and isolated contributed to denial, silence, and secrecy. In fact, service providers were frustrated that some women would rather sacrifice their health than sacrifice their anonymity/confidentiality.

> "You are dead if you have HIV. There is no level of discrimination, if it is out you are finished, nobody will touch you, nobody will touch your children…you are as good as dead and you can't discriminate against a dead person. People who are discriminated against are people who have a chance to be discriminated against; with this women don't have a chance, they become a cast out."
>
> *African Key Informant - Nigerian Woman 1*

These fears lead women living with HIV/AIDS to avoid organizations where they might meet people from their communities or other women living with HIV/AIDS from their communities. This limited the support systems available to help them deal with HIV/AIDS.

> "I am a professional Guyanese woman coming from a Muslim very traditional family who is well known within my community…but I still would not go to a female doctor within my community because the likelihood that she knows my family still prevents me from going to her."
>
> *Caribbean Key Informant - Guyanese woman 2*

In order to be able to provide support, research participants thought it was important that health information, especially HIV status, was kept separate from the communities' social institutions. Solutions suggested included service providers meeting women in coffee shops or their homes so the women wouldn't worry about being exposed to their community. Support groups or service provision from "one of their own" was not feasible for these women because these would be perceived as threatening their anonymity.

> "I have to use myself as a mailing address, so nothing goes to their homes. That is very important."
>
> *HIV Clinic Service Provider 1*

> "The Ethiopian and Somali women don't want to meet with each other in a support group even though they really desperately need support. Anonymity within their own community is an issue. How we actually deal with that and problem-solve around that is that there aren't services that are really tailored to them."
>
> *AIDS Service Organization Provider 5*

Disclosure-related issues

Fear of HIV-related stigma and a need to maintain anonymity of HIV status made disclosure to partners and family a challenging issue. Some African and Caribbean women chose not to disclose their HIV-positive status because they feared being abused or rejected. Some also didn't know how to go about disclosing their status.

Service providers and other research participants also recognized that some men withheld their own HIV-positive status from their partners.

Lack of disclosure of HIV-positive status changes the way that related services could be provided. It eliminated the possibility of family testing/counseling, it required women to find a secret way to access medication, and it limited the development of support systems with groups or other HIV-positive women. Women who did not disclose were also ineligible to access several governmental/pharmacological treatment programs that required partner/family involvement in order to be accepted.

Inability to speak English or French

Participants expressed that, among African women, there was sometimes an inability to communicate in either official language. Evidently, this affected access and impeded these women from having control over the quality of care they were receiving. This was an area of frustration for many service providers who acknowledged that language barriers influenced the amount and quality of information transferred to/from client and provider. This made it challenging to ensure their clients' access to appropriate HIV/AIDS information and services.

> "If they do not speak the language…there are implications in terms of their access to help [and] the treatment they get at the hands of the healthcare providers. In terms of their ability to be educated about what is happening to their bodies and what they can do differently even from just a dietary perspective, to wellness to health, to exercises and all those things. So for me languages impacts on access."
>
> *African Key informant - Kenyan Woman 1*

Some organizations offered or suggested translation by interpreters, family members, or other people speaking the same language. While some women accepted this, many had concerns about confidentiality and anonymity being compromised. Consequently, some refused this service and, instead, struggled in their limited language capacity.

Research participants indicated that they also knew of incidents where a male partner who was acting as a translator would not relay information about the woman's HIV-positive status in order to prevent her from being suspicious about his own status.

Other organizations used AT & T translation services since clients saw it as just a voice on the phone. Clients felt more assured of confidentiality and privacy. This was recognized as an expensive service that is beyond the budget of many agencies/institutions.

Other attempts to deal with language barriers included:

• using staff from other departments to provide translation services when they were available

• referring women to organizations that offered services in their languages when possible

• using a buddy system whereby HIV positive women who speak the same language are hooked up with buddies using services within the organization

While these efforts were usually better than nothing, there was always the risk of inaccurate translation when a professional was not doing it.

silent voices of the HIV/AIDS epidemic

Referral issues

Women were hesitant to accept referrals as they were already dealing with too many service providers for other aspects of their lives. Adding another one stretched them and it felt more comfortable to access all services in one place. As well, they had concerns about their anonymity.

There are community health centres and other organizations that provide integrated health services that include psychosocial counselling, primary medical care, health promotion, education, and outreach services. These providers felt their organizations had managed to create a "one-stop shop" of HIV/AIDS services many of which were similar to those of some ASOs. As a result, they wouldn't always refer their clients, despite knowing that there was usually a longer wait to access these services at their centres. This "one-stop shop" was usually offered to clients that expressed reluctance in going elsewhere and ensured that they were still attended to.

> "The Black women are very difficult to refer…when you try to refer them even to a family doctor in the area that deals with HIV patients and speaks the language…they still won't go. They're concerned that they're going to run into their neighbours in the waiting room, or maybe that other doctor could tell somebody because she has everybody as a patient. They feel safer where nobody knows them…It's different to be a health care provider…and say that it's just a disease and they have to deal with it. What if you walked into a room full of your neighbours and everyone would know about you?"
>
> *HIV Clinic Provider 1*

This reluctance was often due to client concerns around anonymity. Many agencies expressed difficulties in referring African and Caribbean women elsewhere, particularly if the referral was to black ASOs that served their communities. Moreover, these women were disinclined to go to a place that was publicly known to deliver HIV/AIDS services or easily identifiable (e.g. ASOs/sexual health clinics whose names are advertised on building exteriors).

Effects of multiple intersecting discriminatory systems

Systematic discrimination based on race, gender, culture, religion and other characteristics of difference have continually marginalized African and Caribbean women and their communities. These differences intersect with HIV-related stigma and discrimination to further compound their ability to access and utilize HIV/AIDS information and services. African and Caribbean women felt they were at the mercy of different systems within the family, community and the larger systems when they were accessing care. It took women many years to learn how to navigate these multiple systems, if at all, to access services.

Lack of cultural competency, sensitivity, & representation among service providers

There was general agreement that culturally inappropriate services were being delivered by culturally incompetent providers with limited knowledge of the issues affecting African and Caribbean women. There was a lack of knowledge about the social factors that affected risk of infection or coping abilities of women already infected with HIV. Often, this made the quality and usefulness of information from service providers impertinent. On the other hand, agencies that had the ability to tailor services within the context of culture were poorly resourced, a factor that limited their ability to meet the needs of the communities they are serving.

> "The larger agencies providing HIV/AIDS services often do not have culturally appropriate services…the few agencies we do have offering culturally appropriate and contextualized services often don't have the personnel and the facilities to provide adequate services for the people…People have a dilemma, that those services that are available they can't access them effectively because they are not appropriate to their context, and those that are appropriate don't have all the resources or facilities to provide the services"
>
> *Faith Based Aids Service Provider 1*

There was also a feeling among research participants that service providers were sometimes judgmental and insensitive in communicating with these women. There appeared to be a lack of sensitivity with some service providers regarding the women's challenges of coping with multiple intersecting systems. An example was given where service providers appeared critical of women's decisions not to disclose their HIV-positive status to their children without exploring the reasons/explanations behind it. This made women feel patronized and disrespected.

> "The other thing I hear over and over again, particularly with mothers, Caribbean and African women who are moms, is that when they interact with …. in particular around disclosure issues that they don't feel heard, understood and respected for their decision not to disclose to their children and why that is an issue. Women feel patronized by institutions and maybe I don't know how this relates to us as (name of organization), because they really wouldn't necessarily tell me that if its something to do with us, but they really do say how very complex the issues are around parenting.   They receive the judgments about, "Oh my God, you're pregnant again, and I'm going to talk to you about birth control". Because those are the attitudes they get, "You know, you really need to consider making a will and disclosing to your child". It presumes that women aren't thinking about this issue every day of their lives.
>
> *AIDS Service Organization Provider 5*

Involvement of African and Caribbean women as part of the workforce was limited in most mainstream organizations participating in this study. Though most of them indicated that a large proportion of their clientele were from these communities, they recognized the limited role that African and Caribbean women played in planning and delivery of services within their organizations. Women were mostly involved as service users with a limited number being involved as volunteers (buddies, mentors, etc). Those organizations that had tried to include more African and Caribbean women in decision-making or visible roles met some resistance from women who were fearful of the stigma of being involved openly as HIV-positive women.

Lack/limited human & financial resources

Many providers agreed that there was a shortage of family doctors with a basic understanding of HIV/AIDS and related issues. When women tested positive, most family doctors did not want to care for them, nor did they refer them to someone for continuity of care. Most were not able to facilitate appropriate referrals due to a lack of knowledge about the disease and available services and resources. This left women struggling to find proper care and services on their own.

"I will give you an example of my own case…I had this mouth rash and I went to the doctor and…he gave me some antibiotics that's supposed to be the strongest antibiotics when you are having a mouth rash. I was fine and then two weeks later there is the mouth rash again and I go back…so now I'm given another 10 days dose and I go home. Then now I'm in pain for three weeks. And then all of a sudden this rash comes back again. So this time, when I go back, I sit down, I said excuse me, you have to explain to me why this rash is coming back and he goes, well that means your immune system is suppressed…Then I said to him what could be suppressing my immune system and then he said oh, it could mean one or two things…Now, if he was somebody else he could have said to me, why don't you go for HIV testing? But he didn't say that. He said okay, if that's what you want that's what we are going to do. I said no, it's not what I want. It's because I want answers. I don't want to keep on coming back for the same thing and I don't know what it is, you know. So we did the blood test. Did he even say during that visit, call me and or go and get counseling with someone else? No. Nothing. So I walk into his office one day, not suspecting anything...And then, it's like, I need to see you now. Did you get my call? And I said no, I haven't gone home, I just came from work. So he goes, oh, you need to sit down right here. Can you imagine the shock? So after that he asked me, do you have any questions? I said, no, I don't have questions and I walked out. So then after that it was left up to me to try and call the services that are around to get information, to try to find services and try to go and get counseling and get whatever it is I needed. After he said that, I thought the whole world would end. I thought it was the end of me. I don't know how I walked home. He didn't bother to find out how I was going to get home. He didn't even call two days later to find out…whether I'm still living or anything."

African women focus group participant

> "My experience with doctors in Scarborough is they [are] often terrified of working with people who test positive for HIV. A lot of people get dumped, and they do not necessarily know who the specialists are and even if they do, people are just not going to pick up their bags and go down there, especially if there are a lot of barriers."
>
> *Public Health Provider 1*

For service providers, on the other hand, a lack of financial and human resources limited the amount of work they could do specific to African and Caribbean women. Most service providers indicated that the resources available were insufficient to develop and increase the types of programs services needed to adequately meet the needs of African and Caribbean women (i.e. to deal with issues such as poverty, immigration, etc).

Inflexible modes of service delivery

Agencies were not able to support innovative ways of providing services that could be more effective. Previous efforts to work around this issue and tailor services to meet needs of isolated groups did not work due to this inflexibility. For example, African and Caribbean women would benefit more from agencies being flexible in doing satellite work and individual case counseling versus setting up support groups.

Providers' inability or unwillingness to deal with clients' traumatic past

Though many providers recognized that African and Caribbean women might have faced many prior traumas, particularly as refugees fleeing their countries of origin, most acknowledged that the direct impacts of these issues were not incorporated in their HIV service provision. Dealing with traumatic experiences helped women move forward with their lives and impacted positively on their ability to cope with HIV/AIDS. Many providers recognized that these issues might be lurking in the background and might not surface to facilitate discussion. Providers did not have contingency plans to help women work around such issues. Dealing with more tangible, practical matters was easier.

> "There are stories of tremendous abuse or civil wars, genocide, rape, abuse and torture and tremendous loss. Those are things that I'm aware of but generally they don't play a big role in my day-to-day services. We'd have more to do with making sure that people are getting food and drugs, and things like that…it's tangible, it's concrete."
>
> *HIV Clinic Provider 2*

Lack of research & information upon which to base services and programs

Participants identified gaps in research to help guide programs and services provided for African and Caribbean women. Research needs to explore the needs of girls and young women, the context within which infection occurs, and look for accurate epidemiological markers to determine target groups within communities.

Limited services targeted towards African & Caribbean communities

Some participants felt there was a need for more services in these communities and the only way to ensure that this happened was through concerted efforts. Such efforts should be inclusive of African and Caribbean women and be targeted to different levels of government and organizations currently involved in delivery of services to women.

Lack of strategies & plans to develop & deliver services tailored to the identified HIV/AIDS needs of African & Caribbean women

In their program/resource development and delivery, many organizations failed to consider fundamental principles such as needs assessments and community involvement. This resulted in ineffective outreach and resource dissemination strategies. There is a need for community involvement when developing resources and outreach strategies to maximize use of programs/services/resources. African and Caribbean women infected and affected by HIV/AIDS were expected to fit within existing services that were developed for more mainstream populations without any modification to better accommodate different cultural groups.

 "We used to translate to English and French, but then we ended up with thousands and thousands of copies of the French brochures. People didn't use the French, because we didn't have a strategy on how to disseminate it. I do think that is a gap. The only other thing that we can do is make sure that whatever images are in materials that we use are representative, or something that they can relate to. It is a problem if you're not targeting your materials, and ours [are] not targeted particularly to African and Caribbean women".

AIDS Service Organization Provider 5

conclusion

This report highlighted how individual sexual behaviours are directly influenced by broader multiple intersecting factors such as gender, race, economic, socio-cultural, religious and sexual orientation. The intersectionality of these factors increase African and Caribbean women's risk of contracting HIV and compound HIV-positive women's ability to cope with the impacts of the disease.

There is a need for HIV/AIDS programs and services to deal with more than just risk-taking activities of individuals. Programs must address the underlying factors that support the climate in which risk-taking behaviours are allowed to flourish and be maintained. Agencies and providers working with African and Caribbean women must understand and address the context in which they live by increasing their awareness of the values, beliefs, and norms that shape individual and community behaviours. It is upon this basis that effective programs should be built. Infected and affected African and Caribbean women and their communities must be involved in service/program development and delivery within an empowering and community development framework that is based on trust and mutual respect.
Strategies targeted to individuals must be complemented by broader community strategies that are targeted to the whole African and Caribbean community and general Canadian society so as to change norms, values, practices and stereotypes inherent in these multiple intersecting frameworks of oppression. Current and future efforts to work with these communities need to be framed within the determinants of health in order to empower women and their communities to effectively address the HIV/AIDS epidemic.

The attached recommendations provide the basis on which this important work can be undertaken by all stakeholders, including program developers, policy makers, researchers, those living with HIV/AIDS, and those vulnerable to HIV/AIDS infection within the African and Caribbean communities.

recommendations

1. Education & prevention

Better strategies for disseminating HIV information for African and Caribbean women need to be developed.

1.1 Strategies and approaches need to be tailored to effectively meet the needs of the diverse African and Caribbean women. Individual strategies should be complemented by community-targeted strategies to effectively deal with broader cultural and religious factors that increase the risk of contracting HIV for women.

1.2 Information should be disseminated among existing groups where women already know each other and have a level of trust and comfort with each other.

> "I think that making HIV awareness part of an existing group is a good approach. Accessing groups that are already established and providing them with STD information so that you can parachute in an already established intimacy among group members and then you go in as an expert or even coming more than once over a number of weeks and then being prepared to deal with some of that emotional stuff that will come out."
>
> *Community Health Centre Provider 2*

1.3 Women should be reached with prevention and education information before they get infected. Currently most services are targeted to HIV positive women. Out of all the agencies that participated in this study, only 3 had any prevention and outreach services that were targeted to African and Caribbean women at risk of HIV infection. Most African and Caribbean women learnt about HIV/AIDS after an HIV-positive diagnosis.

1.4 Providers should make use of information technology and other non-traditional methods of outreach and dissemination of information. Traditional methods have failed and need to be augmented with more innovative methods that do not require women to come into organizations in order to maintain privacy and confidentiality. Proposed methods included use of telephone services, internet, etc.

"Most people have a primary language that they can understand information in, so if there could be a dial-up service where someone will provide information…If we could find out what the fundamental core information needs are, I think there are ways that we could make access to that. One of the ways that I'd suggest is technological. If someone says Sustiva has a potential nervous system side effect [and] there is a language barrier…if there's a user-friendly way to dial up and have someone explain [it] to you in lay terms. It could be one minute of information of this is what may happen, this is what you may expect. The woman doesn't have to talk to someone else. The woman doesn't need to say that I need this information…I think you have to find a way of disseminating distinct, personal informative in a way that the person doesn't have to feel anxious about it. Some of this could be handled electronically."

HIV Clinic Provider 2

1.5 African and Caribbean women living with HIV/AIDS should be encouraged and supported to play an active role in HIV/AIDS awareness raising and prevention strategies and services.

"Girls say that they need more graphic details…so we got people with the virus, talking to them telling them how they got it. We've got to see not just white people or gays, but Black people, pretty looking Black people, ugly looking Black people…getting someone with HIV/AIDS or a strong Black person to get in people's mind…if you actually had a person who was living with the virus telling you, it would be more real."

Youth Service Provider 1

1.6 HIV/AIDS prevention and education services must be language specific, culturally appropriate, tailored to women's day-to-day contexts, and delivered in comfortable environments.

1.7 Prevention and education services should be integrated within health promotion and services targeted to newcomers, particularly within shelters and settlement services (ESL, LINC Programs), youth programs, etc, while ensuring that such services consider gender, cultural and religious values, beliefs, and practices.

> "Services around HIV and AIDS [should] be integrated on every level…at our language schools and in our heritage language programs…within our faith groups…at ethno specific agencies…supported by our economic endeavours and our businesses. It would be well funded by the government. It would be sort of a seamless thing…{and you would] be able to access it from a wide range of options. Youth access different services in different places, parent, middle aged people, seniors, etc… access their information from different places."
>
> *Community Health Centre Provider 1*

1.8 Testing and counselling should be offered as a part of education and prevention. This will also help ensure that women who test negative have an in-depth understanding of what they need to do to stay negative.

1.9 Anonymous HIV testing services should be made available at sites where African and Caribbean women feel comfortable accessing services. In addition to providing diagnostic services, providers need to ensure that women are prepared to deal with a positive HIV diagnosis or that they understand how HIV can be prevented with a negative diagnosis.

2. Increase accessibility to HIV/AIDS services & programs for women living with HIV/AIDS

2.1 Development of mechanisms to support and facilitate effective disclosure of HIV status in ways that ensures women's safety and well-being. It is important to help these women deal with the stigma they will face and the fears that go with it. Mechanisms should include supportive counselling for family members of the affected women.

> "Counseling should be provided for the families of those that are infected…Also because of the society we live in, the African community, there is that stigma and cultural thing and all that, so the whole family suffers with the individual. Therefore they need a bit of counseling whereby somebody can talk to them and help them to cope…I think that these are very important and they need to go hand in hand."
>
> *Employment skills development agency provider 1*

2.2 One-stop shopping: Foster and support delivery of needed services for African and Caribbean women under one roof so that multiple services are delivered in one visit.

2.3 Provision of onsite childcare. This is a strong determinant of accessibility to information and services. Many of these women live in poverty and cannot afford childcare while they go to appointments.

2.4 Expand services to under-serviced locations where these communities live (i.e. beyond downtown Toronto). Most ASOs and hospital-based HIV clinics are located in the downtown core. Many of these women do not live downtown.

> "I would say services would have to be based in Scarborough…In relation to treatments, we need an HIV clinic in one of the Scarborough hospitals. That has been talked about for sometime, and has never gotten off the ground as far as I know but that would be the ideal."
>
> *Public health Provider 1*

2.5 Improve access to treatment and other health-related services for women without residency status and/or health coverage. This can be done through advocacy efforts and through development of linkages with others that are already working on similar initiatives such as the HMAP project (HIV/AIDS Medication Access Project), HIV and Immigration, etc.

2.6 Increase human resources in social work to facilitate a more effective way of dealing with psychosocially related issues and to provide more comprehensive care and follow-up of HIV-positive women. This is particularly necessary in HIV clinics located in large hospital settings. Years of hospital cutbacks have reduced the numbers of social workers within hospital HIV clinics. People are living longer due to current treatments; hence, the number of patients in clinics has gone up while the amount of time spent with each one has gone down. Social workers have little time to spend with patients to do effective follow-up. This particularly affects African and Caribbean women who often bring multiple, complicated issues to the health care setting.

"If [we] had two staff doing what I do, that means that we could do twice as much...we would be able to do more follow-ups. Then we could develop a more sustained trust relationship. I think once that happens women would talk more about things that are more personal in their lives and things that are more psycho-emotional. I think if you provide the basic necessities of life that's a way to establish a rapport and trust relationship. I don't think that people are often ready to just dive in and start talking about things that are very personal to them that impact on how they are feeling on a day-to-day basis. With a more personal and sustained follow-up approach I think that we'd be able to provide a more comprehensive set of services for these women."

HIV Clinic Provider 2

3. Foster/support development of skills & cultural competency for service providers working with African and Caribbean women

3.1 Service providers need to have an understanding of the various social and individual factors discussed in this report that interact simultaneously to prevent or increase the rates of infection. These factors also influence the medical and non-medical care for those infected or affected by the disease.

3.2 Ensure language specificity and cultural appropriateness within currently funded services. There should be cognizance of the various social factors that create unique challenges for African and Caribbean women living with HIV/AIDS.

3.3 Government and other funding agencies should provide the financial resources required to facilitate skills development among community workers so that they can improve their cultural competency. This is particularly relevant to the staff and management of organizations and institutions providing HIV/AIDS services for African and Caribbean women and their communities.

4. Increase funding for service expansion for African & Caribbean women & their communities

There is a lack of resources available to tailor educational materials, provide effective translation/interpretation services, or increase the available staff to work with the target populations. There is also an under-funding of black AIDS services organizations.

4.1 Increase government funding to expand and develop more targeted programs and services for African and Caribbean women. Most services accessed by African and Caribbean women are delivered within mainstream agencies where women are expected to find a "niche" for themselves in services that were not developed with consideration of their unique situations.

4.2 Support the infrastructure of black ASOs to strengthen their capacity to deal with HIV/AIDS.

4.3 In the absence of more funding, amalgamate black ASOs to build one large, self-reliant organization with consolidated resources.

5. Research

More research needs to be done to document the status, prevalence and impacts of the HIV/AIDS epidemic on African and Caribbean women and their communities. Epidemiological markers can show which subsets of these populations are affected by the disease and can also determine access and impacts of care, treatment, support and prevention. Understanding facilitators of vulnerability/risk reduction can provide useful evidence upon which to base effective programs and services.

6. Link the global epidemics in Africa & the Caribbean to the local epidemic in Ontario and Canada

Based on the influences of cultural traditional and religious practices, the African and Caribbean epidemics have important lessons that can be adapted and used to effectively deal with HIV/AIDS amongst their communities in Canada.

 "We have a really important role to play in bridging, sort of bringing back the issue of HIV/AIDS in Africa and the Caribbean. That is extremely relevant to the federal government and the provincial governments and to communities here. We are part of the communities that we come from. I think there is far too much despair and cynicism around HIV/AIDS that is there on the continent. I think there are many lessons to be learned here from our countries of origin. There is opportunity to experiment, to learn, to explore different ways of exploring our own cultures, our family structures in order to try and find more effective ways and resources."

Community Health Centre Provider 1

7. Community development & involvement

Before women and their communities can be mobilized to take action, they must understand the urgency of the issue. They must be given the basic facts about HIV/AIDS, taught a set of skills and offered access to information and services. They must also perceive the environment to be supportive of changing and maintaining safe behaviours.

7.1 Community mobilization: HIV/AIDS should be made visible to African and Caribbean women and their communities to raise awareness and reduce stigma and discrimination against those infected and affected while acknowledging the impacts of the epidemic on individuals, families and their communities at large.

> "I've been doing work around HIV and AIDS for about 12 years…this is something that has impacted me, my life and my family. It is something that lives in my community…I've become an example and some sort of role model. If I am able to offer a model of communicating about HIV/AIDS it makes it easier for someone else. For example, when we were doing HIV/AIDS education with newcomers who are in various programs that are available for them, they are very reluctant to talk about this thing. We know that on the continents all of us have lost love ones…It's up to us to say that it's been present in our lives, and here is how I'm trying to deal with it, here's how I'm trying to address it...We have to protect ourselves because there is so much stigma around HIV/AIDS…So many of us are coming from a history of displacement, a history of conflict and strife, and we're trying to make the best of a brand new opportunity in Canada…For many of the brothers and sisters that are living with HIV themselves, it is that voice of courage that we need to keep alive and pass on."
>
> *Community Health Centre Provider 1*

7.2 African and Caribbean women must be involved in decision making roles in organizations serving them as paid staff, board/organizational members or as volunteers. The HIV/AIDS epidemic is intricately linked to community structures whose transformation largely depends on community insiders. Open discussion and ownership of HIV/AIDS can only happen if women and their communities understand the urgency of the issue and see that decision makers within government(s) and in service-delivery organizations are accountable to them and supportive of them and their efforts.

> "We should be out there in those organizations…being involved and voicing our concerns as workers…if we have our people out there, even in the government they can even influence the way some of the policies are carried out. They can say, wait a minute, if you are going to carry this out on TV, then why don't we include certain people of colour… everybody realizes that this is a need for everybody. Or why don't we use them in forums to speak about their issues? We need to fight for ourselves."
>
> *African Women Focus group participant*

7.3 Facilitate and support skills development for individuals to reduce poverty and financial dependency.

8. Provide HIV prevention education, treatment, support, & care services on a continuum

HIV/AIDS services targeted to vulnerable women and their communities should be provided as a continuum where education is used simultaneously as a tool for reducing high-risk behaviours and also as a means of identifying those who are infected to facilitate access to treatment, support and care services, while reducing secondary transmission to sexual partners and maternal transmission.

9. Reduce HIV/AIDS-related stigma and discrimination

9.1 Individual agencies and institutions should develop policies, procedures, and action plans to deal with discrimination based on gender, race and sexual orientation.

9.2 Undertake research on how the experience of multiple forms of discrimination (such as gender, sexual orientation, racism, and sexism) intersects with HIV-related stigma and discrimination among African and Caribbean women and their communities.

9.3 Increase education for the general population to raise awareness regarding the consequences of stigma and discrimination and to promote an attitude change about HIV/AIDS and cross-cultural groups.

REFERENCES

Aggleton, P, Parker, R.S. A Conceptual Framework and Basis for Action: HIV/AIDS stigma and discrimination. UNAIDS. 2002

AIDS Committee of Toronto. Women and HIV/AIDS in Canada. 2003. Http://actoronto.org

Baxter, J., C. Brabazon, K. Gunter, D. Willms. Many Voices: HIV/AIDS in the context of culture. Report for the Communities from the Horn of Africa. National AIDS Clearinghouse. 1993.

Becker, H. Outsiders: Studies in Sociology of Deviance. New York: Free Press. 1973.

Braithwaite, K., and Thomas, V. HIV/AIDS Knowledge, attitudes and risk behaviours among African American and Caribbean college women, International Journal for the Advancement of Counselling, Volume 23. 2001.

Bujra, J., Baylies, C. (2000). Responses to the AIDS epidemic in Tanzania and Zambia in Baylies, C and Bujra, J, AIDS, Sexuality and Gender in Africa, New York: Routledge.

Calliste, A., Dei,G.J.S. Editorial, Anti-Racist Feminism Critical Race and Gender Studies in Calliste, A., Dei, G.J.S., Anti-Racist Feminism Critical Race and Gender Studies, 2000.

Calzavara L, Tharao E, Myers T. HIV/AIDS in East African Communities Living in Toronto: A Proposal for Developmental Funding. Final Report. December 2000.

Chin, D. Kroesen-Kendall, W. Disclosure of HIV infection among Asian/Pacific Islander-American women: Cultural stigma and support. Cultural Diversity and Ethnic

Canadian Council on Social Development. Nowhere to Turn? Responding to Partner Violence Against Immigrant and Visible Minority Women. Voices of Frontline Workers, 2004

Minority Psychology Volume 5 No. 3. 1999

Citizenship and Immigration Canada. Women and HIV/AIDS in Canada. 2000. Http://www.actoronto.org

Collins, P.H. Black feminist thought in the matrix of domination. Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment. Boston: Unwin Human, 1990.

Counts, D.A., Brown, J., Campbell, J. Sanctions and Sanctuary: Cultural Perspectives on the Beating of Wives. Boulder, CO, Westview Press, 1992

Dunn, J., Dyck, I. Social Determinants of Health in Canada's Immigrant Population: Results from the National Health Survey. Working Paper Series #98-20. Vancouver: Vancouver Centre of Excellence, Research on Immigration and Integration in the Metropolis. 1998.

Eagan, C., & Gardner, L. Racism, Women's Health and Reproductive Freedom in Dua, E. & Robertson, A, Scratching The Surface: Canadian Anti-Racist feminist thought. Toronto. 1999

Galabuzi, Grace-Edward. Canada's Creeping Economic Apartheid - The Economic Segration and Social Marginalization of Racialised Groups. CSF Foundation for Research and Education, May 2001

George, U., Mwarigha, M.S. Consultation on Settlement Programming for African Newcomers. Citizenship and Immigration Canada, Ontario Administration of Settlement and Integration Services, March 1999.

Goffman, E. Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice-Hall, Inc. 1963

Handa, A. and Negash, A. HETF: Report on Phase Two of the Community Consultation, April 2003.

Henry, F. The Caribbean Diaspora in Toronto: Learning to live with Racism. Toronto, University Press. 1994

Herdt, G. Stigma an the Ethnographic Study of HIV: Problems and Prospects. AIDS Behavior, Volume 5 No. 2. 2001

HIV Endemic Task Force (HETF). Summary Report of the Community Forum "By Us, For Us, About Us": An Opportunity for African and Caribbean Communities to Address the Issue of HIV/AIDS Related Stigma and Denial, November 2001.

Hyman, I., Sepali, G., Makarchuk, M-J., Cameron, J. Micevski, V. Promotion of Healthy Eating among New Immigrant Women in Ontario. Canadian Journal of Dietetic Practice and Research, Volume 63, No. 3.

Hyman, I. Immigration and Health. Ottawa: Health Canada. 2001

Kaleeba, N. Keynote Address: Stigma and HIV/AIDS IN Africa. Stigma - AIDS email Discussion Forum. 2001

Levinson, D. Violence in Cross-Cultural Perspective. Thousand Oaks, CA, Sage, 1989.

MacMillan, D, Jones, R, Aloia, G. The mentally retarded label: A theoretical analysis and review of research. American Journal of mental deficiency. Volume 79. 1974

Manson-Singer S, Willms D, Adrien A, Baxter J, Brabazon C, Leaune V, Godin G, Maticka-Tyndale E, Cappon P. (1996). Many Voices - Sociocultural Results of the Ethnocultural Communities Facing AIDS Study in Canada. Canadian Journal of Public Health. 87(Supp 1):S26-S32.

Massaquoi, N., Ali, A., Brown, M. Racial Discrimination as a Health Risk for Female Youth. The Canadian Race Relations Foundation, 2003

Mbilinyi, M., and Kaihula, N. Sinners and Outsiders: the drama of AIDS, in Baylies, C. and Bujra, J. AIDS, Sexuality and Gender in Africa, New York: Routledge. 2000.

Milan, A., Tran, K. Blacks in Canada: A Long History, Canadian Social Trends. Statistics Canada. Spring 2004.

Monitoring the AIDS Pandemic (MAP) Network, The status and trends of the HIV/AIDS epidemics in the world, Geneva, Switzerland, June 26, 1998.

Monitoring the AIDS Pandemic (MAP) Network, The status and trends of the HIV/AIDS epidemics in the world, Geneva, Switzerland, June 26, 1998.

Nakyonyi, M. HIV/AIDS Education Participation by the African Community. Canadian Journal of Public Health. Supplement 1:S19-S23. 1993.

Nelson, S. H. The West's Moral Obligation to Assist Developing Nations in the Fight Against AIDS. Health Care Analysis. Volume 10, No. 1. March 2002

Netherlands Assistance Research Council (RAWOO), (2002). Making Social Science Matter in the Fight Against HIV/AIDS. Publication No. 24. (RAWOO), the Hague.

Noh S, Hyman I, Fenta H. Pathways and Barriers to Mental Health Care for Ethiopians in Toronto. Culture, Community and Health Studies Program, Centre for Addiction and Mental Health, and Department of Psychiatry, University of Toronto. 2001.

Nzioka, C. The social meanings of death from HIV/AIDS: An African interpretive view. Culture, Health and Sexuality, Volume 2, No. 1. 2000.

Ornstein, M. Ethno-racial Inequality in the city of Toronto: An analysis of the 1996 Census, Toronto, 2000.

Oxman-Martinez, J., S.N. Abdool, M. Loiselle-Leonard. Immigration, Women and Health in Canada. Canadian Journal of Public Health. Volume 91, no. 5 . 2000.

Poindexter, C., Nathan, L., Warner, R. He Listens… And Never Gossips: Spiritual Coping without Church Support among Older Predominantly African American Caregivers of Persons with HIV. Review of Religious Research. Volume 40, no.3. 1999.

Remis R, Whittingham E. The HIV/AIDS Epidemic Among Persons From HIV-Endemic Countries in Ontario, 1981 - 98: Situation Report. Department of Public Health Sciences, University of Toronto. November 1999.

Remis R, Whittingham E. The HIV/AIDS Epidemic Among Persons from HIV-Endemic Countries in Ontario: Update to 2000. Department of Public Health Sciences, University of Toronto. June 2001.

Remis R, The Epidemiology of HIV Infection Among Persons from HIV-Endemic Countries in Ontario: Update to 2002. Department of Public Health Sciences, University of Toronto. November 2003.

Russell, C. & Schofield, T. Where it hurts. Sydney: Allen & Unwin. 1986.

Shultz, A. The phenomenology of the social world. Evanston, North Western University Press. 1967

Sikwiibele, A., Shonga, C. Baylies, C. AIDS in Kaypulanga, Mongu: Poverty, Neglect and Gendered Patterns of Blame. in Baylies, C and Bujra, J. AIDS, Sexuality and Gender in Africa, New York: Routledge. 2000.

Spigelman, M. HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action., A discussion Paper for the Ministerial Council on HIV/AIDS, January 2002.

Statistics Canada. Canada's Ethnocultural Portrait: The Changing Mosaic. Statistics Canada. 2003.

Szasz, T. The Myth of Mental Illness. American Psychologist, Volume 15. 1960

Tharao, E, Calzavara, L, Myers, T. To Test or Not to Test: Factors Influencing HIV Testing in East African Communities in Toronto. Paper Presented at the 10th Annual Canadian Conference on HIV/AIDS Research, Toronto, Canada, May 31st - June 3rd, 2001.

Tharao, E, Calzavara, L, Myers, T. What Service Providers Need to Know to Provide Effective HIV/AIDS Programs and Services for African Immigrants in Canada: East African HIV/AIDS Study. Oral/Poster Presentation, 13th International AIDS Conference, Durban, South Africa, July 9-14, 2000.

Tharao, E. Massaquoi, N. Factors Limiting Access to HIV Treatment for Black Women and Women of Colour. Paper Presented at the Ninth Annual Canadian Conference on HIV/AIDS Research, Montreal Canada, April 27-30, 2000.

Tharao, E., Massaquoi, N. Building Effective HIV/AIDS Initiatives for Immigrant/Refugee Women Living in Developed Nations: A Canadian Experience.   Presentation at the Forty-Fifth Session of the Commission on the Status of Women, United Nations, New York, April 2001.

Torkington, N. Black Migrant Women and Health. Women's Studies International Forum, Volume 18 No. 2, 1995.

UNAIDS. Expanding the global response to HIV/AIDS through focused action. Reducing risk, and vulnerability: definitions, rationale and pathways. 1998

UNAIDS (Joint United Nations Programme on HIV/AIDS). AIDS Epidemic Update: December 2005. Geneva, Switzerland. December 2005.

UNAIDS (Joint United Nations Programme on HIV/AIDS). Report on the Global HIV/AIDS Epidemic. Geneva, Switzerland. June 2000.

UNAIDS (2000). Report on Global HIV/AIDS: what makes people vulnerable.

http://www.UNAIDS.org/epidemic_update/report/vunerable.pdf

UNAIDS/WHO. Fighting HIV-Related Intolerance: Exposing the Links Between Racism, Stigma and Discrimination. Prepared in Consultation with the Office of the High Commissioner of Human Rights. September 2001.

UNESCO/UNAIDS. A Cultural Approach to HIV/AIDS, Prevention and Care, Summary of Country Assessment and Project Design Handbook, May 2000.

UNESCO/UNAIDS. Immigrant Populations and HIV/AIDS - The Development and Implementation of Programmes: Theory, Methodology and Practice. June 2000

Williams, S. Goffman, interactionism, and the management of stigma in everyday life. In G. Scambler (Ed.), Sociological theory and medical sociology. London & New York: Tavistock. 1987

World Health Organization (WHO). World Report on Violence and Health: Summary. Geneva. 2002

Worth H, Reid A, Ackroyd J, Tamirate-Bowden E. Silence and Secrecy: Refugee Experiences of HIV in New Zealand. Institute for Research on Gender. University of Auckland, New Zealand. February 2001.