Black Women and HIV/AIDS

Contextualizing their Realities,

BY ESTHER THARAO AND NOTISHA MASSAQUOI

En dépit du fait que les communautés noires en général et les femmes Noires en particulier représentent un élément important dans l'épidémie du sida, les chercheurEs et les concepteurEs de politiques les ont ignorées. Les auteures demandent que d'autres recherches soient effectuées auprès de cette population et que les résultats obtenus statistiquement soient contextualisés. Il s'agit aussi de mieux comprendre les risques psychosociaux, culturels et structurels déterminants du VIH/sida.

> When you find a snake in your house you don't ask how it got there, you remove it.
> —African Proverb

In the more than 20 years since the emergence of the HIV/AIDS epidemic, the disease has become endemic in many developing countries especially in Sub-Saharan Africa and the Caribbean fuelling a fear of the spread of HIV/AIDS across borders. This factor alone has numerous implications for Black women living in Canada and other industrialized nations. Labels, cultural meanings, and interpretations about the disease formed since its emergence continue to influence both the discourse on HIV/AIDS and the access to programs and services geared to its control for those most vulnerable to or at risk of infection. In the mid-80s as the discourse unfolded, we, as African women living in Canada, were not so much concerned with contracting the HIV virus as we were with the racist undertones of media reports depicting HIV/AIDS as just another tragedy that was plaguing the poor, the powerless, and those living on the margins of society, namely Africans, IV drug users, and gay men. The total absence of any consideration of the social and political realities that left African people so devastated by this disease coupled with the calculated correlation between the magnitude of the infection rates and the ascription of the exact origins of the disease created an emphasis on the duality of "us" versus "them"—a discourse informed by centuries of mistrust based on our historical experiences of colonization and slavery. Our focus was on refuting racist suppositions including the notion that Africans brought AIDS to the world, that Africans engaged in sexual activity with monkeys, that Africans performed barbaric rituals involving the drinking of human blood, that Africans' immoral sexual practices and polygamous family structures were going to be our own downfall. Instead of trying to kill the snake that had just entered into the house, precious time was wasted on futile debates about its origins. We can no longer afford to expend our energy refuting the racist speculation about the origins of HIV/AIDS. As African women living in Canada, it is quite clear that our communities here and globally are dealing with a crisis of major proportions—a reality clearly supported by available global statistics and those emerging in developed countries including Canada.

African women were not so much concerned with contracting the HIV virus as we were with the racist undertones of media reports depicting HIV/AIDS as just another tragedy that was plaguing the poor.

According to the Joint United Nations Programme on AIDS (UNAIDS), by the year 2000 about 36.1 million people were living with HIV, the virus that causes AIDS and that 21.8 million people around the world had already lost their lives to the disease (UNAIDS/WHO). Over two thirds of all the people living with HIV in the world, 25.3 million men, women, and children, live in Sub-Sahara African (UNAIDS/WHO). Today, of the estimated 36.1 million people living with HIV/AIDS, an estimated 16.4 million, or 45 per cent of all people living with HIV/AIDS are women (UNAIDS/WHO). This was not the case in 1985 when many of the current HIV prevention strategies were developed. At that time, for every infected woman, ten or more men were infected and "high risk" groups were the prevailing prevention targets (AIDS captions). Women were not seen as cause for concern and consequently were ignored altogether. As a result, rates of infection for women have skyrocketed.

Statistics indicate that the HIV/AIDS epidemic has also shifted in the Canadian context to include women, girls, and children. The proportion of new HIV infections among women and young girls below the age of fifteen has increased from 18 per cent in 1995 to 24 per cent in 1999/

their Silence and Proposing Solutions

2000 (Health Canada). A closer study of the Canadian landscape reveals that the AIDS pandemic has most significantly impacted Ontario. By the end of 1998, 19,459 people had been diagnosed with HIV in Ontario and women comprised ten per cent of the overall diagnoses with an increase from two per cent in 1985 to 20 per cent in the last three years (Remis *et al.* 1999). Once again, keeping in line with worldwide trends, women comprise the fastest growing proportion of persons affected by the HIV/AIDS epidemic in Ontario. Likewise, the proportion of AIDS cases amongst women also increased from 1.6 per cent in 1996 to nine per cent in 1998. (Remis *et al.* 1998).

Until recently, very little was known or documented about HIV/AIDS in relation to African and Caribbean women in Canada. Anecdotal information from service providers reporting increasing numbers in their client case loads were not taken seriously until very high rates of maternal-infant transmission was first documented amongst Caribbean and African women (Tharao and Massaquoi 2000). A report from Dr. Susan King, Toronto Hospital for Sick Children and the HIV Pediatric Network revealed that, between 1994 and 1996, 70 per cent of maternal-infant transmission of HIV infection had occurred among persons from HIV-endemic regions, mainly Africa and the Caribbean (Remis *et al.* 1998). In addition to highlighting the issue of maternal transmission, this report clearly indicated that African and Caribbean populations had become a significant component of the Canadian HIV epidemic. It revealed that almost ten per cent of AIDS cases diagnosed in 1996 were amongst persons born in Africa or the Caribbean and residing in Ontario, compared to three per cent of the AIDS cases previously diagnosed. This was particularly evident amongst women born in HIV-endemic countries, who represented 32 per cent of AIDS related deaths in women in 1996 (Remis *et al.* 1998). According to Dr. Robert Remis, this population also had a substantially higher AIDS-associated mortality rate than the Ontario population as a whole (14.0 compared to 4.2 per 100,000 in 1996). Modeled estimates suggest that approximately 2,346 persons from HIV-endemic countries were living with HIV in Ontario as of December 1998, constituting about twelve per cent of all HIV infections, a figure surpassed only by men who have sex with men and IV drug users (Remis and Whittingham). According to Remis and Whittingham, about 30 to 40 per cent of these infections occurred after the establishment of residence in Canada contrary to the popular belief that the virus is only transported during migration.

Black women usually appear only in terms of staggering numbers of those infected either in epidemiological updates or in reference to prenatal HIV transmission and prevention.

Despite the fact that Black communities in general, and Black women in particular, represent a significant element of the HIV epidemic, researchers and policy makers have largely ignored them. The absence of Black women in the HIV arena in terms of accessing prevention, treatment, support, and care initiatives is especially evident. They usually appear only in terms of staggering numbers of those infected either in epidemiological updates or in reference to prenatal HIV transmission and prevention. The above statistics indicate an urgent need for further research in this population to contextualize results obtained by statistical modeling and to better understand the psychosocial, cultural and structural determinants of HIV risk.

The Roots of Vulnerability to HIV/AIDS for Black Women in Canada

That HIV/AIDS continues to pose a considerable threat for African and Caribbean women including married women, young women, and girls is not a result of individual risk taking or lives filled with sexual adventures. Their vulnerability is not only biological like all other women but also unique and deeply rooted in socio-cultural and structural factors that intersect with gender, race, class, and political and economic conditions (Tharao and Massaquoi 2000). Lack of economic opportunities which increases dependency on men;

deprivation of rights to autonomy and sexual control over their bodies create an environment of possible gender based violence; cultural practices that increase risk of infection such as genital mutilation, vaginal cleansing, and limited educational opportunities leading to misinformation about the epidemic are all factors many Black women continue to experience in Canada, a country to which they had migrated in search of a better life for themselves and their families. An understanding and documentation of these factors is imperative if efforts to improve access to services and ensure the involvement of Black women in prevention, treatment, support, and care programs are to be successful.

In Canada, healthcare delivery is directed toward the achievement of improved health by preventing diseases, addressing injury, controlling threats to one's life and influencing social conditions in order to ensure the realization of optimal health and quality of life for the community at large. This model of service delivery also guides healthcare professionals in the provision of health programs and services most appropriate for the clients they serve. However, in reality, the healthcare environment in which African and Caribbean communities seek assistance is one that imposes substantial barriers that hinder access to health services (Tharao and Massaquoi 2000; Massaquoi and Lala). Many of the communities' needs do not conform to North American systems of healthcare delivery, systems based primarily on a bio-medical, monocultural model (Massaquoi and Lala). Consequently, Black communities tend to utilize healthcare services less and receive critical diagnosis and treatment significantly later than other populations due in large part to the cultural, linguistic, racial, gender, and class barriers embedded within the system (Tharao and Massaquoi 2000; Tharao and Massaquoi 2001).

It is with the above understanding, coupled with staggering epidemiological reports that we began investigating the contextual realities and barriers faced by African and Caribbean women and their vulnerability to HIV infection. The voices of 65 African and Caribbean women, and of the service providers working with them, were heard through focus groups and key informant interviews conducted by Women's Health in Women's Hands Community Health Centre[1] in 1999. The data provided by these informants, coupled with our years of experience and expertise in community education, support, and care of African and Caribbean women infected and affected by HIV/AIDS has informed our understanding of the issues impacting on Black women and the HIV/AIDS epidemic. It is our hope that this knowledge will illuminate the realities of African and Caribbean women in relation to HIV/AIDS, highlight the cultural context into which epidemiological data should be fitted, and propose some viable solutions to deal with the issues.

People living in poverty are less likely to seek early treatment for HIV infection, and are more likely to have more advanced symptoms when they present themselves for treatment.

Economic Marginalization

By 1996 there were 104,570 Black women of African and Caribbean descent living in Metropolitan Toronto (Statistics Canada 1996). As a largely immigrant and refugee population, these women experience difficulties trying to adjust to a new environment which is often times hostile to newcomers. The settlement of newcomers, especially those of African origin is difficult because of racism and systemic discriminatory practices that severely limit access to employment, housing, education, and other opportunities (George and Mwarigha). According to a study that was published in the spring issue of *Canadian Social Trends* based on the 1996 census data:

> The 1.4 million immigrants who came to Canada in the first five years of this decade were far less likely to get jobs than those who came in the 1980s. The employment rate for immigrant men between the age of 25 and 44, who make up almost half of all immigrants, fell by 10 per cent in a decade to 71 per cent in 1996. For Canadian born men, it fell by only 3 per cent to 86 per cent. Immigrant women were even more disadvantaged. While their employment rate was only 58 per cent in 1986, it fell to 51 per cent in 1996 while for Canadian born women; it rose by 8 per cent to 73 per cent. Almost half of all the newcomers who arrived in between 1990 and 1995—588,000 come to Toronto. Their unemployment rate was even higher than the norm. For men, it was 14 per cent, compared to 6 per cent for Canadian-born males, and for women it was 21 per cent, compared to 6 per cent for Canadian-born females. (cited in Karey)

A second report comparing the incomes and employment opportunities of all newcomers in Toronto, indicates that African immigrants remain in the lowest income group and have one of the highest rates of unemployment and underemployment, despite the fact that a relatively high proportion are well-educated (Ornstein 2000).

Due to lack of employment opportunities, many Black women live beneath the poverty line, making it impossible for them to afford the amenities that only money can buy. As we are all aware, employment is the cornerstone of good health and when this is threatened all other determinants of health are destabilized as well. People living in poverty are less likely to seek early treatment for HIV infection, are more likely to have been less healthy when they contracted the virus and are more likely to have more advanced symptoms when they present themselves for treatment. Consequently they tend to die sooner from AIDS.

Economic marginalization presented itself as one of the most powerful social barriers to HIV prevention for African and Caribbean women. Most of the women who participated in the focus group discussions were either unemployed or employed in minimum wage jobs. This compounded their social conditions as well as their personal levels of stress.

> *I have to worry about feeding, clothing and housing my children. I don't have time to think about AIDS.*

> *I work three jobs, I don't have time for anything else.*

Economic marginalization further offsets the imbalance in gender relations within the women's lives and their decision making power including sexual decision making power.

> *I never go anywhere by myself, I am not allowed. He takes me to all the places I need to go. He has to know I am looking for information (HIV information), I don't need that.*

With this kind of control, women are not in a position to insist on fidelity, demand condom use, or refuse sex with their partner even when they suspect or know that their partner is already infected. Women often lack the economic power to remove themselves from relationships that carry major risks. HIV/AIDS and the risk of infection for Black women is not solely an individual behavioral problem and the extent to which poverty and employment risk factors need to be considered in proposed interventions and programs cannot be underestimated (Tharao and Massaquoi 2000).

Racist experiences with the healthcare system was one of the reasons Black women reported a reluctance to access healthcare services including HIV/AIDS education, treatment, support, and care.

Racism as a Determinant of Health

There is growing evidence that the experience of racial discrimination can have a pervasive and devastating impact on the health and well being of communities of colour (Randall). Racism in Canada has caused distinct barriers to accessing healthcare services. It has created an environment within which quality healthcare is a commodity that has become socially, economically and politically unattainable by particular members of our society. One factor tnat has been implicated in the exacerbation of this impact is the current inadequacy in the provision of culturally-appropriate, anti-racist, inclusive healthcare services for all individuals. This inadequacy is particularly apparent in the context of the need for sensitive and appropriate care for Black women who face multiple oppressive forces of racial and sexual discrimination. Racist experiences with healthcare providers and the healthcare system was one of the primary reasons why Black women reported a reluctance to access healthcare services including HIV/AIDS education, prevention, testing, treatment, support and care. Women's personal experiences of racism included:

- Negative stereotypes about Black women and women of colour

> *I went to a clinic to have an abortion, it was a traumatic event in my life, they treated me very coldly and the only thing I remember the doctor saying to me was "Do you know who the father is?" My white friend went to the same clinic and received all kinds of counseling and support.*

- Practitioners dismissing health concerns as not important

> *... It took a year to finally find out what was wrong with me. My doctor kept saying it was all in my head and my people tended to worry too much and he never really took me seriously. Finally I got a new one who cared. I think if I was white things would have been better.*

- Lack of sensitivity when dealing with issues of cultural differences, acculturative stress and racism.

> *Having my first child in Canada was a scary thing. I didn't speak the language and did not have any family here. When I went for my first prenatal examination the Doctor gasped and said "Oh my God." He had never examined someone who had undergone female genital mutilation. I felt humiliated and very exposed... When I went to the hospital to*

deliver my baby the Doctor called all of his colleagues to look at me without my permission. This is not a human way to treat people.

Lack of Culturally and Linguistically Appropriate Primary Prevention Information

Ensuring access for all to primary prevention HIV/AIDS information and services in formats and languages that people can understand, and are comfortable with, is a fundamental requirement if HIV/AIDS is to be prevented. Access to primary prevention ensures that individuals and communities are equipped with skills to prevent infection, promote safer sex and responsible sexual behaviors, and ensure that women have the necessary skills and tools to enable them to act on the prevention information provided to protect themselves. There are very few prevention programs and educational resources targeted specifically to Black women. This means that most Black women have very little knowledge of HIV/AIDS, modes of transmission and how it can be prevented. Most significantly, they lack an understanding of their own risk of infection (Tharao and Massaquoi 2000).

> *I never thought I was at risk, I was married, I did not use drugs and I was not gay. From all the things I saw on TV or in the paper it looked like a very white thing. In my mind there was no risk of infection for me.*

Very few educational resources such as pamphlets, posters or booklets—the most popular of the HIV/AIDS social marketing tools—have visual representation of Black women or cultural imagery nor are they translated for an audience which does not speak English as its first language. Often times the primary prevention messages are inappropriate for particular groups, for example, encouraging condom use as an HIV prevention method without addressing gender power imbalance, cultural, and social barriers. Such messages are futile for women who do not hold any sexual decision making power within their relationships.

The need for target specific resources became an urgent issue for us when the policy on HIV testing during pregnancy was announced without any culturally appropriate and language specific resources developed for Black women as a part of the program. Women's Health in Women's Hands could not deliver the program effectively without appropriate resources to supplement the information women were getting from providers. The Centre developed "Healthy Options for Women," an HIV-prevention and education resource targeted to Black women. The images in the booklet are of Black women, the information is tailored to meet the needs of Black women in relation to HIV/AIDS, and the booklet is translated into several languages spoken by African/Caribbean women. The importance of targeted information in relation to HIV/AIDS cannot be overemphasized as indicated by the quote:

"I never thought I was at risk, I was married, I did not use drugs and I was not gay. From all the things I saw it looked like a very white thing. In my mind there was no risk of infection for me."

> *Personally when I look at HIV pamphlets or material it does not deal with my issues as a Black woman.*

It is clear that, in the case of Black women, there is a lack of readily available basic information on HIV prevention. This creates a situation whereby women do not understand and cannot accurately assess their own risk of being infected. Consequently they are not prompted to seek information and services. Most still think HIV/AIDS is someone else's problem. This lack of information creates a false sense of safety and reduces the need or the urge to learn more about HIV/AIDS, how it is transmitted and strategies for its prevention.

Limited Culturally Appropriate and Language Specific HIV/AIDS Prevention, Support and Care Programs

In-depth interviews with service providers working in AIDS service organizations and HIV clinics in Metropolitan Toronto revealed that most HIV/AIDS programs are delivered within mainstream settings which often lack the capability or the inclination to provide culturally-appropriate and language-specific services and/or information to meet the HIV/AIDS needs of Black women (Women's Health in Women's Hands). Culturally-sensitive programs ensure comfortable environments where issues can be discussed openly without anyone feeling uncomfortable, offended or excluded. Information can be conveyed in so many different ways but only some of these ways are appropriate for specific cultural groups.

> *Have a discussion about sex in a group, no way, this is not our way. Why are we changing what we grew up with just because we are in a new country?*

When it comes to ensuring that women receive HIV/AIDS information in the languages they are comfortable speaking, the use of translators or cultural interpreters more often than not creates a barrier to service.

Many Black women acknowledge openly that they do not want anyone from their community knowing about their HIV status. They are fearful that confidentiality will be broken and their community will find out about their status.

> *White organizations are a big problem especially when you don't speak English ... they use translators from your community and then word gets around.*

Some women would prefer to struggle and get limited information in English or to have no information at all rather than to use a translator/interpreter who is, in most cases, a person from their community. The need for confidentiality often supercedes the need for information.

> *If people found out I may be rejected by my family and my community.... This is worse for me than to find out that I had AIDS.*

Women are also worried about what people will think if they are seen looking for information. One woman summarized it:

> *Going to an AIDS service organization means either of two things. You are HIV positive and are seeking support or you are looking for prevention information hence your sexual behaviors are questionable.*

As a result of the stigma associated with HIV/AIDS, many women will not want to be linked to an agency providing HIV/AIDS services. This sentiment was also expressed with regard to the practice of designating a specific staff person to address HIV/AIDS issues within a multi-service agency.

> *If you have specific staff people assigned to work with HIV positive women, everyone knows your status as soon as you walk into their office. I would rather not go.*

Understanding of Socio-Cultural issues and Practices that Increase the Risk of Infection for Black Women

Most of the service providers interviewed acknowledged that they experienced multiple challenges in their efforts to provide services for Black women. Some of the challenges included lack of understanding of the cultural values, beliefs, and practices from the cultures of Black women.

"If you have specific staff people assigned to work with HIV positive women, everyone knows your status as soon as you walk into their office. I would rather not go."

> *We don't understand cultural practices and expectations, especially African—there are so many.*

Lack of knowledge and understanding amongst service providers about cultural practices, norms, and values and how these practices increase the risk of HIV transmission further reduces the effectiveness of programs. Practices such as female genital mutilation and vaginal cleansing, issues many healthcare workers in Canada are unaware of, have direct correlations with increased rates of infection and should be part of the risk assessment for women (Tharao and Massaquoi 2001; Tharao, Calzavara, and Myers). To accurately assess the risk of HIV infection for African and Caribbean women, an understanding of these practices is essential.

Religious and health-related beliefs, values, and norms further compound the issue. Most Black women come from settings where healthcare is accessed only when one is ill. Health promotion is a North American concept that has to be understood and accepted before it can be adopted. Religion also plays a central role in the lives of many Black women. Though some religious groups support HIV/AIDS prevention work, others have not acknowledged that it is an issue of concern and continue to portray it as an issue of immorality, hence a punishment from God for those who are infected. This poses a major dilemma since any prevention initiatives are seen to contradict religious beliefs and to go against the will of God or Allah. Given a choice, many women elect to follow what is prescribed by their religion thereby greatly limiting their access to information, prevention tools, support and care. The quotation below is an indication that the concept of prolonging life as a result of treatment is seen by some to contradict religious belief.

> *If it is the will of Allah for me to die tomorrow, no treatment on this earth can change that, so why try?*

Fears Associated with Being HIV Positive and the Implications Thereof

The stigma associated with HIV/AIDS and the social construction of the disease has created a distancing effect in the communities that have long been blamed as its originator. Stigma, with its subjective notions of shame, disgrace, and cultural misinterpretations that result in a "spoiled identity" (Williams) have all greatly influenced how those most at risk react to the threat of the epidemic. AIDS-related stigma is further complicated by other socially discrediting characteristics of the

Karen Augustine, "Brick House," Photomontage, 2001

groups most affected by it.

Visible minority group membership, homosexuality, drug use, commercial sex, and poverty are all characteristics that carried significant negative social implications prior to the epidemic and have now become associated with HIV/AIDS. The racist discourse that dominated the first decade of HIV/AIDS and personal experiences with racism remain major factors in the continuing silence and the increase in HIV infection among Black women and their communities. Once diagnosed with HIV/AIDS one cannot escape the socio-cultural interpretations attached to it creating negative implications for the individual, for their social interactions and for their relationships. Commonly believed images, stereotypes, and attitudes about the disease itself, compounded by constant anxiety about what others think or feel about them determines whether people seek and/or access services. People are shamed, condemned, and ostracized because of their HIV status or perhaps false perception of it.

> *Personally I don't want to know. I couldn't deal with a positive HIV status, the devastation and shame. Leaves people wondering how you got it you know.*

There is an under-representation of Black women and Black communities in general in the utilization and access to HIV testing information and testing services. Information from service providers and preliminary results obtained from a study being undertaken by the University of Toronto, "HIV/AIDS in East African Communities Living in Toronto" indicate that fear of HIV testing and being alienated from one's community and the impact of an HIV positive test on immigration status and/or ability to sponsor family members are definite reasons for the under-utilization of HIV testing services (Tharao and Massaquoi 2000; Calzavara *et al.*; Tharao, Calzavara, Myers, 2001).

The fear of testing HIV positive and its implications are a reality many Black women do not want to entertain. The shame, stigma, and discrimination associated with the disease makes women look at an HIV diagnoses as something they would be better off not knowing. This limits access to testing services, early diagnosis, and early access to treatment and service for those who may be infected.

For immigrant and refugee women, their reality includes the fear that a positive test might result in deportation, losing their children to child protection services, or the possibility of being unable to sponsor other family members to Canada (Tharao and Massaquoi, 2000). Currently, there are restrictions on the immigration of HIV positive persons to Canada. Those who are HIV positive are considered "medically inadmissible" and are denied permanent resident status on the grounds that they would place an excessive burden on Canadian health and social services (Canadian HIV/AIDS Legal Network)

> *Once immigration knows you are sick, what chance do you have of sponsoring family and what happens to your children?*

Due to the economic marginalization of African and Caribbean women, a positive HIV test result would be just another issue in the long list of daily hurdles these women must contend with and many would prefer not knowing instead of adding to their burden.

> *Why would I want to know if I was HIV positive, I don't have OHIP and I could not afford medicine or pay for my doctor?*

For other women, the fear of stigmatization for the community as a whole as opposed to personal stigma was a deterrent for testing.

> *Stigma and discrimination against the whole community will increase if the public becomes aware of increasing rates of infection in communities of colour.... More positive results would lead to more strict immigration policies harming us all.*

HIV prevention strategies traditionally address issues of personal safety, personal choice, and individual rights. For women who are raised in communally-oriented societies, the well being of the family and the community supercedes all rights of the individual.

Successful strategies and programs for many communities must be adjusted in order to address this reality. Individual strategies should be complemented with strategies targeted to whole communities in order to modify cultural values, beliefs, norms, and practices that increase risk of Black women to HIV infection.

Conclusions

If we are to develop an effective strategy to reduce the increasing rates of HIV/AIDS amongst Black women living in Canada, we must base programs and services on the realities of Black women's lives. Historical perspectives such as the long-term effects of colonization and slavery and their role in the interpretation of the epidemic need to be understood and taken into consideration in any strategies developed to deal with the epidemic.

Socio-cultural and economic factors such as poverty, unemployment, gender-based violence such as sexual abuse and rape, harmful cultural beliefs, values, norms, and practices further compounded by racism and other types of discrimination that further increase the risk of HIV infection must to be addressed in programs targeted to Black women.

Finally, the lack of involvement of Black women in the development, implementation, delivery, and evaluation of HIV/AIDS programs and services targeted to them is an issue that demands immediate attention. Black women's involvement in decision-making roles in organizations providing services to them is paramount if their silence is to be broken and their distance from the issue dealt with effectively. They must be part of the solution.

Most Black women in Canada find about their HIV status late in the stages of infection; those who are likely to be infected have not been diagnosed hence only limited numbers can benefit from available services and treatment therapies (Tharao and Massaqoui, 2000). Eliminating barriers to HIV prevention, support, treatment and care information, and services is crucial in addressing HIV/AIDS for African and Caribbean women. Tailoring programs to identified needs within the context of language, culture, gender roles, socio-economic status and creating policies that support the efforts that we as activists are making will increase the numbers of those accessing prevention, testing and care services and hence will increase access to treatment.

Improving quality of care is critical to improving Black women's health and well being. Black women are suffering unnecessary mortality and morbidity resulting from disease prevalence due to HIV infection. More multi-disciplinary research is needed into Black women's health so that an intersectional gender and race perspective may be incorporated into health policies and programs. The existing lack of race and sex-disaggregated data and information in Canada hinders the ability of decision-makers to develop effective, inclusive HIV/AIDS policies and programs. Adequate institutional mechanisms and resources are required for the successful achievement of inclusive health policies and programs to reduce the high rate of HIV infection amongst Black women.

Esther Tharao has been involved in HIV/AIDS work in Canada for over ten years and currently works at Women's Health in Women's Hands in Toronto as a health promoter. She is considered one of Canada's primary voices on HIV/AIDS issues facing Black communities and has presented on this subject at many conferences, including this year's annual conference of the Canadian Association for HIV/AIDS Research. She is a member of the Ontario Advisory Committee on HIV/AIDS, the Ontario HIV Endemic Task Force, and the Ministerial Council of the Canadian HIV/AIDS Strategy. She is also involved in several community-based HIV/AIDS research projects at Women's Health in Women's Hands.

Notisha Massaquoi is originally from Sierra Leone. She holds a Masters degree in Social Work from the University of Toronto and is currently the Health Promotion Coordinator of Womens' Health in Women's Hands Community Health Centre. She has expertise and commitment with respect to the healthcare needs of immigrant and refugee women, and, in particular, is involved in community development, community-based research, and policy development as it applies to the healthcarfe needs of Black women and women of colour.

[1] Women's Health in Women's Hands is a Community Health Centre for women of diverse backgrounds in Metropolitan Toronto and surrounding municipalities. Our mandate is to provide community, mental and clinical health promotion support from an inclusive feminist, pro-choice, anti-racist, anti-oppression, and multilingual participatory framework prioritizing women from the Caribbean, African, Latin American and South Asian communities. We believe that women have the right to receive quality health care and to make informed choices about their health. We work towards enhancing our sense of well-being and health by placing women's health into women's hands. We are committed to being advocates for change in our communities.

References:

Ankrayh, E. Maxine. "Let Their Voices be Heard: Empowering Women in the Fight Against AIDS." *Women and AIDS: Empowerment and Prevention.* 2 (3): May 1996.

Calzavara, L., T. Myers, and E. Tharao. "Influence of Immigration and Country of Origin on Uptake of HIV-Related Services and Programs: East African Communities in Toronto, Canada." Poster Presentation at the Ninth Annual

Canadian Conference on HIV/AIDS Research. Montreal, April 27-30, 2000.

Canadian HIV/AIDS Legal Network. "HIV/AIDS and Immigration.: A Discussion Paper." [Montreal, October 2000.

George, Usha and M.S. Mwarigha. "Consultation on Settlment Programming for African Newcomers." Toronto: Citizenship and Immigration Canada and Ontario Admistartion of Settlement and Immigration Services, 1999.

Health Canada. "HIV and AIDS in Canada, Surveillance Report to December 31, 2000." Health Canada: Ottawa, April 2001.

"HIV/AIDS in East African Communities Living in Toronto: A Proposal for Developmental Funding. Final Report." Prepared for the AIDS Program Committee, Positive Action Fund. Research team: Liviana Calzavara, Ted Myers, and Esther Tharao. December, 2000..

Massaquoi, N. and A. Lala. "Women=s Health in Women=s Hands: an Integrated Approach to Health Care for Black Women and Women of Colour." Presentation at the 2nd International Primary Health Care Conference. Melbourne, Australia, April 2000.

Ornstein, Michael. "Ethno-racial Inequality in the city of Toronto: An Analysis of the 1996 Census." Toronto: Access and Equity Unmit. Strategic Corporate Policy Division. Chief Administer's Office in Cooperation with Public Health Services, Social Development of the Community and Neighbourhood Services Department and the Centre of Excellence for Research on Immigration and Settlement Issues, May 2000.

Randall, R. Vernillia "Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans." *Health Matrix* (3) Spring 1993: (127-194)

Remis, R., C. Major, H. Bangura, E. Wallace and M. Vermuelen. "Report on the HIV/AIDS Epidemic in Ontario, 1981-1996." Toronto: Ontario Ministry of Health, July 1998.

Remis, R, and P. E. Whittingham. "The HIV/AIDS Epidemic among Persons from HIV-Endemic Countries in Ontario, 1981-98: A Situation Report." Toronto: Department of Public Health Sciences, University of Toronto, 1999.

Remis, R., C. Major, H. Bangura, E. Wallace, L. Schiedel and E. Whittingham. "Report on the HIV/AIDS Epidemic in Ontario, 1997-1998." Ontario Ministry of Health and Long-Term Care: Toronto, November 1999.

Tharao, E., L. Calzavara and T. Myers. "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 3- June 3, 2001.

Tharao, E., L. Calzavara and T. Myers. "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., and N. Massaquoi. "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., and N. Massaquoi. "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.

Statistics Canada. *Canadian Census.* Ottawa, 1996.

UNAIDS/WHO. *AIDS Epidemic Update:* December 2000.

Williams, S., and S. Goffman. "Interactionism and the Management of Stigma in Everyday Life." *Sociological Theory and Sociology.* Ed. G. Scambler. Tavistock: London and New York, 1987.

Women's Health in Women's Hands. "HIV/AIDS Initiative: Women's health in Women's Hands." Annual Report. Toronto, 2000.

Women's Health in Women's Hands. "Healthy Options for Women." Toronto: 2000.

ABOUT THE ARTIST:

Karen Augustine is a toronto-based writer, artist, and broadcaster. Her essays and poetry have been published in a number of anthologies and a variety of feminist and art publications. She is the former editor/founder of *At the Crossroads: Black Women's Art Magazine* as well as the indie art journal *MIX.* As an artist, her work has been cited in the book *The Art of Reflection: Women Artists' Self-Portraiture in the 20th Century*, published by Scarlett Press in the UK in 1996.

Artwork: the queen's art project (2001) is part of a larger photo-based installation positioning each image as a sentence ending with a question mark: how do spiritual and colonial history, as well as pop culture trends, inform black female sexuality and self-possession?