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HIV Prevention for Black Women: Structural Barriers and Opportunities

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Abstract: Black women bear a disproportionate burden of HIV/AIDS in North America. The purpose of this investigation was to explore Black Canadian women's perspectives on HIV risk and prevention. Four 90-minute focus groups (n=26) and six key informant interviews were conducted in Toronto with Black women of African and Caribbean descent and low socioeconomic status. Data analysis revealed a number of potent barriers to existing HIV preventive interventions: stigma, cultural disconnections, lack of engagement of Black religious institutions, and multiple intersecting forms of discrimination. Recommended HIV prevention opportunities included the Black church, mainstreaming, health care providers, and ethno-specific agencies. HIV prevention strategies for North American Black women, rather than focusing on HIV and individual risk behaviors, may benefit from a primary focus on social and structural factors (e.g., promoting gender equality, economic opportunity, women-controlled prevention technologies and combating racism in health care) thereby integrating HIV prevention into the larger context of community health and survival.

Key words: HIV, AIDS, women, ethnic minority groups, primary prevention, social factors, prejudice, structural factors, qualitative research, Canada.

HIV incidence and prevalence among Canadian women continues to increase. Women accounted for 14% of people living with HIV/AIDS in 2002, a 13% increase from 1999.¹ Women represented 23% of HIV incident infections in Canada in 2002, suggesting a further shift in the epidemic toward women. Even as women accounted for 16.7% of HIV incident infections among White Canadians, women represented half of the HIV incident infections among Black Canadians in 2002¹—a threefold overrepresentation. Thus, Black Canadian women are especially vulnerable to HIV/AIDS.

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Despite decades of HIV/AIDS research and intervention, reduction of HIV risk among women overall continues to elude public health practitioners.²⁻⁴ Cultural, socioeconomic, relationship-specific and gender-specific factors are crucial to addressing HIV risk among women, and among Black women in particular, given overall socioeconomic disadvantages and a context of discrimination.^{4,5} In particular, the HIV prevention knowledge base is not well equipped with models of intervention that take into account the gender and culture of the target audience, which are more likely to be effective among Black women.^{6,7}

The purpose of this study was to explore in depth the perspectives of Black Canadian women concerning HIV risk and prevention and to elicit their suggestions for effective and acceptable preventive interventions.

Methods

Data collection. A community advisory board (CAB) was recruited, including six service providers from agencies serving diverse African and Caribbean communities in Toronto. The CAB met quarterly and contributed its insights throughout all stages of the project.

Four 90-minute focus groups were conducted: 3 in English—one with women under 30 years of age ($n=7$), a second with women over 30 ($n=7$), and a third mixed age and ethnicity ($n=6$); and one in French ($n=6$). Participants were recruited through community venues (health centers and ethno-specific agencies) serving Black women of diverse national and ethnic origins. Inclusion criteria were being a Black woman 18 years of age or older in the Greater Toronto Area; all women who volunteered were included. Six key informant interviews (5 in English, 1 in French) were conducted with African and Caribbean community leaders, advocates, and health care providers identified by the CAB and the research team.

Focus groups were each led by two experienced co-facilitators, both Black women. Ground rules were established at the inception of each group, including respect for others opinions and differing points of view. A semi-structured interview guide included five questions exploring HIV prevention knowledge, community risk behaviors, service utilization, and HIV prevention barriers and opportunities. French-language study materials were translated into French and back-translated into English. Member checking was conducted by sharing emerging data with participants and key informants towards the end of focus groups and interviews to enable participants to assess the credibility of the data.^{8,9} In addition, the CAB—representing different communities of Black women—participated in reviewing emerging themes and interpretations to enhance the validity of the findings. Saturation was achieved in that no new themes emerged in the final interviews and focus group.

Participants provided individual written informed consent. The University of Toronto Research Ethics Board approved the study. At the end of each focus group, participants completed a two-page anonymous sociodemographic questionnaire and received a \$30 honorarium.

Data analysis. Interviews were digitally recorded and transcribed *verbatim*. French transcripts were translated into English for analysis. Narrative thematic analysis was used

to identify first-level codes (descriptors of important components of the interviews), including *in vivo* codes (codes using the language of participants),^{9,10} which were then tagged to associated segments of text using NVivo.¹¹ Text corresponding to each of the first-level codes was reviewed and organized into categories. Inconsistencies in coding were resolved by consensus among three investigators.

Results

Participants. Sociodemographic characteristics of focus group participants (n=26) are reported in Table 1.

Key informants included five women and one man, three of African and three of

Table 1.
SOCIODEMOGRAPHIC CHARACTERISTICS OF
FOCUS GROUP PARTICIPANTS (N=26)

Characteristic		<i>n</i>
Age, years		
Range	19–68	23
Mean	32.1	23
Monthly income		
Mean	\$1154	23
Years in Canada		
Range	1–40	23
Mean	10.2	23
		%
Country/region of birth		
Africa	43.4	10
Canada	13.0	3
Caribbean	26.1	6
Other	17.4	4
Ethnicity		
African	60.9	14
Caribbean	34.8	8
Other	4.3	4
Highest level of education		
No formal education	13.0	3
Some high school or less	30.4	7
High school or equivalency	13.0	3
Some college/university	21.7	5
Completed college/university	21.7	5

(Continued on p. 832)

Table 1. (continued)

Characteristic	%	<i>n</i>
Employment status		
Full-time (paid)	26.1	6
Part-time (paid)	17.4	4
Full-time homemaker	4.3	1
Unemployed	39.1	9
Other	8.7	2
Canadian immigration status		
Citizen	56.5	13
Permanent resident	13.0	3
Work/student visa	8.7	2
Refugee claimant	13.0	3
Undocumented	4.3	1
Currently in relationship		
Yes	65.2	15
No	34.8	8
HIV testing		
Yes	78.3	18
No	21.7	5
HIV status (self-reported)		
HIV-negative	87.0	20
Unsure	8.7	2
Declined to answer	4.3	1

Note: Three participants did not complete the questionnaire.

Caribbean descent. All had five or more years of experience working with Black women, including HIV prevention. Two were coordinators of HIV education and prevention projects, two were community health and AIDS educators, one was a family physician and one a pastor.

Box 1 outlines themes, subthemes, and subtheme descriptions.

HIV prevention barriers. HIV prevention barriers include sociocultural and structural obstacles to Black women's engaging with HIV prevention information and services.

AIDS stigma: "breaking the silence." Key informants reported intense stigma attached to HIV risk behaviors. HIV was characterized as primarily an issue of moral impropriety rather than community health.

An informant contrasted the shame surrounding HIV with attitudes toward other communicable diseases:

It becomes a moral discussion. So it's not like the flu. People perceive the flu as something that you can catch; but HIV is perceived as this thing that is intricately locked into immoral or inappropriate or untoward sexual behavior.

Box 1.		
OVERVIEW OF MAIN THEMES AND SUBTHEMES		
Theme	Subthemes	Overview
HIV Prevention Barriers	AIDS stigma	HIV/AIDS seen primarily as an issue of moral impropriety rather than a health concern
	Cultural disconnections	Mismatch between predominant HIV prevention discourse and cultural contexts of Black women
	Lack of engagement of Black religious institutions	Omission of major cultural institution & resource hampers ability to effect change
Discrimination	Sexism	Cultural gender norms constrain women's power and choices
	Poverty	Lack of economic opportunity disempowers Black women, demands focus on immediate survival, and constrains choices
	Racism	Discrimination in service provision, disavowal of HIV by already stigmatized communities, and mistrust of mainstream institutions
	Homophobia	Precludes discussion about same-sex behaviors and disclosures of possible risk
HIV Prevention Opportunities	Black religious institutions	Widespread coverage, credibility and power to effect change
	Mainstreaming	Raising public awareness, integrating HIV education, prevention and testing into routine health care services for women
	Health care providers	Important conduits for HIV/AIDS awareness and education to youth and adults
	Ethno-specific services	Culturally competent and representative venues and providers trusted by Black women

The strong link between HIV transmission and behaviors perceived to be forbidden or illegal, such as sex between men and illicit drug use, was described as reinforcing attitudes that divorce HIV from the health domain: “HIV, for many people, is connected to . . . illicit behavior; it’s not being seen as a health issue.”

Key informants described how the connection between HIV and stigmatized communities removes HIV from general public health discourse:

If you approach it in a group form, that’s where stigma is working even harder—because we are looking at the sex workers . . . at the drug abusers . . . at the gays and lesbians; we are looking at people of color from different countries; and that brings stigma . . . so it takes HIV out from the general population.

Stigma was described as supporting silence around HIV. A key informant explained,

It is very hard to engage people in discussion around HIV/AIDS, so that still is a problem. So we are breaking the silence in terms of HIV/AIDS, but still the phase of breaking that silence is challenged by the stigma of HIV/AIDS. We are still at that stage now from my experience.

Cultural disconnections: are prevention programs culturally adapted? The term *cultural disconnections* refers to a perceived mismatch between predominant HIV prevention discourse (language, practices, technologies, and media representations) and the life experiences and cultural contexts of many Black women. As a participant asked in regard to HIV preventive interventions, “I wonder if they are really effective in communities where HIV/AIDS is endemic . . . are they culturally adapted?”

Many cultural values and practices were reported as being in conflict with the perceived demands of HIV prevention. A participant explained, “. . . It is very difficult to get a group of women who have undergone certain traditional rituals to agree or to understand that they need to change some of those rituals in order to avoid any risk; we do have a problem especially when it comes to cultural values.”

An HIV prevention discourse dominated by messages for men (especially, men who have sex with men) was also implicated in disconnections between Black women and prevention messages. A key informant explained, “The media has for so long bombarded us with images from males getting HIV that has blinded or given the women a sense that they are exempted . . . when it comes to this issue, Black women specifically.” Another key informant echoed, “I don’t think that the average Black woman has a clue when it comes to the risk of contracting HIV from a female perspective.”

Cultural disconnections were also attributed to what was seen as the prevailing discourse around risk groups—“gay men, drug users, there are risk groups you know”—which led many Black women to exempt themselves from HIV prevention messages.

Participants also described disconnections between existing HIV prevention technologies and options under women’s control. A key informant explained, “It’s like telling women, ‘Here is a condom you have control over, but for you to be able to use it

you still have to go and talk with your partner.' Women need more, more prevention strategies and tools which they have control over."

Key informants also described disconnections among Black youth, particularly in African families who had recently immigrated to Canada: "Most of the children who are brought up here within our community are very protected children, so that protection puts them at a very higher risk because they don't have all the information that they need to protect themselves. . . ."

Lack of engagement of Black religious institutions: "not having that kind of endorsement from the spiritual community." Lack of engagement of Black churches and mosques was described as reinforcing a cultural and institutional divide between HIV prevention and a major social and cultural bulwark in many Black women's lives. A participant emphasized the importance of the church for any successful prevention strategy: "Not having that kind of endorsement from the spiritual community would inhibit people from being able to make independent decisions, because . . . it's a reality; it's a community."

A key informant explained how church doctrine influenced daily lives and practices in ways that might create vulnerability to HIV: "A lot of women tend to practice what their religion tells them to practice, because religion determines . . . religion prescribes how women should behave. . . ." Participants provided examples of conflicts between religious beliefs and safer sex, such as: "The reason why she wouldn't practice safer sex is because God's seed should not be thrown to the ground . . . that goes against her religious beliefs." The prevalence of this particular belief is unknown, but it is part of a pattern described by a key informant as "the dichotomy between what public health tells women to do and what religion tells them," which creates challenges for HIV prevention.

Discrimination. Multiple intersecting forms of discrimination emerged as a powerful context for understanding HIV risk and prevention among Black women.

Sexism. Sexism was identified as contributing to women's lack of awareness of risk and inability to enact preventive behaviors. Sexism was described as embedded in cultural traditions regulating gender dynamics within marriages and families. A key informant explained, "Women who are at very high risk of HIV infection . . . they come from cultures where there are very big power differences between women and men." A focus group participant discussed how the intersections of traditional African cultures and familial roles and rules that guide marital relationships place women at risk: "Within the African traditional family, even if a woman is aware of her husband's concubines she cannot ask him to use a condom."

The marital relationship and unequal power were invoked as obstacles to condom use. "How are you going to tell somebody who is married or who has been living with a man for ten years or five years to use a condom all the time? It is not realistic," noted a key informant. A participant described a woman's inability to implement condom use in a relationship: "She knows the risks but she does not have any power once confronted by her life partner."

Poverty. Closely linked with sexism, poverty was implicated in women's being compelled (in order to have their basic needs met) to remain in relationships with men who

posed risks for HIV transmission. In some cases, these relationships were unsatisfactory and unhealthy for other reasons as well. As a key informant put it, "A lot of times these relationships are not satisfactory, but women continue to engage in them, because what sustenance comes from them is very needed on a very concrete level."

A key informant discussed the influence of poverty and economic dependency, particularly among younger Black women, as a basis for engaging or enduring in an unsatisfactory relationship:

You hang around with a man who has money because he can take you out, because he buys you nice clothes . . . he pays your rent for you when you are unable to do it. . . . Then you will have a relationship with him because that is the only way you can sustain his interest. That is becoming increasingly a problem, particularly among young Black women.

A key informant also explained the more explicit trading of sex for money or in-kind support: "Sex in exchange for goods or whatever you get out of it is increasing. The majority of . . . Black communities are living in poverty, so people have to find out a way of earning an income, or supplementing their income."

Racism. Racism on multiple levels was also described: historically based mistrust of mainstream North American institutions, stigmatization of people of African descent, devaluation of Black women and presumptions about inability to understand HIV/AIDS and HIV transmission.

A key informant explained the relationship between a legacy of racial discrimination and Black women's mistrust of HIV prevention services: "The history of Black people is very interlinked to discrimination. You know you have colonization, you have slavery . . . and I have actually heard women say, 'You didn't care about me before, so why should I believe you care about me now, that you're going to be doing these things for me?'"

A participant described feeling offended and distressed by the stereotyping of people of African descent as intrinsically at risk for AIDS:

I feel like the women in Africa or Africans in general are kind of being picked on, because they aren't the only people who have AIDS. . . . It's unfair that sometimes when people think of AIDS they think Africa or gay people or something like that. It hurts me on a deep level because I'm from Africa and . . . that's not true . . . I'm from that country. Everyone's different, so you can't judge an entire race or an entire majority.

Participants also reported feeling as if they are not treated with respect when seeking or receiving HIV information. A key informant explained:

When it comes to Black women of color, they are treated as if they will not understand information. It's almost like you're not worthy of spending time with, of trying to explain to you so that you understand. There is an inherent assumption even if I explain to her I don't think she's smart enough to get it, so they just leave you struggling with very limited understanding.

A participant contrasted her experience with that of White women in describing racial discrimination at a pharmacy:

The typical White female . . . she can go to a drugstore and get whatever she needs . . . but, I even noticed this, if me and my mom go, there's always tension and they think we're going to steal aspirin or Flintstone vitamins or something; and I'm like, "We don't need that."

Homophobia. Key informants also discussed taboos that prevented discussion about homosexual or bisexual activity in their communities. Women are made vulnerable by lack of opportunities to identify risks and to speak openly about the need for safer sex; and men may feel constrained to keep same-sex behaviors hidden. As a key informant reported:

I know men who have sex with men within the community they tend to stay in the closet. They tend to have girlfriends as a cover, so that people won't suspect that they have another different sexual orientation or that they are gay or whatever you may want to call it. And because of this hidden dimension, it becomes a risk for women; because you can never know when or if your partner or so has sex with another man.

Women's resistance to acknowledging homosexual relationships among men in their lives complemented men's lack of disclosure about same-sex relationships. A key informant explained, "Given the level of homophobia, which is quite high . . . most straight Black women don't want to hear about bisexuality, don't want to hear that men have the capacity to have relationships with other men." A key informant described the power of the image of heterosexuality in maintaining an impression of a man, even though he may sleep with other men, as necessarily HIV-negative:

There are women that are having unprotected sex with their man that they sleep with from time to time. It's on the down low; not everyone knows their business . . . and he's perceived as clean, because he has a family of his own. So he's clean. He is not a player.

HIV prevention opportunities. HIV prevention opportunities were identified in strategies that capitalize on existing community institutions and strengths.

Black religious institutions. The church was invoked as a powerful cultural institution that could be tremendously effective in supporting HIV prevention. A participant described the widespread reach of the church as an important resource for disseminating HIV/AIDS information: "Maybe church . . . that's a good idea isn't it; everyone goes there. After Sunday service. . . ." A key informant also commented on the power of the church in Black communities and articulated the strong ties of Black women to the church:

There's lots, I mean thousands of Black women that fill up the churches in Toronto. They may not be the highest income earners, but can find money to support their churches. So we're talking about emotionally, economically, and spiritually tied to these institutions . . . unless it comes from the pulpit, it is not happening.

Mainstreaming. Participants offered a number of suggestions for making HIV prevention a routine part of general education and women's health care. A participant expressed the importance of increasing HIV awareness among Black women: "I think it's important that there is this general knowledge and awareness of what HIV is all about." Similarly, a key informant explained, "I think with a lot of information, with raising public consciousness there could be a change of behavior, an improvement of the risk behavior." Another key informant pointed to the urgency of addressing HIV as being similar to other diseases and health conditions:

Until, as African and Caribbean people, we feel like, cancer happens, diabetes happens, we all know that they're related to diet, and environment, and some personal choices, and some genetics; it's a mixture. . . . Until HIV is in that place, connected to larger pieces, it feels very much like someone's branding you with something that you have no real understanding of why, and I've heard it repeatedly: "Why they always want to put us and HIV together? Why?"

Key informants offered specific suggestions for mainstreaming HIV education and testing in general health education programs: "You could be talking about breast cancer, and mention women's health as generally speaking . . . integrate it into your programming so as you talk to women . . . AIDS will be an issue that will be brought into that context." Another key informant provided a clinical example: ". . . Now it's your general exam; okay these are the blood tests we are doing. I think we should include HIV testing at this time."

Health care providers. Health care providers were seen as important resources for providing AIDS information. A key informant explained the importance of making AIDS education "accessible through their own family doctor settings . . . in clinics. . . ." Health care providers were specifically acknowledged as conduits for imparting HIV information to Black youth, particularly immigrant youth, who were described as vulnerable due to lack of exposure to HIV education and being protected by their families: "There's no other service outside of a family doctor's setting to help these young people."

Nevertheless, key informants pointed out, "Physicians are not exempt from the stigma that we have with HIV" and "Several physicians once they find out that you are positive, they don't serve you anymore." Key informants also discussed obstacles presented by providers' "paternalistic attitude that I know what is good for you" and the need for providers to break through this stance to "explain to me why you think it's good for me so that we can at least be on the same page."

Ethno-specific services. Ethno-specific agencies were invoked as vital to HIV prevention for Black women. A key informant explained obstacles to Black women's utilization of mainstream services: "People will refuse to go somewhere because they say, 'Oh, they don't treat us well and I went and I am not going back' and that is very common among Black women accessing care in different settings." More emphatically, a key informant reported, "I never believe mainstream service providers will ever advocate on behalf of Black women and women of color. That is the belief I have no matter what someone tells me . . . it's based on experience; it's based on what I have seen as I have worked within the field."

In lieu of reliance on mainstream services, “you need to look for another way: which groups of people do community education and which groups of people have that relationship with Black women. . . .” Another informant spoke about the power of “specifically, a doctor from their cultural background; my doctor is from the Caribbean, she is Jamaican, she is a woman, and that’s who my doctor is.”

Discussion

Black Canadian women of African and Caribbean descent identified a network of social and structural factors that present obstacles to HIV prevention. As a whole, the present findings suggest that many current models of HIV preventive intervention may be experienced by Black women as either irrelevant or requiring them individually to combat powerful structural forces, including sexism, racism, and AIDS stigma, and to circumvent social pressures emerging from cultural institutions such as the church and the family. HIV prevention strategies that require individuals to protect themselves at the cost of alienation from traditional bastions of support seem ill-conceived and unlikely to be effective.

The myriad social and institutional factors implicated in vulnerability to HIV infection among these women suggest that HIV risk is less a consequence of individual choices and more a product of structural forces. Rather than augmenting predominant individual-focused and androcentric models and theories in culturally specific ways, it may be more prudent to turn the paradigm upside down:^{5,12} create HIV prevention models that begin from the social contexts, life experiences, and perspectives of Black women.

Paradoxically, optimal HIV prevention strategies for Black women might rely on interventions decisively *not* focused on HIV, sexual practices, or risk behaviors, but on women’s identified concerns—poverty, gender-inequality, and lack of women-controlled prevention technologies—that create a context of vulnerability and constrained choices.¹³ HIV prevention for North American Black women may be most effectively positioned as one of many strategies for cultural and individual survival in an often hostile social and institutional context, rather than as an end in itself.

While strategies focused on women’s experiences are clearly important, men are an undeniable component of Black women’s vulnerability to HIV infection (as well as being vulnerable themselves). African men in particular can play a significant role in lowering Black women’s HIV risk.¹⁴ Black women come from diverse cultures, immigration statuses, and socioeconomic levels, all of which intersect with experiences of sex and gender, and must inform the focus and substance of gender-based interventions. In particular, in the present study, women from African countries indicated greater obstacles than women of Caribbean descent did to existing HIV preventive interventions due to cultural traditions, gendered power imbalances, and AIDS stigma wedded to Africa. Gendered power dynamics were implicated across ages, but for younger women tended to center more around unsafe sex in dating relationships and using sex to develop a relationship, while for older women it centered on maintaining relationships and family security. Participants under 30 also seemed more conversant and comfortable with sexual vernacular than older women.

Focus group participants echoed and provided examples of the themes raised by key informants, although the latter were often more adept at summarizing the issues. Notably, some themes—the influence of homophobia and AIDS stigma in supporting silence about HIV risk, and the power of poverty in constraining women's choices in relationships—emerged predominately from key informants. The fact that focus group participants largely did not discuss these issues is compatible with arguments about the power of stigma, racism, and homophobia in engendering silence around HIV risk among Black women.^{15,16}

Finally, while women-controlled prevention technologies, such as vaginal microbicides¹⁷ and HIV vaccines,¹⁸ and mainstreaming of HIV prevention in women's health care may meet the needs of Black women better than existing options, training and monitoring of health care providers is vital to ensuring respectful and culturally appropriate service delivery.

Limitations to this study include the small purposive sample of Black women from one urban area, which limits the generalizability of the findings and our ability to make comparisons among Black women (e.g., by age, acculturation, religion). Nevertheless, we were successful in recruiting diverse, low-socioeconomic status Black women of African and Caribbean descent. Triangulation of methods (focus groups and interviews), data sources (key informants and women from the communities) and investigators (three investigators reviewed the coding and themes) enhance the trustworthiness of the findings.^{8,9} Additional investigations are needed to determine differences among Black women by various demographics, as well as studies of Black women in other settings to assess the transferability of the present findings and to determine local needs and preferences for intervention.

Conclusion

This in-depth investigation of low-socioeconomic status Black women's and community service providers' perspectives on HIV risk and prevention suggests the primacy of structural (e.g., institutional, social, economic, and policy) factors in producing heightened vulnerability to HIV infection among North American Black women. Opportunities for HIV prevention tailored to the needs of urban Black women include strategies focused on community survival in hostile social and institutional environments, rather than HIV *per se*, that build on existing Black community institutions. The engagement of Black women in designing, implementing and disseminating HIV prevention research is itself a structural intervention to support culturally appropriate, gender-focused strategies to address the escalating AIDS epidemic among Black women in North America.

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