HIV Prevention and HIV Vaccine Acceptability among African and Caribbean Black Women in Toronto

Sisters, Mothers, Daughters, and Aunties; Protecting Black Women Against HIV/AIDS. HIV Prevention and HIV Vaccine Acceptability among African and Caribbean Black Women in Toronto

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1. EXECUTIVE SUMMARY

This report discusses findings from "Sisters, Daughters, Mothers and Aunties: Promoting Equity in Access to Future HIV Vaccines for Black Women in Canada." The project is a collaboration between Women's Health in Women's Hands Community Health Centre (WHIWH), researchers at the Factor-Inwetash Faculty of Social Work, University of Toronto and a Community Advisory Board. Data collection was conducted from 2005 through 2006, funded by the Canadian Institutes for Health Research (CIHR).

Black women remain especially vulnerable to HIV/AIDS. This research project examined the perspectives of black women in the Greater Toronto Area on HIV risk, HIV prevention, and acceptability and access to future HIV vaccines. We used an integrated mixed-method design to collect both qualitative and quantitative data, in collaboration with a Community Advisory Board. In the first phase, we conducted four focus groups with women of African and Caribbean descent and six key informant interviews with community advocates and service providers. In the second phase, we developed and conducted a venue-based survey of 206 black women.

Barriers to current HIV prevention and future vaccine acceptability included HIV/AIDS stigma, cultural and gendered disconnections with HIV/AIDS information and interventions, and lack of engagement of HIV prevention strategies with black community organizations. Discrimination emerged in terms of sexism, racism, poverty and homophobia, resulting in constrained choices for black women, diminished access to appropriate health care, and obstacles to communication regarding HIV/AIDS.

Opportunities for HIV prevention, and facilitating future HIV vaccine acceptability and access, included mainstreaming HIV/AIDS initiatives as part of routine women's health care; engagement with black community institutions, including the black church and ethno-specific agencies, in the design, development and dissemination of HIV prevention initiatives; and addressing HIV prevention under the broader rubric of community health and survival. This investigation highlights the centrality of social and structural factors in producing heightened vulnerability to HIV/AIDS and decreasing potential benefits of future HIV vaccines to black women in Canada. Culturally-appropriate, gender-specific approaches that engage black communities and community-based organizations are vital to effective HIV prevention and future HIV vaccine dissemination initiatives.

2. INTRODUCTION

About the Study

What are the perspectives of African and Caribbean women living in Toronto on HIV risk and prevention? What are the viewpoints of African and Caribbean service providers and community advocates on barriers and opportunities facing this community? What do African and Caribbean women in Toronto think about future HIV vaccines? To address these questions, Women's Health in Women's Hands (WHIWH), a community health centre serving women of colour in downtown Toronto, entered into a partnership with researchers at the Faculty of Social Work, University of Toronto to conduct a two-year research project. With funding from the Canadian Institutes of Health Research (CIHR) from 2004-2007, the research team developed a community advisory board, held focus groups, conducted face-to-face interviews, and administered survey questionnaires with African and Caribbean women in Toronto.

About this Report

This report was developed to share African and Caribbean women participants' perspectives on HIV education, prevention and future HIV vaccines. It also includes viewpoints from key informants—community leaders, advocates and service providers involved with HIV prevention among African and Caribbean black women. The background information, methodology, and results are provided with the intent of sharing the findings with African and Caribbean communities within Canada, service providers, health care providers, people living with HIV/AIDS, policy makers and the general public. This report addresses both current HIV prevention needs and challenges facing African and Caribbean women, and future challenges for dissemination of HIV vaccines—in order to avoid replicating strategies that disenfranchise black women and, instead, to build on community strengths.

Literature Review and Background

Despite decades of HIV/AIDS research and intervention, success in reducing HIV risk among women overall, and Black women in particular, continues to prove largely elusive. Black women are disproportionately affected by HIV/AIDS in Canada. Among people from HIV-endemic countries, women had a 64% increase in HIV diagnosis from 2000 to 2004 compared to a 29% increase among men. HIV incidence continues to rise among women, who accounted for over 27% of HIV+ cases in Canada in 2006 (PHAC, 2007). Black women are over three times more likely to be HIV+ than white women: 54% of HIV infections among black Canadians between 1998 and 2006 were among women (PHAC, 2007) while 16.7% of HIV infections among white Canadians between 1998 and 2003 were among women (PHAC, 2005).

Cultural, gender, socioeconomic and relationship factors heighten vulnerability to HIV among women. This is particularly true for black women as a result of discrimination and socioeconomic disadvantage. While HIV vaccines may be an important component of integrated HIV prevention efforts in the future, structural inequalities (e.g., stigma, racism, poverty, gender inequality, homophobia) that create particular vulnerability to HIV/AIDS among black women in the present may pose formidable barriers to the acceptability and accessibility of future HIV vaccines (Newman et al., 2006; Newman et al., 2008; Rudy et al., 2005). Formative research to identify barriers and opportunities for the distribution and uptake of future HIV vaccines among black women in Canada is vital—before a vaccine is available—in order to inform culture and gender appropriate interventions to ensure equity in access and informed decision-making on the part of black women, their families and communities.

3. STUDY OBJECTIVES

The overall objective of the study was to explore and understand barriers and opportunities in regard to HIV prevention and HIV vaccine acceptability among African and Caribbean black women in Toronto. Specifically, the research objectives were to:

1. Explore in depth the perspectives of Canadian black women on HIV risk and prevention; and,
2. Understand the barriers and facilitators to Canadian black women's acceptance and utilization of future HIV vaccines.

4. METHODS

Description

A team of university- and community-based researchers and service providers conducted a research project centered at a large urban community health centre serving women of colour. A community advisory board (CAB) was developed, including community advocates, AIDS educators and service providers serving diverse African and Caribbean communities in Toronto. The CAB provided input and consultation throughout the research process.

Project staff including the research coordinator, outreach workers, interviewers, focus group facilitators, translators, data entry operators, graphic artists and web designers were recruited from diverse black communities. Written informed consent was provided by all participants prior to the start of each focus group, key informant interview and survey interview. The study received approval from the Research Ethics Board of the University of Toronto.

Overview

This research project involved the development of a community advisory board (CAB); Phase I: focus groups and key informant interviews; and Phase II: a venue-based community survey. Debriefing was conducted at the end of each focus group, key informant interview and survey interview to answer any questions about the study and to provide accurate information about HIV vaccines: No vaccine to protect against HIV/AIDS is currently available. Written materials about HIV prevention and a local HIV/AIDS resource list, including ethno-specific agencies, were distributed to all participants.

Phase 1: Focus Groups and Key Informant Interviews

I. Data Collection

Phase I included four 90-minute focus groups (3 in English, 1 in French) with 26 African and Caribbean black women. Six in-depth key informant interviews (5 in English, 1 in French) were conducted with African and Caribbean community leaders, advocates and health care providers identified in consultation with the Community Advisory Board. Key informants included five women and one man, three of African and three of Caribbean descent. All had five or more years of experience working with black women, including HIV/AIDS and its prevention. Focus group and interview questions explored: 1) HIV risk and prevention knowledge, attitudes and beliefs; 2) health and risk behaviors, and vulnerability; 3) health care service utilization; 4) current challenges in HIV prevention for black women; and 5) barriers and opportunities regarding future HIV vaccines among Canadian black women. Participants filled out a brief socio-demographic questionnaire at the end of each focus group

II. Data Analysis

Focus groups and interviews were digitally recorded and transcribed verbatim (and translated into English). Data were analyzed by a team of three independent investigators using narrative thematic analysis, including line-by-line, in vivo, axial and theoretical coding, with NVivo qualitative software. The use of different data sources (clients and providers; i.e., data source triangulation) and methods (interviews and focus groups; i.e., methodological triangulation), along with member checking (key informants were re-contacted to ensure the validity of the data and, along with the Community Advisory Board, to provide input into overall interpretation) and peer debriefing (discussion with researchers from African and Caribbean communities) increase the trustworthiness of the findings.

Phase 2: Survey of African and Caribbean Black Women

I. Data Collection

We built on findings from Phase I, along with input from the Community Advisory Board, to guide development of a survey questionnaire. The Community Advisory Board and researchers from the community and the university reviewed all survey questions to ensure cultural competency, sensitivity and relevance to the community. Women from diverse African and Caribbean populations were trained to administer the anonymous survey questionnaire, which took approximately one hour to complete. Questions examined: 1) socio-demographics (e.g., income, education, marital status); 2) social determinants of health; 3) HIV risk perceptions and behaviours; 4) HIV prevention and health care services utilization; and, 5) acceptability of and access to future HIV vaccines. Participants were each presented with 8 different hypothetical HIV vaccines which they ranked and rated in terms of their acceptability. Sensitive questions about risk behaviour and drug/alcohol use were included in an anonymous self-administered questionnaire.

Recruitment was conducted through community organizations serving diverse black women through outreach staff and with flyers, as well as newspaper ads in community publications.

II. Data Analysis

We used univariate and multivariate statistics were to analyze demographics, social determinants of health, HIV risk behaviours and risk perceptions. HIV vaccine acceptability was assessed using a special method borrowed from market research, conjoint analysis. Each participant was presented with eight laminated cards, each of which described a different hypothetical HIV vaccine. Each vaccine had a mix of different characteristics: efficacy (99% vs. 50%), side effects (none vs. minor), cost ($10 vs. $250), duration of protection (10 years vs. 1 year), type of protection (cross-clade vs. single-clade), doses (1 vs. 4), and route of administration (oral vs. injection). Participants rated each vaccine in terms of how likely they would be to accept vaccination. We calculated the average acceptability overall for HIV vaccines and the level of acceptability for each of the eight hypothetical vaccines. We then estimated the influence of each vaccine characteristic on vaccine acceptability for each participant, and then averaged across participants using ANOVA to determine the impact of each vaccine attribute on vaccine acceptability.

5. RESULTS

Overview

Phase I (focus groups and key informant interviews) preceded Phase II (survey questionnaire) in the data collection. In this report, we begin with presentation of results from Phase II in order to provide an overview of HIV vaccine acceptability among Canadian black women, and the importance of various vaccine characteristics on acceptability. Then we report results from Phase I to give in depth perspectives on issues raised in the survey, and to provide a context for understanding HIV prevention and HIV vaccine access and acceptability.

Phase 2: Survey of African and Caribbean Black Women

I. Participant Demographics

Overall, 206 African and Caribbean women completed face-to-face survey questionnaires. Table 1, below, provides detailed participant demographic information. Most participants (81%) were born outside Canada; the majority (85%) had Canadian citizenship or permanent residency. Half of participants (48%) had high school or less as their highest level of education, while over a third had completed community college. Over one-third of participants were employed full-time outside of the home, while one-quarter worked part-time and one-quarter were not formally employed.

Table 1. Socio-demographic Characteristics of Survey Participants (n=206)

Characteristic	Mean	Range
Age, years	35	18-68
Years in Canada (for foreign born)	18	1-57
Monthly Income	$1112	
	Number	**Percent**
Born in Canada	39	19%
Ethnic Origin		
African	93	45%
Caribbean	100	49%
Multiple	10	5%
Highest Level of Education		
Less than high school	17	8%
Completed high school	82	40%
Completed college	71	35%
Completed university	34	17%
Relationship Status		
Single/never married	87	42%
Married/common law	81	39%
Separated/divorced/widowed	37	18%
Employment Status		
Working full-time (paid)	79	38%
Working part-time (paid)	49	24%
Unemployed/work at home	55	27%
Permanent/temporary disability	6	3%
No response	17	8%

II. Key Findings

A. Overview: HIV Prevention Findings

Information collected on HIV prevention risks and opportunities for African and Caribbean black women in Toronto included perceptions of personal and community risk for HIV/AIDS, risk behaviour (number of sexual partners, frequency of condom usage), acceptability of future HIV vaccines and post-vaccine changes in risk behaviour.

B. HIV Risk and Vulnerability

i) Risk Perceptions

As indicated in Table 2, when asked about perceptions of personal risk for HIV, 60% of respondents reported that sex with their primary partner or husband was not risky. Over half (52%) of participants indicated sexual assault posed a high personal risk for HIV infection. Almost half (45%) responded that not being able to say no to sex posed a high risk for HIV infection.

Table 2. Perception of Personal Risk for HIV/AIDS (n=199)

Source of risk	No risk number (%)	A little risk number (%)	Some risk number (%)	High risk number (%)
Sex with husband/ primary partner	120 (60%)	49 (25%)	20 (10%)	10 (5%)
Sexual assault	70 (36%)	8 (4%)	15 (8%)	102 (52%)
Not being able to say no to sex	83 (42%)	13 (7%)	14 (7%)	89 (45%)

In terms of HIV risk perceptions on a community level, the majority (53%) of women indicated that sex with a husband or primary partner posed no risk. Half (51%) of the women perceived sexual assault as posing a high risk for HIV within their community; and half (50%) indicated that not being able to say no to sex was a high risk for their community. One-third (34%) of participants reported that using alcohol before or during sex posed a high risk for HIV infection within their community, and over one-third (37.5%) indicated using drugs before or during sex as a high risk in the community.

ii) Risk Behaviours

Two-thirds of participants reported engaging in sex in the past year. As indicated in Table 3, of those who engaged in sex, three-quarters (72%) had one sex partner; 17% had two partners; and 11% had 3 or more partners. Most women (62%) did not use a condom during their last sexual encounter, and 14% used condoms consistently during the past 12 months (see Table 4). One in twenty (5%) participants indicated awareness that at least one of their male sex partners in the last 12 months also had sex with men. During the past 12 months, 5% reporting being told by a doctor or health care provider that they were exposed to a sexually transmitted infection.

Table 3. Number of Sexual Partners During the Past 12 Months (n=200)

Number of sex partners	Number of respondents	Percent
0	67	34%
1	96	48%
2	23	12%
3	7	4%
4	2	1%
5 or more	5	3%

Table 4. Frequency of Condom Use During Sex in the Past 12 Months (n=191)

Frequency	Number of respondents	Percent
All of the time	27	14%
Most of the time	35	18%
Occasionally	19	10%
Rarely	13	7%
Never	97	51%

C. HIV Vaccine Acceptability

Overall, the average level of HIV vaccine acceptability was moderately positive—56 on a 100-point scale—among African and Caribbean women. Nevertheless, the level of acceptability varied widely depending on the characteristics of a vaccine. Table 5 shows the acceptability of the highest (84 = highly likely to take the vaccine) and lowest (26 = somewhat unlikely to take the vaccine) rated HIV vaccines along with their characteristics.

Table 5. Vaccine Characteristics of Highest and Lowest Ranked Vaccines

HIV vaccine acceptability (mean)[a]	Vaccine characteristics						
	Efficacy (%)	Side effects	Cost	Duration of protection	Doses	Protection	Route
84	99%	None	$10	10 years	1	Cross-clade	Mouth
26	50%	Minor[b]	$250	1 year	1	Canada	Injection

[a] Vaccine acceptability mean on a scale from 0-100
[b] Minor side effects: temporary side effects of body aches and fevers

The efficacy (how effective the vaccine is at protecting against HIV infection) of a future HIV vaccine had the greatest impact on participants' acceptance. As shown in Table 6, below, a change from 99% to 50% efficacy resulted in a drop in acceptability from 65 (somewhat likely to accept vaccination) to 39 (somewhat unlikely to accept vaccination). The second most influential feature of an HIV vaccine was possible side effects, followed by cost, duration of protection (how long the vaccine would protect against HIV infection) and number of doses needed.Cross-clade protection (ability of the vaccine to protect against different HIV subtypes) and route of administration were not significant predictors of hiv vaccine acceptability.

Table 6. Impact of HIV Vaccine Characteristics on HIV Vaccine Acceptability

HIV vaccine characteristics[a]	Values of characteristics	Acceptability of vaccine with preferred characteristic (mean)[b]	Acceptability of vaccine with non-preferred characteristic (mean)[b]	Impact on vaccine acceptability (mean)[b, c]
Efficacy**	99% vs. 50%	65	39	27
Side effects**	None vs. minor	57	47	10
Cost**	$10 vs. $250	57	47	10
Duration of protection**	10 years vs. 1 year	56	48	7
Doses*	1 vs. 4	53	51	2
Protection	Cross-clade vs. Canada	53	51	1
Route	Mouth vs. injection	52	52	-1

Statistical significance: * p<.05 for one-sample t-tests, **p<.001 for the one-sample t-tests
[a] Presented in order of decreasing impact of attributes on HIV vaccine acceptability
[b] Mean acceptability on a scale of 0 - 100
[c] Impact score is the mean impact of each vaccine characteristic on vaccine acceptability

D. Risk Behaviour Change After an HIV Vaccine

The majority of women (58%) reported they would either not change their HIV risk behaviour if they received an HIV vaccine or that they would use condoms more often following HIV vaccination (24.5%). However, 17.5% of the women surveyed reported they would use condoms less following HIV vaccination. Very few (3.5%) participants indicated they might increase their number of sexual partners after receiving an HIV

Phase 1: Focus Groups and Key Informant Interviews

I. Participant Demographics

Nearly two-thirds of the 26 focus group participants were of African origin; one-third identified as Caribbean. Participants' mean annual income was $13,836.00. Overall, 43% were unemployed and 43% had not completed high school. Most (87%) participants reported they were HIV negative, but 22% overall had never been tested for HIV.

Table 7. Socio-demographic Characteristics of Focus Group Participants (n=26)

Characteristic	Mean	Range
Age, years	32	19 - 68
Years in Canada (for foreign born)	10	1 - 40
Monthly Income	$1154	
Ethnic Origin	**Number**	**Percent**
African	14	61%
Caribbean	8	35%
Other	4	4%
Highest Level of Education		
No formal education	3	13%
Some high school or less	7	30%
Completed high school	3	13%
Some college/university	5	22%
Completed college/university	5	22%
Immigration Status in Canada		
Citizen	13	57%
Permanent resident	3	13%
Work/student visa	2	9%
Refugee claimant	3	13%
Undocumented	1	4%
Currently in Relationship		
Yes	15	65%
No	8	35%
Employment Status		
Working full-time (paid)	6	26%
Working part-time (paid)	4	17%
Unemployed/work at home	1	4%
Permanent/temporary disability	9	39%
No response	2	9%

II. Key Themes: HIV Prevention

A. Overview: HIV Prevention

As described Table 8, below, three overarching themes emerged regarding HIV prevention with African and Caribbean black women in Toronto: HIV prevention barriers, discrimination, and HIV prevention opportunities.

Table 8. HIV Prevention Barriers, Discrimination, and HIV Prevention Opportunities among African and Caribbean Black Women in Toronto

Theme	Subthemes	Description
HIV Prevention Barriers	HIV/AIDS stigma	HIV/AIDS was perceived as an issue related to moral impropriety rather than health
	Cultural disconnections	A mismatch between predominant HIV prevention discourse and cultural contexts
	Lack of engagement with Black Religious institutions	The church doctrine influences people's attitudes and specific behavioral practices
Discrimination	Sexism	Cultural gender norms place women at risk for HIV and limit their ability to enact HIV preventative measures
	Poverty	A structural context that forces choices between immediate risks (i.e. shelter) versus longer-term risks (i.e. contracting HIV/AIDS)
	Racism	Racism results in mistrust of the healthcare system, a disavowal of HIV/AIDS by already stigmatized communities, and discrimination in healthcare information and services
	Homophobia	Homophobia precludes open discussion about the need for safer sex practices and may be more likely to place female partners at risk
HIV Prevention Opportunities	Black religious institutions	Messages originating from the pulpit and HIV prevention initiatives on church grounds
	Mainstreaming	Raising public awareness, integrating HIV prevention and testing into regular health care services, and using community health centres
	Provider training	Doctors could be trained to explain and communicate more effectively about HIV
	Utilize existing advocacy groups and priorities	Integrate HIV prevention into groups advocating for anti-racism and basic needs

B. HIV Prevention Barriers

i) Stigma: "A moral discussion"

Participants described how the stigma associated with HIV has led HIV to be perceived as an issue related to morality rather than community health.

> *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.*
>
> *Participant*

This stigma supports silence around issues related to HIV/AIDS.

> *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.*
>
> *Key Informant*

ii) Cultural Disconnections: "This is somebody else's issue"

HIV prevention initiatives were described as conflicting with certain cultural values and practices of black women. The focus on men, and gay/bisexual men in particular, in HIV prevention messages contributes to the perception that HIV/AIDS is not a concern for black women.

> *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, that somehow this issue is not their issue, that this is somebody else's issue. Women have exempted themselves when it comes to this issue, black women specifically.*
>
> *Key Informant*

Participants also described disconnections between technologies for HIV prevention, such as condoms, and options that would give women control.

> *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.*
>
> *Participant*

iii) Lack of Engagement of Black Religious Institutions: "Religion prescribes how women should behave"

The lack of engagement with black religious institutions was described as an obstacle to HIV prevention with black women, as the church may influence attitudes and behaviour.

> *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.*
>
> *Participant*

> *A lot of women tend to practice what their religion tells them to practice, because religion determines…religion prescribes how women should behave.*
>
> *Key informant*

C. Discrimination

Multiple intersecting types of discrimination were described that constrain black women's choices.

i) Sexism: "She knows the risk, but she doesn't have any power…"

Sexism was described as lowering both women's awareness of risk for HIV and their ability to take action to reduce this risk. Power differentials within marriages limit women's ability to enforce condom usage:

> *She knows the risks but she does not have any power once confronted by her life partner.*
>
> *Participant*

> *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.*
>
> *Key Informant*

ii) Poverty: "The majority of…black communities are living in poverty…"

Poverty and economic dependency were discussed as a basis for engaging or enduring in unsatisfactory relationships with men that often placed women at risk for HIV.

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.

Key Informant

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 the income.

Key Informant

iii) Racism: "You didn't care about me before, so why should I believe you care about me now"

Racism was described as resulting in reduced trust in health institutions, stigmatization of people of African descent, and devaluation of black women.

The history of black people is very interlinked to discrimination. You know you have colonization, you have slavery and you have all those things; 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?'

Key Informant

Participants reported feeling devalued and disrespected by service providers when seeking information about HIV/AIDS. As a result, they often do not receive adequate information:

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.

Key Informant

iv) Homophobia: "…most straight black women don't want to hear about bisexuality"

Key informants reported taboos around talking about homosexual or bisexual behaviour limit awareness and opportunities to discuss HIV risk. Lack of safe spaces to engage in same-sex relationships may result in men's engaging in heterosexual relationships as a cover.

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 has sex with another man.

Key Informant

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.

Key Informant

D. HIV Prevention Opportunities

i) The Black Church: "Unless it comes from the pulpit, it is not happening"

The black church was discussed as a powerful cultural institution with the potential to support HIV prevention and education. Participants described the church as a vital forum for disseminating information regarding HIV/AIDS.

Maybe church …that's a good idea isn't it; everyone goes there. After Sunday service.

Participant

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.

Key Informant

ii). Mainstreaming: "HIV…connected to larger pieces"

Participants suggested integrating HIV/AIDS information and HIV prevention into general education and women's health care instead of treating HIV/AIDS as a separate issue.

I think it's important that there is this general knowledge and awareness of what HIV is all about.

Participant

A key informant articulated how addressing HIV in a similar manner to other major diseases may be vital to reducing stigma and blame:

> *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 Informant*

iii) Ethno-specific Agencies: "…which groups of people have that relationship with black women"

Ethno-specific agencies were described as providing advocacy for black women and having established links to black communities.

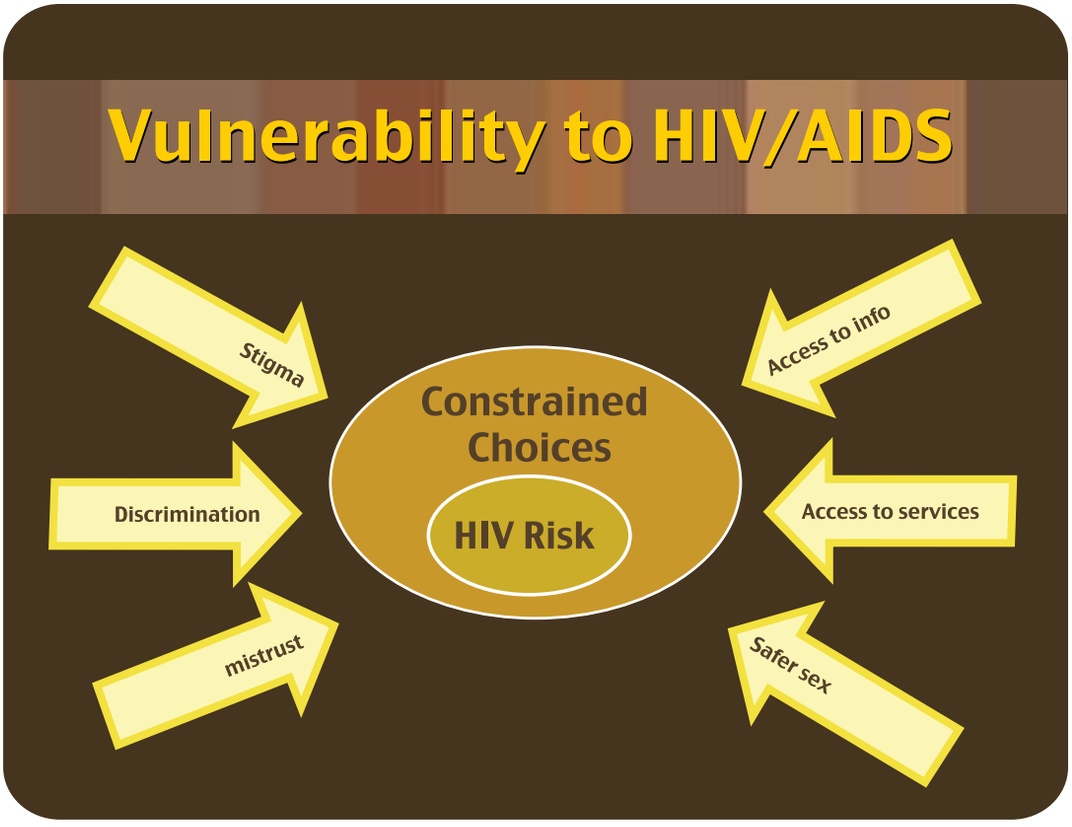
> *I never believe mainstream service providers will ever advocate on behalf of black women and women of color. That is the belief I have no matter what someone tells me, no matter how much education you might do with me, but it's based on experience; it's based on what I have seen as I have worked within the field.*
>
> *Key Informant*

> *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.*
>
> *Key Informant*

E. Vulnerability to HIV/AIDS

Figure 1. illustrates vulnerability to HIV/AIDS among Canadian black women as influenced by constrained choices due to multiple social and structural factors.

Figure 1. Social and Structural Factors and HIV Vulnerability



III. Key Themes: HIV Vaccine Acceptability

A. Overview of HIV Vaccine Acceptability Themes

Several themes emerged in regard to barriers and facilitators to acceptability of an HIV vaccine among black women. Table 9 provides an overview of the major themes and sub-themes in this domain.

Table 9. Barriers and Facilitators to HIV Vaccine Acceptability Among Black Women in Toronto

Overarching Theme	Theme	Sub-theme	Description
Barriers	Disparities in health research	Lack of inclusion in clinical trials	Limited involvement of black communities and women within vaccine trials
		Mistrust in vaccine development	HIV vaccines were viewed as being developed with white consumers in mind.
		Population-specific side effects	Concerns that physical differences may mean vaccines impact black women differently than white woman
	Cost and access	Affordability	Vaccines should be free or covered by governmental health care plan
		Accessibility to non-status women	Women not covered by health care plans should also be able to access HIV vaccines
	Socio-cultural factors	Stigma	The stigma surrounding HIV/AIDS may persist despite the development of HIV vaccines
		Low perception of risk	The perception that women in Canada are at low risk for HIV and don't need a vaccine
		Certain religious beliefs	Certain religious beliefs may result in women not taking vaccines or medicine
Facilitators	Community support	Community outreach and education	Community outreach and education regarding HIV and HIV vaccines is key to vaccine acceptability
		Social saturation	Word of mouth and knowing people in one's community who have already been vaccinated promote vaccine acceptability
		Hope	Vaccines represent hope of helping black communities and others impacted by HIV/AIDS
	Women-controlled prevention technology		Vaccines are a prevention technology women could control to protect themselves/family
	Mainstreaming		Vaccine distribution in community health centres will reduce stigma and promote access
	Relationships with PLHA (people living with HIV/AIDS)		Relationships with people living with HIV and having HIV+ partners would increase acceptance

B. Barriers to HIV Vaccine Acceptability

i) Disparities in Health Research

Lack of inclusion in clinical trials: "very limited involvement of ethnic minority populations…women"

Inclusion of black communities, and black women, within future clinical trials to test HIV vaccines was seen as integral to successfully disseminating HIV vaccines in the future:

> *Unless people make concerted efforts around inclusion you may end up having people look at them and say 'you know what, I'm not too sure I should be touching this'.*
>
> *Participant*

> *Clinical trials, whether it's vaccines, whether its treatment, very limited involvement of ethnic minority population but far worse; involvement of women.*
>
> *Participant*

Mistrust in vaccine development: "All this stuff is made for white people"
HIV vaccines were discussed as being developed for white consumers with little thought given to the possible differential effects on black people:

> *All this stuff is made for white people; I'm not going to lie. I think when scientists make things, they're making it based on how the white consumer will feel with it and how their bodies will react to it.*
>
> *Participant*

> *When these scientists do make it, the majority of them are white and even if there are black ones, they're working for the white people. So when they do make these medicines it's going to be for their market, the people they're looking to help.*
>
> *Participant*

Population-specific side effects: "…something that might cure white women might give us another disease". Participants expressed concerns that physical differences between black and white women may result in HIV vaccines impacting black women's bodies differently.

> *Black women, I'll say, and white women, are different.*
>
> *Participant*

There could be more side effects for us. So something that might cure white women might give us another disease. So we get rid of AIDS and get cancer.

Participant

ii) Cost and Access: "…the cost would be high in the beginning"

Cost and access emerged as significant concerns regarding black women's ability to benefit from future HIV vaccines:

If it's not covered by OHIP (Ontario Health Insurance Plan) then it is not accessible. I think the cost would be high in the beginning if they have HIV vaccine.

Participant

Issues were raised regarding accessibility of HIV vaccines for non-status and refugee women who may not be covered by government health care plans. There are a lot of black women who have no legal status here so you have to make sure that they also get the vaccine.

Key Informant

iii) Socio-cultural Issues

Stigma: "…over 25 years and the stigma is still there"

Strong stigma associated with HIV/AIDS was reported in black communities, which may present barriers to acceptance of future HIV vaccines:

HIV has a stigma, period. Within our community. Period, across the board. But we're talking specifically about African and Caribbean black people.

Participant

To believe that the vaccine would vaccinate people against the stigma and against the issue surrounding HIV, ok, is to inoculate yourself against reality because this epidemic now is over 25 years and the stigma is still there.

Participant

Low perception of risk: "What are you going to get a next vaccine for?"
Some participants viewed themselves as not at risk for HIV infection, and thus not in need of an HIV vaccine. People who were unmarried or living in HIV endemic countries were viewed as higher risk populations that may be more likely to accept HIV vaccines.

We do not live in a country where we are at high risk. If the vaccine was to become available in Africa tomorrow, they would not hesitate, they would take it. But for us the risk of getting infected only depends on us.

Participant

What are you going to get a next vaccine for? You're not married, you don't have one person, what are you doing that you need to be in the street getting a vaccine?

Participant

Certain religious beliefs: "according to my religion…I don't take vaccines"
Certain religious beliefs may impact black women's acceptance of HIV vaccines, including a range of beliefs from non-use of vaccines in general to the immorality of HIV and any associated vaccine:

Depends on people's faith; like there is some people they don't take vaccine. Some people don't take injections, they say according to my religion, I don't take medicine, I don't take vaccines.

Participant

There's a lot of other woman, who for moral reasons, for religious reasons… wouldn't want to engage with that vaccine.

Participant

C. Facilitators to HIV Vaccine Acceptability

i) Community Support

Community outreach and education: "...lots of information and consciousness-raising in order to break the distrust"
Key informants and participants described the links between community outreach and education, and vaccine acceptability:

People are already skeptical about vaccines so when you talk about HIV/AIDS vaccine I think there will be a need for lots of information and consciousness raising in order to break the distrust.

Key informant

Offering information about what vaccines are, how they work, what the benefits are, first discussion. Second discussion: does it make sense for me?

Participant

Social saturation: "hearing from your home girls and your sisters"
Uptake of HIV vaccines by others in the community (social saturation) and word of mouth emerged as facilitators to HIV vaccine acceptability.

People usually agree to be vaccinated if they already know someone who was vaccinated before them …the major influence when it comes to vaccine in this particular community is what is being said and what people have already heard about the vaccine.

Key informant

One of the biggest things, especially in the black community, is word of mouth and hearing from your home girls and your sisters, what are they using, what do they feel about it.

Participant

Hope: "If there is a vaccine, that means there is hope"
Acceptance of vaccines was also associated with hopefulness towards helping the black community and other populations disproportionately impacted by HIV/AIDS.

Black people need it because we are one of the highest demographics who are getting HIV. We need it, anything to cure our people, I'm all for it.

Participant

If there is a vaccine, that means there is hope.

Key informant

ii) Women Controlled Prevention Technology: "I don't know where my husband goes"

HIV vaccines were described as a prevention technology that women could control to protect themselves and their families.

I don't know where my husband go…he will come back and tell you 'Honey I came back from work' and you don't know where he has gone for lunch…If I am his wife and I have taken that vaccine, he is the one to die and not me.

Participant

Women who planned on having children may be willing to take the vaccine to protect themselves and their baby:

We could easily recommend the HIV vaccine and I believe we will be more successful with women who wish to procreate.

Key informant

iii) Mainstreaming

Participants recommended offering HIV vaccines as part of routine care in community-based health centres, rather than in HIV-specific venues, as a way to enhance acceptability and reduce stigma.

Vaccines should be offered by all health centres & maybe also in specialized hospital...not everyone has time to access the vaccine.

Participant

Figure out a distribution mechanism that moves it away from around HIV. It's like you could actually go to your provider who takes care of your health, you're going for your flu vaccine you could get the HIV vaccine too…so it has to be marketed in a way that it just doesn't come saying: 'Oh, we have the HIV vaccine, come line up.'

Key Informant

iv) Relationships with People Living with HIV/AIDS: "I know what parents go through, what those patients go through"

Engaging with people living with HIV/AIDS was described as a facilitator to HIV vaccine acceptability. A participant described personal experiences with people living with HIV/AIDS that may increase vaccine acceptability:

I've seen, I have volunteered with AIDS patients. I know what parents go through, what those patients they go through…I don't think there is somebody who can refuse to go for the HIV vaccine.

Participant

Individuals with HIV-positive partners were also seen as motivated to take an HIV vaccine:

Individuals I think would be the most willing to take it, people who are married to somebody or whose partners are HIV positive…that would give them an extra sense of stability and safety and willingness to get vaccinated, that would be the number one population.

Key informant

6. DISCUSSION

Acceptability of future HIV vaccines is not guaranteed among Canadian black women. The overall moderate level of HIV vaccine acceptability, combined with the low acceptability of partially effective vaccines (i.e., that provide less than 100% protection), suggests that uptake of future HIV vaccines is not guaranteed.

Women in this study described vulnerability to HIV infection that arises as a result of difficulties in negotiating condom use with men, as well as husbands' sometime extramarital sex, and overall gendered and culture-specific barriers to using condoms, particularly with male spouses. Nevertheless, HIV vaccines may be encumbered by numerous obstacles that may decrease their acceptability and accessibility to black women. The present data from diverse black women identifies a variety of potential obstacles and offers routes to overcome those obstacles in order to increase access to and acceptability of future HIV vaccines.

Overall, important parallels emerged between obstacles that arise in current HIV prevention strategies that hamper engagement and appropriate dissemination to black women, and challenges for future dissemination of HIV vaccines. Structural barriers to HIV prevention in the present that result from multiple intersecting forms of discrimination (e.g., gender inequity, racism, poverty and homophobia), socio-cultural factors such as powerful HIV/AIDS stigma and certain religious beliefs, and disconnections between dominant HIV prevention messages and black women, were discussed as barriers that may similarly impede accessibility and acceptability of future HIV vaccines.

A number of opportunities to increase the effectiveness of current HIV prevention efforts in reducing vulnerability among black women also emerged as important interventions to increase the effectiveness of future HIV vaccines. Community outreach and education, mainstreaming of HIV vaccines through ethno-specific agencies, engagement with the black church, and engaging black communities in HIV vaccine development efforts emerged as methods to increase the acceptability and uptake of future HIV vaccines.

In addition to identifying specific characteristics of HIV vaccines that may affect their acceptability to black women, the present study suggests the feasibility of conducting research in collaboration with black women to identify their preferences and concerns in regard to HIV vaccines. Our survey data indicate that the level of vaccine efficacy, side effects and the cost of the vaccine may have the greatest impact on the acceptance of an HIV vaccine. Furthermore, low perception of personal risk and the identification of HIV vaccines as for certain designated "risk groups" were associated with lower levels of vaccine acceptability.

Overall, this mixed-method project highlights the vital importance of addressing social and structural barriers, rather than a sole focus on individual-level knowledge,

attitudes and behaviour, and the importance of community-level interventions in ensuring equity in access to future HIV vaccines among Canadian black women.

A participant aptly stated, "offering information about what vaccines are, how they work, what the benefits are, first discussion; second discussion, 'does it make sense for me?'" Ultimately, the goal of this project is to ensure that Canadian black women are provided with information, in a respectful, accessible and relevant manner, to enable decision-making to support the best choices for themselves, their families and communities. Integral to supporting black women's choices around future HIV vaccines is the mobilization of community strengths and facilitating institutional change—in HIV/AIDS education and prevention strategy and interventions, health care providers and institutions, and government programs—to ensure equity in access to future HIV vaccines.

The present project is an important first step in that direction: 230 diverse Canadian black women volunteered as participants, 12 key informants and community advisory board members provided pivotal insights and direction; and a research staff of over 20 women from the community made this project a success.

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8. HIV VACCINE MYTH BUSTERS

- There is NO HIV vaccine currently available.
- An HIV vaccine CANNOT cause HIV or AIDS.
- There is NO vaccine testing without people's consent.
- There is NO cure for HIV or AIDS.
- Researchers are currently testing possible vaccines that may be available in the future.
- It usually takes at least 10-20 years to bring a vaccine from initial research to public availability.

For more information about the Sisters, Daughters, Mothers and Aunties project, please visit ***www.protectsisters.com.***

9. INFORMATIONAL RESOURCES

- For more information about HIV/AIDS
  http://www.hc-sc.gc.ca/dc-ma/aids-sida/index_e.html

- For more information about HIV vaccine candidates currently in testing
  http://www.iavi.org

- Women's Health in Women's Hands
  http://www.whiwh.com

- University of Toronto, Factor-Inwentash Faculty of Social Work
  http://www.socialwork.utoronto.ca

- African and Caribbean Council on HIV/AIDS in Ontario
  http://www.accho.com

- Canadian Institutes of Health Research
  http://www.cihr.ca


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