

WCBR Project Community Report



**Involving Ontario HIV-Positive Women and
Their Service Providers in Determining Research
Needs and Priorities**

WCBR Project Community Report



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Women's Health in Women's Hands Community Health Centre
In partnership with
Women's College Research Institute, Women's College Hospital



WOMEN'S HEALTH
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EXECUTIVE SUMMARY

This report provides the results and recommendations from the community-based research project entitled: Involving Ontario HIV-Positive Women and Their Service Providers in Determining Their Research Needs and Priorities, also known as the WCBR project. This 2007-2011 study was a collaborative effort between Women's Health in Women's Hands Community Health Centre (WHIWH) and the Women's College Research Institute (WCRI), with funding from Canadian Institutes of Health Research, the AIDS Bureau, and the Ontario Ministry of Health and Long Term Care.

Due to lack of research, there is limited knowledge and understanding of the impacts of HIV on the lives of women, the challenges they face, and their experience engaging with health and social systems. The WCBR projected targeted groups of women who were particularly vulnerable to HIV to generate research priorities, understand women's relationships with researchers, and identify how to maximize women's participation in HIV research.

The project consisted of 2 phases: A qualitative phase of 19 focus groups: 15 with 104 Women living with HIV in 5 Ontario cities, and 4 with 45 service providers in 3 Ontario cities. Women living with HIV were trained to participate as Peer Research Assistants and assisted with focus group recruitment and implementation. Stigma and discrimination related to HIV status, race, gender amongst other factors emerged as one of the major issues in all the focus groups, and informed the direction of Phase 2: a quantitative survey focusing on one of the groups of women highly impacted by HIV/AIDS in Ontario - African, Caribbean, and Black (ACB) Canadian women.

Other main themes that emerged from the Phase 1 data were: poverty, employment barriers, mental health and emotional issues, social isolation, physical health, and the need for more gendered and women specific research that engages Women living with HIV. Phase 2 results showed that higher levels of sexism, racism and HIV-related stigma were associated with higher levels of depression, lower quality of life and reduced access to care. The results also indicated that higher levels of resilient coping were associated with lower rates of depression.

The research priorities identified by the participants highlighted current gaps in knowledge, and the need for gender-based research and programming. There was a disconnect between the research community and the HIV community, which drastically reduces research participation. Recommendations emerging from the study included: 1) need for improved relationships between researchers and HIV positive women, 2) heightened awareness of the need for more research for and with women living with HIV and 3) an increase in accountability and transparency



WCBR

The Women's Community Based Research (WCBR) project got its name from the use of community based research as a method/process. Community-based research (CBR) is collaborative and equitable; bringing together the knowledge and skills of community members, peer research assistants, and researchers. The "W" represents that this was one of the first CBR projects with Women living with HIV in Ontario.

The project team represented people from different backgrounds and areas of expertise. The CBR process ensured that the voices of women in these communities were valued and impacted the future directions of this project.



□ INTRODUCTION

“The lack of participation of ACB populations in research has been linked to historical experiences of colonialism, slavery, and systematic racism within medical research studies.”

INTRODUCTION

□ About the Project

The proportion of new HIV diagnoses found in women living in Canada and Ontario has drastically increased in the past eight yearsⁱ. This fact coupled with the lack of research carried out involving the women living with HIVⁱⁱ, made it crucial to determine which topics of research are priorities to this community. Historically, there has been a lack of collaboration and trust between academic researchers and community groups, particularly in African, Caribbean and Black (ACB) communitiesⁱⁱⁱ. The lack of participation of ACB populations in research has been linked to historical experiences of colonialism, slavery, and systematic racism within medical research studies.

The most prominent example of this racism is the Tuskegee Syphilis study which took place from 1932-1972 by the U.S. Public Health Service. The study tracked the natural progression of untreated syphilis in rural black men who thought they were receiving free health care from the U.S. government^{iv}. None of the men were told they had syphilis, nor were they treated for their illness when penicillin became available. Thus, “for many Blacks, the Tuskegee study became a symbol of their mistreatment by the medical establishment, a metaphor for deceit, conspiracy, malpractice, and neglect, if not outright racial genocide.”^v The historical experiment creates a prejudice against medical research that can sometimes outweigh the commitment of individual investigators or organizations, creating a negative impact on participation^{vi}. Hence, there is a need for better communication between academics, investigators and the ACB community, including an increased input from community members and individuals affected by HIV in regards to what research is being done, and what research questions should be addressed.

The WCBR project sought to gain a comprehensive understanding of the lives and research priorities of women living with HIV in Ontario and their opinions on HIV research. With funding from the Canadian Institutes of Health Research (CIHR), the AIDS Bureau, and the Ontario Ministry of Health and Long Term Care, the study gathered data using focus groups and surveys from 2008 to 2010. To truly capture the lived experiences of women living with HIV, the project worked with women of various races, ethnicities and identity characteristics (e.g. transwomen, heterosexual and queer sexualities, drug users, sex workers, etc.), who were affected by HIV through various routes, and who are often underrepresented in research. In addition to topics surrounding research, the women were also invited to share the structural and social issues they experience in their daily lives, such as issues with HIV-related discrimination and stigma.

In addition to gathering information from women living with HIV, the WCBR study also sought to gain input and collaboration from the service providers who have been involved in the care and support of women living with HIV in Ontario. This included social workers,

counselors, nurses, physicians and others. By gathering data from both women living with HIV and their service providers (some of who were also HIV researchers), we gained valuable and holistic insight on the basic issues women were struggling with on a day-to-day basis as well as the current gaps in HIV research, funding and policy.

□ About This Report

This report provides an overview of the goals and objectives of the WCBR project, and briefly explains the methodologies, recruitment strategies and data collection for both the qualitative and quantitative phases of the project. It summarizes the findings from the qualitative and quantitative analyses, and provides the reader with insight into the different social and structural issues facing women living with HIV. The topics range from housing and economic security to HIV-related stigma and violence. The majority of the report will focus on the key themes and recommendations in relation to what women living with HIV and their service providers think about HIV research, and what their research priorities are. Particular attention will be paid to the stigma and power dynamics between women living with HIV and researchers, and the recommendations made by the participants to combat these issues.

This report is created with the intention that it will be shared with and acted upon by communities, service providers, researchers, physicians, councilors, AIDS Service Organizations (ASOs) and policy makers. Due to the extensive amount of information collected over this project, this report only represents an overview of the data gathered, and is meant to be used in conjunction with the other knowledge translation and exchange (KTE) activities and papers ^{vii,viii,ix} for and from the WCBR project as well as the ongoing research happening at Women's Health in Women's Hands Community Health Centre (WHIWH) and the Women and HIV Research program (WHRP) at Women's College Research Institute (WCRI), Women's College Hospital (WCH), the two women institutions leading the project. The main intention for all KTE strategies from the WBCR project is to inform and impact future action-oriented research, improve overall health of and healthcare services for women living with HIV, and reduce HIV-related stigma and discrimination.

□ About WHIWH

Women's Health in Women's Hands is a community health centre for women of diverse backgrounds in Metropolitan Toronto and surrounding municipalities. In addition to providing primary health care services to Black Women and Women of Colour, WHIWH conducts research to build scientific knowledge on the health of Black women and women of colour. The purpose of this research is to:

1. Generate knowledge and evidence to inform and support the centre's strategic plan, programs and services
2. Promote research capacity for multiple stakeholders
3. Build, promote and support effective mechanisms for knowledge translation and exchange for and between researchers, policy makers, service providers, service users, and community members.

WHIWH's research framework is based on anti-oppression practice and recognizes the intersecting, multiple oppressive systems including gender, culture, sexual orientation, and other dimensions of difference that impact on the health of women and their ability to access and effectively navigate the health care system.

□ About WHRP, WCRI, WCH

Women's College Hospital (WCH)

Women's College Hospital is the first and only independent, academic, ambulatory care hospital in Ontario with a primary focus on the health of women. It is a teaching hospital affiliated with the University of Toronto, and supports research in women's health.

Women's College Research Institute (WCRI)

Women's College Research Institute is a multidisciplinary research institute based at WCH. The institute focuses on many aspects of women's health including HIV, breast cancer, musculoskeletal health, mental health, diabetes, heart disease and the impact of violence and trauma. Researchers at WCRI also explore the social, political and economic forces that influence women's health and their access to health care.

Women and HIV Research Program (WHRP)

The Women and HIV research Program at WCRI was created to better understand and address the research needs of women living with HIV, and improve clinical care for women living with HIV. Women living with HIV face different issues than men including unique complications of infection, sex-specific side effects from anti-HIV treatments, emotional and mental health support needs, as well as unique concerns around pregnancy.

The WHRP team works collaboratively with women living with HIV and affected communities, through partnerships with community advocates, researchers and community organizations. This collaborative work has led to a planned series of focus groups, interviews and a survey to gather information from women and their service providers that will guide and inform the team's research aims.



METHODS

“this project is grounded in anti-oppressive, participatory and community based research paradigms. The theory is framed by anti-discriminatory, anti-oppressive and feminist approaches”

METHODS

□ Research Approach

The research approach for this project is grounded in anti-oppressive, participatory and community based research paradigms. The theory is framed by anti-discriminatory, anti-oppressive and feminist approaches, which highlight exploitation, discrimination, power and voice within the research. The framework takes into account the unequal distributions of power and resources that lead to personal and institutional relationships of oppression and domination. The research aims to empower and support critical analysis and incorporate the perspective of those who have been marginalized into policy and action ^{xi}.

Research must be about empowering the marginalized and promoting action against inequities. Questions about the relationship between the researcher and the researched are highlighted, as is the question of whose voice(s) the research (re)presents... It is concerned with empowerment and/or emancipation of those marginalized by society or in a particular sphere of society.

-Strega ^{xii}

The guiding frameworks mentioned above were put in practice throughout the study, beginning with the formation of a community advisory board (CAB) before the research took place. The CAB comprised of 11 members from agencies providing health/social services to HIV-positive women, and provided consultation on research design and data interpretation. The CAB included one HIV-positive LBQ woman and one HIV-negative transgender woman ^{vii}.

Research Design

This research project consisted of two parts: 1) A qualitative phase consisting of multiple focus groups followed by 2) A quantitative survey phase. The data generated from the qualitative phase informed the theory and methodology behind the quantitative phase. In keeping with the above-mentioned CBR guiding approach, the researchers collaborated extensively with peer research assistants (PRAs) during both phases of the project.

Peer Research Assistants (PRAs)

For this research project, a PRA was defined as a person who shares in common at least one lived experience with focus group participants or HIV-positive serostatus. The PRAs took a very active role in the project by assisting with recruitment of participants and co-facilitation of focus groups along with the research consultant. PRAs received two and a half days of training to provide them with the necessary skills to support the project effectively, as well as remuneration for their time and effort. Once the focus groups were completed, the research team debriefed with the PRAs one-on-one over the phone, and

conducted a focus group with all PRAs present. A “Thank you” event was held for the PRAs, at which they were presented with a report on the research project, the data analysis and interpretations of the results.

□ Data Collection

Phase 1 – Qualitative Phase (Focus Groups)

Phase 1 of the project involved 15 focus groups with a total of 104 women living with HIV from across Ontario (see Appendix A for socio-demographic information). The women self-identified as Aboriginal, African, Caribbean, South Asian, Latina, women involved in injection drug use, women involved in sex work, lesbian, bisexual, queer and transgender women. 4 additional focus groups were conducted with service providers, with a total of 19 focus groups conducted overall. The focus groups took place in Toronto, Ottawa, Hamilton, Sudbury, and Thunder Bay, and were conducted with PRAs who had similar lived experiences and/or existing relationships with the women they were recruiting for focus groups. A semi-structured interview guide was employed to explore the women’s perceptions of research priorities.

Moving from Phase 1 to Phase 2

Upon completion of Phase 1, a select group of participants were invited to participate in the Women and HIV Roundtable based on Grounded Theory to review the Phase 1 findings and develop the plan for Phase 2. Women living with HIV, multidisciplinary researchers and service providers were brought together for full day discussion to utilize the results from Phase 1 to inform the theory and methods for Phase 2. The outcomes of the roundtable were to develop a cross-sectional survey that focuses on one specific population that reflects the epidemiological trends of increasing HIV infections and who had significant unmet needs in Ontario, and to implement this survey across multiple sites. The Roundtable members decided that African, Caribbean and Black (ACB) women living with HIV over 18 years of age best fit the recommendation that emerged from the focus groups and roundtable.

Phase 2 – Quantitative Phase (Surveys)

A survey was developed to further investigate themes and priorities of women living with HIV (that emerge from focus groups, literature, and community mobilization efforts) focusing on ACB women’s quality of life and access to services. A total of 166 women ranging from 18 – 69 years of age participated in the survey (see Appendix B for socio-demographic information). The survey was conducted in three regions: Ottawa, Toronto and Southwestern Ontario, and addressed the following research questions:

1. What is the influence of HIV-related stigma, gender-based discrimination and racial discrimination on quality of life, depression and access to care among Black, African, Caribbean and Canadian women?
2. What is the influence of social support and resilient coping on quality of life, depression and access to care among Black, African, Caribbean and Canadian women?

The background of the slide features a dark red color with a lighter red silhouette of two people in profile, facing each other as if in conversation. The person on the left is holding a clipboard and pen, while the person on the right is gesturing with their hands.

FINDINGS

“Racism as a general life experience was expressed, and particular mention was made of racism within research”

FINDINGS

□ Phase 1 – Qualitative Phase (Focus Group Findings)

As previously stated, phase 1 involved 15 focus groups with 104 women living with HIV from across Ontario (Appendix A). The women self-identified as Aboriginal, African, Caribbean, South Asian, Latina, women involved in injection drug use, women involved in sex work, lesbian, bisexual, queer and transgender women. Below are some of the key themes that arose from these focus groups, and quotes from the participants themselves.

□ Key Themes

HIV-Related Stigma and Discrimination

HIV-related stigma and discrimination was widespread, and came from multiple sources. Each group of participants shared their own experiences of HIV-related stigma, with underlying themes of HIV being viewed as “dirty” or a “gay disease”. Discrimination was felt from the general public, but also directly from healthcare providers. 65% of the survey participants stated that most people with HIV are rejected from society when others find out, while others said being HIV+ made them feel dirty and disgusting, revealing internal stigma. Many participants felt they were treated differently or with caution due to their status.

I was in crisis I had to go see a doctor. I was in the waiting room, when she came in she was wearing a pair of gloves; she had three pairs of gloves and yet it wasn't even a problem related to HIV. It was just a normal crisis. She kept her distance. She asked, “Is it you that is sick?” I said yes. She then asked me what my problem was. I said, “Well, you have the document right in front of you.” She could barely touch me. So when she finally came closer I said, “If you do not remove your gloves you do not touch me!” And I was really repulsed because as far as doctors are concerned I say that the doctor must always be a support to the patient regardless of what sickness the patient has.

-Francophone Participant

Disclosure of an HIV positive status affected participants' relationships with friends and family, and impacted their place within churches and religious communities. HIV-related stigma resulted in invisibility and silence surrounding not only HIV, but sexuality of people living with HIV, and lesbian, gay, bisexual and transgender women.

I can't even see a church talking about HIV or AIDS. Which is kind of sad because I think that would be a really good place to discuss it. Like we went on a spiritual retreat on Monday. And I just feel that like if there was a group that was religious that talked about that, I think it would benefit a lot of people who have HIV or know someone with HIV. Because God's a strong presence in a lot of people's lives.

Discrimination

Discrimination attributed to racism, homophobia and transphobia was described by a majority of the participants as something they encounter on a daily basis. Racism as a general life experience was expressed, and particular mention was made of racism within research - particularly the exploitative relationships between White researchers and Black participants. Participants also felt that their race was an issue when accessing healthcare services in both ASOs and general healthcare agencies. In addition to racism, homophobia and transphobia was also described within healthcare workshops and agencies with manifestations of stigma, discrimination and even violence. This discrimination manifested in many forms, but limiting information for lesbian, bisexual and trans-women was a key theme.

The research is always done on the black folks to find out how we think, how we breathe, how we eat, how we sleep. There is no difference. If you cut me, my blood is red just like yours. I have a heart, I have a kidney; I have all of that, so why do you want to do research on the black folks?

-African-Caribbean Participant

It's difficult for some of the people to really accept that there is homosexuality. So, in a workshop that doesn't involve lesbians, and then you just talk about your girlfriend and you are a girl, some people look like, oh! ... So, it's not easy to be out there in the open when you are just presented as a lady, and then you talk about, oh, my lover, she is at home. They are like, oh my god! You feel like you need to get down there and hide yourself.

-Queer Participant

Economic Security

Financial, housing and employment issues were highlighted as integral components of economic security for women living with HIV. The median monthly income of the participants was \$1400.00; more than 60% sent money abroad to their families and 22.4% of the participants perceived themselves to be living in poverty. Poverty was described as a serious challenge for women living with HIV and hindered activities or factors necessary to improve quality of life, such as access to affordable housing, difficulty with savings and long term investments, adherence to medication, or proper nutrition.

Because of poverty you have housing issues, and then you have lack of access to adequate nutrition. You have lack of transport... increased costs going back and forth between doctors and pharmacists... people making decisions about whether

they have enough money for milk or to take the bus to see the doctor... you rely on AIDS service organizations. They're so under-funded we can't rely on their programs, because one year they have this program and then the next year they have that program.

-HIV Positive Participant

Participants also described difficulty securing employment, often due to lack of opportunities for women living with HIV, lack of training and support, and the conflict it poses with the Ontario Disability and Support Program (ODSP). More than 54% of the survey participants were part of the ODSP, and many described the struggle between wanting to secure employment, while simultaneously losing the support from the ODSP – especially if they were caring for children.

Another challenge would be the way the system in Ontario works, especially the federal system whereby most women that are HIV positive are on ODSP or some social assistance. And, if you pick up a part-time job or whatever, the system is so slow in getting that together it affects your benefits. And, most women who are breadwinners, the financial independence just goes away.”

-African-Caribbean Participant

Immigration and Citizenship

Challenges with immigration status have multi-faceted impacts on the lives of women living with HIV. Participants described challenges with accessing health services and education based on immigration status. Many participants felt alone, and had difficulty sponsoring partners or family members due to their status.

Refugees and non-status people, immigration, legal status in Canada. It is a big battle to get access and services. In the last two months I've seen, women have been called to return, there are women who have been in Canada for maybe five, six years, they maybe applied for refugee status, they were denied, then they went underground and have never gone to see a doctor. They have never taken their medication; they've just been living, working under the table, living in hiding because they fear deportation. These women cannot access anything and that's a big barrier for them.

-Service Provider

Social Inclusion/Exclusion

The participants felt strong isolation and exclusion from communities and the larger society as a result of HIV-related stigma. Over 50% of the survey participants stopped socializing with some people, or lost close friends after sharing their status. Criminalization of HIV was brought forth as a complicated topic, with some women against and some women for – but most agreed that the criminalization increased their social exclusion.

Women struggle with their sense of isolation even when we have high functioning women in their 30's, white, with jobs; they feel like they're alone in their experience. There's no one else. And the impact on their body, esteem and their sense of self is they describe themselves often as defective, tainted. They don't feel like they can really allow themselves to move forward and engage in new relationships because they're marked. So there's a real sense of isolation.

-Ottawa Service Provider

Strengths and attitudes that helped with the stress of feeling isolated included hope, perseverance and self-determination. Analysis of survey data showed that social support and resilient coping were significantly correlated ($r= 0.40$, $p <0.001$), and both of these were also correlated with continuity of care ($r=0.50$, $p<0.001$). These results show that participants who used different ways of coping with or combating social exclusion such as community solidarity or support groups were more resilient, took a more active role in their care, and also experienced less HIV-related stigma and gender-based discrimination.

Well, the thing that really keeps me going is this old phrase that says: It's not over until the fat lady sings. To be honest, because sometimes the things that you have to face, you become so suicidal at many points in your life that you want to just end it yourself. ... I want to do it my way. But then you meet friends, there are groups that – I mean being here in Canada now there are groups that can really help you to pull through. And, they give you strength.

- Queer Participant

Health Care Needs

The healthcare needs of the participants varied throughout each group, but many of the issues were shared across groups. According to survey data, over 83% of the ACB participants used an ASO in Ontario; however, only 21% of them felt that their ASO met their needs as ACB women. There was lack of access to appropriate services and support for queer women, women living with HIV, women whose primary language was not English. Also, lacks of emotional and mental support were major themes. Many of the women also spoke about the emotional trauma they faced when they found out they were HIV+, and how the side effects from their HIV medication created barriers to treatment and disrupted their daily function.

Loneliness, you're lonely, depressed. ... Even when you go to see a psychiatrist or psychologist, they don't really address my issues as a women living with HIV. ... You're told, okay you're depressed, go take this medication. You take the medication and it doesn't help so I think more needs to be done. Having support groups, yeah, where you can go and talk and ease your stress.

- Young HIV+ participant

Other barriers to treatment included poor finances, fragmentation of services, and lack of

services for women, people living on reservations and former drug users.

Most of these ASOs did not cater specifically for women. And, I think that comes from the fact that long back HIV and AIDS was well known to be a white gay man's disease. But I think it's been years and the face of HIV has changed. And, it's high time they changed.

- African-Caribbean Participant

Violence against Women

Violence against women was a staggeringly common experience in the lives of these women. Although silenced and stigmatized, violence against women living with HIV occurred very frequently in all groups of participants involved. HIV+ status, immigration status, non-heterosexual and transgender identity were all factors that the women described as putting them at a higher risk for violence, and many felt there was little to nothing that could be done.

When you have HIV, sometimes some people go through, you want to be loved unconditionally So fear of leaving the relationship, that you wouldn't find another person to love you, to treat you the way that he was treating you before. ... You take abuse thinking that he will change, that he will change and go back to the same person when you first started out. But sometimes they never change.

- Young HIV+ Woman

In my community they know that I'm bisexual, back home. Actually I got my HIV through my brothers, they gang raped me. So, before that I was a lesbian, even before that, bisexual, because I was forced to be bisexual because in my country there is no lesbian, gay, or what. So, you need to hide. Like, okay I am seeing a man, if ever your parents ask you who are you dating, obviously you need to point a man, not a woman.

- Queer Woman

□ Phase 2 – Quantitative Phase (Surveys) Findings

Phase 2 of the research project was to conduct a survey among women who self-identify as living with an HIV positive diagnosis, black African, Caribbean and/or Canadian, 18 years old or older and living in Ontario. The survey was conducted in three regions: Ottawa, Toronto and Southwestern Ontario (Niagara/St. Catherine's, Hamilton region, Kitchener/Waterloo/Guelph/Cambridge and Windsor). Socio-demographic information of participants (n = 166, unless specified otherwise) are described in detail in Appendix B. The average participant age was 40.7 years and the median monthly income was \$1400.00 (USD) (range \$0 – \$7916). Most participants (n = 154; 89.0%) were born outside of Canada: 69.5% in 25 different African countries, and 29.9% in 7 Caribbean countries.

Education and Employment

The educational level of participants included: 28.6% (n=44) with less than high school; 26.6% (n=41) with high school; 28.6% (n=44) with a college diploma; 16.2% (n=25) with a university degree. Employment status included: 17.3% working full-time; 17.8% working part-time; 4.3% on employment insurance; 54.0% on ODSP; 4.9% on CPP; 11.7% on Ontario Works; 17.8% received Child Tax Benefit; 9.0% were students receiving OSAP; 16.0% volunteered.

Monthly Income

The median monthly income was \$1400.00 (Range 0-7916). When participants (n=155) were asked if they sent money abroad to family, 94 (60.6%) said yes, 50 said no (32.3%), and 11 (7.1%) said it was not applicable. The average amount of money in Canadian dollars sent home monthly was \$251.65 (SD: 220.31 and the range was \$0 - \$1100).

Relationship Status

The current relationship status of participants (n=162) included: single (n=69; 42.6%), in a relationship/dating (n=16, 9.9%), married (n=29; 17.9%), common law/living with partner (n=8, 4.9%), separated (n=23; 14.2%), divorced (n=4; 2.5%) and widowed (n=13; 8.0%). The majority of participants (55.8%) currently had children living with them; these participants had an average of 2.2 children (SD 1.5) and 16.9% of the children were HIV-positive.

Health Status

Participants (n=163) rated their health as: very good (n=27; 16.6%); good (n=75; 46.0%); neither poor nor good (n=44; 27.0%); poor (n=10; 6.1%); very poor (n=7; 4.3%). Participants (n=158) described their HIV serostatus as: asymptomatic (n=125; 79.1%); symptomatic (n=25; 15.8%); and AIDS converted (n=8; 5.0%). The average length of time since HIV-positive diagnosis was 7.48 years (n=154).

□ Quantitative Analyses

The survey used multiple linear regression to assess the relationship between independent (HIV-related stigma, gender based-discrimination, racial discrimination, social support, resilient coping) and dependent variables (quality of life, access to care, depression)

Depression

The regression analyses for predictors of depression indicated that HIV-related stigma and gender-based discrimination were significant predictors of depression, indicating that participants with higher HIV-related stigma and gender-based discrimination scores tended to have higher depression scores. Social support and resilient coping accounted for a significant proportion of variance in depression scores after controlling for the effects of HIV-related stigma, gender-based discrimination and racial discrimination. Resilient coping was a significantly associated with depression, indicating that participants with higher resilient coping scores tended to have lower depression scores.

Quality of Life

The regression analyses for predictors of quality of life indicated that income, HIV-related stigma, gender-based discrimination and racial discrimination accounted for a significant amount of variability in quality of life scores. Income, HIV-related stigma and gender-based discrimination were significant predictors of quality of life, indicating that participants with higher income and lower HIV-related stigma and gender-based discrimination scores tended to have higher quality of life scores. Social support and resilient coping accounted for a significant proportion of variance in quality of life scores after controlling for the effects of income, HIV-related stigma, gender-based discrimination and racial discrimination. Social support was a significant predictor, indicating that participants with higher social support scores tended to have higher quality of life scores.

Continuity of Care

The regression analyses for predictors of continuity of care indicated that HIV-related stigma, gender-based discrimination and racial discrimination accounted for a significant amount of variability in continuity of care scores. HIV-related stigma and gender-based discrimination were significant predictors of continuity of care, indicating that participants with higher HIV-related stigma and gender-based discrimination scores tended to have lower continuity of care scores. Social support and resilient coping accounted for a significant proportion of variance in continuity of care scores after controlling for the effects of HIV-related stigma, gender-based discrimination and racial discrimination. Social support was a significant predictor, indicating that participants with higher social support scores tended to have higher continuity of care scores.

Access to Care

The regression analyses for predictors of access to care indicated that gender-based discrimination and racial discrimination accounted for a significant amount of variability in access to care scores. Gender-based discrimination was a significant predictor of access to care, indicating that participants with higher gender-based discrimination scores tended to have lower access to care scores. Social support accounted for a significant proportion of variance in access to care scores after controlling for the effects of gender-based discrimination and racial discrimination. Social support was a significant predictor in indicating that participants with higher social support scores tended to have higher access to care scores.

The background of the slide features a dark red color with faint, light-colored silhouettes of two people standing and facing each other, appearing to be in conversation. One person on the left is holding a clipboard and a pen, while the person on the right is gesturing with their hand.

RECOMMENDATIONS

“You never call us to see if we’re dying. You never call us to see if we’re alive, but as soon as you have a study you call us. Which is really sad ”

RECOMMENDATIONS

□ Research Priorities

The participants and service providers prioritized key areas of research that would improve their quality of life.

1. Finding a Cure for HIV

Finding a cure for HIV was the most common hope expressed by the participants. The importance of researching towards an HIV cure, or a medical intervention that could improve the quality of life for women living with HIV was also mentioned.

HIV we never heard about it so many years ago. But I mean you hear about it all the time right now. And there are always messages about protecting yourself so you don't get HIV. And like you said, women are at greater risk of catching the virus. And so it's beneficial for us to find a cure or, if not a cure, at least something that you can take that you can still have some quality of life.

-Sex worker Focus Group

2. Reproductive Health

Participants strongly emphasized the need for more research, information and education around reproductive health, particularly on pregnancy and HIV planning for HIV-positive women. As mentioned above in the themes, women living with HIV faced discrimination when discussing pregnancy with their healthcare providers, and lack of support when looking for information around becoming pregnant while living with HIV, medications and vertical transmission of HIV (mother to child).

As I am a woman living with HIV, if I want to get kids, I think it's a challenge. Like, the doctor doesn't discuss that with me, then, if I say I want to think of giving birth. So I think there is need for assistance to be put in place if you are HIV positive and you're a woman. They should give us information on how to go about it. Because it doesn't mean that if you are HIV positive you cannot give birth.

-Young woman

3. Lipodystrophy

Lipodystrophy is condition where dramatic fat loss occurs in one or more areas of the body, most commonly occurring on the face. The mechanisms for HIV-associated lipodystrophy are still largely unknown, but scientists have hypothesized that it could be caused by anti-retroviral medication or the by the HIV virus in the absence of anti-retroviral medication . In the case of HIV-associated lipodystrophy, there is often fat loss in the face, legs, arms and buttocks in addition to fat accumulation in various body parts. Personal experiences with lipodystrophy resulted in participants wanting further research on this issue:

I've been noticing different parts growing... It started here, it went here and it's on my belly. Now I've got a third breast on my private part, and now my thighs are starting to start. It's my fifth year how I'm growing. I'm watching how I'm growing, but nobody's doing anything. Nobody has done anything and nobody can do anything. So, personally I would like to see side effects of medication and what it does to women, especially this new branch what's happening to our body going deformed.

- Peer Research Assistant

4. Other Side Effects

In addition to lipodystrophy, participants commented on the lack of research and information on other HIV medication side-effects. Many women experienced bleeding during intercourse, or stopping of the menstrual cycle all together due to HIV medication. The women all recognized that HIV medication affects women differently than men, and asked for gender-specific information regarding this issue for themselves and the effects the medications will have on their children.

I think for a woman we have a lot of other issues and a lot of different issues than men actually because for one thing, certain HIV medications affect us differently. It changes our whole reproductive system; you know our menstruation cycle changes all the times. Our sexual health changes all the time.

- Asian/South Asian

5. Co-infections

Co-infections occur when people living with HIV become infected with one or more viruses. An example would be a patient who is infected with both HIV and Hepatitis C, or HIV and tuberculosis. Many of the participants expressed concerns regarding the impact of co-infections with HIV as well as interactions between medications.

HPV, human papillomavirus, can cause cervical cancer and they don't do the research on that. With HIV positive, you can tend to have cervical cancer easier especially people who have HPV in their system.

- Asian/South Asian Participant

If you have HEP C and you're taking medication for that and then you all of a sudden got HIV and you have to take medication, how are they going to react to together? Like is there going to be some counter reaction to taking all these different medications and stuff like that.

- Sex workers Focus Group

6. Co-Morbidities

Co-morbidities are the effects of all other diseases a person might have other than the primary disease of interest xiii, in this case HIV. Comorbidities can include illnesses such as cardiovascular disease, liver disease or cancer. Participants wanted asked for

more research to be done on whether HIV increased the risk of comorbidities, and why comorbidities exist more in people living with HIV.

In regards to other illnesses that are linked often to people who have HIV, they have a tendency to have other diseases. Is it because of HIV? Or age? Or often it may be related to cholesterol or people who are diabetic. Is it related? Can we know why people get these things/diseases?

- Francophone Participant

7. Ethno-racial Specific Research

Participants described the need for more research with ethno-racialized groups of women, especially taking into account the intersectionalities of culture, race, religion, age and other factors. Many women felt that the current state of research tended to lump together all women into a single category, causing the different manifestations of HIV, medication side effects, or poor health to be overlooked.

Women as a minority group need to remember that within that group, that huge group and it's not homogeneous, there's so many differences that they, so women of colour, queer women of colour and then Trans women of colour I think are probably bottom of the bottom and their voices need to be brought forth to the table and I, it's, I don't often see them represented in research, in the discussions where they can have a say in it and actually have it go somewhere.

-Service Providers

And, also, the research that has been done before, I don't know if I'm wrong, has been focused on the white community and not focused on the black community. And the way we react to the drugs, black people, is different from the white community. So, I think the research should be more specific, not just gender, but our ethnic culture and ethnic background.

-African-Caribbean Participant

□ Gender-Specific Concerns

Some of the participants expressed concerns with the general lack of HIV research specific to women, particularly queer women and recommended that more research should be done in these areas. Queer, transsexual and transgender women often got lumped into HIV education for gay men, and many of the women found that in HIV workshops or education materials for LGBTQ populations, the focus was primarily again on gay men. In addition to lack of HIV prevention materials, participants stated that information about women and aging in relation to HIV was also information they would be interested in learning more about.

*I was at city hall this morning at a presentation and they were talking about statistics and stuff. And all they talked about this morning was men for men sex, heterosexual stuff. I stood up and I said – I'm twenty-three years HIV positive. When am I going to see some statistics up there for transsexual and transgender people? I don't want to wait another f***ing twenty-three years to see a statistic up there.*

- Transgender Woman

I'm like 45 but I'm pre-menopausal so me, it's in that age, like what the viruses may be doing or not doing to my body and what's the virus and what's the menopause, you know, like? Because I'm getting a lot of things that they say, you know, that it's probably menopause you know, or then the doctors will say, no that could be your meds. So something and along that lines, like aging, so it would be aging and for me it's menopause and living with HIV.

- Participant from Sudbury

Participants described the need for research focused on gender differences in HIV treatment, particularly the side effects of anti-retrovirals on women.

Dosage. Definitely the dosage, because what I've noticed on being on the board is that the same dose you would give to a 400 lbs. male is the same dose you give to a 110 lbs. female. And, our bodies and theirs is not the same. And, we shouldn't be taking the same thing that they're taking. We should be on a specific dose. A dose to go with your body type, with the kind of food that you eat, or the kind of food that you can afford. That's what they need to be fixing these medications to work with the way we work.

- African-Caribbean Participant

Issues relating to pregnancy and parenting were also discussed. Many women felt that they had limited information regarding HIV and pregnancy, and that more research was needed so they could make informed decision regarding their bodies.

In Ottawa we don't have a fertility clinic for women living with HIV. They'll ask you to go to Toronto or to Montreal so that makes it more difficult for us. I don't know if that can be improved. Sometimes you go to a clinic and you mention anything about having babies and they ask you why you want to have babies, so to me it's kind of discriminating.

- African Caribbean Participant from Ottawa

□ Relationships between researchers and HIV positive Women

One of the most important findings and subsequent recommendations from this study was the discussion of power dynamics between participants and researchers. Participants described a power imbalance whereby researchers had more power than women living with HIV and relationships were not mutually supportive, and were often exploitative and based on HIV-positive women providing information for researchers without receiving credit or support. Power dynamics and mistrust of research were discussed as barriers to building relationships between researchers and women living with HIV, while community engagement strategies were seen as facilitators to strong relationships (next section). In addition to this power imbalance, participants also felt that they were used which created mistrust in research and the government.

You have our information. You have all of our stuff. You never call us to see if we're dying. You never call us to see if we're alive, but as soon as you have a study you call us. Which is really sad. And, that's what happens with these groups. Nobody pays us any attention until they need something from us.

- African- Caribbean Participant

How they define community members, lack of intelligence or lack of knowledge. Even if you get an opportunity to work with them or you are given an opportunity to work with them, they take or demand all the credit for the work that has been done... and then at the bottom, they put your name A, B and E, community members. They take all the credit and they just put you at the bottom of the list.

- Asian/South Asian Participant

□ Community Engagement

Community engagement was described as imperative to building equitable and respectful relationships between researchers and women living with HIV. Strategies included: community and peer researchers; knowledge dissemination; and the need for heightened awareness of research with women living with HIV. Participants described that research should involve the community at every step and employ peer researchers in the process.

I really think we could create a very good economy for ourselves and do our own research with our money from wherever, and train women to do the work themselves, because I think there are opportunities all the way through the spectrum and I really think that we have to be recognized for more than just as participants... We should be directing it.

- Participant from Hamilton

Knowledge dissemination was highlighted as an important aspect of community engagement and also as a means to effect change. Participants described multiple strategies to raise awareness of research being conducted with women living with HIV.

Have little booths set up on different corners in the city with lots of pamphlet. The government building down there where you get your driver's license or your birth certificate or your health card, so you could get to people that ordinarily would not.

- IDU Participant

Not necessarily just where HIV positive women go because I know some positive women who don't access any services. So, in a library or somewhere that it won't be associated with you.

- IDU Participant

The background of the slide features a dark red color with a lighter red silhouette of two women standing and facing each other, appearing to be in conversation. The woman on the left is slightly taller and has her hair pulled back, while the woman on the right is shorter and has her hair styled in a bun. They are both wearing sleeveless tops and pants. The overall aesthetic is professional and focused on the theme of women's empowerment.

**RECOMMENDATIONS
FOR SERVICE PROVISION
WITH WOMEN LIVING
WITH HIV**

“we have seen that support groups work, but we should refocus on empowering women ”

RECOMMENDATIONS FOR SERVICE PROVISION WITH WOMEN LIVING WITH HIV

Participants highlighted recommendations for service provision with HIV-positive women that included: resource needs; recommendations for service providers; accountability; and improving medical care and treatment.

□ Resource needs

Resources that were empowering, improved access, provided support and education were recommended by participants. Participants described power imbalances with organizations and the need for programs and services to promote empowerment for women living with HIV.

I think the ASOs, they need to refocus. Yes, support groups, we have seen that support groups work, but we should refocus on empowering women...many women are at home because they feel that they can't afford it. So, what is the role of ASOs in terms of empowering us. What is empowerment to them? Is it offering us programs? Is it childcare? Or, is it support groups? Yes, support groups are good, but we need to move further than support groups.

- African-Caribbean Participant

Addressing transportation and language barriers were described by participants as strategies to increase access to resources, services and information. Recommendations included increased support and education for women living with HIV.

I don't know a lot of big words and stuff like that. And when you think research, you get a little intimidated by the whole idea. Statistics and stuff like that. You ... don't want to feel like you're less educated than other people by asking a question like, what does that word mean? Even if it's a simple word and you forgot the meaning of it or you haven't heard of it in a while. Or you think it means something else. Like I sometimes feel embarrassed asking oh can you say what that word means again. Because I don't want other people sitting there snickering saying oh she doesn't know what that means. Like why should she be here kind of thing

- Sex worker Participant

Maybe you can help us out, have workshops open just for lesbian, queer, and – so that people won't really be so afraid to talk about what they want to talk about, and get help from there, other than just shutting down, you know, keeping everything into your heart and causing stress. ... With your own people you don't have to be stressed.

- Queer Participant

□ Service Provider Recommendations

Due to the discussions around HIV-related stigma, racism and discrimination arising from healthcare settings or ASOs, many of the women felt that service providers should be required to have anti-oppression and sensitivity training regarding: women, people living with HIV, and queer and trans women.

I wouldn't say fire them all, but give them sensitivity training. HIV 101 and 102, and you can tell them about the stigma, because they need it. And, it's so sad that they're there and every two weeks they get a fat pay cheque, because that's what they're there for. They forget why they were put in the position and it's so sad.

- African Caribbean

I think it's a disadvantage to the community when you put so much stress into one area rather than making it safe for us to go to our churches and our recreational centers and our schools, and be able to access service in those places where we already are, you know, instead of having to rely on - like, there's a time and a place for a specialized organization. I'm not saying that that's not true. But I should be able to go to Catholic counseling services here in Hamilton and not have to worry about disclosing my status.

- Hamilton

Both service providers and women living with HIV expressed that it is a challenge, but a necessity to enhance medical care for women living with HIV. Participants described strategies for building relationships between women living with HIV and service providers and researchers.

A challenge,

I'm not sure that it's the patient sees the challenge but access to primary care. At least I think they feel they can receive primary care at clinics and that's not something we're necessarily good at or necessarily want to do but they may not see that as a challenge because if they can get one-stop shopping, why would they complain or whatever. So I see that as an issue but they may not, patients may not see that as an issue.

- Ottawa service providers

Sometimes we have some emergency come up but having to wait to see an HIV specialist for three months, by the time I see him in three months, my symptom is gone... The healthcare system; they should have something like a specific walk-in HIV medical clinic. That means if we are a woman or even a man, if we have some problem, we can go to see the doctor in a HIV walk-in medical clinic instead of waiting for our steady medical HIV specialist, the one that we're regularly seeing. Do you see?

- Asian/South Asian

□ Accountability

Participants discussed how accountability and transparency of funds in research was missing. Participants recommended that women living with HIV be involved in evaluating the performance of service providers.

An evaluation will determine whether these service providers are really serving us or are they just serving their own personal interests. Because if you think about it, if you are HIV positive, you meet someone who is going to be really mean to you, that's exclusion, that's isolation right there. And, yet they are busy talking about inclusiveness, trying to accommodate us. How do you say you're accommodating someone if you're being nasty to that person who is supposed to be receiving some warmth from you?

- African-Caribbean Participant

Additionally, participants felt that resources should be allocated to smaller organizations serving women living with HIV for support and education, and there be efficient use of funding and results from research.

Instead of spending the money on doing research studies constantly, find a way to help these stressed, depressed, lonely, black women out there that have nothing to do. Find something for them to do. Find something out there that they would love doing. Find out what their weaknesses and strengths are and work on that, because, first of all, we need self-esteem, self-love, self-worth, and without those guys we are nobody. We're just a shell walking down the street. And, it's very, very sad to know that nobody ever comes to us and asks us, so, how are you feeling today?

- African Caribbean

There's all this money going out for research and how's it coming along? ...What kind of progress is happening out there? Like what kind of drugs are they testing? It wouldn't hurt to know, how it's going. Like are people getting cured? Like I have no idea.

- Formerly Incarcerated Participant

The background of the slide features a dark red color with a lighter red silhouette of two people in profile, facing each other as if in conversation. The person on the left is holding a clipboard and a pen, while the person on the right has their hands clasped in front of them.

DISCUSSION

“researchers need to tackle issues of trust and transparency when engaging with communities for HIV research ”

DISCUSSION

The participants from the WCBR project were generous enough to share detailed accounts of their lived experiences as women living with HIV, and how their status influences their place in society. Both the qualitative and quantitative data compiled for the purposes of this report only represent a small fraction of the vast and rich information gathered from this study. The reported data was chosen to demonstrate the overall intersections and complexity of factors that manifest in poor health and quality of life for women living with HIV. HIV impacted almost every aspect of these women's lives and caused them to face hardships often deprioritized their HIV-related care.

For many women, economic security was a major factor in their well-being, affecting all aspects of their life from housing to getting proper HIV medication. Many of these women are also new to Canada, missing the social connections and support needed to cope with a positive status. Cultural and religious exclusion also adds to this sense of isolation and can manifest in depression or other pressing mental health issues. The most shocking and critical data however comes from participants' accounts of stigma, racism and discrimination in healthcare settings and ASOs – organizations that should be striving to eliminate these issues. The data also showed that this type of treatment in society and in healthcare settings dramatically affects the quality of life of the participants, and impact their health seeking behavior.

The research priorities identified by the participants highlight current gaps in knowledge, and the need for gender-based research and programming. However, researchers first need to tackle issues of trust and transparency when engaging with communities for HIV research. There is a disconnect between the research community and the HIV community, which drastically reduces research participation. As many of the participants stated, current procedures in research make them feel used and taken advantage of in multiple ways. Some participants stated that they are only contacted when a new study begins; others stated that they receive little to no credit for their work. This detracts from the importance of HIV research, and how crucial community involvement is for a research project to be successful.

For increased participation in HIV research, and gender-based HIV research in particular, it is crucial that we find ways to implement the recommendations laid out by the WCBR participants. Before beginning any HIV research, a community advisory board or community forum could be established to identify the research needs and priorities of that community. This step also allows for the researchers to acknowledge and start to address any issues (historical, cultural, gendered, etc.) the community may have regarding research. The formation of a CAB allows for participants to have on-going interactions with the researchers, promotes a feeling of ownership of the data, and a chance to provide input towards the study protocol. Lastly, the WCBR participants strongly stressed the importance of KTE at the end of the project. Sharing the information collected, and how this information is going to be used to improve the health of the community is important for

establishing trust, forming and maintaining community ties, and keeping the participants informed about the impact and value of their information.

This report seeks to share the direct opinions of women living with HIV and their relationship to research and researchers, in the hopes that future studies will use it to reflect upon the current paradigm. Although it is difficult to fully appreciate the challenges facing these women, it is important to keep in mind the struggle they face from society and themselves and the strategies they use to cope with these issues. By doing so, not only will it establish trust and transparency of the research process, the information gathered will reflect the complexities of these women's lives, and be a tremendous asset in creating effective policies and practices to improve their overall health.



APPENDICES/REFERENCES

Appendix A: Socio-Demographic Data of Focus Group Participants

Note: Groups with small numbers have been collapsed to maintain participant confidentiality.

Variable	Mean	Range	Standard deviation
Participant age (n=96)	38.3	20-57	9.1
Variable		Frequency	Percent
Gender (n=97)	Biological female	76	78.4
	Transgender women	17	17.5
	Transgender man	4	4.1
Sexual orientation (n=96)	Heterosexual	74	77.1
	Bisexual	15	15.6
	Lesbian	3	3.1
	Queer	4	4.2
Education (n=96)	No formal education	2	2.1
	Grade 8 or less	6	6.3
	Some secondary education	20	20.8
	High school graduate	22	22.9
	Some university, college or technical/vocational school	21	21.9
	College diploma	9	9.4
	Bachelor's degree	7	7.3
	Some graduate school	5	5.2
Income level (n=93)	Graduate school	4	4.2
	0 - \$19,999	58	62.4
	\$20,000 - \$39,999	29	31.2
	\$40,000 - \$59,999	2	2.2
	\$60,000 - \$79,999	1	1.1
Sources of income (n=100)	>\$80,000	3	3.3
	ODSP	55	55.0
	Ontario works/social welfare	17	17.0
	Part time paid employment	11	11.0
	Full time paid employment	7	7.0
	Unemployed/seeking employment	2	2.0
	Canada Pension	2	2.0
	Long term disability	2	2.0
	Full time caregiver/homemaker	1	1.0
	Peer worker	1	1.0
	Sex work	1	1.0
Maternity leave	1	1.0	
Religion (n=99)	Catholic	33	33.3
	Christian (Catholic/Protestant)	23	23.2
	Protestant	14	14.1
	Other	10	10.1
	Muslim	6	6.1
	None/Atheist	6	6.1
	Hindu	4	4.0
Geographical location (n=100)	Aboriginal traditional	3	3.0
	Toronto	59	59.0
	South West	13	13.0
	Northern	9	9.0
	Central East	6	6.0
	Ottawa	6	6.0
	Central West	4	4.0
	Eastern	3	3.0
Region of Birth	Country of Birth	Frequency	Percentage
North America	Canada	37	38.5
	Total for region	37	38.5
Africa	Burkina Faso, Congo, Cote D'Ivoire, Nigeria,	6	6.2
	Burundi	5	5.2
	Cameroon, Rwanda,	6	6.3
	East Africa, Tanzania	5	5.2
	Kenya	5	5.2
	Namibia, South Africa, Swaziland, Zambia, Zimbabwe	8	8.2
	Total for Region	35	36.3
Mexico, Central and South America	Bolivia, Guatemala, Guyana, Honduras, Mexico	7	7.3
	Total for Region	7	7.3
Caribbean	Grenada, Jamaica, St. Vincent, Trinidad	9	9.4
	Total for Region	9	9.4
Europe	England, France, Germany, Serbia	5	5.2
	Total for Region	5	5.2
Asia and South Asia	China, India, Vietnam	3	3.1
	Total for Region	3	3.1

Appendix B: Socio-Demographic Data of Survey Participants

Note: Groups with small numbers have been collapsed to maintain participant confidentiality.

Variable	Mean	Range	Standard deviation
Participant age (n=166)	40.7	18-69	8.8
Variable		Frequency	Percent
Sexual orientation (n=160)	Heterosexual	156	97.5
	Bisexual or Lesbian	4	2.5
Education (n=154)	Less than high school	44	28.6
	High school graduate	41	26.6
	College diploma	25	16.2
Variable	Mean		Range
Income level (n=162)	\$1400.00		\$0 - \$7916
Variable		Frequency	Percent
Sources of income (n=162)	ODSP/Disability	88	54.0
	Ontario works/social welfare	19	11.7
	Part time paid employment	29	17.8
	Full time paid employment	28	17.3
	Unemployed/seeking employment	34	21.0
	Canada Pension	8	4.9
	Child Tax Benefit	29	17.8
	Retired	2	1.2
	Self Employed	4	2.5
	Student/OSAP	15	9.3
	Volunteer	26	16.0
Geographical location (n=166)	Toronto	84	50.6
	Ottawa	33	19.9
	Windsor	8	4.8
	Niagara	15	9.0
	Kitchener	13	7.8
	Hamilton	13	7.8
Region of Birth	Country of Birth	Frequency	Percentage
Africa	Unidentified African Country, Benin, Burkina Faso, Central Africa, Djibouti, or Nigeria	8	4.3
	Burundi	14	9.1
	Cameroon	6	3.9
	Congo	11	7.1
	Ethiopia, Somalia, Sudan	7	4.5
	Ivory Coast, Guinea, Liberia, Sierra Leone, or Togo	9	5.7
	Rwanda	12	7.8
	South Africa, Swaziland or Zambia	10	6.5
	Uganda, Tanzania, or Kenya	7	4.5
	Zimbabwe	23	14.9
	Total for Region	107	68.3
Caribbean	Grenada	6	3.9
	Guyana	6	3.9
	Haiti	7	4.5
	Jamaica	14	9.1
	St. Vincent	5	3.2
	Trinidad	8	5.2
		Total for Region	46
Immigration Status (n=161)	Canadian Citizen	58	36.0
	Landed Immigrant/Permanent Resident	56	34.8
	Refugee Claimant	27	16.8
	Visa Holder (e.g. work, student)	2	1.2
	Without Documents	5	3.1
	Convention Refugee	13	8.1

Appendix C: Outcomes of Quantitative Survey

Note: n=166 unless stated otherwise

Depression

Sub-scale	Item		Percentage (%)
Somatic	Sadness N=158	I do not feel sad	38
		I feel sad much of the time	49.4
		I am sad all the time	8.2
		I am so sad or unhappy that I can't stand it	4.4
Affective	Pessimism N=158	I am not discouraged about my future	46.2
		I feel more discouraged about my future than I used to be	35.4
		I do not expect things to work out for me	9.5
		I feel my future is hopeless and will only get worse	8.9
	Past failure N=161	I do not feel like a failure	49.7
		I have failed more than I should have	21.1
		As I look back, I see a lot of failures	21.7
		I feel I am a total failure as a person	7.5
Somatic	Loss of pleasure N=161	I get as much pleasure as I ever did from the things I enjoy	28.6
		I don't enjoy things as much as I used to	44.1
		I get very little pleasure from the things I used to enjoy	18.5
		I can't get any pleasure from the things I used to enjoy	8.7
Affective	Self-dislike N=159	I feel the same about myself as ever	42.8
		I have lost confidence in myself	37.7
		I am disappointed in myself	16.4
		I dislike myself	3.1
	Self-criticalness	I don't criticize or blame myself more than usual	45
		I am more critical of myself than I used to be	26.3
		I criticize myself for all of my faults	13.1
		I blame myself for everything bad that happens	0.6

HIV-Related Stigma

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I have been hurt by how people reacted to learning I have HIV n=159	17.5%	11.9%	13.2%	22.6%	44.7%
I have stopped socializing with some people because of their reactions of my having HIV n=158	12.0%	17.1%	19.6%	17.7%	33.5%
I have lost friends by telling them I have HIV n=157	12.1%	19.7%	22.3%	15.9%	29.9%
I am very careful who I tell that I have HIV n=159	5.7%	6.3%	3.1%	15.7%	69.2%
I worry that people who know I have HIV will tell others n=161	8.7%	2.5%	5.0%	18.6%	55.2%
I feel that I am not as good a person as others because I have HIV n=160	33.1%	16.9%	16.3%	13.1%	20.6%
Having HIV makes me feel unclean n=161	40.4%	24.2%	9.9%	11.2%	14.3%
Having HIV makes me feel that I am a bad person	43.8%	23.5%	9.3%	10.5%	13.0%
Most people think that a person with HIV is disgusting	8.0%	6.1%	9.2%	27.6%	49.1%
Most people with HIV are rejected when others find out	5.5%	2.5%	7.4%	20.2%	64.4%

Sexism

In your day-to-day life how often have the following happened because you are a woman	Almost everyday	Frequently	Sometimes	Not that often	Almost never	Never
You are treated with less courtesy n=162	3.1%	21.0%	33.3%	17.3%	14.8%	10.5%
You are treated with less respect n=163	3.7%	22.1%	31.3%	17.8%	14.1%	11.0%
You receive poorer service n=160	2.5%	16.9%	33.8%	19.4%	14.4%	13.1%
People act as if you are not as smart n=159	4.4%	21.4%	38.4%	8.8%	17.0%	10.1%
People act as if they are afraid of you n=162	4.9%	11.1%	24.7%	15.4%	21.6%	22.2%
People act as if you are dishonest n=162	5.6%	14.2%	27.8%	11.1%	22.2%	19.1%
People act as if they are better n=160	13.1%	22.5%	32.5%	6.9%	15.0%	10.0%
You are threatened or harassed n=162	3.7%	9.9%	26.5%	14.8%	18.5%	26.5%

HIV-Related Rascism

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Research is all about the white folks and what the white folks want to get from the Black people n=162	10.5%	13.0%	30.3%	23.5%	22.8%
HIV researchers are thinking: you come from Africa you don't understand n=163	5.5%	10.4%	17.8%	32.5%	33.7%
In my community people are not afraid to go against service providers and speak how they are taken advantage of in research n=162	9.9%	11.1%	29.8%	22.8%	26.5%
The research that has been done before has been focused on the white community not the Black n=160	7.5%	8.1%	31.3%	27.5%	25.6%
I think the way Black people's bodies react to HIV drugs is the same as white people n=162	17.9%	16.0%	20.4%	23.5%	22.2%
I think HIV research should find out if race makes a difference in how you get/treat HIV n=158	5.7%	5.7%	8.9%	32.4%	45.6%
When white women living with HIV want to have a child they are supported more than Black women n=160	4.4%	7.5%	35.5%	20.6%	31.9%
Fertility clinics are welcoming if you are HIV positive n=158	8.2%	7.0%	53.8%	17.1%	13.9%
When Black women with HIV inquire about having a child they are actively discouraged n=162	4.9%	8.0%	32.1%	27.2%	27.8%
Programs at most ASO are made to meet the needs of gay and white gay males n=160	4.4%	9.4%	23.1%	25.0%	38.1%
Black women are silent about their needs and what they want from ASOs n=163	7.4%	14.1%	11.0%	30.7%	36.8%
Black women don't want to voice their opinion because they are afraid what they receive will be taken from them n=162	5.6%	16.0%	11.7%	32.1%	34.6%
I prefer to receive services from organizations that have mostly white staff n=158	3.8%	5.7%	21.5%	30.4%	38.6%
Women living with HIV are the ones who are supposed to make the decisions about research and services that affect our lives n=161	5.6%	6.8%	11.8%	29.2%	46.6%
It would be easy to sit in a room with 5+ white male researchers as the only Black PHA researcher and say 'ok this is what needs to be done' n=161	12.4%	13.7%	16.8%	21.2%	36.0%

Continuity of Care: Access/Getting Care Results

Access/ Getting Care	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I have regular appointments with my doctor n=162	3.7%	15.4%	4.9%	61.7%	14.2%
I am able to get to my appointments easily n=161	4.3%	23.0%	14.9%	40.4%	17.4%
I am able to get emergency care easily n=160	8.8%	25.0%	28.1%	28.7%	9.4%
I am getting follow-up for my HIV when needed n=162	3.1%	9.3%	8.6%	61.6%	17.9%
I am able to get medical tests for my HIV when needed n=162	1.9%	7.4%	8.0%	65.4%	17.3%
I get feedback in a reasonable amount of time about any tests I have had n=160	5.0%	16.9%	15.0%	50.6%	12.5%
I have been referred to other health professionals when needed n=163	6.7%	16.0%	9.8%	54.0%	13.5%
I want to see the same doctor each time I have an appointment n=162	3.7%	5.6%	8.0%	47.5%	35.2%
When my health changes so does my healthcare n=160	6.3%	12.5%	33.1%	35.6%	12.5%
All the healthcare professionals I see have similar ideas about treating my HIV n=164	8.5%	15.9%	30.5%	32.9%	12.2%

Resilient Coping

	Does not describe me at all	Doesn't describe me that well	Neutral	Describes me somewhat well	Describes me very well
1. I look for creative ways to alter difficult situations n=158	3.8%	5.7%	34.2%	37.3%	19.0%
2. Regardless of what happens to me, I believe I can control my reaction to it n=156	7.1%	6.4%	22.4%	37.2%	25.0%
3. I believe I can grow in positive ways by dealing with difficult situations n=159	5.7%	5.7%	23.3%	35.2%	30.2%
4. I actively look for ways to replace the losses I encounter in life n=158	5.7%	8.9%	24.7%	35.6%	25.3%

REFERENCES

- ⁱ Public Health Agency of Canada. HIV/AIDS Epi Updates August 2006. Public Health Agency of Canada, Centre for Infectious Diseases Prevention and Control. 2006.
- ⁱⁱ CIHR, NSERC, SSHRC. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Interagency Secretariat on Research Ethics. 1009 (2000, 2002 and 2005 amendments.)
- ⁱⁱⁱ Women's Health in Women's Hands. The 1st African and Caribbean HIV/AIDS Research Summit Report: Priority Setting, Self Determination and the Role of Research. Unpublished.
- ^{iv} "Tuskegee Syphilis Experiment." Wikipedia. Wikimedia Foundation, 19 Apr. 2013. Web. 25 Apr. 2013.
- ^v Corbie-Smith, Giselle, Stephen B. Thomas, Mark V. Williams, and Sandra Moody-Ayers. "Attitudes and Beliefs of African Americans toward Participation in Medical Research." *Journal of General Internal Medicine* 14.9 (1999): 537-46. Print.
- ^{vi} Freimuth, Vicki S., Sandra Crouse Quinn, Stephen B. Thomas, Galen Cole, Eric Zook, and Ted Duncan. "African Americans' Views on Research and the Tuskegee Syphilis Study." *Social Science & Medicine* 52.5 (2001): 797-808. Print.
- ^{vii} Logie, Carmen H., Llana James, Wangari Tharao, and Mona R. Loutfy. "'We Don't Exist': A Qualitative Study of Marginalization Experienced by HIV-Positive Lesbian, Bisexual, Queer and Transgender Women in Toronto, Canada." *Journal of the International AIDS Society* 15.17392 (2012): n. pag. Print.
- ^{viii} Logie, Carmen H., Llana James, Wangari Tharao, and Mona R. Loutfy. "HIV, Gender, Race, Sexual Orientation, and Sex Work: A Qualitative Study of Intersectional Stigma Experienced by HIV-Positive Women in Ontario, Canada." Ed. Karen Daniels. *PLoS Medicine* 8.11 (2011): E1001124. Print.
- ^{ix} Logie, Carmen, Llana James, Wangari Tharao, and Mona R. Loutfy. "Opportunities, Ethical Challenges, and Lessons Learned from Working With Peer Research Assistants in a Multi-Method HIV Community-Based Research Study in Ontario, Canada." *Journal of Empirical Research on Human Research Ethics* 7.4 (2012): 10-19. Print.
- ^x "Physical and Biochemical Changes in HIV Disease - HIV: Health and Medical Information About HIV and AIDS on MedicineNet.com." *MedicineNet*. N.p., n.d. Web. 13 Mar. 2013.
- ^{xi} "What Is AOSW?" *What Is AOSW? AOSW*, n.d. Web. 21 May 2013.

^{xii} Strega, S. (2005). The view from the poststructural margins: Epistemology and methodology reconsidered. In L. Brown, & S. Strega (Eds.), *Research as resistance: Critical, Indigenous and anti-oppressive approaches* (pp. 199-236). Toronto, ON: Canadian Scholars' Press.

^{xiii} "Comorbidity." Wikipedia. Wikimedia Foundation, 20 May 2013. Web. 21 May 2013.