THE WOMAN I HAVE BECOME

DISCUSSION GUIDE
Written by: Monika Goodluck, One World Partners
Project Supervisor: Wangari Tharao
Project Coordinator: Claire Langevine
Film Director: Alison Duke
Graphic Designer, Logo & Guide: Frantz Brent-Harris
Executive Producer: Women’s Health in Women’s Hands Community Health Centre (WHIWH)

This publication was a joint initiative between WHIWH and African Community Health Services, Africans in Partnership Against AIDS (APAA), Black Coalition for AIDS Prevention (Black CAP), and Voices of Positive Women (VOICES), with funding from the AIDS Bureau of Ontario’s Ministry of Health and Long-term Care through the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO).

To order copies or for more information, contact:
Women’s Health In Women’s Hands Community Health Centre (WHIWH)
2 Carlton Street, Suite 500
Toronto, ON
M5B 1J3
Phone: 416-593-7655
Fax: 416-593-5867
www.whiwh.com

This discussion guide will be available online, as a PDF, through the resources section of the following websites:
ACCHO: www.accho.ca
APAA: www.apaa.ca
Black CAP: www.black-cap.com
VOICES: www.vopw.org
WHIWH: www.whiwh.com

We would like to acknowledge the many volunteers, focus group participants, and reviewers who contributed to the development of this guide.

In memory of Rhonda 1971-2007

Copyright © 2008
Dear readers,

Women’s Health in Women’s Hands Community Health Centre (WHIWH-CHC) has been providing HIV support, care, treatment, and research services for African and Caribbean women in Toronto for almost ten years. Over this period, we have seen the number of new HIV infections among Black women in Toronto escalate to the point that we currently have the highest rates of new HIV infections in the city. Our communities continue to struggle with misinformation, HIV stigma, social exclusion, and a host of many other factors that leave us, as Black women, in a state of overexposure and vulnerability to this devastating virus. The making of the documentary, “The Woman I have Become,” is our way of speaking to our communities. The strategic goals of WHIWH-CHC are to INCREASE, INNOVATE, and IGNITE. In keeping with these, we aim to increase our awareness of HIV/AIDS, use innovative strategies to accomplish this goal, and we strive to ignite action and mobilize our communities to fight collectively against the spread of HIV/AIDS.

There has been no experience more humbling in this journey than the creation of “The Woman I Have Become.” This documentary tells the stories of Black women with incredible strength and character. The dignity with which they live their lives is an inspiration for anyone who has the privilege of meeting them. A simple thank you is not enough for the women in this documentary who allowed us into their homes and shared their families and their lives – all in an effort to make things easier for others. We feel privileged to have been given this opportunity.

This has truly been a collective effort and, if not for the belief in our vision, willingness to participate, dedication, and the support of numerous individuals and community agencies, this documentary would not have been possible. Our greatest gratitude goes to the director, Alison Duke and Goldelox Productions. Through her vision, insight, and generosity, a remarkable documentation of the lives of HIV positive women was created. This documentary demonstrates how HIV positive women can lead dignified lives, which, in turn, will contribute to greatly altering negative perceptions about HIV. It is with pride that we are able to showcase the lives of these remarkable women and the tireless work of their service providers. We all shine with the completion of this project.

All Black women’s Lives Matter
All Black women’s Lives are Important
Our Stories about those lives are Powerful

Notisha Massaquoi
Executive Director
Acronyms & abbreviations used

ACCHO  African and Caribbean Council on HIV/AIDS in Ontario
ACWHA  African and/or Caribbean woman or women living with HIV or AIDS
ADC    AIDS Dementia Complex
ARV    Anti-retroviral drug
ASO    AIDS service organization
CAAT   Committee for Accessible AIDS Treatment
CHALN  Canadian HIV/AIDS Legal Network
CIC    Citizenship and Immigration Canada
E/F    English/French
GTA    Greater Toronto Area
HAART  Highly active anti-retroviral therapy
HALCO  HIV/AIDS Legal Clinic (Ontario)
IME    Immigration Medical Examination
MAC    Mycobacterium avium complex
OCASI  Ontario Council of Agencies Serving Immigrants
OHIP   Ontario Health Insurance Plan
PHA    Person/people living with HIV or AIDS
S&D    Stigma and discrimination
SDOH   Social determinants of health
STI    Sexually transmitted infection
WHIWH  Women's Health in Women's Hands Community Health Centre

Glossary

AIDS     Acquired Immunodeficiency Syndrome, the most advanced stage of HIV, characterized by specific signs and symptoms, including opportunistic infections

AIDS Dementia Complex Neurological problem that can show up during the later stages of HIV infection; ADC causes memory loss, change of personality, irritability, poor coordination, and a host of other symptoms

CD4 Cells Key blood cells that protect the immune system and fight infection; HIV infects and kills CD4 cells

CD4 Count Measurement of the number of CD4 cells in the blood used to judge the status of the immune system and the progression of HIV in the body

HAART  Combination treatment of 3 or more ARV drugs used to suppress HIV and halt progression of HIV infection to AIDS

Mycobacterium avium complex Infection caused by a type of bacteria regularly found in soil and water; it is an AIDS-defining opportunistic infection because it is rarely found in people who are HIV-negative

Opportunistic Infection An infection by an organism that wouldn’t usually cause illness or disease in a person with a healthy immune system, but does so in a person living with HIV

Social determinants of health Universal term that refers to the social conditions that affect how and whether communities of peoples will experience barriers to achieving good health and success in life

Viral load  The amount of HIV in the blood, measured as ‘number of copies/ml of blood’; an indicator of how the immune system is responding to HIV and HAART
# Table of Contents

1. **Introduction**  
The project  
Before viewing the documentary

4. **Background information**  
About stigma & discrimination  
About the social determinants of health  
About HIV  
About African & Caribbean people, including women

9. **From Infection to Diagnosis**  
HIV infection  
HIV testing  
HIV diagnosis

14. **HIV & the Law**  
Disclosure of HIV status to a sexual partner  
Partner notification  
HIV testing & disclosure in the workplace

18. **Knowing Their Status has Enabled Them to Get the Appropriate Treatment**  
Medication and pills  
Taking it all in: Treatment adherence

22. **The Cost of HIV/AIDS**  
PHAs who are OHIP eligible  
Interim Federal Health Program for refugees  
PHAs without status or health coverage  
Immigration and HIV

26. **Coping with HIV**  
African and Caribbean women: Similar but different  
Shame, blame, & disclosure: The weight of stigma and discrimination  
Support for children and families  
Speaking out and becoming empowered

30. **Love and Sex**

31. **Saying Goodbye**

32. **Hope for the Future**  
After viewing the documentary

34. **Afterword: About the documentary**

35. **Resources & Training Tools**

36. **Additional References**
Introduction

The Project

In 2006, Women’s Health in Women’s Hands Community Health Centre (WHIWH) published a report that highlighted the results of a community-based research project entitled “Silent Voices of the HIV/AIDS Epidemic: African and Caribbean Women in Toronto 2002-2004” (Tharao, Massaquoi, & Teclom). One of the findings of this report was that service providers had limited cultural awareness and access to culturally appropriate resources, which hindered their ability to provide more effective HIV-related services to African and Caribbean women living in Canada. Most notably, African and Caribbean women living with HIV/AIDS have expressed their continued dissatisfaction and frustration with service providers, especially medical health professionals, who lack training and/or skills to provide proper care, support, and sensitivity to them and their families as they navigate through health and social service systems.

The film, *The Woman I Have Become*, is a documentary that was developed by the HIV Education, Prevention and Risk Reduction Project (HEP) to directly address this limitation. It is an educational resource for any service provider whose clients include African and/or Caribbean women who may or may not be HIV-positive and are living in Canada, with a primary focus on the Greater Toronto Area (GTA). The film offers insight into how many African and Caribbean women live with and experience HIV, the circumstances that challenge them, and their coping strategies. It also provides some context to consider when developing prevention strategies for these communities.

This guide offers an overview of the topics and issues that are raised in the film. Here, you will find supplementary information and opportunities for reflection, action, and further learning. Together, the film and guide are tools for education, awareness building, and training. They should be used in conjunction with other resources, referred to throughout this document, that support service providers whose clientele include members of the African and Caribbean populations in the GTA and across Canada.

Development of the documentary and guide has been an inclusive process that sought to empower African and Caribbean women living with HIV/AIDS (ACWHA) by facilitating their involvement in HIV prevention and education for their communities. The process was also grounded in principles of anti-oppression that recognize the intersecting, multiple oppressive systems (including race, gender, culture, immigrant status, sexual orientation, and other dimensions of difference) that have an impact on the health of women and their ability to access and effectively navigate health-care systems. The methodology used to develop the guide included researching updated information on topics and issues discussed in the documentary and conducting focus groups and interviews to inform the content and evaluate the usefulness of the guide at various stages of its development. Consultation was sought via focus groups from service providers, graduate students of social work, and many African and Caribbean community members, including women living with HIV, young women (aged 16 to 25), and women of varying ages. Additional input was also obtained via individual interviews with women featured in the documentary and key participants in the film’s development, i.e., director, producers, and staff members of the partnering organizations.
Please remember:

- The information contained in this documentary and guide is for educational use only and does not constitute medical or legal advice.
- When you encounter a situation that entails and/or requires knowledge outside your area of expertise, it is important to refer your client to an appropriate professional resource.
- Information in this guide applies mainly to the GTA, and to a lesser extent, Ontario. If you are located outside this region, you should consult your municipal and provincial laws and resources for the most accurate and relevant information. Nevertheless, this film and guide can generally be applied to African and Caribbean women living across Canada, as they do share comparable life experiences in this country.

Increased knowledge usually leads to increased capacity to effect change. It is our hope that you will learn from this project and apply your newfound knowledge to better understand and provide services to African and Caribbean women living in Canada today and in the future.

**Before Viewing the Documentary**

Before watching the documentary, take a few moments to jot down your thoughts about HIV and about African and Caribbean women. This exercise encourages you to consciously acknowledge your perspectives and awareness of the issues that are raised and discussed in the documentary and this guide.

Reflect on what you know, what myths exist, and how you feel about HIV. What comes to mind when you hear or think about:

- HIV? Is it relevant to your life in any way?
- Living with HIV? How life changes for someone once diagnosed with HIV? Do you know anyone who is living with HIV?
- How it is transmitted? Who is at risk of HIV infection? Why?
- What challenges might you experience if you found out you were HIV positive?
- Who should be told about someone’s HIV-positive status?

Reflect on what you know, what myths exist, and how you feel about African and Caribbean women who are living in Canada:

- Do you know any? In what capacity and to what degree? How are they and their experiences similar and different from you and yours?
- Does your agency/organization provide any services to them? What kind of services?
- How do social issues (e.g. poverty, immigration, racism, sexism, sexual orientation, gender identity, etc.) affect them?

People often say that HIV/AIDS affects everybody and nobody is safe from it. However, certain subsets of the general population are more highly impacted by HIV/AIDS than others. This is true of African and Caribbean women in Canada.
Reflect on why African and Caribbean women are more vulnerable to being infected by HIV. What distinct challenges might ACWHA face? In regards to everyday life (i.e., at home, work, in their communities)? In regards to receiving services?

Viewing the documentary will likely be an emotional experience. Recognize the sadness and gloom that you see and hear, but, remember the hope, strength, laughter, and optimism that shines through too.
Background Information

In order to be a responsible service provider to African and Caribbean women who may or may not be dealing with HIV/AIDS, it is important to have a basic awareness of HIV, African and Caribbean women, and the contextual roles of stigma, discrimination, and the social determinants of health.

About stigma & discrimination

Stigma refers to the negative labelling, blame, or discrediting associated with a person, group, or community based on a characteristic or condition. It occurs in “specific contexts of culture and power; it has a history which influences…the form it takes, and it is used by individuals, communities, and the state to produce and reproduce social inequality” (Lawson et al., 2006). Stigma is usually expressed as discrimination, which refers to the negative and unfair treatment of a person, group, or community based on specific characteristics or conditions. Stigma also negatively affects the self-image and sense of self-worth of the person and groups being stigmatized.

Discrimination is practiced by individuals, communities, societies, and institutions. It can be experienced in various ways, including hate crimes, rejection (e.g., as a friend, lover, employee, or colleague), double standards, name-calling, limited/no opportunity for employment or job advancement, prejudiced comments and behaviour, and limited/no access to services (e.g. health care, childcare), etc.

Human rights & discrimination in Ontario and Canada

In Ontario, every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, marital status, family status or handicap.


Under the Canadian Human Rights Act, it is against the law for any employer or provider of a service that falls within federal jurisdiction to discriminate on the basis of one or more of the prohibited grounds of discrimination (including race, national or ethnic origin, colour, religion, sex, sexual orientation, or disability).


N.B. It is also a violation of human rights to discriminate against a person or group because you assume them to be identifiable with persons defined by one of the grounds (e.g., it is a violation to discriminate against someone because you assume they are HIV-positive or a single parent or an immigrant, etc).
About the social determinants of health

‘Social determinants of health’ (SDOH) is the universal term that refers to the linked social conditions that affect whether and how communities of peoples will experience barriers to achieving good health and success in life. For our purposes, some of the most relevant SDOH include, but are not limited to:

- **Social exclusion** (e.g. experiencing inequity and oppression based on race, gender, religion, immigrant status, language, health status/ability, etc)
- **Income insecurity and limited access to gainful employment** (e.g. living in poverty, inability to be gainfully employed, not having work/education credentials recognized, financial dependency on a partner, earning low-income wages and no benefits, etc.)
- **Inaccessibility and insecurity of housing, childcare, and education** (e.g. lack of options, prohibitive costs, lacking support for childcare, long waiting lists for subsidies, etc.)

Stigma and discrimination (S&D) have a tremendous influence on a people’s place among the SDOH. Those who place low, such as people living with HIV/AIDS (PHAs) or African and Caribbean women, are often marginalized in society, i.e., excluded from and ostracized by the mainstream populace. Changing this reality requires conscious, diligent, and collective efforts by individuals, communities, and society.

About HIV

HIV, the Human Immunodeficiency Virus, is a virus that attacks the immune system. The immune system is a complex natural system that protects the body from disease and infection throughout an entire lifetime. By attacking the immune system, HIV prevents the body from fighting back properly. This means that the immune system is not able to work at its full capacity and the body is much more vulnerable to other illnesses and infections.

**CD4 & viral load**

A major way that HIV attacks the body is by immediately infiltrating the immune system's **CD4 cells**. These cells normally fight off infection and illness by reproducing, but, because HIV infiltrates them, when they reproduce, so does HIV. Over time, the immune system and HIV battle, and HIV causes the number of CD4 cells (**CD4 count**) to decline, which is associated with the weakening of the immune system. The CD4 count of an HIV-negative adult is about 700 to 1500 CD4 cells/ml of blood; the CD4 count of an HIV-positive adult (PHA) is about 50 to 500 CD4 cells/ml of blood. For a PHA, a CD4 count of 500 or above is generally considered to be good; a CD4 count of 200 or below is often associated with severe illness, including opportunistic infections, and an AIDS diagnosis. As expressed by Lisungu and Paulina, stress can cause the CD4 count to drop dramatically.

PHAs also have regular viral load tests. Viral load refers to the amount of HIV in the blood and is reported as the number of copies per milliliter of blood. Viral load tests are used to measure changes in HIV infection (e.g., progression to AIDS), monitor how treatment is working, and guide treatment decisions. Treatment can reduce and/or control viral load. When a viral load is undetectable, this means that the amount of HIV being reproduced is very low and cannot be accurately counted.
Regular lab tests verify and record patterns of CD4 count and viral load to measure the body’s response to HIV infection and HIV treatment.

The medically-defined stages of HIV
Typically, HIV progresses through four stages.

Stage 1: Primary Infection
HIV has entered the body and starts to reproduce within CD4 cells. Flu-like symptoms occur about 2 to 12 weeks after infection. This stage is characterized by rapid increases in viral load and a marked drop in CD4 count. HIV infection is highly transmittable/contagious during this stage due to the high levels of the virus in the blood and other body fluids. Due to HIV’s physiology, an accurate HIV diagnosis can usually only be made three to six months after primary infection.

Stage 2: Asymptomatic Stage
A PHA may have few or no HIV-related symptoms for numerous years (currently estimated at 10 years) and HIV infection is only evident through lab tests. During this stage, viral load and CD4 count may or may not fluctuate. Length of this stage depends on numerous factors, including stress, nutrition, genetics, immune response, strength of virus, quality of life, monitoring, etc. Treatment with medication may or may not be initiated during this stage. Each PHA may experience this stage differently. During filming, Paulina, Chantal, and Lisungu appear to be at this stage.

Stage 3: Symptomatic Stage
Some HIV-related symptoms appear. CD4 count drops more significantly and some opportunistic infections may occur. Medication will be used to treat the symptoms and prevent further drops in CD4 count.

Stage 4: AIDS, Acquired Immunodeficiency Syndrome
AIDS is the most advanced stage of HIV and, in Canada, is defined by the presence of one or more opportunistic infections, which are also called AIDS-defining illnesses. An opportunistic infection is an infection that would not typically cause illness in a person with a healthy immune system, but causes serious illness in a person living with HIV/AIDS because of their weakened immune system. Examples of opportunistic infections are mycobacterium avium complex (MAC) and a type of pneumonia called PCP, both of which have afflicted Rhonda in the film. It is possible to manage AIDS to some extent with medication.

PHAs do not die from HIV or AIDS; they die from the opportunistic infections.

Currently, there is no vaccine or cure for HIV or AIDS, though research continues in both of these areas. In developed countries, including Canada, various treatment options are available to help PHAs remain as healthy as possible and prolong their lives.

As you will see throughout this documentary, being infected with HIV affects much more than just the physical body. HIV affects every possible dimension of life: psychological, social, financial, physical, sexual, emotional, etc. In Canada, being HIV-positive is considered a disability; therefore, discriminating against a person/group based on their actual or presumed HIV-positive status is a violation of human rights. However, HIV/AIDS related S&D does exist and is intensified by the S&D that exists around some of the modes of HIV transmission, i.e., sexual behaviours, sexual identity, and drug use.
HIV-related S&D affects everybody. It contributes to fear, secrecy, denial, isolation, withdrawal, low self-worth, and impedes HIV prevention, treatment, care, and support efforts.

HIV-related S&D:
- Hinders efforts to talk about HIV;
- Discourages people from getting tested and getting treated for HIV;
- Discourages people from disclosing and/or accepting their HIV-positive status; and
- Hinders support for those living with HIV.

Worldwide, it is recognized that there is a strong relationship between the SDOH and HIV. The Public Health Agency of Canada states that the SDOH influence a person’s and/or community’s vulnerability to HIV infection, ability to manage and live with HIV, and the progression of HIV to AIDS. Specifically, it cites discrimination and inequities based on race, gender, and income among the most important SDOH related to HIV (Public Health Agency of Canada, 2002, Executive Summary).

About African & Caribbean people, including women

African and Caribbean people are diverse based on their countries of origin, mother tongues, religious and cultural practices, experiences, etc. Collectively, however, they share experiences of stigma, discrimination, and low positioning among many of the SDOH.

### Findings from Statistics Canada’s (2007) ethnic communities profiles on African and Caribbean people living in Canada

- Constitute 3% of Canada’s population
- Majority were born outside Canada and arrived in Canada after 1981
- Most live in Toronto, making up 9% of Toronto’s population
- Most are Christian and, among Africans, 22% are Muslim

Compared to the entire Canadian population, Canadians of African and Caribbean descent are more likely to:
- Not be married or living in a common-law relationship
- Be lone (single) parents, and usually, single mothers (as are most lone parents across the entire Canadian population)
- Be unemployed (with even higher rates of unemployment among the women)
- Have a lower income, including an income that falls below the Statistics Canada Low-Income Cut-off (with an even lower income among the women)

The findings also stated that, overall, African and Caribbean people in Canada feel a sense of belonging in Canada and a sense of belonging to their ethnic and/or cultural group. More than half reported having experienced discrimination in Canada that they felt was based on their race or skin colour.

The Statistics Canada findings clearly point to the disadvantaged position of African and Caribbean people, and more so, women in Canada. African and Caribbean women face S&D and low placement among the SDOH based on multiple interconnected factors, including their race, gender, income, employment status, immigrant status, ethnic origin, religion, etc. In short, to ensure survival and success in life, African and Caribbean women must constantly pre-occupy themselves with defying the major odds that are stacked against them.
This background information lays the framework for illustrating how African and Caribbean women in Canada are highly vulnerable to HIV infection and may be unable to properly respond to and live with HIV/AIDS. As discussed, this is largely based on the intersection of stigma, discrimination, and the social determinants of health, as they relate to HIV, being African and/or Caribbean, and being women. For those living with HIV/AIDS, these dimensions intersect and can cause the stresses of life to intensify exponentially. *The Woman I Have Become* explores their stories.

**Learn more:**

**Social Determinants of Health:**


**Profiles of African and Caribbean communities in Canada from Statistics Canada:**


(both available E/F via www.statcan.ca or 1-800-263-1136; refer to the subject or catalogue number to search)

**HIV/AIDS-related stigma:**
British Columbia People with AIDS Society: www.endhivstigma.ca


**HIV/AIDS-related stigma experienced by African and Caribbean communities in Ontario:**

From Infection to Diagnosis

“In Ontario, 33% of women living with HIV are African or Caribbean women.”
(2004 statistic from Remis & Liu, 2006)

HIV infection

The bodily fluids that can carry enough HIV to infect someone are blood, vaginal fluid, semen, and breast milk. HIV can only be transmitted when these fluids come into contact with each other, which can occur in an abundance of ways. The primary modes of HIV transmission in Canada are through unprotected sexual intercourse (vaginal, oral, anal), using non-sterile or contaminated injecting equipment (e.g., for drug injection), or mother to child transmission during pregnancy, birth, or breastfeeding. Many resources are available to learn more about assessing and reducing risk of HIV transmission and infection.

An Introduction to Four Women Living with HIV

While *The Woman I Have Become* shares the stories of numerous women, it introduces viewers specifically to four African and Caribbean women, living in the GTA, whom are HIV-positive.

**Rhonda, 36, from Grenada, mother, activist for PHAs, without legal immigrant status**
Rhonda was diagnosed with HIV in 1994, approximately one year after birthing her third child. In Ontario, since 1999, all pregnant women must be counselled on HIV and tested with informed consent as part of prenatal care. In 2006, 93.4% of pregnant women were tested for HIV (Public Health Agency of Canada, 2007, p.44). This has helped decrease mother to child transmission of HIV. Prior to her HIV infection, Rhonda had also suffered from several sexually transmitted infections (STIs). Having other STIs increases vulnerability to HIV infection. At filming, Rhonda was suffering from AIDS. Rhonda believes she was infected with HIV through her boyfriend at the time, whose HIV status had been unknown but was later confirmed as being HIV-positive.

**Paulina, 42, from South Africa, mother, social worker, landed immigrant**
Paulina believes she was infected with HIV through a blood transfusion she had in South Africa. Currently, in Canada, blood used for transfusions is tested for HIV, making it almost impossible to become infected this way. Paulina discovered she was HIV-positive after an employer requested that she undergo testing for STIs upon employment in 2003. HIV testing at the workplace is rarely justifiable and is discussed later.

**Chantal, 42, from Rwanda, mother, activist for PHAs, refugee**
Chantal believes she was infected with HIV as a victim of sexual violence and rape during the Rwandan genocide. She was already HIV-positive prior to immigrating to Canada. HIV status and immigration is discussed later.

**Lisungu, 38, from Zimbabwe, mother, AIDS education coordinator, refugee**
Prior to immigrating to Canada, Lisungu was already aware of her HIV-positive status and was an activist in the area. She believes she was infected with HIV through sex with her husband at the time, who later passed away. As part of the immigration process, she underwent the Immigration Medical Examination (IME), without receiving the appropriate HIV test pre- and post-counselling. This topic is discussed later.
The film states that, in the GTA, the most common (though not exclusive) mode of HIV infection for African and Caribbean women is through heterosexual sex with someone who is HIV-positive. African and Caribbean women are highly vulnerable to HIV infection for numerous reasons, many of which are associated with stigma, discrimination, and the social determinants of health, as discussed earlier. To expand, these reasons include, but are not limited to:

- Their disadvantaged position based on the social determinants of health
- Vulnerability due to the existence and practices of stigma and discrimination
- Some cultural and religious beliefs and values that negatively impact HIV prevention and treatment efforts (e.g. homophobia, perception of HIV/AIDS as a punishment from God, sex as taboo for discussion)
- Increased likelihood of infection because of female physiology
- HIV-related stigma and discrimination that inhibits discussion, disclosure, and fair treatment of PHAs
- Lack of and limited access to culturally appropriate HIV-related prevention information
- Lack of awareness of risk (e.g., believed partner was being monogamous, didn't know risk factors and/or methods of transmission, etc.)
- Lack of control over sex (e.g., presence of threat such as rape/abuse, domineering partner, partner who's unwilling to use condom, cultural/religious values that stigmatize condom use, etc.)
- Presence of other STIs
- Cultural practices such as douching, vaginal cleansing, Female Genital Mutilation

The above points directly impact an African or Caribbean woman’s ability to practice safer sex and also demonstrate how HIV infection can be affected by circumstances beyond an individual’s control. Whatever the method, no one deserves to be infected with HIV and a PHA should not be judged on the way she/he was infected with HIV.

Learn more:

- **African and Caribbean women's vulnerability to and experiences with HIV:**

- **HIV transmission and assessing risk:**
HIV testing

Generally, the women in the documentary expressed shock, frustration, and dissatisfaction with the process and circumstances surrounding their HIV tests and how they were informed of their diagnoses. Since African and Caribbean women tend to be marginalized in society, they may be unaware of, uncomfortable with, or misinformed about their rights and options for HIV testing.

The Public Health Agency of Canada states that HIV testing must occur with informed consent and pre- and post- test counselling. Informed consent means that no one should be given an HIV test without their explicit knowledge and approval, and, no one should presume their health-care provider has tested them for HIV as part of routine bloodwork tests. Pre-test counselling is an opportunity to discuss and assess risk factors, HIV knowledge/ awareness, testing options, etc. Post-test counselling for an HIV-negative person includes discussing prevention methods, future testing, etc. Post-test counselling for an HIV-positive person involves a balance between addressing the emotional impact of diagnosis with providing useful information on next steps. Pre- and post- test counselling play a critical role in empowering the person being tested to take action, regardless of the test results. Only those who are trained in this multi-step approach should conduct HIV testing.

HIV testing is done via collection and laboratory examination of a blood sample. Across Canada, there are three ways to get tested for HIV: nominal, non-nominal, and anonymous. The difference among these methods is how the person being tested is identified and whether the HIV test and its results are recorded in the person's medical record. Both nominal and non-nominal HIV tests and the results are recorded in the person's medical record. Nominal testing identifies the person by full name (such as through a family doctor); non-nominal testing identifies the person through a code or their initials on the laboratory requisition forms; anonymous testing uses a random number code for identification. Availability of these testing methods varies from province to province. In Ontario, all three HIV testing methods are available.

**Anonymous testing**

As of 2008, anonymous testing is available at 50 sites across Ontario and does not require the presentation of any identification or health coverage, nor will the tester ask for the identity of the person receiving the test. The test and its result do not go into a person's medical record because the person is anonymous. However, if a person is found to be HIV-positive, wherever they seek treatment (i.e., medication), they will have to provide identification and will no longer be anonymous. N.B. A person's family doctor cannot administer an anonymous test. Anonymous tests are only available at designated sites.

**Point of Care “rapid” testing**

The Point of Care HIV test is a "rapid" HIV test that involves pricking a finger for blood and receiving results within 60 seconds. This test is available at all of Ontario's anonymous sites as well as an additional 10 sites. If a result is "positive", a larger blood sample is taken and sent for a confirmatory test, which takes up to 2 weeks. If the initial test was done through anonymous testing, the confirmatory blood sample test is also sent anonymously.
Across Canada, everyone is entitled to confidentiality of their medical records, which includes records of having been tested for HIV, as well as test results. This means that an HIV diagnosis should only be revealed to the patient, in privacy, and should not be revealed to anyone else without the consent of the patient. No medical information should ever be discussed openly and/or in public spaces without the patient’s approval.

**HIV diagnosis**

“For me, my life is over. Diagnosis was the beginning of the end of my life…I’m alive, but I don’t think that I’m living. I’ve locked myself away from society.”

Undisclosed Caribbean woman

**Reflect/Discuss**

Have you ever received bad news from your doctor or someone else that made you feel like the world was crashing down on you? How was it delivered and what were you told? What was your reaction? Were any supports made available to help you cope?

Being diagnosed with HIV is often experienced as a shocking, emotionally traumatic event that can lead to short/long-term depression, suicidal thoughts, and post-traumatic stress. The voices and outlooks of the various ACWHA express this feeling of traumatization throughout the film for example Rhonda speaks of how she nearly dropped her baby when she received her diagnosis. This re-emphasizes the purposes of pre- and post- test counselling, especially in the case of HIV diagnosis. It is crucial that emotional support is made available to the newly diagnosed person – both immediate and ongoing support. Accepting an HIV diagnosis and all that it entails can take several months, years, or an entire lifetime.

**What can you do?**

- Get informed about how HIV is and is not transmitted, testing options, and the concepts of informed consent and pre-/ post- HIV testing and counselling
- Inform and/or remind women of their options for testing and their right to pre- and post- HIV testing and counselling
• Acknowledge the ways that African and Caribbean women are at increased risk of HIV infection; do not pass judgment on how an ACWHA was infected with HIV
• Encourage women diagnosed with HIV to seek care from healthcare providers who specialize in HIV
• If you are involved in the process of telling a client they are HIV positive, have additional support and extra time readily available for the client

Learn more:

**HIV transmission and testing guidelines:**
AIDS and Sexual Health Info Line (Ontario wide): 1-800-668-2437 (English and other languages); 1-800-267-7432 (French); offers multilingual services, including locations of anonymous and point-of-care test sites, testing options and sites, counselling, sexual health information, referral, etc.


HIV & the Law

In many cases, PHAs can maintain their privacy about their HIV status and decide when and whom to disclose this information to. This section provides a synopsis of the laws and guidelines related to disclosure of HIV status in the context of current/new sexual partners, notification to previous sexual partners, and HIV testing and disclosure in the workplace. Laws and guidelines about disclosure, obligation to disclose, and the duty of health professionals and/or other service providers are complex and often have situational applications. For more information, please consult the “learn more” and resources sections.

Reflect/discuss

If you found out that you were living with HIV, how would you feel about telling your lover, ex-lovers, family, friends, colleagues, boss? Who do you think should have the right to know? Who do you think doesn’t have to know? Why? What could be the advantages and disadvantages of disclosing your status? How, why, and when would you tell people? How would you feel if people found out from someone else?

Disclosure of HIV status is an intricate and sensitive issue that can be very difficult, especially because of HIV-related stigma and discrimination. It is one of many things that a PHA must constantly think about.

Disclosure of HIV status to a current/new sexual partner

Along with practicing safer sex, an important way that a diagnosed PHA can contribute to reducing the transmission of HIV is by disclosing HIV status to current and new sexual partners and consistently engaging in ‘safer sex’ practices.

What the law says:

“[In Canada,] a person has a legal duty to disclose his or her HIV-positive status to sexual partners before having sex that poses a ‘significant risk’ of HIV transmission. This includes anal and vaginal sex without a condom. What else it includes is not clear.”


This means that if a PHA does not disclose his/her status in the circumstances described above, he/she may be considered to have broken the law and that may lead to criminal prosecution.

“[Legislation also exists that] permits physicians to disclose confidential information without a patient’s consent, [like HIV status], if there are reasonable grounds to believe that this will avoid or minimize a danger to another person…[However], no Canadian court has yet ruled that a health professional must breach confidentiality in these or similar circumstances.”


This means that a physician could possibly reveal a patient’s HIV-positive status to the patient’s current sexual partner(s) if the physician does not believe the PHA has done so and also believes that telling the PHA’s current sexual partner(s) would reduce or eliminate their risk of HIV infection from the PHA.
The ambiguity of the laws makes it difficult for PHAs to understand when, how, and to whom they should disclose, and doesn’t address how PHAs prove that they have disclosed or made a legally acceptable attempt to disclose. Circumstances may lead some PHAs to hesitate to disclose their HIV status to their partner. The stigma, discrimination, and barriers experienced by many ACWHA often means that they are living under stressful and complicated circumstances that might influence their willingness to disclose their HIV status. Examples of these circumstances include, but are not limited to:

- Living under the immigration sponsorship of a husband/common-law partner, often resulting in financial dependency, concern about maintaining immigration status, and a fear of abuse/violence, abandonment and/or moral judgment
- Living within cultural/religious beliefs that reinforce sexual behaviour as a taboo topic and HIV as a moral punishment
- Awaiting processing of their immigration application or living without legal immigrant status, (e.g., constant concern of being rejected or deported)
- Being a single mother with few supports

In the film, several of the women mention that, upon receiving their HIV diagnosis, they disclosed to their respective partner, and suggested he get tested. In each case, the partner was subsequently found to be HIV positive, but then denied the diagnosis, and the relationship ended some time after that. A partner’s reaction to disclosure can range widely from support to rejection. ACWHA experience and witness a range of reactions and have real concerns that, upon disclosing to their partner, the partner will react by: denial of own status, ending the relationship, telling others, violence, and/or cutting off other supports, such as family, money, community, etc. If any or all of these things happen, based on an ACWHA’s location among the SDOH and other barriers she may face, she may find herself propelling downward into a spiral of depression, isolation, poverty, and even worse health.

Note:
A situation that may influence disclosure and a partner’s reaction in a relationship is when HIV testing by one person results in HIV diagnosis, disclosure occurs, and then the partner’s test comes back HIV-negative. One person is HIV-positive and the other person is HIV-negative. This means that the HIV-positive person became infected prior to or outside the current relationship and may not have known they were living with HIV until having taken the HIV test.

What can you do?
- Upon diagnosis, help her determine who can provide her with immediate support and have supports in place for her
- If her partner reacts negatively to her disclosure, do not make her feel bad for the reaction. Give her hope in her personal future.
- Refer her to resources, AIDS service organizations (ASOs), and/or other agencies trained to assist with disclosure-related issues.
THE WOMAN I HAVE BECOME DISCUSSION GUIDE

Partner notification

Also called contact tracing, partner notification is the process of contacting individuals who were sexual or drug-injection partners of a newly HIV-diagnosed person to inform them that they may have been exposed to HIV and should get tested. Partner notification can stop someone from unknowingly spreading HIV and enable her/him to access treatment, if also found to be HIV-positive. In Ontario, partner notification can be carried out by the HIV-positive person, by the diagnosing physician, or by the municipal public health department. When done by a public health nurse, notified partners are also counselled and offered services. Partner notification is different from disclosure because it does not require revealing the identity of the HIV-positive person; it only requires revealing the possibility of exposure. However, the identity of the PHA can sometimes be figured out based on the notified person’s sexual history and relationship with the PHA (e.g. long-term or only sexual partner). Persons diagnosed with HIV via the anonymous testing process are counselled on partner notification and are encouraged to provide the testing site with contact information for previous sexual or drug-injection partners that will be forwarded to a public health nurse who will carry out the partner notification.

- Recognize any potential bias you may have about disclosure. Try to listen without judgment to what she says about how she feels about sharing her HIV-positive status with her sexual partner(s). See if you can provide any support/resources to address the reasons behind her hesitation that are within your professional scope (e.g., as a social worker, you may be able to address her concern about being abandoned and becoming a single parent by helping her figure out how she would manage on her own and what supports exist)
- Provide a basic explanation of the circumstances (i.e., ‘significant risk’) that legally oblige her to disclose her HIV status. Let her know that the laws regarding disclosure are not simple and refer her to information resources that she can explore without compromising her confidentiality.
- In the meantime, if appropriate to your work and the situation, refer her to resources and information on ‘safer sex’ practices.
- Consider reviewing and revising your agency/organizational policy on client record-keeping. Some agencies have reduced the amount of note-taking they do, so that in the event of a subpoena, their records don’t incriminate a client. On the other hand, a method by which notes may potentially help your client is, in the case of disclosure, if your records show that the client has discussed the fact that she disclosed her HIV status to her partner. Clearly inform your client of your organization’s record-keeping policy.
- Do not make presumptions about whom she has disclosed her status to. Never discuss HIV status in non-private situations without her explicit consent.
HIV testing and disclosure in the workplace

In Canada, living with HIV/AIDS is protected as a disability under anti-discrimination laws. Therefore, no one can be refused an offer of employment or continued employment because they are HIV-positive, and work accommodation must also be provided to the disabled employee, if necessary. As with any disability, there are specific conditions and guidelines that dictate accommodation and what type of medical information must be disclosed to receive it. Requesting accommodation does not necessarily mean that the person’s HIV status must be disclosed to the employer.

The Ontario Human Rights Commission Policy on Employment-related Medical Information and Policy on HIV/AIDS-related discrimination (1996) state that employers may not conduct a medical examination prior to making a conditional offer of employment. Testing for HIV would constitute a medical examination. In most work settings, it is unlikely that testing for HIV infection is necessary or justifiable, as it poses virtually no risk to those with whom PHAs interact. Medical tests, after being hired, can only be required to assess whether or not an individual is able to perform the essential duties of a particular job. To protect confidentiality, any employee’s medical information, including HIV test results, must remain in their medical file and not in their personnel file. A PHA does not have to disclose HIV status to other employees.

Learn more:

**Disclosure, partner notification and the law:**


**Workplace-related disclosure, testing, and accommodation:**

Knowing Their Status Enabled Them to Get the Appropriate Treatment

Managing HIV involves a multi-disciplinary approach that requires consideration of every aspect of life.

Medication and pills
“A whole heap of things that we need to do to keep ourselves healthy”
Rhonda

Anti-retroviral drugs (ARVs) are the chief medications that PHAs take. ARVs function by stopping or reducing the reproduction of HIV in body, restoring immune function, and slowing down HIV progression. In Canada, there are more than 20 different ARVs available. Highly Active Anti-Retroviral Therapy (HAART) is a treatment regime that prescribes a combination of three or more ARVs. HAART is used in Canada and has been shown to be more effective at fighting HIV than taking a single ARV. It is sometimes referred to as a drug cocktail or combination therapy.

Though the objective of the ARVs used in HAART is to improve the lives of PHAs, the daily experience of being on HAART is awash with challenges. One of the chief criticisms of HAART is the magnitude and multitude of highly unpleasant side effects caused by the pills. Many PHAs feel sick every time they take their medication, and some experience side effects so severe enough to debilitate them. The intensity and duration of these side effects strongly affect how well a PHA will stick to their prescribed HAART, a vital point that is discussed shortly. The most common side effects of HAART, experienced at varying intensity and duration, include diarrhea, vomiting and nausea, liver problems, gas, appetite loss, lipodystrophy (body distortion due to fat gain/loss), increased levels of fat in the blood, fatigue, anemia, bloating, kidney problems, pain in joints and muscles, nerve damage, skin problems, sexual difficulties (low sex drive, trouble reaching orgasm), and mineral and vitamin deficiencies.

Along with HAART, PHAs often take other pills to manage HIV symptoms and the side effects of HAART. In the film, Rhonda mentions several other medications that she takes for pneumonia, MAC, and nausea. Chantal shows us the various ARVs that she takes, along with different vitamins and supplements. Many PHAs must take vitamins and minerals to make up for deficiencies in their body that are caused by HIV. This is in addition to trying to maintain a healthy, nutritious diet and lifestyle.
Rhonda

“...it made me black... One day I woke up, I looked in the mirror, and I was black”

In North America, ARVs have been approved and prescribed for use based on clinical trials conducted mostly using white male PHAs. Hence, it is not surprising that female and black PHAs have been reporting stronger and/or more side effects from some ARVs than white male PHAs. In the context of this project, since black people, including African and Caribbean women in Ontario, make up a disproportionate percentage of PHAs, it is very important to solicit their participation in clinical trials and research the possibility of varying reactions to ARVs. A side effect of Retrovir, an ARV, is the darkening of the nails and skin that Rhonda talks about; this tends to be more pronounced in black PHAs. Another ARV, Sustiva, can produce nightmares. This side effect has proven to be more pronounced in some black PHAs.

Additionally, black people are generally more susceptible to numerous other diseases (e.g. cardiovascular disease, diabetes, and anemia) that can be negatively affected by HIV and ARVs.

When to start HAART and what combination of ARVs will be prescribed is determined on a case-by-case basis. The main factors are the physician, the PHA, and the PHA’s health status. HAART is a demanding regimen, so it is crucial that the physician has extensive knowledge of HIV and ARVs, that the PHA is well-informed, and that the PHA’s input and opinions are respected. Hence, there must be a strong, open, and ongoing physician-patient relationship.

Taking it all in: Treatment adherence

“I forget maybe 5 or 6 things that I’m supposed to do a day. That’s why I am how I am right now.”

Rhonda

As seen in the film, a PHA could be taking 8 to 10 medications/pills per day. They may be in various formats (liquid, tablet), of varying sizes, in varying quantities, and may have to be taken at various times. As well, some medications can only be taken on an empty stomach, while others must be taken with food.

Reflect/Discuss

Have you ever taken any pills/medication on a regular basis? Were you asked for any input on what medication you would be prescribed and/or whether you wanted to take it? Did you have to adhere to a strict schedule and instructions? How did you do? How did the pills taste? Were you able to swallow them with ease? How did you feel after taking them? Better, worse, or the same? Did they give you any side effects? How did you handle them?

Following the prescribed HAART correctly is called treatment adherence. It is estimated that a PHA must adhere to their treatment correctly at least 95% of the time in order for it to be properly effective. This is because HIV can mutate and reproduce itself very quickly, thereby negatively affecting the health of the PHA. The consequences of missing, reducing, or skipping doses of HAART medication are significant – it can result in illness/infection due to the compromised effectiveness of ARVs on viral load and CD4 count, also called treatment failure. It can also result in developing permanent resistance to some of the prescribed ARV drugs, called drug resistance, and having to change HAART regime.
Tips that can improve adherence that you can suggest and/or help with:

- Practicing with multi-coloured candy or jelly beans for several weeks before starting HAART
- Using pillboxes to arrange the dosages
- Programming an alarm for reminders, such as a medication beeper or cell phone/watch alarm

As mentioned earlier, the severity and multiude of side effects from HAART are what often tempt PHAs to reduce, stop, or skip their medications. For an ACWHA, there could be additional stressors present in her life that could hinder her ability to adhere to such a strict course of treatment. Some of these stressors might include:

- **Marginalized position** as an African or Caribbean woman and a PHA
- **Poverty**: inability to afford food or properly balanced diet to take with medication; limited access to services/supports; stress of trying to manage finances
- **Stress and depression**: living with HIV and having to adhere to HAART adds to an already stressful life; stress and depression can be related to HIV and/or other issues (parenting, dealing with diagnosis and disclosure, navigating immigration and/or health care systems, etc.)
- **Low health literacy**: inaccessible language and format of information related to HIV and HAART, poor doctor-patient relationship; inability to act on medical information given
- **Non-disclosure**: isolation and lack of social support to remind and encourage her to take her pills; there may not be a secure, private place to store the medication at home/work

Taking HAART is a double-edged sword; in the long-term, it prolongs and improves life for PHAs; in the short-term, the side effects can bring on bouts of sickness and adhering to the demanding treatment regime can be relentlessly stressful.

**What can you do?**

- Look for barriers that may negatively affect an ACWHA’s ability to adhere (poverty, low social support, illness, etc); help her deal with these stressors
- Help her think about her capacity to start and to adhere to HAART; questions she may consider include: Does she feel comfortable taking ARVs? Is she able to access food/drink when required for pills? Does she have access to a bathroom easily (in case of nausea, gas, diarrhea, etc)? Can she store/take HAART discreetly? How will she manage HAART side effects with the responsibilities of work, family, etc? Will someone be able to take over for her if she doesn’t feel well and/or how feasible will it be for her to take time off work or other responsibilities if the side effects are too much?
• If she is taking HAART and hints at or speaks of not adhering well to the treatment, do not scold her. Remind her that, in the long run, HAART makes her healthier, encourage her to speak with her physician about her challenges with HAART, and look for ways to support her adherence
• Empower ACWHA to use their voice and choice about HAART with their physician/health-care teams
• Provide access to healthy foods and other supports
• Find sources for ACWHA to become more educated about HAART medications, treatment and how to manage adherence
• Advocate for better awareness and sensitivity from health-care professionals to empower ACWHA and other PHAs to be in control of their health

Learn more:

**Stages of HIV and HAART:**

**Managing HIV, including tools for charting lab results and checking for drug interactions:**
www.aidsmeds.com

**HAART side effects specific to black people and/or women:**
Current clinical trial (GRACE study) looking at the effects of an ARV based on gender and race: http://clinicaltrials.gov/ct/show/NCT00381303?order=1


*The Body. How is HIV different in African-Americans?*
The Cost of HIV & AIDS

Living with HIV has costs that extend beyond medication. The cost of being a PHA rises considerably once indirect expenses are accounted for, such as the price of:

- Maintaining a nutritious diet
- Paying for necessary non-prescription medicine (e.g. vitamins, remedies against HAART side effects, etc)
- During times of illness and/or weakness, paying for child-care, transportation to appointments and/or the hospital, etc
- Affording basic necessities of life when income is low
- Affording basic necessities of life (housing, food, etc) after paid sick days (if there are any) at work have been exceeded
- Saving money for family in case of future illness and/or death, since a PHA may not have or qualify for life insurance

Some PHAs will be able to afford their cost of living, while others may have to use credit, borrow from family/friends, or do without some things.

“In Canada, treating HIV can cost up to $12,000 per year, and treating AIDS can cost as much as $23,000 per year.”

This statement refers to the direct calculable expense of medication. In Ontario, there are some sources of financial support to assist PHAs with the costs of medication and other HIV-related expenses.

PHAs who are OHIP eligible

In Ontario, it is easier to access funding and support for the cost of HIV/AIDS if you are eligible for provincially funded health coverage, called the Ontario Health Insurance Plan (OHIP). Generally, to be eligible for OHIP, you must live in Ontario and be a landed immigrant, permanent resident, or citizen. If you apply for OHIP and meet the eligibility requirements, you must endure a mandatory three month waiting period before your OHIP coverage begins. OHIP pays for a range of medical services, including visits to doctors and lab tests. For PHAs who are eligible for OHIP, the cost of drugs is covered through the provincially funded Ontario Drug Benefit, Special Drugs Program, and/or the Trillium Drug Program.

Children born in Canada and living in Ontario are eligible for OHIP, even when their parents are not OHIP-eligible because of their own immigrant status. Under the Privacy Act of Ontario, the information that the parents reveal about their immigrant status, employment, or address should not be shared with Citizenship and Immigration Canada [http://www.ociasi.org/index.php?qid=794&catid=116, retrieved on April 30th, 2008]. Therefore, parents living in Ontario without legal immigrant status who apply for OHIP coverage for their Canadian-born children will not be reported to immigration.

Financial support for rent, child-care, food, and other non-drug related costs of living are available through various sources, including some ASOs, each with its own eligibility requirements, application process, and calculations for the amount and type of support. In Ontario, general requirements for government programs are residency and valid immigration
or refugee status. There are two primary government sources of financial support for PHAs who are Ontario residents: Ontario Works, also known as social assistance or welfare, and the Ontario Disability Support Program (ODSP), which provides financial and employment support.

**Interim Federal Health Program for refugees**

The Interim Federal Health Program is federally funded Canada-wide health insurance that temporarily covers essential medical costs for refugee claimants, refugees, and their dependents. This insurance terminates when a refugee receives permanent resident status and qualifies to receive provincial health insurance (OHIP in Ontario). The insurance is also terminated if the refugee’s application is refused, which leaves the refugee without coverage.

**PHAs without status or health coverage**

Living as an ACWHA without legal immigrant status or health coverage is a huge barrier to accessing medications and financial support. Often, the PHA must shoulder the direct and indirect cost of living with HIV. This generates added stress and can result in someone’s HIV progressing more quickly into AIDS due to lack of proper treatment, care, and support. Rhonda, who had been living in the GTA without status for 16 years, probably had some of these experiences. For PHAs without status or health coverage, limited sources for support or medical services exist and there are often waiting lists to access them. Those in the GTA and Ontario include:

- The Toronto People With AIDS Foundation (PWA), which administers a Treatment Access Program that provides temporary access to medical care and medications. Sources of medication often come from donations by pharmaceutical companies and distributing drugs that are no longer in use by other PHAs. This is done under the supervision of a physician and attempts are made to keep HAART consistent.
- Community Health Centres, which provide health services to people facing significant barriers, including those without status and/or health coverage.
- Hospitals, which are required to admit anyone, if failing to do so would jeopardize life; those who do not have health coverage are billed after. In the case of PHAs, the hospital’s social worker can be a resource for dealing with these bills.

**Coping with the costs**

Because there are limited options for treatment and financial support for PHAs without status or health coverage, some may try to cope with their situation on their own by:

- Postponing treatment and/or only seeking treatment when very ill, i.e. through a hospital
- Taking ARVs that are given to them by another PHA
- Enrolling in clinical trials that provide temporary access to some medications and financial compensation in exchange for participation

These coping methods will not provide the consistent and appropriate treatment needed by these PHAs and may actually decrease the quality and length of their lives.
There are different ways that an African or Caribbean woman who has immigrated to Canada can be without or lose status and/or health coverage, including, but not limited to:

- Being in Canada as a temporary resident; generally, temporary residents are not eligible for provincial health coverage and may not be able to afford private health insurance
- Dissolution of the relationship that was tied to her immigration sponsorship
- Decline of refugee status claim application by Citizenship and Immigration Canada
- Denial of permanent residency application by Citizenship and Immigration Canada
- Inability to afford private health insurance until OHIP waiting period has passed

**Immigration and HIV**

There is no simple answer to whether a PHA will be allowed to immigrate to Canada. As part of the standard immigration process, Citizenship and Immigration Canada (CIC) usually requires applicants to pay for and undergo an extensive medical examination, called the Immigration Medical Examination (IME). Only a CIC-authorized physician, called a Designated Medical Practitioner (DMP), can carry out this examination. The IME usually occurs in the country that the applicant will emigrate from, but can occur in Canada, if the applicant is already here. A diagnosis of HIV reported by an IME may or may not negatively affect an application for immigration.

Sometimes, the IME is the first time that an immigrant is being tested for HIV, so it is very important that they receive the pre- and post-test counselling that is required for this test, regardless of where it occurs. As Lisungu explains in the film, the DMP often fails to do so, and instead only enumerates a list of things the person should not do because they have HIV. Receiving an HIV diagnosis this way can cause tremendous stress to a person who is already undergoing the difficult process of immigration.

People who are already living in Canada as immigrants – awaiting residency or those living here without status – often worry about the possibility that their immigration application will be rejected and/or that they will be deported. Consequently, they will usually keep away from any situation that they believe could jeopardize their chances of remaining in Canada. This includes getting tested and/or treated for HIV, since it is commonly felt that this information will be shared with CIC. However, it is important for these immigrants to know that if they get tested for HIV through a public health department, this information is part of a separate government system that does not connect with CIC. According to a document by the Committee for Accessible AIDS Treatment (2006), public health departments and CIC do not have a formal information sharing arrangement; therefore, CIC does not expect to receive information from public health departments about HIV positive diagnoses of individuals going through the immigration system or who are living in Canada without status. If an individual expresses concerns about being reported to CIC, their best option is to get tested for HIV through an anonymous site, where their identity is completely unknown.
## What can you do?

- Encourage and assist ACWHA to access HIV treatment and services from reliable sources.
- Protect their confidentiality by facilitating the investigation of possible sources of support.
- Inform ACWHA who are refugees that they have some health coverage through the Interim Federal Health Program.
- Advocate on behalf of people living without status or health coverage (advocate to your agency, medical institutions, government, etc.).
- Advocate for increased financial supports for PHAs.
- Develop or set aside funding and/or supports to help ACWHA and other PHAs cope with the cost of HIV.
- Inform African and Caribbean women going through the immigration system or without status that, in Ontario, they can get tested for HIV through anonymous testing sites.

## Learn more:

### Clinical trials in Canada:
Canadian HIV Trials Network: [http://www.hivnet.ubc.ca](http://www.hivnet.ubc.ca), 1-800-661-4664

### HIV & immigration:


### Sources of medical/financial support for PHAs in Ontario:
Community Health Centres: [www.aohc.org](http://www.aohc.org)

OHIP & ODSP through the Ministry of Health and Long Term Care: [www.health.gov.on.ca](http://www.health.gov.on.ca), 1-866-532-3161

Toronto People With AIDS Foundation: [www.pwatoronto.org](http://www.pwatoronto.org), 416-506-1400
Coping with HIV

African and Caribbean women: Similar but different

“[African women]...are dealing with HIV... [in a way that’s] very different from the way Caribbean women are dealing with HIV and we have to acknowledge that and try to figure out how do we work around that...And it’s not us against them...You can’t force someone to be ready...it’s about giving information...the solution has to come from themselves”

Service providers discussing how to encourage ACWHA to disclose

Though African and Caribbean women are being discussed as a group, it is important to recognize that there are differences between them, and among them. Countries in Africa and the Caribbean are rooted in different realities and histories of governments, economies, cultures, religions, geographies, etc. These realities and histories make for different experiences for the populace in every aspect of life, including health and HIV. As such, how African and Caribbean women living in Canada react to HIV tends to be strongly influenced by the status and management of the HIV epidemic within their countries of origin. A woman who comes from a country where HIV/AIDS-related issues were ignored and/or kept hidden will probably deal with HIV differently from a woman who originates from a country that has been visibly active in dealing with HIV/AIDS. One of the greatest challenges for service providers is to provide services that address common needs and barriers, but also recognize diversity within these groups.

Shame, blame, & disclosure: The weight of stigma and discrimination

“I would like to show my face to tell people that HIV is real because I would like to help people...the price...for me to tell everybody is very high because people really turn against you”
Undisclosed African woman

“It’s society...it’s not HIV that kills people. It’s the stigma and discrimination and rejection that makes people go into depression and stop taking their medication...stop taking care of their health...and that’s when they get sick...”
Undisclosed woman

The film and this guide illustrate how stigma and discrimination weigh heavily on the lives of ACWHA. Several women in the film share their feelings of sadness, depression, guilt, and shame. Many feel that their own and their peers’ negative experiences with disclosing to seemingly trustworthy, dependable persons (e.g. friends, family, health-care professionals) outweigh the possible benefits of further disclosing. The reality and fear of these experiences can contribute to ACWHA’s isolation, depression, and low self-esteem. Stigma and discrimination can incline an ACWHA to shelter herself from these experiences, even at the expense of receiving medical care, support, etc. When disclosure is well-received, the greatest benefits include increased support, increased self-worth, and, hence, improved health. Many ACWHA have very small support networks that they trust and confide in. Some ACWHA also note that their primary sources of reliable support are people or communities that remain in their countries of origin.
Support for children and families

An incessant grievance from ACWHA and other PHAs is the lack of support for their children, both those who are HIV-negative and HIV-positive. ACWHA find limited support through friends, family, ASOs, and other organizations. This is an area of service that desperately needs to be developed, especially since child welfare agencies can become involved when a parent is unable to care for their child(ren). Apart from the common challenges of parenting, some of the struggles that ACWHA experience with their children, that are expressed in the film include trying to:

- Support the emotional needs of their children related to HIV/AIDS, especially at various ages and levels of understanding
- Maintain a parental role and provide care to children instead of receiving care from children
- Provide care for children when ill/hospitalized
- Deal with stigma and discrimination directed towards their children from child-care/school facilities
- Care for themselves when they haven’t disclosed to their children
- Care for and support their HIV-positive children

Many ACWHA feel like their diagnosis is a burden to their loved ones. They feel guilty about how their HIV-positive status has negatively affected and continues to affect their children’s lives. They feel guilty about the possibility of not being able to provide proper care for their children and families.

Speaking out and becoming empowered

“S’il n y a pas quelqu’un qui parle, il y a rien qui va s’avancer…alors ce qui m’a poussé de parler - c’est pour aider les autres. Donc c’est le plaidoyer, c’est l’advocacy que je fais.”

(Translation: If no one speaks, then nothing will move forward…so, what has pushed me to speak, is to help others. It’s advocacy that I’m doing.)

Chantal

Coming to terms with HIV takes varying amounts of time. Lisungu expressed that it took her two years to accept her diagnosis. Empowerment is often a personal journey that can be assisted through supports – emotional, financial, social, medical, physical, etc. In the film, each of the women was shown receiving and giving support at different times. Rhonda says, “I’m getting better at asking for help when I need it…because I realize that we all need each other, some way, somehow.” Chantal finds strength in speaking out about HIV and Paulina empowers herself as a speaker at schools and community groups as an expert resource on living with HIV/AIDS. All of these women also take time to celebrate life.

Each of the four women featured in the documentary is shown carrying on with daily life as best they can. This helps them cope with HIV. A common trait is having supports and finding joy and purpose in life, whether it be through working, caring for children, having a party, dancing, being in love, cooking, etc. Having a strong support system is particularly important since these women are highly stigmatized due to their race, ethnicity, gender, and disability status. AIDS service organizations (ASOs) provide sources for support to PHAs. In the GTA, there are also several ASOs that provide services and support specifically to African
and Caribbean people.

“I said to my doctor, ’I got black’ and he’s telling me no, that’s my complexion…my pharmacist…my family doctor … and they’re telling me, no, that’s my complexion”

Rhonda

Service providers have a role in the empowerment of ACWHA by recognizing them as valuable resources of information about coping with and managing HIV. No one should ever have to validate their experience or reality to a medical professional or service provider. In the scenes with Rhonda and the nurse (Ann), the nurse recognizes Rhonda as an expert regarding her own health when she states that Rhonda knows best whether she needs emergency care or not.

What can you do?

Life is complicated for African and Caribbean women living with HIV/AIDS. It is imperative that they are supported and treated holistically. As a service provider, your role should be to set them up for success in every aspect of their lives. Some of the best ways to find out how you can help is to become informed, ask questions and listen to the answers.

- Increase your awareness of the tremendous challenges that ACWHA must deal with
- Do not automatically presume that every African or Caribbean woman that uses your services will think the same way and have the same experiences
- Empower ACWHA by enabling their involvement in: planning their healthcare regime, HIV program planning; education/awareness initiatives, and peer education programs
- Find ways to involve ACWHA in advocacy & HIV-related projects without compromising their anonymity (e.g., voice-over in ads, advisory/planning committee participation, media interviews via telephone, writing educational articles, etc)
- Advocate for the acceleration of immigration proceedings for family members living abroad who can provide support to ACWHA living in Canada
- Provide safe space for ACWHA to congregate & become empowered
- Provide and advocate for supports for children of ACWHA
- Incorporate anti-oppression practices at your workplace

Learn more:

Toronto-based ASOs that specialize in providing services and support to African and Caribbean people:
Africans in Partnership Against AIDS (APAA): www.apaa.ca; 416-924-5256
Black Coalition for AIDS Prevention (Black CAP): www.black-cap.com; 416-977-9955

Support for children and family members of PHAs in Ontario:
Teresa Group: www.teresagroup.ca; 416-596-7703

continued next page
GTA opportunities available for empowerment of ACWHA through training and/or support programs:

Ethno-racial Treatment Support Network: Learning and Helping Out: multicultural and multilingual peer training to become an educator, mentor, peer counselor; 416-971-8022

Voices of Positive Women: Various peer and community training programs and support groups that cater to different populations of women; www.vopw.org; 1-800-263-0961

Ontario AIDS Network: People with HIV/AIDS Leadership Development Training Program; www.ontarioaidsnetwork.on.ca; 1-800-839-0369

CAAT and Regent Park Community Health Centre: HIV & Immigration Service Accessibility Training; www.hivimmigration.ca; 416-364-3030

WHIWH Community Health Centre: Health Promotion and Skills Development Project; www.whiwh.com; 416-593-7655
Love and Sex

“I’ve never been in love the way I am now”
Paulina

Like anyone else, ACWHA also have a right to experience romance, love, and to be sexually active. In fact, exercising these rights may contribute to positive self-esteem, self-worth, and empowerment.

“C’est pas parce qu’on est infecte par le VIH/SIDA qu’on ne peut pas faire la relation sexuelle.”
(Translation: Just because we’re infected with HIV/AIDS doesn’t mean we can’t have sexual relations.)
Chantal

PHAs can engage in sexual activities. Feelings about having sex may vary for a PHA, just as they sometimes do for someone who is HIV-negative. The general health of a PHA and ARV side effects also affect the level of interest in sex. Having sex as a PHA means taking precautions to protect oneself, HIV-negative, and HIV-positive sexual partners from HIV and from getting an STI. It is important to note that different strains of HIV do exist, so it is possible for a PHA to become re-infected with a different strain of HIV.

A document entitled, “Managing Your Health” (1999) by CATIE provides this statement:

“The basic rule for having safer sex is that you don’t want your partner’s blood (including menstrual blood), semen, pre-cum (the fluid that leaks out of the penis before you come), or vaginal fluid to get into your body, and you don’t want any of your fluids to get into him or her. You can hug, neck, lick, massage, dry hump, masturbate each other, share fantasies, have phone sex, dress up, and do lots of other fun things. Safer sex is a great excuse to be inventive with your partner(s).”

There are many resources through ASOs and the Internet that provide ideas for enjoying safer sexual activity. Sometimes, exploring non-traditional methods of sexual arousal and satisfaction can arise from having to re-think sex as a PHA. Both Rhonda and Lisungu express this in the film.

“One of the positives that has come as a result of me knowing my status is discovering my sex and sexuality. Before…I would just do it…[now I am] wanting to know more about sex…how to make it more pleasurable instead of just doing it.”
Lisungu

What can you do?

- Help clients explore their feelings towards sex, sexuality, and sexual activity
- Get to know and discuss resources that help PHAs figure out sexual activities that eliminate or reduce risk of HIV and STI transmission/infection
Saying Goodbye

Rhonda’s health deteriorates and it is evident in the film that she has lost her signature zest and is struggling through the days. As discussed, HIV/AIDS can take over every aspect of life and, in Rhonda’s case, there may have been a development of AIDS Dementia Complex (ADC), a neurological problem that can show up during the later stages of HIV infection. ADC causes memory loss, change of personality, irritability, poor coordination, and a host of other symptoms.

Death is always hard to predict and even harder to expect. In the documentary, the women from the WHIWH’s Health Promotion and Skills Development Project gather to celebrate Rhonda’s life and provide bereavement support to each other over her death. Bereavement is the grief experienced due to someone’s death. As observed in the film, people understand death and grieve in different ways.

What can you do?

Death is a sensitive topic and is probably best discussed when a PHA is feeling healthy and well. As a service provider, you can encourage your client to think about what sort of arrangements can be put into place to support and care for children and family if the client passes away. You can also encourage the client to explore their feelings about death, to talk to loved ones about the possibility of death, and to think about having prepared for death (having a will, deciding whether it is important that they die at home, in hospital, etc; what type of funeral/memorial service they would like, etc.). Some PHAs may find this process of preparing for death scary while others may find it empowering.

When someone dies from an AIDS-related death, you can respect and support your client’s need to grieve in a way that makes them comfortable. For a PHA, bereavement of an AIDS-related death can be very deep since it may stir up thoughts and emotions about their own mortality. Many ASOs offer AIDS-related bereavement support through groups and/or individual counselling. There are also other sources for support, including places of faith worship or cultural groups.

Learn more

AIDS-related bereavement support: Contact your local ASO

AIDS Bereavement Project of Ontario “supports organizations to strengthen resiliency in AIDS-related loss”: www.abpo.org, 416-205-9888

AIDS Dementia Complex from Project Inform: http://www.projectinform.org/info/adc/index.shtml or www.projectinform.org, click search, enter “ADC”.

Bereaved Families of Ontario: www.bereavedfamilies.net
Hope for the Future

“Parce que j’ai accepté ma séropositivité…je peux vivre longtemps…je suis vraiment à l’aise avec ça…et puis je suis bien…et puis la vie continue.”
(Translation: Because I’ve accepted my HIV status…I can live a long time…I’m truly at ease with that…and so, I’m okay…and life goes on.)

Chantal

There is life with HIV. There are African and Caribbean women, like Chantal, who have learnt how to successfully manage HIV and address the odds that are against them. Because of advances in treatment and increasing availability of supports, HIV is becoming a more manageable chronic illness instead of a terminal illness and so in Canada, people living with HIV/AIDS have an opportunity to have longer, high quality lives.

“Approximately 50% of African and Caribbean people who are infected with HIV do not know it and have no recognizable symptoms. 3% of African and Caribbean people in Toronto get tested every year.”

For African and Caribbean women in Canada, stigma, discrimination, and the social determinants of health related to their identity and to HIV continue to be tremendous barriers to getting tested, accessing treatment, and seeking support. Developing effective and targeted prevention and educational tools is a continuous and dynamic process that should adapt and respond to the diverse and unique qualities that characterize African and Caribbean women across Canada. This film and guide are part of a bold effort by African and Caribbean community members and several organizations and government agencies that strive to empower African and Caribbean people and their service providers with tools and resources that will improve their health, their lives, and their futures in Canada.

“I just wish that one day…we can talk about HIV like we’re talking about a cold…and someone would say, oh, you’re not alone…what are you doing…to take care of your HIV.”

Paulina

After viewing the documentary

Before viewing the documentary, you took some time for reflection and/or discussion in order to recognize your perspective on themes that would arise in the film and guide. Think back to what you thought and/or discussed. Now, take a few moments to answer the following questions through reflection and/or discussion:

- Have your feelings or your awareness changed after viewing the documentary? How?
- How do you understand HIV in the context of being an African or Caribbean woman?
- What do you think the experiences of African and Caribbean women (HIV-positive and/or HIV-negative) have been with your workplace? How have they been impacted by your services, or lack thereof?

It is our hope that this experience has increased your awareness and understanding of HIV, from the perspectives of African and Caribbean women in Canada. The recurring theme is that there are huge challenges to navigating health care, social services, and government systems as an African or Caribbean women living with HIV/AIDS. Stigma and discrimination,
coupled with perceptions about HIV/AIDS and African and Caribbean women create multiple intersecting barriers that need to be addressed in order to reduce HIV infection and to support people living with HIV/AIDS. These challenges cannot be overcome without your help.

“Strategies and interventions that focus on stigma and discrimination should be complemented with broader interventions targeted at whole communities to change social and cultural norms, beliefs and practices.”
Service Provider - Focus Group Participant

Many topics and feelings were presented and addressed in this documentary and guide. A multitude of suggestions have been put forward that you can consider implementing in your service provision to African and Caribbean women, as well as other communities at risk of HIV infection. Use this documentary and guide as tools for education and inspiration.

<table>
<thead>
<tr>
<th>What can you do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What can you do as an individual to improve how you provide services to African and Caribbean women immediately?</td>
</tr>
<tr>
<td>• What can you do as a department or as an agency/workplace immediately? In 1 month? In 1 year? Long-term?</td>
</tr>
<tr>
<td>• How can you increase the engagement of African and Caribbean women in their health care?</td>
</tr>
</tbody>
</table>
Afterword: About the Documentary

“I chose to get involved in the project because I received some health support from Women’s Health in Women’s Hands in the past and I thought this would be a wonderful way of giving back and showing my appreciation for their valuable services. I also was very perturbed about the attention given to black women living with HIV/AIDS in Toronto and wanted to contribute to a wider awareness of the issues...once I met the women in the monthly women’s group I was convinced that I should make this film.”

Alison Duke, Director of The Woman I Have Become

The Woman I Have Become arose from hundreds of hours of taping. The nature of the topic made creating the documentary an intimate and emotionally charged undertaking for the film crew and the participants as they confronted bittersweet experiences of living with HIV, struggle, sickness, and death in real-time. Some of these experiences affected the filming process and, so, it was important for everyone to work compassionately, patiently, and collectively. Most importantly, it meant respecting the participants’ needs and what was happening in their lives; e.g., maintaining participants’ confidentiality through voice distortion or face-blurring, re-scheduling filming and supporting them during times of illness and/or high stress, and aspiring to present an authentic account of their lives.

The process of filming the documentary began early in 2006 and it was first pre-screened on World AIDS Day 2007 in Toronto. More than 500 people, including the Ontario Minister of Health and Long Term Care and other politicians, service providers, community members, and policy makers attended this screening. The response to the documentary has been tremendous; there has been endless support for its creation, and great anticipation for its wide release and distribution.

This was the first time that WHIWH and the associated organizations undertook a project of this magnitude, and many African and Caribbean women living with HIV/AIDS willingly and courageously participated in the production of the documentary. Inspired to be part of this project, the women contributed in various capacities: showing their faces on film, having their stories/experiences shared in the film, acting in recreated scenes, recruiting participants, supporting the featured women and their families, and collaborating with the film’s director. This groundbreaking project drew attention to the women’s strong conviction to be seen as role models to their children, families, and communities, and highlighted their value as experts in the lived experience of HIV/AIDS. Their participation has and will continue to make significant contributions to stimulating positive change in their communities, reducing HIV-related stigma and discrimination, inspiring other PHAs to demand more support and resist isolation, promoting HIV awareness and testing, and facilitating improvement in services for other African and Caribbean women living with and/or at risk of HIV/AIDS in Canada.
Resources & Training Tools

HIV/AIDS-related resources and/or services that target African and Caribbean women in the GTA

African and Caribbean Council on HIV/AIDS in Ontario (ACCHO)
www.accho.ca, (416) 977-9955

Africans in Partnership Against HIV/AIDS (APAA)
www.apaa.ca, (416) 924-5256 (E/F)

Black Coalition for AIDS Prevention (Black CAP)
www.black-cap.com, (416) 977-7725

Women's Health in Women's Hand Community Health Centre
www.whiwh.com, (416) 593-7655

Sources for information on HIV/AIDS in Canada

Canadian AIDS Treatment Information Exchange (CATIE)
www.catie.ca, 1-800-263-1638 (E/F)
*Many of the documents referenced throughout this guide are available from CATIE

Canadian AIDS Society
www.cdnaids.ca (E/F)

Public Health Agency of Canada – HIV/AIDS information site
http://www.phac-aspc.gc.ca/aids-sida/index.html (E/F)

www.treathivglobally.ca
Canadian portal that provides multilingual HIV/AIDS treatment information

Sources for information related to immigration and/or legal issues & HIV/AIDS

Canadian HIV/AIDS Legal Network
www.aidslaw.ca, (416) 595-1666 (E/F)

Committee for Accessible AIDS Treatment (CAAT)
www.hivimmigration.ca, (416) 364-3030

HIV/AIDS Legal Clinic (Ontario) - HALCO
www.halco.org, 1-888-705-8889

Training and e-learning opportunities

Black CAP (see above for contact info)

CATIE (see above for contact info)

Ontario AIDS Network, www.ontarioaidsnetwork.on.ca, 1-800-839-0369

Contact: local/regional Public Health Units, ASOs, Community Health Centres
**Additional References**

Note: Documents and sources whose references were listed in the 'learn more' sections of this document have not been re-referenced here.


