

*Perinatal HIV Testing:
Implementing the Ontario
Program amongst Black
Women and Women of Color*

Presenter:

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Context of HIV Testing:

- Majority of black women and women of color's experience of HIV testing is not a matter of choice
- Testing occurs mainly through implementation of government policies:
 - Testing through immigration process – Policy implemented in January 2002
 - Testing due to pregnancy – in Ontario since December 1999
- Other contexts of testing include:
 - Mother tested after child is diagnosed with HIV first
 - AIDS defining illness – usually in late disease progression
 - Insurance purposes
 - Employment – particularly for care givers working without legal documents
 - While applying for life insurance

- “Some of the issues that these particular women face that I think are **unique** is that in life they’ve dealt a **multitude of crises** at one particular time. Many women are **diagnosed in the context of pregnancy**, so they’re adjusting to the reality of being HIV positive. Sometimes they’re dealing with the crisis of diagnosis at a time when there is **pressure for them to take medication to prevent prenatal transmission**, they have to actually deal with the drug and being HIV positive.....So again, they may be dealing with various **members of the family being tested together** at the time that they’re being referred to the clinic. So they’re also dealing with that. **Trying to assimilate new information**, maybe in the **middle of immigration process application** for status in Canada, so they’re going through a status shift. They may be trying to maintain some course of action through, They may have an immigration broker that they don’t want to deal with because now they’re **afraid that that person knows that they’re HIV positive, and they may be uncomfortable** with that broker. Sometimes the women feel abandoned, or their partners in the context of the diagnosis treat them in a hostile or **sometimes abusive manner**.”. - HIV Clinic Provider 2 -Silent Voices Study)

A: Experiences of Black women and women of color and perinatal HIV testing

- Findings are based on a qualitative study done with:
 - 29 African, Caribbean, Latin American and South women
 - 8 Prenatal care providers

Study objectives

This study investigated the following:

1. The experiences of African, Caribbean, Latin American and South Asian women and their service providers with HIV testing during pregnancy.
2. Women's understanding of informed consent.
3. Reasons for testing or not testing for HIV.

Lack of/or limited basic HIV information and Resources

- Most women did not receive the necessary information or counselling to permit informed decisions;
 - most had limited information on HIV transmission, testing and treatment
 - South Asian women received the least information and were not offered testing,
 - Black women were tested without any information or counselling
 - Latin American women though receiving limited or no information at all, were very trustful that their healthcare providers would do the best for them and their unborn children.

Reasons why women get tested for HIV during pregnancy:

1. Doctors' recommendations or insistence

- "I took the test because my doctor told me that it was important for me to have it done."
- "The doctor told me that there was this test he was going to do but I did not need to worry about it because it is only prostitutes who get that disease. He said it was AIDS. He did not explain it to me until the results came and he said I had it. I did not believe him because I had never been a prostitute in my life. He told me he cannot see me any more and gave me a number to call. I called my friend from ... and what he told me really scared me".

Reasons why women get tested for HIV during pregnancy (cont'd):

2. For the sake of the baby/to save the baby:

- “Yea there is a chance they could do something to help the baby. It’s my choice to find out if I wanted to have it or whatever. You don’t want to bring a child into the world with HIV to come and suffer.”
- “I took it maybe if I have some disease I will pass it on to my baby. Maybe the baby can have it. That’s why they have to check”

Reasons why women get tested for HIV during pregnancy (cont'd):

3. They were told "something" could be done (but not what)
 - "I knew that if they found something they could help the baby, but I'm not sure how."
 - "Yea there is a chance they could do something to help the baby. It's my choice to find out if I wanted to have it or whatever. You don't want to bring a child into the world with HIV to come and suffer."

Reasons why women get tested for HIV during pregnancy (cont'd):

4. To show provider not all African women were infected with HIV:

- "I already knew I was HIV negative, my partner and I got tested just before we decided to get pregnant, but I wanted to show the doctor that there are some African women who are not infected."

Reasons why women get tested for HIV during pregnancy (cont'd):

5. To facilitate effective decision making if infected:

- “Well, the decision to keep the baby or not if you have it. Just to know that you can get treated. I mean if I found out that I had HIV, I would decide on the option of having or not having the baby. I don't know if I can care for a child. Knowing that, that's how life is going to be, full of needles and pills and potions and not even a long life.

Reasons why women get tested for HIV during pregnancy (cont'd):

6.No of partners one has been involved with/lack of trust in relationship(s):

- “ you have been with more partners, you can never trust someone one 100% you never know and.... If you have been sleeping around yourself or if you don't trust your partner or you know your partner is doing something because a lot of people it has happened to them. They know that something is going on but they try to avoid it and hope it is going to get better”.

Reasons why women get tested for HIV during pregnancy

(cont'd):

- Many women made it quite clear that if testing was not suggested, they would never have thought about it.
 - “No I would not have asked about the test. Well I decided not to get tested, I trust my partner.....”
 - “You know what, for three years I have not done it. Oh no. I wouldn't have thought about it to be honest with you.. I wouldn't have and I should have because this person that I have been dating, I have known him for only a year....”

Reasons for not Testing:

1. Failure of provider to offer the test/conviction of provider/woman that there was no risk
 - “My doctor knows me very well. She knows I do not need that kind of information. Women who need this information are not good women. They sleep around. These are the women who need the information. My doctor knows me and my family very well. She knows our character. She has been our doctor for a long time.”
 - “No I would not have asked about the test. Well I decided not to get tested, I trust my partner because you know, and I know for sure that I haven't been with, you know just anyone.”

Reasons for not Testing (cont'd):

2. Had been tested previously – women with a previous negative test results felt they were not likely to be infected

"I already knew I was HIV negative, my partner and I got tested just before we decided to get pregnant. "

3. Fear about the implications of testing on immigration:

"I only agreed to get tested at this health centre because I trust the doctors here, otherwise I don't have immigration papers and I wouldn't trust anyone else with this information."

Reasons for not Testing (cont'd):

4. Implications of a positive HIV test on ones character:

- “they think you have been around and if you have it they blame you..... You go to somebody they are just going to blame you for this kind of thing. You are this or you have been sleeping around or whatever. Who knows what you are doing? I am sure they will not want to be close to you”.

Reasons for not Testing (cont'd):

5. Lack of health coverage – women without health coverage were fearful of accessing services because of their immigration status.
6. Employment status:
 - “You cannot miss going to work so that you can go to see a doctor. If you take time off, you don't get paid”
7. Fear of stigmatization and isolation
 - “What if I have AIDS? How is my family going to feel about it? What am I going to go through and how am I going to deal with it. It would have been very hard for me especially on my mom.”

Women's understanding of "informed consent"

- Most women did not understand the meaning of "informed consent"
- For most women, it meant being asked whether they wanted the test done or not.

How can Perinatal HIV Testing Uptake be Improved

- Increasing understanding of issues that impact on black women and women of color in relation to access and uptake of HIV testing during pregnancy
- Incorporation of identified issues into perinatal HIV testing policy implementation

What is the context within which Perinatal HIV testing takes place?

- Occurs within an environment filled with challenges and struggles at different levels:
 - Challenges related to the migration/settlement process
 - Challenges related to social determinants of health including stigma and discrimination – based on HIV status, racism, gender discrimination and homophobia
 - Challenges related to lack of access to culturally appropriate services and information

Challenges related to the migration/settlement process

- Trauma & Loss related to migration
 - Why did black women and women of color come to Canada?
 - Are they economic migrants?
 - Refugees fleeing from:
 - war torn countries
 - political, gender, sexual orientation or religious persecution?
 - Loss /separation from families, previous jobs, support etc.
 - If refugees, how did they get here?
 - Did they live in a refugee camp prior to leaving?
 - What were their experiences in their flight for freedom
 - What is their legal status (or lack of), how does it impact on their ability to access information and services? How does it impact decision to test or not test for HIV?

Challenges related to the migration/settlement process (cont'd)

- Stress related to process and time taken by immigration/refugee process:
 - Process is very long and very complicated
 - Acknowledgement of refugee claims (3 weeks to 6 months)
 - Waiting for hearing (9 months to 3 years)
 - Appeal(6-12 months) /PRRA (3-10 months)
 - Human & Compassionate (2-10 years)
- Costs: (application/ROLF/ Legal fees etc.)

Challenges related to the migration/settlement process (cont'd)

- Eligibility to services/treatment:
 - Refugee claimants: IFH if claim is acknowledged (difference if applied at border vs. inland (3 wk-6 months), limitation of services covered), some docs will not accept women with IFH (takes too long to get paid)
 - Rejected claimants: have no coverage
 - H&C, TRP, Visitor, Post-PRRA refugees, non-status: no coverage

Challenges related to the migration/settlement process (cont'd)

Economic status/Poverty:

- Struggles with basic settlement issues e.g obtaining gainful employment, affordable housing, food, etc.
 - High unemployment/underemployment rates
 - Limited advancement opportunities even for the highly educated
 - Most employed in low paying jobs in factories, restaurants, as caregivers, etc.

Challenges related to the migration/settlement process (cont'd)

- Struggles to alleviate poverty take first priority
- Childcare and transportation costs to facilitate access, affordable shelter, food, etc become major issues of concern
- Limited time to take care of ones health usually done when it becomes an emergency, a requirement or is often left unattended
- Struggle to deal with health problems with little/or no information at time of diagnosis, while simultaneously struggling with basic survival and poverty related issues

Racism/ Racial Discrimination

- Systems such as the health care system are viewed as inherently racist
 - Immigrant/refugee communities are always struggling against such systems to meet basic needs such employment, shelter, healthcare, education, etc.
- Racism is seen as one of the factors:
 - leading to high unemployment/underemployment rates
 - determining whether people got employment or not and the type of employment they get
 - Determine whether people accessed services, the type of services they access and the quality of services offered.
- The public, the government and its systems are generally viewed as uncaring about what happens to black women and women of color – currently seen as partly to blame for targeted mandatory testing – HIV testing as part of immigration policy is seen as a way to keep people out

Gender Discrimination

- Prenatal HIV testing programs targets women without proactive involvement of their partners
- Lack of recognition of power imbalances in women's sexual relationships:
 - Limits communication between partners about sex and safer sex practices
 - Limits power to negotiate safer sex or influence partners decisions in all areas of life including sex and sexuality
 - Creates economic dependency on men
- Effective programs hinges on the ability to effect change in this area

Homophobia

- Many immigrant/refugee cultures are inherently homophobic, a factor further compounded by religion.
 - Homosexuality is unacceptable
 - seen as a moral aberration –
 - communities react violently against those who are presumed to be queer/gay
 - fear of homophobia causes gay men/queer or MSM to:
 - live underground/in the closet
 - keep girlfriends or get married.
 - Without acknowledging sexual orientation there is risk of STIs/HIV being transmitted from gay to MSM to women and in vice versa
- Programs must factor this possibility in when working with black women and women of color

HIV related Stigma Discrimination:

- Promotes silence and secrecy around HIV/AIDS
- Delays diagnosis & treatment leading to poorer outcomes once care is accessed
- Promotes fear about confidentiality when accessing services - limits uptake of testing, ability to facilitate more holistic services that can be attained through referrals
- Inability to disclose to service providers, sexual partners, etc, leading to transmission to children and sexual partners

Lack of access to services

- Limited data on which to base programs and services - there is a great need to highlight:
 - the context within which perinatal transmission is occurring
 - the factors that facilitate or reduce transmission.
- Limited understanding of:
 - The major forces that are driving transmission
 - How above forces interact to create multiple oppressive systems and unique risk situations
- How does this impact on access and uptake of HIV testing for pregnant women?

Lack of access to services (cont'd)

- Lack of interrogation of cultural, religious, health related beliefs and values in testing programs:
 - Effects of religious, cultural and ethical values, taboos, family and power structures, gender roles and relationship norms, child rearing practices, monogamous/polygamous marriage systems, sexual norms and legitimized practices, representations of health/disease, life/death, time and conceptions of the future left unattended
- These should provide the framework and base for building relevant and sustainable testing services for women, their partners and their communities.
- Should also be used as a resource for relevant and sustainable actions

- “Some of the issues that these particular women face that I think are **unique** is that in life they’ve dealt a **multitude of crises** at one particular time. Many women are **diagnosed in the context of pregnancy**, so they’re adjusting to the reality of being HIV positive. Sometimes they’re dealing with the crisis of diagnosis at a time when there is **pressure for them to take medication to prevent prenatal transmission**, they have to actually deal with the drug and being HIV positive.....So again, they may be dealing with various **members of the family being tested together** at the time that they’re being referred to the clinic. So they’re also dealing with that. **Trying to assimilate new information**, maybe in the **middle of immigration process application** for status in Canada, so they’re going through a status shift. They may be trying to maintain some course of action through, They may have an immigration broker that they don’t want to deal with because now they’re **afraid that that person knows that they’re HIV positive, and they may be uncomfortable** with that broker. Sometimes the women feel abandoned, or their partners in the context of the diagnosis treat them in a hostile or **sometimes abusive manner**.”. - HIV Clinic Provider 2 -Silent Voices Study)