# RESPONSE TO THE HIV CHAPTER: GAPS, CHALLENGES AND OPPORTUNITIES

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# OUTLINE:

- Context within which comments are based
- Chapter developmental process
- Women's entry into care
- Contexts of women's lives
  - Poverty
  - Stigma and discrimination
  - Mental Health
  - Isolation and disclosure
  - Women's physical health concerns
- Concluding remarks

# CONTEXT OF MY COMMENTS:

- I am a service provider & Community Based Researcher:
  - Work in a CHC the has been providing HIV services within a Primary healthcare model for a decade
  - Have a cohort of approximately 400 women living with HIV
  - More than 95% are immigrant refugee women from countries with high HIV prevalence particularly Sub-Saharan (SSA) and the Caribbean
  - A substantial number are undocumented/no legal status in Canada
- Many years working with African, Caribbean and Black (ACB) particularly women around HIV
- Involvement in the development of PHAC's two Population-Specific HIV/AIDS Status Reports:
  - Women and Status report – going through bureaucratic approval processes
  - People from Countries where HIV is Endemic - Black people of African and Caribbean descent living in Canada

# DEVELOPMENTAL PROCESS: WHO WAS AT THE TABLE AND WHO WAS MISSING? (1):

- HIV is a disease that has biological, medical, economic and socio-cultural implications
  - Information needs and strategies require the same multifaceted approaches

- Understanding women and HIV requires expertise to be drawn from multiple disciplines across academia, service delivery, community and policy settings recognizing the principles of meaningful involvement of people living with and at risk of HIV

- Project team mostly located within academia and clinical fields
  - Voices of infected and at risk women are missing.
  - Report missing the social, community and institutional contexts within which HIV transmission, prevention, support and care takes place

# DEVELOPMENTAL PROCESS: WHO WAS AT THE TABLE AND WHO WAS MISSING? (2):

- Why is the community and the work they do missing from the report?
- Are there other sources of information that could have complemented what is provided to ensure a  more balanced view of what is happening around women and HIV in Ontario?
- Ontario has a rich HIV response that is driven my multiple stakeholders including researchers, people living with HIV, Service providers and policy makers which is not clearly evident in the report
- Has provincial strategies to support effective responses among populations highly impacted HIV:
  - ACB populations, Gay men, Aboriginal and more recently a women and HIV strategy

# ENTRY INTO SERVICES AND CARE:

- Majority of mobile, immigrant and refugee (MIR) women don't get tested for HIV by choice
- HIV testing and diagnosis occurs through government driven policies and protocols:
  - Immigration Medical Examination (IME)
  - Perinatal HIV Prevention Programs
  - Insurance policies
- Diagnosis due to AIDS related illness
  - may explain the higher rates of AIDS diagnosis among ACB women
- Testing experience rarely adheres to prescribed protocols of pre and post test counselling
- Optimization of HIV prevention within the context of the testing experience is limited particularly during IME (Rubin, Tharao and Muchenje, OHTN Conference 2009) and pregnancy (Tharao et al, CAHR 2010)
  - How long does it take for people diagnosed with HIV outside the country to access care?
  - What impacts does limited information at the point of testing have on access to, and navigation of health services?
  - What is the impact of lack of legal status/health coverage at point of diagnosis and entry into care?
- Few viral load tests/year may due to other factors other than lack of adherence to prescribed guidelines

# CONTEXTS OF WOMEN LIVES:

- Once diagnosed with HIV, a study of patterns of illness and outcomes of care needs to be situated in the day to day contexts of women's lives
- What is this content?
  - High rates of poverty, under-employment and unemployment
  - Stigma and discrimination
    - Mental health/emotional issues
  - Social isolation and fear of disclosure
  - Lack of health coverage
  - Physical health issues

# POVERTY:

- In a CIHR funded study (PIs Loutfy & Tharao), 15 focus groups were done with women living with HIV (n=104) in 5 cities in Ontario and women identified the following as issues of concern:
  - Poverty - meeting basic needs (food, housing and transportation) is a struggle
  - Poverty impacted ability to adhere to antiretroviral medications
  - Barrier to accessing health care

*Because of poverty you have housing issues, then you have lack of access to adequate nutrition. You have lack of transport, you know, increased costs going back and forth between doctors and pharmacists. You know, people making decisions about whether they have enough money for milk or to take the bus to see the doctor – Hamilton woman, WCBR project.*

# STIGMA AND DISCRIMINATION (S/D) (1):

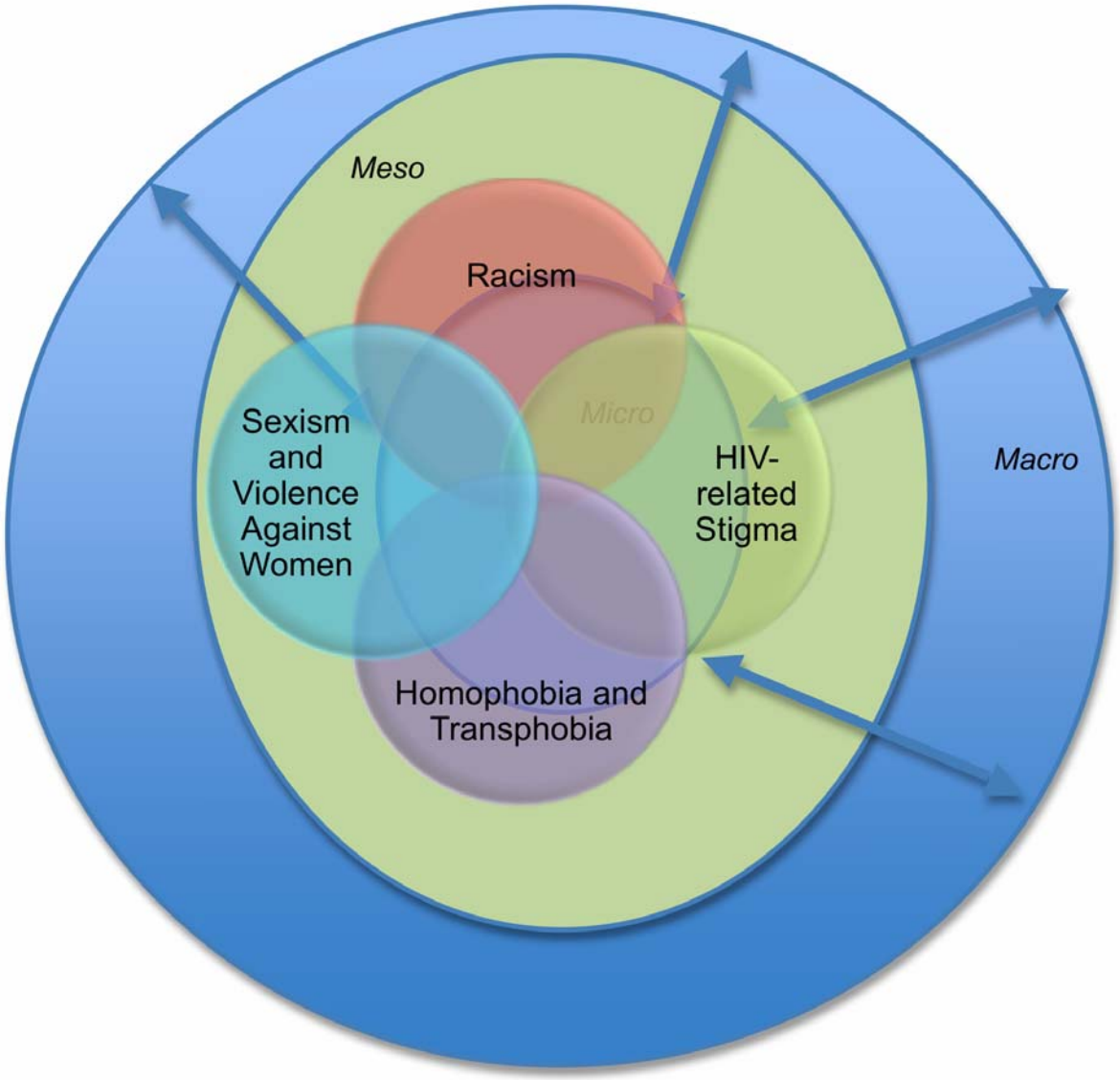
- The overrepresentation of marginalized populations within the HIV epidemic highlights importance and understanding of intersecting facets of S/D and their influence on HIV risk and health outcomes

- S/D has been highlighted as one of the most important factors influencing access and utilization of HIV services

- Research Participants in our CIHR funded project attributed stigma to:
  - Being HIV positive, sexism, racism, homophobia, transphobia, and marginalized identities (e.g. sex worker, injection drug use)

- Stigmatizing processes operating on multiple levels:
  - **Micro** (individual): knowledge, skills, attitudes, coping, resilience
  - **Meso** (community): community and social norms, cultural values and beliefs, social support systems
  - **Macro** (structural): economic, organizational and political power and domination; structural laws and policies, health systems (e.g. Parker & Aggleton, 2003; Sumartojo, 2000)

**Conceptual Model of Multi-level Intersecting Forms of Stigma Experienced by Women Living with HIV**




- May partly explain service usage patterns and health outcomes particularly mental wellbeing - not highlighted in the report as an important factor

# MENTAL HEALTH ISSUES (1):

- Loneliness, anxiety, depression and suicidal ideation stemming from the stress of living with HIV and experiences of HIV-related stigma:

*I had a massive heart attack in April, a quadruple bypass, and I was going to go to St. John's Nursing home for rehab for two weeks and I had a hell of a time getting in there because their facilitator there said – we don't have any place to put something like that in our rehab. Something like that*

*- Trans woman, WCBR project*

# MENTAL HEALTH ISSUES (2):

*Loneliness, you're lonely, depressed. Like, even when you go to see a psychiatrist or psychologist, they don't really address my issues as a woman living with HIV. Like, you're told, okay you're depressed, go take this medication. You take the medication and it doesn't help so I think more needs to be done*

*- Young Queer woman*

*It's like sometimes you do not know what to do with your emotions or how to deal with them. So, when you need help, you don't get it. The same when you get sick, there is nobody to help you.* *– Latina woman*

# ISOLATION AND DISCLOSURE ISSUES:

- Social isolation and fear of disclosure compounded participants' mental health concerns.

  *I did not tell my ex. Somebody wrote him a letter and told him. I was not the one that told my ex, because I knew he was going to take my son away. Somebody wrote him a letter and said keep your son away from his mother, she's HIV positive. My son would not even touch a $700 gift because he was told by his daddy he's going to catch AIDS*

  *- Thunder Bay, WCBR project*

- Lack of disclosure and limited condom usage are major issues in relation to HIV transmission and prevention
  - Criminalization of non disclosure on the rise
    - ACB men make up 50% of criminal charges laid in the last 5 years

- Criminalization of non disclosure is not an effective HIV prevention strategy

# WOMEN'S PHYSICAL HEALTH CONCERNS (1):

- Lipodystrophy:

  *I really want to see research done on lipodystrophy. For five years, I've been suffering with this and there have been no answers*

  *– Asian/South Asian woman*

- Co-infections e.g. HPV, diabetes, Herpes, high blood pressure

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

  *– Asian/South Asian woman*

# WOMEN'S PHYSICAL HEALTH CONCERNS (2):

- Gender/ethno-racial -specific medication side effects.

*I remember a long time ago when I was taking ….. I became really, really dark and I told my Doctor I'm becoming really, really dark he said he didn't see that. Many people saw that. It has nothing to do with race I guess he just doesn't see that. I don't think he was being racist. He just didn't see it. Because we have different shades*

*- African Caribbean Ottawa, WCBR project*

# WOMEN'S PHYSICAL HEALTH CONCERNS (3) :

- HIV and reproductive Health:

*When I get my period it starts five days spotting and then the next five days are heavy. I get my period 15 days out of the month; that's two weeks straight…I can't do anything. There is so much complication. Both of my doctors are males and I can't go to tell them that this is happening. Even if I have sex, I'm not having my period and I have sex, I start bleeding for no reason*

*– Asian/South Asian woman.*

# WOMEN'S PHYSICAL HEALTH CONCERNS (4) :

- Pregnancy planning and HIV:
  - Need for more research, information and services on pregnancy planning was also identified

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

- *African Woman, Ottawa, WCBR project*

# CONCLUSIONS:

- Improving women access to, quality of life and health outcomes requires paying attention and mitigating the determinants of health:
  - Issues of daily survival (food, housing, transportation) are the first priority for and women and their children, concerns about health are lower on list of priorities
- The influence of S/D on mental health issues and social isolation suggests the need for social support groups and stigma reduction interventions
- Need for gender and ethno-racial specific research is needed:
  - Meets the needs in their daily lives, there physical and mental wellbeing
  - Engages them in the entire research process
  - Has effective KTE strategies to influence programs, interventions, policies relevant to women.
- Need for relevant and appropriate health literacy strategies and programs