

# CHIWOS Formative Phase Focus Group Analysis: Exploring the Complexities of Peer Involvement in Women's HIV Care

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# Acknowledgements

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# Conflict of Interest Disclosure

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- No conflicts of interest to declare

# The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)

- **Goals:** Among HIV-positive women...
  - To assess barriers to and facilitators of women-centred HIV/AIDS services use
  - To assess the impact of such patterns of use on sexual, reproductive, mental and women's health outcomes
- **Hypothesis:**
  - Use of women-centred services will a) be lower among more marginalized and stigmatized communities, and b) correlate with improved sexual, reproductive, mental and women's health outcomes
- **Methods:**
  - Five year, multi-site, prospective cohort study; two waves of Peer Research Associate – administered surveys
  - In BC, ON and QC, with a target sample size of 1,450 HIV-positive women
  - Operates within CBR and GIPA approaches

# Emergence of the Formative Phase

- For survey development, a better understanding of ‘women-centred care’ in the context of HIV services and related care was needed
- Defining women-centred care:
  - Literature review (accepted to Journal of the International AIDS Society)
  - Focus groups to develop and refine a community-based definition
- Development of a women-centred care scale from literature and focus group findings for CHIWOS survey

# Methodology

- 3-4 focus groups per study province (ON, BC, QC)
  - In Ontario: 2 groups in Toronto (n = 6 + 7), 1 in Ottawa (n = 8), 1 in Sudbury (n = 4)
- Participants completed demographic surveys, and then focus groups were facilitated by trained peer research associates (PRAs)
- Researchers, coordinators and PRAs conducted thematic analysis of the transcriptions from focus group discussions
  - Main themes identified followed by sub-themes and selection of quotes

# Demographics of Focus Group Participants

n = 25		
Study Site	Toronto	n = 13
	Ottawa	n = 8
	Sudbury	n = 4
Age	Mean	41.5
	Range	31-61
Ethnicity	Black/African	n = 11
	White/Caucasian	n = 8
	Aboriginal	n = 6
Sexual Orientation	Heterosexual/straight	n = 21
	Two-spirited	n = 2
	Bisexual	n = 1
	I don't know	n = 1

# Themes Identified

- Family centered care, and considering children, in service provision
- Addressing barriers to accessing care
- Accounting for women's experiences of stigma
- Importance of social support and peer involvement

# Importance of Peer Involvement and Social Support

## Social Support:

“I attend that group too, and I really like the fact that it’s a peer-run group. We do what we need to do, rather than depending on ‘professionals’ or service providers to provide it to us. [...] It’s PHAs giving ideas to PHAs.”

“I think that women really are a magical thing when you get them together. It’s like the support that women offer each other in the right environment is pretty amazing, and I think it beats anything else, like any kind of professional support or whatever.”

“You can really express yourself really because you are the same and you can really talk what is bothering you and what’s affecting your life. And whether you are going to have any problem. [...] Who do I tell? I have to go to fellow woman.”

# Importance of Peer Involvement and Social Support

## Peer involvement in care planning and delivery:

“I personally need peer involvement at every level. Your doctor may not be HIV-positive, but they consult and meet with HIV-positive women. An organization has at least a certain percentage of HIV-positive women at every level. That sounds so cliché, but at every level HIV-positive women are included so that their input is heard, but also that you have the opportunity to choose between seeing a peer or not seeing a peer if you want.”

# Barriers to Accessing Peer and Social support

## Need for social spaces not being met:

- “ - So there’s no time for self-care. It’s always about trying to teach you something, rather than appreciate the fact that you just need some time and space to be with your community.
- [...]
- Yes, because we used to have really good social nights, a long time ago. [...] When it come to the event, you want to have a social event, you just want to relax and talk, and eat, and enjoy. But no, we have to have workshop.”

# Barriers to Accessing Peer and Social support

## Structural barriers to provision:

“I think sometimes they are restricted by the funding. I’m now speaking from a service provider perspective. I would have ideas that I would want to create programs for the women because what I realized is it’s not the workshop they come for; they just want to talk. They just want social things to do. But because, when I write a proposal, I am expected to have workshops on HIV.”

# Potentially Adverse Effects for Women who take on these roles

## Multiple (conflicting?) roles:

“I don’t access really any services. I’m on the board of directors for most of them, but I don’t access them.”

“I can’t participate in some of the things because I’m told because of conflict of interest, that organization is our partner. So I can’t participate in some of those initiatives in that organization, because it’s assumed there is a conflict of interest. So even if I am a PHA, now that I’m working I’m seen at a different level.”

# Potentially Adverse Effects for Women who take on these roles

## Shifting roles, losing support:

“- I used to access X-Hospital, but since I started working I stop.

- Just because of time?

- Not only that. Because of it seemed that I don't need any more. Not me, but the perception that I don't need it anymore.”

“I used to go to this African-Caribbean support group, as a member, and since 2009 I'm a facilitator. The roles change. I don't get really the support that I need from my peers, because I'm not anymore peers.”

# Conclusions

- Following considerations are crucial to informing women-centred care delivery
  - Social support and peer involvement are essential
  - Some structural barriers may need to shift to allow for the provision and access of such support
  - Despite importance of peer led care and peer involvement in research, need to account for potential downsides for those who take on these roles
- The findings are useful for sites and organizations prioritizing care for women living with HIV

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**Special Thanks To Our Community Partners!**



# Questions?

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Thank you!