"You know exactly where you stand in line... its right at the very bottom of the list"

Negotiating place and space among women living with HIV seeking health care in British Columbia, Canada

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Conflicts of Interest Disclosure

I have no conflicts of interest to declare.

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I would like to acknowledge that we have gathered together on the traditional territory of the Mi'kmaq people.

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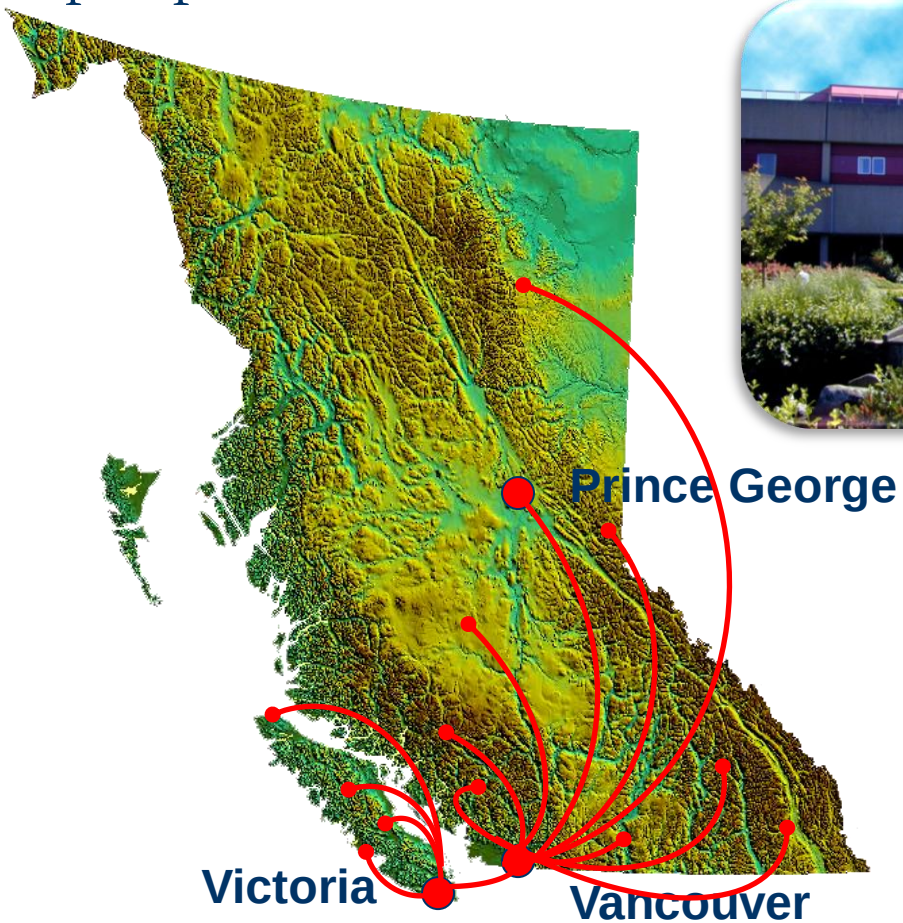
Background

- Re-thinking the **meaning of 'place'** from a health services perspective



Place and Space for Women Living With HIV in BC

- **The women:**
  - Now represent about 1 in 4 of all people living with HIV in BC
  - Diverse across both geographical and social axes

- **The services:**
  - Largely concentrated in urban centres and targeted towards gay men, people who inject drugs, or sex workers
  - BC's only HIV speciality clinic for women is located in Vancouver

Study Objective: To explore how women living with HIV understand, experience and negotiate 'place' and 'space' in attempting to access HIV-related care in British Columbia

The CHIWOS Study

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Étude sur la santé sexuelle et reproductive des femmes vivant avec le VIH au Canada

Canadian HIV Women's Sexual and Reproductive Health Cohort Study

- A multi-site, longitudinal community-based research study
- Enrolling >1,250 women living with HIV from BC, ON & QC
- **Study goals:** To assess the patterns of use of women-centred HIV care, & the impact on sexual, reproductive, mental & women's health outcomes
- **Methods:** Peer-administered survey at baseline with 18 month follow-up
- **Guiding Frameworks:** Community-Based Research, Social Determinants of Health, Critical Feminism, Anti-Oppression & Social Justice

CHIWOS Formative Phase Methods

- Nationally: 11 focus groups with 77 women living with HIV
- This study focuses on the 28 women we spoke to in BC
- Peer Research Associates conducted 4 focus groups in Vancouver, Victoria, and Prince George (Aug - Oct 2011)
- Focus groups were 2-3 hours long, semi-structured, audio-recorded and transcribed verbatim
- Transcripts were analyzed using:
  - Thematic analysis
  - Peer debriefing
  - Investigator triangulation

*All names were changed and pseudonyms used to protect confidentiality

Focus Group Participants

- **The women (n=28) represented diverse communities:**
  - Lived in and around Vancouver, Victoria and Prince George
  - 50% Caucasian, 39% Aboriginal, 7% Asian, and 4% African
  - 14% were <30 years, 65% were 31-50 years, and 21% >50 years
  - 43% and 32% had drug use and sex work histories respectively
  - Over half had an annual household income <$20,000
  - 25% identified as lesbian, gay, bisexual, transgender or queer (LGBTQ)
  - Most were linked to HIV services:
    - 85% received care from an HIV specialist
    - 54% accessed AIDS Service Organizations (ASO)

Results:
Navigating 'urban ghettos'

- At the geographic core of the HIV service landscape in BC is Vancouver's Downtown Eastside (DTES)

***Nancy**: "Originally, I came from Downtown Eastside. I was a drug user and I worked on the street. I still go into the X-clinic I used to go ten years ago, which has my HIV specialist... They do everything for you there...PAPs...full blood work...They have a TB office...social worker...counsellor."*

- While a crucial service location, the socio-spatial dynamics of the area present challenges for women who have either made their way out of the DTES or who have never lived there

***Nancy**:"I just wish there were more...clinics like that because not everyone can travel that long to go to X-clinic or come downtown...It's really hard...I wish there was more places that have HIV specialists...not only Downtown Eastside..."*

Results:
Navigating 'urban ghettos'

- Beyond the geographic clustering of services, women also navigate a terrain shaped by popular media as a 'skid row' place

Mae: *"There is one clinic that is available for the HIV people...But...If you have no experience with drug addiction. It is like you're in a strange place..."*

Lisa: *"Yeah... the area that it's in…everybody is in active addiction and people asking you if you want to score right out front. If you're in recovery or if you're not a person that's been using, it can be a really intimidating area."*

Mae: *"Yeah, I don't really want to go there."*

Lisa: *"And there's a lot of violence there. There's cops and sirens. It can be an intimidating… That's a barrier to seeking treatment."*

Mae: *"It's almost worse in Vancouver."*

[Multiple women in agreement]

Results:
Journeys for women outside the 'big city'

- Outside of Vancouver, a huge disconnect often exists between where women live and where HIV clinical services are consumed
- Women reported travelling long distances to care and highlighted multiple and competing demands as they navigate these journeys

***Shelia**: Just the distance, taking the boats. Having to take a day off work is really hard to do.*

***Mary**: Not to mention how damn tired you are when you get home, and you have to go back to work the next day.*

***Shelia**: Yeah, and paying for gas to drive there is a lot...You have to eat.*

***Mary**: Parking...*

***Rena**: There are so many trade-offs too, because you go and you separate that time from your life to do your X visit. And that means that you don't do A, B, and C. Maybe because you then don't have any money to do it, you don't have any time, and you don't have any energy..."*

Results:
Journeys for women outside the 'big city'

- This geographical transition proved especially challenging for HIV-positive mothers:

Michelle: *"I live in Victoria...For me to get to X-Clinic, it's a 12-hour day for a 2-hour appointment, and depending on whether I can afford it...And I've had to bring my children with me to my appointments many, many times, which interferes with their education... It's obviously a barrier."*

- These narratives beg the question: Why do women take these particular journeys, and are they imposed or chosen?
  - Vancouver is where the province's only HIV speciality clinic for women is located

Jenna: *"The gay men that came before us, if it weren't for them we wouldn't have this. So it's not about lack of gratitude...or prejudice. It's about reality...when we were five percent...then those five percent of women that had to go and access those services, kudos to them. But we are becoming higher in numbers. And when there's one in four, maybe that environment will change..."*

Results:
Women need a space to be

- Women want a space where they can exist without judgement, harassment, exclusion, or disempowerment

Sarah: *"From my experience, being a woman and going into X-ASO, they have a lot of workers there that are young and they are positive...There's a lot of young women that access that service, and it's just a really warm, comforting environment...when I did go there I was able to open up a little bit because, for me, I felt like my word was valued that that it was trusted and that it was actually cared about. I wasn't just talking out of my ass, kind of thing...I felt like I was being heard there."*

- But as our conversations continued, women reported being pushed to the margins of healthcare spaces

Ann: *"I also see Dr. X. The first time I met him I just knew that he rushed me through. He wasn't answering my questions...or addressing my concerns. It made me feel like I was just another number, like he didn't even care. And, like you said, he doesn't specialize in just women, so that's a problem."*

Results:
Women need a space to be

- The challenges accessing care are made worse by:
  - Social ostracism

Kay**: "I hate going to our hospital ER... If you're Aboriginal and you're complaining. Say if you had been drinking that night or whatever, it does not matter. They are... all White, all the staff, and they're very racist...They will help you eventually. But you are so tired at one point that you're either trying to curl up on a chair or you've got to leave. And then you haven't been helped and they're saying well you know you were next in line. Well that's bullshit. **You know exactly where you stand in line and it's right at the very bottom of the list..."

  - Not being able to see yourself within the services provided

***Sheila**: "I go to X-ASO and I don't feel like I have anything in common with anybody there... whenever I'd go in there I'd be like, whoa, I'm totally not in the right place...I think a lot of people... have huge barriers to getting resources...because they don't think there is a place for them...Or if there is a place, it isn't really accessible to them...I never went to X-ASO because it seemed just like it was more focused towards drug users and gay men, and not...straight white girls like me."*

Results:
Resisting Marginalization

- Women employed strategies to resist their marginalization
- Some women described actively rejecting available services

Karen: *"After a while what happens, for me anyway, is I don't want to access anything, I don't want to, it's like, no, I'm done. It's too exhausting....It is really emotionally difficult."*

- Other women described taking care into their own hands

Michelle: *"I've started doing my own HIV care... What I mean by that is I just call them when I need a second opinion... I get all my labs, I get all my copies of my blood work myself... I've learned how to manoeuvre through the system, and if I'm not concerned about something, I don't... go to the doctor... But what I will do is I'll pick up the phone and make them deal with me. I'll make them do that over-the-phone consultation..."*

- Women also highlighted the role of peer support

Jenna: *"One of the services that I accessed the most since I was diagnosed and probably helped me get to a place of helping others was X, which is an on-line support group for women…what I found profoundly helpful about it was that it didn't matter where I was. It was accessible by e-mail and I could respond to whoever was a member"*

Conclusions

- Proximity and distance does not fully define the separation of people and places
- Available care doesn't mean accessible care
- Existing services, even if proximally close, can still be socially marginalizing as women confront HIV stigma, racism, sexism, and classism, which operate to exclude and displace women
- Our findings stress the urgent need to acknowledge socio-spatial barriers to care and work with women towards the co-creation of spaces that reflect women's diverse identities and experiences

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Thank you

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Join us Sat 3:15 PM (social sciences track): **Angela Kaida, et al.** Hiring, training, and supporting peer researchers: Operationalizing community-based research principles within epidemiological studies by, with, and for women living with HIV.

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