

Establishing a community-based definition of women-centred care: A thematic analysis from focus group discussions with women living with HIV across Canada

N. O'Brien¹, J. Lewis², A.J. Carter^{3, 4}, S. Greene⁵, D. Bakombo¹, J. Dayle¹, G. Kwaramba², S. Margolese², B. Ménard¹, V.J. Nicholson³, S. Smith², S. Rawson³, A. Kaida³, A. de Pokomandy¹, M.R. Loutfy², CHIWOS Research

1. McGill University Health Centre, CVIS 2. Women's College Research Institute, Women's College Hospital 3. Simon Fraser University, Faculty of Health Sciences 4. BC Centre for Excellence in HIV/AIDS 5. McMaster University, Faculty of Social Work

BACKGROUND

Growing numbers of women living with HIV in Canada (Figure 1), and the gendered realities driving this trend, have evoked calls for tailored services that address women's specific needs. In response, the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) was created to study the health impacts of 'women-centred care' (WCC).

We explored definitions of WCC by women living with HIV across Canada towards developing a community-based definition of this emergent concept.

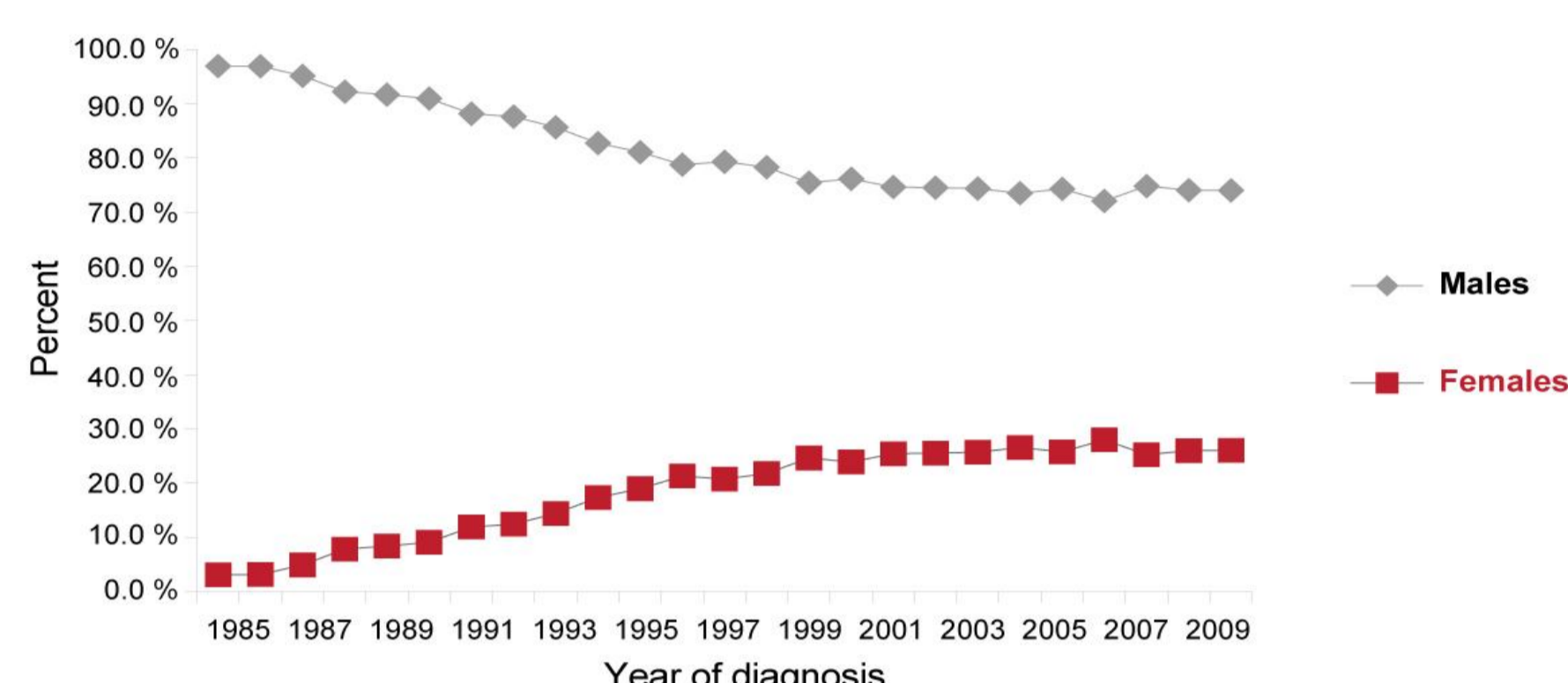


FIGURE 1: Proportion of HIV+ test in Canada reported by sex, 1985-2009¹

RESULTS

NATIONAL PARTICIPANT DEMOGRAPHICS:

	Quebec, N =24	Ontario, N = 25	British Columbia, N = 28	National, N = 77
Age				
< 30	4%	0%	14%	7%
31-50	60%	78%	64%	68%
> 50	36%	22%	21%	26%
Ethnocultural background				
Aboriginal	0%	25%	39%	22%
Afro-Caribbean	44%	46%	4%	30%
Caucasian	52%	29%	50%	44%
Annual Income				
< 20 000 \$	63%	30%	58%	> 50%
HIV Treatment				
HIV diagnosed < 2000	46%	50%	52%	55%
ARV Treatment	96%	67%	92%	85%

NATIONAL FOCUS GROUP THEMES:

Three themes regarding the definition of women centred care emerged. These included care environments that:

1. Address social determinants of health (SDoH) (e.g., housing, employment, gender).

"When somebody needs emergency money for food, clothing, housing and there's nothing here. They're going to make me choose between taking my medication or paying for my car or paying for my mortgage. It doesn't make sense." ON-FGD

2. Are cognisant of stigmatizing experiences and intersecting forms of oppression.

« J'ai vécu des préjugés bien forts dans l'hôpital de la part des infirmières... » ah, vous avez le SIDA... ». Il y a deux, trois autres personnes là. Alors je dit, je suis séropositive. «Là vous avez le SIDA? » Elle parlait fort. J'ai arrêté de parler. » QC-FGD

3. Encapsulate care for women's unique health needs (e.g., gynaecological health, reproduction, menopause).

"I'd like to see...somebody who is maybe a female who is well versed in women and HIV issues. Especially let's say if you want to get pregnant and you're HIV positive, because I know Dr. X just doesn't agree with that...And it's not his choice to make." ON-FGD

CONCLUSIONS

Varying perspectives on the definition of WCC highlight the diversity of women with HIV in Canada. Care must therefore be flexible and adaptable to suit the needs of different communities and individuals. Nonetheless, women living with HIV identified strong commonalities, indicating that the shared reality of being a woman living with HIV in Canada is a sufficiently defining experience to warrant the development of a WCC approach to serve this growing population.

NOTES:Source: Public Health Agency of Canada. HIV and AIDS in Canada. Surveillance Report to December 31, 2009. Surveillance and Risk Assessment Division, Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada, 2010.

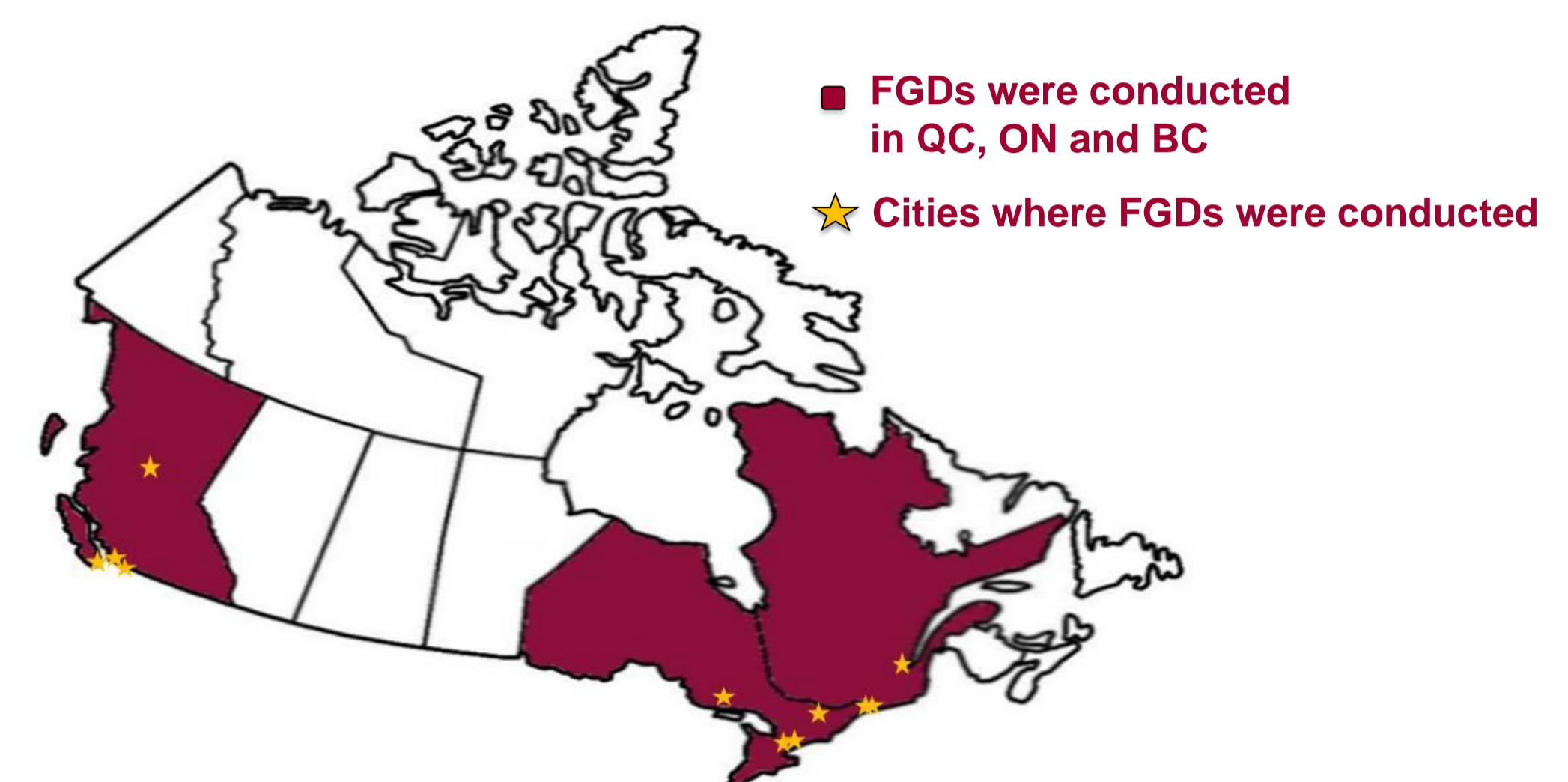
Allison Carter (British Columbia) :
Allison_carter@sfu.ca

Jamie Thomas-Pavanel (Ontario):
Jamie.Thomas-Pavanel@wchospital.ca

Nadia O'Brien (Quebec):
obrien.nadia@gmail.com

METHODS

Eleven focus group discussions (FGD) were conducted with 77 women living with HIV in Quebec, Ontario and British Columbia from August 2011 to April 2012. FGDs were led by trained Peer Research Associates and conducted in collaboration with community organizations and medical clinics. FGDs were audio recorded, and transcribed. Thematic analysis was conducted provincially, and themes were subsequently compared nationally.



PROVINCIAL FOCUS GROUP THEMES:

Key features of women centred care varied within and between provinces.

1. In BC and Ontario emphasis was placed on women's meaningful involvement in HIV care development and delivery through peer support and leadership.

"That's a clear indication that [Organization X] doesn't follow GIPA principles... It's very disturbing... I'm expected to put in volunteer hours. I see a couple of my neighbours, they drive them like slaves. They work like dogs and don't get a penny for it. They don't get recognition. They don't even get a cake or something on volunteer day. It's like there's this glass ceiling." BC-FGD

2. In BC and Quebec, women prioritized the need for safe (physical and emotional) care environments.

"...I would like to see a women's-only clinic where I can go in there, I can be comfortable seeing a woman doctor, woman social worker, someone that has gone through menopause even. Somewhere where I can sit around like here and talk to a group of women that have so many wonderful ideas...Just a safe space where I can actually talk about my period's really heavy, my boobs have got, just something that some other people can relate to... I want to do girl things. It's kind of a weird thing to say, but I don't have a place where I'm comfortable." BC-FGD

3. In Ontario, participants advocated for family-focused care.

"I don't know how to emphasize enough that, like especially in terms of women who have children, unless you support the children you're not supporting the mother. Somehow it's all tied together." ON-FGD

4. In Quebec, women highlighted the importance of long-term supportive services and permanent staff.

« Je pense que souvent dans les organismes y a des projets mais à court terme. Une année ça suffit pas là, il faut que ça soit à long terme, et ça se fait. Et une année c'est trop court. [...] parce que notre maladie c'est une maladie à long terme, à vie. [...] Il fallait la continuité, moi je condamne pas les organismes, mais je condamne les gens qui financent. » QC-FGD

Participants expressed divergent perspectives on whether WCC must be delivered in women-only spaces or exclusively by female health care providers.

ACKNOWLEDGMENTS

We gratefully acknowledge all the women living with HIV who participate in CHIWOS, the national team of co-investigators and collaborators, and the three provincial Community Advisory Boards (CABs) and CHIWOS Aboriginal Advisory Board (CAAB) members. For more info, please contact the coordinator in your region or follow us on twitter:

twitter.com/CHIWOSresearch

CHIWOS is supported by:



CHIWOS

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