

# Health care encounters and engagement in care: Lessons learned from the lived experiences of women living with HIV in accessing HIV and non HIV-specific care services

N. Ennabil<sup>1,2</sup>, N. O'Brien<sup>2</sup>, D. Bakombo<sup>2</sup>, J. Dayle<sup>2</sup>, B. Ménard<sup>2</sup>, A. de Pokomandy<sup>2</sup>, A. Kaida<sup>3</sup>, M. R. Loutfy<sup>5</sup>, CHIWOS Research Team

1. Université de Montréal - Faculté de Pharmacie, 2. McGill University Health Centre, Chronic Viral Illness Service, 3. Simon Fraser University, Faculty of Health Sciences, 4. Women's College Research Institute, Women's College Hospital

## BACKGROUND

Given the increasing number of women living with HIV in Canada (Figure 1), healthcare services must adapt to fit their unique requirements.

Due to women's multiple intersecting needs (e.g., social, gynaecological, physical, psychological), and the long term nature of HIV, healthcare is not administered solely by HIV-specific clinics. Women also interact with emergency departments, family doctors, drop in clinics, and numerous specialists.

In developing a range of services that adequately support women living with HIV, it is imperative to understand women's lived experiences of accessing HIV and non HIV-specific care to facilitate optimal engagement in care.

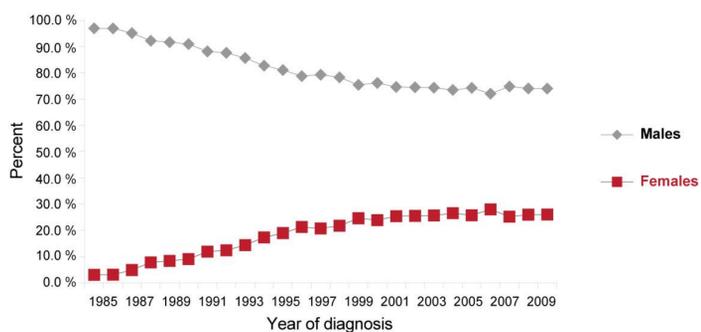


FIGURE 1: Proportion of Canadian HIV+ test reported by sex, 1985-2009<sup>1</sup>

## METHODS

Focus group discussions (FGD) were conducted within the formative phase of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS).

This analysis focuses on three Quebec FGDs (2 in French, 1 in English) with 24 women living with HIV in Montreal and Quebec City. FGDs took place in March and April 2012. FGDs were led by trained Peer Research Associates and conducted in collaboration with community organizations and medical clinics. FGDs were audio recorded, transcribed, translated and analysed in English and French using thematic analysis.

## RESULTS

In describing supportive engagement in care, women living with HIV identified contrasting experiences within and outside HIV-specific healthcare settings.

Women underlined the significance of positive patient-provider relationships, enabled by long-term interactions with HIV-specific clinics and HIV-providers.

*"Everything has been referred to my HIV specialist, Dr. X, and other doctors that I've seen through the years at the clinic. It's been a fabulous experience. Lots of terrific..., they know me, I know them."* QC-FGD

In general healthcare settings, participants highlighted the lack of basic HIV knowledge (e.g. HIV transmission routes) leading to instances of stigmatization, humiliation, and involuntary HIV-disclosure.

*"I had to educate the [head] of the department and I'm a professional in the healthcare. I had to. And she felt bad. I brought her some medical journals and everything to tell her where we're at right now."* QC-FGD

## RESULTS (CONTINUED)

*"I went to the pharmacy and said: 'I need my medication.' He [the pharmacist] said: 'here's your medication for HIV'. and everybody started looking at me. I felt so uncomfortable."* QC-FGD

Participants also addressed the need for improved communication between HIV-specialists and general care providers to better support their engagement in care.

*"I think that all the healthcare professionals could be on site, on location. They should communicate with one another, so we don't have to go to 10 different places."* QC-FGD

### Principal themes

Women living with HIV described facilitators and barriers to care, which need to be considered when creating health care that is responsive to their needs.



FIGURE 2: Barriers & Facilitators to engagement in care

## CONCLUSIONS

Various healthcare providers are essential to the provision of care for women living with HIV.

Experiences described by women living with HIV in Quebec offer a cautionary note that despite decades of the epidemic, stigmatizing experiences still occur and a lack of HIV-knowledge still persists within the healthcare system, limiting the feasibility of decentralizing HIV-specific care.

Finally, in addressing engagement in care amongst women living with HIV it is crucial that women be consulted to ensure that care is both effective and appropriate.

## 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 (CAB) and CHIWOS Aboriginal Advisory Board (CAAB) members. For more information, please contact the coordinator in your region or connect with us online:

www.chiwos.ca  
twitter.com/CHIWOSresearch

CHIWOS is supported by



NOTES: 1. 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.