



BACKGROUND

Antiretroviral therapy has transformed HIV from a near universally fatal diagnosis to a manageable chronic disease, prompting the need for changes in HIV care delivery. Access to primary care is particularly lacking for **Women Living with HIV (WLHIV)**, who now account for nearly a quarter of those infected in Canada and for whom women's health services (e.g. gynaecological screening, contraceptive counselling, pregnancy planning, and menopause management) have yet to be adequately adapted.

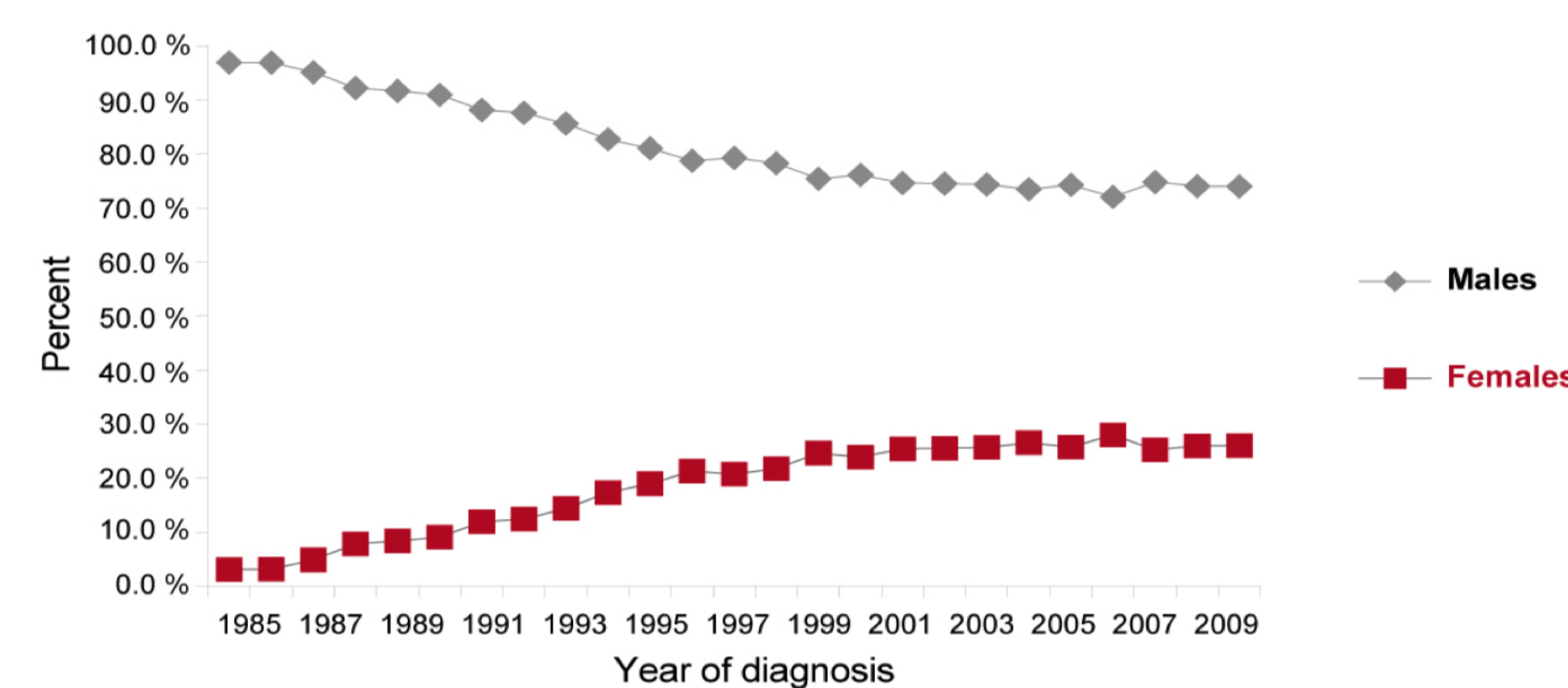


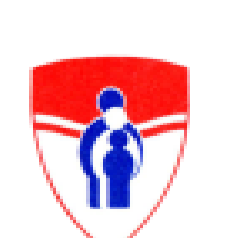
FIGURE 1: Proportion of HIV+ test in Canada reported by sex, 1985-2009¹

METHODS

Objective: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOs) was initiated in 2011 to investigate the impact of a women-centred HIV care approach on health outcomes among WLHIV.

Design: We conducted a qualitative inquiry into the meaning and value of women-centred HIV care, utilizing focus groups to garner women's accounts of HIV-care, healthcare needs, and visions of women-centred care. Interview guides were developed drawing upon patient-centred care principles. Our work is guided by the Social Determinants of Women's Health and Intersectionality frameworks.

Setting/Participants: Seventy-seven WLHIV participated in 11 focus groups between August 2011 and April 2012 across the study provinces of British Columbia, Ontario and Quebec. Peer researchers (WLHIV with training) recruited participants and co-facilitated focus groups. Participants self-identified as WLHIV aged 16 or older and represented various ethnicities, languages, and lived experiences, reflecting the diversity of WLHIV across Canada.



RESULTS

Women described their experiences of care and their recommendations for health care services according to their increasingly complex needs as a patient, a person, a woman, and as a WLHIV.

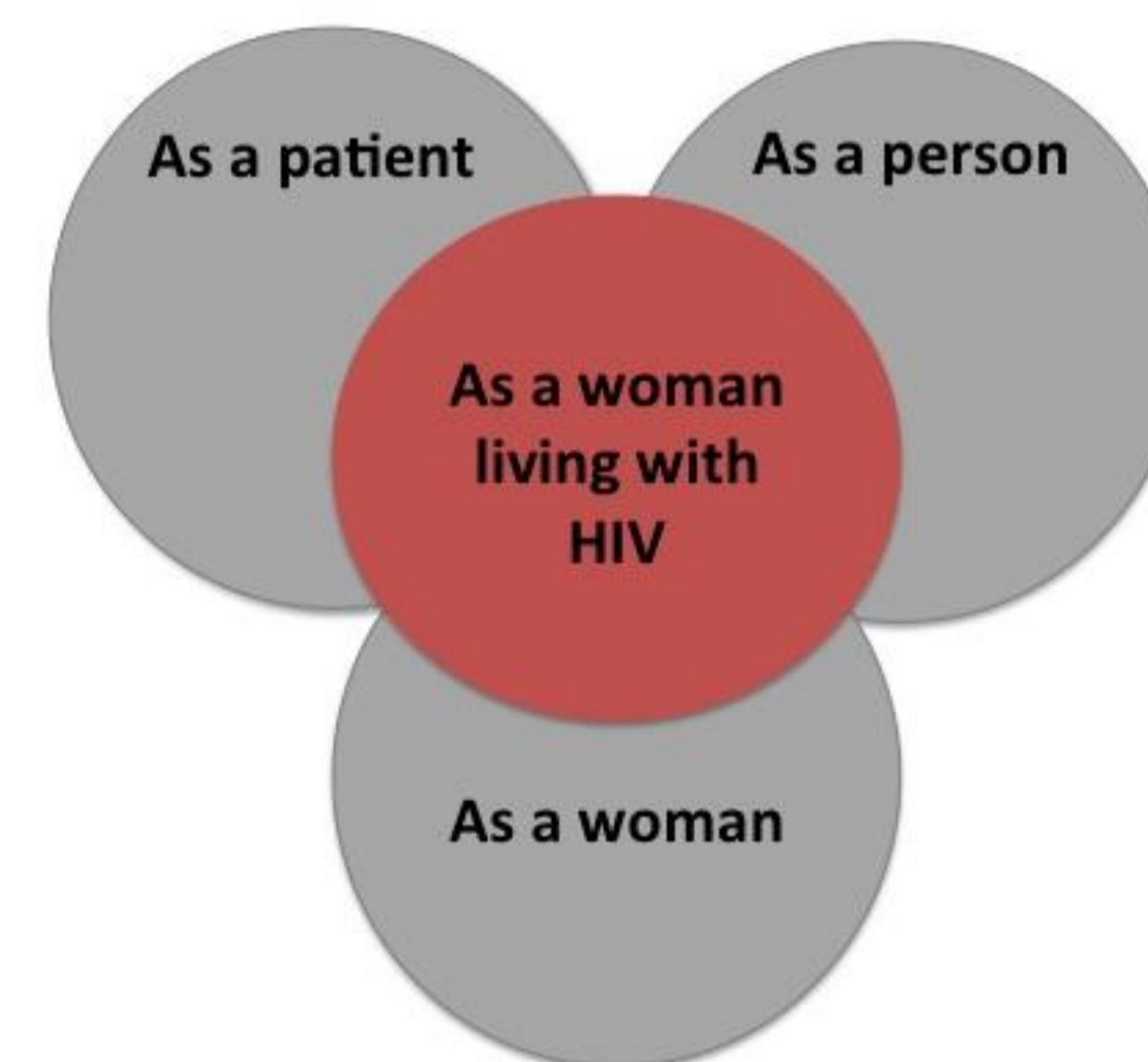
As a patient: "We are the ones who educate them"

They don't know much about this [HIV] . . . depending on the family doctor. Some of them don't have any HIV positive patients.

I went to see a gynecologist and he didn't know about HIV and I was trying to explain to him where I was, you know my CD4 count, and I was informing - educating my doctor.

As a person: "I felt like he cared about me as a whole person and not just a disease"

He doesn't just check with your health. He wanted to know if your kids were okay, and how your relationship was going. And everything, sexual health, emotional health, all of it. He was interested in all those aspects that make you a whole person . . . He'd always ask me if I'm working in my garden . . . You weren't just a chart with a bunch of numbers.



As a woman: "Services would have to be specific to women"

It's been 3½ years that I haven't managed to get an appointment . . . I'm no longer pregnant, but I'm still living with HIV and I need follow-up [for a Pap Test].

I don't know how to emphasize that enough . . . unless you support the children you're not supporting the mother . . . it's all tied together.

As a woman living with HIV: "She still made me feel human, she treated me with dignity and respect"

I think that everything is working well when we go to [HIV] specialized clinics . . . They know us, and they're very friendly. However, when we go to other clinics, when we're asked for our [HIV] status, then they discriminate against us.

One of the things that made the experience the best for me was the doctor . . . I told him I was not hauling my HIV-positive pregnant ass into [the] waiting room . . . I wasn't going to sit there pregnant and have everybody judge me . . . He was so good, he said, 'okay, you don't have to go there. We'll meet on another floor, and no one will ever know.

RESULTS (CONT.)

Envisioning Women Centred HIV Care

Coordinated and Integrated care: "Like a one-stop-shop"

"Everything that I need regularly is there . . . like the gynecologist, the pharmacist, the nutritionist. I don't have to go running from place to place".

Whereas if you've got a place . . . you're not having to repeat your life story.

Peer Led : "You don't know unless you've lived it"

Maintain and increase solidarity among women . . . to divide the sorrows and to multiply the joys and to be able to share, exchange and understand.

DISCUSSIONS

Our findings, drawn from women's experiences of care, are consistent with existing patient-centred care approaches, summarized by Hudon et al. (2011) of valuing the peer illness experience, being cared for "as a whole person", the value of doctor-patient relationships, being accorded sufficient time for concerns to be addressed, and being treated with dignity and respect. This study expands on three features, which respond to women's needs as patients, persons, women and women living with HIV. These features promote the provision of care in a manner that is safe, accessible, and ensures medical competency in both HIV and women's health. These key components of women-centred HIV care include:

- i. **coordinated and integrated services that address both HIV and women's health care needs;**
- ii. **care that is responsive to socio-structural barriers to care, such as stigma, violence, poverty, motherhood, and HIV-disclosure; and**
- iii. **care that prioritizes peer support and peer leadership in design and delivery of care.**

CONCLUSIONS

In envisioning a women-centred HIV care approach, WLHIV revealed significant gaps in care and proposed key solutions to ameliorate health services. In this era of HIV-optimism, where effective treatments reduce morbidities and increase life expectancy, new strategies must be incorporated to ensure that women's comprehensive health care needs are met and that health care advances benefit populations equitably.

Acknowledgments We gratefully acknowledge everyone involved for their invaluable contributions to the study. Thank you to all the women living with HIV involved in this study; the PIs, Coordinators, Peer Research Associates, and all the Co-investigators and Collaborators; the Steering Committee, Community Advisory Boards, and Aboriginal Advisory Board; Our funders: CIHR Institute of Gender and Health, the CTN (262), and OHTN; Our affiliated studies: CANOC, REACH & OSC; and all of our partners for supporting the study. N O'Brien also thanks the CIHR for funding to present at this conference.

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.