

## Envisioning Women-Centred HIV Care: Perspectives from Women Living with HIV in Canada

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## **Abstract**

**Background:** Women comprise nearly one-quarter of people living with HIV in Canada. Compared with men, women living with HIV experience inequities in HIV care and health outcomes, prompting a need for gendered and tailored approaches to HIV care.

**Method:** Peer and academic researchers from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) conducted focus groups to understand women's experience of seeking care, with the purpose of identifying key characteristics that define a women-centred approach to HIV care. Eleven focus groups were conducted with 77 women living with HIV across Quebec, Ontario, and British Columbia, Canada.

**Results:** Women envisioned three central characteristics of women-centred HIV care, including: (i) coordinated and integrated services that address both HIV and women's health care priorities, and protect against exclusion from care due to HIV-related stigma; (ii) care that recognizes and responds to structural barriers that limit women's access to care, such as violence, poverty, motherhood, HIV-related stigma, and challenges to safe disclosure; and (iii) care that fosters peer support and peer leadership in its design and delivery to honour the diversity of women's experiences, to overcome women's isolation, and to prioritize women's ownership over decisions that affect their lives.

**Conclusion:** Despite advances in HIV treatment and care, the current care landscape is inadequate to meet women's comprehensive care needs. A women-centred approach to HIV care, as envisioned by women living with HIV, is central to guiding policy and practice to improve care and outcomes for women living with HIV in Canada.

## **Key Words (from available list - 6 max)**

Focus group; HIV/AIDS; Community Based Research; Women's Health; Access to Health Care;

Gender Disparity

To be added if possible: CHIWOS

## **Introduction**

Medical advances in the treatment of HIV have greatly increased the health and survival of people with HIV, transforming HIV into a manageable chronic disease (Deeks, Lewin, & Havlir, 2013). These improved health outcomes are dependent on consistent engagement in HIV care, including achieving HIV RNA viral suppression through early and sustained use of antiretroviral therapy (ART) (Gardner, McLees, Steiner, del Rio, & Burman, 2011; Nosyk et al., 2014). Despite advances, numerous inequities in HIV care and health outcomes have been reported among communities of people living with HIV in Canada (Lourenço et al., 2014). Amongst these are gendered inequities in care, with women living with HIV experiencing poorer access to care, HIV related outcomes, and life expectancy compared with men, suggesting the need for tailored approaches to care (Carter et al., 2013; Carter et al., 2014; Cescon et al., 2013; Patterson et al., 2015; Tapp et al., 2011).

## **Women living with HIV in Canada and Globally**

Over the last two decades, the proportion of new HIV infections occurring in women has nearly doubled in Canada, from 12% of positive tests in 1999, to 23% in 2012 (PHAC, 2010, 2012). Women now represent nearly one-quarter of the 75,500 people living with HIV in Canada (PHAC, 2014). The increase of women living with HIV in Canada echoes global trends, whereby over 50% of people living with HIV are women (UNAIDS, 2010). The rise in HIV rates among women is a consequence of both women's increased biological susceptibility (Quinn & Overbaugh, 2005) and increased sociostructural vulnerability to HIV, the latter arising from multiple intersecting social determinants of health such as poverty, racism, and gender and power inequities (Higgins, Hoffman, & Dworkin, 2010; Logie, James, Tharao, & Loutfy, 2011; Schafer et al., 2012). These inequities, coupled with the legacy of colonialism in Canada, are visible in

the higher rates of HIV in many marginalized communities, including Indigenous women, African Caribbean and Black women, newcomer and immigrant women, trans women, incarcerated prison, and women with histories of sex work and injection drug use (PHAC, 2012).

Sociostructural factors influencing HIV susceptibility continue to affect women seeking HIV care, across several levels of the HIV care cascade (Gardner et al., 2011; Lillie-Blanton et al., 2010). Research from Canada and other high-resource settings suggests that, compared with men, women are diagnosed with HIV at more advanced disease states (Girardi, Sabin, & Antonella d'Arminio Monforte, 2007); have longer delays before initiating ART (Cescon et al., 2015; Nicastrì et al., 2007); are less likely to be retained in care, adhere to ART, and achieve sustained viral suppression (Cescon et al., 2013; Lourenço et al., 2014; Puskas et al., 2011; Puskas et al., 2017); and receive poorer quality of care during their first year of treatment (Carter et al., 2014). The impact of these indicators of poorer engagement along the HIV cascade of care is exemplified in the lower life expectancy of women living with HIV in Canada compared with men (6.8 years less), which contrasts with overall population trends (Patterson et al., 2015).

In the US and Canada, the initial focus on men who have sex with men at the historical debut of HIV care, the relative minority (~25%) of women living with HIV, and the underrepresentation of women in decision-making have all contributed to a care landscape where women's comprehensive care needs are not prioritised (Steiner, Finocchiaro-Kessler, & Dariotis, 2013). For instance, although medical advances can ensure that women living with HIV can safely become pregnant and have an HIV-uninfected child (Forbes et al., 2012), substantial gaps persist in high-income countries regarding the availability of suitable pregnancy planning support (Finocchiaro-Kessler et al., 2012; Greene, Ion, Kwaramba, Smith, & Loutfy, 2016; Squires et al.,

2011; Steiner et al., 2013). Care gaps also include contraceptive counselling (Loutfy, Sonnenberg-Schwan, Margolese, & Sherr, 2013), cervical and breast cancer screening (Baranoski, Horsburgh, Cupples, Aschengrau, & Stier, 2011), aging and menopause support (Imai, Sutton, Mdodo, & del Rio, 2013), comorbidity management (Kendall et al., 2014), and services that address the social determinants of health (Johnson et al., 2015).

### **Envisioning a Women-Centered HIV Care Approach**

Given the chronic nature of HIV and the persistent gaps in care, primary care approaches such as patient-centred care have been identified as promising models for addressing the comprehensive care needs of HIV affected populations (Chu & Selwyn, 2011; Hudon, Fortin, Haggerty, Lambert, & Poitras, 2011; Justice, 2010; Katz, 2011). To date, however, limited work has explored whether or how patient-centred care models apply within the HIV care context. Further, little is known regarding what features of care are crucial in supporting women's engagement in care from the perspective of women themselves. Our qualitative investigation sought to answer the question: what does women-centred HIV care mean to women seeking HIV care in Canada?

## **Methods**

### ***CHIWOS – Community-Based Research Approach***

The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) was initiated in 2011, in Quebec, Ontario, and British Columbia (Loutfy et al., 2016). The qualitative phase informed the survey creation and implementation of the national cohort comprised of 1425 women living with HIV. Our study's objectives were to examine access to women-centred HIV care and the impact of corresponding patterns of use on health outcomes (Loutfy et al., 2016).

CHIWOS is guided by principles of equitable involvement of those affected *by* the research *in* the research process by establishing community-academic partnerships and shared decision-making throughout the study (Cargo & Mercer, 2008; Israel, Schulz, Parker, & Becker, 1998). This participatory research approach, predominantly named Community-Based Research in Canadian HIV studies, was enacted in part through the involvement of women living with HIV as trained Peer Research Associates (PRAs) in each stage of the research (Kaida et al., 2014).

### *Focus Groups*

Focus groups were our chosen method of qualitative data collection, as we were committed to hearing the perspectives and priorities of women living with HIV. Further, when facilitated by a skilled moderator, focus groups have been identified as a useful method for soliciting information from marginalized groups, as they foster the creation of an environment where women can share their experiences while challenging the status quo (Aanand, 2013) and taking control of the agenda (Kitzinger, 1992). Importantly, our approach to focus group interviewing also reflects our commitment to mitigating potential ethical concerns about the power of the researcher (Wilkinson, 1998). Of particular note, PRAs led focus groups with participants with whom they shared identities or experiences (e.g., ethnicity, newcomer, history of injection drug use) in an effort to encourage truthful disclosure, mitigate perceived stigma, and reduce “social difference” between the researchers and participants (Green & Thorogood, 2013). All associated academic and health institutions provided research ethics approval.

### *Participant Recruitment*

Eleven focus groups were conducted with women living with HIV (N=77), across Quebec (N=24), Ontario (N=25), and British Columbia (N=28). Eligibility criteria included self-identifying as a woman, living with HIV, being 16 years of age or older, and residing in one of

the three study provinces. Each focus group included 6-9 participants, with one exception in a northern community where four women attended. A purposive, convenience sampling strategy was employed. The focus group locations were chosen purposefully to garner the perspectives of ethno-racial and linguistically diverse participants from across the country, while maintaining fairly homogenous groups to encourage participants to feel at ease (Krueger & Casey, 2009). To recruit participants, PRAs leveraged their personal networks and knowledge of local AIDS Service Organizations, while provincial investigators liaised with HIV clinics and community organizations. The study goals, voluntary nature of the research, and limits of confidentiality within focus groups were explained to potential participants.

#### *Data Collection*

Prior to the focus group discussions, we provided participants with a meal and \$50 compensation for time and expenses incurred, including lost wages, transportation, and childcare. Focus group discussions lasted 2-3 hours, and included obtaining informed consent, discussing individual and group confidentiality, and completing a brief demographic questionnaire. The facilitators used a semi-structured interview guide to ensure consistency across moderators. Questions were structured in a ‘funnel-like’ manner (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007), drawing first from women’s experiences of care before moving to women’s perspectives regarding what a women-centred HIV care approach would entail. All focus groups were audio-recorded, and a co-facilitator took field notes to record observations.

#### *Data Analysis*

In preparation for analysis, audio-recordings were transcribed verbatim. Potentially identifying information (e.g., name, age, ethnicity, doctor, clinic) was removed from the transcripts to protect confidentiality given the numerous peer and academic researchers involved in the interpretation

and analysis of the data. For the analysis, we adopted an inductive thematic content analysis approach, as described by Braun and Clarke, as its focus on “experiences, meaning and the reality of participants” corresponded with our research aims and is considered suitable for participatory research (Braun & Clarke, 2006). In order to facilitate PRA involvement in the data analysis, each provincial team of PRAs and investigators analyzed their transcripts before results were combined at the national level. Individuals in each province read and coded transcripts independently, then met numerous times as provincial teams to re-read transcripts, confirm codes, describe and interpret patterned themes within and across focus groups, and identify illustrative passages. Preliminary results were then reviewed by all authors nationally and presented at CHIWOS Community Advisory Boards, local community events, and national conferences to confirm whether the main themes resonated with women living with HIV and pertinent stakeholders.

## **Results**

Seventy-seven women participated in the 11 focus groups. Most participants were 31-50 years of age (67%), and were born in Canada (60%). The ethno-racial identity reflected the diversity of women living with HIV in Canada, including White (44%); African, Caribbean, and Black (30%); and Indigenous (22%) women, with variability across provinces. Half of the participants reported low incomes (< \$20,000/year), while 68% of participants had completed high school or more advanced education. The majority of participants reported taking antiretroviral medication (85%). Participant demographics are summarized in Table 1.



**Table 1: Participant Demographic Information (n = 77)**

Characteristics	Value n (%)
Age Category	
< 30	5 (7)
31-50	51 (67)
> 50	20 (26)
*1 missing	
Born in Canada	45 (60)
Ethnicity	
Indigenous	17 (22)
African, Caribbean, and Black	23 (30)
White	34 (44)
Additional ethnicities	3 (4)
Language	
English	44 (57)
French	14 (18)
Bilingual	19 (25)
Income < \$20,000/year	35 (51)
Education ≥ High school	52 (68)
Taking Antiretroviral Treatment (ART)	64 (85)
Year of HIV diagnosis	
2006-to 2012	15 (20)
1996-2005	36 (48)
Before 1996	24 (32)
*2 missing	

Throughout the focus groups, women relied on their experiences of care to make recommendations regarding what features compose a women-centred HIV care approach. Drawing on existing patient-centred care literature (Hudon et al., 2011), we present women's contributions, organized by their stated care needs as a patient, a person, a woman, and a woman living with HIV.

#### *Care needs as patients - "We are the ones who educate them"*

As patients with diverse health needs, women living with HIV seek out medical care from a variety of health providers. Women expressed concern and frustration regarding the lack of HIV

knowledge among family doctors, gynaecologists, and other providers, which resulted in women being burdened with educating their providers in order to receive suitable care.

I went to see a gynaecologist 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.

For women, foundational to meeting their care needs were providers with sufficient HIV-related competencies to provide quality care, whether this care was sought within specialized HIV clinics or within the broader health care system.

*Care needs as persons - "He cared about me as a whole person, not just a disease."*

Within the discussion, women juxtaposed what it felt like to be treated as a *"whole person"* against feeling like *"just a number"*. A woman shared her positive experience of care:

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.

In contrast, women shared experiences of care providers not according enough time for their health concerns to be addressed:

They don't give the proper care to a lot of us women. We're shuffled in and shuffled out . . . like a cow . . . the personal interaction is pretty well gone . . . it's really hard.

Consistent with a patient-centred care approach, women expressed the desire to be viewed as "whole persons." Part of that consideration includes responding to sociostructural barriers to care, including low income, unemployment, and lack of stable housing. Though physician

consultations are provided free-of-charge in Canada, prescription coverage varies per medication and between provinces. As one woman illustrates, financial barriers continue to hinder care:

Sometimes the bill is very steep, and when you're in a group insurance plan 80% is covered, but you can't manage to find the remaining 20% . . . We skip medications, it's not easy to cover the costs and we're ashamed to always have to go and ask.

Addressing sociostructural factors that impede women's health success, access to care, and treatment adherence is thus a key component of women-centred HIV care.

*Care needs as women - "Services would have to be specific to women."*

Women across focus groups expressed that care services must recognize and respond to the needs of women living with HIV *as women*. Women discussed both their biological care needs, such as pregnancies, Pap tests, and menopause, and the particularly gendered sociostructural barriers to care, such as experiences of violence, motherhood and caregiving responsibilities. For example, a woman shared her concerns about giving birth to "*a child who's healthy*" and wondered: "*Are there such services available? I don't know how to go about it*". Of equal concern were challenges associated with accessing gynecological services post-pregnancy and care that met their needs regarding aging, menopause, and the effects of medication-induced lipodystrophy (abnormal accumulation or loss of body fat in certain parts of the body). The following women shared specific care considerations for 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].

You're not alone, I've been asked by my grandson if I had a baby in my belly... you know HIV affects your self-esteem . . . because of lipodystrophy, it has a devastating affect on your femininity.

Across the focus groups women also spoke of the diverse social positions women inhabit, which influence their health and their abilities to access care. Here, women discussed their identities as caregivers of children, family members, and friends, and how these must be recognized in order for care to be effective.

When I was first diagnosed, a counselor said to me, the ones that he always worries about were the caretakers, because the caretakers always put themselves last, and you're taking care of anybody else . . . we self-isolate, because we're protecting our children, or protecting our families, or protecting our spouses, because we don't want them to have the stigma . . . But we don't think of protecting ourselves.

Women also highlighted that gendered and sexual violence must be considered in the delivery of care and may result in a preference for a health provider of a specific gender. One woman highlighted that while an issue, such as violence, is not unique to women the experience of being “*under-served*” in terms of woman-specific services contributes to feeling overlooked in the context of health care.

To respond to this gap in the accessibility of women's specific care, participants articulated the benefits of the coordination or integration of services, such as a “ . . .*one-stop shop*” where multiple care services could be accessed under one roof. As one woman shared: “*Everything that I need regularly is there . . . like the gynaecologist, the pharmacist, the nutritionist. I don't have to go running from place to place.*” Women's descriptions of a coordinated and integrated care

approach went beyond the physical space and included the need for communication between care providers. For example, one woman explained that: *“regardless of what you have as a problem, they [care providers] should all meet so they can be on the same page, so they can be able to help the person on their medical journey.”* Given the limited HIV-specific knowledge in the broader health care system and the need for women’s health care, coordinated and integrated care was posited as a care feature that would meet their needs *as women*.

*Care needs as women living with HIV - “She still made me feel human, she treated me with dignity and respect.”*

Women’s experiences of care became defined not only through their identities as patients, persons and women, but also through their identity as women living with HIV. Women encountered HIV-related stigma as they navigated the health care system, particularly in instances where they were required to disclose their HIV status to unfamiliar medical staff. One woman shared her experience of HIV stigma at a drop-in clinic.

She [the nurse] removed the paper [from the examining room bed], which is normal, but she also removed the sheets underneath the paper. She stripped the entire bed. She removed everything. There’s . . . a bin where you put soiled bed sheets, but actually she put them in the garbage can . . . that’s not the way to treat people.

Another woman shared how her experience at a pharmacy resulted in exposing her HIV status to other customers. She shared: *“He [the pharmacist] said, ‘here’s your medication for HIV . . . everybody started looking at me. I felt so uncomfortable.’* These experiences were described as stigmatizing events and painful care interactions. Women also linked their experiences of stigma to their social position as women:

Because of our lives we don't go around advertising we're positive. And if you're in a smaller community it's even more so. And if you've got family, it's even more. You know, it just sort of compounds over and over again. And I think, as women, we wear that more than the men do.

As such, care that was responsive to women's experiences of stigma was described as women-centred. For instance, care features that did not require women to continuously repeat their HIV status, such as coordinated and integrated care, were key to the creation of safe and accessible care. As one woman stated: *"Because I'm doing it on my own . . . every time you go in you're going, 'okay, yes, and I am HIV positive' . . . [you're] having to repeat your life story."* Care providers who were aware of, and could mitigate, instances of HIV-stigma were also described as providing women-centred care.

One of the things that made the experience the best for me was the doctor that I was seeing at the time . . . I told him I was not hauling my HIV-positive pregnant ass into [the] waiting room . . . because you sit in that waiting room everyone knows you're positive, and I wasn't going to sit there pregnant and have everybody judge me and look at me and whatever. 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'.

Hence, instances of stigma illustrate that, despite great advances in the field of HIV, considerable misinformation and prejudice remain amongst care providers and fellow patients. This distinguishes care for women living with HIV from other models of care developed to support women more generally.

Given their positioning as women living with HIV, mutual understanding through peer support was portrayed as being integral to fulfilling women's need for community, empathy, and empowerment. Peer support was described as filling a gap in support services, and was viewed as a way to: *"maintain and increase solidarity among women . . . to divide the sorrows and multiply the joys, and to be able to share, exchange and understand."* Another woman stated: *"I don't care how much compassion, I don't care how much education you have, you don't know what we're experiencing unless you've lived it."* Women also emphasized the importance of peer leadership in the design and delivery of care. As one woman articulated: *"for a service to really respond to our needs it has to be a service that we are a part of."* Illustrating both the vision of comprehensive care under one roof, and the desire for peer influence in program delivery, one focus group closed with the following exchange: *"this is our house guys," "our house"*.

To summarize our findings we created a conceptual model in the shape of a house to depict the participants' priorities and experiences regarding women-centred HIV care (see Figure 2). This model represents women's vision of a women-centred HIV care approach as one that builds upon basic care competencies, is grounded in patient-centred care principles, and is attentive to both women's health and HIV care priorities. A women-centred HIV care approach is also designed to bridge gaps in care for women living with HIV through improved care coordination between providers, by acknowledging and addressing the impacts of HIV-related stigma and other structural challenges to care, and by prioritizing peer involvement and leadership. Additional quotes further elucidating each theme described above are presented in Table 2.

**Table 2- Women-Centred HIV Care as envisioned by women living with HIV**

Themes	Sample Quotes
<b>Care needs ...</b>	
As a patient	<p>I feel that medical professionals, whether they are a doctor, psychologist, social worker, etcetera, they should be comfortable with HIV/AIDS.</p> <p>They don't know much about this [HIV] . . . depending on the family doctor. Some of them don't have any HIV positive patients.</p> <p>The doctor came in waving this piece of paper and it said HIV-positive . . . they started making arrangements for me to be sent to X-Hospital . . . it was the worst possible thing, why aren't the doctors and nurses trained in empathy or whatever training they need to deal with us in every hospital in the province . . . I was treated like they had no clue as to what was going on.</p>
As a person	<p>The first time I met [this doctor] 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.</p> <p>He was pretty busy, and I felt like I was just a number. I would spend 10 minutes in his office and then it was done. And now, with my new physician, I can spend a half an hour, an hour with her. And we cover all aspects [of my health] and things are progressing.</p> <p>I've been going there since late 1990's . . . And all of my care, whether it's gyne, Pap smears, eye doctors, eye specialists, rheumatology, everything has been referred to my HIV specialist . . . It's been a fabulous experience . . . they know me, I know them.</p>
As a woman	<p>Women are under-served . . . there's services for gay men, but . . . services would have to be specific to women, in terms of reproductive health, violence . . . It's not that violence is experienced only by women, but women-specific services are not available so we don't feel recognized or acknowledged in all of this.</p> <p>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.</p> <p>Unfortunately, some of our members had to go through a traumatic experience to get what they have [HIV] and they don't want to see a male gynecologist or a male HIV specialist.</p>
As a woman living with HIV	<p>I think that everything is working well when we go to [HIV] specialized clinics . . . We know them, 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.</p> <p>I still would love to have the chance to have another child . . . I'd have to leave here [this clinic] if I was to have a child here, I know that because I would be stigmatized. I know Dr. X would come in bitching and complaining. So it would be nice to have a female, well versed in women, in HIV, or an OB/GYN who doesn't judge you for that, number one.</p> <p>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 . . . so that their input is heard.</p>



## **Discussion**

This study outlines the key components of a women-centred HIV care approach as envisioned by women living with HIV. In the process of taking us on their journeys of care, the women who participated envisioned what key features of care would tend to their needs as patients, people, women, and women living with HIV. Their conceptualization of a women-centred HIV care approach identified factors ranging from basic care competencies (Scholl, Zill, Harter, & Dirmaier, 2014), which all patients interacting with the health care system should be accorded, to health care needs specific to women living with HIV. Women described basic care competencies as including empathy, confidentiality, especially regarding HIV status, and access to care providers who possess basic knowledge regarding HIV as a chronic health condition. Women also depicted care characteristics consistent with patient-centred care approaches such as being viewed as a whole person, having their care needs met across their life course (e.g. from pregnancy to menopause), and positive provider-patient relationships in shaping their experiences of care (Hudon et al., 2011). Finally, women identified three features of care specific to women living with HIV: (i) coordinated and integrated services that are designed to address both HIV and women's health care priorities, as well as to prevent exclusion from or discrimination during care due to HIV-related stigma; (ii) care that acknowledges and responds to structural barriers to care, such as violence, poverty, motherhood in the context of HIV, HIV-related stigma, and challenges to safe disclosure; and (iii) care that fosters involvement of women living with HIV as peer support and peer leadership in its design and delivery as means to overcome isolation, cater to the diversity of women's experiences, and prioritize women's ownership over key decisions that affect their lives. A women-centred HIV care approach should include basic care competencies, patient-centred care principles, and features specific to women living with HIV. These combined features of a women-centred HIV care approach would promote the provision of

care in a manner that is safe and accessible, while ensuring medical competency in both HIV and women's health.

The findings of this research are consistent with an international literature review, which summarizes 11 features of women-centred HIV care, such as safe spaces for care, gender specific care services, and the involvement of women living with HIV in the development and provision of services (see Appendix)(Carter et al., 2013). The identified priorities for care in our research, including the depiction of these principles within the figure of a house, also echo findings from the research “Building a safe house on firm ground”, an international survey of 945 women living with HIV from 94 countries ranging in resources and health care contexts (Orza, Welbourn, Bewley, Tyler Crone, & Vasquez, 2014). Similar to our focus group findings, this priority setting project highlighted the importance of safe, non-stigmatizing health care spaces, respect for diversity, care that meets needs across the life course, and the meaningful involvement of women living with HIV (Orza et al., 2014). Similar findings have also been reported in multiple studies in Canada (Carter et al., 2015; Greene et al., 2016; Ion & Elston, 2015); in the United States (McDoom, Bokhour, Sullivan, & Drainoni, 2015); in lower resource settings such as Southern and Eastern Africa (Gibbs, Crone, Willan, & Mannell, 2012); and in international collaborations (Loutfy et al., 2013; Johnson et al., 2015). As these studies demonstrate, HIV trajectories across many international contexts share certain similitudes, including the feminization of HIV, the evolution of HIV to a chronic disease when access to treatment is secured, the persistence of HIV-related stigma, and the inequitable positioning of women within societies. These commonalities suggest that our women-centred HIV care model may be applicable to diverse settings within and beyond Canada.

Our study contributes to the continued call for research and care priorities to be dictated by those most affected (Boivin, Lehoux, Lacombe, Burgers, & Grol, 2014; Domecq et al., 2014;

UNAIDS, 2007). As demonstrated by the recent proliferation of patient-oriented funding calls by agencies such as the Canadian Strategy for Patient-Oriented Research (SPOR) and the Patient-Centered Outcomes Research Institute (PCORI) in the United-States, prioritizing community and patient engagement is increasingly recognized as a key strategy for improving health outcomes (SPOR, 2017; PCORI, 2017). Obtaining clear direction *from the patients themselves* on what gaps persist and what mechanisms may best address their health concerns is considered paramount for improving the quality and accessibility of care. Thus our participatory research with 77 women living with HIV across Canada identifying persisting gaps and care priorities, provides two direct contributions. Firstly, our research demonstrates how patients (here women living with HIV) can be meaningfully incorporated into each stage of the research process to identify patient-led priorities. Secondly this research constructs a conceptualization of a women-centred approach to HIV care, which may serve as guideposts for the creation of policies, care practices, and further research driven by women living with HIV.

These care priorities, identified by women living with HIV, have already informed the CHIWOS study's quantitative survey instrument. Questions regarding the features of HIV care received, including women's perceptions of women-centredness and satisfaction with their care, have been posed to 1425 women from the Canadian provinces of BC, Ontario, and Quebec, with planned expansion to Manitoba and Saskatchewan (Loutfy et al., 2016). These questions based on community-informed conceptualization of women-centred HIV care will be used to quantitatively assess women's access to women-centred HIV care and the corresponding impact on quality of life (Carter et al., 2017), as well as a variety of HIV and comprehensive health outcomes across the life course. These findings will further inform changes in health care delivery, to address gaps in care for women living with HIV and redress current health inequities.

## Study Limitations

There are limitations to this study, which should be considered and addressed in future research. In particular, due to the multiple authors (peer researchers, coordinators, clinician investigators) involved in the analysis and interpretation of the findings, and our concern for anonymity, participant identifiers such as age, ethnicity, and years living with HIV were not included in the transcripts analyzed. Our findings therefore do not speak to the differing experiences and perspectives of sub-groups amongst women living with HIV (e.g., urban vs. rural, Indigenous vs. White, recent HIV diagnosis vs. long term survivor). Our findings speak to the commonalities amongst women living with HIV seeking care in Canada and, potentially, in other settings.

## Implications for Policy and/or Practice

In envisioning a women-centred approach to HIV care, women living with HIV provide clear directions for improving policy and practice to meet their care needs. We encourage policy makers and providers to consider our proposed women-centred HIV care model and, in dialogue with women living with HIV, identify local priorities for action.

Within our focus groups, foundational to meeting women's care needs were providers who possess basic knowledge of HIV (routes of transmission, effective ARVs, HIV as a manageable chronic disease), and women's health. HIV knowledge must not be sequestered to HIV clinics as patients' care needs and preferences have diversified given the long-term, chronic nature of HIV infection, and given emerging evidence that the vast majority of people with HIV (84%) die of non-AIDS related causes (Weber et al., 2013). Expanding educational endeavors to general practitioners and non HIV-specific specialties would enable the provision of higher-quality care in diverse care settings, thereby improving overall health care (Bradley-Springer, Stevens, &

Webb, 2010; Chu & Selwyn, 2011; Landon et al., 2005; Wong, Luk, & Kidd, 2012). Such education would also alleviate certain barriers to care, by reducing misinformation and stigma-based behavior within health care settings (Greene et al., 2016; Ion & Elston, 2015). To address the knowledge and service gaps specific to women's health, participants in the focus groups put forth that the coordination and integration of services is key to a women-centred HIV care approach as women living with HIV navigate a care landscape seldom competent in both HIV and women's health. As the participants detailed, gaps in care are exacerbated by the limited provision of women's health care *within HIV clinics*, and HIV related stigma and poor HIV knowledge among providers *outside of HIV clinics*, leaving women living with HIV marginalized from both care environments. Care strategies that address this fragmentation of care may include “one-stop shops”, where multiple services are offered within a single setting, or corridors of collaboration between physicians with women's health and HIV expertise to, as a participant expressed, “*help the person on their medical journey.*” Indeed, models of coordinated or integrated care have been shown to improve the health care experiences and health outcomes of HIV-positive patients managing chronic health conditions in high-resource settings (Mangal, Rimland, & Marconi, 2014; Page et al., 2003; Pillai, Kupprat, & Halkitis, 2009; Proeschold-Bell, Heine, Pence, McAdam, & Quinlivan, 2010).

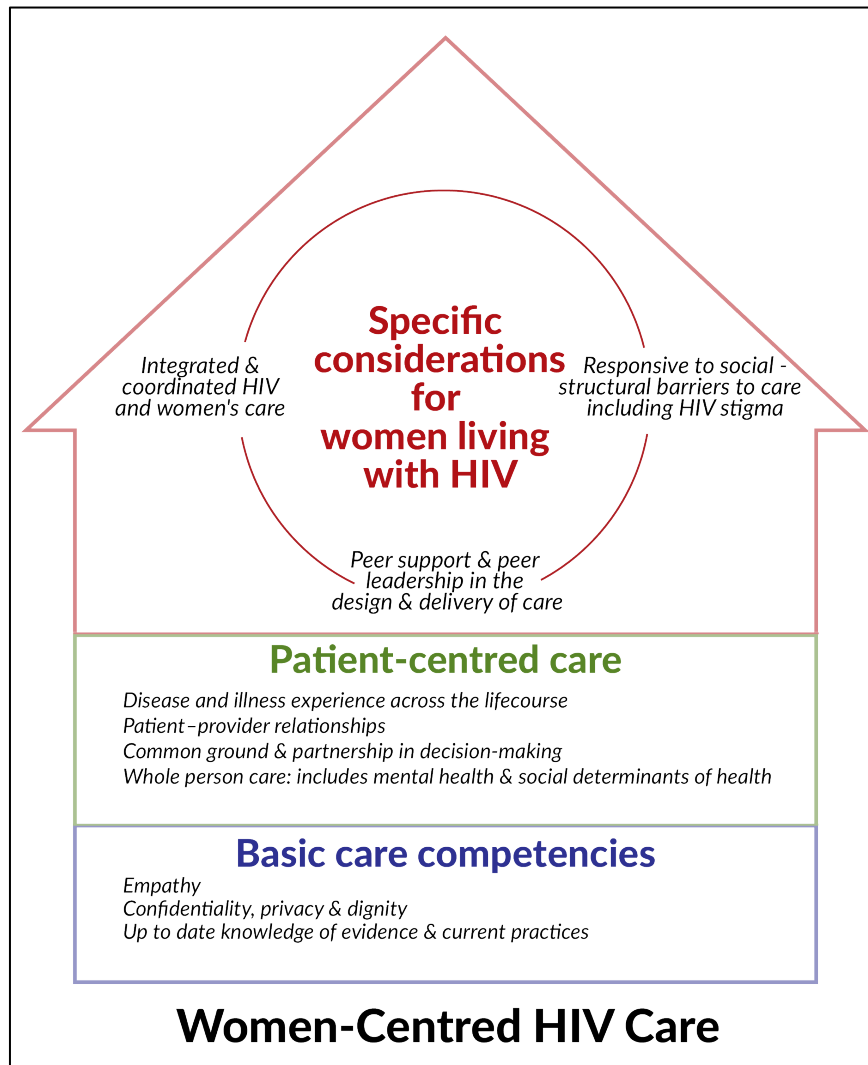
To improve access to care, women also made explicit that services must view the patient as a whole person, including their social determinants of health (Wuest, Merritt-Gray, Berman, & Ford-Gilboe, 2002). These specific care considerations are imperative given the socially disadvantaged position that many women living with HIV unjustly occupy (Greene et al., 2016; Ion & Elston, 2015; Jones et al., 2010; Logie et al., 2011; PHAC, 2012). As others have noted, social determinants of health, though crucial to addressing barriers to care, are challenging to adequately address within care settings as numerous factors (poverty, education, housing) lie

outside the purview of the health care system (Andermann, 2016; Swain, Grande, Hood, & Inzeo, 2014). Nonetheless, strategies such as interdisciplinary teams (Halkitis, Kupprat, & Mukherjee, 2010), revised prescription financing policies that address financial barriers (CMA, 2013), and continuing to educate and advocate for all healthcare professionals to acknowledge social factors that produce and reproduce poor health (Andermann, 2016), may help mitigate structural barriers which impinge on women's care seeking and overall health.

An innovative and timely implication of our research is the proposed incorporation of peer support and peer leadership in the design and delivery of care. Peer and patient engagement is gaining legitimacy as a means of facilitating the navigation of complex health care systems, reducing stigma and social isolation, providing care that is culturally safe, and meeting patient priorities, especially in the context of care for chronic health conditions (Boivin, Lehoux, Burgers, & Grol, 2014; Carter et al., 2015; Greene et al., 2015; IDC, 2015). Peers' means of *knowing*, rooted in their lived experience, may offer a rich complement to provider-led care. To reiterate one woman's view: *"for a service to really respond to our needs it has to be a service that we are a part of"*.

Though each component elaborated above may improve care when applied separately, a women-centred HIV care approach, as conceptualized by women living with HIV, involves consideration of all the factors proposed within our model. Given current gaps in care and inequities in health, innovative strategies which address the care priorities of women living with HIV must be incorporated into care delivery to ensure that women's comprehensive care needs are met and to enable diverse populations to benefit equally from health care advances.

**Figure 1: Conceptual Model of Women-Centred HIV Care**



**Appendix 1: Literature Review by Carter et al. 2011.**

**Feature of Women-specific HIV/AIDS services:**

1. A safe atmosphere for care;
2. Opportunities for peer support;
3. Involvement of women with HIV in the development and provision of services;
4. Women's active participation in their care;
5. Programming to address gender-specific medical, social, and ancillary needs;
6. Services that attend to women's diversity and lived experiences;

7. An integrated array of services;
8. Family-friendly service;
9. Access to information on women- and HIV-specific issues;
10. Gender- and HIV-sensitive training to providers;
11. Engagement in gendered HIV research.

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