Breaking the Glass Ceiling: Increasing the Meaningful Involvement of Women Living With HIV/AIDS (MIWA) in the Design and Delivery of HIV/AIDS Services

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The meaningful involvement of women living with HIV/AIDS (MIWA) is a key feature of women-centred HIV care, yet little is known about transforming MIWA from principle to practice.

> *Drawing on focus group data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), we explored HIV-positive women's meaningful involvement in the design and delivery of HIV/AIDS services in British Columbia, Canada. In this article, we highlight the benefits and tensions that emerge as women traverse multiple roles as service users* and *service providers within their care communities, and the impact this has on their access to care and overall health.*

Women-centered care models of health care delivery prioritize the meaningful involvement of women in the design and delivery of health services (Barnett, White, & Horne, 2002; Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Broom, 1998; Carter et al., 2013; Klima, 2001; Rolfe, Sutton, Landry, Sternberg, & Price, 2010; Taylor & Dower, 1997; Van Wijk, Van Vliet, & Kolk, 1996; Vancouver/Richmond Health Board, 2001). In the context of HIV/AIDS, working within this model of care includes a commitment to the meaningful involvement of women living with HIV/AIDS, known as MIWA (Carter et al., 2013; International Community of Women Living with HIV/AIDS, 2008; Orza, 2012).

The right of women living with HIV and other affected populations to participate as active and equal agents of change in their own health, not simply passive recipients of services, has long been recognized. In 1994, at the Paris AIDS Summit, 42 governments, including Canada, endorsed the principle of the greater involvement of people living with HIV/AIDS (GIPA), as follows:

> Aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision making processes that affect their lives.... GIPA also aims to enhance the quality and effectiveness of the AIDS response. (UNAIDS, 2007, p. 1)

It is important, however, that such involvement is meaningful, not tokenistic, giving rise to GIPA's companion principle: the meaningful involvement of people living with HIV/AIDS (MIPA; UNAIDS, 2007). The MIPA principle demands that organizations move beyond token efforts that create an appearance of inclusiveness toward the genuine, *meaningful* involvement of people living with HIV in all aspects of the HIV response. While no definitive criteria exists to assess "meaningful" engagement, and implementing MIPA may be challenging in some contexts, this rights-based approach to programming should ideally support the involvement of affected communities at all levels of an organization, including designing, delivering, and monitoring of services, managing or leading organizations, and influencing policy- and decision-making processes (UNAIDS, 2007).

These principles have helped give recognition to the many ways in which people living with HIV have contributed to the HIV sector. Since this

declaration, many researchers have examined the contributions of people living with HIV in community-based research and critiqued the benefits, challenges, and ethical tensions emerging from this involvement (Flicker, Roche, & Guta, 2010; Flicker et al., 2009; Greene, 2013; Greene et al., 2009; Guta, Flicker, & Roche, 2010; Harris, 2006; Radda, Schensul, Disch, Levy, & Reyes, 2003; Roche, Guta, & Flicker, 2010; Travers et al., 2008). The extent and nature of peer involvement in AIDS service organizations (ASOs) have also been well described in the international literature, again highlighting the consequences that emerge when organizations endeavor to uphold the GIPA/MIPA principles, with issues that are both unique and common across country contexts (Collins et al., 2007; Cornu, 2003; Horizons Program and International HIV/AIDS Alliance, 2003; Maxwell, Aggleton, & Warwick, 2008; Roy & Cain, 2001). As this research demonstrates, the benefits derived from involving peers are numerous (e.g., more appropriate services, reduced demands on health care institutions), but challenges remain (e.g., funding constraints, pervasive stigma related to HIV and other marginalizing identities; Horizons Program and International HIV/AIDS Alliance, 2003; Roy & Cain, 2001). While less work has examined GIPA/MIPA in clinical settings, available studies primarily focus on the role of peers in improving treatment literacy and advocacy among patients (Bresalier et al., 2002) and delivering sensitivity training for health professionals (Solomon, Guenter, & Stinson, 2005).

Despite clear gendered vulnerabilities that influence women's lives and care experiences, however, very little is known about the involvement of women living with HIV. As the International Community of Women Living with HIV/AIDS highlights (2008, p. 67), "the [GIPA] principle was never gendered," and women living with HIV, particularly more marginalized women such as sex workers and injection drug users, face significant barriers to their meaningful involvement in the design and delivery of HIV/AIDS services. In response, women living with HIV coined a new principle, MIWA, and have demanded meaningful engagement and leadership of women living with HIV at every level within HIV treatment, prevention, care, and support (International Community of Women Living with HIV/AIDS, 2008; Orza, 2012).

The objective of this study was to explore the lived experiences of HIV-positive women's meaningful involvement in the design and delivery of HIV/AIDS services in British Columbia(BC), Canada. British Columbia is home to approximately 17% of all women living with HIV in Canada, and women in BC comprise nearly one-quarter of the estimated 9,300–13,500 individuals living with HIV in the province (BC Centre for Disease Control, 2012). Drawing on data from four focus groups conducted as part of the formative phase of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS; study website: www.chiwos.ca), we highlight the benefits and tensions that emerge for women as they traverse multiple roles as service users *and* service providers within their care communities and the

impact this has on their access to care and overall health. Identifying and mitigating potential consequences of operationalizing MIWA must be considered as women's participation in HIV/AIDS services gains prominence in Canada and worldwide. The study is particularly timely and important to the international, interdisciplinary HIV community as the rights of HIV-positive women come to the forefront of the international human rights agenda and as demand grows for gender-specific and peer-driven approaches to HIV treatment, prevention, care, and support.

METHODS

Study Background

Data were collected as part of the CHIWOS study, a multisite, longitudinal, community-based research study that is enrolling over 1,400 women living with HIV from three Canadian provinces, including British Columbia, Ontario, and Quebec. The overall study aims to assess the barriers and facilitators to use of women-centered HIV/AIDS services, and the impact of such patterns of use on reproductive (e.g., contraceptive use, pregnancy), sexual (e.g., sexual abstinence, satisfaction, functioning), mental (e.g., depression, resiliency), and women's health (e.g., menopause, cervical and breast cancer screening) outcomes among women living with HIV in Canada. Before the use and impact of women-centered care could be assessed, we engaged in formative research to understand how women living with HIV define and envision these services.

Theoretical Frameworks

The CHIWOS study draws on critical feminist and social determinants of health (SDoH) frameworks and is grounded in a community-based research (CBR) approach. A critical feminist framework (Bredström, 2006; Hudson, 2005; Reus, Few, & Blume, 2005) examines how women's many social identities, inequities, and issues (e.g., gender oppression, racism, homophobia, classism, sexuality, ableism, and HIV-related stigma) can intersect to limit their role and status in society. For women living with HIV, this type of systemic inequality corresponds with a lack of equal opportunities to participate meaningfully in society or be involved in decisions that directly impact their lives. By grounding our work in this framework, we aim to conduct emancipatory research that challenges oppression, promotes social justice, and positively impacts policies and practices to improve the lives and health of women living with HIV in Canada.

Further, an SDoH framework was adopted as we work from the premise that many intersecting social factors, experiences, and identities affect women's health. These determinants include the following: aboriginal status, gender, disability, housing, early life experiences, income and

income distribution, education, race, employment and working conditions, social exclusion, food insecurity, social safety net, health services, unemployment, and job security (Raphael, 2009), as well as culture, language, and HIV stigma and discrimination (Ontario Advisory Committee on HIV/AIDS, 2002). Moreover, our SDoH approach explicitly incorporates a gendered lens that recognizes social inequities between women, men, and other gender groups, and seeks to examine how these unequal social positionings shape women's experiences of health and health care (Benoit & Shumka, 2007; Wuest, Merritt-Gray, Berman, & Ford-Gilboe, 2002). Engendering the SDoH framework allowed us to examine how women experience peer engagement within their care communities and the unique impact that this has on their health, as well as link these accounts to uneven sociostructural forces, powers, and contexts.

Last, in order to contribute to social change that improves women's health, we have implemented a collaborative partnership approach to research that equitably involves *all* relevant stakeholders—including clinicians, researchers, AIDS Service Organization workers, service providers, policy-makers, activists, and, especially, in this case, women living with HIV—in identifying research priorities and questions, shaping and implementing the research process, and actively working to change and improve conditions seen as problematic (Wilson, Lavis, Travers, & Rourke, 2010). In and through this radically different research team and approach, all members' contributions and experiences (both professional and lived) are valued and respected. Women living with HIV, whose health is the focus of this research, are thereby engaged as primary stakeholders in the identification and measurement of policy-relevant inquiries.

Study Design

As part of the cohort's formative phase, a total of 11 focus group discussions were conducted with 77 women living with HIV from across each of the three study provinces. In this article, we draw on qualitative data emerging from four focus groups conducted between August and October 2011 with women living with HIV in Vancouver ($n = 2$), Victoria ($n = 1$), and Prince George ($n = 1$), BC, Canada. As part of our CBR model, women living with HIV who were familiar with the local HIV-related health and social care context were recruited, hired, and trained as peer research associates in community-based research and focus group facilitation. All four focus groups were then cofacilitated by a local peer research associate and the CHIWOS BC provincial research coordinator (A.C.).

Participant Eligibility

Women living with HIV were recruited to participate in the focus groups through a mix of recruitment strategies including advertising through HIV

clinics, ASOs, online (e.g., websites and listservs), word-of-mouth, peer networks, and other informal channels. Eligibility criteria included self-identifying as a woman, living with HIV (self-reported), aged 16 years of age or older, residing in BC, and willing and able to provide voluntary, informed consent.

Data Collection

Each focus group was between 2 and 3 hours long. Participants were first asked to complete a brief intake questionnaire that elicited information on demographics and use of HIV health care and support services. Following the demographic questionnaire was a focus group discussion that followed a semistructured interview guide in order to ensure consistency across the multiple moderators and prioritize the main topic of inquiry, while also allowing for flexibility in the emergence of themes. The questions were open ended and focused primarily on developing an in-depth understanding of women-centered care. The focus groups were audio-recorded and transcribed verbatim. One cofacilitator also took notes during the focus group in order to record observations of critical discussion moments and group dynamics.

Data Analysis

Transcripts were analyzed using thematic analysis, where emerging themes were coded and compared across transcripts (Aronson, 1994). Peer debriefing and triangulation was also conducted. This process included a debriefing between the provincial research coordinator and peer research associates following each focus group and an ongoing reflexive discussion at multiple points in the analysis process about key emerging themes among the provincial research coordinator, peer research associates, and an investigator who provided the training (S.G.). All names and places were changed and pseudonyms used to protect confidentiality. Ethics approval for this study was provided by the Research Ethics Boards of Simon Fraser University, Providence Health Care/University of British Columbia, Women's College Hospital, McGill University Health Centre, and McMaster University.

In total, 28 women living with HIV participated in four focus group discussions. Sociodemographic characteristics of participants are shown in Table 1. The women lived in and around Vancouver (50%), the epicenter of BC's HIV epidemic; Victoria (25%), the capital city of BC on the islands to the west of Vancouver; and Prince George (25%), a northern city surrounded by First Nations communities. Half of the women identified as Caucasian and 39% reported being of Aboriginal ancestry. By age group, 14% were 30 years or younger, 64% were 31–50 years, and 21% were older than 50 years. About half of the women (52%) reported an annual household income below

TABLE 1 Sociodemographic Characteristics of Participants ($n = 28$)

Characteristic	n (%)
Region	
Vancouver	14 (50)
Victoria	7 (25)
Prince George	7 (25)
Age category (years)	
< 30	4 (14)
31–50	18 (64)
> 50	6 (21)
Ethnicity	
Caucasian	14 (50)
Aboriginal ancestry	11 (39)
African, Caribbean, Black women	1 (4)
Chinese	2 (6)
Annual household income < $20,000	14 (52)
HIV diagnosed in or prior to 2000	14 (54)
Currently taking antiretroviral medications	24 (92)
Currently receiving care from an HIV specialist with expertise in women	18 (72)
Additional HIV-related services accessed over the past year	
AIDS service organizations	15 (54)
Income support	11 (39)
Counseling	9 (32)
Obstetrics / gynecology	6 (21)
Food bank services	6 (21)

$20,000. Most participants were linked to HIV services: 54% were diagnosed with HIV prior to 2000; 92% were currently taking antiretroviral medications; 72% reported receiving HIV-related medical care from an HIV specialist with expertise in women and HIV; and the median number of additional HIV-related services accessed over the past year was five (interquartile range [IQR]: 3–7), including ASOs (54%), income support (39%), counseling (32%), obstetrics/gynecology (21%), and food bank (21%) services. What follows is a discussion of the findings that emerged from the focus groups with these 28 women.

FINDINGS

In attempting to understand what women-centered care means to women living with HIV, we asked women to describe their experiences of accessing local HIV services and to share their visions of care that best meet the unique needs of women. This question resulted in a lengthy and often heated discussion of what many women viewed as one of the most valued yet under-represented features of women-centered care, namely, women's meaningful involvement in the design and delivery of HIV/AIDS services within their local clinics, ASOs, and other community-based organizations. A

significant finding that emerged from this analysis was the range of experiences that women possessed with regard to peer involvement and the unique benefits and tensions that emerge from such participation. The overarching themes that transcended these differing experiences were recurring narratives about how transforming MIWA from principle to practice ultimately impacted women's access to care and overall health.

Women-Centered Care Is . . . "Capacity Building . . . Mentorship . . . Ownership . . ."

Throughout the discussions with women across the province, it became clear that women living with HIV view MIWA as foundational to women-centered care. Women in all four focus groups shared their experiences of both receiving and providing peer-driven services and highlighted the range of benefits associated with care that is by and for women living with HIV. For the women, these benefits were seen to have positive effects on their on-going engagement in care as well as their overall health and well-being.

Valuing the peer in peer support. When asked where women living with HIV can go to find HIV services that meet their needs as women, participants in separate focus groups described new online communities created by and for women living with HIV:

> Facebook. I have a community of women, particularly Positive Aboriginal Women, PAW, that I support, I network, I share information, and that's my big thing . . . helping people maneuver. (*Emma*)

> 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 [living with HIV]. It's a daily support. It's not dictated by where you live. All you have to do is join anonymously on a list. (*Sheila*)

The experiences of Emma and Sheila highlight a number of key benefits of peer-driven services. First, these narratives illustrate the value that women living with HIV find in *"helping people maneuver"* the system. The importance of peers as informational support was also echoed by other women, as Roxy explains:

> Each one of us has a story, but we're not that unique. Our story isn't completely mine. There's a portion of mine that X knows, and there's a portion of X's that somebody else knows. . . . But if we don't share that information, the other person has to go through it all over again. . . . One day a month or something, or a phone list or something where just people can help each other. (*Roxy*)

Hence, many women view their personal story as resonating with the experiences of other women living with HIV and, as such, value opportunities for connection, sharing information, and providing support.

These narratives also draw attention to the advantages of networking with peers remotely, by phone, or online. Substantial evidence highlights the alarming impacts of HIV-related stigma on access to care (Logie & Gadalla, 2009; Mahajan et al., 2008). This rang true for many women in this study, who spoke of avoiding walking in the door of some organizations where HIV is visible from the streets for fear of being "outed" as HIV positive. For many women, connecting with peers anonymously by phone or online removes this visibility, thereby facilitating their access to necessary care and support.

Another issue emerging from these narratives is how these types of online peer networks make care geographically accessible. Many women discussed how HIV services are sorely lacking outside of Vancouver and they noted numerous challenges around traveling long distances to get the care they may need. This included the time and toll it takes on the body, the money needed for food and accommodation, and having to secure child care. As Sheila explains, with online peer support, "women's voices [can] be heard" no matter where they live:

> What I found profoundly helpful about it was that it didn't matter where I was. It was accessible by e-mail. ... It was just an excellent way for women's voices to be heard and not necessarily present in a room or having to get there. (*Sheila*)

Nevertheless, as Sheila's narrative continued, it became clear that women remained eager to access peer-run programming in spaces where they could connect with other women living with HIV in person:

> The retreat that I went to at X was the first one I'd been to. It was absolutely life-affirming, single most important service I've accessed. Because, I got to surround myself with positive people . . . there was a commonality that you don't find. (*Sheila*)

For Sheila, participating in a retreat where she was surrounded by peers was revitalizing. This highlights the support that women living with HIV derive from being around one another, a sentiment that was shared by women in Prince George who repeatedly spoke about the importance of peer support in helping to ease social isolation, as Laurie articulates:

> It's interesting just having that feeling of when you're not alone. When you're experiencing something and you think, "Oh, I'm the only person who's experiencing that." And when you talk to somebody and they're experiencing the same thing. And you can go, "Oh, you know." (*Laurie*)

In another focus group in Vancouver, Lauren, a woman in her twenties, described her experience of receiving support from other young, HIV-positive peers at a local ASO:

> They have a lot of workers there that are young and they are positive, and they're on the Board, so they run the place. . . . It's just a really warm, comforting environment. . . . When I did go there I was able to open up. . . . I felt like my word was valued, 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. (*Lauren*)

Lauren's narrative underlines the emotional safety, comfort, and validation many women find from receiving peer support, in addition to a deep-seated feeling of trust that their experiences and needs are important.

From receiving to providing peer support.   Although the women were keen to share their experiences of receiving peer support, what emerged most prominently were their reflections regarding taking on peer-related roles. While the extent and nature of involvement varied between organizations, most women described being involved as volunteers rather than paid staff members. Roles included sitting on boards, starting social groups, coordinating peer retreats, and providing peer education and support, as the women shared:

> I'm employed by X [an ASO]. I've sat on the Board. I've coordinated the retreats. (*Karen*)

> We have this thing called X [an education program] where we go out in the communities and do HIV 101. (*Lauren*)

In discussing peer roles in the clinic setting, women described the importance of the "Peer Navigators" pilot project at a local HIV clinic:

> X [a clinic]. . . they have this pilot project with Peer Navigators. . . . So, if you want to go and sit and talk to someone that's positive, while you're waiting for your appointment there's someone there from 9:00 a.m. to 7:00 p.m. that's positive, every day. . . . To have peers in a clinical environment I think is taking what GIPA Principles were about in the late–midnineties to what they should be today. (*Sheila*)

When we asked women to elaborate on the importance of having peers as service providers, Roxy, reflecting on the organization run by young peers, spoke to the safe space created by "the fact that it is geared not only in recipients but staff as being young people." Roxy's response highlights how women value organizations where both the users and the providers of the services are peers. This sentiment was echoed by a woman from Prince

George, who underscored the importance of HIV-positive support workers who have similar lived experiences as the clients they aim to help:

> How about peers there that understand what you're going through, kind of like myself? Who have done the drug addiction, who have been homeless, who have worked the streets, who are HIV positive who will help you to understand exactly what your needs are. (*Elina*)

As these narratives reveal, when hierarchical patient–provider dichotomies are blurred, women living with HIV are able to benefit from occupying both patient and provider positions. HIV-positive women feel supported through receiving this kind of care from providers who "get it" not only from an emotional and support perspective but also from an experience perspective. While at the same time, as providers, HIV-positive women feel supported through receiving capacity building and mentorship opportunities that lead to a sense of ownership and recognition of their lived experiences. This mutual exchange of support and reciprocity that occurs was strongly articulated by Sheila who noted, "I do it for others as much as it is for myself," stressing the value of integrating peer-driven services into the overall care system.

Rhetoric Versus Reality … "GIPA … Is a Term That's Thrown Around"

Although women living with HIV reported wanting to be engaged in the very places where they receive support and were able to express the benefits of both accessing and providing peer-driven services, the conversations then turned to the multitude of tensions that arise as their role shifts from service user to service provider within organizations. Described below, these tensions included the following: (a) being required to choose between remaining clients or becoming paid employees; (b) being positioned unequally as providers who are good enough to volunteer yet not good enough for paid work; (c) serving as a resource for organizations but without equal representation, ownership, or control throughout levels of decision making; (d) confronting organizational attitudes that espouse empowerment yet fail to fully acknowledge women's capacity to contribute in practice; and (e) needing transparency around having women with HIV working in organizations while balancing the need to protect HIV status confidentiality. For the women, these challenges not only restricted them from becoming further engaged as peer leaders in their care communities, but, in many cases, they also served to compromise their access to care and overall health.

"Because you're HIV positive, you can't work here." Perhaps the most striking tension that emerged through the focus groups was how women who traversed service user/provider roles often found themselves in the

distressing situation of having to choose between remaining clients or be-coming employees, as Veronica explained:

> They will not hire anybody who is accessing any of X's [a community-based organization's] health's programs. So, if you access the Food Bank you can volunteer there. They'll take your hard work on a volunteer basis. I've got a resume that I could get a job there as a support worker, no problem. But because I'm accessing the services, I have to be out of the program for 2 years [before I can be an employee], which makes no sense whatsoever. And it makes me really angry. . . . Basically what they're saying is, "No, sorry, because you're HIV positive . . . you can't work here. (*Veronica*)

This organizational policy was also powerfully reflected in Hope's nar-rative:

> I agree with that because I started volunteering there. . . . We had X group. I started that group. But, I felt very uncomfortable, that because I access their Food Bank I can never work there. And because of that, I stopped doing it. It was like I'm wasting my time. It's ridiculous. I went to their board meetings. I went to all their high-power meetings, doing all things, and I'm like, "But why am I doing this?" You can never really get into the system or get help just because you have HIV. I stopped going there and doing volunteering, keeping up with this group. (*Hope*)

In both stories, the women volunteered to improve services in their com-munity in the hopes of eventually securing a paid position. Any chance of "get[ting] into the system," however, was jeopardized by the threat of losing access to the very sources of care and support that they contributed to and needed for themselves. Not surprisingly, this policy discouraged Veronica and Hope from pursuing a paid position within their respective organiza-tions. Further, women's exclusion from the formal organizational structure weakened their sense of belonging and affective commitment to the or-ganization, which created barriers to maintaining access to their own care, thereby compromising their health and well-being. Others in the group noted the irony of this policy:

> I think it's ironic. . . . I mean, it's quite a natural, normal process of getting yourself informed and educated. . . . And you did a lot for a long time for nothing before you got in. But the idea was that's why you were there. . . . There's a pay off at the end. . . . I don't expect that we can all of a sudden have ASOs run by positive people overnight. But the idea that there should be any discrimination towards that, I just find absolutely bizarre. (*Sheila*)

Hence, what emerges here is a conflicting message where HIV-positive women report being encouraged to become involved as service providers yet only so far, with HIV-related "discrimination" curtailing chances of promotion and advancement to paid positions.

"They work like dogs and don't get a penny for it." This tension between service user versus service provider intersects with another critical tension around unpaid versus paid work. Importantly, even those who attempt to become service providers at the risk of losing access to care are nonetheless positioned unequally as providers who are good enough to volunteer but, as Veronica explains, not "good enough to get a paycheck," underlining how little value is placed on lived experience in the workplace. The impact this has on women emerged as Veronica and Hope continued to share their stories:

> It's very disturbing. ... I'm expected to put in volunteer hours. I see a couple of my neighbors; 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. And it's like, "Oh, you're accessing our programs, so you can't ... " It's terrible and discriminatory. ... If I have time, I'll come back and do something, but I'm not going to feel obligated to do this. My time is money. I need to go and find a job. (*Veronica*)

> You want to do all these things for people, but they have to be recognized to keep doing it. You also have to think ahead that, what is in it for me. Is there a future there? If I can't get anywhere through the system, why should I do it? I can do it somewhere else and move on with my life. (*Hope*)

There are a number of key issues conveyed in these narratives. First, on the one hand, as earlier narratives highlighted, some organizations are committed to MIWA and involve HIV-positive women on the frontlines as paid support workers. On the other hand, however, these same organizations also depend on the unpaid contributions of other HIV-positive women like Veronica and Hope. Moreover, these contributions are often not recognized in ways that are meaningful to women. As Veronica and Hope suggest, involvement without reward makes MIWA meaningless. Consequently, women feel unacknowledged and underappreciated for their time, effort, and lived experience, which leads to decreased motivation and engagement with the organization.

"I'm paying somebody's salary ... but I have no control over how they use my membership." As the narratives thus far highlight, despite the rhetoric about the importance of peer engagement, women's involvement is still perceived as tokenistic. As our conversations continued, women reported that few women living with HIV are meaningfully involved in all structures

and levels of organizational decision making. Although the women provided examples of organizations that attempt to involve HIV-positive women, many were frustrated by their exclusion from the formal organizational structure, as Roxy described:

> The fact of the matter is I watched it go from three staff people to 11 staff people, and the only person.... I knew that was positive that was on the staff was let go and never hired back. (*Roxy*)

Furthermore, the women were also disheartened by the lack of explicit organizational policies that recognize women living with HIV as valued employees, partners, and leaders within organizations. In reflecting on what would need to change right now for services to be more accessible to women, Emma explained her view:

> They would have to implement policies ... that actually include the values of GIPA ... which is a term that's thrown around. ... But then ... you go to these organizations, they're not membership driven on their board, which is huge, because if you have member-driven organizations, membership-driven boards, members actually have input. Members actually get to question, change policy, but it's also about capacity building, it's also about mentorship and ownership. (*Emma*)

For the women in this study, the ways in which organizations involved them were not truly reflective of what MIWA means to women living with HIV. For them, MIWA means more than occupying a position as board member. Rather, a genuine commitment to MIWA reflects "member-driven boards," where the women have input into changing policies and increasing their capacity to be leaders within the agency.

In addition, women also expressed frustration over their exclusion from strategic decisions on policy, priorities, and resource allocation. As Emma's personal experience highlighted, there exists a tension in which organizations secure funding through the use of women's membership and volunteer efforts yet give women little ownership or control over how that money is spent, and, thus, eventual policy and programming decisions:

> Every time I walk in that door ... I'm paying somebody's salary and they're able to write another grant because I fit into many different demographics. So, if they're applying for Aboriginal money, we have Aboriginal women. ... But I have no control over how they use my membership. I have no control over whether they hire positive people, Aboriginal people, and I'm not about to get on the board and try and change things. Not my thing. What I would rather do is revoke my membership ... and say, "See you later." (*Emma*)

These narratives highlight how ownership and control are two key components of enacting MIWA. This is particularly true for PAW like Emma in this study, for whom the principles of "ownership, control, access, and possession (OCAP) have become a rallying cry against colonial approaches that fail to meaningfully involve Aboriginal Peoples (Schnarch, 2004). Moreover, this story highlights the trade off some women have to make concerning regaining ownership and control. While revoking her membership and removing herself as a resource for the organization allowed Emma to reclaim her right to self-determination, this may have come at a cost to her health as she had to forgo her sources of care and support that she would have been receiving at this organization.

"I really, really cringe when I get that feeling of . . . we need to help you. well, you know what, we can do this."   By excluding women as equal partners in decision- and policy-making bodies, a narrative is constructed that confines many women living with HIV to roles as passive recipients of services. While a key component of women-centered care is about empowering women to become involved in the design and delivery of care (Carter et al., 2013), some women encountered the opposite: disempowering organizational attitudes toward their capacity to contribute. This was perhaps most clearly articulated by Reba:

> Where I live, it's X [a community-based organization]. And for whatever reason, the further you get away from Vancouver, the more closed-minded and weird they get. They just seem to have this mentality of, "Oh those poor people. We're going to help them. We're going to give them all these services but we're not going to recognize their ability to help themselves." There's no empowerment. (*Reba*)

Drawing on Reba's reflections, it appears women face multiple barriers en route to empowerment, relating to both the *opportunity* to become involved in the care process as well as the *experience* of being involved itself. First and foremost, many women reported being denied the opportunity to have a voice and a hand in the provision of care; rather, it was felt that some organizations were more apt to "give them all these services." Further, in many settings, women living with HIV continue to be viewed as "those poor people" who require "help" rather than as women who have the capacity to inform and shape the care that they want and need. This echoes the experiences of other women to whom we spoke:

> They are more protected than we are. They have their nice, little code of conduct of how . . . they are to be treated . . . but it's not reciprocated. There's not that respect, and these are all . . . educated, privileged social workers, a lot of them that work in this one agency. You really do get patronized . . . by them. I hate to say it, even though they claim to be feminists, they're not. (*Emma*)

Emma's narrative highlights how hierarchy is a defining and pervasive feature in some organizations, in which people with status (related to education) have the power to make decisions and control valued resources. Moreover, Emma's story highlights how this hierarchy works to disempower HIV-positive women. This was further evidenced by Karen:

> I really, really cringe when I get that feeling of that condescending kind of tone, that idea that "We need to help you." Well, you know what, we can do this. (*Karen*)

These stories further demonstrate the way in which HIV-positive women are positioned unequally as service providers. These uneven exchanges are compounded by disempowering stereotypes in which HIV-negative women are viewed as educated and healthy compared with their assumed poorly educated and ill counterparts. For women who view their health as incorporating physical, mental, emotional, and spiritual components, being confronted with these kinds of negative attitudes is disempowering, which not only affects their ability to become further engaged in their care community but may also increase barriers to attending to their ongoing health-related needs.

"I don't know who those people are." While the narratives thus far highlight some women's disempowering and disingenuous experiences of involvement, it is important to note, however, that no visibility does not necessarily mean no involvement, as Roxy revealed:

> I learned a couple of weeks ago that one of the staff is positive, and I didn't know. I have known her for 10 years. I didn't know she was positive. (*Roxy*)

In this story, Roxy's peer chose to be involved without making her HIV status public. It should be stressed that MIWA does not require full public disclosure of one's HIV status. As the conversation continued, however, it became clear that the community is divided over how to balance demands to see women living with HIV working in organizations with a need to protect confidentiality. Women's request for greater transparency is reflected in Darlene's narrative:

> At X [an ASO]... I don't know if any of them are HIV positive or not. I don't get a feeling that they really know what they're talking about. If they would just come out and say, "Look, I'm not HIV positive, but I am a support worker" I just feel like there needs to be more openness about the situation there. ... Then, I did ask somebody and they said, "Yes," but it's very secretive who on the board at X [an ASO] is HIV positive, very, very secretive. I just thought if that's the case, I'm just not up for

that kind of a place where there's this big, secretive thing happening. (*Darlene*)

For Darlene, not only is it important for "more openness" from HIV-negative staff about their status, but having women on the frontlines who are open with clients about living with HIV is also crucial. This is because of the significant value that women living with HIV place on lived experience. Women expressed wanting to know whether the support they receive is coming from a place of lived experience or is simply empathy, since actually living the experiences, thoughts, and feelings of another person is considered far different from being sensitive to them. Moreover, transparency around the kinds of people who are hired and provided with their personal information was discussed as an issue of trust. In reflecting on how services could be improved, Darlene shared further:

> Transparency, can you put that in? Because I don't like X [an ASO] because I don't know who those people are. I don't trust them, for some reason. . . . And I do as little as possible with them now. (*Darlene*)

Making MIWA visible, however, is challenging in a context of HIV stigma and discrimination. Although transparency with regard to HIV status was important to some women, others were concerned that this would violate their right to privacy and confidentiality. This tension was reflected in a continued exchange between Darlene and Roxy, two women at very different points in their lives:

> *Roxy:* We've got to be careful because we've made a lot of this work on confidentiality. We've put that in place, especially because of the stigma of HIV. So, when you say you want to know the HIV status when you go in there . . .

> *Darlene*: I go in there. I have to be HIV positive to go in the door.

> *Roxy:* But the fact of the matter is that we have a confidentiality law in the HIV community and you can't say, "Are you positive?"

> *Darlene*: But you can't walk through that door unless you're positive.

Hence, while Darlene, a woman who has been diagnosed with HIV for 4 years, spoke to the need for transparency, Roxy, a woman who has been diagnosed for over two decades, was quick to prioritize the right to confidentiality. For Roxy, women living with HIV have experienced many years of stigma where trust was repeatedly violated, and so they fought hard for laws and policies around confidentiality. As Darlene reveals, however, some women, including some of those who are newly diagnosed, still go

into organizations and find themselves in that same position of "Who can I trust?" As will be discussed later, while this tension may not be completely resolvable, it must be acknowledged, discussed, and attended to by organizations. The consequence of failing to address these concerns is that women may not feel comfortable accessing care at these organizations, which can have serious consequences for their health and well-being.

Visions of Women-Centered Care . . . "I've Dreamt About This . . . "

During the closing stages of each focus group, women were asked to reflect on our discussion thus far and share their vision of women-centered care. In one of the focus groups, the women shared their dreams of a community-driven care center created by and for women living with HIV. Emerging from this conversation was the interweaving of their dreams, giving voice to what this group of women view as women-centered care:

> *Karen:* I've dreamt about this. . . . I'd want a house . . . a big house . . . someplace rural, with a garden to grow fruits and vegetables. . . . I see a community kitchen. . . . I see a home that also functions as . . . a safe place . . . a place where children are welcome.
> *Monika:* Yeah.
> *Vera:* Community, a real community.
> *Veronica: I* think of the Ronald McDonald House, where kids go and they can just be themselves. We can just hang out with other women.
> *Karen:* A summer camp for adults.
> *Linda:* This is our house, guys.
> *Multiple voices:* Yeah. Our house.

While several themes emerged from this discussion, one of the most prominent sentiments was women's strong desires for a place that embodies elements of grassroots organizations. For the women, having a place that comes from the community, a place that they can call "our house" is essential to meeting their needs as women. Sheila and Veronica explained their vision further:

> *Sheila:* There needs to be more peer education, peer mentoring, empowerment, opportunities.
> *Veronica:* Yeah, a big word, "opportunity." There needs to be more opportunity out there for people, for those who are positive. We have a lot of skills to bring to the table.

These closing narratives demonstrate the central role that "peer education, peer mentoring, empowerment, opportunities" play in creating care environments that women view as women centered. Further, they highlight

the strong desires and motivation of women living with HIV to meaning-
fully contribute to their care communities. Women's narratives support the
need for organizations to be more responsive to what women want and pro-
vide the most meaningful opportunities and environments possible to help
women living with HIV to maximize their potential, as Roxy shares:

> Is this not true ... that the wealth of the information is on the people
> who have lived the experience? [Multiple women in agreement].... So
> why is it that nobody sets up something that is absolutely peer driven...?
> We've been saying it from day one .... We've got to unlock that mystery
> door that says, "How does it actually change?" (*Roxy*)

This important question underscores the great potential value of MIWA
in practice, policy, and research. The narratives above have set the ground-
work for providing a critical response to developing and delivering women-
centered care that includes a genuine and operationalized commitment to
MIWA.

DISCUSSION

The findings from this study highlight the lived experiences of HIV-positive
women's involvement in the design and delivery of HIV/AIDS services in
BC, Canada. A strength of this study is that the analysis of women's narra-
tives provides an understanding of MIWA from the perspective of women
themselves, whereby they highlight the multiple benefits and tensions that
are experienced by women living with HIV as they take on peer leadership
roles within their care communities and the impact this can have their access
to care and overall health. Our theoretical approach strengthened this study
through explicit acknowledgment that the intersection of women's social
positions (e.g., gender, HIV positive, Aboriginal ancestry, economic status,
and education) complicates their experiences of MIWA, without homogeniz-
ing such positions and experiences. The approach also helped highlight the
rocky terrain that women must navigate when their roles as service users and
providers collide. A limitation of the study is that a review of organizations'
own policies and challenges to supporting peer involvement has not been
considered. Further, these findings were part of a larger study that was not
primarily focused on MIWA. As such, the focus group questions were not
specifically geared to exploring the complexities of the women's experiences
on this topic. Our findings reflect the range of peer engagement issues faced
by women living with HIV, however, and, to the best of our knowledge,
this is the first study to report these experiences specifically among women
living with HIV in Canada.

The women in this study were deeply affected by both receiving
and providing peer-driven services. This resulted in experiences of health
and other social supports as more fully meeting their unique needs in a

supportive, inclusive, and accessible manner. This was evident by the informational support, emotional safety and comfort, sense of belonging, social connectedness, and validation women felt when accessing care from HIV-positive women who shared their lived experience. Further, for the HIV-positive women positioned as service providers, they too experienced unique benefits in the form of capacity building, mentorship, and ownership. These findings echo previous research done in Ontario, Canada, in which authors have highlighted the success of peer support in helping women cope with disease by providing informational, social, emotional, and practical supports (Campbell, Phaneuf, & Deane, 2004). The benefits women experienced also correspond with other research conducted elsewhere in Canada and the United States where authors have shown the long-term positive effects of peer support on mental health, social functioning, and vitality (Helgeson, Cohen, Schulz, & Yasko, 2000), as well as reducing isolation and improving social support and coping strategies (Burrage & Demi, 2003; Campbell et al., 2004; Stewart & Tilden, 1995). In fact, there is international and cross-cultural evidence that highlights the benefits of peer support not only to clients, but to the organizations themselves. This includes more effective and appropriate services (Horizons Program and International HIV/AIDS Alliance, 2003; Ramirez-Valles & Brown, 2003; Stephens, 2004), reduced demands on health care institutions and professional resources (Burrage & Demi, 2003; Stewart & Tilden, 1995), greater credibility with potential clients and funders (Horizons Program and International HIV/AIDS Alliance, 2003; Roy & Cain, 2001), and a wealth of added resources by virtue of the "personal investment, motivation, dedication, compassion and commitment" that women living with HIV bring to the table (Roy & Cain, 2001, p. 425).

While women highlighted several benefits to peer support and engagement, the most salient findings from this study were the numerous complex and interconnected tensions that emerged for women as they endeavored to shift from services users to service providers within their care communities. These included tensions between service users versus providers, unpaid versus paid work, contribution versus attribution, empowerment versus disempowerment, and transparency versus confidentiality. Several authors in Canada and the United Kingdom have studied the role of people living with HIV in the HIV sector and found similar structural, attitudinal, disclosure, and resource constraints (Maxwell, et al., 2008; Roy & Cain, 2001; Travers et al., 2008). Other obstacles to peer involvement cited in the literature in Canada, Cambodia, India, and Indonesia include health-related concerns, transportation issues, and child care needs (Paxton & Stephens, 2007; Roy & Cain, 2001; Travers et al., 2008).

For the women in this study, these issues put them in challenging positions where they were forced to weigh the risks and benefits of engaging in peer-related roles. Peer engagement proved particularly challenging for women who chose to become involved within the same organizations where

they received support, as organizational policies forced women to choose between two hazards: to engage as paid peer leaders but forgo their access to important health services and supports or to disengage but protect their access to care. Not surprisingly, most women had to make accommodations that resulted in some form of engagement but only as volunteers, not paid staff members. Similar to findings from previous authors (Travers et al., 2008), these women were frustrated by the lack of extrinsic and intrinsic forms of recognition for their contributions to the organization, the clients, and the paid staff. Further, these frustrations were compounded by problematic stereotyping of HIV-positive women as poorly educated and very ill, which often resulted in them being assigned low-level activities rather than meaningful, challenging work, a finding that has been echoed by peers in earlier research in other Canadian settings (Roy & Cain, 2001). Moreover, even when women were involved in some form or another, MIWA was often invisible due to lack of community ownership over strategic decisions and murkiness around the HIV status of employees. These interlocking issues were disempowering and served as major barriers to sustaining involvement and maintaining engagement in care.

Women living with HIV can bring widely different and important talents, skills, education, experience, and passion to organizations. Unfortunately, the experiences of women in this study suggest that women living with HIV still battle against stigma and discrimination related to their social positioning as HIV-positive women. Their intersecting experiences of HIV stigma and sexism, amongst other social determinants of health such as ethnicity and socioeconomic status, yield serious consequences for their overall health and well-being. These consequences are consistent with earlier research in which authors have highlighted the stigma associated with HIV and gender and the role that this plays in marginalizing women living with HIV (Logie, James, Tharao, & Loutfy, 2011).

While the notion of MIWA is rooted in a desire for community capacity building, the women's narratives raise important ethical questions: Who benefits and in what ways from the so-called meaningful involvement of HIV-positive women in these organizations, and at what cost to each? Drawing on the above narratives, it is clear that the benefits to HIV-positive women themselves are being compromised as they push up against numerous tensions that operate to keep stringent boundaries between HIV-positive women in need of a worker versus HIV-positive women who want to become workers. Overall, "this glass ceiling" prevents women from rising as peer leaders in their care communities, while also serving to compromise women's access to care and overall health.

THE WAY FORWARD: IMPLICATIONS FOR POLICY AND PRACTICE

The narratives shared by the women who participated in this study raise important implications for the way forward in addressing the key challenges

that arise when their roles as service users and providers collide within the same organization. A long-term response to these concerns demands that organizations facilitate and support ongoing, meaningful dialogue about these issues with their members and clients, and then collectively design and implement strategies to address these concerns in a sustainable way. Some immediate responses are also warranted to facilitate women's agency, empowerment, and active participation in health system improvement in a way that is effective, respectful, and valuable, and also protect women's right to access these very sources of health services and support.

This starts with an end to employment discrimination against an organization's own clientele. While this may raise conflict of interest concerns and create new tensions around negotiating provider–patient boundaries, it is possible to ease these tensions with appropriate safeguards and processes, including, for example, a criminal records check, mutual confidentiality agreements, providing clients the option to consult with nonpeers, and ongoing open and honest discussions about challenges that may arise.

Further, clinics, ASOs, and other community-based organizations must continue to develop policies and structures that explicitly support women's involvement and better facilitate a range of peer roles, including representation on boards, involvement in management meetings, peer support work, peer networking opportunities, retreats and skills development workshops, participation in research and conferences, assistance with administrative tasks, questionnaires to elicit feedback on programs and services, consultation events on new initiatives, and, importantly, senior-level and decision-making positions (Cornu, 2003; Maxwell et al., 2008; Roy & Cain, 2001).

Moreover, proper recognition for women's contributions is essential. This includes remuneration that may involve salaries, hourly wages, honoraria, or gift cards, as well as other forms of recognition such as certificates, thank you letters, and appreciation events, all of which help to support women and demonstrate that their work is valued. Supporting women also requires that organizations address stigma and discrimination in the workplace. This could involve providing workers with peer-led, on-going training to reduce attitudinal barriers faced by women living with HIV and promote an understanding that different forms of knowledge and experience are equally valued.

On the subject of transparency versus confidentiality, organizations need to find the appropriate middle ground where they can effectively embrace the two. Constructive measures include understanding the disclosure-related needs and worries of both staff and clients, having all parties sign mutual confidentiality agreements, allowing individuals to protect their true identity through the use of pseudonyms or a "first-name basis only" policy, encouraging HIV-negative staff to be upfront about their health status with clients, and supporting HIV-positive staff to self-disclose only information about which they feel comfortable and to talk with clients about confidentiality policies

that can help to protect both parties such as how to approach one another if they meet in public.

The right of women living with HIV to experience self-determination and to participate in decision-making processes that affect their lives is fundamentally tied to the complete application of the GIPA, MIPA, and MIWA principles (International Community of Women Living with HIV/AIDS, 2008; UNAIDS, 1999). Grounded in critical feminist theory concerned with access and equal opportunities for women living with HIV, our research highlights an urgent need for policymakers and care providers to take notice of what women living with HIV are saying and ensure that the pathway to women's meaningful engagement and leadership in the design and delivery of HIV/AIDS services is unobstructed and that their health and access to care is uncompromised in the process. By supporting meaningful user engagement, organizations have the potential to contribute to more effective health services and improved health outcomes for women living with HIV. This will be evaluated in the next phase of CHIWOS and will have important implications for models of system design and delivery in Canada and worldwide. Sheila shared her view:

> I think that those changes are coming. I think that they're coming over the next 10 years. And I do believe the more women empower themselves to get experience and education and opportunity in this field, we will bridge this gap from positive and nonpositive.

Hospital), Guillaume Colley (British Columbia Centre for Excellence in HIV/AIDS), Tracey Conway (Women's College Research Institute), Curtis Cooper (Ottawa Hospital Research Institute), Jasmine Cotnam (Women's College Research Institute), Janette Cousineau (Women's College Research Institute), Janice Dayle (McGill University Health Centre), Marisol Desbiens (Women's College Research Institute), Hania Dubinsky, (McGill University Health Centre), Danièle Dubuc (McGill University Health Centre), Janice Duddy (Pacific AIDS Network), Brenda Gagnier (Women's College Research Institute), Jacqueline Gahagan (Dalhousie University), Claudine Gasingirwa (Women's College Research Institute), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Saara Greene (McMaster University), Trevor Hart (Ryerson University), Catherine Hankins (UNAIDS), Bob Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Terry Howard (Positive Living Society of British Columbia), Shazia Islam (Women's College Research Institute), Evin Jones (Pacific AIDS Network), Charu Kaushic (McMaster University), Alexandria Keating (ViVA and Southern Gulf Islands AIDS Society), Logan Kennedy (Women's College Research Institute), Mary Kestler (Oak Tree Clinic, BC Women's Hospital and Health Centre), Maxime Kiboyogo (McGill University Health Centre), Marina Klein (McGill University Health Centre), Gladys Kwaramba (Women's College Research Institute), Andrea Langlois (Pacific AIDS Network), Rebecca Lee (CIHR Canadian HIV Trials Network), Lynne Leonard (University of Ottawa), Johanna Lewis (Women's College Research Institute), Viviane Lima (British Columbia Centre for Excellence in HIV/AIDS), Elisa Lloyd-Smith (Providence Health Care), Carmen Logie (University of Toronto), Shari Margolese (Women's College Research Institute), Carrie Martin (Native Women's Shelter of Montreal), Renee Masching (Canadian Aboriginal AIDS Network), Lyne Massie (Université de Québec à Montréal), Melissa Medjuck (Positive Women's Network), Brigitte Ménard (McGill University Health Centre), Cari Miller (Simon Fraser University), Deborah Money (Women's Health Research Institute), Marvelous Muchenje (Women's Health in Women's Hands), Mary Mwalwanda (Women's College Research Institute), Mary (Muthoni) Ndung'u (Women's College Research Institute), Valerie Nicholson (Simon Fraser University), Illuminée Nzikwikiza (McGill University Health Centre), Kelly O'Brien (University of Toronto), Nadia O'Brien (McGill University Health Centre and Université de Montréal), Gina Ogilvie (British Columbia Centre for Disease Control), Susanna Ogunnaike-Cooke (Public Health Agency of Canada), Joanne Otis (Université du Québec à Montréal), Ali Palmer (Simon Fraser University), Sophie Patterson (Simon Fraser University), Doris Peltier (Canadian Aboriginal AIDS Network), Yasmeen (Ashria) Persad (Women's College Research Institute), Neora Pick (Oak Tree Clinic, BC Women's Hospital and Health Centre), Alie Pierre (McGill University Health Centre), Jeff Powis (Toronto East General Hospital), Karène Proulx-Boucher (McGill University Health Centre), Corinna Quan (Windsor Regional Hospital),

FUNDING

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