What is this study about?

- 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.

**Study Objective:** To explore the benefits and tensions of operationalizing MIWA in the design and delivery of HIV/AIDS services, from the perspective of women living with HIV in BC, Canada.

How was this study conducted?

- Four focus groups were conducted with 28 women living with HIV in three urban centres in BC (Vancouver, Victoria, and Prince George) between August and October 2011.
- Focus groups were facilitated by trained Peer Research Associates, lasted 2-3 hours, were audio-recorded, and transcribed word-for-word.
- Transcripts were analyzed using thematic analysis (where emerging themes were coded and compared across transcripts), peer debriefing, and investigator triangulation.

What did this study find?

- Women described engaging as peer workers within their care communities, highlighting the informational, emotional, social, and capacity-building benefits of operationalizing MIWA.
- However, several tensions emerged as their role shifted from service user to service provider within organizations: (1) Being required to choose between remaining clients or becoming paid employees. (2) Being positioned unequally as providers who are good enough to volunteer yet not good enough for paid work. (3) Serving as a resource for organizations but without equal ownership or control. (4) Confronting organizational attitudes that espouse empowerment yet fail to fully acknowledge women's capacity to contribute in practice. (5) Needing transparency around having women living with HIV working in organizations while balancing the need to protect HIV status confidentiality.
- Overall, “this glass ceiling” limited women from rising as peer leaders in their communities, while also serving to compromise women’s access to care and overall health.

Implications for policy: Why is the study important?

- Identifying and mitigating unintended consequences of MIWA is critical as peer participation in care gains prominence in Canada and worldwide.
- Organizations must facilitate and support meaningful dialogue about these issues with their clients, and implement strategies to address these concerns in a sustainable way.
- Further, women's narratives demand that organizations: (1) End employment discrimination against their own clientele. (2) Develop of policies and structures that explicitly support a range of peer roles for women with HIV. (3) Recognize women's contributions through remuneration. (4) Address stigma and discrimination in the workplace. (5) Identify the appropriate middle ground where they can effectively embrace transparency and confidentiality.


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