

Indigenous Women-Centered HIV Care: Responding to Culture and Safety

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Background

- Indigenous women globally are disproportionately affected by HIV. In 2014, 30% of new diagnoses among women in Canada were among Indigenous women, despite Indigenous peoples (First Nations, Métis and Inuit) representing just 4.3% of Canada's population.
- Alongside gender inequalities, the intergenerational impacts of colonialism in shaping Indigenous women's exposure to HIV infection are well known; and yet we know less of the voices and experiences of Indigenous women living with HIV (WLWH) in navigating HIV care and culturally safe practices.

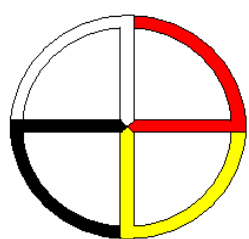


"Residential school counselling [would help]. My mother didn't go to residential school, but some of my aunts and my uncle did. And, my grandparents did and, I got it the worst. I've dealt with sexual abuse ... physical violence...neglect. And finally I ended up in care. So, I've had a very tough life...that affected the way that I parented. That affected my non-belief in myself, that I don't deserve my children because I chose to be with an abusive person. It's just in these last ten years that I've finally believed I deserve better than this." (Bena, 42, cisgender woman, First Nations)

- Indigenous women's narratives about interlocking oppression from care providers and agents of the State made accessing care and achieving balance challenging. Many Indigenous women shared stories of racism and paternalism from practitioners that interfered with the care they needed and requested.

Methods

- As part of SHAWNA (*Sexual Health and HIV/AIDS: Women's Longitudinal Needs Assessment*), a community-based longitudinal project, we conducted 56 qualitative in-depth interviews with WLWH in Vancouver, Canada in 2015, 25 of whom were Indigenous women.



- Indigenous women participated in the development of the interview guide, the interviews and the data analysis. An adapted Medicine Wheel was used to identify conceptualizations of health. The Medicine Wheel represents a common understanding of the interconnectedness and interrelatedness of all things.

- Indigenous women's narratives were analyzed drawing on decolonizing, critical, and feminist theories and participatory research with WLWH.

Results

Defining wellness and wellness practices

- Many Indigenous WLWH shared the significance of spirituality and balance in their conceptualizations of health and HIV care. When explaining her health using the Medicine Wheel, Abey said:

"It just means getting the nutrition that I need. Taking your ARVs. Spiritually, I'm just using my own prayer...and meditation, in order to help me with my anxiety and getting to sleep instead of the drugs. Emotional...I use a lot of the supports... and any exercises that are part of my [support] groups. They help me.

Physical's a lot easier for me in the summer because I can walk. Social...my family and my friends help me keep balanced and grounded...every day is not the same, so everybody can rely on each other to pick each other up. Cultural, I have a lot of gifts... I can help make the medicine bags, or I can help do the dream catchers. Or cooking." (Abey, 46, cisgender woman, Coast Salish)



Historical challenges and ongoing barriers to wellness

- Narratives about health conjured up the legacies of colonialism wherein women recalled how culture, community and safety were stolen from them through policies like the residential schools. The schools were government-funded, church run institutions to remove children from the influence of their homes, families and cultures. Generations of children were exposed to abuse by the time the last school closed in 1996.
- When asked what supports Indigenous women need, Bena made a direct link between intergenerational experiences of violence, her self-esteem and the need for collective healing.

Indigenous women's wish list

- Many identified culture as part of treatment but women stated obstacles to cultural revitalization, including limited access to women-only circles and urban healing ceremonies, and economic barriers to visiting home communities. Women wanted greater access to HIV services delivered by Indigenous peers, Elders and in groups.

"There's an elder at Aboriginal Front Door. She usually gives me some medicine. She's the only one that actually smudged my place. There's always a need for...like a talking circle or a sharing circle with other women that are HIV positive. ...Because I know a lot of Aboriginal women have...gone through the same things right." (Dyani, 33, cisgender woman, First Nations)

"Like I said, just more Native peer navigators that are more in tune with the spiritual side, because I think a lot of us would really, totally benefit from it. Because there are a lot of us that turn back to our spiritual side because- our diagnosis, right." (Ehawee, 36, cisgender woman, First Nations)

"I know that's where I got my strength, is learning about, who I was. Cause growing up I grew up around the bottle. I'm the first one who brought out an eagle feather in my family. I think that's what we need more of is teaching those in recovery. Family support too. I had to go to the island, for family treatments." (Felicia, 43 cisgender woman, Inuit/First Nations)

Conclusions

- Indigenous women shared wellness strategies and cultural practices they engage in to maintain balance in their lives.
- Presently, Indigenous family-centered HIV care that is responsive to women's complex realities is not available and the current care landscape – too frequently racist or paternalistic – further jeopardizes Indigenous WLWH's health outcomes.
- Despite the high prevalence of Indigenous WLWH, HIV services offer limited engagement with Indigenous epistemologies, spiritualities and collective healing.
- These stories construct a call for services to be more responsive to Indigenous women. Ultimately, women want their HIV care delivered in culturally safe and holistic ways that honour their resilience and Indigeneity.



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