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Sharing circles with Indigenous women – understanding perceptions of HIV to inform the scale up of behavioural change strategies in Quebec, Canada.

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Background

As a result of historical and structural processes, Canadian Indigenous women are disproportionally affected by the HIV epidemic. Although Indigenous women (First Nations, Métis, Inuit), are 4.3% of the Canadian female population, they represent 30.6% of new female diagnoses[1,2]. Counter to national trends, available data suggests that the HIV-epidemic among Indigenous women in Quebec is not as widespread. This research was undertaken to better understand Quebec Indigenous women's perceptions of HIV, and prevention and care services. The overall goal is to identify innovative, culturally safe behavioral intervention for HIV prevention specific to Indigenous women in Quebec.

Methods

This research is imbedded within the Canadian HIV Women's Sexual and Reproductive Health Cohort Study – Prioritizing the Health Needs of Positive Aboriginal Women **(CHIWOS-PAW).** From December 2015 to December 2016, four full-day research retreats were conducted with 14 Indigenous women, led by Indigenous researchers in Quebec. Drawing on Indigenous Methodologies, and under the guidance of an Indigenous Elder, sharing circles, reproductive justice-based sexual health workshops, and arts-based behavioral change strategies were conducted. Research participants then collaboratively interpreted and confirmed the findings in an interactive closing circle.

Findings

Participant demographics

The fourteen Indigenous women who participated were quite diverse. Participants ranged from 24-74 years of age; Inuit, Metis and First Nations were represented; were from 12 different communities; and seven distinct languages were spoken in the home. 11 of 14 had stable housing, and all women reported an income of $20,000 or less per year.

Health Information

HIV-status varied from HIV-positive, HIV-negative, to serological status unknown. 10 women reported having a regular family doctor.

When asked how they would rate their access to health care, women replied: great = 6, adequate = 3, lacking = 2, terrible = 3.

Main Themes

In the sharing circles, emphasis was placed on root causes of HIV, including gendered violence, unequal relationships, and intergenerational trauma. Recommendations for improving the care and prevention response included ensuring safe spaces for women to meet, share, and learn from one another. Programming must also be peer and youth led to be effective. Strategies to ensure confidentiality within health care settings, and when seeking risk reduction services should be improved. Education and awareness regarding HIV must also be revived to communicate the risks of transmission and to dispel persisting HIV misconceptions, stigma and discrimination. During the circles, women also exchanged stories of self-care and building self-esteem as part of overall health.

"I don't' know how to say this, but I tried the 'white people way'. I had anxiety and depression and pills, and I tried and I couldn't. . . I started seeing an Elder in my community, and we started doing sweats and healing circles, and that helped me a lot… I also do follow up with a psychologist. These are the two main ways that I follow up with my health"

"I realized that healthy was that I could go back, and hold myself, and tell myself I was a good girl, and that I'm lovable and I'm good . . . That is when I realized that I was healthy, that I could still do it now, bring peace to a lot of the suffering that I went through when I was little."

"No one talking about it, nothing is being done. But first thing is talking about it . . . Even my family they don't even want to say the word HIV. They say "it". One time we were running around town, and they said. Oh that lady has "it". And I said, what is that "it". That is a problem today, people said "it". Why can't you just say HIV or AIDS? You can't even say it"

"I spent most of my life surrounded by people, needing to have another person in my life to make me feel worthwhile, and to make me feel complete. So for me, health is being able to sit by myself in my house, and feel whole and feel happy. That is health for me because I spent so many years, looking outside myself, and it wasn't there. . . so for me that is health, being able to be with me."

"I have a good doctor communication, and I'm getting along well with her, there is nothing to hide, even sometimes I have to apologize because she has to work on me, and she says, 'No, no, don't apologize it's my job'."

"We need that safe spaces. We need that space where we can bring the women, and say we are going to talk about it, we are going to educate each other, we are not going to educate them, they are not going to educate us, we are going to educate each other in a safe environment".

Conclusions

Peer-led design and delivery of HIV-prevention and care programs are key to ensuring a response that meets Indigenous women's needs, including addressing structural factors which impact their health and healthcare seeking.

Work Cited: A Gender-based Statistical Report. March 30, 2015. Retrieved from: http://www.statcan.gc.ca/pub/89-503-x/2015001/article/14152-eng.htm#a6.

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