

DECOLONIZING METHODOLOGY

Using sequential sharing circles as a trauma-informed method
of data collection with Indigenous women living with HIV

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ABSTRACT:

Background: For years, Indigenous women living with HIV have been voicing the need for separate safe spaces where they can be themselves together, free from stigma and violence. Where do the voices of Indigenous women go? Colonization and patriarchy has left a strong resistance of structures to change those aspects that create health inequities. However, Indigenous women are living with HIV 20-30 years longer than expected, they do not just want to live; they want to live well, supporting each other.

Methodology: Using a Two-eyed Seeing approach, a small but proud group of Indigenous women all aging with HIV gathered for four days of sequential sharing circles over a two-week period. The women shared – without fear of judgment or consequence – both the challenges as well as the things that brought them joy and made them well. They explored the services, supports, health and wellness interventions that they know will assist them and other women aging and living with HIV. The implications if one listens are profound.

Discussion: Using sequential sharing circles as a data collection method and by using it in such a way that it honours the lived experiences of Indigenous women living with HIV therefore, it is then both a trauma and gendered informed practice for research.

Keywords: *Indigenous Women, , trauma-informed, genere-informed, culturally responsive*

INTRODUCTION

In this inquiry we explain the processes that we took to explore how Indigenous women living with HIV, age well, and what they need in regards to interventions, service provision and programs to age. Many Indigenous women through colonization, patriarchy, oppression, trauma and the continuation of structural inequities (Cameron et al., 2014), have been denied their traditional roles as mentors and decision-makers in their communities. While their voices are excluded in health service planning, and program development they remain over-represented among victims of violence and infectious diseases such as HIV, as well as other chronic diseases (Loppie-Reading & Wien, 2009). Culture and gender-informed interventions are needed to restore and promote social, physical, mental, emotional and spiritual wellness for Indigenous women living with HIV. The objective of this inquiry is to understand how decolonizing methodologies and Indigenous research tools such as sharing circles are suitable when researching sensitive health issues with Indigenous women living and therefore aging with HIV. The aim of this particular inquiry is to highlight the efficacy of the use of sequential sharing circles when conducting research with Indigenous women living with HIV. Indigenous women are more vulnerable to HIV and violence which is a direct result from structural inequities created by the social, historical, and political contexts of colonization and patriarchy, affects still remain today (CAAN, 2009; Canadian HIV/AIDS Legal Network, 2016).

This research project involved a total of 4 days over a two-week period. Participation in this project involved wellness and cultural-based healing activities (making a trade-bead necklace, medicinal sage & sweetgrass balm), traditional Westcoast cedar brushing and a blanket Ceremony, an abundance of nutritious foods shared, along with sequential sharing circles. The women shared – without fear of judgment or consequence – both the challenges as well as the things that brought them joy and made them well. They explored the services, supports, health and wellness interventions that they know will assist them and other women aging and living with HIV. This shaped an environment for the participants to make authentic truthful acknowledgements that the services and supports being funded in the mainstream HIV community, which participants at times did not see these services as being culturally or gender-informed, making them feel, both emotionally and physically unsafe when they did attempt to access these supports. The findings from these four days of sequential sharing circles reveal the specific characteristics of services and supports that facilitate the wellness of aging Indigenous women living with HIV and those that were unsafe, thereby providing tangible wise practice for future wellness services, supports and interventions, and directing us towards further research. An additional finding and the primary focus of this inquiry was that by using sequential sharing circles it in a way that honoured the lived experiences of these women, thus, can be considered both a-trauma and gender-informed practice for future research.

METHODOLOGY

We specifically wanted to use methodologies that would assist us in answering our research question: how do Indigenous women aging with HIV experience wellness, and what do they want and need for wellness in relation to interventions, service provision, programs and healthcare? As researchers, we

decided early that we would use decolonizing methodologies that privilege the voices and experiences of Indigenous women living and aging with HIV. Therefore we sought out to ensure that the experiences of Indigenous women living with HIV would be honoured and each woman's stories would be treated with dignity and respect, and done so in a good way. We decided that we would embark on using Indigenous-ways of sharing which in many Indigenous communities have been talking or sharing circles, and utilizing them as research tools (Kurtz, 2013). It also must be noted that traditionally in Indigenous communities sharing circles are used for healing and self-determination purposes, and ultimately community survival (Kurtz, 2013; Smith, 2012). Specifically, these sharing circles allow for Indigenous communities to share knowledge among their members and give the community the information needed to make needed decisions (Smith, 2012).

As a research tool, sharing circles are adept at gathering stories and capturing people's experiences, and have been used by Indigenous communities to teach culture and tradition, promote and research health, and provide emotional and spiritual healing (Macklin, 2016; Nabigon, 1999; Rothe, Ozegovic, & Carroll, 2009). In addition, sharing circles promote an abundance of decision-making and life skills, because women learn and guide other Indigenous women through and by sharing their own stories and lived experiences (personal communication January 4, 2018 Elder Juanita Black-tailed Deer women; Loppie, 2007)) In comparison to a stand-alone sharing circle, the sequential sharing circles elicit deeper exploration and understanding the challenges related to Indigenous women's experiences with societal and health-related issues (Jacklin et al, 2017) especially as these challenges relate to aging well with HIV. Our project utilized sequential sharing circles, whereby multiple sharing circles with the same participants were conducted during four days over the course of two-weeks. This process was shown to enhance trust in each other and the research process, built rapport between researchers and participants, nurture a sense of communal connection among the women, as well as facilitated a sense of empowerment through these group discussions, making them stronger together.

RESULTS

In the end, the study identified that for HIV services to be truly trauma-informed, HIV service and supports, health structures must acknowledge the truths about the intergenerational impacts of colonization and how it perpetuates stigma, discrimination, inequity, and continues to perpetuate abuse and gendered violence (CAAN, 2009; Canadian HIV/AIDS Legal Network, 2016). This includes the recognition that, through patriarchy, residential schools, the 60's scoop and the many traumas associated with the child apprehension system; trauma is entrenched and remains a reality for all Indigenous women through both their lived experiences and intergenerational impacts (Sasakamoose et al., 2017). These findings are similar to what primary healthcare research scholars have recommended including that culturally responsive approaches to care can be wise practice for Indigenous people experiencing health inequities. Culturally responsive approaches to care are strengths-based and spiritually grounded, and incorporate cultural safety, contextually- and community-tailored care, trauma- and violence-informed care (Sasakamoose et al., 2017). Participants identified these aspects, when available, would have been important throughout their lives as well as being important today for their wellness. Therefore, trauma and gender-informed and culturally-safe HIV services must promote self-

determination and autonomy. At present, an urgent need exists to decolonize HIV services for Indigenous women. Foundational to this approach will be purposeful actions taken to de-colonize healthcare, services, supports and interventions. This results in the need for Indigenous women living with HIV voices' to drive and lead in the creation, implementation and evaluation of research and these services. Ultimately, the study gives validity to the importance of Indigenous research methodologies and culturally responsive programming through the incorporation of Indigenous knowledges, Indigenous research tools, lived experience, ancestral wisdoms and community involvement throughout the research process.

Many hours during the analysis process were spent re-analyzing the sharing circle transcripts, review and discussion of researcher reflective notes between researchers and an Indigenous Elder. We challenged ourselves as researchers to critically understand why the four days of group discussions were successful in gathering relevant data. Using an approach that honoured both Indigenous and western knowledges to find an appropriate analytical direction it is important because this study data that will be used to inform future research methodologies, research protocols, plus inform future directions of supports and services for Indigenous women living with HIV. Our first thought was that these are women who had to navigate the HIV health services systems for over 20 years, they are thoughtful and direct. However, if that was the only answer we would have gotten our research question completely answered on the first day but that was not the case. We further concluded that it must be in the research process itself.

CONCLUSION

Consequently, we realized that the intrinsic nature of sequential sharing circles as both a trauma and gender-informed method of data collection created safe and supportive environment with Indigenous women living and aging with HIV. A trauma-informed practice provides choice, collaboration and connection (BCCEWH, 2013; Poole & Greaves, 2007). In the sharing circles the women could disclose as much or as little they chose- meeting these women *wherever they were at* in their healing journeys. The women gradually built rapport among themselves and the researchers during the four-days over a two-week period. This gave the time needed to feel safe and respected at the same time giving each woman the necessary reflective time to fully experience the healing nature of the sharing circles. Trauma-informed means practices that promote cultural, emotional and physical safety, self-determination, autonomy, social inclusion and participation, resulting in women being treated with *dignity, respect* and they can determine their level of involvement at any time (BCCEWH, 2013; Poole & Greaves, 2007). Indigenous healings can be considered trauma-informed care. (Fayed et al., 2018), which is the healing experienced by those who participate in sharing circles.

One of research findings' limitations of the research is that four of the women lived in Vancouver's downtown core and frequented many of the same HIV support services and that, in the past year one of the only gender-specific positive women's spaces lost funding, resulting in it closing its doors and a major loss for these women. Consequently, the results from the study informed us as to a direction on what approaches, research methodologies and data collection tools must be used in the process of de-colonizing both the research process and health and wellness services and supports while respectfully

engaging with Indigenous women living with HIV. Further finding that by using sequential sharing circles and reflecting the need to honour the lived experiences of Indigenous women living with HIV. Sequential sharing circles as a data collection method is a trauma and gender informed approach to engage in research with Indigenous women.

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