


AGING WITH WISDOM

Indigenous HIV and Aging

Preliminary



Report on preliminary results from Nov 1, 3, 6 & 8, 2017 research

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Where do our voices go?

- *participant*

Completed by: Cynnimon Rain, Elizabeth Benson and Juanita *Black-tailed Deer Woman* Dejarlais

For years, Indigenous women have been voicing the need for separate safe spaces where they can be themselves together, free from stigma and violence. Yet, meager funding sources have evaporated. Where do the voices of Indigenous women go? Colonization and patriarchy has left a strong resistance to change, especially change from the people who are enjoying the status quo. The medications have improved and positive people are living 20 and 30 years longer than they imagined. They do not just want to live; they want to live well, supporting each other.

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.

Instead of the challenges of aging as Indigenous women living with HIV, they focused on their roles within their families and communities, overcoming adversity by using their strengths, and the importance of friendships with other positive Indigenous women. They acknowledged that even with all the barriers and discrimination within the healthcare system, specific relationships with specific respectful and compassionate healthcare professionals added to their overall wellness. However, they also identified the need for positive Indigenous women's only spaces, cultural-based programming, the promotion of self-determination and having a purpose to get out of bed every day. They are the ones that need to be empowered to envision, create, implement and facilitate their own services and supports. They see being offered one support group a month is tokenistic. They no longer want permission to enter. They want to see their faces across the front desk when they walk through the front door. Together, they questioned why the HIV services and supports are not meeting all of their needs.

How the story began...

This project sought to answer two main research questions:

- 1) How do Indigenous women aging with HIV experience wellness; and
- 2) What do Indigenous women aging with HIV want and need for wellness (interventions/service provision/programs/healthcare).

This research project involved a total of 4 days (10am-3:30pm) over a two-week period in November 2017. 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.

Objectives were to:

1. Guide and facilitate culturally appropriate activities during the 4-day project;
2. Facilitated sequential sharing circles during the 4-day project; and
3. Compile, analyze, and synthesize findings into a written report and an anticipated oral report which will be shared with various Indigenous people and organizations, health advocates, and researchers in order to better inform and refine future wellness interventions for Indigenous women aging with HIV/AIDS.

Findings

To answer the two research questions three research team members analyzed relevant researcher reflection notes and the transcripts of the four audio recorded sequential sharing circles. An overlap of themes, perceptions, and recommendations emerged from the sequential sharing circles.

Main themes:

Culture & Ceremony : The importance of actively engaging in Indigenous, wholistic approaches to health practices that encourage spiritual, physical, emotional, and mental wellness, which includes but is not limited to Ceremony, Ceremonial practices (sweat lodges, cedar brushing, smudging, harvesting, drumming, singing, feasting, Powwows) and Traditional Medicines & Gifts {i.e., interconnectedness of medicines and gifts include the physical e.g., plant-based (sage, sweetgrass, tobacco, cedar), food and laughter; the emotional e.g., love, kindness, respect and compassion; the mental e.g., teachings and wisdom; the spiritual aspect of all physical, emotional, and mental feelings, thoughts, practices, actions with individual and collective stories – all of these are both medicines and gifts}. Elders in Indigenous communities are individuals who have a deeper understanding of the physical, mental, emotional and spiritual, and who offer the teachings, guidance and support of the various Indigenous Ways and Knowledges. Elders for spiritual and emotional guidance were seen not only as quite important, but essential/

Relationships: The importance of having relationships that include a network of friends, family and community, intimate and sexual partnerships, other positive women (Sisters) and respectful and compassionate healthcare professionals that support a women's physical, emotional, mental and spiritual wellness.

A lot of love, I've got a lot of love for my children, I've got friends, I will not give up.

And my sister's here, who I love dearly, dearly, dearly. – Participant

...friends, I guess it's the only people that I have, that have HIV – that's my family. I consider my family, my friends, my sister's here, and people that go to the [HIV places], I guess that's my family now.

And community, where I live in. – Participant

Self-determination & autonomy (having a purpose): The importance of self-determination and having a purpose every day for their wellness. Self-determination is having the abilities and

opportunities to make decisions about one's life choices. Being able to have control over how and when they obtain needed services while at the same time having the opportunity to participate in and contribute to their own decision making in what makes them happy and well. This includes having opportunities and choices for training, education and leisure.

Safe-spaces: Importance of having access to places and spaces where positive Indigenous women can feel safe and supported amongst other women. Is a place where positive women feel a sense of belonging. A space where racial or sexual violence is not a concern and this includes not being subjected to racist, sexist, misogynistic or stigmatizing speech and behaviors. For Indigenous women, a safe space is culturally responsive where cultural practices are promoted e.g., smudging and other sacred ceremonies.

Recommendations

- 1- Promoting Culture, Ceremony and Traditional Medicines as approaches to wellness

- 2- Indigenous woman created, driven and led program models that include respectful and compassionate allied health professionals that focus on mental health and substance use supports
- 3- Promoting Indigenous women leadership, self-determination and autonomy in all program model components
- 4- Creation of a positive Indigenous women's only safe space that is culturally responsive, where cultural practices are promoted.
- 5- Ongoing opportunities for training and education
- 6- Ongoing emotional and spiritual support from Elders
- 7- Ongoing appointment, housing, employment and health system advocacy support from designated area-specific trained Peers

See Appendix I for a sample wellness support-service intervention

"... living in hope says to us, 'There is a way out,' even from the most dangerous and desperate situations ..." *"There is no change without dream, as there is no dream without hope."*

– P. Fiere *Pedagogy of Hope*

What we did...

Sequential sharing circles

Four days in November 2017- 1st , 3rd , 6th , & 8th

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 spiritual counselling and healing (Rothe, Ozegovic, & Carroll, 2009). In addition, sharing circles promote an abundance of life skills. In comparison to a stand-alone sharing circle, the sequential sharing circles elicit deeper exploration and understanding of the complex, and at times, challenges related to Indigenous women's experiences with societal and health-related issues (Jacklin et al, 2017) while 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 from November 1st to November 8th 2017. This process was shown to enhance trust, built rapport between researchers and participants, nurture a sense of community, as well as facilitated a sense of empowerment through these group discussions and sharing food.

Sharing Circle questions

Day 1 – Objective: Creating relationships with each other (establish rapport and safe space)

1. How does it feel to be an older Indigenous woman living with HIV?
2. What nourishes you and your spirit?
3. Have you ever included traditional medicine or land-based healing practices and activities in your health and wellness? If so, so how? How did you find these practices and activities while aging with HIV?

Day 2 – Objective: Relationality

1. How has your experience of HIV shaped your identity as an Indigenous woman, through the different stages of your life? (i.e., *social, physical, emotional, mental, spiritual aspects of menopause, motherhood, partnerships, widowhood*)
2. As an Indigenous woman living and aging with HIV, has your culture helped you through the different stages of aging. If so, in what ways has it been helpful?
3. How has HIV affected your relationships with your family/friends? With your community? With other generations, past, present and future?

Day 3 – Objective: Nurturing challenges

1. As an Indigenous woman living and aging with HIV, what challenges do you face physically (e.g., menopause, interactions with medication, money), emotionally (e.g., hormone fluctuations), mentally (e.g., stress, depression, anxiety), and spiritually?
2. What has helped you get through (navigate) these challenges, and in turn live and age well with HIV?
3. As an Indigenous woman living and aging with HIV, what types of community supports have you used to help you maintain health and wellness?

Day 4 – Objective: Future Focused

1. As an Indigenous woman living and aging with HIV, what supports do you envision needing as you age and what should these services look like?
2. What have you learned that you can share with others about living long-term with HIV?
3. Is there anything we forgot or something important that we should know about?

Who we are...

The research and analysis team are part of an Indigenous Wellness team in British Columbia Canada led by Dr. Alexandra King.

Team roles:

Elder, Sharon Jinkerson-Brass-White Thunderbird Woman, a storyteller from Key First Nation in Saskatchewan. Sharon received her cultural teachings from her beloved Anishinabe Grandmother, who was a midwife and traditional healer.

Peer Research Associate/Collaborator, Elizabeth Benson an advocate and researcher in the HIV community locally, provincially and nationally for over 20 years. Elizabeth's role on the team was to assist the Elder with cultural practices and Ceremonial requirements and in the co-facilitation of the sharing circles. In addition, Elizabeth was a fundamental part of the initial thematic analysis of the research data, identifying important recommendations and necessary calls to action.

Indigenous Community Research Associate, Bernice Thompson ensured the team addressed important group guidelines, kept the team on-time and on track, and assisted in co-facilitating the sharing circles. She was integral in meeting the support needs of the participants. In addition, she was the team member who took care of the research requirements and protocols during data gathering.

Indigenous Community Research Associate, Juanita 'Black-tailed Deer Woman' Desjarlais was central to the deep analysis of the research data, perceptions, recommendations and calls to action. She focused on the importance of the many Indigenous Ways of Knowing, giving a Western way of data analysis an Indigenous-lens.

Community Research Associate, Cynnimon Rain's role was to be of service to the team, so team members could focus on meeting the physical, emotional, mental and spiritual needs of the participants and logistical and ethical requirements of the research project.

On the homeland of...

We conducted our research on the traditional unceded lands of the Tsleil- Waututh people. The specific location was the Tsleil- Waututh Nation's Cultural and Recreation Centre located in North

Vancouver, British Columbia. The space used was an important community space called the Tsleil-Waututh Nation's Elders Lounge. The Elders space fitted the needs of our participants, with its large open windows that overlooked Burrard Inlet waterway and a great sacred cedar tree just outside the private entrance. A local community family catering company nourished the bodies of our participants, our Elder and the three research team members.

A demographic snap shot of who these women are...

All Six participants self-identified as women. One participant self-identified as Two-spirit, trans-woman and gender-fluid.

Age range 47-60 years of age. It was determined that because of the context of the research study taking place in Metro Vancouver we would include self-identified women over the age of 45 years to be included. This was accepted by both peer and Indigenous Research Associates and an Elder. An Indigenous person living with HIV can be considered to be an Older Adult and/or Elder in Metro Vancouver and the Fraser Valley of British Columbia when they are over the age of 45 years.

- Two participants between 47-49 years (one would be over the age of 50 and living with HIV for almost 25 years by the end of the project; the other was accepted by peer and Indigenous Research Associate and an Elder because of her lived experiences and length of time living with HIV)
- Four participants between 50-59 years (2/3rds or 67% of participants)
- One participants aged 60+

Indigenous identity represented (self-identified)

- First Nations
 - Three Cree Nation
 - Two Treaty 8
 - One Treaty 6
 - One Coast Salish
- One Metis/Cree
- One Urban Indigenous from Treaty 3

Years living with HIV

- One <20 years
- Four >20+years
- One >30+years

Estimated average years living with HIV 23.7 years

What we learned...

Healthcare, services, supports & wellness interventions (*facilitators for wellness*)

Over the length of the project we identified the major aspects, philosophies, frameworks, and intervention components that facilitate wellness for aging Indigenous women living with HIV. Relevant researcher reflection notes and the transcripts of the four audio recorded sequential sharing circles were analyzed through thematic coding to answer: how do Indigenous women aging with HIV experience wellness and what do they want and need for wellness, for the purpose to find out what healthcare services, supports, and wellness interventions facilitate wellness.

I. Philosophies and frameworks

Our project found that there are six major aspects that all services, supports and interventions require that are necessary to meet the unique needs of Indigenous women living with HIV, irrespective of life stage or age. Participants identified these aspects, when available, would have been important throughout their lives as well as being important today for their wellness. These include the promotion of culture-based, trauma-informed, gender-informed, harm reduction supports, self-determination and autonomy. In general, these services, supports and interventions need to focus on wholistic wellness rather than the narrow view of health as only being the absence of the negative physical symptoms of HIV.

Culture-based

These women identified that in all services, supports and interventions there must be opportunities to actively engage in Indigenous, wholistic approaches in health practices that encourage spiritual, physical, emotional, and mental wellness. This includes spaces for Ceremony and Ceremonial practices with plant-based Traditional Medicines available for them to partake in, if they so choose, alongside whatever Western medicines they decide to take. In addition, having access to Elders is important for Indigenous women's wellness journey when the women themselves feel Elders would support them emotionally and spiritually at any time in their wellness journey.

Furthermore, our findings indicated that a cultural-based approach to wellness includes accepting that, for Indigenous women, the definitions of relationships to self, family, community, Nation, land, water, air and Creator are interrelated and interconnected and cannot be separated from their physical, emotional, mental and spiritual wellness. Our participants identified that family and community are those all-encompassing relationships that make up all other people who support them or they support, physically, emotionally, mentally and spiritually, regardless of biological or the

Western view of familial ties. It is also necessary for services, supports and interventions to keep in mind that there are many Indigenous Nations and cultural practices and all need to be respected equally-there is no one or 'right' way of being Indigenous. Many Nations and cultural practices were represented and discussed as being important for wellness. The only conclusion about culture practices was that each woman knows what will make themselves well, if they are given the opportunity.

More culture centres, I believe, would help, where people can group together and learn things, and they'll disperse the groups to have [sharing] circles and whatnot. – Participant
... it's about women, it's about congregating together, it's about donating our time to learning, culturally. We're all open to have it. – Participant

Trauma & Gender-informed

For services, supports and interventions to hold a place of being trauma-informed these must identify the truths about the intergenerational impact of colonization within their own structures that perpetuate stigma, discrimination and inequity; 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 truth for all Indigenous women living with HIV through both their lived experiences and intergenerational impacts.

To be trauma-informed and gender-informed includes understanding the ways that colonization and that its impact perpetuates abuse and gender violence. Therefore, services, supports and interventions must meet people where they are at in their wellness journey and promote self-determination and autonomy when Indigenous women are engaging in services and supports. There must 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 these services and supports.

Safe space

An insightful finding is the importance of having access to places and spaces where positive Indigenous women can feel safe and supported amongst other women. A safe place is where positive Indigenous women and positive Two-spirited people feel a sense of sisterhood, community and belonging. It's a space where racial or sexual violence is not tolerated and this includes not being

subjected to racist, sexist, misogynistic, or stigmatizing speech and behaviors. In addition, a safe space is identified to also be a place where cultural practices are promoted.

And once again, unfortunately, a lot of services are not fully inclusive... Cause this is such a huge lack of intersectionality, regarding how people organize themselves, and people are excluded, especially two-spirited people, in the community. – Participant

The women identified safe space includes the act of honouring cultural practices and respecting the significance of ceremony and the importance of traditional protocols in a trauma-informed, gender-informed way that promotes self-determination and autonomy, while meeting people where they are at in their healing and wellness journey. It is a space that the guiding principles include respect and compassion in a harm reducing manner, which promotes the acceptance of where people are at in their substance use along with an understanding that open ‘drug-talk and use’ could undermine the health and wellbeing of others sharing that space.

I think we need more centres, that we can go to safely, and get the care that we need, the medication, without being judged, without being turned away, because of other matters. Socially, the social networks, they're there. It's sad that some people have to travel for them, a long distance, but they're there. So, we obviously need more of them, in the smaller communities, more based towards the reserves, because, like, my reserve, I can't go back there and feel safe. They don't feel safe with me, so how am I gonna feel safe with them? That's just the way it is, and we need more of them, closer to our home-based networks there. – Participant

II. Healthcare services and personnel including allied health professionals

Patient-healthcare provider relationships (doctor, nurse or allied healthcare professional) were identified as impacting an Indigenous women’s physical, emotional, mental and spiritual wellness. For these relationships to facilitate wellness, the women must be the ones who guide and determine the boundaries. There must be a reciprocal rapport and respectful engagement between women and her provider. *When healthcare providers stick it out, no matter what, [that] facilitated [women’s] wellness.* In large part, most of the participants’ relationships within their current healthcare system of care added to participants’ wellness – only in selected instances when participants had to go outside their built trusted relationships did mistreatment and abuses occur. Most of the participants have had to navigate the HIV healthcare system for over 20 years. This further proves the point that these

women's abilities and resiliency to get to a place of wellness by finding and sticking with the providers that treat them with respect and compassion while promoting self-determination.

III. **Training**

Another type of wellness support includes providing opportunities for women to gain skills and enhance their abilities to advocate for self and others. It has long been identified that for people to be well they must also feel like they are purposeful and contributing to their communities. They, as aging women living with HIV, felt the same. This may be even stronger with Indigenous women because traditionally an Indigenous women's sense of belonging cannot be separated from family and community. The importance of having the skills to be useful and contribute to one's community is a social and community responsibility for Indigenous women. Participants identified wanting to have training in cultural practices. This training could include how to mentor other women or facilitate cultural practices for others including younger positive Indigenous women, children and the larger community about HIV. Traditionally, older women mentored and guided younger women in all aspects of life. An act of de-colonizing mainstream HIV services, supports and health promotion interventions would be to provide opportunity for older positive Indigenous women to return to their roles as mentors and teachers.

And why not empower us ... and let us have a job? So we can get up every morning, and go make that money. Or have that sense of accomplishment... – Participant

IV. **Education**

Education about wholistic health promotes Indigenous women's wellness. It provides opportunities to be informed/given knowledge about health issues and alternative and traditional wellness options, which promotes self-determination and, in-turn, promotes wellness. The women want and need specific types of education regarding traditional teachings, medicines, ceremonies and other cultural practices, such as, education about traditional foods and how to prepare them for family and the larger community.

V. **Leisure**

Participants recognized the importance of leisure in their lives. They have a profound understanding that behaviors can change when their knowledge, skills, and abilities improve through engaging in healthy leisure activities that are culture-based and that promote healthy social support networks.

The women understood that quality of their lives increases through these culture-based leisure pursuits.

*Maybe taking us on a Vision Quest, or taking us to pick medicines. Out of town. Fishing.
Making a garden. All that good stuff. – Participant*

Discussion

Routinely, the research done with Indigenous women and aging focus on three areas: the physical health deterioration of all older persons and how to address these physical challenges, the challenges Indigenous women encounter with the mainstream healthcare system (stigma, discrimination, aftermath of colonization, of which there are many documented accounts) and the roles aging Indigenous women have within their families and communities. First it must be acknowledged that during the sequential sharing circles there was much discussion about the lack of culturally responsive health and wellness supports and services available for aging Indigenous women living with HIV. Much discussion was on the services and supports being funded in the mainstream HIV community, which participants did not see these services as being culturally responsive or gender-informed, and at times felt emotionally and physically unsafe when they did attempt to access these supports.

However, to move forward and look to the future, this research project focused on other sides to aging Indigenous women's health and wellness that emphasizes the importance of social and health support networks and friendships, with both other positive women and other Indigenous women, their involvement in Traditional Cultural and Ceremonial practices, and purposeful community involvement, contributing to their wellness and enjoyment of daily life. For the most part, these women voiced the love and support they have in their social and health support networks and specifically with other aging Indigenous women living with HIV. The most important facilitator of wellness they shared was how important it is for them to have a safe positive women's only space that is culturally responsive to their unique needs of aging Indigenous women living with HIV. A space where they can make new friendships, nurture old ones and feel like they belong.

One of research findings' limitations is that all but one of the small group of participants lived in the city of Vancouver. Four of the women lived in Vancouver's downtown core and frequented many of the same HIV support services. Of note, 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.

Another limitation is that it is difficult to determine if the reflected optimism and hope by participants is due to the life-stage they are now in or if hopeful or optimistic participants are more likely to assist in research studies than their counterparts. Despite the limitations, the findings from these four days of sequential sharing circles reveal what specific characteristics of services and supports facilitates the wellness of aging Indigenous women living with HIV, thereby providing tangible wise practice for future wellness services, supports and interventions, and directing towards further research.

A call to action and next steps:

- 1) Bring report back to participants and get their input.
- 2) Check preliminary results in another context/location of aging Indigenous women living with HIV and get their input.
- 3) Oral/poster presentation and/or special Indigenous Wellness panel at CAHR 2018
- 4) Further the research and pilot the wellness intervention that takes into consideration the recommendations of this report.

References:

Jacklin, K., Kristen, M., Henderson, R., Green, M., Walker, L., Calam, B., & Crowshoe, L. (2017). Healthcare experiences with Indigenous peoples in Canada. *CMAJ* 2017 January 23;189:E106-12. doi: 10.1503/cmaj.161098

Rothe, J., Ozegovic, D., & Carroll, L. (2009). Innovation in Qualitative Interviews: "Sharing Circles" in a First Nations Community. *Injury Prevention*, 15, 334-340. doi:10.1136/ip.2008.021261

APPENDIX I Sample Cultural-based wellness programming components

Sample project based on data, perceptions and recommendations gathered from four days of Sequential Sharing Circles

16 Week Wellness Intervention Project- aging Indigenous Women living with HIV derived program

First 8 weeks training of 9-12 peer leaders/facilitators (aging Indigenous Women living with HIV) for the Wellness Project and the Advisory Group determines 8 week program schedule and specific individual components (activities) in collaboration with Elders and 1 allied healthcare professional (e.g., Recreation Therapist, Community Social Service Worker or Occupational Therapist)

Second 8 weeks Wellness project with up to 16 participants

Advisory Group Driven – determine schedule and individual activities

Peers leaders rotate each week day among 9-12 peer leaders depending on facilitation specializations including health, HIV, harm reduction, substance-use, Culture & Ceremony, Sexual Health, nutrition

Days last 10am-3:30pm – three days per week (hot lunch and nutritious snacks included each day)

Day 1 Training/education	Day 2 DROP IN- Ongoing	Day 3 Cultural/Ceremonial
Staffing: Peer leader- trauma informed facilitator trained, food-safe Allied health professional - trauma informed facilitator trained, food-safe	Staff: Peer leader- trauma informed facilitator trained, food-safe Allied health professional - trauma informed facilitator trained, food-safe	Staff: Peer leader- trauma informed facilitator trained, food-safe Elder- trauma informed Allied health professional- trauma informed facilitator trained, food-safe
Activities	Activities	Activities
1 st week of month Health Education	1 st week of month Drop In appointment with MH&A Professional	1 st week of month Ceremony & Teachings Sharing Circle
2 nd week of month Relationship Education	2 nd week of month Drop In appointment with Nurse/Nurse Practitioner Sharing Circle	2 nd week of month Ceremony & Teachings Sign up to bring Grandchild or another woman family or friend Additional Staff: Child & Youth Worker
3 rd week of month Professional Skills Development & Sharing Circle	3 rd week of month Drop In appointment with MH & A Professional & Sign up to bring children or other women friend Additional Staff: Child & Youth Worker	3 rd week of month Cultural-Outing
4 th week of month Cultural Education	4 th week of month Drop In appointment with Nurse/Nurse Practitioner	4 th week of month Ceremony & Teachings Sharing Circle
<u>Ongoing alternative activities each week</u> Arts and Crafts ; Games and cards Seasonal-Community Garden	<u>Ongoing alternative activities each week</u> Arts and Crafts; Games and cards_Seasonal-Community Garden	<u>Ongoing alternative activities each week</u> Arts and Crafts Games and cards Seasonal-Community Garden