

Table of Contents

Introduction	1
 Section 1: Indigenous community-based HIV and AIDS research development and findings	
A Culturally Specific Approach: Developing A Métis Methodology for HIV Research.....	3
<i>Renée Monchalín and Carrie Bourassa</i>	
 Graphic Facilitation as a Tool to Guide Community-Based Research on Indigenous Boys’ and Men’s Sexual Health.....	20
<i>Nicole Doria, Maya Biderman, Dave Arthur Miller, Aaron Prosper, Matthew Numer</i>	
 Section 2: Commentary	
 The WoW Gathering: A Land-Based Positive Action Initiative to Support Indigenous People Living with HIV.....	28
<i>Andrea Mellor, Madison Wells, Sherri Pooyak, Valerie Nicholson, Chad Dickie, Sandy Lambert, Knighton Hillstrom, Renée Monchalín, Stephanie Nixon, Marni Amirault, Tracey Prentice, Renée Masching</i>	

The WoW Gathering: A Land-Based Positive Action Initiative to Support Indigenous People Living with HIV

Andrea Mellor¹, Madison Wells², Sherri Pooyak³, Valerie Nicholson⁴, Chad Dickie⁵, Sandy Lambert⁶, Knighton Hillstrom⁷, Renée Monchalin⁸, Stephanie Nixon⁹, Marni Amirault¹⁰, Tracey Prentice¹¹, Renée Masching¹²

Author Note

1. Andrea Mellor, WoW Research Coordinator, PhD Candidate at the University of Victoria
2. Madison Wells, WoW Research Assistant, Master of Public Health Student at the University of Victoria
3. Sherri Pooyak, Cree, WoW Nominated Principal Investigator, CAAN/AHA Centre, Sessional Instructor at the University of Victoria and First Nations University
4. Valerie Nicholson, Haida/ Mi'kmaq, HIV Older, WoW Steering Committee Member
5. Chad Dickie, Dene, HIV Older, WoW Steering Committee Member
6. Sandy Lambert, Cree, HIV Older, WoW Steering Committee Member, AHA Centre
7. Knighton Hillstrom, Cree, HIV Older, WoW Steering Committee Member, CAAN
8. Renée Monchalin, Algonquin/Huron/Metis/Scottish, WoW Principal Investigator, Assistant Professor at the University of Victoria
9. Stephanie Nixon, WoW Principal Investigator, Associate Professor at the University of Toronto
10. Marni Amirault, WoW Knowledge User, CAAN/AHA Centre
11. Tracey Prentice, WoW Co-Investigator, Postdoctoral Fellow at the University of Victoria
12. Renée Masching, Iroquois Nation, WoW Principal Investigator, CAAN/AHA Centre

Abstract

There is a growing literature on land-based approaches to wellness in general, but little research investigating land-based strategies for improving the health of Indigenous people living with HIV and AIDS (IPHAs). The Weaving our Wisdoms Study, a community-based research project, organized a five-day land-based gathering to learn about and contribute to emerging ideas about land-based wellness for IPHAs. Attendees included 15 IPHA participants living in British Columbia and Saskatchewan and the WoW team which included five HIV Olders and eight community and university-based researchers. The Gathering began with a pipe ceremony at a team member's family home on Mosomin Reserve, where we were invited to take part in cultural activities including a sweat, picking medicines, animal therapy, and a traditional feast. Wisdoms from participants based on their living experience with HIV about the significance of a land-based approach to wellness, the role of peer and intercultural support, and the influence of sex and gender, were offered during sharing circles at Wanuskewin Heritage Site and conversational interviews at our hotel in Saskatoon, Saskatchewan. This commentary presents

reflections from the WoW team and participants about their experiences at the Gathering and situates them within broader themes in Indigenous health and decolonizing literature.

Acknowledgements

This commentary began with the vision of three Indigenous HIV Olders, Indigenous people living with HIV and AIDS (IPHAs) who have lived long term with HIV and are considered knowledge holders who have both the wisdom and experience to support HIV wellness for other IPHAs¹. Together with the Canadian Aboriginal AIDS Network (CAAN), they initiated and continue to guide this journey to support the ‘rising up’ of the Indigenous HIV community. From this work, new and emerging HIV Olders have joined in sharing their wisdoms and teachings. We also acknowledge those who have departed, and all our relations.

The Weaving our Wisdoms (WoW) research team acknowledges the support of CAAN, financial support from the Canadian Institutes of Health Research (CIHR) (FRN 156942) and the Waakebiness-Bryce Institute for Indigenous Health (2016-002-B). This project has received ethics approval from the University of Victoria and the University of Toronto. All participants at the WoW Gathering provided their free and informed consent and gave permission to share their words.

We wish to extend our gratitude to Peter and Shona Gladue, Sylvia Wuttunee and the Swiftwolfe family, and our/their four-legged friends for opening their home to the entire WoW team and leading our group in both opening and closing ceremonies and preparations for the Traditional Feast. We extend our thanks also to their extended family who helped with the sweat and shared our meal.

We wish to express our gratitude to the staff at Wanuskewin Heritage Centre who guided us through our nature walk, prepared the fire for our sharing circles, placed the buffalo blankets in the tipis, curated a menu of local foods, and performed many other behind-the-scenes efforts. Thank you, thank you.

An enormous thank you to all the participants who opened their hearts and minds to the project and who so generously shared their stories so that those who follow may walk a path knowing that they are supported, loved, and accepted.

¹ For a more in depth discussion of the term HIV Older, see the WoW team’s 2018 commentary in the Journal of Indigenous HIV Research, “I’m here and I’m going to do what I’m going to do”: What is an HIV Older? (Mellor et al., 2018).

Introduction

“There is an acceptance here, and everyone accepts the uniqueness of everyone – we’re all unique here, we all have lived through things...and there’s guidance here...we’re here to teach land-based things...Olders are here to teach us...we’re all in it, all learning from each other.” (WoW Participant)

The *Weaving Our Wisdoms Study (WoW): Using a Land-Based Approach to Optimize Whole-istic Health among Indigenous People Living with HIV* is exploring how connecting to the land offers important teachings for Indigenous people living with HIV (IPHAs). There is a growing literature on land-based approaches to wellness in general, but little research investigating land-based strategies for improving the health of Indigenous people living with HIV and AIDS (IPHAs). Indigenous people in Canada are disproportionately affected by HIV, yet initiatives to support their health and wellness are commonly based on Western ways of knowing. Because HIV is now a manageable condition for those with access to treatment and care (Cahill & Valadez, 2013), there is a need for culturally relevant positive action initiatives designed to support IPHAs to live longer, healthier lives (PHAC, 2014). This commentary discusses how the experiences of WoW team members and participants at a five-day land-based WoW Gathering align with the emerging ideas of HIV and land-based wellness. Throughout this article, we share the voices of both participants and research team members who co-created the experience of the Gathering. The comments in italics at the start of each sub-section reflect voices of researchers, whereas all other quotes are from participants.

Moose Meat and Sweetie the Sausage Dog

Our first day was spent connecting in so many ways. For some it was a space of remembrance – of family, cooking with Mum, being in ceremony – others, healing through the magic of horses, wandering the hills and picking medicines, and some, that healing came during the sweat. Our reflections were nourished during the traditional feast that evening. The rice and raisin soup with moose meat was a hit, the bannock and the butter with all that sugar, the Saskatoon berry mixtures, and above all, the sharing of a meal with strangers who had become friends and family. (WoW team reflection)



Figure 1: Horses getting in on the action

Redvers, in a study exploring the concept of “land as healer” in Indigenous communities, tells us, “...the term land-based is being used across the north to describe an Indigenous understanding of the world, and the inseparability of land and water from our health and wellbeing” (2016, p. 1). Being on the land contributes to physical, emotional, mental and spiritual health in a variety of ways and facilitates the re-establishment of respectful relationships with ourselves, our bodies,

ancestors, future generations, and our communities (Luig, Ballantyne, & Scott, 2011; Wilson, 2003). This is emphasized by a participant who reflected on three days of WoW Gathering activities on the land as follows:

...[connecting with Mother Nature] grounded me a lot better from having no belief system and no identity, to this is where my roots are, this is my family, this is my culture and medicine and it helped me become more positive and proud of myself and my identity.

Cumulative and ongoing impacts of colonization are felt in ways that include cultural disconnection, intergenerational trauma, and the interruption of traditional gender roles, which among other health impacts, play a role in the disproportionate incidence of HIV amongst Indigenous people in Canada (Prentice et al., 2018, p. 238). We sought to provide participants with an opportunity to engage in traditional cultural activities such as a pipe ceremony, attending a sweat, picking medicines, and learning from Elders, as one way to learn if these activities could support a part of each individual's wellness journey and counter the ripple effects colonial legacies may have in peoples' lives. A qualitative research study exploring cultural competence in health care found that IPHAs who participate in traditional practices "...seem better able to come to terms with HIV or deal with addictions and ... adhere to treatment regimes" (Barlow et al., 2008, p. 11). Ensuring that we remained focused on wellness as a personal journey, we were also cognizant that "[participating in] ...traditional ceremonies and practices is a very personal decision, varying according to family, religious, and cultural backgrounds, as well as individual experiences and beliefs" (Barlow et al., 2008, p. 11). Respecting this was important to honour the relationships between the WoW team and participants and uphold the ethical framework within which we are operating.

Braiding our Journeys

On day two we were back on our bus and off to follow the bison trail at Wanuskewin Heritage Centre. With the smell of sage and damp grasses in our noses, we started by looking across the river valley to get our bearings, before descending into the coulee at the bottom of the bluff. Here, we found ourselves standing on a mountain of living history, and as one participant remarked, "we too are living histories that have passed through cycles of life death and life again." We came back to the present moment, to a lunch of local foods, curated by the Centre's Chef. After lunch, we made our way to the tipis and sitting in circle around the fire, we received a teaching from one of our HIV Olders. She used three pieces of fabric to represent culture, HIV, and ourselves, and asked us to braid these together to reflect on how these elements interacted in our lives. Following this, we took our braids to the tipis and used them to guide our four sharing circles. (WoW team reflection)



Figure 2: View of the South Saskatchewan River from Wanuskewin Heritage Site

Reflecting on the shapes of our braids was a way to visualize the pathways that our lives have taken; like the many turns a river takes when it makes its way around rocks and debris, until it finds an even course. One participant described in a sharing circle that when he began his braid, it reminded him of braiding his sister's hair. Then when thoughts of a strand representing HIV came, it got tighter and tighter. Then finally, at the end, it became neat again.

Ensuring that the research was done in a “good way”, that is, ensuring that the research would be conducted respectfully and benefit the community as a whole while honoring tradition and spirit (AHA Centre, 2018; Flicker et al., 2015), helped to acknowledge that feelings of unease would arise at the Gathering, but that this dis-ease held knowledge and wisdom too. Luig, Ballantyne, and Scott (2011) state that being on the land “provides the right frame of mind and spirit – the sounds, sights, and smells of the land are very powerful and relaxing” (p. 17). During group discussions, many participants spoke to the ways they connect to land in their lives such as:

“...berry picking, Saskatoon bushes... there’s always something to do standing around for hours in the bush or out hunting and walk around, setting snares, laughing and talking with whoever I’m out there with. I realized it’s good for my mental health being out there – it’s so calm, everything is alive around you. It’s impossible to feel alone out there because everything is alive”.

Neale (2017) explores how understanding ways that Indigeneity “transcends” urban, rural, and remote geographies helps to deconstruct fixed identities that have been prescribed, internalized, and projected on Indigenous Peoples in Canada. One of these ways is to strengthen “...relationships, kinship networks, and community because they help to reinforce Indigenous identities” (Newhouse, 2011, p. 26). However, opportunities to reinforce relationships with the land can be more challenging in the context of wellness, and as one participant noted, “food wise, healthy living ... is to eat from the land rather than store bought. But I don’t have the opportunity to live like that.”

Embodying Spaces and Places

Our one-on-one interviews on the last day provided an opportunity to reflect on our stories and our roles as co-researchers and participants. Sharing stories is central to Indigenous research. Kovach writes, “stories remind us of who we are and of our belonging” (2009, p. 94). For all the sharing and gathering that took place, these interviews were a reminder of our oneness - both as individuals and as a collective. We were now part of each other’s stories. (WoW team reflection)



Figure 3: Tipis for sharing our stories at Wanuskewin Heritage Site

Ermine (2007, 2011) tells us that when you enter an ethical space of engagement, you leave your “shoes” outside of the circle; a symbolic act of leaving status, position, ideologies, and other constraints that work to prevent us from having a dialogue that can shape what kind of future we envision together, for our community. Creating an ethical space of engagement for the Gathering

was an important part of beginning the research in ceremony. As university-based and community-based researchers, HIV Olders, and IPHA research participants, we have privileges, oppressions, and living experiences that may or may not have been readily apparent to everyone. We recognized that stepping into a shared space of engagement required us to reflect on the “fundamental importance of relationships and relational accountability in community-based research” (De Leeuw, Cameron, & Greenwood, 2012, p. 188). The importance of Ermine’s leaving our shoes outside the door (or tipi) was reinforced with the recognition that the support from peers and guidance from HIV Olders was one of the most important elements of the Gathering, as exemplified by this participant:

I feel so much stronger... being at home there on my land, and with my own people and being safe for 10 years, it was nice, but then once I was offered this opportunity to come here... that’s when I realized ...the one thing that’s been missing is the socializing with other HIV people...

Emerging Tomorrows

One of the participants said the Gathering “...felt like coming home to something and somewhere I didn’t know was waiting for me.” This *returning to* is part of an emergent decolonial space in Indigenous research, where “...the process in research of returning to oneself is a healing journey” (Absolon, 2011, p. 93). We were brought together because of a desire to understand land-based wellness for IPHAs. What the WoW team members learned from the participants in our brief time together will fill our reflections for many years to come.

“My mind and body healed. Being surrounded by trees, grass, animals, I felt I belonged and healed in this natural state” (WoW Participant)

Bibliography

- Absolon, K. (2011). *Kaandossiwin: How we come to know*. Winnipeg: Fernwood Publishing.
- AHA Centre. (2018). *Doing Research in a Good Way*.
- Barlow, K., Loppie, C., Jackson, R., Akan, M., Maclean, L., & Reimer, G. (2008). Culturally competent service provision issues experienced by Aboriginal People living with HIV/AIDS. *Pimatisiwin*, 6(2), 155–180. <https://doi.org/10.1167/iovs.07-1072.Complement-Associated>
- De Leeuw, S., Cameron, E. S., & Greenwood, M. L. (2012). Participatory and community-based research, Indigenous geographies, and the spaces of friendship: A critical engagement. *The Canadian Geographer/Le Geographe Canadien*, 56(2).
- Ermine, W. (2007). The ethical space of engagement. *Indigenous Law Journal*, 6(1), 193–203.
- Ermine, W. (2011). *Ethical Space in Action*. McMaster University.
- Flicker, S., O'Campo, P., Monchalain, R., Thistle, J., Worthington, C., Masching, R., ... Thomas, C. (2015). Research done in “A good way”: The importance of Indigenous elder involvement in HIV community-based research. *American Journal of Public Health*, 105(6), 1149–1154. <https://doi.org/10.2105/AJPH.2014.302522>
- Kovach, M. (2009). *Indigenous Methodologies: Characteristics, Conversations and Contexts*. Toronto: University of Toronto Press.
- Luig, T., Ballantyne, E. F., & Scott, K. K. (2011). Promoting well-being through land-based pedagogy. *International Journal of Health, Wellness and Society*, 1(3), 13–26.
- Mellor, A., Webb, N., Pooyak, S., Nicholson, V., Dickie, C., Lambert, S., ... Prentice, T. (2018). “I’m here and I’m going to do what I’m going to do”: What is an HIV Older? *Journal of Indigenous HIV Research*, 9, 66–71.
- Neale, K. (2017). Feeling ‘at home’: Re-evaluating indigenous identity-making in Canadian cities. *PlatForum*, 15, 74–94.
- Newhouse, D. (2011). Urban Life: Reflections of a middle-class Indian. In C. Proulx & H. A. Howard (Eds.), *Aboriginal Peoples in Canadian Cities: Transformations and Continuities* (pp. 23–39). Waterloo: Wilfrid Laurier University Press.
- Prentice, T., Peltier, D., Benson, E., Johnson, K., Larkin, K., & Shore, K. (2018). "Good Medicine": Decolonizing HIV Policy for Indigenous Women in Canada. In S. Hindmarch, M. Orsini, & M. L. Gagnon (Eds.), *Seeing Red: HIV/AIDS and Public Policy in Canada*

(pp. 235–256). Toronto: University of Toronto Press.

Redvers, J. M. (2016). *Land-based practice for Indigenous health and wellness in Yukon, Nunavut, and the Northwest Territories*. Calgary.

Wilson, K. (2003). Therapeutic landscapes and First Nations peoples: An exploration of culture, health and place. *Health and Place*, 9(2), 83–93. [https://doi.org/10.1016/S1353-8292\(02\)00016-3](https://doi.org/10.1016/S1353-8292(02)00016-3)