Understanding Métis peoples' experiences with a life-limiting Illness in Alberta

Abstract

Access to palliative care is an urgent health priority for Indigenous peoples in Canada (Health Canada, 2019). Palliative care improves the quality of life of individuals and their families facing the challenges associated with a life-limiting illness (World Health Organization, 2002). The Métis are a distinct people with their own customs, culture, and shared past (Métis Nation of Alberta, 2021). A true picture of Métis peoples' experiences with life-limiting illnesses is largely absent in Canada. The purpose of this study is to explore together with citizens of the Métis Nation of Alberta, their experiences with a life-limiting illness. Working with key local Métis organizations and knowledge keepers, I will follow a Two-Eyed Seeing community engaged research process that is grounded in Indigenous ways of knowing and relating. Participants will be invited to talk about their experiences of living with a life-limiting illness. Particular attention will be given to community support, traditional health practices, access to palliative care services and resources, and any other elements that in their views are relevant to their experiences. This research will generate Indigenous knowledge on how Métis people care for each other during this time and will shed light on elements that are integral to Métis health and wellness when living with a life-limiting illness. Additionally, this research will highlight key issues in palliative and end-of-life care from the local Métis perspective and inform the design of initiatives for and with Métis people in Alberta.



Self-Location

I am the daughter of Velma Henderson and John Weisgerber. I am Métis on my Mothers side and Settler German on my Fathers side. My family names are Henderson, Taylor, Whitford, Monkman, and Thompson. I am a proud and grateful Citizen of the Métis Nation of Alberta. My family came to Alberta from the Red River Settlement and settled in the Smoky Lake area along the North Saskatchewan River, which is located on Treaty 6 Territory.

I acknowledge and honor all Indigenous People who have walked these lands, continue to walk these lands, and all future generations.



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Background

Although Canada is recognized as an international leader in palliative care, disparities in access to palliative care remain problematic for Indigenous people (Bourassa et al., 2018). Additionally, a true picture of Métis peoples' experiences with life-limiting illnesses is absent in Canada.



Method

I will follow a Two-Eyed Seeing Community Engaged Approach

Settings and sample: Following ethics and Métis Nation of Alberta approvals, I will invite Métis Elders and Knowledge Keepers, Métis individuals with a life-limiting illness, and Métis Albertans who have journeyed with someone with a life-limiting illness. I will aim for a sample size of 30 participants, though the final size will depend on the depth and richness of research data.

Data collection: I will engage in 1-3 conversations with each participant using the Visiting Way, an Indigenous method that offers an open-ended conversational structure to accommodate Indigenous principles of oral tradition and storytelling (Gaudet, 2019). This involves an informal discussion through which both the researcher and participant share stories relevant to the study (Bessarab & Ng'andu, 2010). Participants will be invited to talk about their experiences of living with a life-limiting illness. Particular attention will be given to community support, traditional health practices, access to palliative care services and resources, and any other elements that in their views are relevant to their experiences.

Data analysis: Data will be analyzed using an Indigenous relational approach that enables the researcher to listen to the core of each person's stories (Archibald et al., 2019). I will listen to recordings and read participants' transcripts line by line and as a whole. Moving back and forth between transcripts and the oral account will enable me to revisit the storytelling experience. Transcripts and preliminary interpretations will be shared with each participant for their review and feedback. The goal will be to generate a thoughtful rendering of participants' experiences with a life-limited illness that can inform health system practices to increase Métis health and wellness.



This research will generate Indigenous knowledge on how Métis people care for each other during this time and will shed light on elements that are integral to Métis health and wellness. Additionally, this research will highlight key issues in palliative and end-of-life care from the local Métis perspective and inform the design of initiatives for and with Métis people in Alberta. Knowledge dissemination and implementation will be developed in collaboration with the Métis Nation of Alberta, Knowledge Keepers, Elders, and the Métis community to honour Métis data and narrative sovereignty, which is Indigenous peoples' right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as their intellectual property" (First Nations Information Governance Center, 2019).

Métis people have a unique culture and history, making them distinct from First Nations and Inuit peoples. They are one of the three Indigenous peoples in Canada. Métis Albertans need access to culturally safe programs, services, and providers. It is therefore crucial to have distinctions based inquires that can inform the creation and implementation of culturally relevant programs that address the unique needs of Métis people in Alberta.

Outcomes



Equity, Diversity and Inclusion & Sex- and Gender-**Based Analysis+ Considerations**



Conclusion

For Métis people, health is more than merely the absence of disease and includes a wide range of social, spiritual, cultural, political, and economic influences (National Aboriginal Health Organization, 2008). It is therefore crucial that Métis Albertans have access to comprehensive, holistic, and culturally relevant programs that address the unique needs of Métis people in Alberta.

• Lisa Vaughn is a recipient of the 2023 Alberta SPOR Graduate Studentship in Patent-Oriented Research. Alberta SPOR Graduate Studentships in Patient-Oriented Research are jointly funded by Alberta Innovates and the Canadian Institute of Health Research. • I would like to acknowledge my PhD Supervisor, Dr. Anna Santos Salas, and each member of my Dissertation Committee. In immense gratitude for all their support.



Acknowledgments

Contact Information

• For questions about this project, please contact Lisa Vaughn at lweisger@ualberta.ca

References

- Archibald, J., Xiiem, Q. Q., Lee-Morgan, J. B.J., & De Santolo, J. (Eds.). (2019). Decolonizing research: Indigenous storywork as methodology. Zed Books.
- Bessarab, D., & Ng'andu, B. (2010). Yarning about yarning as a legitimate method of Indigenous research. International Journal of Critical Indigenous Studies, 3(1), 37-50.
- Bourassa, C., Oleson, E. & McElhaney, J. (2018). Palliative Care of Indigenous Peoples and Peoples of Different Ethnicity: The Example of Canada, Roderick MacLeod and Lieve Van den Block (Eds.) In: Textbook of Palliative Care. Springer, doi:10.1007/978-3-319-31738-0 65-1 First Nations Information Governance Center. (2021). The First Nations
 - principles of OCAP. https://fnigc.ca/ocap-training/
- Gaudet, C. (2019). Keeoukaywin: The visiting way-fostering an Indigenous research methodology. Aboriginal Policy Studies, 7(2), 47-64.
- Health Canada. (2019). Action plan on palliative care: Building on the framework on palliative care in Canada.
- Métis Nation of Alberta. (2021). Métis in Alberta: History.
 - https://albertametis.com/metis-in-alberta/history
- World Health Organization (2002). National cancer control programmes: policies and managerial guidelines (2nd ed.).

