

Lisa Vaughn - University of Alberta

Project: *Understanding Métis Peoples' Experiences with a Life-Limiting Illness in Alberta through Two-Eyed Seeing Community Engaged Research*



Background

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).

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; Health Canada, 2019). Severe health disparities such as late diagnoses, a higher burden of disease and shorter survival rates in comparison to the larger Canadian population, and the absence of culturally safe practices, have had a detrimental effect on Indigenous people with life-limiting illnesses (Schill & Caxaj, 2019; Greenwood et al., 2018; Kim, 2019). The Métis are a distinct Indigenous people with their own customs, culture, and shared past (Métis Nation of Alberta, 2021).

For Métis people, health is more than merely the absence of disease and includes a wide range of social, cultural, political, and economic influences at individual, family, community and nation levels (National Aboriginal Health Organization, 2008). Métis people need access to culturally safe services and providers. However, a true picture of Métis peoples' experiences with life-limiting illnesses is largely absent in Canada.

Purpose: The purpose of this study is to explore together with Citizens of the Métis Nation of Alberta, their experiences with a life-limiting illness. During the period of the award, I will refine this proposed doctoral research to ensure that it is culturally relevant and addresses the needs and

priorities of Métis people in Alberta. I will also continue to build relationships within the Métis community in Alberta, and undertake this doctoral study.

Guiding Frameworks: This study will be guided by an Indigenous approach that honours the hopes, visions, and wisdom of individuals and communities (Tuck, 2009). I will follow the Principles of Ethical Métis Research and the Four R's of Research, namely, respect, relevance, reciprocity, responsibility (Kirkness & Barnhardt, 2001). I will seek to leverage the traditional knowledge and strengths of Métis culture as it pertains to experiences with a life-limiting illness.

Design and methods: In my doctoral study, I will follow Two-Eyed Seeing community engaged research, an Indigenous methodology that requires the involvement of individuals and communities at every stage of the research process (Wright et al., 2019). **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 those 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; Kovach, 2010). 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. Through an iterative process of engagement with the data and participants, 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. **Knowledge mobilization:** Knowledge dissemination may include a final report on the Métis Nation of Alberta website, community presentations, and at least 2 open access publications in high impact factor health care journals.

Outcomes and Deliverables: 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).

Lisa Vaughn is a proud Citizen of the Métis Nation of Alberta. Her passion is to be grounded in and with Community. She has been a Registered Nurse for 16 years and has worked primarily in critical care and palliative care. She is a 3rd year PhD student with the Faculty of Nursing at the University of Alberta and also the Manager of Community Wellness for the Métis Nation of Alberta, She has a lovely 7 year old daughter, four cats and a dog.