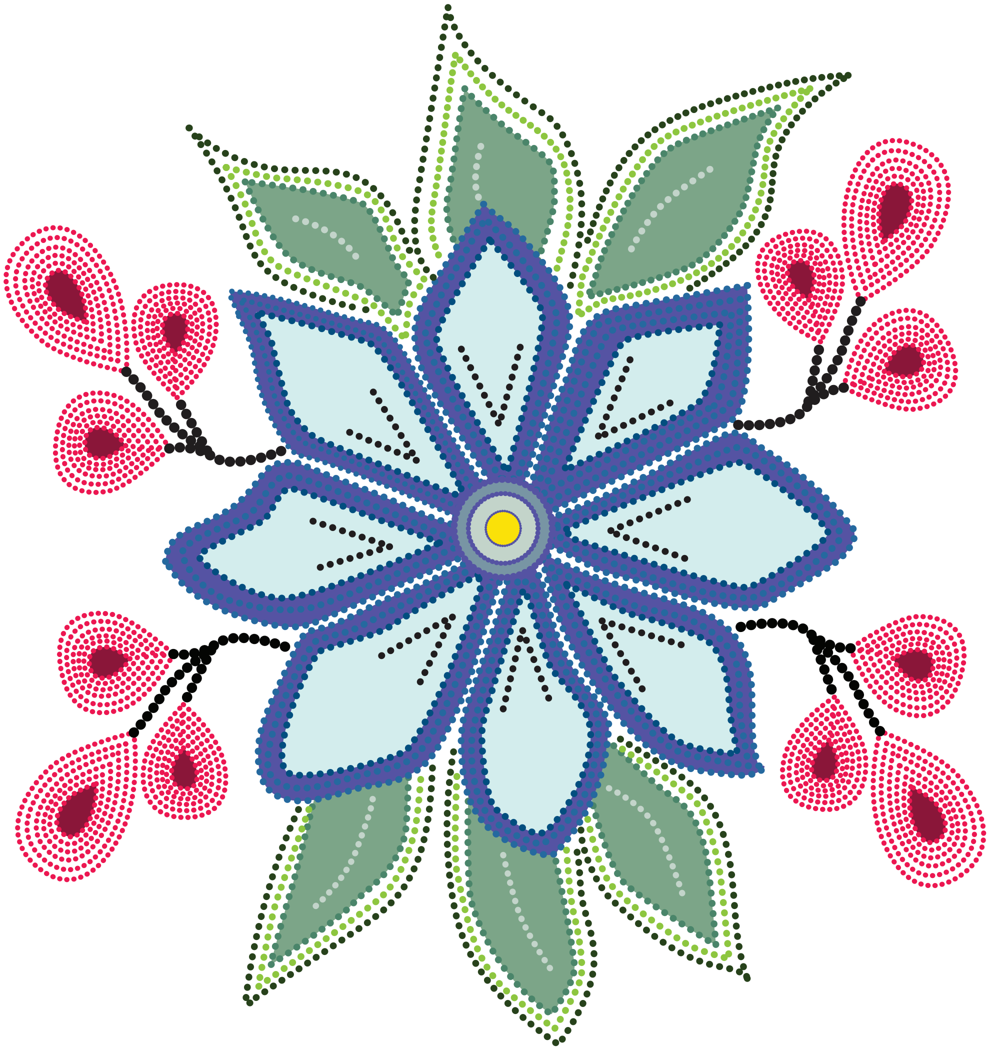
CARING FOR SELF AND KIN

A MÉTIS GBA+ PERSPECTIVE ON PALLIATIVE CARE

July 2024

WOMEN OF THE MÉTIS NATION
LES FEMMES MICHIF OTIPEMISIWAK



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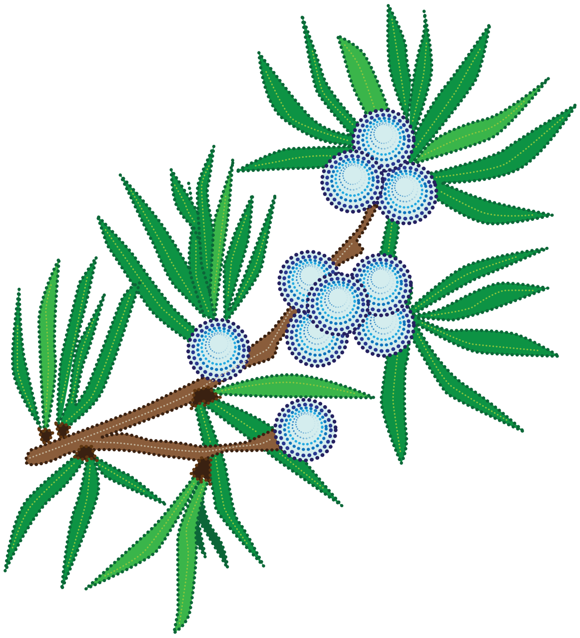
INTRODUCTION

Palliative care is an essential component of comprehensive healthcare (1). For people experiencing a life-limiting diagnosis, the goal is "to relieve the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms" (2). Métis communities have their historical knowledge and approach to illness and dying, viewing death and dying as a natural part of the life journey. Valuing relationships, Métis communities have cared for one another during the dying process. However, the impacts of colonialism on intergenerational relationships, knowledge, and health disparities have undermined the quality of life and dignity of many Métis people with a life-limiting illness (3,4). Accessing quality, community-based palliative care remains a challenge, as does navigating additional layers of intersectional discrimination (5–7).

There are many approaches for improving the palliative care landscape for Indigenous peoples, and many of these approaches have been successful in their local contexts (8,9). A comprehensive national strategy is needed to improve high-quality palliative care across Canada (10). To be equitable and effective, this strategy must include Indigenous voices - through an intersectional, distinctions-based lens (3). With support from Health Canada, Les Femmes Michif Otipemisiwak (LFMO) engaged Métis women and 2SLGBTQQIA+ Métis on their perspectives on palliative care. We approached this topic through a strengths-based lens, with the goal of advancing equitable, culturally safe palliative care for all Métis people across the homeland. The results of this engagement are detailed in this report.



METHODS

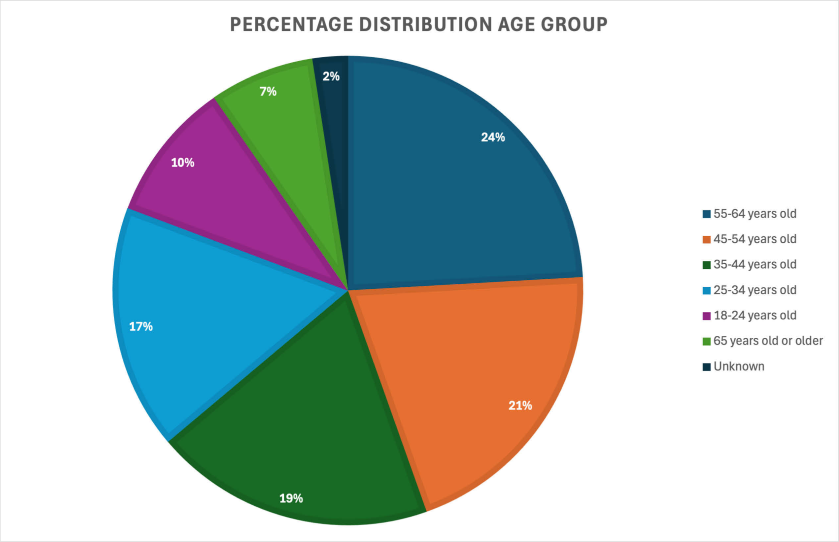
In 2023-2024, LFMO received funding from Health Canada to engage Métis women and 2SLGBTQQIA+ community members in discussions about their perspectives on palliative care. The objective of these engagements was to better understand what culturally relevant, safe, and gender-inclusive palliative care looks like from a Métis perspective. To guide this inquiry, we focused on key questions including:

- What are the main palliative care priorities for Métis communities?
- How do women and 2SLGBTQQIA+ people experience and access palliative care?
- What are the experiences of families with kin receiving palliative care?
- How do services providers support people throughout their palliative care journey?
- What does culturally relevant and safe palliative care mean to Métis women and 2SLGBTQQIA+ people, what does it include?
- What are the current gaps in the deisgn, delivery, and expericne of palliative care within Métis communities?
- What changes are needed - whether it be policies, education, resources, or other areas - to improve the palliative care experiences of Métis women and 2SLGBTQQIA+ people?

We took a qualitative approach to answering these questions guided by Métis principles of storytelling, reciprocity, and relationality (1). To establish a safe(r) setting for these sensitive conversations, LFMO hosted an in-person engagement with 83 Métis women and 2SLGBTQQIA+ people as part of a health forum focused on Métis health and wellness. This approach provided space to care for one another and created a space for participants to collectively share and build their own knowledge about palliative care to bring back to their communities.

The breakdown of participant demographics, including age, gender identity, sexual orientation, and geographic distribution, is presented in Figures 1-4 below:

Figure 1



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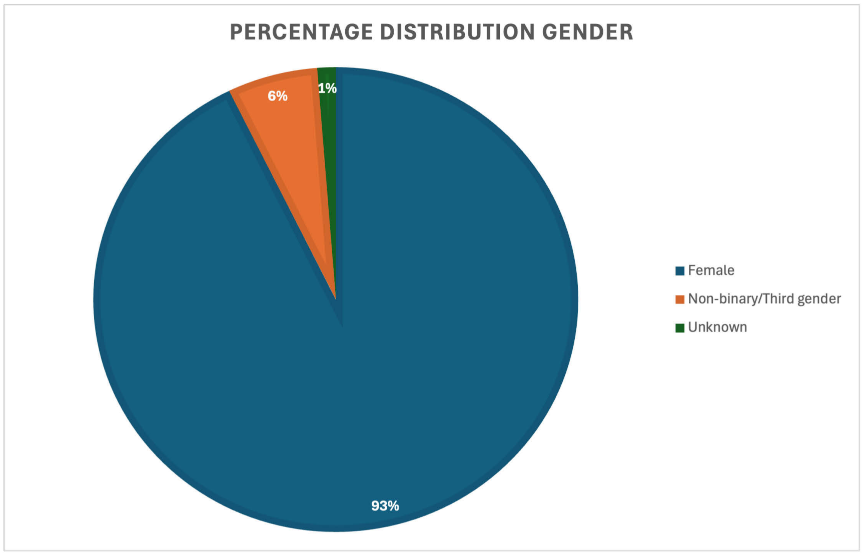

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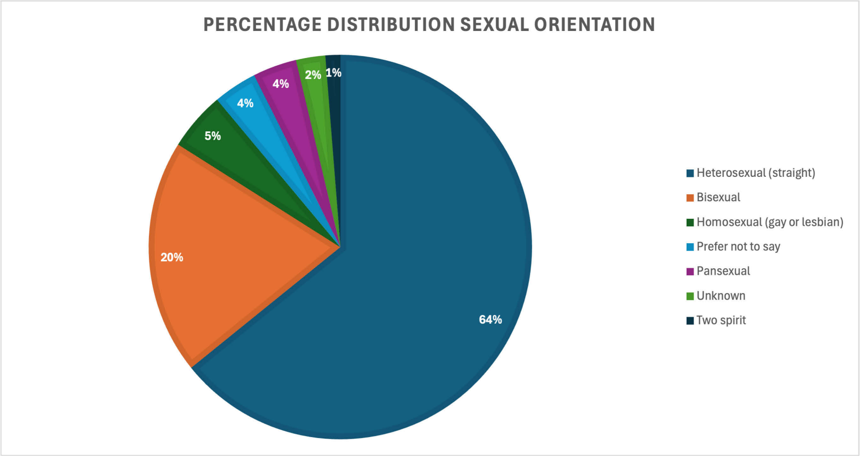
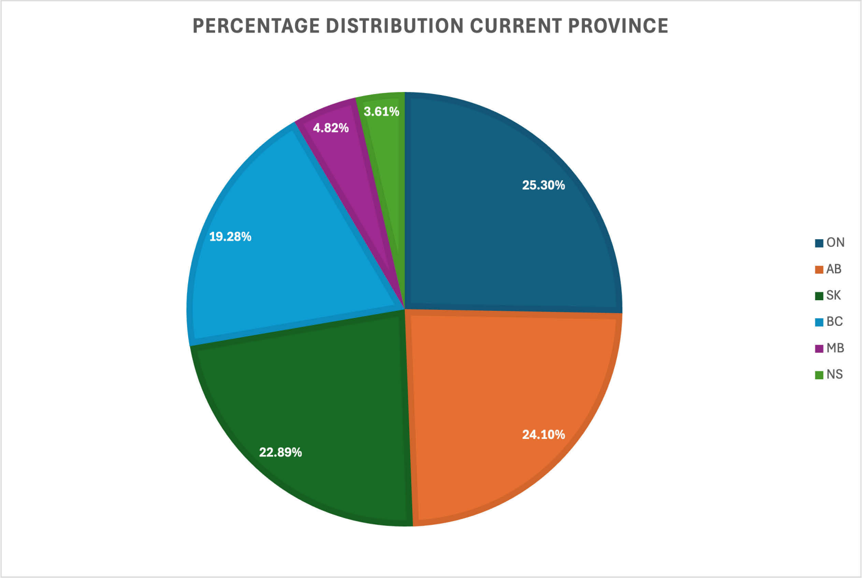


Figure 4



In the spirit of reciprocity, the palliative care engagement started with a speaker's panel that included perspectives from a Métis nurse and end-of-life doula, Indigenous patient navigator, and Métis researcher and storyteller on death and dying. This speaker series aimed to provide community members with a basic understanding of palliative care, how it functions in the healthcare system, and how Métis teachings and ceremonies can be incorporated into this model of care. Furthermore, it offered a safe space for participants to ask questions to subject matter experts. The speakers approached the topic through a two-eyed seeing framework - integrating Métis storytelling and ceremony with Western medicine.

This approach to knowledge production is integral to working with Métis communities who have historically not had equitable access to healthcare providers, which may worsen with increasing shortages of primary care providers (2–4). It was important that the community had the opportunity to gain knowledge before sharing their knowledge with us.

Following the speaker's panel, LFMO facilitated a discussion with participants grounded in the abovementioned questions. Participants were asked each question and then broke into small groups for disc Responses to the questions were then explored collectively. Participants were also provided with pens and paper to give a written response if they preferre A note taker and graphic recorder were present to capture the verbal responses. To ensure cultura safety and informed consent, an LFMO Grandmother oper the sessions with a prayer and smudge, and LFMO team members reviewed informed consent procedures before the start of the engagement.

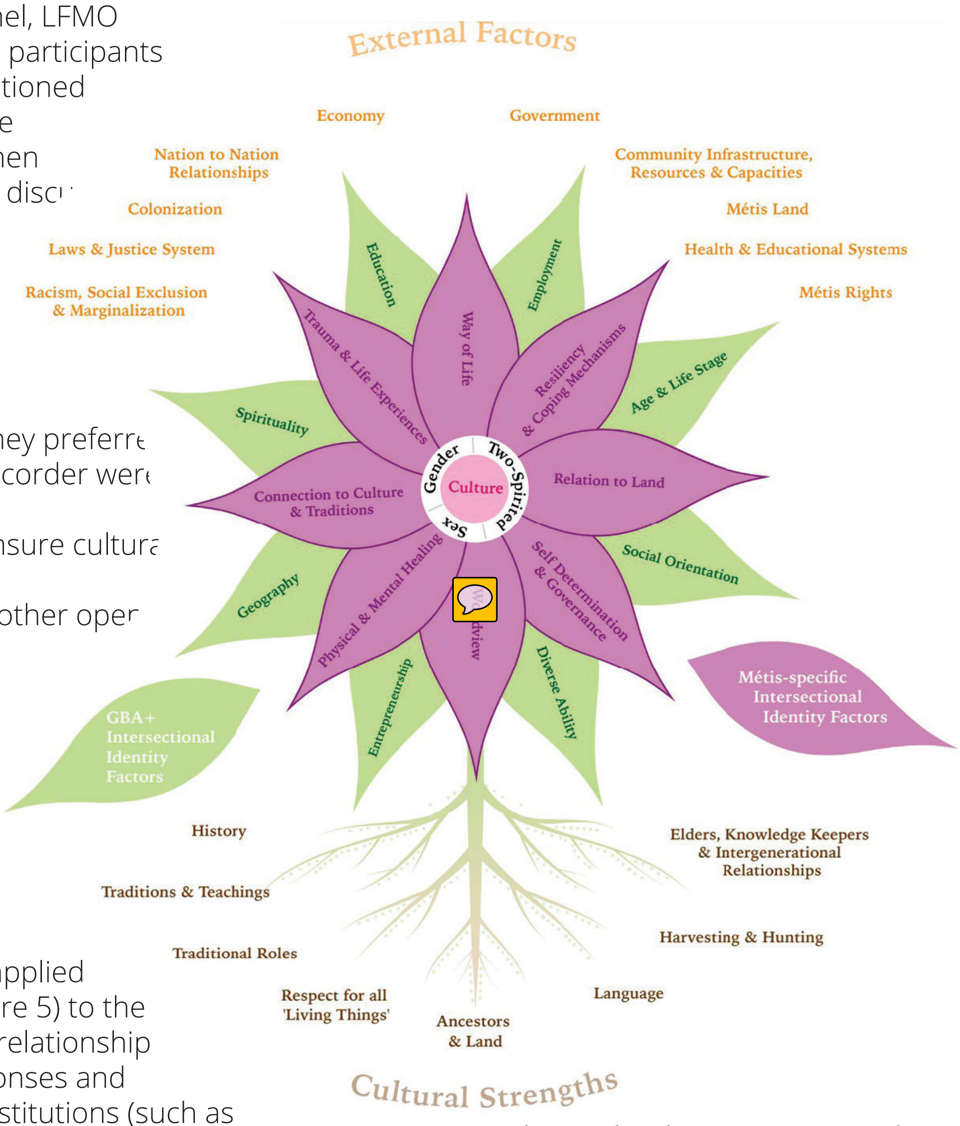


Figure 5: LFMO Gender-Based Analysis (GBA+) Framework

The results were then thematically analyzed. We applied LFMO's GBA+ analysis (Figure 5) to the themes to understand the relationship between participant's responses and Canadian structures and institutions (such as the healthcare system). The report will open in what follows with a story from the end-of-life doula, followed by a thematic analysis.

RESULTS

"COME FLY WITH ME"- JULIE HANDRAHAN

I've sat at many tables – kitchen, buffet, dinner, and now an airplane table. I ended up getting upgraded as I waited to board the aircraft. It was, I believe, an encounter I was supposed to have. It wasn't until the inflight service began and our food arrived that a conversation with my seatmate began.

We began with the usual, "Where are you from? What do you do?" It was then, when I told him I was a nurse and an end-of-life doula, that he responded with an eye-popping expression and an uncomfortable, "That must be hard work." I said it was my passion and calling, and it was so needed. He then expressed his concern about his wife's failing health due to the demands of caregiving for her 90-something-year-old mother-in-law. We must have spoken for an hour. A safe space was offered, and this gentleman genuinely opened up. It's all in the conversation, and it happened on a plane. This got me thinking, as we flew over our vast country; what if we equate palliative care/end-of-life care to a plane ride? Come fly with me.

You arrive at the airport, and the first think you do is check in. This is where we have a suspected life-limiting diagnosis. We go to the doctor with symptoms, and tests are ordered. Then, it's off to security—the area where the scans, x-rays, and maybe lab tests occur, baring yourself to strangers. Emotions and anxiety are high. Only to find ourselves at the gate, where you find out if you have a life-limiting diagnosis. Maybe your pre-boarding call is an announcement indicating that your flight is delayed and you have to wait.

Finally, the boarding call happens – amplified on the loudspeaker. As you board this flight, your anxiety grows, you put on a brave face, and you buckle in. The engines roar, and here you go down the runway. Things are a whirlwind. The speed picks up, but all the while, you feel like things are moving slowly. Wheels up, take off, and now you are on your way.

You're on your journey. You are living with a life-limiting diagnosis. Who are the people who come alongside you? Your support system? It's now time to make your table bigger. You have no choice but to create your "circle." Those who will sit at your table and offer you support. During the flight, you may experience turbulence, some turns, banking left or right, or maybe going west to go east. This is the journey of palliative care. My definition of care is that it provides emotional, social and spiritual support – realizing there will be peaks and valleys - with the aim of improving quality of life.

The captain comes on and indicates that you will begin your descent, and your destination is the end of life. The turbulence hits as you bank left and right, as services change. Where do you want to die? At home? Hospice? Or Hospital? The turbulence continues. Only to find yourself at your destination – end of life – where comfort care is implemented to provide dignity. The focus begins to turn to your family as the end of life is descending on you. We land—our last breath.

Now, what if, as part of the planning for your trip, you began this conversation while you were healthy? You planned for your end of life as you would plan for your trips. What can you ask yourself to start the conversation around your end of life? You could determine what kind of patient you are. Do you need to know everything? Coles notes version, please? Have you let your doctor know? What are your fears? Perhaps it's incontinence, loss of mobility, loss of independence or loss of dignity. What are your beliefs? What traditions/ceremonies would you like? Is the church involved? What about MAiD – Medical Assistance in Dying? What do you value? Community? Friends? Independence? Who is in your circle?

Create your end-of-life journey, as we will all check in at some point. Let's begin the conversation with ourselves, have the conversations with our family and friends and continue to have the conversation while we are healthy.

May you be seen. May you be heard. May you be respected.

RESULTS

MÉTIS WOMEN AND 2 SLGBTQQIA+ PERSPECTIVES ON PALLIATIVE CARE

For health forum participants, Métis-Specific Palliative Care is:

- Holistic, Person-Centred, and Culturally Relevant
- Culturally Safe
- Community-Centered and Land-Based
- Cares for the Carers
- Accessible and Equitable
- Includes Métis-Specific Resources

HOLISTIC, PERSON- CENTRED, AND CULTURALLY RELEVANT CARE

“Culturally relevant and safe palliative care means...the fluffiest bannock and deadliest aunties”
(Health Forum Participant, 2024)

For the Métis women and 2SLGBTQQIA+ people sharing their perspectives at the health forum, palliative care must start from a person-centred framework. This means including the person accessing palliative care as “a valued member of an interdisciplinary team”. This is accomplished, in part, by seeing:

> “The person in their entirety, not just in this moment of their illness. [Seeing] what they loved, what is important to them, and who they were throughout their lifetime.” - Health Forum Participant, 2024

Part of a person’s palliative care planning should include understanding what activities are meaningful to them and working to integrate those “final boat rides...favourite flowers, foods, and colours” into their care (Health Forum, 2024).

Some participants described person-centred care as part of their right to self-determination. This not only requires that Métis people’s knowledge, needs, desires, and voices lead their palliative care journey but that the care they access is holistic and culturally relevant. An overwhelming number of participants identified culturally relevant care as having “access to our medicines and teachings on an equal level as Western medicines.” They wanted the integration of medicines and ceremonies into palliative care, particularly into institutions such as hospitals, hospices, and long-term care centers. This included spaces to smudge, storage areas for sacred medicines, access to the land, and access to Métis knowledge carriers.

Part of providing culturally relevant care involves the “normalization [of] being asked about our cultural preferences” because Métis people practice their culture, religion, ceremony, and spirituality in varied ways" (Health Forum Participant, 2024). Participants shared that Métis people are not a monolith and have diverse and varied histories, cultural practices, and identities. While many folks wished that health providers had a broader understanding of who the Métis people are, they also wanted care providers to approach them with cultural humility to understand how they individually practiced their Métis cultural identity. This was further reiterated by Two-Spirit participants, who expressed that additional consideration needed to be made for their cultural needs as Two-Spirited Métis people (including pronouns).

CULTURAL SAFETY

Given the historical and ongoing legacy of colonialism and anti-Indigenous racism in Canada's healthcare system, cultural safety was identified as an essential component of palliative care. Participants focused on healthcare providers' education and training as a critical site for intervention.

"Educational institutions need more inclusion of cultural competency and safety training." - Health Forum Participant, 2024

They wanted institutions to ensure that healthcare providers are taught **and** assessed on cultural safety, sensitivity, and humility. Furthermore, they wanted this education to be ongoing and embedded throughout their training.

Ensuring the cultural safety of Métis people accessing palliative care also requires representation.

"[We need] more representation on institutional boards to be the voice for the people and community" - Health Forum Participant, 2024

Echoing Article 23 of UNDRIP (5), participants discussed the importance of Métis people - including Knowledge Carriers and Elders - being active members on palliative care boards, advisory groups, and policy working groups.

Article 23: Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

Participants emphasized the need for more Métis healthcare providers and allied health professionals in palliative care. Participants felt that the most effective way to address this gap is by increasing sustainable federal grants to support these educational pathways for Métis people pursuing careers in healthcare, particularly in palliative care. By providing sustainable and long-term funding, more Métis people could access the training and resources necessary to become healthcare professionals, promoting better representation within Canada's healthcare system.

Finally, they shared that the physical features of palliative care settings can undermine their sense of cultural safety. Publicly funded long-term care homes, hospice centres, and hospitals that have overtly religious imagery (i.e. statues) or follow a faith-based doctrine of care were identified as problematic by some participants. This concern is not insignificant, with 1 in 4 palliative care beds in Alberta in 2015 reportedly being maintained by Catholic organizations. While participants did not share their specific reasons for why this felt culturally unsafe, the historical connection between religious-based hospitals and colonialism is well documented (6). Then, cultural safety considerations must expand to include not only education, policies, and practices but also the physical spaces in which palliative care is practiced.

COMMUNITY- CENTRED AND LAND-BASED

“A Métis definition of health recognizes that health is holistic and is influenced and shaped by larger social structures and determinants of health, which include family and kinship ties, community, culture, and relationship to the land” (7).

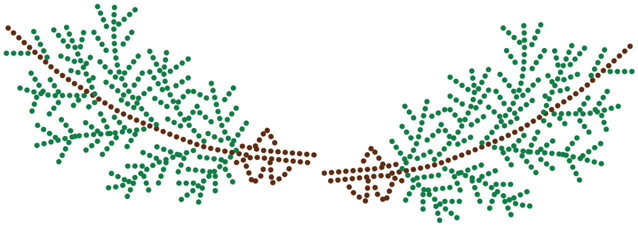
Participants echoed with the definition of health as holistic and community-centered, expressing a desire to “bring death back to the community.” They envisioned a future where Métis people could receive palliative care in the comfort of their own homes and communities, surrounded by kin. However, participants noted that achieveing this vision would require significant investment that included more in-home health care supports that are both accessible and cost-effective.

Cost was a major concern, especially due to the lack of non-insured health benefits and "the difficult-to-navigate [existing Canadian] healthcare systems." Participants higlhighted the neds for better access to serviced that alleviated the financial burden on families, making quality palliative care achievable. In addition, an overall lack of continuity of care was an issue. Many participants shared how individuals and their loved ones experienced lapses in their care or drug interactions due to the fragmented or inconsistent healthcare serviced. This highlights the urgent need for a more integrated and reliable palliative care.

Ensuring that palliative care supports are available and accessible to rural and remote Métis communities was an important priority for participants, noted that “services need to be in our communities rather than having to be removed.” Achieving this visions will require the development of flexible and adaptive care delivery models, such as creating wrap-around remote service delivery. Models needs to bring care closer to home, respecting cultural and geographic realities of Métis people, and ensuring supports are available where they are needed most. Participants also suggested a more integrated, interdisciplinary palliative care model to help keep Métis people in their community:

“Offering in-home supports from the local clinic and community stakeholders. Paired with remote access to palliative care physicians and in-home suppliers along with family collaboration”- Health Forum Participant, 2024

They felt that virtual care may be one way to support in-home, community-based care. Community-based care was also a model that honoured many Métis people’s connection to the land. Honouring this connection was viewed as a way to honour cultural safety and relevancy for people in the final stages of their lives.



CARING FOR THE CARERS

Métis culture is relational and values kinship ties. Participants wanted to see a palliative care model that understands the "love and connections we have in families." This involved including family members in the palliative care process and caring for family members. They suggested that this could take the form of having food and space for family members and more time spent including them in the palliative process (with patient consent). Additionally, it involved "funds for loved one's travel and accommodations," especially for rural and remote Métis.

Participants recognized the mental health impacts of grief and loss for caregivers and kin. They recognized caregiving is often gendered, with women performing most care work. Because of this, support for caregivers is necessary. Participants wanted to see more mental health support available throughout the palliative care process for the person, their family, and their healthcare providers. One participant shared, "hospital employees involved in the palliative care team need access to a debriefing if the worker has been affected emotionally and mentally throughout the journey." They expressed concern for the strain healthcare providers are under and wanted to ensure they are cared for, too.

ACCESSIBLE & EQUITABLE

Equity and accessibility were at the heart of many of the conversations at the health forum. Participants raised significant concerns about the impacts of intersectional discrimination and inequity for Métis families:

> "As Métis citizens, as Indigenous peoples, we utilize the healthcare system, justice system, and social systems to the nth degree. Indigenous people also bear the inequities of those structures. We must be vigilant to protect citizens from having to utilize MAiD because they cannot bear the brunt of the healthcare costs, see their loved ones or afford their medications. We must secure funding." - Health Forum Participant, 2024

The affordability of palliative care felt out of reach for many. They felt that healthcare providers did not know who they were as Métis people and often assumed they had access to non-insured health benefits. This left them struggling financially within the healthcare system to find the necessary resources.

Participants raised concerns about experiencing anti-Indigenous racism while accessing palliative care. As one person shared, "families should not have to suffer PTSD due to improper staff encounters."

Participants detailed a range of traumatic experiences within the healthcare system: discriminatory treatment and comments, invisibilization, and a lack of understanding of intergenerational trauma. This was compounded for 2SLGBTQQIA+ community members who experienced additional layers of discrimination, including a lack of respect for their identity and relationships. Many felt that palliative care needed to take a harm-reduction approach. One woman shared:

"Our great grandma was at an End of Life home and had smoked her whole life; she was told she could not smoke in the home, so she would go outside and pick up and smoke other peoples' cigarette butts." - Health Forum Participant, 2024

Participants felt this undermined a person's dignity and took away a small comfort from someone in their last stages of life. They also expressed the need for a harm reduction approach for people who were previously unhoused because "they are living shorter lives due to living harder lives." Entering into an institution after years of houselessness could present unique challenges requiring care providers' empathy.

MÉTIS-SPECIFIC RESOURCES

Having Métis-specific resources was seen as an important component of palliative care. This included "Indigenous care bundles as opposed to pamphlets with a template for an end-of-life care guide that is accessible to all." Many wanted to see community-level education and engagement that could empower them to navigate the palliative care journey for themselves and their loved ones. They wanted a proactive approach to information sharing based on human connection.

One way to accomplish this is through funding and increasing access to Indigenous Patient Navigators and End of Life Doulas. Navigators and doulas were viewed as an invaluable part of the palliative care team in the forum discussions because they could support Métis families, translate complex medical jargon into digestible information, and help patients tackle difficult end-of-life discussions:

"I am a new Death Doula...I work for a funeral home and do all the pick-ups from hospitals. I get in touch with the families and ask what the deceased enjoyed and what they would like me to do for the last drive. I have flipped off a semi, driven by a ballgame, sang a Willie Nelson song, prayed, and talked until I was blue in the face. It is so important to have that. No matter what you can do for someone, for some semblance of closure, it helps. There are little things like that you can do for a family."
- Health Forum Participant, 2024

Furthermore, they could honour the deceased and give peace to their families.

RECOMMENDATIONS

This report outlines a series of recommendations aimed at improving palliative care services for Métis people and communities. Participants from the health forum emphasized the need for culturally relevant, accessible, and community-based care that aligns with Métis culture - values and traditions. The following recommendations highlight key areas where action is needed to ensure equitable access to palliative care resources, support Métis healthcare professionals, and create culturally safe environments for Métis people and their families during end-of life care. These recommendations address exisiting gaps in servicesm enhance the quality of care, and empower Métis communities to shape their healthcare futures. They adovcate for comprehensive approach to improving palliative care for Métis people, focusing on investment in culturally relevant services, education, and community-based resources. They emphasize the need for Métis representation in healthcare decision-making, alongside the integration of community-driven solutions to ensure equitable, compassionate care. Ultimately, these initiatives aim to provide Métis families with accessible, dignified, and culturally appropriate support throughout end-of-life care.

Expand Investments For Palliative Care Education and Community-Based Resources

Increased support for palliative care education and initiatives for Métis people, ensuring that communities have access to essential healthcare resources likes physicians, personal support workers, and medical equipment. relavant resources and knoweldge to navigate end-of-life care.

Call for investments in Home-Based Palliative Care and Community-Based Hospice Centres

Expands investments for home-based palliative care servives and the establishment of community-based hospice centres (e.g., Elder's Lodges) to provide Métis people and families with culturally relevant and local care.

Develop a program to provide essential health benefits for Métis people

Supports the establishment of comprehensive health benefits for Métis people, including funding for culturally relevant end-of-life planning resources, such as Métis-specific documentds for end-of-life planning and wills.

Engage Métis Communities to Develop Cultural Safety Training

Engage Métis Elders and Knoweldge Keepers to co-develop and implement cultural safety training for healthcare providers ensuring care that respects Métis culture - traditions and values.

Integrate a Harm Reduction Approaches into Palliative Care Models

Integrate harm reduction strategies into national and provincial palliative care policies and practices to ensure care that is safe, compassionate, and equitable for Métis people.

Increase Métis Representation in Healthcare Decision-Making Bodies

Equitable Métis representation in decision-making panels, advisory groups, and boards to ensure that Métis perspectives are included in healthcare policy and palliative care planning.

Sustainable Investments for Métis Individuals Pursuing Healthcare Education

Long-term funding provide in terms of grants and scholarships for Métis people pursuing healthcare education, particularly in palliative care, and create funding for Métis end-of-life doula training programs.

Develop a Centralized Database and Expand Investment of Indigenous Patient Navigators

Invest in the development and maintenance of a centralized palliative care database for Métis people with easily accessible resources and education aimed at improving visibility and availability of services across communities.

Expansion of Indigenous Patient Navigators to provide culturally relevant guidance for Métis through the palliative care system, ensuring safe and competent support at every stage of care.

CONCLUSION

In envisioning the future of palliative care, Métis people with a life-limiting illness must have equitable access to culturally safe care. It must approach palliative care through a two-eyed seeing lens that seamlessly integrates Métis medicines, ceremonies, and teachings with evidence-based medicine. Culturally safe care requires continuous cultural competency and safety training for healthcare providers to mitigate the effects of colonialism and racism. Representation of Métis people in decision-making roles within healthcare institutions ensures that policies and practices reflect their community's needs.

Community-centered and land-based care is essential. Participants emphasized the importance of receiving palliative care within their communities and maintaining a connection to the land. This requires investment in in-home healthcare support and flexible service delivery models for rural and remote Métis communities. Developing and disseminating Métis-specific resources, such as end-of-life care bundles and educational materials, is crucial.

Supporting caregivers is vital. Palliative care models should extend support to family members, providing resources and mental health support. This includes financial assistance for travel and accommodations, particularly for those in remote areas. Funding and increasing access to Indigenous Patient Navigators and End of Life Doulas is a viable strategy for realizing these goals.

Accessibility and equity are fundamental. Financial support is needed to cover healthcare costs and medications, reducing the economic burden on Métis families. A harm reduction approach respects the dignity and choices of individuals in palliative care, acknowledging their life experiences.

The recommendations in this report call for increased funding and support for community-based, culturally relevant palliative care programs. Enhancing home-based care, ensuring equitable access to resources, and embedding harm reduction frameworks are essential. Engaging Métis communities, Elders, and Knowledge Carriers in program development and providing representation in decision-making processes will create a palliative care system that honours the unique needs and identities of Métis people.

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