



**First Nations, Inuit and Métis and Palliative Care:
Working Together to Identify Opportunities**

July 28th, 2021

MEETING SUMMARY

*There has been lots of attention around prevention, screening, and treatment for cancer, which is great, **but we're dying of cancer**, and there hasn't been a lot of attention around palliative care or that end journey.*

- **Holly Prince**, Project Manager and Co-Investigator, Centre for Education and Research on Aging & Health at Lakehead University

Background

Priority 5, Action 2 of the Canadian Strategy for Cancer Control (CSCC) is a call to address the limited and unequal access to palliative and end-of-life care across Canada. In support of this, funds have been allocated to address the specific needs and priorities of First Nations, Inuit and Métis relative to palliative care.

To better understand where these funds will have the greatest impact; the role of the Partnership in this space; and alignment with the three, People-specific priorities of the CSCC; and the People-specific cancer plans under development in each province and territory, the Partnership convened a group of First Nations, Inuit and Métis Elders, Knowledge Carriers¹, community health professionals, and researchers, all with experience and knowledge of palliative care, in July 2021.

The objectives of the meeting were:

- Identify priorities and needs of First Nations, Inuit and Métis caring for family or community members who require palliative care
- Identify promising or best practices in palliative care specific to First Nations, Inuit and Métis
- Discuss opportunities for the Partnership to support the self-determined palliative care priorities of First Nations, Inuit and Métis

This report summarizes the themes and priorities which emerged from the discussion, along with paraphrased stories, recommendations, and examples shared by participants.

Of note, while the Partnership takes a distinctions-based, People-specific approach, and endeavors to include representation from First Nations, Inuit and Métis in all the work we do, most participants in this meeting identified as First Nation or represented a First Nations organization. The need for Métis and Inuit representation was identified as a next step.

We gratefully acknowledge the time and contributions of each participant.

¹ The individuals have identified “Knowledge Carrier” as preferable to “Knowledge Keeper”, in reflection of their desire to share, rather than keep, knowledge.

Theme: Continuity of Care

Priority: Address jurisdictional challenges and improve discharge planning and care coordination to ensure patients are seamlessly supported

Recently, I was contacted directly about an Indigenous patient who was being transferred home and asked if I could coordinate the care for this patient. In our region, there are specific Indigenous palliative care services, but the local referral forms don't include our program, so it's sometimes difficult to identify patients who require support.

The patient was transferred on a Friday, with no care or medication supports. As soon as we learned of this on Monday, our team quickly mobilized, and the family assured us they could manage the patient's needs until the following day when the nursing services could start. Travelling to the patient's home the next day, we learned that the patient had rapidly deteriorate over the past twenty-four hours, and their family was now distraught, unequipped to address the situation.

In the home, we assessed the patient, identifying that they hadn't urinated, perhaps for several days. Fortunately, the nurse had a catheter in the car, and a neighbor had lorazepam. The patient had arrived without support or a clear referral, we hadn't known the equipment or medications we would need, and even in this relatively urban area, a prescription would take at least four hours to arrive.

As we worked to address the patient's symptoms, we learned from the family that it was important to the patient that as they were leaving this earth, that they have proper words spoken for them, and ceremony. Unfortunately, I don't speak my language, but an Indigenous colleague who does reassured me over the phone that whatever words I knew, I should give them to the patient, the Creator would understand.

Not having a hospital bed, we lay the patient on the floor, and I lay down beside him. I remembered a hymn, Fishers of Men, that I had learned in the Oneida language as a child. Hearing this, the patient immediately began to settle. His spouse laid by his side, and shortly after he passed.

- **Dr. Amy Montour, Palliative Care Physician**

This experience illustrates both the strengths of Indigenous peoples relative to palliative care, and the gaps and challenges patients, families and care providers may face while accessing or delivering care. It speaks to the need for improved discharge planning and care coordination, particularly between jurisdictions.

Many participants highlighted the need for improved discharge planning and care coordination specific to the jurisdictional challenges faced by First Nations, Inuit, and Métis. These challenges include disputes between provincial, territorial, and federal governments over who pays for services and prescriptions, particularly in the case of status First Nations or registered Inuit; and the inability to seamlessly transfer relevant medical information from the referring health professional to health professionals in the patient's community.

Nobody is really claiming ownership for health service delivery for Indigenous peoples, especially when it comes to end of life. In the work that I have done, we've worked with hospitals, cancer centres, and communities, and nobody really know what happens outside their own context. Physicians prescribe medications that aren't covered by Non-Insured Health Benefits – I tell community members to make friends with the pharmacist, because they seem to know everything about coverage.

- **Holly Prince, Project Manager and Co-Investigator, Centre for Education and Research on Aging & Health at Lakehead University**

We experience many of the same challenges in Manitoba around discharge planning, it's never seamless, and it can be tough when people are sent to different hospitals.

- **Bonnie Fisk, Home and Community Care Coordinator, West Region Treaty 2 & 4**

Combined with these challenges, geography can further complicate access to care. In rural or remote communities, services may be hours away by car, or in some cases, only accessible by plane or boat. Communities located across multiple jurisdictions, such as Akwesasne, which straddles Ontario and Quebec along the St. Lawrence River, extending into New York State, face additional challenges when trying to access palliative care services.

My friend up north, she was the primary caregiver for her father, he wanted to die at home, which is two and a half hours from the closest hospital. She was unpaid, caring for her father, changing bandages and all of that, until the point of death. Sadly, he passed on a weekend, and they needed to move the body back to town for burial, but there was no driver available.

This is what people don't realize, in a rural, reserve, or remote context, those staff may not be accessible. My friend was going to transport her father's body in the back of her car. I mean, who has to do that in Canada, take their parent to the funeral home in the back of their car?

Fortunately, the driver became available, and a hearse was sent, but it could have happened, and it probably does happen.

- **Elder Albert McLeod**

Several participants provided examples of local solutions to gaps in discharge planning. In Ontario, Mamaweswen, The North Shore Tribal Council has worked with their member communities to identify gaps and design solutions.

We've started to identify where the ball gets dropped. In the hospitals it was the discharge planning, the connection back to communities. We developed a system navigator role, there are now two nurses supporting discharge planning from the six hospitals in our region. They are stretched thin, but it makes a difference in terms of building a connection between the hospitals and communities.

- **Edith Mercieca, Director of Community Support Services, Mamaweswen, The North Shore Tribal Council**

Participants also discussed the need for improved understanding of the realities of Indigenous communities, or the services available when a First Nations, Inuit, or Métis patient is

discharged². Without this awareness, the discharging care provider or organization might assume services or supports are available when they are not.

Jurisdictional barriers also exist in terms of program funding for First Nations, Inuit, and Métis palliative care.

The federal government says no, that's a provincial or territorial problem, and the provinces and territories say, no that's the federal government's problem, and then it takes years and years for anything to happen, and when there is funding it's often specific to a program, and you have to submit proposals and there's always a competition for money.

I don't believe it's our way to be put in competition with each other. If there isn't sustainable funding for programs, all we have is short-term things and we're always trying to get enough money to make sure we can continue.

- **Dr. Amy Montour, Palliative Care Physician**

The jurisdictional challenges faced by First Nations, Inuit, and Métis attempting to access palliative care cannot be understood outside colonial policies and practices, both past and present, and ongoing systemic, entrenched racism against Indigenous peoples³.

² As a partner in the *Continuity of Care Initiative*, funded by the Partnership, Eastern Health and their partners identified discharge planning as a concern among cancer patients being discharged home to Labrador from cancer care in St. John's. The team developed [community and clinic profiles](#), which can be accessed by healthcare providers to guide discharge planning.

³ Allan, B. & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada*. Toronto, ON: the Wellesley Institute.

Theme: Never forget the past

Priority: Improve healthcare providers knowledge and understanding of First Nations, Inuit and Métis histories and current realities, including strengths, challenges, and opportunities

I had the privilege of walking alongside an elderly couple for the last few years. The husband passed, and the wife was hospitalized several times after his death. The last hospitalization occurred on the same day it was announced that 215 children's bodies had been found on the grounds of the former residential school in Kamloops.

My patient was a residential school survivor, and while the news was not shocking to her because she knew there were children who hadn't come home, her family was very upset. My patient had experienced trauma in residential school, and within the healthcare system, so the news caused the family a great disturbance. COVID rules meant the family couldn't go into the hospital with the patient, and they were very worried.

There was no understanding from the hospital, no support or recognition of the circumstances we were dealing with as a community.

- **Dr. Amy Montour, Palliative Care Physician**

Racism and colonization are deeply intertwined, and together profoundly impact the health experiences and outcomes of First Nations, Inuit, and Métis. Racism exists in several, often intersecting forms, including negative and stereotypic attitudes about 'racialized' groups, the dominance of western knowledge systems, overt aggression and more subtle discriminatory behaviors, as well as structural inequities and social exclusion.⁴

In addition to the jurisdictional challenges discussed above, which are often rooted in colonial policies and laws, participants identified a lack of cultural competency among healthcare providers as contributing factor to inadequate and inappropriate palliative care experiences for First Nations, Inuit and Métis. Participants highlighted the need for cultural competency training within hospitals and more broadly, for all providers delivering palliative care. This training would support providers to understand their own biases, beliefs, and practices, in addition to educating providers about the colonial practices and policies that continue to impact First Nations, Inuit and Métis.

It's very important we address cultural competency in hospitals not just for those who are dying, but others who are admitted for other health issues.

- **Elder Rosella Kinoshameg**

Several participants commented on the indirect impacts of colonization and racism on palliative care delivery.

⁴ Reading, C. (2013). Understanding Racism. Prince George, BC: National Collaborating Centre for Aboriginal Health.

Many communities can't dedicate health or social resources and capacity to palliative care. Traumatic death and loss or suicide epidemics sometimes overshadow expected death and dying.

- **Holly Prince, Project Manager and Co-Investigator, Lakehead University**

Mainstream society has this romantic notion of Indigenous communities, that we all take care of each other, and everyone is cared for. But the reality is, sadly, many people are alone, due to family breakdowns or other reasons. In those situations, it's not realistic to expect the family members to step in and provide care.

- **Edith Mercieca, Director of Community Support Services, Mamaweswen, The North Shore Tribal Council**

Physical spaces can also be a source of discomfort or trauma and can serve to reinforce colonial or non-Indigenous narratives around what is appropriate during the palliative process.

The nearest hospital, forty-five minutes away, just has one palliative care room. A very small room, furnished in the 1970s or 80s. When somebody is going to die it's normal for the room to be filled with 20 people, being there to support the family and the person that's leaving.

The other hospital is an hour and fifteen away, that's the other choice people have. It isn't culturally appropriate, it's very westernized, clinical, and it's often uncomfortable for our members.

- **Erica Williams, Health Director, Gitwangak First Nation**

Despite the past and current challenges created by colonial policies and practices, racism and discrimination, many participants saw opportunities to collaborate with non-Indigenous organizations to develop and deliver improved palliative care for First Nations, Inuit, and Métis.

Theme: Amplifying Strengths, Education and Capacity

Priority: Amplify the strengths of communities through Indigenous led education and capacity building to enable palliative care delivery in communities

Throughout the meeting, participants shared the strengths of their communities relative to palliative care, and ways in which collaboration with the Partnership and other non-Indigenous organizations could amplify these strengths, resulting in improved palliative care for First Nations, Inuit and Métis.

We identified that even when there was a referral for home care from the hospital, in some of our communities there wasn't a provider able to deliver those services. We've worked closely with the Local Health Integration Network (LHIN) in our area to coordinate delivery of services, but we've often been disappointed.

To address this, we have worked to receive designation as a service provider organization within our LHIN. It took a number of years to demonstrate our passion and commitment to take on that next level of care, but it will support a smooth transition from hospital to home.

- Edith Mercieca, Director of Community Support Services, Mamaweswen, The North Shore Tribal Council

We've built strength into our home and community care program by having monthly 'palliative care practice' meetings with the home and community care nurses, and myself. we go over the home and community care clients, review early indicators of decline – really that early identification piece, keeping track of changes in our clients. When we identify changes, we can pull in family, loved ones, community, whoever that caring circle is, and plan a palliative approach to care.

The other thing I see as a strength is how the nurses build capacity and caregiver confidence within families. If a client is receiving palliative care in the home, we provide the family or caregivers with lots of information on how to deliver that next level of care. We spend a lot of time talking about the medications and what to expect, and we make sure our clients have access to relevant reading material that is necessary to their care plan. Our team prioritizes care giver education, we invest time teaching and supporting our families and care givers with training on how to care for their loved one.

Another strength is that our agency offers major flexibility for our schedule, so we are available afterhours or on weekends. Caregivers have the confidence to reach out to us, even in the night, if something comes up. We talk about what is going on and troubleshoot from there. It helps community members stay home, they don't have to go to hospital, and it provides that sense of calm for everybody.

When we debrief as a nursing team, when we discuss what went well, what didn't, what always went well was that we were available.

- Laura McCormick, Palliative Care Lead, Fort Frances Tribal Health

The value and importance of Indigenous-led education and capacity building among community members was emphasized.

One of the things I think we do really well in the education we deliver is, number one, it's Indigenous led. It's led by Elders; these are not my teachings – these are teachings given to me by many different Elders from many different Nations. We train Indigenous health and social workers to be education facilitators. We always support local artists, crafters, Elders, we take a community capacity development approach.

One of the other things we've been really successful with is having a really strong community engagement strategy. We learn from communities what their cultural values are, what language do they use or not use. In some communities it's not appropriate to use the words death, dying or palliative, so we've delivered training without using those words.

We also recognize that the training we're providing comes from a western perspective, that we're giving people the tools and language to interact with the westernized healthcare system, hospitals, cancer centres they're able to communicate across those jurisdictions. Having an Elder or Knowledge Carrier from the community and engaging with the community to understand their values and beliefs keeps the training grounded. Our training is really just the beginning, from it communities can start to develop their own local programs.

- **Holly Prince, Project Manager and Co-Investigator, Lakehead University**

The idea of a death doula comes to mind – maybe it's not the right terminology, but I think in many communities there are people who function as death doulas, unofficially or voluntarily. They're the go-to when someone is quite ill at home or in the community, they have that particular expertise.

- **Elder Albert McLeod**

We do have a death doula training program provided by First Nations Health Authority, here in British Columbia. Quite a few people from our area have taken the training and it does help, especially when someone wants to die with a culturally safe environment.

Things do happen in our area with ceremony and process and people involved, that's a good strength, we still do have a lot of Elders and Knowledge Holders who practice our old ways, they're knowledgeable. Usually, it's an automatic response when somebody is in their final stages, people just naturally gather at the hospital, in the facility or wherever.

- **Erica Williams, Health Director, Gitwangak First Nation**

We looked at how we could build capacity within the community, in terms of informal caregivers, our family caregivers. We're not all nurses, and when you're trying to support someone in the night and strange things are happening – the training gives caregivers confidence, the information to do the work they need to do.

We partnered with Saint Elizabeth to develop a caregiver education and training curriculum, so we have a tool to continue to train community members who step up.

The training is not just one-off, we did the training but what has to follow is keeping the connection going. When we need the support of informal caregivers, we need a system to reach out to them, they won't just 'show up', there's work to do around coordination and determining where these caregivers fit in.

- **Edith Mercieca, Director of Community Support Services, Mamaweswen, The North Shore Tribal Council**

Others spoke to the importance of collaboration with non-Indigenous palliative care services, to augment what communities can provide.

A lot of care actually falls on family or community members and not registered staff, or it's just a couple hours a day where you have access to formal care. One of the things our team has been able to leverage is the hospice system and their 24-hour call system. Nurses, patients and families in the community can call 24 hours a day and get an expert nurse clinician.

If somebody is very short of breath, the family is panicking, you need somebody to walk through what needs to be done, because even if you have the tools in the house you may not know how to use them – and in that moment it doesn't do any good that I make one visit per week.

- **Dr. Amy Montour, Palliative Care Physician**

The word grief came up throughout the meeting, in reference to individual and community experiences of racism, colonialism, the discovery of unmarked graves on the grounds of former residential schools, traumatic and expected deaths, and providing end of life care for family members or loved ones while simultaneously caring for community members in your role as a healthcare provider.

We've all alluded to this, but we haven't actually said it, we have strengths, we have people who are working at maximum capacity as healthcare providers in our communities, and they're also palliating aunts, uncles, cousins and children. We need to think about the spiritual toll that takes on staff members, working in their own communities.

We don't have resources for debriefing or supporting Indigenous caregivers. You might watch your aunt die and have to go on to the next house and next person and there's no time to think.

- **Dr. Amy Montour, Palliative Care Physician**

COVID has been the great magnifier of gaps in Indigenous communities, and what's happening around the recovery of our little people that were killed and murdered in residential schools, there's a lot of trauma that's happening right now in communities. Because of COVID we don't have the healthy networks that we would primarily rely on. We rely on these networks because of our concepts of kinship, but also because we don't have a lot of formalized services, so our community and family are of utmost importance.

COVID has hampered our ability to grieve and to mourn and to do the work we need to do in communities. Grief is becoming a big thing, I hear it from the healthcare providers

because they are the sons. Daughters, nieces and nephews of the people they are providing care for.

We have tremendous amounts of grief right now. When we're looking at educational needs and resources and how to support communities, that's definitely something I would like to see happen, not only around palliative care but just in general, around loss in communities, that grief aspect.

- **Holly Prince, Project Manager and Co-Investigator, Lakehead University**

In response to COVID-19, most hospitals have restricted visitors, even for patients in their final hours, limiting the capacity of community members to support one another and support each other in grief.

With hospitals limiting the number of visitors, usually it's just one person being allowed in to visit, it's very difficult for the other family members. It's very, very difficult, it's very different during this COVID time when we're so limited as to number of people gathering. There needs to be work done with the community, as far as addressing that grief.

- **Elder Rosella Kinoshameg**

Next Steps

The Partnership is committed to working with First Nations, Inuit and Métis to support the implementation of People-specific, self-determined priorities relevant to cancer care. As such, we are grateful to all the participants for sharing their time, stories, experiences and advice with us, which will guide our work going forward.

In addition to the discussion themes and priorities shared above, there were several clear recommendations for next steps, and how the Partnership can work with partners.

CPAC could be part of highlighting pockets of good practices, because, as you probably heard on this call, all of us want to work with our non-Indigenous collaborators, but we all do eight jobs in one day. When we're called for consultation, writing proposals, or trying to do research and provide evidence our care is doing what it should, it takes away from patient and family care.

There is a role for non-Indigenous organizations to come behind us and support us and pick us up. There's a role too for non-Indigenous organizations to look at their asks from us – how can we streamline the proposal process, how can we make it easy, take away the administrative burden.

- **Dr. Amy Montour, Palliative Care Physician**

As you can see on this call, there's many different Nations doing tremendous work in resource development, program development, framework development – it would be nice for CPAC to take the lead in identifying these across the country, the one-offs that are happening that would be great to share. To collate all of these best practices, promising practices and innovative projects so that we could all share, I think that would be an amazing thing to do.

- **Holly Prince, Project Manager and Co-Investigator, Lakehead University**

In response to these recommendations, the Partnership has started to gather information regarding best and promising practices in palliative care specific to First Nations, Inuit and Métis. The Partnership is also planning a meeting for September 2021, bringing together non-Indigenous home and palliative care organizations with Indigenous health professional organizations and the Elders, Knowledge Carriers, community health professionals and researchers we met with in July. The discussion will focus on possibilities for collaboration and partnership.