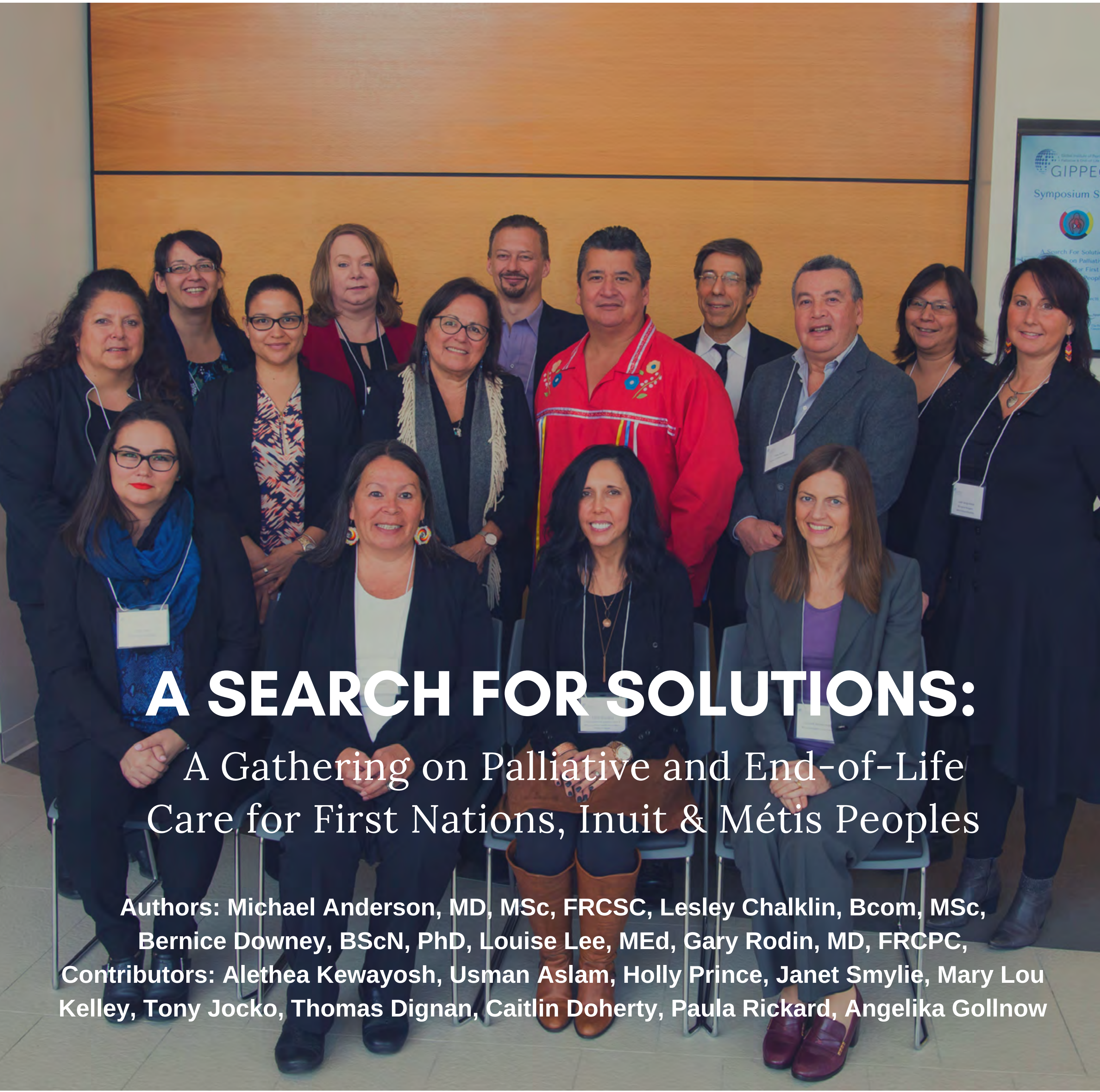
GIPPEC SYMPOSIUM REPORT

GLOBAL INSTITUTE OF PSYCHOSOCIAL, PALLIATIVE & END-OF-LIFE CARE



A SEARCH FOR SOLUTIONS:

A Gathering on Palliative and End-of-Life Care for First Nations, Inuit & Métis Peoples

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Dr. Carrie Bourassa, Chair in Northern & Indigenous Health and Senior Scientist, Health Sciences North Research Institute

10:00-10:30 Canadian Virtual Hospice's Indigenous Voices Project
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DAY TWO AGENDA

BUILDING AN ACTION PLAN FOR ONTARIO

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Dr. Bernice Downey, Regional Aboriginal Cancer Lead, Toronto Regional Cancer Program

3:35-3:45 Closing
Dr. Michael Anderson, Indigenous Surgeon, PhD Candidate (Palliative Care), Symposium Director

PLANNING COMMITTEE

A special thank you to Dr. Michael Anderson
who lead the planning of the 2016 GIPPEC symposium
and contributed to the development of this summary document.

This symposium would not have been possible without our planning committee, who played a vital part in the decision making and planning of this symposium.

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Holly Prince, End-of-Life First Nation, Lakehead University

Dr. Janet Smylie, Director, Well Living House, St. Michael's Hospital

Dr. Mary Lou Kelley, End-of-Life First Nation, Lakehead University

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EXECUTIVE SUMMARY

As the Canadian Indigenous population continues to age, there is a growing need for culturally appropriate palliative and end-of-life care. The Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC) facilitated the planning and organizing of A Search of Solutions: A Gathering on Palliative and End-of-Life Care for First Nations, Inuit and Métis Peoples held in Toronto in November of 2016. This symposium would not have been possible without the valued input and direction from the planning committee. The overarching objective was to bring together stakeholders from FNIM health care and the community to consider approaches to improve access to palliative and end-of-life care for First Nations, Inuit and Métis peoples (FNIM) in Ontario. The symposium took a broad view, addressing both the national and provincial contexts.

The following report is intended to provide a summary of the events of the symposium and highlight the emerging themes. The recommendations offered are formulated from the discussions and presentations that took place and are by no means final. Resilience of the FNIM community was identified as an important reminder when considering a way forward. Existing strengths and programs should be built upon and not forgotten.

EXECUTIVE SUMMARY

Barriers to accessing quality palliative and end-of-life care were perceived to be interconnected and stem from colonial and neo-colonial practices. Colonization and the effect of systemic racism were identified as barriers in quality health care for FNIM peoples. Health care providers and researchers need to invest time to build meaningful relationships with FNIM peoples. Education on culturally safe care would support centering FNIM patients and their families in the care journey. Additionally, the positive role of Aboriginal Patient Navigators was discussed as well as the impact that they have as advocates for FNIM needs and culturally safe care. Jurisdictional challenges are another barrier faced by the FNIM community. In the current context, there are many government players with no clear mandate, which has led to unorganized care and poor health outcomes. In this type of system, barriers in urban and rural communities exist leaving the burden to fall on FNIM communities. Many of the policy recommendations sought to address jurisdictional challenges, cultural practices, funding gaps, autonomy, and partnerships.

Recommendations from the symposium are grouped under three broad categories; research, policy, and education and practice. Recommendations are considered in the current context of reconciliation and align with the final report of the Truth and Reconciliation Commission of Canada.

BACKGROUND

Palliative care for Indigenous peoples is of international interest. In Canada, the United States, New Zealand, Australia and elsewhere, there is a growing need for culturally appropriate palliative and end-of-life services as Indigenous populations continue to age and face a high burden of chronic disease. In Canada, FNIM peoples represent the fastest growing segment of the population. Among those of Indigenous identity, the number of persons aged 65 and older will more than triple from 4.7% in 2006 to 15% in 2031 (Fruch, Monture, Prince, & Kelley, 2016).

Significant health disparities between Indigenous and non-Indigenous populations exist. Today, Indigenous people continue to be marginalized, due in large part to lasting effects of colonization (Kelley, 2010). As a result, their social power, health, and economic status are lower than that of non-Indigenous Canadians (Kelley, 2010). Furthermore, poor housing conditions, language barriers, cultural differences, and geographic isolation contribute to health inequity.

Ontario is home to Canada's largest number of FNIM peoples (Kewayosh et al., 2014). Approximately 21.5% of Canada's Indigenous population reside in Ontario, of which 21% are remote First Nation communities (approximately 90 000 people). These remote communities are isolated without regular flights or year-round road access, creating barriers to accessing health services. Many Indigenous people are forced to leave their communities to receive palliative and end-of-life care in unfamiliar settings, in a health care system that is inconsistent with their beliefs and lacks cultural competence (Kelley, 2010).

PALLIATIVE AND END-OF-LIFE CARE FOR FNIM

Cultural beliefs and practices play an influential role at the end-of-life. The optimal experience of death and dying is socially constructed and end-of-life care needs may differ between Indigenous and non-Indigenous peoples (Hampton, Baydala, Bourassa, McKay-McNabb, Placsko, Goodwill, & Boekelder, 2010). A report conducted by the Health Council of Canada found there is a lack of culturally appropriate, safe palliative and end-of-life care in Indigenous communities. There is no funding through Health Canada's First Nations and Inuit Health Branch (FNIHB) or First Nations Inuit Home and Community Care program to provide 24 hour care for patients' and families' palliative care needs (Hampton et al., 2010). Jurisdictional disagreements regarding responsibility for the provision of services have resulted in significant service gaps in communities and a lack of planning and development to make services available (Kelley, 2010).

Existing guidelines developed by non-Indigenous health practitioners do not always include culturally relevant care and there is often little understanding of traditional Indigenous beliefs and practices (Hampton et al., 2010). Many facilities do not support Indigenous cultural beliefs, values, and end-of-life practices. Practices, such as smudging (burning sacred medicinal herbs such as sweetgrass, tobacco, sage, or cedar to produce smoke for purification or healing ceremonies) and the inclusion of large, extended families, are often prohibited in hospital settings. Practice must be adapted for Indigenous people to have confidence in palliative and end-of-life services.

SYMPOSIUM SUMMARY

The Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC) is devoted to promoting and developing interdisciplinary research that addresses the medical, psychological, social, legal, ethical, cultural and religious problems related to psychosocial and palliative care of individuals with advanced and terminal disease. The planning of A Search for Solutions: A Gathering on Palliative and End-of-Life Care for First Nations, Inuit and Métis Peoples was facilitated by GIPPEC, and is tied to the Institute's aim to inform local health policy, enhance public awareness and improve access to palliative care.

A diverse planning committee made up of FNIM community representatives and leaders from organizations including the Aboriginal Cancer Control Unit through Cancer Care Ontario, Lakehead University, and the Health Canada First Nation and Inuit Health Branch informed the direction of the symposium. The majority of the voices throughout the planning and participation in the symposium were Indigenous.

SYMPOSIUM SUMMARY

The objective of the two-day symposium was to consider approaches to improve access to palliative and end-of-life care for FNIM peoples in Ontario. The symposium was organized to provide a national overview on the first day, and focus on the provincial context in the second day to produce actionable recommendations. Although insights into the national context provided a framework for a broader understanding, the consensus was to focus on concrete policy, education, research, and practice strategies in the province, where health policy and services are organized. Aims of the symposium included:

- To determine the current state (strengths and challenges) of palliative and end-of-life care for FNIM communities nationally.
- To highlight the unique challenges in urban, rural, and remote FNIM populations.
- To produce actionable recommendations for Ontario.

Symposium attendees were from a wide range of backgrounds and regions. Participants consisted of community members, knowledge keepers, researchers, clinicians, frontline health care workers, Aboriginal Patient Navigators, and a diverse mix of stakeholders (managers, health policy makers, federal and provincial government, health agency representatives). The symposium was intended to facilitate an opportunity for dialogue, understanding, and shared learning. See appendix A for the complete delegate listing.

SYMPOSIUM SUMMARY

3. Cultural safety:

When navigating the healthcare system, Indigenous clients often feel the impact of colonization, neo-colonialism, stigmatization, and systematic racism that are pervasive within institutions and can inform health care providers' attitudes. There is a need to define and educate on “cultural safety” for inclusion in health care provider practice to support cultural competency. The National Aboriginal Health Organization (2008) defines cultural competency as the health care provider’s ability to deliver care in a manner which the patient regards as safe. Cultural competency involves the health care provider’s awareness of the historical and current contexts for Indigenous patients and their ability to “adapt the way care is provided to more effectively meet their patients’ distinct needs” (Health Council of Canada, 2012: 5). This allows for safe and respectful interactions between health care providers and Indigenous patients (Health Council of Canada, 2012). A central tenet of cultural safety is that the patient defines what “safe service” means to them. Cultural safety was identified in presentations and discussion throughout the symposium.

4. Funding:

Funding challenges severely limit the extent of quality end-of-life care that can be enjoyed by FNIM peoples. The First Nations and Inuit Health Branch’s (FNIHB) Home and Community Care plan does not “fund palliative care as an essential part of home or community care.” Due to limited supports, communities are “piecing together” care to ease this journey for their people. Informal caregivers play an enormous role in providing palliative and end-of-life services in home communities. However, as more people leave communities for economic and other opportunities this informal resource will be less available.

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1.2 CULTURALLY COMPETENT AND CULRTURALLY SAFE CARE

The lack of culturally competent and safe care for FNIM communities is of great concern. Holly Prince, Project Manager and a Co-Investigator presented on the five-year CIHR grant funded project: “Improving end-of-life care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development.” The focus of this project was on developing palliative care programs and teams within four participating First Nation communities to provide opportunities to receive end-of-life care in the home surrounded by family, friends, loved ones, community, and culture.

The following keys to success for implementing culturally safe palliative care programs were identified:

1. Utilizing a bottom-up capacity building approach to developing programs and services
2. Acknowledging that dying is not only a medical event, but also a social event that happens in family and the community
3. Being whole community-focused (informal and formal systems, getting the “right” people involved, and assessing and strengthening community readiness
4. Educating front line providers and the community
5. Working together/teamwork
6. Local leadership and control
7. Developing an internal catalyst for change (change agent)
8. Moving through the phases of the model (incremental progress, non-linear, flexible)
9. Strong partnerships with external resources and supports as requested

For further information on this work and other resources discussed at the symposium see Appendix C.

SYMPOSIUM SUMMARY

1.3 URBAN AND RURAL CHALLENGES

A panel discussion, moderated by Dr. Camilla Zimmermann, Head of Palliative Care at University Health Network, examined the differences in challenges between rural and urban communities and Indigenous and westernized models of care.
Dr. Bernice Downey, Regional Aboriginal Cancer Lead, Toronto Regional Cancer Program, spoke to urban challenges. The following physical and structural challenges were identified:

- Systemic racism
- Lack of cultural safety and cultural competency training for health care providers.
- Toronto's significant Indigenous homeless population, which is not likely to receive any kind of Indigenous-specific support.
- Deficiencies in current surveillance data and the challenges associated with inadequate data.
- In recognition of the values of self-determination in the era of reconciliation, Dr. Downey strongly advocated for an Indigenous hospice in Toronto.

Further strategies are needed to address barriers in remote and fly-in communities (lack of resources, logistical barriers, etc.).

SYMPOSIUM SUMMARY

1.4 ONTARIO CONTEXT

Usman Aslam, Sr. Manager, Prevention & Cancer Control, Aboriginal Cancer Control Unit (ACCU), CancerCare Ontario, spoke of the successes and future plans for the ACCU.

The ACCU was created in 2000 and has developed roadmaps and programming for FNIM people across the cancer journey. The ACCU does not create pan-Indigenous programming, but reaches out to FNIM specific organizations that represent the interests of FNIM peoples in Ontario.

The Aboriginal Cancer Strategy (ACS) was developed collaboratively with FNIM organizations and provides the strategic direction for CCO initiatives. The ACCU was able to accomplish the following Aboriginal Cancer Strategy II (2010-2015) deliverables: Developing a network of 10 Aboriginal Patient Navigators to guide individuals and families through the cancer system, a pain and symptom management pathway, a mobile Interactive Symptom Assessment and Collection (mISAAC) application (proof of concept on Manitoulin Island), and a “Tools for the Journey” Palliative Care Toolkit.

SYMPOSIUM SUMMARY

1.1 OVERVIEW OF THE NATIONAL CONTEXT

Dr. Carrie Bourassa, Chair in Northern and Indigenous Health and Senior Scientist at Health Sciences North Research Institute, began with an overview of the current national context. This opening presentation was intended to provide background on challenges faced by FNIM peoples in accessing palliative and end-of-life care.

In summary four themes emerged:

1. Building on existing strengths and assets

In the process of identifying current barriers that exist in accessing quality palliative and end-of-life care, the current strengths and assets need to be recognized to ensure they are not forgotten. Improving palliative and end-of-life care will be aided by tapping into these strengths and assets. Discussions throughout the remainder of the symposium focused on identifying current strengths and programs already underway in FNIM communities. See appendix B for further information on the strengths and challenges outlined in the presentations focused on community palliative care programs.

2. Challenges experienced in remote and fly-in communities

Remote and fly-in communities have unique challenges with respect to service delivery. While dying at home is often preferred, communities frequently lack long-term care facilities, health care providers, and adequate home care resources to facilitate death in the community. Logistical barriers such as inadequate housing and lack of equipment are also commonplace. This combination of barriers has resulted in people being dislocated and dying away from family, kin and land.

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Dr. Michael Anderson, Indigenous Surgeon, PhD candidate (Palliative Care), spoke of the concepts of interrelatedness and balance that inform Indigenous worldviews. He referred to the concept of “Two-Eyed Seeing”, developed by Elders Murdena and Albert Marshall with Cape Breton University. “Two-Eyed Seeing” places value on both Western and Indigenous ways of knowing and integrating them for the benefit of all. This concept of “Two-Eyed Seeing” may enable provision of culturally safe care to FNIM peoples in any location.

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In the Aboriginal Cancer Strategy III (2015-2019), the ACCU supports the following initiatives in palliative care: continued support for Aboriginal Navigators to improve patient experience and to inform the Patient Family Advisory Committee; dissemination and enhancement of the “Tools for the Journey” educational materials for FNIM people with cancer and their families; complete implementation of Mobile ISAAC pilot (tools to support pain and symptom management); expansion of Aboriginal Health Access Centres and major First Nations, Inuit and Métis health centres; introduction of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) in a culturally appropriate and sensitive manner; work with Pallium Canada to develop and implement LEAP curriculum with FNIM groups; address the gaps in service delivery through discussions with regional, provincial and federal programs and services to improve jurisdictional coordination.

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1.5 ONTARIO ABORIGINAL PATIENT NAVIGATORS – LESSONS LEARNED IN INDIGENOUS CARE

Three Aboriginal Navigators, Joanna Vautour, Toronto Regional Cancer Program, Sherri Baker, North Eastern Ontario, and Leah Bergstrome, North Simcoe Muskoka, shared personal stories and cases from their work with Indigenous peoples. The mix of navigators provides representation from both urban and rural areas of Ontario.

From their experiences, a number of key lessons can be drawn:

- Aboriginal Patient Navigators play a key advocacy role in the patient and family journey
- Listening to the patient and family is vital.
- The importance of ceremony as medicine, as ceremony and teachings enables healing.
- The importance of building trust and relationships, which require time, even in challenging circumstances. Difficult conversations require the building of the relationship.
- The end-of-life is an auspicious opportunity for individual and intergenerational healing. Intergenerational trauma expands unless faced.
- Dignity is paramount.
- Cultural safety is integral to dignity.

Read the complete personal stories and cases discussed in Appendix D.

CONCLUSION

Speakers and participants engaged in a robust dialogue about issues relevant to palliative and end-of-life care for Indigenous peoples in Canada and Ontario. While numerous challenges exist, the speakers identified successes within communities and strategies to develop palliative and end-of-life programs. The strengths and resilience that resides in Indigenous communities should not be dismissed.

EMERGING THEMES

Over the course of the symposium, specific themes emerged from the presentations, facilitated discussions and informal conversations. These themes helped shape the recommendations drawn from the symposium. Although they are presented in a problematized fashion, it should be highlighted that tremendous resilience and optimism resides in the Indigenous community. The themes presented below are by no means exhaustive but capture the flavour of the dialogue.

> “First Nations, Inuit and Métis sometimes feel invisible in the system. And if they don’t feel invisible, sometimes they are visible in a very disrespectful manner. Racism and stigma are alive and well in our system. We have systemic racism that is often not acknowledged or [is] minimized or it is put back onto the individual, saying, ‘Well, that is your perception’. No, it is a very real experience and it exists.”

2.1 COLONIZATION, SYSTEMIC RACISM, AND INTERGENERATIONAL TRAUMA

Dr. Bourassa and others highlighted the impossibility of delinking colonial and neo-colonial practices from the health inequities experienced by Indigenous people in Canada. It is the underlying cause of many of the themes discussed below.

Prior to colonialism, Indigenous peoples practiced their cultural customs, beliefs, and ways of knowing, which grounded health care practices. Colonialism intentionally disrupted these practices. The continued dispossession and expulsion of Indigenous peoples from their lands by European settlers, residential schools, and government policies all created intergenerational trauma that is still felt today. The Indian Act made “Indians” wards of the state. The paternalistic nature of this relationship was reflected in the incursions on land that was agreed to belong to Indigenous peoples.

The residential school system, created by the Canadian government, was in existence from 1831 until 1996. This system removed over 100,000 children from their families and disrupted the transmission of cultural and traditional values. These schools played a fundamental role in severing ties between children and their parents, communities, language, and traditional knowledge. Further, the unimaginable cruelty, violence, and sexual assaults perpetrated in these institutions have had psychological and physical consequences. Today, institutional racism continues in Canada, which is reflected in health inequities and poor health care services for Indigenous peoples.

2.2 BUILDING MEANINGFUL AND LONG-LASTING RELATIONSHIPS

Building authentic (equal power and understanding) and meaningful relationships was a central theme that emerged. Relationship building was considered in many combinations:

1. Health care provider and patient relationships, and the role of health care institutions

Health professionals (i.e. physicians, nurses) and health care institutions (i.e. hospitals, hospices) should be aware of erecting unnecessary barriers for FNIM peoples seeking comfort in their final days. Such barriers include failing to allow space for death to be a spiritual and communal activity. Institutions often restrict the number of people allowed in patient rooms or do not provide space for the family. Participants also spoke of the importance of smudging. Currently, a consistent policy does not exist across health care institutions. Barriers discourage spiritual practices and exacerbate structural violence against FNIM peoples.

Structural violence is defined as a combination of factors, such as racism and poverty, which limit "life choices" (263) for marginalized people (Farmer, 1996).

2. Researcher and Government relationships with FNIM peoples

Researchers and government officials must engage with FNIM peoples in a meaningful way. Indigenous participants stressed feeling like a “check box” on a long list of deliverables, which does not constitute meaningful engagement. Participants acknowledged that early engagement is essential, but input and collaboration should be ongoing. If it is not feasible for continuous travel to communities, other methods should be utilized to ensure lines of communication remain open. Best practices to develop authentic Indigenous partnerships include the involvement of elders throughout program development, creating Indigenous advisory committees, establishing community consultations, and integrating Indigenous ways of knowing into models of care. In all relationships that occur in accessing the continuum of care, respect should be the foundation.

2.3 RESEARCH PRACTICES AND METHODS OF DECOLONIZATION

Participants spoke of palliative care as a significantly understudied area of research. Informing palliative care policy, education, and practice is of great importance for FNIM communities. Participants reflected on the historical context that has created an environment of distrust of researchers. There is a well-documented history of exploitation (i.e. nutrition experiments), abuse, minimal or no community consultation, lack of feedback to communities and no benefits for the participants.

Finally, establishing relationships based on respect and ongoing consultations were identified as key components to good research practice. Participants favoured research methodologies that allowed a space for voices to be heard, such as participatory action research (PAR).

With the knowledge that death and dying is a community event, PAR is an effective research approach to gather relevant and usable information. Throughout the symposium, both Indigenous and non-Indigenous participants noted that it was often through story-telling and sharing real experiences that opportunities for trust, respect, and collaboration were created. The opportunities extended to gaining community buy-in for palliative care programming, supporting non-Indigenous healthcare providers to become more responsive, and bridging health gaps with the practice of cultural safety.

2.4 JURISDICTIONAL CHALLENGES

A significant challenge identified by speakers, participants and supported in the literature, is the disjointed jurisdictional health care system that currently exists. While healthcare is the responsibility of the provinces, in the case of First Nations and Inuit peoples there are multiple government players involved in the funding and provision of services. The consequences of such a system are the poor healthcare programs and services that currently exist for Indigenous peoples. With several federal and provincially mandated service providers, funding and provision of services becomes a game to see who folds first. In particular, hard-to-reach communities bear the burden of living with significantly underfunded and inadequate healthcare services and worse healthcare outcomes than the general population. The following points were emphasized:

1. Community Care Access Centres (CCACs) and the impact on the delivery of care:

CCACs were considered a prime example of how a multi-jurisdictional care system resulted in poor access to services. Several challenges were cited with provincial CCACs, including:

- Confusion over roles and responsibility
- Failure to coordinate care that meets the needs of Indigenous clients
- Little or no services for remote communities
- No effort to create Indigenous-specific services

Participants who worked with CCACs commented that the agencies assumed very little to no responsibility in the delivery of adequate care and services for Indigenous clients living in remote regions. As CCACs are provincial agencies, they often shuffled responsibilities to other levels of federal providers. When CCACs failed to show up the burden of responsibility fell on resource-strapped communities. Participants spoke on the absence of Indigenous voices and desire to engage with FNIM communities within CCAC. In small groups, one participant noted how front-line staff often had no cultural competency training or understanding of Indigenous beliefs and values. These failures cumulate in the continued mistreatment and negative healthcare interactions experienced by Indigenous peoples.

2. Funding

The First Nation Inuit Health Branchdoes not fund palliative care as essential home or community care. Many communities are piecing together support for members that wish to die at home. The current, uncoordinated healthcare system that exists for Indigenous people results in funding not maximally utilized for the intended purpose - providing access to quality healthcare. When communities have input, they are able to tackle and deliver culturally safe and appropriate care for their members where the Canadian governments have failed.

3. Ensuring the delivery of health services to Indigenous clients:

Often mentioned was the expansion of Jordan's Principle to include the provision of health services to all FNIM peoples approaching the end-of-life. 'Without denial, delay or disruption' is essential to providing quality end-of-life care to Indigenous peoples. The principle is of significance when considering the continuum of care required at the end-of-life to address the physical, emotional, and spiritual needs of patients. The danger of playing jurisdictional games can result in preventable poor health care outcomes and even, death. In breakout sessions and question periods, criticisms of Jordan's principle arose; namely, that jurisdictional confusion still existed, there was very little implementation and narrow interpretation which still left children being denied care, and there was no enforcement mechanism to ensure that governments remained accountable for failure to provide care. In discussions, several participants expressed that the absence of a mandate or clear national policy is one of the reasons that inaction on the part of governments remain.

2.5 STIGMATIZING LANGUAGE

Throughout the conference, participants spoke of the resistance they faced from family, community and healthcare providers when bringing up palliative care. The negative stigma attached to palliative care prevents Indigenous and non-Indigenous patients from seeking early care. Receipt of such care was often associated with loss of hope and belief that death is near.

Participants spoke of the difficulty in relaying the information that palliative care was about improving the quality of life while living with serious illness. Other concerns included the current language of palliative care, which is in contradiction to Indigenous worldviews. Speakers of different tribal affiliations mentioned that often there is no word for death and dying in their languages. Incorporating culturally safe practices requires understanding that these different ways of knowing exist. One participant shared:

"We did it [planning palliative care program] very carefully. We went to Elders first and asked. We told them what the whole topic was - palliative care. [But] we don't use those terms: death, dying and palliative. So, from the beginning, we learned early on we can't introduce it [the project] like that. We had to find creative ways. So how we opened up dialogue was that we had one elderly lady share her story about her elderly father when he fell ill."

Strategies to combat the fears were discussed and included: changing technical and palliative care language, using story-telling to gain buy-in, and grounding educational resources in Indigenous customs and beliefs.

2.6 GAPS IN THE CONTINUUM OF CARE - DISCHARGE PLANNING

FNIM peoples who wish to return to their home community for palliative care often face loss of continuity in their care once they leave the hospital. Participants were adamant that discharge planning - ensuring that patients returning home do not suffer disruptions to their follow-up care, is crucial to adequate care.

Facilitation for patients to access programs and services is especially challenging for Indigenous populations because of the jurisdictional issues of funding that affect the procurement of necessary equipment and medications. For example, payment for a simple transportation between hospital and community may involve the regional health authorities, the province, and the federal government.

Additional barriers were mentioned, including: lack of knowledge of existing resources available in northern and remote communities, coordinating travel plans to access care, and housing conditions. The obstacles listed above are significant with great impact on the patients' access to timely care and quality of life. The Winnipeg Regional Health Authority discharge planning protocol for First Nation patients who wish to return home to die was discussed as a resource for developing similar protocols for FNIM peoples in Ontario. Similar guidelines were discussed as necessary for families to understand the roles and duties they will have to take on. Participants also acknowledged that including coordinators and Aboriginal Patient Navigators late in the discharge planning process contributed to poor service coordination. While the role of Aboriginal Patient Navigators is valued at any stage, engaging earlier in the process could improve outcomes.

2.7 BARRIERS FOR RURAL AND REMOTE COMMUNITIES

The lack of access to healthcare providers and services within rural and remote communities, and the need to travel outside to unfamiliar locations to receive adequate care were listed as high priority barriers. Particularly, discharge planning was an area repeatedly discussed with poor coordination and harmonization of health services to facilitate the dying process for Indigenous peoples.

Housing insecurity remains a significant barrier for informal caregivers. Poor housing conditions exist for many Indigenous communities, which makes providing adequate care difficult. Such difficulties include overcrowding, room for equipment, pain medication storage, and access to running water.

Participants reflected on the convergence of living in dry communities or with members of the family/community living with addiction and the necessity of pain medication at the end-of-life. Finally, the limitations of providing basic care for dying family members was impacted by the lack of access to running water in some communities.

Logistic challenges in rural, remote and fly-in communities were compounded by the stark reality of job insecurity. Caregivers have often been children who have lived nearby. As previously noted, the availability of children as caregivers is declining as the younger generations are moving to cities for economic opportunities. Participants also noted that benefits, such as the Compassionate Care Benefit available through Employment Insurance (EI), were not adequate to prevent loss of income or employment.

Expanding the use of OTN (Ontario Telemedicine Network) to bridge current service gaps in rural and isolated First Nation communities was touched on by a couple of conference participants. Virtual health care delivery is a model that is already being used by many rural and isolated communities. The benefits may include improved access to primary care, decreased wait times for specialists, and increased access to urgent care and early intervention.

2.8 ELDERS, INFORMAL CAREGIVERS AND SUPPORT SYSTEMS

Throughout the symposium, speakers and participants spoke about death and dying as a community event. A participant touched on how systems of family may differ between FNIM people and the general population. A larger support system (i.e. kinship system) is more common for Indigenous people. Participants spoke of the importance of Elders in the palliative process, and how they provided guidance, healing, ceremony, and transmission of traditional ways of knowing.

Discussion among participants described the interconnectedness of the community and existing support systems that provide meals, transportation, economic, or social support. The informal community plays a significant role in filling in the gaps of end-of-life care in isolated communities. This was both a traditional mandate and a necessity because of poor service provision by CCACs, health institutions and government agencies. Participants felt that community support is part of their culture, spiritual healing, and revealed the strength and enduring resiliency of traditional beliefs.

Small group discussions revealed the nuances of providing such services, such as managing the work-life balance. Others mentioned the difficulties of providing long distance care and the impact of navigating culturally unsafe health institutions for caregivers. The negative effects of providing 24/7 care have been well documented among other populations and include burn out and financial challenges.

It was stressed that there is no pan-Indigenous, one-size fits all model of care. FNIM communities are highly diverse groups with different beliefs, customs, and traditions. Healthcare providers, in the process of engaging in cultural safety, must remember to treat a FNIM patient as an individual with their own set of needs and tailor their treatment plans accordingly.

2.9 CENTERING THE PATIENT THROUGH THE PRACTICES OF CULTURAL SAFETY

Participants spoke regularly of healthcare providers employing culturally safe care with Indigenous clients. Culturally safe care requires a patient-centered approach, ensuring that the patient is a partner in the decision-making process. This culturally relevant approach ensures that the patient's ways of knowing and being is respected and accepted as valid. Healthcare providers should be aware of the power dynamics between themselves and the patient, another central tenet of the cultural safety concept. A strategy in providing culturally safe care is the use of self-reflexivity. Becoming self-aware and evaluating hidden biases might help providers identify their own cultural assumptions that surround death and dying. Through the experience of self-reflection and emphasizing acceptance, the end goal would be to facilitate positive healthcare approaches for Indigenous patients.

2.10 THE SUCCESS OF ABORIGINAL PATIENT NAVIGATORS

Within healthcare institutions, Aboriginal Patient Navigators are considered one of the strongest assets for patients and their families. Their role is to facilitate and provide support for Indigenous people accessing healthcare services at the end-of-life.

Through personal stories, shared both as presentations and in groups, it became clear that Aboriginal Patient Navigators often act as advocates and mediators between different sets of values. Through their cultural brokering approach, patients and their families become empowered to voice their wishes and concerns in the care plan. It was reflected that the existence of Aboriginal Patient Navigators might also encourage members of the family to seek out early treatment and avoid late-stage diagnosis of diseases.

Professionally and personally, Aboriginal Patient Navigators face numerous challenges. A participant acknowledged the emotional hardship that was caused by witnessing direct and systematic discrimination. The participant further stated that mandating cultural competence courses would create safer spaces for not only the clients, but FNIM workers too. Other concerns included being called in too late to properly coordinate services for clients. In the end, there was a consensus of the necessity to increase the number of Aboriginal Patient Navigators and FNIM healthcare providers. The notable success of the Aboriginal Patient Navigator program might encourage the training of more FNIM community members.

2.11 CULTIVATING INDIGENOUS AND NON-INDIGENOUS CHAMPIONS AND ADVOCATES WITHIN THE HEALTH CARE SYSTEM

Dr. Bernice Downey and other conference attendees identified the importance of fostering the development of Indigenous and non-Indigenous champions and advocates within the healthcare system. By creating influencers, we can support and facilitate the uptake of initiatives that will improve health outcomes for FNIM peoples. Leaders can be cultivated on every level of the healthcare system.

RECOMMENDATIONS

Emerging themes and facilitated discussions on research, education and practice, and policy formulated the recommendations outlined below.

RECOMMENDATIONS

RESEARCH

Palliative and end-of-life care continues to be a pressing issue for FNIM people. Unfortunately, there is a paucity of information to help guide service delivery and support individuals, families and communities. Much of the traditional knowledge surrounding death and dying is held by knowledge-keepers, who themselves are aging. One of the intentional acts of colonial assimilation was to break down family structures and disrupt the exchange of cultural teachings between generations, including ceremonies. Ceremonies are considered to be healing medicine in Indigenous worldviews and of particular relevance at the end-of-life. Given that the main avenue of knowledge continuity is oral, there is a real risk of losing a wealth of traditional knowledge. It is imperative that research about dying and death be based upon community wishes, benefit Indigenous communities and individuals, and follow Ownership, Control, Access and Protection (OCAP) principles. Although Indigenous people have experienced the damaging effects of unethical and culturally harmful Western research practices, research itself has been integral to survival for over 10,000 years. It is not that research per se is problematic but rather how research is conducted, which must be considered and respected. Recommendations from symposium participants are summarized below.

RECOMMENDATIONS

RESEARCH

1. Continue to Build research capacity in Indigenous communities:

A. Support and encourage research partnerships
B. Explore questions identified as relevant to and driven by Indigenous peoples
C. Develop a 'vision' for research to direct questions and identify gaps and opportunities
D. Acknowledge the history of trauma, do not conduct research without a community's knowledge and/or approval and ensure research benefits the community
E. Expand the role of research advocacy
F. Explore means to address gaps in data due to people not identified as FNIM
G. Create centers of excellence with stable funding

2. Follow culturally sensitive research principles:

A. Explore innovative forms of knowledge sharing (ex. documentary as knowledge translation)
B. Respect OCAP principles
C. Identify "best practices" from an Indigenous perspective and involve front line health care workers
D. Foster community driven research including PAR
E. Expand and scale-up leading practices (ex. EOLFN – Lakehead program)

The above recommendations are in alignment with the goals set out by the Truth and Reconciliation Commission of Canada (TRC) to address the health disparities that exist for FNIM people in Canada. Call to Action - #19 calls for the development of tools and measures to improve access and quality of care for FNIM communities in Canada.

RECOMMENDATIONS

EDUCATION & PRACTICE

Health navigation, as a new profession, has garnered a strong, positive reputation. Health navigators provide a critical service in bridging the gap between patients and an increasingly complex healthcare system. Navigators with an FNIM background can more easily establish trust and relationships with Indigenous patients. Based on these findings and the experience of conference participants, training of FNIM community members as navigators, discharge coordinators and other healthcare roles have the potential to produce similar results and help informal caregivers provide the best possible care.

The above recommendations are in alignment with the goals set out by the TRC to increase the presence of Indigenous health professionals and non-Indigenous advocates within the healthcare system. Calls to Action 22, 23, and 24 in the TRC final report offer significant opportunities for creating a health system that is equipped to provide better services for Indigenous people approaching the end-of-life and their families.

All efforts must be made to improve communication between palliative care professionals, clients, families, and communities. Culturally relevant language can reduce unwillingness to access early palliative care, develop advanced care plans, reach wider audiences and significantly increase the quality of life for clients and their loved ones. FNIM-specific does not mean pan-Indigenous, but is designed to meet the needs of individual communities. All programs and resources should be based on local need and community-specific beliefs.

Other language barriers include lack of adequate language supports for patients speaking an Indigenous language. Calls to Action 13 and 14 from the TRC final report mandate the presence of language translators that recognize Indigenous language rights and the need for respect and preservation of Indigenous language. For example, respect can be seen through the timely provision of language translators in healthcare settings. One way to do this is to increase funding for translators in hospitals, hospices and other health facilities.

RECOMMENDATIONS

EDUCATION & PRACTICE

1. Provide palliative care training for health care workers working with Indigenous communities
A. Conduct face to face training (online is ineffective) to increase community capacity
B. Integrate grief and death education into health care worker training

2. Mandate cultural competency/safety training for all health care workers including the effects of colonization

3. Develop education for FNIM peoples
A. Develop public education programs on advance care planning and early palliative care
B. Integrate grief education into community education

4. Implement practice changes to support the generation of quality, culturally sensitive care
A. Adapt the current language of palliative care to be grounded in Indigenous customs, beliefs, and traditions to reduce the stigma associated with palliative care
B. Continue to train and implement Aboriginal Patient Navigators and other FNIM health care workers and advocates
C. Develop and inform FNIM peoples of language services available for patients who speak Indigenous languages

RECOMMENDATIONS

POLICY

Participants had a robust discussion about policy measures designed to improve the quality and accessibility of palliative and end-of-life care for FNIM people. Many of the issues that policy recommendations sought to address revolved around jurisdictional challenges, cultural practices, funding gaps, autonomy, and partnerships. Some of the recommendations are easily achievable in the short to medium term and several are long term visions.

As it currently stands, there exists a disjointed healthcare system for Indigenous communities. This creates confusion among health care service providers, agencies, and clients. For quality care at the end-of-life, an integrated coordination of healthcare services is essential. Provincial and Federal governments should work towards lessening the impact of these disputes for FNIM peoples. Different levels of governments must work together to streamline services and develop performance measurements to ensure the delivery of quality care. There should be measurable outcomes and annual progress reports that describe the actions that have been taken to achieve them. Access to high quality end-of-life care should not be “denied, delayed, or disrupted” due to jurisdictional disputes. The uncoordinated and fragment health system must end immediately to prevent poor health care outcomes including, death.

It is imperative that Indigenous peoples are given the option to die in their communities, surrounded by their loved ones. Where you live should not determine access to quality palliative and end-of-life-care. With legislating a provincial mandate, there will be a responsibility to ensure that all supports are given to those who choose to return to their communities. This will include expanding the NIHB program, a program developed as a national plan to provide essential medical services to Status First Nation and Inuit peoples. Yet, Indigenous communities in remote regions have continuously been failed in provision of responsive care that is timely and comprehensive. Even transportation to and from hospitals in other regions can be subject to delays and disruption, without the accompaniment of a family member.

RECOMMENDATIONS

POLICY

With the establishment of hospices and palliative care services in Indigenous communities, regardless of location, we can facilitate the physical, emotional, spiritual and mental healing that can often take place at the end-of-life. These services would include access to traditional healing and healers, language services, and culturally responsive care. Death is a part of the healing process and as described by first-hand accounts, a significant time for reconciliation by addressing the physical, mental, emotional and spiritual harms of colonization and displacement. The creation of these facilities will move towards the stated objective of the TRC report.

In 2013, the First Nations Health Authority (FHNA) was established in British Columbia. It disentangled the jurisdictional entanglement of federal and provincial programming and funding by placing control into Indigenous hands. Ontario should follow suit. A unique opportunity exists in Ontario to advance this priority. Both liberal provincial and federal governments have committed to the processes of reconciliation and relationship building. FNIM organizations in Ontario should use this opportunity to advocate for transformation of a disjointed and failed healthcare system into the creation of a First Nations Health Authority in Ontario.

There is a housing crisis that exists for both on-reserve First Nations and FNIM populations living off reserve. On-reserve First Nations can live in bleak housing situations with inadequate shelter, lack of access to water, overcrowding, no space for necessary equipment or safe storage for medications. FNIM populations in urban centres across Ontario are over-represented in study findings on homelessness and precarious housing. There are additional barriers such as discrimination in accessing housing, healthcare services, and the job market. The housing epidemic directly impacts whether a patient can return to their community and the level of a care that caregivers can provide.

The recommendations are in alignment with the goals set out by the TRC to adopt and implement the United Nations Declaration on the Rights of Indigenous Peoples of which Canada is a signatory. In the TRC report, housing is barely mentioned. In the UN Declaration, there a several articles that refers to the responsibilities for governments to include in providing improvement in areas, including housing. Article 21 in particular, refers to these obligations that states have towards Indigenous peoples. Article 23 in particular, clearly refers to the right to establish a First Nations Health Authority in Ontario, if so desired by Indigenous people in Ontario.

RECOMMENDATIONS

POLICY

1. Create multi-jurisdictional partnerships that operate under the principles of meaningful collaboration, respect and transparency

A. Expand services of existing or develop new programs/services to support palliative and after-hours care for First Nation communities

B. Develop comprehensive discharge planning procedures and protocols across Ontario

C. Develop policies with leadership from the Indigenous community

2. Develop policies to facilitate the physical, emotional, spiritual and mental healing in health care institutions

A. Mandate a formal provincial wide policy to allow Indigenous traditional or spiritual services (ex. smudging, drumming) in health care institutions

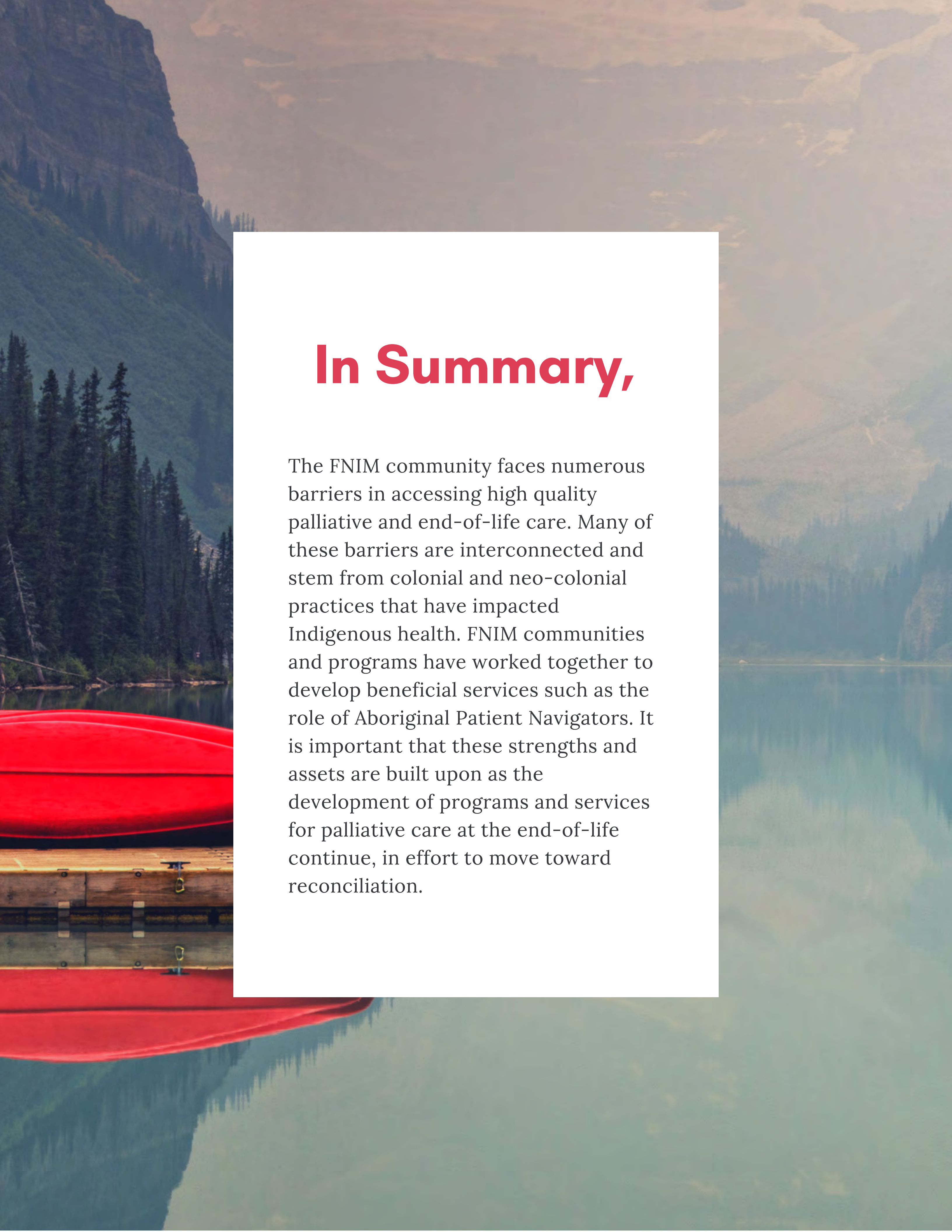
B. Develop policies with leadership from the Indigenous community

3. Develop policies to support Indigenous communities to facilitate palliative care within the community

A. Develop and create a multi-disciplinary strategy to solve the housing crises for on-reserve and off-reserve FNIM communities in Ontario

B. Expand Non-Insured Health Benefits (NIHB) programs to provide medicines for palliative care and include transportation benefits for patients and an escort

C. Fund First Nations organizations to build suitable and culturally appropriate hospices



In Summary,

The FNIM community faces numerous barriers in accessing high quality palliative and end-of-life care. Many of these barriers are interconnected and stem from colonial and neo-colonial practices that have impacted Indigenous health. FNIM communities and programs have worked together to develop beneficial services such as the role of Aboriginal Patient Navigators. It is important that these strengths and assets are built upon as the development of programs and services for palliative care at the end-of-life continue, in effort to move toward reconciliation.

REFERENCES

Allan, F., Dr., & Smylie, J., Dr. (n.d.). (2015). First Peoples, Second Class Treatment The Role of Racism in the Health and Well-Being of Indigenous Peoples in Canada (Rep.).

Farmer, P. (1996). On Suffering and Structural Violence: A View from Below. Daedalus, 125(1), Social Suffering, 261-283.

Fruch, V., Monture, L., Prince, H., & Kelley, M. L. (2016). Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care. International Journal of Indigenous Health IJIH, 11(1), 50. doi:10.18357/ijih111201615303

Hampton, M., Baydala, A., Bourassa, C., McKay-McNabb, K., Placsko, C., Goodwill, K., . . . Boekelder, R. (2010, May). Completing the Circle: Elders speak about end-of-life care with Aboriginal families in Canada. Journal of Palliative Care, 26(1), 6-14.

Health Council of Canada. (2012). Empathy, dignity, and respect: Creating cultural safety for Aboriginal people in urban health care. Toronto: Health Council of Canada.

Kelley, M. (2010, May). An Indigenous Issue: Why now? Journal of Palliative Care, 26(1), 5-5.

Kewayosh, A., Marrett, L., Aslam, U., Steiner, R., Lum-Kwong, M. M., Imre, J., & Amartey, A. (2014). Improving Health Equity for First Nations, Inuit and Métis People: Ontario's Aboriginal Cancer Strategy II. Hcq Healthcare Quarterly, 17(SP), 33-40. doi:10.12927/hcq.2014.24007

National Aboriginal Health Organization (NAHO). (2008). Cultural Competency and Safety : A Guide for Health Care Administrators, Providers and Educators. Retrieved May 18, 2017, from http://www.naho.ca/documents/naho/publications/culturalCompetency.pdf

Population growth. (2015). Retrieved September 08, 2016, from http://www.statcan.gc.ca /pub/89-645-x/2010001/growth-pop-croissance-eng.htm

APPENDICES

A. DELEGATE LISTING

- Aboriginal Patient Navigator, Central East, Kathy MacLeod-Beaver
- Aboriginal Patient Navigator, North Simcoe Muskoka, Leah Bergstrome
- Aboriginal Patient Navigator, Northeast Cancer Centre, Sherri Baker
- Aboriginal Patient Navigator, South East, Dionne Nolan
- Aboriginal Patient Navigator, Toronto Central, Joanna Vautour
- Canadian Partnership Against Cancer, Director, Strategy Implementation, FNIM Cancer Control Unit, Pam Tobin
- Canadian Virtual Hospice, Shelly Cory
- CCO, Sr. Manager Prevention and Cancer Control, Usman Aslam
- CCO, Director, Aboriginal Cancer Control Unit, Alethea Kewayosh
- Hamilton Niagara Haldimand Brant Regional Hospice Palliative Care Program, Regional HPC Program Director, Susan King
- Health Canada, Robin Buckland
- Independent First Nations Alliance, Gail Winter
- Indigenous Medicine, University of Toronto, Dawn Maracle
- Lakehead University, Project Manager and a Co-Investigator on the Improving End-of-Life Care in First Nations Communities Project, Holly Prince
- Moose Cree First Nation, Karen Pine
- Naotkamegwanning's Home and Community Care Program, Coordinator, Maxine Crow
- Native Canadian Centre, Seniors Program, Case Manager, Caroline Francis
- North East Cancer Centre, Health Sciences North, Director, Research and Regional Psychosocial Oncology Lead of the Supportive Care Program, Carole Mayer
- North East LHIN, Officer , James Bay Coastal Region NE LHINs, Debbie Szymanski
- North Simcoe Muskoka LHIN, Senior Advisor, Melissa Mei
- Ontario Palliative Care Network, Manager OPCN Secretariat, Rachel Boissonneault
- Ontario Palliative Care Network, Provincial Clinical Co-Lead, Melody Boyd
- PFAC Representative, Leslie Koshed-Currie

A. DELEGATE LISTING

- Post Doctoral Fellow, McMaster; Regional Aboriginal Lead Toronto Central, Bernice Downey
- Six Nations Home and Community Care/Long-term Care, Manager, Lori Monture
- South East LHIN, Planner, Lori Van Manen
- Spectrum Health Care, Debra Sayewich
- St. Michael's Hospital, Director Cancer Services Planning and Performance, Susan Blacker
- St. Michael's Hospital, Aleksandra Petkovska
- The Seniors Department at The Native Canadian Centre of Toronto, Community Health Navigator, Christine Lynne
- Toronto Central LHIN, Senior Consultant, Rose Cook
- Toronto Regional Cancer Program, Project Manager, Upasana Saha
- University Health Network, Madeleine Stoney

B. COMMUNITY PERSPECTIVE

Maxine Crowe - Coordinator of Naotkamegwanning's Home and Community Care Program

In 2010, Naotkamegwanning partnered with Holly Prince's team at Lakehead University to develop a palliative care program in their community. Naotkamegwanning First Nation (NFN) is a small community that remains rooted in strong Anishinaabe cultural practices and beliefs. The Ojibway language is spoken by 48% of the population and Elders have continued to play a vital role in passing on teachings, language and cultural practices. Elders help to inform services and initiatives in the community and access to Elders occurs through monthly Elder meetings. External health services are accessed in Kenora, Ontario. Most people receiving support live independently in their own homes while some receive care in the Elders' apartment complex.

Community needs assessments were conducted from 2011-2012, which included surveys, focus groups, and interviews. Based on this information, strategies to meet end-of-life care needs were developed. This information is contained in the Wiisokotaatiwin Guideline Booklet: 9 steps from the client being identified to the passing and closing of the file.

The team was in continuous consultation with Elders in developing the program and creating cultural competency programs for healthcare providers. The example of the leadership, guidance and support provided by Elders is contained in the following passages:

"We ha[d] to change the name, we can't say palliative care program. So, we were fortunate to have our elders sit with us and talk about different ways we can say it so that it's called Wiisokotaatiwin. And basically, it means taking care of each other and supporting each other. So again, with Elder approval, we introduced the Wiisokotaatiwin program to the larger community. And then we branched out into established relationships with our external health care providers, district hospitals, CCACs, Kenora health agencies, [and more]"

B. COMMUNITY PERSPECTIVE

On When creating sensitivity workshops for healthcare providers:

> “*“Now we have to teach them how to navigate our home and people in respectful ways. [We] created sensitivity workshops. Went to elders and asked them, 'what do you want healthcare providers to know when they step into your homes?'. … [The Elders decided that] we will sit in a circle and have a discussion. And it was simple as that. We cumulated all the questions, picked out topics and had a discussion. That is how our workshop went and it went very well.”*

The team went through many changes to make sure they were able to reach community members by employing strategies such as story-telling and using language that was culturally relevant. The project was able to achieve notable success in the following areas: staff education (Palliative Care Training for Frontline), community education (volunteer training), coordinator education (LEAP training, using specialized equipment), less emergency visits, less hospital admissions, length of stay in hospital towards end-of-life significantly reduced, and ease of stress on family supports. There were challenges that remained due to difficulties in coordination with EMS services, funding and jurisdictional barriers.

B. COMMUNITY PERSPECTIVE

Lori Monture - Manager of Six Nations Home and Community Care/Long-term CareLori Monture - Manager of Six Nations Home and Community Care/Long-term Care

Lori belongs to the Six Nations of the Grand River Territory (pop. ~26,503 as of December, 2015). Challenges to providing quality end-of-life care for First Nations people were identified, reemphasizing problems outlined in previous talks, including: insufficient support for clients choosing to die at home, lack of coordinated palliative care services, inadequate hospital discharge planning, and a lack of understanding of First Nations and Inuit Health Branch (FNIHB) and Non-Insured Health Benefits (NIHB) policies and procedures. Other issues that were highlighted were housing that was inadequate and could not accommodate the needs of clients or service/healthcare providers.

The development of the shared outreach team was based on evidence and a best-practice model. The team was not created to replace or reduce the CCAC role and responsibility but to be an integrated and seamless shared care team involving primary providers, forming a partnership of care with expert clinicians. Primary care physicians continued their routine follow-ups, testing, and prescribing medications and outreach physicians monitored pain and other symptoms. Teams were created according to population and geography and were tasked not to duplicate services.

The shared outreach team is comprised of palliative care physicians, clinical nurse specialists, psychosocial/bereavement counselor and traditional knowledge carrier, and personal support workers. They work in close partnership with community agencies including CCACs, hospices and Six Nations LTC/HCC. Members have defined roles and work to deliver comprehensive end-of-life care respecting the personal, cultural, financial, legal, health care and spiritual needs of the client. The team is guided by the following principle that Lori read to conference goers.

Worldview: Haudensosaunee Philosophy Statement

Traditional philosophical principles have a crucial relevance to the challenges our people face today. Ohenton Karihwatehkwen, which means the words that come before all else, are a reminder of the place that we, as human beings, are meant to occupy in relation to all of Creation; a place of balance and respect. Our worldview comes from the Creation Story, the Original Instructions, and is expressed in our annual cycle of ceremonies of thanksgiving. Our worldview teaches us that we exist with purpose, with a sacred intent and a duty to uphold the human responsibility to all of Creation. Our core philosophy is simply expressed as one body, one mind, and one heart. In the Haudenosaunee tradition, acceptance comes from a view of the natural order that accepts and celebrates the coexistence of opposites; our purpose is contained in the quest for balance and harmony, and peace is gained by extending the respect, rights, and responsibility of family relations to other peoples. The values are the state of peacefulness, the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. In the words that come from the Thanksgiving Address "we must see the cycle of life continue"-and ensure the health and wellness of the people

C. RESOURCES

1. Canadian Virtual Hospice

The Canadian Virtual Hospice is a web-based platform to address existing gaps in palliative care in Canada. Evidence-based tools, resources and research findings are available for patients, families, healthcare professionals and researchers. The Indigenous voices videos use personal narratives to help explain Indigenous approaches to palliative and end-of-life care and identify existing barriers and challenges. The team used 24 story-tellers from communities as diverse as Haida Gwaii and Six Nations.

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

2. Improving end-of-life care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development

The need for palliative care services for First Nations people is increasing due to an aging population and the high burden of chronic and terminal disease amongst this population. Many First Nations people want the opportunity to die in the communities where they have lived all of their lives; however people in First Nations communities have limited access to culturally relevant and formalized palliative care programs. Providing equitable access to health services for all Canadians is a compelling social obligation that includes developing accessible palliative care programs for First Nations people.

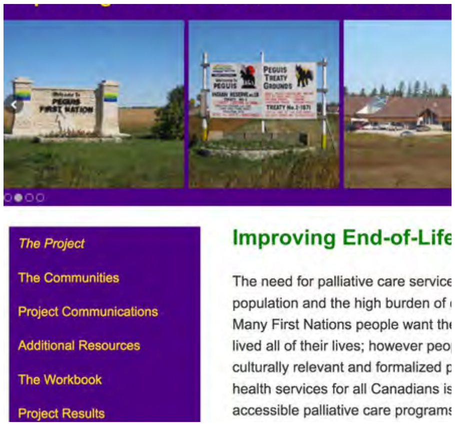
The overall goal of this 5-year (2010-2015) Aboriginal Health Intervention grant was to improve the end-of-life care in four First Nations communities through developing palliative care programs and creating a culturally appropriate theory of change to guide palliative care program and policy development nationally.

http://eolfn.lakeheadu.ca/

3. Aboriginal Cancer Control Unit – Programs and Resources

Our Indigenous programs work to improve cancer care for Ontario's First Nations, Métis and Inuit people. These programs are mandated to make sure Indigenous people in Ontario have access to quality cancer prevention, screening and symptom information that incorporates the Indigenous holistic approach.

https://www.cancercare.on.ca/about/programs/aborstrategy/



Improving End-of-Life

The need for palliative care service
population and the high burden of
Many First Nations people want th
lived all of their lives; however peo
culturally relevant and formalized p
health services for all Canadians is
accessible palliative care programs

D. PERSONAL STORIES FROM ABORIGINAL PATIENT NAVIGATORS

1. Supporting Patients and Families at the End-of-life in an Urban Setting

Joanna Vautour - Aboriginal Patient Navigator, Toronto Regional Cancer Program

Joanna discussed a story of supporting a family that was in Toronto and a considerable distance from home. The family's wish was to return to their home with their dying mother so she could spend her last days at home, rather than in hospital. This became impossible due to logistical issues. The family had experienced distrust and felt disconnected from the healthcare workers and there was a lack of cultural understanding by the healthcare providers. The family wished to have a last smudging ceremony together but felt unable to advocate for themselves. Joanna advocated on behalf of the family, who were then permitted time to perform a smudging ceremony in their mother's room. Such ceremonies have great importance for Indigenous families and enable healing, particularly at the end-of-life.

Lessons:

- Aboriginal Patient Navigators play a key advocacy role
- Listening is vital
- The importance of ceremony as medicine, ceremony enables healing
- The importance of building trust and relationships

D. PERSONAL STORIES FROM ABORIGINAL PATIENT NAVIGATORS

2. Having Difficult Conversations:

Sherri Baker - Aboriginal Patient Navigator, Northeastern Ontario

Sherri told the story of a middle-aged woman with metastatic breast cancer, who was receiving treatment in a cancer center several hours from her home community. She had several young teenaged children, minimal support and financial challenges. She was initially referred to Sherri for emotional support, financial support, and advanced care planning. She declined this opportunity to engage with the navigator and returned to her community. Nine months later, she developed a health crisis, returned to the cancer center, and ultimately ended up on life support in the ICU. There had been little discussion amongst family members about her prognosis or her wishes, let alone advanced care plans (ACPs). Her daughter had been designated substitute decision maker, a role she felt poorly prepared for. The ICU team recommended withdrawing care, given her prognosis, which presented significant challenges for the family. Sherri listened to the daughter's concerns and allowed time for the conversations to occur. The family wished the timing of her death to coincide with a pow-wow in their community and also for several ceremonies to occur (smudge, healing lodge) prior to her death. Self-care was also discussed with the daughter.

Lessons:

- Difficult conversations require building a relationship
- Relationships require time, even in challenging circumstances
- Importance of ceremony for healing of families
- The value of advanced care planning to guide family and substitute decision makers

D. PERSONAL STORIES FROM ABORIGINAL PATIENT NAVIGATORS

3. Intergenerational Trauma and Healing at the End-of-Life

Leah Bergstrome - Aboriginal Patient Navigator, North Simcoe Muskoka

Leah shared a heartfelt personal story of her father that touched on the journey of identity, belonging, healing and finding peace at the end-of-life. She began by describing her father's childhood, the forces of deep loss and displacement that had shaped his early life and how he was able to heal at the end-of-life through the rediscovery of his Métis traditions. Leah described her father as someone between two worlds; happiest when he was outdoors in the North connected to the land and Métis lifestyle and struggling with his more westernized lifestyle in the city. Her father struggled with his Métis identity and experienced fear, guilt, and shame about this. When he became ill, he reconnected with a family member who shared Métis stories, teachings, medicines, and cultural perspectives on the end-of-life. Leah reflected on how important this time was in her dad's healing process, reiterating a previous speakers comment, "we are healing and also dying simultaneously".

Reconnecting to his Métis culture at the end-of-life provided healing in her dad's journey. It was a gift and an opportunity for him to retrieve many of the pieces that he had lost of himself and gave him an opportunity to revision himself, to see himself from a different perspective. Understanding himself more deeply from a cultural perspective allowed him to reflect on his life, gain a deeper respect for himself, and see himself in wholeness with more dignity.

Leah commented on the intergenerational healing and acts of reconciliation that occurred throughout her father's journey at the end-of-life. This demonstrated how the provision of dignity in a culturally safe way has a healing effect that ripples through immediate family, community members, and the broader community. Her dad's journey also had a healing effect on her own identity and she expects this will positively affect her son.

D. PERSONAL STORIES FROM ABORIGINAL PATIENT NAVIGATORS

"We know that when we can affect people's lives in this way, we are really creating change seven generations forward. And this really, to me is what reconciliation is about. You know, really being present in these very important moments and opportunities now and creating that healing effect for many generations forward".

Lea also recounted a teaching from an elder about the effects of unhealed wounds on intergenerational trauma. If we don't heal our own issues in our lifetime they live on through intergenerational trauma. Unhealed wounds lead to expanded triggers and the experience becomes more difficult. The end-of-life is an auspicious time for healing. We are close to the creator and our ancestors, which affords a greater opportunity to heal. Supporting people in a culturally safe fashion through this healing moves us in the direction of reconciliation. "Every end is a new beginning".

Lessons:

- The end-of-life is an auspicious opportunity for individual and intergenerational healing
- Dignity is paramount
- Cultural safety is integral to dignity
- Cultural teachings, medicines enable healing
- Intergenerational trauma expands unless faced