COMMUNITY VOICES:

EQUITABLE ACCESS TO PALLIATIVE CARE FOR FIRST NATIONS IN ONTARIO

SE First Nations, Inuit and Métis Program

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Contents

EXECUTIVE SUMMARY

Palliative care in Canada continues to evolve. Ontario's *Compassionate Care Act* (2021) demonstrates the growing recognition of the need for equitable palliative care for children and adults across Ontario. First Nations people are recognized as an underserved population in terms of health care generally and palliative care specifically due to a complex array of factors, including the social and Indigenous determinants of health that are inclusive of ongoing systemic racism and discrimination.

Palliative care standards for Ontario are clear; these standards inform the public on what services and supports they can expect in terms of quality palliative care (HQO & OPCN, 2018; OPCN, 2019a). However, when First Nations reality is measured against these standards, significant gaps to essential effective palliative care service delivery are evident. Community input was collected through a combination of survey and interview responses from First Nations Home and Community Care team members in Ontario involved with the coordination and delivery of palliative care. This community-based participatory process provides a grassroots view of real-life issues faced by First Nations in palliative and end-of-life care.

The findings from *Community Voices* and other available research validated the efforts of the Ontario Palliative Care Network in their *Palliative Care Health Services Delivery Framework* (2019). An effective palliative care strategy for First Nations in Ontario will include recommendations from this Framework as guiding principles.

Input from survey participants indicates that there are aspects of a palliative approach to care as outlined by provincial standards and the Ontario Palliative Care Network Framework that are currently beyond the reach of many First Nations. Major gaps identified include:

- Lack of access to a full interdisciplinary palliative care team. No First Nations report 24/7 access.
- Lack of access to pain and symptom management and delays related to geography and jurisdictional barriers.
- Lack of palliative care supplies and equipment.
- Limited virtual access to palliative care specialists / interdisciplinary palliative care team.
- Lack of collaboration between all levels of health systems (local, provincial, federal) that are anticipatory / flexible to the needs of First Nations.
- Staffing resources stretched beyond limits with no surge capacity.
- Multigenerational, overcrowded, unsafe houses.
- Access to hospice-like settings is rare.
- Individuals that would benefit from palliative care are not identified in a timely manner.
- Lack of role clarity among community-based staff.
- Lack of culturally safe approaches and tools.
- Lack of culturally safe guidelines to support the provision of palliative and end-of-life care.
- Lack of comfort regarding culturally safe difficult conversations.

Strategies that address current and future palliative care needs include:

- Establishing a toolkit that is easily accessible and compiles screening tools to support and reinforce best practice in culturally safe palliative and end-of-life care. This toolkit would focus on the early identification of the client who would benefit from a palliative approach to care.
- Integrating a palliative approach to care into Home and Community Care Policies and ensuring best practice guidelines to support care across the palliative care continuum.
- Establishing Indigenous Palliative Care Coordinators with advanced competencies in palliative and end-of-life care that can assist the Home and Community Care Coordinator and community-based team to ensure quality, accessible and coordinated palliative care services. The Indigenous Palliative Care Coordinator can work in collaboration with the Home and Community Care Coordinator / Nurse to coordinate extended services and help fill the gaps in the core team by identifying and bridging partnerships with provincial palliative care teams and external systems. Envisioned as a 1-800 number to call when a client is identified as needing palliative and end-of-life care, this role will ensure that the community has access to 24/7 support, as well as coordination of care through the establishment of these partnerships. These coordinators will take the lead in educating, mentoring and supporting the community-based teams as well.
- Exploring the role of a community-based End-of-Life / Death Doula and how that role can help to support clients/families along the palliative care continuum and support culturally safe end-of-life care. This role can help to facilitate community-based awareness by providing education regarding a palliative approach to care; to revitalize the Traditional view of death as a natural part of the life-cycle; and to support culturally safe approaches to difficult conversations and supports for grief and bereavement. Education examples include: home-based palliative care, hospice-based palliative care, advance care planning and Medical Assistance in Dying. This role could also provide essential support to families and caregivers in their palliative and end-of-life journey.
- Leveraging technology to support virtual care to the fullest potential, using the technology that First Nations have access to. Palliative Care Coordinators would play a key role in supporting community comfort and access to virtual care and the development of linkages to 24/7 access supports.
- Integrating tools that support a palliative care approach in communities that have access to electronic medical records. Some examples include the Clinical Frailty Scale, Surprise Question, RESPECT tool, Do Not Resuscitate Orders, and an Advance Care Plan that identifies a substitute decision maker. For communities without EMR, consider strategies to integrate these tools into existing care and documentation processes.
- Collaborating with Non-Insured Health Benefits to support the use of symptom response kits in all First Nations and educating First Nations around the use of these kits.
- Having a standardized phone line where clients/families have 24/7 access to prescriber / palliative care specialists. Involving Palliative Care Coordinators to assist in the development of these services.
- Collaborating with Non-Insured Heath Benefits to create a physical resources list necessary for the provision of palliative and end-of-life care. Establishing a process that ensures communities have timely access to the supplies/equipment.
- Indigenous Palliative Care Coordinators to support communities to develop emotional, psychological and spiritual care as a virtual care option that is available 24/7.

- Supporting First Nations to create access to hospice like spaces, either within or less than 30 minutes away from the community. This access can be developed through provincial or not for profit, charitable partnerships.
- Providing opportunities for communities to share lessons learned regarding their experiences in providing palliative and end-of-life care.
- Improve and tailor multi-sectoral (local, provincial, federal) collaboration that is responsive to the needs of First Nations.

A First Nations palliative care strategy for Ontario informed by First Nation communities, and providers in those communities who currently provide palliative care, will guide current and future palliative care strategic investments and initiatives. This strategy will assist First Nations to honour the last wishes of those who wish to pass away (die) with dignity and respect, at the place of their choice.

BACKGROUND

Aging Populations

Although the Indigenous population is younger than the non-Indigenous population in Canada, there is a demographic trend toward aging (Conference Board of Canada, 2018; Walker et al. 2019). Aging populations are influencing health and social care systems in Canada, however, living longer does not always equate to living better. Most people will live for years at the end of life with symptom burdens and care requirements, related to chronic disease and frailty (including functional and/or cognitive decline). This reality has increased awareness of and demand for palliative care (PC) that aims to improve the quality of life of people living with life limiting illness (OPCN, 2019a).

Determinants of Health

Some variations in age-related health are linked to genetics, however, the majority of chronic diseases (e.g. diabetes, heart disease, cancer, lung disease) are related to social determinants of health, such as income and education. For First Nations people these determinants include Indigenous-specific determinants such as colonialism, racism, and discrimination. The impact of these health inequities causes First Nations people to experience a disproportionate burden of chronic disease and frailty at younger ages with poorer outcomes, increasing the need for access to quality, culturally safe PC (House of Commons Canada, 2018; ISC, 2017; WHO, 2018).

Palliative Care

Palliative care is an approach that aims to improve the quality of life of clients (adults and children) who would benefit from such an approach and is particularly important for those who are in their final year of life (EOLFN Research Team: Lakehead University, 2015; WHO, 2013, 2018, 2020). The PC continuum starts with the onset of a life-limiting condition regardless of age, diagnosis or prognosis, through to the end-of-life (EoL), and is inclusive of grief / bereavement. The focus of care often shifts from a curative approach or treatment of the disease to symptom management when therapy is no longer effective, or unwanted. Across the continuum, care is client/family-centered and wholistic—it incorporates physical, mental, emotional, and spiritual aspects of health and wellbeing (see Appendix A) (Improving End-of-Life Care in First Nations Communities Research Team (EOLFN), 2015).

A life-limiting illness is defined as any medical condition caused by injury or disease that cannot be cured. It includes chronic diseases such as cancer and diabetes, however, it also includes progressive conditions such as frailty and dementia (Kelley et al., 2018).

In 2018, the World Health Organization identified access to PC as a human right (WHO, 2018). In Canada, publicly funded PC programs exist across the country, however, there is inconsistency in terms of access, eligibility, support and resources. There is also variability within provincial jurisdictions; this is especially evident when reviewing First Nations access to PC (CIHI, 2018), despite the inclusion of PC as an essential element of First Nations Home and Community Care (HCC) programs in 2017.

Palliative care emerged in the late 1970s as a way to improve the EoL experience of cancer patients and their families. As a specialty, PC worked to understand the needs of the terminally ill within a system that had institutionalized death and dying. As a result, the first hospice/palliative programs were in hospitals. Since then PC has expanded beyond cancer to include anyone living with a life-limiting illness, with increased emphasis in the last year of life, while the delivery of these services has moved closer to home (EOLFN, 2015; Fedel & Pennington, 2021; OPCN, 2019b).

Although some hospitals continue to provide PC, especially for clients that have complex and persistent care needs, more clients are opting to receive their care and die at home. Palliative care can be provided wherever the client lives. Long-term care facilities and Elders' lodges provide palliative/EoL care and may have designated hospice beds. Community residential hospices provide PC in a home-like setting with 24/7 support where full EoL needs are met. Eligibility criteria attempt to identify those in the last months of life. Access to hospice beds varies widely across Ontario and remains out of reach for many First Nations (CIHI, 2018; Health Canada, 2018; Ministry of Health and Long-Term Care, 2014).

Palliative Care in Canada

In the 1980s the demand for PC in Canada increased. In response, the federal government developed the first *Palliative Care Services Guidelines*. This was followed by the establishment of a national organization, the Canadian Hospice Palliative Care Association (CHPCA). The CHPCA provided leadership for the development of provincial and territorial hospice PC programs and continues to act as a national voice to promote PC (CHPCA, 2019).

Despite the creation of provincial/territorial palliative programs, gaps in access remained evident. In 2004 the Canadian Virtual Hospice (CVH) was created by a group of PC leaders across Canada, to improve access to palliative specialists, for clients, families, and health care providers. Last year, over 2 million people accessed the CVH for evidence-informed content and to have their personal questions answered by an interdisciplinary team that includes an Indigenous Elder (CVH, 2021).

Advance Care Planning

Advance care planning (ACP) is about making a plan for future health care needs. Health care teams often support clients and families to develop an ACP that respects the client's values and beliefs, identifies what kinds of health care the client wants, and assists the client to identify a substitute decision maker (SDM) that will make decisions on the client's behalf only when the client is unable to do so (Luckett et al., 2014).

Respect for individual choice at the EoL is a client / patient right. According to ACP Canada (2021), although 80% of Canadians believe ACP is important, fewer than 1 in 5 Canadians has an ACP. A palliative approach to care promotes the integration of early ACPs.

In June 2021 ACP Canada released an online resource guide for HCC providers to promote best practices in ACP in the community (CHCA & CHPCA, 2021). Lakehead University has developed culturally safe ACP resources for Indigenous populations in Canada.

Medical Assistance in Dying (MAiD)

Since June 2016, Medical Assistance in Dying (MAiD) has been a legal option across Canada for competent adults who clearly consent to the termination of life and who have an irremediable condition that causes enduring suffering that is intolerable, and death is reasonably foreseeable. Following extensive consultation, the MAiD law was strengthened in 2021 and is now an option for eligible persons whose death is not reasonably foreseeable. Canadians have the right by law to request an assisted death. Clients receiving PC may choose MAiD to be part of their care path (Government of Canada, 2021).

Ontario's *Compassionate Care Act*

There is new legislation in Ontario aimed to support equitable access to PC across the province, with a focus on underserved populations, including First Nations people. The *Compassionate Care Act* came into force in June 2021 and will build a framework to ensure that every child and adult that could benefit from PC has access to wholistic, culturally safe, quality care in a timely manner (Legislative Assembly of Ontario, 2020; OPCN, 2021).

Palliative Care in First Nations in Ontario

The majority of First Nations people indicate they would prefer to spend their last days in familiar surroundings with their family and in their First Nation.

There are 133 First Nations in Ontario, representing the largest Indigenous population in Canada (374,395), 23% of which live on reserve (Chiefs of Ontario, 2021; Statistics Canada, 2016). Six Nations has an on-reserve population over 12,000, however, the majority of communities are much smaller (under 1000) and are located in rural and remote parts of the province.

Although most First Nations people in Ontario have a primary address outside of a First Nation community, the majority indicate that they would prefer to spend their last days in familiar surroundings with their family and in their First Nation (Walker et al., 2019; Kelley et al., 2018). There are at least seven major First Nations cultural and linguistic groups. Each group carries their own customs and beliefs regarding death and dying, some of which are known, while others remain protected. Broadly, death is viewed as part of the natural life cycle (Chiefs of Ontario, 2021; Kelley et al., 2018).

Various levels of inequity exist due to a complex array of factors including: federal / provincial jurisdictional issues; complicated service delivery models of care; funding formulas; and rural/remote/isolated locations.

The level of health service available to First Nations people living on-reserve varies between communities. Various levels of inequity exist due to a complex array of factors including: federal / provincial jurisdictional issues; complicated service delivery models of care; funding formulas; and rural/remote/isolated locations. Within First Nations, PC is delivered through the local HCC program that partners with external organizations to meet the needs of clients and families. The delivery of PC services is most effective when it builds on existing strengths and understands the inherent values, beliefs, and culture of people (Fruch et al., 2016).

First Nations have been providing palliative care to their people long before colonization. Despite the challenges First Nations have faced, they have always demonstrated resilience and creativity, caring for their most vulnerable to the best of their ability.

Historically, the experience of imposed colonialism, accompanied with ongoing racism and discrimination, has created feelings of distrust and trauma in many First Nations people. Experiences with institutions outside of First Nations, such as hospitals, can be culturally unsafe, anxiety producing, and may re-traumatize individuals. As the demand for PC increases, efforts to provide care closer to home supports cultural safety (ISC, 2017; Kelley et al., 2018).

Effective PC requires timely pain and symptom management as well as basic supplies and equipment. The Non-Insured Health Benefits (NIHB) program provides coverage for medically necessary goods and services for First Nations clients (ISC, 2021). Under the NIHB PC formulary, First Nations individuals near the EoL who meet the eligibility criteria have access to specific medications and supplies (ISC, 2021).

It is important to remember that First Nations have been providing PC to their people long before colonization. Despite the challenges First Nations have faced, they have always demonstrated resilience and creativity, caring for their most vulnerable to the best of their ability (based on human and/or financial resources) despite never being well resourced to do so.

Palliative Care Education and Training

When PC was recognized as an essential service element within the First Nations HCC program, communities worked to strengthen their competencies. Clients, families, and health care providers can access competency-based PC education and training through a variety of Canadian sources (see Appendix B). Many of the available resources are either First Nations specific or have adaptations to include various cultural backgrounds.

PURPOSE / RESULTS OF THE SURVEY AND FOLLOW-UP INTERVIEWS

In the fall of 2020, Ontario Region, First Nations and Inuit Home and Community Care Program funded the SE First Nations, Inuit and Métis (FNIM) Program to conduct a palliative and EoL survey and follow-up interviews to collect information as a method to inform the development of a PC strategy. The goal of the strategy is to support First Nations in Ontario to provide equitable access to culturally safe, quality PC services for clients and their families.

Initially, the focus of the project was specifically on the provision of EoL service delivery. However, it was quickly apparent that separating EoL care from the PC continuum was difficult as the factors that occur early on the PC continuum inevitably impact the provision and quality of EoL care. Therefore, the project pivoted to understand the factors and barriers that exist within First Nations that impact quality, accessible care along the whole PC continuum.

Key Ontario-Based Palliative Care Initiatives

Three key PC initiatives informed and guided the development of the Exploratory Survey on EoL Services and Communities' Delivering EoL Care Interview questions.

I. Developing Palliative Care Programs in First Nations Communities:
A Workbook (EOLFN, 2015)

The workbook is the result of a five-year project with First Nations in Ontario and Manitoba. It provides guidance to First Nations in the development of community-based PC programs. A flexible community development approach is presented that is grounded in community values, principles, and culture. A summary of the resource is available in Appendix C, along with a visual of the process of PC program development (see Appendix D).

II. Palliative Care Standards, Health Quality Ontario and the Ontario Palliative Care Network (OPCN) (2018)

Ontario’s PC Standards were developed to promote best practices that support clients, families, health care workers, and organizations (see Appendix E).

III. Palliative Care Health Services Delivery Framework, OPCN (2019a)

The PC framework presents recommendations that help put the PC Standards (2018) in to practice in a manner that is wholistic, equitable, proactive, and timely (see Appendix F).

Recommendation #11 is specific to First Nations:
“The First Nation, Inuit, Metis or urban Indigenous patient and their family/caregivers will receive PC that utilizes a grassroots, participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.” (p. 4)

Methodology

> **"*Community Voices* needs to be loud and clear and far-reaching". (Six Nations)**

Home and Community Care team members working in Ontario First Nations were the audience for the survey. The surveys were completed online using Survey Monkey and consisted of 97 questions, including a combination of multiple choice and short answer questions. Survey results were collected between February and April 2021. A total of 67 health care workers completed the survey. Survey participants were also invited to sign up for a phone interview to further share their thoughts regarding PC. A total of 25 respondents (64%) volunteered for a follow-up phone interview. The interviews were approximately 30-60 minutes in length and took place between April and June 2021. Interview responses were transcribed, results were compared, and themes identified to help inform and guide the development of a First Nations Palliative Care Strategy.

Participating First Nations were given opportunity to review the *Community Voices* report prior to finalization to ensure authenticity and to promote reciprocity in the data collection process. Along with the draft report, participants were given a survey that consisted of 12 questions to validate the findings of *Community Voices*. Questions asked in the validation survey appear in Appendix P. Overall, sufficient feedback was received to validate the report. Participants consistently reported that they felt they the *Community Voices* report reflected their current reality in delivering palliative and EoL care within their communities and that that it would bring opportunities to ensure equitable palliative and EoL services within Ontario First Nations. In the words of one reviewer: **"I am very hopeful for the future of Palliative Care in First Nations Communities"**

Survey

There were five sections to the online survey (see Appendix G) collecting both quantitative and qualitative data:

I. Community Information
II. Home Care Program and Team
III. Key Roles and Current Level of Services
IV. Enablers to Palliative and End-of-Life Care
V. Physical Resources

Interviews

The follow-up phone interview was designed to gather qualitative data to enrich the understanding of PC from the health care worker's perspectives (see Appendix H). The interview consisted of six questions aimed to broadly explore strengths, wise practices, barriers and challenges in delivering PC care in First Nations. Since the phone interviews were conducted with people that had already completed the online survey, the interview used the survey results to inform the interview process.

Limitations

The World Health Organization declared COVID-19 a global pandemic in March 2020. When the survey went out to First Nations, they had been dealing with the realities of the pandemic for a full year and every community was forced to shift priorities. The pandemic likely affected the survey/interview response rate (non-response bias), however, it also drew attention to the importance and increased demand for culturally safe community-based PC.

Survey / Interview Results

The survey /interview results are presented using the headings of the five sections of the online survey. For each section the results are presented separately by survey results and interview results.

I. **Community Information**

Survey Results

The online survey invited participation from HCC teams. The survey was emailed out in February 2021 to all 133 First Nations in Ontario and 67 responses were received from 40 First Nations/ tribal level organizations. Although the raw numbers suggest a 30% response rate, at least six of the responses reflect tribal level organization responses, indicating greater community response representation. All five Political Territorial Organizations (Anishinabek Nation; Nishnawbe Aski Nation; Grand Council Treaty #3; Association of Iroquois and Allied Indians; Independent First Nations) are represented in the responses (see Appendix I for map of Ontario First Nations / tribal- level organizations).

In Ontario, 83% of First Nations have a Health Centre (more common in rural locations) and 11% have Nursing Stations (more common in remote and isolated locations).

- The majority of community / tribal-level responses represent rural communities (80%, n=51) that are defined as having road access to medical services within a 20-90 km distance.
- 5% (n=3) of responses reflect remote communities, where road access to medical services is greater than 90 km.
- 16% (n=10) of survey responses come from isolated communities. Isolated communities are those without year-round road access, these communities can be reach by air or winter roads.

Survey responses represent all population categories: 56% of respondents work in First Nations of less than 1000 people; while 44% work in First Nations with populations greater than 1000.

Interview Results

Over half of the survey respondents volunteered to take part in the follow-up phone interview. A total of 22 interviews were conducted, representing 16 First Nations and 3 tribal-level organizations. Although the majority of First Nations respondents came from rural communities (n=11); remote (n=1) and isolated (n=4) First Nations were also represented. In terms of population, small (less than 500; n=7), medium (500-100; n=4), and large (1000+; n=5) First Nations were all represented in the interview responses.

The three tribal-level organizations that participated in the interview are: Fort Frances Tribal Area Health Services; Maamwesying North Shore Community Health Services; and Windigo First Nations Council.

II. Home and Community Care (HCC) Team

Survey Results

> **Despite the wide population differences from First Nation to First Nation, more than 70% of all responding communities indicated that they have over 30 Home and Community Care clients.**

The survey gathered insight from HCC team members. The respondents reflect the make-up of the HCC teams and can be categorized into three broad groups:

- Health Care Professionals (HCPs) 31% (n=18)
- Community Based Workers (CBWs) 31% (n=18)
- HCC Leaders 38% (n=22)

A closer look at the three groups helps to further expand our understanding of the make-up of each category:

- HCPs: (HCC Nurses (n=15); CHNs (n=2); Dietitian (n=1))
- CBWs: (PSWs (n=11); CHR +Wellness Workers + HSWs (n=7))
- HCC Leaders: (Coordinators (n=16); Case Managers (n=4); Directors (n=2))

Teams are managed by HCC managers/coordinators that are employed at the First Nation or tribal- level organizations; 96% of respondents indicated available support at this level. Similarly, 96% of First Nations have nurses in the community as part of the HCC team and most First Nations have more than 1 nurse and some of the larger First Nations / tribal- level organizations have 10 or more nurses.

The most common category of health worker on the HCC team is the personal support worker (PSW). Not only do 98% of First Nations report having PSWs as part of the team, the average number of PSWs is ~5. Approximately half of the First Nations report having CHRs (community health representatives) and/or HMs (homemakers) as part of the HCC team, however, the actual number of CHRs and HMs is significantly less than PSWs.

Despite the wide population differences from First Nation to First Nation, more than 70% of all responding communities indicated that they have over 30 HCC clients. These clients and their families are cared for by HCC teams that vary in size from 2 members to over 100 members.

Palliative Care Education and Practice Guidelines

Over 70% of HCC staff believe they have the competencies to provide palliative and end-of-life care but only 37% report having established policies and practice guidelines.

Survey participants were asked if their HCC team had the skills, knowledge, and comfort to provide palliative and EoL care. Over 70% of respondents believe that the HCC staff possess these competencies. This is significant, since only 37% report having established policies and practice guidelines to support clinical decision making.

Interview Results

The survey respondents that volunteered to participate in the follow-up interview represent all three categories of HCC team members, however, there is a higher percentage of HCC leaders (n=11) and health care professionals (n=7) versus community-based workers (n=1). One of the HCC leaders is a health director. The three tribal- level organizations interviewees hold leadership positions.

Palliative Care Education and Practice Guidelines

Both First Nations and tribal-level respondents report that their teams have developed their PC competencies through available training (see Appendix B). Most common training cited includes:

- End-of-Life First Nation (EoLFN) resources through Lakehead University (2015)
- LEAP Program through Pallium Canada (2021)
- CINA / SE FNIM Program: Palliative / End-of-Life Care in Indigenous Communities online course (2021)
- SE FNIM Program: Supporting Natural Caregivers online course (2015)

When asked about practice guidelines, all respondents agree and recognize the value of guidelines to support clients, families, and health care workers. However, there is a lack of consistency in the use and identification of guidelines.

"We have a lot of resources on it (PC)*… and HCC policies, but we need a palliative care strategy"* (HCC Coordinator, Biigtigong Nishnaabeg).

Only 37% of respondents report having established policies and practice guidelines to support clinical decision making. When guidelines are specifically identified, the two most common PC guidelines mentioned are:

- EOLFN resources developed by the Centre for Education and Research on Aging and Health at Lakehead University in northern Ontario (Thunder Bay) (EOLFN, 2015), and

- Registered Nurses Association of Ontario (RNAO) Palliative Care Best Practice Guidelines (RNAO, 2020).

In Tyendinaga Mohawk Territory, the HCC manager indicated the HCC team uses the Registered Nurses of Ontario (RNAO) PC guidelines and integrates local cultural practices that reflect Traditional knowledge and spirituality.

Some First Nations / tribal organizations are working to develop their own PC models. Maamwesying North Shore Community Health Services continues to work on a *"palliative care model which we call the Creators Care"*. The model is described as a wraparound service to support communities; however, at the time of the interview, funding has not yet been secured. In Attawapiskat First Nation, they use the policies and procedures from a partner organization, Weeneebayko Area Health Authority (WAHA) to guide care.

III. Key Roles and Current Level of Services

Survey Results

> **Since the start of the COVID-19 pandemic, respondents (59%) have noticed an increased interest in people choosing to die in at home, in their First Nation. Despite this increased interest to die at home, over 85% of clients with a terminal illness that come home to die, end up going to the hospital (or other location) to die.**

At least 75% of First Nations that responded indicate that their HCC team provides palliative and EoL care services, the majority (59%) of which have been doing so for over 12 years. As expected, 95% of First Nations provide service delivery during day-time business hours, with deceasing coverage in the evening hours (48%) and on weekends (62%). Virtual support is available for clients and family / caregivers by phone in 55% of First Nations. Virtual services include nursing visits in 29% of First Nations and nursing support for PSWs (24%).

According to the survey results, the majority of First Nation members (75%) are aware that dying at home in their First Nation is an option, although many (45%) who are terminally ill put off making plans. Since the start of the COVID-19 pandemic, respondents (59%) have noticed an increased interest in people choosing to die in at home, in their First Nation. Despite this increased interest to die at home, over 85% of clients with a terminal illness that come home to die, end up going to the hospital (or other location) to die when care needs become too heavy or pain and symptom management is not effective. The majority of First Nations do not have access to a community-based hospice-type setting or a hospice within a 30-minute drive of the First Nation. The average number of deaths per First Nation/tribal organizations reporting, per year is approximately 11, with a range of 0 to 107 deaths.

Medical Assistance in Dying (MAiD)

In most First Nations (76%), information about MAiD is either not provided or not provided consistently to clients at the EoL. Although the reasons for not providing information about MAiD varied, the most common response indicated that this responsibility rested with another individual or organization (e.g. doctor, hospital, Local Health Integration Network (LHIN)).

Eleven (11) respondents reported that they had experienced a request for MAiD from an HCC client. Nine (9) respondents indicated that MAiD has been used in their First Nation in the past year; one of the respondents indicated MAiD had been used four times in the past year.

Prescriber / Pharmacy

End-of-life care includes helping the dying person to be comfortable; this includes pain/symptom management. Good pain/symptom management requires access to a prescriber that is familiar with the client situation and a pharmacy that is able to fill the prescription. Both the prescriber and the pharmacy need to be accessible as care needs change, especially as EoL approaches.

The majority of respondents (57%) indicated that their First Nation has regular consistent access to a prescriber who is comfortable in providing care to clients until the EoL. Although the majority of prescribers (52%) have coverage when the primary prescriber is away, access to the prescriber is limited and pharmacy access to fill the prescriptions is even more restricted.

Access	Prescriber	Pharmacy
24/7	37%	2%
Weekday business hours	67%	94%
Weekday evenings	30%	6%
Weekends	27%	38%
Other	Some First Nations have emergency support coordinated with local nursing stations / pharmacies / hospitals.	

When access to the prescriber and / or pharmacy is impaired, delays in receiving medication occur. The survey revealed that the average delay is 1-2 days; 19% of the respondents indicated that there is not a problem with delays; and one response identified the NIHB program's approval process as contributing to delays.

Although 96% of respondents agree that 24/7 access to pain/symptom management is important, less than half (48%) indicate that their community has achieved this goal.

Interview Results

First Nations interview data revealed the flexibility and creativity of HCC teams to stretch coverage beyond funded day time hours to provide PC to support clients and families.

"We do provide end-of-life care; however, we don't have any true funding…to support that care, (but) *we still provide it. It's not necessarily 24-hour care, but we're flexible. So, if there's somebody that needs night time services, we are able to adjust our work schedule to accommodate that or we hire somebody to come in…"* (HCC Manager, Atikameksheng Anishnawbek).

In Attawapiskat First Nation, the nurses also flex their shifts to provide more coverage. The last nurse of the day visits the family and sets up the medication, including breakthrough pain medication for the client, *"I explain/educate the family to give the medication…"*

Medical Assistance in Dying (MAiD)

Interview responses from First Nations that have had clients choose MAiD, report consistently positive experiences for the client, family, and staff. First Nations work with external agencies to support the coordination of MAiD. The HCC coordinator from Algonquins of Pikwakanagan described a situation where a client requested MAiD, the community responded by creating a make-shift hospice out of a house that happened to be empty at the time, *"it was set up and we allowed her to move in…the services were set up for PC / EoL care until the MAiD program came in."*

Prescriber / Pharmacy

Even when a prescriber is accessed, the medication is not always available.

Many First Nations report that timely access to medication for pain and symptom management is key to making their PC efforts effective. However, there are reports of challenges related to:

- Timely access to prescribers;
- Delays related to NIHB approval/coverage;
- Physicians that are not familiar with EoL medications and care;
- Lack of availability of medications in the pharmacy when prescribed;
- Transportation challenges to deliver medications in a timely manner; and
- Lack of access to 24/7 specialists, to prescribe required medications, guide care, answer questions and support staff and family.

An HCC nurse at Kingfisher Lake First Nation also works in Ottawa with PC clients; this nurse reports having access to a prescriber in Kingfisher Lake First Nation, and emphasizes the need for access to specialists that *'understand the use of end-of-life medications'*. The nurse recognizes that even when a prescriber is accessed, the medication is not always available. The nurse advocates for First Nations to have pre-planned '*EoL care* (medication) *kits*' (also referred by others as 'symptom relief kits').

Many of the nurses that work in First Nations have experience with PC clients in other settings. At least three other nurses interviewed talked about the need to coordinate access to *'PC symptom relief kits'* (Tyendinaga Mohawk Territory, Wikwemikong Unceded Territory, Sagamok Anishnawbek First Nation).

End-of-Life / Death Doulas

A number of interview reports mentioned the use of community-based End-of-Life / Death Doulas (EoL/DD), however, it was unclear if any First Nations actually employ someone in this capacity, or if the terminology is culturally acceptable. More information, especially regarding the role of the EoL/DD is required.

IV. Enablers to Palliative and End-of-Life Care

There are a number of factors that work to enable palliative and EoL care, these factors have been grouped together under the following headings:

- Culturally Safe Care
- Palliative Care / Advance Care Plans
- Funding
- Collaborative Partnerships
- Virtual Care

Culturally Safe Care: Survey Results

A community-based end-of-life program must include input from local experts and Knowledge keepers in order to be culturally safe and effective.

All respondents (98-100%) agree that clients who are at the EoL should have access to culturally safe care that address their wholistic needs including: emotional; mental; spiritual; practical and social support needs. According to the survey results, these needs are met in a culturally safe manner on average, 68% of the time (range 64-71%).

Over half of respondents (55%) reported that the community has regular, consistent access to Traditional-based healers and natural caregivers. Some First Nations have established education/training for natural caregivers (41%) and established relationships with them as part of the HCC team (48%).

There is clear acknowledgment (97%) that a community-based EoL program must include input from local experts and Knowledge keepers in order to be culturally safe and effective. Over half (51%) of the respondents indicated that their First Nation has such local expertise to help develop a program. When asked to identify a potential EoL community leader the responses varied. The most common response included a person in a health care provider role, the second most common category identified respected Elders.

Culturally Safe Care: Interview Results

Interview respondents explain how natural caregivers play a role in promoting culturally safe care. Atikameksheng Anishnawbek is a small (less than 500 people) First Nation in central Ontario. When someone in this First Nation is dying, the health care workers know how to reach out to the natural caregivers:

"If I know a person is requesting a cedar bath or a person is dying, and they want to have drumming, or we need a sacred fire…I know who to reach out to, and so does most of the community." (HCC Manager, Atikameksheng Anishnawbek)

Some of the communities that Windigo First Nations Council serves use the local radio station to reach out to natural caregivers when a family is in need.

An HCC Manager at Six Nations integrates culturally safe care by establishing Memorandums of Understandings (MoUs), which they refer to as "treaties". These MoUs are created with external partner agencies using *"Traditional concepts…based on trust, respect, honesty, integrity and collaboration."* The HCC team from Tyendinaga Mohawk Territory integrates Traditional knowledge and spirituality into the RNAO PC guidelines. Cultural safety is defined and integrated into PC approaches in a manner that reflects each First Nation's values and beliefs.

Palliative Care / Advance Care Plans: Survey Results

- **Home and Community Care staff recognize the importance of early identification of those who would benefit from a palliative care approach…but only 36% indicate this is a reality.**
- **Fewer than half of communities report that clients/families have access to a multidisciplinary team.**

Respondents (71%) recognize that it is important to identify clients that could benefit from a palliative approach early in the course of their illness. However, only 36% indicate that this is a reality.

Similarly, the vast majority (93%) of respondents believe that clients receiving EoL care and their families/caregivers should have 24/7 access to a multidisciplinary PC team, yet fewer than half (48%) report that this is common within their First Nation. Even fewer (38%) indicate that the HCC team has access to a PC specialist for consultation.

Although 87% of respondents agree that it is important for a care coordinator to be actively involved throughout the duration of a client's EoL care, only 65% report that this is currently happening in their First Nation. First Nations do report that at least 80% of the time, clients with a recent diagnosis of a terminal illness are assessed by an HCC nurse, including a review of their goals of care and a re-assessment when there is a health status change. These actions are recognized as integral to the palliative care process (93%).

Despite the fact that 93% of survey participants view ACPs that includes the identification and participation of a SDM, as important, only half (51%) report that this is commonly happening in their First Nation.

Palliative care includes working with and supporting clients and their families/caregivers throughout the client's EoL care. Although 98% of survey participants agree that this is important, only 68% report that it is commonly occurring in their First Nation. This percentage decreases to 51% when the grief and bereavement phases of the PC continuum are included.

Palliative Care / Advance Care Plans: Interview Results

Fort Frances Tribal Health Services hired a PC coordinator who has EoL doula training, to help support their eight First Nations. The PC coordinator's interview response is reflective of the collective interview responses regarding a palliative approach to care:

"*We need guidelines that help to identify our clients early…to allow for a more planned approach…including conversations to identify what the client's wishes truly are…and develop advance care plans, so that everybody within the circle of care is aware."* (Fort Francis Tribal Health Services)

The need for increased community comfort to talk about death as part of the natural circle of life is apparent in responses that describe clients as 'stoic', withholding their diagnosis until the very end, when it is difficult to coordinate supportive EoL care. (Six Nations)

Interview responses consistently talk about the importance of including family in PC:

"The role that family and the natural caregivers play is probably the most important…we rely on the family, we don't have resources to provide 24 hour (support)*"* (Six Nations).

Although there is a reliance on family, there is also evidence that families need education about what to expect and specialist support to answer their questions.

"Families need to be educated on their loved-one's diagnosis and what it means to bring their loved-one home and how much care is involved and how much they will need to be involved." (Naotkamegwanning First Nation)

Gaps in education or support combined with the stress of increased care needs often results in family *'anxiety/panic/fear'* (Aroland First Nation) that starts a process that ends with the client back in hospital. Some of the interview respondents suggest that if the family had access to a virtual PC specialist, fears and anxiety could be alleviated and a return to hospital avoided.

Funding: Survey Results

All survey participants (100%) recognize that stable funding is necessary to ensure PC is supported. Within current funding arrangements half of all respondents report that their HCC program is able to provide this care always (27%) or at least sometimes (24%).

Qualitative survey data revealed 3 categories of funding gaps:

1. Human Resources:
   Funding to support existing staffing (competitive wages, part-time to full time); adequate staffing (increase number of nurses / PSWs); education and training.

2. Program Infrastructure:
   Funding to support coverage for after hours and on call needs.
   Funding for 24/7 staffing (flexible, as required), especially for EoL care.
   Funding to support specialized equipment and virtual care (VC)/support from a PC specialist.

3. Community Infrastructure:
   Overcrowding in homes, is a barrier to providing palliative/EoL care in the community.
   Funding to support Indigenous hospice options in First Nations.

Funding: Interview Results

Only 29% of respondents indicated that they receive support from provincial palliative care programs in delivering end-of-life care.

Interview results are consistent with the survey results. There is agreement that stable funding is necessary to support the provision of PC. Interviewees' report that as an individual transitions to EoL care, the amount of resources (human and physical) required by the client and family usually increases. Despite the creative efforts of HCC teams to stretch coverage, it is evident that additional funding is needed to support the increased needs of clients/families.

"One of the biggest challenges is staffing, we just don't have enough staff to provide support, the way it is needed. It's very, very hard on everyone." (Chippewas of Rama)

"We do provide end-of-life care; however, we don't have any true funding …to support the care that we do provide." (Atikameksheng Anishnawbek)

Collaborative Partnerships: Survey Results

There is consistent agreement (100%) that it is important to establish and support collaborative partnerships with external organizations in an effort to ensure palliative and EoL care is available and effective in communities. Only 29% of respondents indicated that they receive support from provincial PC programs in delivering EoL care. Despite this fact, there appear to be positive relationships (83%) with various external health partners.

Collaborative Partnerships: Interview Results

Every First Nation and tribal-level organization interview revealed collaborative partnerships with external partners to support PC. The partner agencies vary from community to community. The most common partnerships mentioned are: nearby hospitals/primary care groups; long-term care facilities/Elders' lodges; hospice centres/PC centres; provincial health organizations (Local Health Integration Networks-LHINs); and help-lines. Overall, the partnerships are recognized as necessary and described in a positive manner. First Nations work to ensure care extended to clients/families is culturally safe. One of the nurses from Oneida Nation of the Thames helps external partners understand client choices related to EoL based on local belief systems (Traditional and Christian) and client history (survivors of residential school) to help support culturally safe care.

Tyendinaga Mohawk Territory created partnerships with external health systems and established competencies within their local network to build an "*Indigenous Interdisciplinary Primary Care Team*", sharing:

> *"Our nursing staff is available 24/7 as well. We do have on call services and with palliative, like I mentioned, we make sure that a team is available whether that's a team of nurses or whether we have our community support worker with us. It's important to be available to the family in a pair because there's often more than one person there".*

Six Nations share their creative approaches in collaboration and creating partnerships:

> *"So, the outcome of those things includes providing palliative care end of life in client's homes. We do it in our long-term care facility as well. And we have an MOU with the local Stedman hospice in Brantford. And we have our own outreach team, a shared care team at Six Nations and it's based on some funding through the province as well as some federal funding that we're able to provide basically 24/7 care through a collaboration with the LHIN services".*

Virtual Care: Survey Results

Virtual care (VC) options were available before the COVID-19 pandemic; however, the pandemic has increased interest and support for virtual connections. Over 90% of participants agree that access to VC is important, however at least 1 in every 4 First Nations still struggles to attain reliable access to the Internet. Still the majority of communities use VC to support EoL care through:

- Phone appointments (100%);
- Phone consults (85%);
- Telemedicine (69%);
- Videoconferencing (65%); and
- Email consults (38%).

Participants (71%) believe that additional VC could easily be integrated into their current health service model.

Virtual Care: Interview Results

Interview results revealed that not only has the COVID-19 pandemic increased interest in VC, it has also increased optimism and community support. Some First Nations shared how laptops are used to connect with those in isolation (diagnosed with COVID) with concerned family:

"We purchased laptops…clients in the hospital could talk with their family members." (HCC nurse, Algonquins of Pikwakanagan)

One Tribal Council shared their creative approach in bringing VC into practice:

> *"Like we do Facetime and not necessarily just for palliative care, but definitely for palliative care too. I've been to homes where I'm unsure of what dressing I want to put on so I'm doing a Facetime call with the RN at her desk and she's, you know, providing some guidance to me and I'm able to provide that service because sometimes you're not – you know, not everybody can, especially with the pandemic, we have to be a little bit more creative in how we're delivering that care. And we do lots of like pictures and stuff. Families send us pictures, whether it be wounds, medications, whatever it may be so that we're, you know, updating care plans"*

Most of the people interviewed report that their First Nation uses some level of VC to support PC. The most common method of VC is telephone access to doctors/specialists. Some communities are investigating/accessing VC through existing established partner organizations (Attawapiskat First Nation, Chippewas of Rama, Tyendinaga Mohawk Territory, Wikwemikong Unceded Territory).

All respondents agree that timely access to VC and PC specialists would be beneficial to:

- Support clients/families cope with palliative/EoL questions
- Include interpreters to support understanding
- Decrease travel out of the community for specialist consults
- Provide consultation and education to health care providers and family
- Support equitable implementation of PC guidelines
- Avoid/decrease EoL clients returning to hospital, through reassurance and guidance provided by virtual specialist(s)
- Access prescribers to support timely pain and symptom management
- Access PC specialists to guide physical and occupational therapy
- Access PC mental health support for families and health care teams

The biggest concern regarding implementation of VC is connectivity. It is unclear if respondents are aware that palliative and EoL support (consult and education) via telephone can be an effective form of VC and fill in many service gaps (Chavarri-Guerra et al., 2020; Ritchey et al., 2020; van Gurp et al., 2015). First Nations recognize that health staff and community members would require some training and exposure to increase their comfort level with VC.

V. Physical Resources

Survey Results

Most First Nations lack the supplies and equipment required to provide palliative/end-of-life care.

An important part of home-based PC is the safe access, storage, management and disposal of supplies and equipment. The online survey investigated the access to a list of physical resources (supplies and equipment), that were identified as required for PC delivery by the Indian Association of Palliative Care (2007). The results are summarized in the table below.

Supplies and Equipment Available in Communities	
Percent of Communities that have the Resource	**Resources to Support Palliative End-of-Life Care in Home Settings**
90 - 100%	Stethoscope; Blood Pressure (BP) machine; Thermometer; Gloves
70 – 89%	Grab bars; Wheelchair; Walker; Bath chairs; Bedpans; Commodes; Blue pads; Dressing supplies; Cotton balls; Scissors; Needles and syringes; Alcohol swabs
50 – 69%	Oxygen concentrator; Oxygen tubing; Hospital beds; Railings; Incontinent products; Soaker pads; Specialized wound care supplies; Toothettes

Less than 50%	Back rests; Heating pads; Cooling pads; Suction machine; Nebulizer; Mechanical lift and slings; Bed linens / draw sheet; Fan; Suction Catheters; Urinary catheters / drainage bags / catheter trays; Condom catheters; Blunt plastic cannulas / interlink needle-less injection cap / end cap; BD Saf-T-Intima safety system 24 gauge winged SQ infusion device; Transparent, moisture responsive dressings (to keep SQ in place and visible); Pre-filled syringes of 0.9% normal saline for injection

Based on the survey results, it is clear that there are issues related to supplies and equipment considered basic and necessary to provide palliative/EoL care in a home-based setting. The 90- 100% category lists items that would normally be part of an HCC nursing bag. Automated BP machines are currently recommended by the Hypertension Guidelines (hypertension.ca) for use in home care settings; the survey is not able to determine if First Nations have the automated version or the older non-automated version.

Interview Results

Many of the communities talk about effective ‘loan cupboards’, a system that stores and coordinates the use of supplies and equipment (Algonquins of Pikwakanagan, Biigtigong Nishnaabeg, Naicatchewenin First Nation). Loan cupboards are effective if they are stocked with the basic supplies.

At least two communities reported client/family concerns regarding the use of hospital beds, when asked if someone else had died in the bed (Aroland First Nation, Naicatchewenin First Nation).

In addition to overcrowding in houses, safety has also been identified as an issue related to physical resources when coordinating EoL care. The HCC nurse from Attawapiskat First Nation shared a story about a community member that wanted to die at home. The home was assessed as unsafe for the client’s oxygen supply needs. The HCC team put in a request to the Band office for repairs. The client waited in the hospital during the repairs and unfortunately passed before the repairs were completed.

Timing, funding, and jurisdictional issues were identified as barriers in the following supply and equipment example:

“One of the biggest challenges in some cases is the delay in getting certain supplies or equipment…because of funding concerns or having to out source referrals to the LHIN. And again, that could be due to timely interventions, which in the last few deaths we’ve had here on the territory, it has been a time issue. We weren’t in there and involved early enough to get appropriate measures (in place)” (HCC Manager, Tyendinaga Mohawk Territory).

HIGHLIGHTS: PROMISING PRACTICES / CURRENT INITIATIVES

Promising Practices

● **Each First Nation is unique in terms of its culture, geography, proximity and partnerships with external resources.**

The survey and interview qualitative data revealed many promising practices created to support delivery of high-quality programs that make a positive difference. Promising practices are rooted in each First Nation's cultural teachings and values and may be linked to evidence from the health field. Each First Nation is unique in terms of its culture, geography, proximity and partnerships with external resources. First Nations gather ideas from real life practices that may resonate with their reality (HCC, 2011).

Treaties / Memorandums of Understanding (MOUs)

Six Nations is a large community in southern Ontario. They work to establish MOUs with external partners. These MOUs are referred to as *'treaties'* by the HCC manager and are based on Traditional concepts, acting as a form of knowledge exchange which outlines the roles and responsibilities of each party. The MOUs are reviewed on a regular basis and referenced when new staff join the team.

Creator's Circle

Maamwesying North Shore Community Health Services continues to work on a *"palliative care model which we call the Creators Care"*. The model is described as a wraparound service to support communities. At the time of the interview, Maamwesying North Shore Community Health Services was looking to secure funding to implement their model.

Traditional Medicine

Some First Nations and organizations (Algonquins of Pikwakanagan, Fort Frances Tribal Area Health Services) talked about supporting clients/families dealing with EoL issues with the offering of Traditional medicines (pouch/basket). Since the interview did not ask specifically about this supportive cultural practice, it is likely that the practice is wider spread. The Traditional medicines offered to help support the client/family, contain medicines that reflect the beliefs of that community, such as tobacco, cedar, and sage.

Creating a Hospice Setting

Home and Community Care teams work with community supports to help to create positive, safe spaces for clients to spend their last days. Few First Nations have resources such as a long-term care facility, Elders' lodge/residence, hospice or hospital. Most First Nations are dealing with chronic housing challenges including overcrowding and safety issues. This has a direct effect on efforts to create space for safe, quality palliative / EoL care.

Although Sagamok Anishnawbek First Nation partners with a hospice in nearby Espanola hospital to support EoL care, they also have an Elders' Lodge in the community. One of the apartments in the Lodge has been designated as a hospice suite, *"to help support people who want to stay in the community, that aren't able to stay in their own home."* The HCC manager of Sagamok Anishnawbek First Nation identifies an additional advantage of using the Lodge, stating that it is much easier to increase staffing in accordance with client needs in a setting that is staffed 24/7.

Other First Nations work to upgrade houses to accommodate medical equipment or convert temporary vacant houses to a hospice-like setting to allow clients to spend their last days in their home land.

Building Relationships to Support Early Conversations/Planning

The HCC manager from Naicatchewenin First Nation recognizes the importance of building trusting relationships with the client and family to support early open discussions that focus on hearing the '*voice of the client'* and their EoL wishes. First the nurse meets with the client and then with the family, the final step is to bring them together so they can build and understanding of expectations. *"I let them know that this is your plan. This is not my plan, I am only here to tell you the options available."* The nurse ends with: *"If there is something that I haven't mentioned that you think you need, then let me see how I can help facilitate that."*

The HCC nurse at North Spirit Lake First Nation also practices early conversations with clients regarding a palliative approach to care and EoL care. Despite the fact that it is sometimes difficult to get a 'palliative' designation from the doctor, the HCC nurse introduces ACPs to clients and family that include the identification of a SDM and power of attorney, *"I print off the online forms."* ACP's help to ensure that, *"we are meeting their needs, and have things like equipment set up and ready to go."*

Palliative Care Coordinator

As demand for PC increases, Fort Frances Tribal Area Health Services has hired a PC coordinator with EoL/DD training to support its First Nations. This position will be able to identify strengths and gaps and work with external partners to support First Nations in developing their PC services. The Tribal Council is currently conducting a survey to assess the First Nations' thoughts on palliative/EoL care; supporting EoL education for caregivers; integrating tribal-level counsellors to support grief debriefing for HCC teams and holding monthly PC meetings to allow the teams to *"unload and recharge."*

Care for the Caregivers

> **Caring for caregivers is an area that requires further exploration in all First Nations.**

All three tribal-level interviews expressed concern regarding staff burnout and supporting care for the caregivers. Caregivers in First Nations, especially smaller communities, often have connections to the clients facing their EoL. The other reality is the volume of community deaths—one does not have an opportunity to complete the grieving process for one person, before another person's death (related to any/all causes). This is known as cumulative grief and can be a risk factor for complicated grief, burnout and contribute negatively to staff retention. Caring for caregivers is an area that requires further exploration in all First Nations.

In recognition of this burden, the community of Tyendinaga Mohawk Territory (population ~2,500) ensures that when a client in the community requires EoL care, the care is provided by two health care providers. This pairing approach, *"allows for more support for the client and the family and each other"*.

Maamwesying North Shore Community Health Services and the SE FNIM Program partnered in 2019 on a Ministry of Health and Long-Term Care funded project to co-design with community caregivers a training program to support natural caregivers providing palliative and EoL care within their communities.

Prior to launching the caregiver training program, two, one-day sharing sessions were held to determine the training, resource and self-care needs of natural caregivers. Sharing sessions incorporate a strength-based approach to create an atmosphere for open dialogue and sharing amongst natural caregivers, health care providers and leadership. The sessions also provided an opportunity to celebrate natural caregivers, their role in communities and culture-based approaches to care. A number of skills and knowledge priorities were identified by caregivers, with priority given to the following topics, which formed a 2-day curriculum:

- Traditional practices,
- Illnesses and conditions,
- Medication support,
- Palliative care, and
- Self-care.

Elders and Knowledge Keepers played a key role in the delivery of the education. Learning took place using, sharing circles, scenarios, interactive learning games, case studies, and collaborative learning. A facilitator's guide has also been developed for community health care providers to support the delivery of education. It is the hope of the SE FNIM Program and Maamwesying to develop a train the trainer program to spread the reach of this program to all Ontario First Nations.

The Use of Symptom Response Kits

The OPCN (2019) Framework identifies symptom management kits as an implementation consideration in managing pain and other symptoms. As per the survey data, 98% of First Nations do not have 24/7 access to a pharmacy.

Tyendinaga Mohawk Territory shares their experience in using symptom response kits in palliative / EoL care:

> *"Medication is also a factor that needs to be addressed for end-of-life care and we're also able to get that without any hassle with figuring out who's going to cover it in terms of OHIP or non-insured benefits or private. We have that covered because we are linked to a palliative support team who sends out the symptom management kit when the patient is deemed palliative".*

Current Initiatives

The province of Ontario is a leader in Canada as they assist to pave the way to achieving culturally safe, quality, and equitable PC for all. This is apparent with OPCN's (2019) inclusion of vulnerable populations (First Nations, Inuit, Métis, and vulnerably housed) within their framework recommendations. The recommendations within this framework are intended to "guide communities through transformational change to improve PC in Ontario" (OCPN, 2019, p. 4). Ontario's commitment to PC equity is further reinforced with the recent introduction of the *Compassionate Care Act* (2021) where one of the mandates is to "address health equity concerns around hospice care, including regional equity" (Ontario Medical Association, 2021). Beyond provincial commitments to improving PC, it is also evident that ISC HCC, Ontario Region share this commitment to improving PC services for the communities that they serve. Several current initiatives by ISC, HCC Ontario Region that demonstrate this commitment are presented in Appendix K.

ANALYSIS / DISCUSSION

Significant gaps that exist in the coordination, delivery, and support of palliative care in First Nations across Ontario.

Each First Nation is unique in terms of its culture, geographic location, access to health services, population, capacity, leadership, and infrastructure. All First Nations provide some level of PC services through their local HCC program. Provision varies from community to community based on capacity (available infrastructure, human and/or financial resources). Although PC was not added to the list of essential services for HCC until 2017, First Nations have long been supporting members in their EoL journey.

Despite the strengths and creative solutions of HCC to deliver quality, timely and accessible palliative and EoL care, the data collected within the survey and interview highlight significant gaps that exist in the coordination, delivery, and support of PC in First Nations across Ontario.

The following discussion points provide an analysis of the of the survey and interview findings, while also interweaving promising practices, current initiatives and factors that are known to support the provision of quality palliative and EoL care, as found in the OPCN Framework (2019) and current literature. The discussion is categorized using the five sections of the online survey and concludes with a comparison of the OPCN (2019) Framework recommendations to the realities of palliative and EoL service delivery in Ontario First Nations.

I. Community Information

Survey and Interview Analysis / Discussion

Isolated communities that are serviced by Indigenous Services Canada Nursing Stations have the opportunity to establish processes that involve a collaborative approach among Nursing Station Staff and Home and Community Care teams to offer quality, 24/7 palliative and EoL care in the First Nations they serve.

The online survey and follow-up interview process was successful in reaching a comprehensive and representative sample of HCC health care workers from Ontario First Nations in terms of geography (rural/remote/isolated; north/south); population (small/medium/large); and available local health services (health centre/nursing station). The three tribal-level organizations that participated in the interview contributed data from the north, middle, and southern sections of Ontario. Therefore, it is safe to assume the data presented reflects an unbiased view of the current realities of the PC experiences in Ontario First Nations.

As per an evaluation on HCC services by ISC in 2019, “smaller and remote communities have challenges with adequate services in part due to funding constraints and recruitment/retention issues of qualified personnel”. The same report found that there are gaps in respite and PC services. As per ISC Developmental Plan for 2018-19, there was a commitment to “strengthen the support of health practitioners working in isolated contexts and also to improve the quality of care in these setting” (ISC, 2019). Isolated communities that are serviced by ISC Nursing Stations have the opportunity to establish processes that involve a collaborative approach among Nursing Station Staff and HCC teams to offer quality, 24/7 palliative and EoL care in the First Nations they serve.

II. Home and Community Care (HCC) Team

Survey and Interview Analysis / Discussion

First Nations creatively stretch human resources in an attempt to meet the needs of the regular Home and Community Care clients and the added requirements of palliative care clients/families. However, the lack of surge capacity linked to policy / funding barriers needs to be addressed.

Despite the wide population differences from First Nation to First Nation, more than 70% of all responding communities indicated that they have over 30 HCC clients. This is consistent with the ISC Evaluation of the FNIHCC Program (2019), noting that the ability to deliver quality and effective respite and PC services is negatively impacted by staff shortages. First Nations creatively stretch human resources in an attempt to meet the needs of the regular HCC clients and the added requirements of PC clients/families. However, the lack of surge capacity linked to policy / funding barriers needs to be addressed. Some First Nations report available respite support for family caregivers, although this aspect was not specifically part of the survey data.

There is evidence in the interview data of staffing gaps and ongoing human resource challenges that act as ongoing barriers to the delivery of effective PC including:

- Part-time and rotating staff;
- Inadequate funding to support required health care workers;
- Lack of flexible staffing to respond to changing/increasing needs of PC clients;
- Lack of dedicated funding to address specific EoL needs;
- Staff that come into First Nations that may not be familiar with the culture;
- Lack of competitive wages, forcing local staff to seek jobs in near-by communities.

Palliative Care Education

Palliative care requires specialized knowledge and skills that can be built through competency-based education and training (OPCN, 2019c). First Nations are able to identify and access available PC education and training for members of the HCC team, including health care providers and natural caregivers. They feel their teams have the competencies required to provide safe PC and resources to educate clients / families.

First Nations have demonstrated strength in supporting staff to develop PC competencies. Home and Community Care teams share their knowledge with clients, families, and the members of the First Nation. Teams work together to translate their knowledge into culturally safe approaches and some share these approaches with external partner agencies to promote the cultural competency of all care providers. Some HCC teams work with clients and families to provide individualized education regarding the PC process and what to expect, building competencies within family / caregivers to support their loved ones when they are on their own.

First Nations report that they have access to multiple resources for clients and family, however, they do not elaborate on the resources used. The Aboriginal Cancer Control Unit of Cancer Care Ontario (2014) developed a palliative care toolkit for Indigenous communities. The content tends to be more cancer focused; however, they do include all life-limiting illnesses within the PC continuum. Lakehead University has developed numerous, culturally safe resources to support the provision of palliative and EoL care. The Canadian Virtual Hospice (2011) has Aboriginal EoL videos *'Completing the Circle'* that can be helpful for community- based sessions. A data base / toolkit of Indigenous PC resources would benefit all communities.

Despite the strengths of many First Nations as it relates to PC education, there are gaps in the provision of caregiver education (only 41% of communities report they have established caregiver education programs). Moving forward it will be important to advocate and support access to competency- based, culturally safe education for all levels of the HCC team including natural caregivers, Traditional knowledge keepers, volunteers, as well as interested family members. Many First Nations indicated that they create opportunities for these groups to participate in available educational opportunities. Research supports that education and support for clients/caregivers are critical factors in the provision of a successful home deaths, with a focus on: caring for oneself, learning practical skills, and knowing what to expect (Angelo et al., 2013). The OPCN Framework (2019) advocates that clients/families have 24/7 access to this type of support.

Palliative Care Guidelines

Awareness and use of PC guidelines is less clear. There is some evidence of First Nations using guidelines and implementing 'adjustments' (Algonquins of Pikwakanagan) to make them culturally safe and meaningful at the community level.

Fort Frances Tribal Area Health Services First Nations has implemented the use of an EoL basket that holds Traditional medicines such as tobacco, cedar, and sage. The basket might also contain other items (tea, drumming music, a bible), dependant on client preference.

Respondents believe that the implementation of culturally safe practice guidelines would strengthen PC at the community level guiding:

- Increased community awareness of palliative/EoL options,
- How to have difficult conversations with clients/families,
- Early identification of clients that could benefit from palliative and EoL care,
- Consistent and early implementation of ACP, including the identification of substitute decision makers and increased awareness of options (hospice, MAiD,)
- Access to and use of a PC 'symptom relief kit / medication care kit', and
- Bereavement support for families and debriefing process for team members.

Guidelines are used to influence practice through the implementation of best practices, resulting in high quality care across various clinical areas (Graham et al.; Schunemann et al., as cited in Fearns et al., 2016). As retention of staff in First Nations can sometimes be an issue, practice guidelines can ensure all staff (especially new) are meeting minimum requirements in PC service delivery, promoting some standardization of care in this area. Practice guidelines can also support delegation processes of health care professionals to non-regulated health care workers (PSW), natural caregivers and families.

The challenge is to ensure that First Nations across the province have equitable access to best practices that support clients and their families through the palliative / EoL experience. Although there are numerous palliative care resources, there is no national set of PC guidelines. Instead there are guidelines linked to:

- Provincial programs (e.g. Ontario Palliative Care Network);
- Specific disease groups (e.g. Cancer Care Ontario);
- Professional associations (e.g. Registered Nurses Association of Ontario); and
- Specific aspects of care (e.g. Pain and Symptom Management BC).

Work is currently underway in First Nations in Ontario to develop HCC Policies and Procedures. It is critical that these policies and procedures reflect a palliative approach to care and support the provision of palliative and EoL care throughout the entire PC continuum.

The HCC nurse manager of Sagamok Anishnawbek First Nation reminds us that guidelines would definitely be beneficial; however, front line workers still need timely access to specialists: *"If the physician (prescriber) is not available or not returning your calls, then the guidelines are no good, right?"*

Interdisciplinary Palliative Care Teams

Establishing interdisciplinary palliative care teams that are comprised of community-based and external health care providers is critical.

A key factor in effective PC service delivery is the availability of interdisciplinary PC teams and is a key focus of the OCPN (2019) Framework, referring to effective PC being "delivered by providers at all levels of competency participating as members of an interdisciplinary PC team" (p. 10). "Since palliative care is holistic in nature, it is provided by a team of physicians, advanced practice registered nurses, physician assistants, nurses, social workers, chaplains, and others based on need. The palliative care team works with other clinicians and community service providers supporting continuity of care throughout the illness trajectory and across all settings, especially during transitions of care" (National Coalition for Hospice and Palliative Care, 2018, p.23).

Many First Nations report fragmented interdisciplinary PC teams. Establishing interdisciplinary PC teams that are comprised of community-based and external health care providers in First Nations will naturally impact other areas needing further development in the provision of palliative and EoL services, such as families having timely access to PC support.

III. Key Roles and Current Level of Services

Survey and Interview Analysis / Discussion

Although the majority of Canadians say they want to die at home, only 15% manage to do so (CIHI, 2018). The survey and interview results are consistent with this statistic, indicating that First Nations people that wish to die in the comfort of their home/First Nation usually end up dying in a hospital setting far from home. There is a need to strengthen supportive PC systems in order to honour the final wishes of First Nations people to be able to transition to the spirit world in familiar surroundings (Compassionate Ottawa, 2021).

The majority of HCC teams provide palliative/ EoL care in creative ways with available resources and large caseloads. Teams work with families, volunteers and external agencies to support clients at the EoL. However, there is consistent recognition and agreement that EoL care requires extra staffing, resources, timely access to specialists/prescribers, medications and 24/7 coverage. The need for flexibility in service delivery hours and additional staffing for palliative and EoL was also identified by ISC (2019) in their Evaluation of the FNIHCC Program.

Stretched staffing increases the demand and expectations of family members and caregivers. When the family is no longer able to cope due to increased complexity of care; insufficient pain/symptom management; anxiety/fear; caregiver burnout; or lack of after hour coverage/support, clients end up back in hospital and too often end up dying alone and away from home. This can be devastating for the client, family, and First Nation.

Interview respondents consistently report that family members and natural caregivers are essential and necessary components that enable First Nations to provide palliative/EoL care. Families/caregivers need to be supported. When there are gaps in support, families/caregivers face not only the increased demands of complex care, but also *"stress, fear, anxiety, and exhaustion"*. This is reinforced by the survey data which revealed that almost 85% of clients who come home (to the First Nations) to pass, end up back in the hospital as care needs become too heavy.

The nurse from Kingfisher Lake First Nation describes a situation where a client wanted to die at home, but the care needs increased significantly as the EoL approached,
"We ended up sending them out, because we do not have the staff resources to provide the care they required…it was physically impossible and we were all exhausted."

A nurse from Naicatchewenin First Nation reminds us that when a PC client is added to the HCC list, the other clients still need care: *"Palliative care and end-of-life care is not a small thing to do. It requires a huge amount of commitment and a huge amount of time if you're going to do it and do it right."*

Pain and Symptom Management

The availability of symptom relief kits is essential to ensure optimal pain and symptom management and unnecessary hospitalization as end-of-life nears.

The survey and interview results revealed gaps in the process to coordinate pain and symptom management consistently for clients who require PC, especially as they approach EoL. When pain and other distressing symptoms are not controlled, the stress and anxiety of the situation often triggers hospital admission, where the client too often receives overly aggressive care. This type of treatment is distressing for clients, their families and the HCC team.

Symptom relief kits are standardized packages of medication and related supplies for clients approaching EoL to help relieve unanticipated or rapidly escalating symptoms (Hospice Palliative Care Teams, 2013; 2017). Timing of the placement of kits in homes requires careful consideration, this is an issue that access to a PC specialist could help navigate. First Nations that report having access to and using these kits describe positive experiences. However, it appears that the majority of First Nations do not have access to symptom relief kits. Given the extremely limited hours that First Nations have access to pharmacies, the availability of symptom relief kits are essential to ensure optimal pain and symptom management and unnecessary hospitalization as EoL nears.

Grief and Bereavement Support

Grief and bereavement support in First Nations is of utmost importance.

Grief and bereavement are recognized as the final step of the PC continuum. According to the survey and interview results, First Nations recognized the integral role of grief and bereavement for the family/caregivers as well as staff involved with the client. Robust grief and bereavement support in First Nations is of utmost importance as there are many factors that can potentially spur complicated grief. For example, Indigenous people in Canada have higher rates of avoidable and traumatic deaths due to unintentional injury and suicide (Park et al., 2015).

The three tribal-level interviews all expressed concern for staff dealing with grief and bereavement following the death of a client. This is supported by reports from HCC staff of feeling *'exhausted'* when trying to meet the needs of clients and families in challenging PC situations. Some First Nations coordinate debriefing sessions for the HCC team members following the death of a client. Many communities report supporting HCC staff to attend the wake/funeral of PC clients, although there are limitations in the data to understand ongoing grief and bereavement practices for families/caregivers.

Best practice supports bereavement support / follow-up at these critical times following death (Alberta Health Services, 2013):

- 2 weeks to 1 month
- 3 months
- 6 months
- Anniversary of the death
- Holidays, birthdays and other anniversaries

The process of grief and bereavement support can start before (anticipatory grief) the death of the client, however, this aspect of care was not investigated. Natural caregivers in First Nations play an important role in the grief/bereavement process of families, by providing physical (cooking, cleaning, and transportation) and emotional/spiritual (coordinating wake and funeral) support.

Each First Nation has its own cultural practices around grief and bereavement. Building a culturally safe understanding of these practices will help to inform the best way forward in terms of support for the family, community, and caregivers left behind.

End-of-Life / Death Doulas (EoL/DD)

Palliative care strategies need to include clear direction to continue to support strengthening PC competencies for health care providers and First Nations. A number of interview reports mentioned the used of community-based EoL/DD, however, it was unclear if any First Nations actually employ someone in this capacity, or if the terminology is culturally acceptable. A possible explanation for health care provider reluctance in having PC conversations with clients/families may be culturally-based. Interview results talk about the importance of community support demonstrated through natural caregivers, Traditional knowledge keepers, and Traditional healers. There may be a community-based feeling that EoL conversations should start with a more culturally safe Traditional person/approach, however, this answer lies within First Nations.

Although there is currently no regulation or certification for EoL/DD in Canada, there is an End of Life Doula Association (2021) that has information about education programs and resources. This may be an option that First Nations want to build community comfort around palliative/EoL care; spread awareness of available options; integrate culturally specific ceremonies, medicines, and prayers in accordance with the client's values and beliefs; and promote knowledge exchange with external partners.

Indigenous Palliative Care Coordinator

Similar to Indigenous Transition Coordinators, an Indigenous Palliative Care Coordinator (Indigenous PCC) role can assist to remedy the issues related to the lack of surge capacity in First Nations. This role should be multifaceted and broad and used in all areas from navigation to bridging gaps with external organizations to mentorship (practice support/education/consultation) for community-based HCC teams. As per Persut et al., 2017, “a nurse-led navigation service can meet the unique needs of rural communities by enhancing support and access in the face of limited healthcare resources” (p. 8). It would be expected that these positions would work closely with Regional Palliative Care Networks and that they would use the OPCN Framework guiding principles.

The Indigenous PCC would work closely with communities to build on existing strengths and identify solutions as needed that best suits the needs of their communities. Solutions should be chosen to reinforce or build upon what is currently being done in each community to support palliative and EoL care. The Indigenous PCC is not intended to replace the role of the HCC team; instead, is being visualized as a supplementary / complementary role. “Implementation (of PC Coordinators) in rural contexts should follow a similar community-based approach, which draws upon existing palliative champions who are well known in the community, to maximize the potential for sustainability and effectiveness” (Pesut et al., 2017, p. 8). Envisioned as a 1-800 number and 24/7 resource, consideration will need to be given to how these coordinators are supported within a broader structure to develop competencies, skills, and relationships to navigate pathways, partnerships, and resource connections to support communities and to advocate where gaps exist.

IV. Enablers to Palliative and End-of-Life Care

Interview and Survey Analysis / Discussion

First Nations recognize the importance and necessity of the linkages to external organizations to support the provision of palliative care.

There are many factors that work together to enable palliative/EoL care in First Nations. Over the years, each First Nation has worked to establish partnerships with external organizations that can support clients and families with their PC needs. All First Nations recognize these linkages as important and necessary, however, the effectiveness is often relationship dependent.

Home and Community Care teams help to establish cultural safety by integrating natural caregivers and Traditional knowledge keepers and providing education for external providers to help them understand and respect community specific culture.

The lack of 24/7 staffing support and palliative care specialist access results in situations that deteriorate rapidly, despite the best efforts of Home and Community Care teams and family/caregivers.

First Nations have been successful in building PC competencies of their team members. Working in situations burdened with housing overcrowding and minimal access to hospice-type settings, HCC teams collaborate with families to provide the best care possible. There are aspects of a palliative approach to care as outlined by provincial standards that are beyond the reach of First Nations under the current funding realities (OPCN, 2019a, 2019c). Current HCC systems lack surge capacity. As a client nears the EoL and care needs increase, local health care teams struggle under policies / funding models and are unable to respond. The lack of 24/7 staffing support and PC specialist access results in situations that deteriorate rapidly, despite the best efforts of HCC teams and family/caregivers. The result is predictable: care needs are overwhelming, pain and symptom management is not effective, anxiety increases, and the client is transferred to hospital. The experience leaves those affected feeling exhausted and inadequate.

Culturally Safe Care

Perhaps the single most important aspect of all the work around palliative and EoL care is to promote a culturally safe space for the person that is passing from the physical world to the spiritual world (Compassionate Ottawa, 2021). For First Nations people, the comfort of familiar surroundings, people, language, music, and culture holds special significance. According to Elder Annie Smith St.-Georges, "you cannot leave one-quarter of the (medicine) wheel out", spiritually needs to be supported with comforting rituals that will help the client and family cope (Compassionate Ottawa, 2021).

In order to provide effective health care for First Nations, cultural safety must be intertwined within all aspects of care and within all health care systems (Allan & Smylie, 2015; Ward et al., 2016).

Early Integration of Palliative Care

The concept of PC originated around EoL cancer care. Although the definition of PC has moved beyond cancer and extended beyond EoL, there is a reluctance from clients, families, and health care providers to discuss PC or to label a client as 'palliative' (CIHI, 2018; Firth et al., 2019). There is a need to continue to normalize, and educate First Nations in relation to, the concept of a PC approach. The work of Lakehead University and McMaster University must continue to emphasize education regarding a palliative approach to care in First Nations. There is also a need for an internal, community-based individual (e.g., EoL/DD) to provide education and normalize the palliative approach to care for First Nations.

Early identification and integration of PC is important because it is linked to better outcomes for clients, families, and health care workers including:

- Improved quality of life for clients and their families;
- Better symptom control, reduced anxiety and pain;
- More support for emotional, social, and spiritual needs;
- Reduced avoidable hospitalizations and aggressive treatments;
- Improved physical and emotional outcomes for clients and families;
- Coordination of ACPs and SDM;
- Coordination of medication, supplies, equipment, and housing;

- Coordination of multidisciplinary support; and
- Provision of education regarding the illness, what to expect, and options.
  (CPAC, 2017; ElMokhallalati et al., 2020)

In the PC Workbook developed for First Nations by a Lakehead University research team (EOLFN, 2015), PC is defined as:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. It begins when a person has been identified as having a progressive, life-limiting or terminal disease that cannot be cured and is particularly important in the last year of life (p. 4).

All chronic diseases, like diabetes, heart disease, lung disease, cancer and dementia can be defined as life-limiting illnesses; the key is to identify these clients early, as they can benefit from a PC approach. Many of these people will become HCC clients as they will likely require on-going supportive services. Some communities have kept the practice of maintaining chronic disease registries, although it is unclear of how this practice influences case management / early identification. The work being done by McMaster University might assist HCC teams in identifying / recognizing individuals that would benefit from an early palliative approach to care.

Hospital Discharge and Identification of Palliative Care Needs

There are mixed reviews from the interview responses regarding the effectiveness of hospital discharges for individuals with life-limiting illnesses. Positive reviews are more likely to come from systems that include discharger planners.

Another critical factor for community-based teams is the ability to recognize when an individual's chronic disease has progressed to a point where they will require an increased levels of services or are approaching their last year of life (CSPCS, 2016).   Disease trajectories are highly variable and not easy to predict (Evans et al., 2019; Hsu et al., 2021; Rocker et al., 2016). Identification of early PC can also happen when someone is discharged home from the hospital. These transitions in care are critical and vulnerable points in the management of individuals with life-limiting illnesses. Effective hospital discharges include: comprehensive assessment; identification of early PC needs; education of clients/family; communication with First Nations to support seamless transition that allows time for the community to establish required medication; supplies, and equipment (HQO & OPCN, 2018).

There are mixed reviews from the interview responses regarding the effectiveness of hospital discharges for individuals with life-limiting illnesses. Positive reviews are more likely to come from systems that include discharger planners, for example Attawapiskat First Nation, and Sagamok Anishnawbek First

Nation. In First Nations that do not have discharge coordinators, the Indigenous Transition Coordinators (where available) can fill this gap, promoting effective discharge planning of individuals back to their communities after hospitalization.

"A systems navigator, hired through Mnaamodzawin, follows clients from admission through to discharge…they will know what equipment and support the client will need…in the community, we start working on the care plan from the get-go, which is very helpful." (HCC nurse manager, Sagamok Anishnawbek First Nation).

The Indigenous Transition Coordinator could be a key role in influencing early identification through effective discharge planning of individuals back to their communities after potential disease exacerbations that require hospitalization.

Screening Tools

The usefulness of screening tools that attempt to identify individuals with potential EoL needs has been limited (ElMokhallalati et al., 2020). Despite this, systematic use of a PC screening tool can help promote communication between care providers, act as a benchmark between assessments, support equitable access, and help trigger the need for further investigation/assessment (ElMokhallalati et al., 2020).

When clients are admitted to HCC for PC, the first step in the process is the completion of a comprehensive and wholistic assessment. Teams may use a standard HCC assessment form; however, additional online assessment tools may be useful to assess clients and guide care (Dalhousie University, 2021b; OPCN, n.d.). Individualized, client-centred care plans will come out of the assessment process and should include goals of care and an ACP that outlines the client's wishes and identifies their future SDM. Whenever possible, the screening tools that support palliative and EoL care should be integrated into electronic medical records.

Interview responses indicate that currently, late identification of PC needs impairs/prevents completion of ACPs an issue magnified by health care providers discomfort around difficult conversations and the public's discomfort/reluctance to talk about death and dying.

Recently, the RESPECT (Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool) tool was validated in an Ontario based study informed by information available in the RAI-HC (Resident Assessment Instrument for Home Care) database. (Hsu et al., 2021). The web-based (17 question) interactive RESPECT tool is meant to be used with frail older adults living in the community. The tool can be completed in under 5 minutes by the client, their family, or a health care worker. Using the tool helps promote communication regarding EoL and the calculated survival estimates, and inform and advocate for supportive care and services. The most predictive factors linked to six-month mortality are measures associated with functional capacity (ADL and IADL) (Hsu et al., 2021). The cultural safety of the RESPECT tool in First Nations people requires further study.

Community health teams may benefit from standardized PC screening with clients that have advanced progressive disease to assess and document decline. Teams can explore which screening tool(s) work best using a Plan-Do-Study-Act cycle approach (HQO, n.d). Some electronic medical records are able to identify those that may benefit from a palliative care approach.

The following tools are quick and easy to use and are currently promoted in the PC literature:

Palliative Care Screening Tools to Help in the Early Identification of PC Needs
Clinical Frailty Scale (CFS) (see Appendix J) As frailty increases, adults are more susceptible to functional decline and mortality. The Canadian Frailty Network (2021) reports that Indigenous adults are twice as likely to suffer from frailty. Frailty is a useful concept to integrate into PC. The CFS is a quick and easy tool to establish a baseline frailty rating, by which progression can be measured in adults. The tool summarizes the overall level of fitness or frailty (Dalhousie University, 2021a). The CFS is also recommended for use by Diabetes Canada for older adults, to help predict complications and death, therefore, it is a best practice that may already be in place in communities (Amblas-Novellas et al., 2020; Diabetes Canada, 2018; Rockwood & Theou, 2020).
RESPECT (Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool) (RESPECT tool: https://www.respect.projectbiglife.ca/) The RESPECT tool was developed in Canada using data from the RAI-HC (Resident Assessment Instrument for Home Care) to calculate an older person's survival (how long they will live). The short tool can be completed in less than 5 minutes, it promotes EoL communication and identifies those that may benefit from PC services (Hsu et al., 2021).
Palliative Performance Scale Version 2 (PPSv2) (see Appendix K) Interview responses indicate that some communities are already using the PPS as part of their assessment process to determine functional capacity and progression toward the end of life. Health care providers use clinical judgement to measures a client's status based on their ambulation, activity, self-care capacity, intake and level of consciousness. Some sources suggest a palliative approach to care may be appropriate for individuals with a PPS rating of 70% or less, triggering comprehensive assessment including completion of an ACP (Victoria Hospice, 2001).

Supportive and Palliative Care Indicators Tool (SPICT)
(see Appendix L)

Interview responses indicate that some communities are using the SPICT tool to help identify people whose health is deteriorating. Unlike the CFS and the PPS, the SPICT tool includes disease specific clinical indicators. The tool does not use a rating scale and instead provides health care providers with guidance for care planning (University of Edinburgh, 2019).

The Surprise Question
(see Appendix M)

The ‘surprise question’ approach asks health care providers to consider the following questions: “Would you be surprised if the patient died within the next year?” If the response is no, the health care provider is encouraged to initiate a process with that client that includes: a conversation to discuss the future and care planning; ACP; identification of an SDM; client values and preferences; and goals of care (Mayo Clinic, 2015).

Difficult Conversations

Talking about dying is identified as a barrier.

Home and Community Care clients are aware that dying in the First Nation is an option, however, talking about dying is identified as a barrier. This could be improved with processes that support early identification of clients that would benefit from a PC approach to care, early conversations with clients/families regarding expectations and use of ACPs, and access to PC specialists. In further supporting conversations around death and dying in First Nations, the idea of the community-based EoL/DD is appropriate. A portion of their role might be to re-affirm the Traditional view of death as a natural part of the life cycle in First Nations.

All of the education/training programs listed previously include sections on communication and having difficult conversations with clients and families. However, the interview results reveal that most First Nations are not comfortable talking about death and dying and most health care providers feel they need more guidance to be effective in this action. Conversations around early planning, ACP and MAiD are impacted by this lack of comfort among health care providers in First Nations. Some health care providers feel that it is not their role to have the ‘palliative care’ talk with clients/family. When asked who they believe should have the conversation regarding PC, they most often list doctors and external provincial partner agencies (LHIN-Local Health Integration Network). However, some First Nations express frustration with doctors who are reluctant to confirm the client’s prognosis. A nurse from North Spirit Lake First Nation describes frustration when a hospital discharge doctor states that an extremely frail client is not palliative, "*he has anywhere from 6 months to 5 years to live.*" Difficulty defining PC consistently is a barrier.

Discomfort around PC conversations is one of the challenges to early identification of clients that could benefit from a palliative approach (Hsu et al., 2021). Research has consistently shown that the ability to engage in difficult conversations / early identification is foundational to quality care throughout the PC continuum. An HCC Nurse from Aroland First Nation summarizes the barrier of having difficult conversations and the negative impacts that follow:

> *"I think a lot of times, you know, the stress on the family. The family will want them there and then when things start getting tough and closer to their time, it just, I think it just freaks them out. And they, you know, panic, call the hospital or whatever. Maybe sometimes the patient or the client isn't clear with their family what they want, you know, as far as their final wishes and stuff. So, like I know we need to do a little more advanced care planning with people, but it's really tough to approach there with some people. It is. I mean, I have brought it up a few times with folks, but I get a sort of not want to talk about it kind of feeling from people. So, it's tough. Like it's, I think, part of the belief system".*

We can learn from some positive community practices in this area:

The HCC nurse manager in Naicatchewenin First Nation, believes that establishing a trusting relationship with the client/family makes it easier to start talking early on. The nurse speaks with the client first, then the family, and finally brings them together so they understand the client's wishes and the expectations of the family members.

In Biigtigong Nishnaabeg, they integrate the support of mental wellness workers, or social workers to support clients/families through difficult conversations and to support the HCC team.

24/7 Access to Palliative Care and Virtual Care

The number one factor forcing clients that wanted to die at home to return hospital is linked to family's inability to cope with the caregiver demands.

Palliative care standards affirm the need have virtual 24/7 PC support for health care providers and families working to manage the needs of someone dying at home (Ritchey et al., 2020). Virtual care has long been recognized as a solution to address global health inequities related to the accessibility of health care (WHO, 2010). The Assembly of First Nations (2017) suggested that "health care services in First Nations be innovative and tailored to community needs" (p. 9) and identified the necessity of a 24/7 response in the provision of EOL services. The use of virtual care solutions in palliative and EoL care has been recently validated with countries pivoting to provide services in the time of the pandemic

(Brook et al., 2020; Chávarri-Guerra et al., 2020; Ritchey et al., 2020). Furthermore, the survey and interview data confirmed that First Nations are open to virtual care solutions. Despite the concerns of First Nations regarding connectivity, the use of "technology is imperfect" and that the use of a telephone is a viable backup plan (Ritchey et al., 2020, p. 996).

Data reveals that the number one factor forcing clients that wanted to die at home to return hospital is linked to family's inability to cope with the caregiver demands, due to lack of available PC specialist support (pain/symptom management, advice/guidance) and lack of health care coverage to address increased care needs (CVH, 2021; Landers et al., 2018).

This support includes access to a PC specialist (Bakitas et al., 2020; Chavarri-Guerra et al., 2021; OPCN, 2019a). The PC specialist can prescribe/regulate pain and symptom management medication, provide advice on a client's physical and emotional care, and through this support help to prevent unnecessary returns to hospital. The PC specialist access can include access to a team of multidisciplinary professionals that have the capacity to address the various components of care. This virtual support is not meant to replace ongoing partnerships with external organizations, rather to support collaborative efforts in an attempt to increase coverage (24/7).

The Canadian Society of Palliative Care Physicians (2016) suggests that the most efficient way to ensure 24/7 support and access to a PC specialist for both clients/families and health care workers is to create a single point of contact. This can be as simple as a one-stop phone number or can include other levels of virtual support. Survey and interview respondents expressed a high level of support for VC/support, however, questioned connectivity capacity at the community level. Creative solutions will be required to work around issues related to connectivity.

Many First Nations report relationships with local hospitals, doctors, or PC centres to access specialist support with varying degrees of success. Most First Nations identify the inability to have 24/7 access to a PC specialist as a major gap and an ongoing challenge in the delivery of PC. In areas like Fort Francis Tribal Health who have found a way to implement 24/7 care, palliative care delivery is smoother, reminding us: *"obviously palliative care doesn't just happen Monday to Friday, 8 to 3 or 8 to 4. So, we really do provide that – like that around the clock flexibility support".*

Virtual care solutions that are available 24/7 will support First Nations in honouring the last wishes of those who want to pass away (die) in their home community.

Collaborative Partnerships

Identifying and strengthening partnerships between First Nations and existing health care systems (including provincial palliative care teams) is critical for First Nations in meeting the Ontario Palliative Care Network's Framework recommendation.

Collaboration and flexibility between all levels of health systems (local, provincial and federal) that work to anticipate and address barriers among all levels of health systems (local, provincial and federal) is critical to improve First Nations based PC services (Schill & Caxaj, 2019; Cajax et al., 2018).

Examples that demonstrate the power of collaborative partnerships were showcased in the results (Tyendinaga Mohawk Territory and Six Nations), however data from the survey reveals that less than 30% of respondents report having support from provincial palliative care programs. Prince et al., (2017) reinforced this notion, asserting that there is a lack of existing partnerships between First Nations and external health care systems.

Identifying and strengthening partnerships between First Nations and existing health care systems (including provincial palliative care teams) is critical for First Nations in meeting the OPCN's Framework recommendations. Non-Insured Health Benefits must consider reviewing / adjusting their policies to enable timely access to supplies and medications that support palliative / EoL service delivery.

It is anticipated that the Indigenous PCC could play a key role in supporting communities to strengthen partnerships and in advocating for NIHB policy changes. In turn, it will be important to support the Indigenous PCC in understanding how to build intersectoral / interagency / multi-jurisdictional partnerships as part of their role. Inclusion of the Indigenous PCC that supports communities is an option that can be explored as a next step. In this model the Indigenous PCCs have access to clinical and medical expertise as well as backend infrastructure supports for 24/7 service provision. Exploring other models that support the development and collaboration of multidimensional partnerships is important. For example, health care models that are inclusive of Managed Clinical Networks link "groups of health professionals and organizations from primary, secondary, and tertiary care working in a coordinated manner, unconstrained by existing professional and [organizational] boundaries to ensure equitable provision of high quality effective services. (Luckett et al., 2014, p. 4).

Finally, there are a number of organizations working to support palliative and EoL services in Ontario First Nations through education initiatives (SE FNIM Program, Lakehead University, McMaster University). Collaboration among all involved organizations with the same goal fosters synergy, minimizes duplication, and is more likely to result in social and systems change (Samali et al., 2016).

V. Physical Resources

Interview and Survey Analysis / Discussion

Home and Community Care teams work with existing available resources to try to meet the needs and requests of families.

Supplies/Equipment for Palliative and End-of-Life Care

● **Lack of basic supplies and equipment makes it more difficult to care for someone at the end-of-life at home.**

There are basic supply and equipment lists available that are recommended to support the provision of home-based palliative care (CHCA, 2021; Indian Association of Palliative Care, 2007). First Nations currently lack the majority of items on the lists. Most First Nations report using a loan cupboard system to coordinate PC supplies and equipment, this system works, however, attention to ensure that every First Nation has the basic supplies and equipment is necessary (this can be coordinated at the community or tribal level).

Timing is also identified as a barrier to accessing supplies and equipment to support EoL care. This issue likely has many layers. As per the evaluation on HCC services by ISC in 2019, this issue is not new as NIHB was identified as a program requiring improvements, citing:

> Most comments pertained to the timelines of NIHB request approvals. Respondents felt that the processes are cumbersome, complex and should be streamlined. Several respondents suggested better communication from NIHB (e.g., regular updates, clear information, straightforward guidelines, and feedback on refusals). Respondents also felt that coverage should be increased to allow clients to access medication, supplies and specific services.

The Canadian Home Care Association (2021) lists the following additional essential supplies and equipment that may be necessary to support palliative/EoL care in a home-based setting. This list is for reference only and was not included in the survey assessment:

- Bi-Pap and C-Pap machines (these machines help you breathe while you sleep)
- Central line dressing change kits
- Feeding tubes
- Pressure relief mattresses
- Positioning devices like wedges and cushions
- Over-the-bed table
- Hospital bed (electric adjustable)
- Extra oxygen
- Adult wipes

First Nations are working to provide palliative / EoL care, however, they need basic resources to support their efforts. The creation of an updated physical resource list can be shared with communities, NIHB, and funding partners to advocate/coordinate community readiness. Lack of basic supplies and equipment makes it more difficult to care for someone at the EoL at home. This reality increases stress for the client, family, natural caregivers and community-based health care providers and is a factor that contributes to the transferring of the client back to hospital when the care needs are overwhelming and unmet.

Determinants of Health: Housing

Overcrowding in homes is one of the main reasons clients are transferred to the hospice for end-of-life care.

Within First Nations, the challenge to achieve equity in the provision of PC lies in the disparities between Indigenous and non-Indigenous communities. Home/community-based PC is not always a safe or viable option.

Overcrowding, unsafe housing, and access to safe water is an ongoing challenge in First Nations. A 2018 First Nations National Housing and Infrastructure Strategy in Ontario asserts:

> Massive housing shortfalls exist and homes that have been built are often inappropriate and inadequate for the climate, geography and culture in which they are developed. Standardized housing metrics identify crisis but are not tailored to the specific issues, values and goals of the diversity of First Nations across NAN territory (Nishnawbe Aski Nation (NAN) & Together Design Lab, 2018)

In Sagamok Anishnawbek First Nation, the community has developed an effective partnership with Espanola Hospital that has hospice beds. The Health Director states that overcrowding in homes is one of the main reasons clients are transferred to the hospice for EoL care.

In Attawapiskat First Nation, the HCC nurse shared a story where they tried to support a community member to die at home. The client required oxygen, *“the house was not ideal to accommodate the oxygen needs*”, so the Band Office was working on renovations to support safety. Unfortunately, the client passed at the hospital, before the renovations were completed.

As most First Nations work to strengthen their existing PC offerings, there are some First Nations, like Animakee Wa Zhing 37 First Nation in northern Ontario, that are unable to offer services because the community lacks basic amenities including safe drinking water. *“There is water here, but the water isn’t good, there is a water treatment plant being built and it’s almost done. Community members requiring care have to go to the hospital in Kenora.”* (Mental Health Community Wellness Worker)

When asked about their dreams for the future of palliative care the most common response was access to community based hospice care.

It is not surprising that when asked about their dreams for the future of PC in their First Nations, the most common interview response is linked to having access to community-based hospice care. First Nations want to be able to care for their people in their final journey, in settings that are culturally safe, physically safe, and comforting for the client and family. First Nations offer suggestions for the creation of community-based hospice settings that range from setting up a vacant apartment in the community; creating flexible spaces in current Elder's lodges; to non-institutional flexible housing that incorporates Traditional, cultural, and spiritual care.

Comparison of the OPCN Framework with Community Voices

The Ontario PC standards were developed to help the public understand what they could expect in terms of quality PC. The Ontario Palliative Care Network (OPCN) framework helps put the standards into practice (OPCN, 2019a).

The following table provides a snapshot of the current state of PC in Ontario First Nations, by comparing the OPCN framework recommendations to the community voices data gathered through the survey and interview results.

Table Key

- Comments in green indicate areas where First Nations excel in their ability, despite limited resources, to achieve OPCN recommendations / standards.
- Comments in red indicate areas that require attention or do not meet the OPCN recommendations / standards (gaps).

Ontario Palliative Care Network (2019) PC Delivery Framework Recommendations	**Ontario First Nations Community Voices Survey and Interview Data**
The patient who would benefit from PC will be identified early in their illness.	• There is a lack of culturally safe approaches & tools to identify PC early. • Education to support consistent use of tools is needed. • Competency regarding difficult conversations needs to be strengthened, to increase comfort level of providers. • Role clarity within the health care team can support early identification. • Comfort around PC can be strengthened by re-establishing the Traditional viewpoint that death is a natural part of the life cycle.
At any point from when the patient's illness is identified through EoL and bereavement, there will always be a designated care coordinator.	• Inconsistency in meeting this standard • Lack of culturally safe guidelines. • The HCC team works together to support needs of client /family.

All patients & family/caregivers will have 24/7 access to an interdisciplinary PC team.	• This is a major gap, no First Nations report 24/7 access to an interdisciplinary PC team. • Lack of access is identified as a primary cause for PC breakdown. • Most First Nations do not have HCC support available 24/7, they stretch capacity beyond limits, with limited resources. • Some First Nations have established limited virtual access to PC specialists.
The Core Team will collaborate with the patient (or Substitute Decision Maker (SDM)) & their family/caregivers to regularly assess their needs, & to develop & document a care plan that is based on the patient's wishes, values and beliefs, & their identified goals of care, & to obtain consent.	• In most situations, PC needs are not identified in a timely manner, this results in missed opportunities to develop ACPs & to designate SDMs; First Nations recognize the need for improvement. • In situations where First Nations are able to identify PC needs early & complete ACPs, the lack of 24/7 specialist support & effective pain/symptom management often causes PC breakdown. • Most First Nations report wholistic assessments of clients upon admission into the HCC program that is inclusive of establishing goals of care and re-assessment when there is a change in their condition
The patient will have 24/7 access to pain & symptom management from the Core Team or the on-call providers (in-person or via telemedicine).	• This is a major gap that often results in PC breakdown. • Communities need training & access to PC pain/symptom relief kits, free of jurisdictional barriers, available at the right time & right place. • Delays in access to medication due to pharmacy / prescriber access and approval from NIHB.
The patient & their family will have access to emotional, psychological and spiritual care to address their needs in a culturally safe manner.	• HCC teams feel confident in the competency-based PC skills they develop through available programs, they share this information with clients/families & the wider community. • Respite care is often available/coordinated at the community level. • HCC teams excel at providing wholistic PC & translating their knowledge to ensure it is culturally safe for client/ families. • HCC teams support external providers to ensure they understand the culture & provide culturally safe care. • HCC teams struggle with limited resources, to meet palliative/EoL needs; staffing coverage is limited & not flexible. • Multigenerational, overcrowded, unsafe houses, present multiple challenges to providing PC. • Access to hospice like settings is rare.
The patient & their family/caregivers will have access to practical & social supports that addresses their needs in a culturally safe manner.	• PC supplies/equipment are needed to provide safe care, these practical supports are often not accessible in a timely manner at the community level, increasing stress on the client, family, & staff and can lead to PC breakdown. • Access to recommended supplies/equipment needs to be prearranged, free of jurisdictional barriers, & accessible. • First Nations rely on local social support through Elders & natural caregivers for clients & families.
Planning for end-of-life care will begin as early as possible and when it is acceptable to the patient & their family / caregivers.	• This is a major gap that often leaves community-based health care teams scrambling to coordinate services. • An early identification process is needed to assist in planning for EoL. • First Nations need to determine and define culturally safe approaches to difficult EoL conversations. • First Nations may benefit from increased conversations / education about ACPs. • Funding has been provided for Indigenous Transition Coordinators who can help to support this gap.
The family/caregivers of the patient with a life-limiting illness will be supported throughout the person's illness trajectory, at the end of life, and through death and bereavement.	• HCC teams and communities identified varies ways they support family and caregivers across the PC continuum including grief & bereavement. • First Nations may benefit from the opportunity to share their culturally safe and supportive ways with others. • It is not clear if grief and bereavement support extends beyond the funeral.
The palliative care needs of the patient living in long-term care homes will be supported by the home in which they reside	• Most First Nations do not have access to long-term care facilities, Elders' lodges, or hospice settings. • First Nations are experiencing increased demand for PC & supportive living spaces due to aging populations that are burdened with high rates of chronic disease. • Situations of overcrowding and unsafe housing underscores the urgency to address the need for supportive living situations.

	• Hospice like spaces have been approved for funded in some First Nations.
The First Nation, Inuit, Metis or urban Indigenous patient & their family / caregivers will receive PC that utilizes a grassroots, participatory & collaborative approach & incorporates cultural knowledge into all aspects of care.	• Need for the development of culturally safe guidelines to support best practice. • HCC teams and First Nations continue to integrate a grassroots, participatory and collaborative approach to PC. • The capacity development approach used by the Lakehead University team helps to incorporate cultural knowledge into all aspects of PC and needs continued support moving forward. • Community-based HCC teams can access courses that support palliative and EoL care through an Indigenous lens (ie. SE FNIM Program).
The palliative care needs of the patient who is homeless or vulnerably housed will be identified as early as possible and care will be provided wherever the patient is	• Housing and infrastructure shortages / safety continues to be a major barrier, maintaining gaps in palliative / EoL service delivery in First Nations • Hospice like spaces funded in some First Nations

MOVING FORWARD

Ontario First Nations Palliative Care Strategy

> **The findings from *Community Voices* validated the efforts of the Ontario Palliative Care Network in their publication of *Palliative Care Health Services Delivery Framework* (2019).**

The gaps in quality, accessible palliative care for First Nations have long been recognized. In 2011, the Parliamentary Committee on Palliative and Compassionate Care made recommendations to address this discrepancy:

- The need to strengthen capacity in palliative care by building on existing services;
- Strengthening home care services to improve palliative care options and to better support Indigenous people living with chronic illnesses;
- Taking action to curb the relocation Elders experience at the end-of-life that keeps them away from their families; and
- Developing community-based models that facilitate recognition of the unique cultural values, traditions, and languages of Indigenous people.

Since the release of this report, there have been numerous initiatives to improve First Nations-based palliative and EoL care, however, the development of a First Nations PC model / framework / strategy is still an area that requires attention.

The purpose of *Community Voices* was to inform the development of a First Nations PC Strategy that can support strategic investments and initiatives that will enable First Nations in Ontario to provide equitable access to culturally safe, quality PC services for clients and their families. Strategies, models of care, and frameworks to support PC service delivery have been cited as an essential need in “rural areas of the country (Canada) where access to PC care specialists and competencies are extremely limited”

(Morrison, 2017, p. 64). The findings from *Community Voices* further reinforced the notion that First Nations require a PC Strategy to support them in their efforts in successfully bringing home all interested individuals to pass (die) at home.

Some communities have created their own models of care to support palliative and EoL service delivery as seen with Maamwesying North Shore Community Health Services and their Creator's Care program. Unfortunately, the reality is that not all First Nations have the capacity to undertake this complex initiative. Recommendations / solutions presented in this report will be available for all First Nations in Ontario who choose to build their own PC strategy, sharing the position of the *Compassionate Care Act* (2021) that addresses equity concerns related to PC. The recommendations and potential solutions are meant to complement / reinforce the work that is already being done in First Nations as a method to spur transformative palliative and EoL service delivery within Ontario First Nations.

The findings from *Community Voices* validated the efforts of the OPCN in their publication of *Palliative Care Health Services Delivery Framework* (2019). Therefore, the recommendations from this doctrine are the guiding principles for the First Nations PC Strategy in Ontario. In honoring the diversity of all First Nations, the importance of flexibility, innovation, and creativity is a key factor rooted within the recommendations and potential solutions. Seow & Bainbridge (2017) reinforce this approach, asserting that in order "to create impactful, sustainable homecare programs, it is critical to capitalize on existing processes, partnerships, and assets" (p. 37).

Recommendations / Potential Solutions

This section is organized by recommendation, followed by potential solutions that are inclusive of current initiatives, promising practices and proposed solutions/initiatives where necessary.

It is the assumption that all solutions will be implemented using an Indigenous lens and would be rooted in cultural safety.

GUIDING PRINCIPLES
Recommendation: The patient who would benefit from palliative care will be identified early in their illness.
Solutions: Current Initiatives • Lakehead University to continue their work in educating front line workers in generalist PC competencies, with a focus on early identification of those who would benefit from a PC approach and enhancing education regarding engaging in difficult conversations. • McMaster University to continue their work in creating capacity within community-based palliative and EoL teams, with a focus on role clarity, early identification of those who would benefit from a PC approach, and engaging in difficult conversations. • SE FNIM Program to continue to deliver education and vocational training, emphasizing the aspects of early identification of those who would benefit from a PC approach and engaging in difficult conversations, especially in their PSW PC module.

- Ensure that the HCC Policies and Procedures are inclusive of the identification of those who would benefit from a palliative approach and tools that support identification (RESPECT, The Surprise Question).
- When an individual is diagnosed with an illness in a provincial hospital, where Indigenous Transition Coordinators exist, education regarding the palliative approach to care can begins and a referral is sent back to the community for follow-up by the HCC team.
- Indigenous Transition Coordinators to receive training in palliative and EoL care with a focus on early identification of those who would benefit from a palliative approach.

Solutions: Promising Practices

- Involve other member of the health care team / community in difficult conversations (Elders, Mental Health Workers).
- Engage in difficult conversations in pieces, consider talking to the client first prior to bringing family together.
- A systems navigator, hired through Mnaamodzawin, follows clients from admission through to discharge…*they will know what equipment and support the client will need…in the community, we start working on the care plan from the get-go, which is very helpful.* (HCC nurse manager, Sagamok Anishnawbek First Nation).
- Some First Nations have chronic disease registries (this method can prevent individuals from falling through the cracks by prompting regular check-ins).

Solutions: Proposed Solutions

- Create a community of practice among HCC workers in varying First Nations to increase support in activities related to the early identification of those who would benefit from a palliative approach.
- Consider the development of a role similar to the EoL/DD that is culturally safe with the role and training required for the role to be co-designed with First Nations.
- First Nations to continue creating community awareness of a palliative approach to care. A community-based EoL/DD could help to revive the traditional viewpoint of death as a natural part of the lifecycle.
- Review HCC job descriptions to ensure role clarity and the integration of requirements / activities that support a palliative approach to care.
- Establish a toolkit that is easily accessible and compiles screening tools to support and reinforce best practice in palliative / EoL care. Consider the addition of including generalist information regarding PC and how to support caregivers to reinforce current education initiatives.
- All First Nations to have chronic disease registries with accompanying guidelines for use, such as regular check-ins, follow-up, etc.
- Implement tools that support the early identification of those who could benefit from a palliative approach to care into electronic medical records or existing documentation/assessment processes.

Recommendation: At any point from when the patient's illness is identified through end-of-life and bereavement, there will always be a care coordinator.

Solutions: Current Initiatives

- Indigenous Transition Coordinators to send early referrals at onset of diagnosis and after unexpected hospitalization.
- Ongoing education (Lakehead, McMaster and SE FNIM Program) to send consistent messages to support PC competencies / service delivery in First Nations.
- HCC Policies and Procedures to support health care provider's roles at regular intervals of the PC continuum ranging from diagnosis until death, extending into grief and bereavement.
- Case management education to continue or be accessed virtually. Education should highlight case studies of individuals / families all throughout the PC continuum from onset of illness through death, and extend into grief and bereavement. Case studies / education should also be consistent with the reality of First Nations and barriers health care workers are likely to encounter. Case management education to be woven into orientation training.
- Chronic disease management / wound education to continue (in-person or virtually) to support a palliative care approach that is aligned with best practices.

Solutions: Promising Practices

- The First Nations HCC coordinator to remain involved as case manager at regular intervals throughout PC continuum (assessment, planning, facilitation, and advocacy).
- Fort Frances Tribal Area Health Services has hired a palliative care coordinator with EoL/DD training to support its First Nations. This position will be able to identify strengths and gaps and work with external partners to support First Nations in the delivery of palliative and EoL services.

Solutions: Proposed Solutions

- Consider establishing Indigenous PCC with advanced competencies in palliative and EoL care that can assist the HCC coordinator and community-based team to ensure quality, accessible PC. The PC Coordinator can work in collaboration with the HCC nurse to coordinate extended services and help fill the gaps in the core team by identifying and bridging partnerships with provincial PC teams and external systems. This role can also be inclusive of providing education, mentorship and consultation to the First Nations. Consideration should be given to the competencies, training and support required for this role.
- Strengthen / create partnerships with provincial health systems (including local primary care clinics) to create pathways that support communication / early referrals. As per the OPCN (2019), regional and local planning needd to include processes and tools that support effective communication between care providers. As noted, the PC Coordinator would play a key role in supporting communities and organizations in this regard.
- First Nations to continually inform community members about services available to support palliative and EoL care. As noted, a community-based EoL/DD could play a key role in supporting this initiative.

Recommendation: All patients and family caregivers will have 24/7 access to an interdisciplinary palliative care team.

Solutions: Current Initiatives

- First Nations Digital Health Ontario (FNDHO) continuing work in supporting digital health solutions for First Nations that will support all health-related services, including palliative and EoL care.

Solutions: Promising Practices

- Some First Nations have established partnerships with hospices / external health systems to support some 24/7 access.
- First Nations are open to, and currently using some level of VC, to support the delivery of health services.
- First Nations with full interdisciplinary PC teams are comprised of internal and external members.
- Some health care providers in First Nations flex their hours to ensure some evening coverage for clients/families are available, especially near the EoL.

Solutions: Proposed Solutions

- All available technology should be leveraged to support virtual care to the fullest potential, using the technology that First Nations have access to.
- Strengthen linkages and partnerships with provincial / external health systems to offer 24/7 care. As noted, the PC Coordinator would play a key role in supporting communities and organizations in this regard.
- Training to use VC services to the fullest extent possible is required for health care providers.
- Address availability of surge capacity in First Nations, especially as someone is nearing the EoL.
    - A local community-based EoL response team or the role of a community-based EoL/DD can help to support clients/families after hours.
    - A dedicated Indigenous PCC with advanced palliative EoL competencies to bridge partnerships and coordinate extended services in palliative / EoL care.
    - Continue to grow community-based PSWs, emphasizing a palliative approach to care.

Recommendation: The Core Team will collaborate with the patient (or SDM) and their family/caregivers to regularly assess their needs, and to develop and document a care plan that is based on the patient's wishes, values and beliefs, and their identified goals or care, and to obtain consent for the plan.

Solutions: Current Initiatives

- HCC Policies and procedures to support key action areas defined in the recommendation:
    - How often/when to assess needs (using a wholistic approach),
    - What full informed consent should cover (ie. MAiD, treatment options, etc.) ,
    - How to develop/document a care plan,
    - How to establish goals, and
    - How to obtain consent for the plan
- Lakehead / McMaster University to continue their work in strengthening generalist-level PC competencies.
- SE FNIM Program's Overview of First Nations Chronic Disease Management course and Care Coordination/Case Management webinars to continue their work in educating community-based staff in providing care that integrates a palliative approach.

Solutions: Promising Practices

- The majority of First Nations report wholistic assessments being completed upon HCC admission and throughout the illness trajectory as needs change.

Solutions: Proposed Solutions

- Ensure regular case conferences with all involved community-based / external health care providers throughout the PC continuum that includes the client/SDM and family. If

needed, PC Coordinators can provide education / referral to existing education for HCC staff on case management.
- Work with First Nations to identify culturally safe approaches to difficult conversations.
- Review palliative / EoL education being offered by all organizations to ensure consistent messaging / approaches and strengthen education around difficult conversations, including opportunities for community-based teams to practice these skills (e.g., role playing).
- Consider integrating tools that support palliative/EoL care into electronic medical records (in First Nations that have access).

Recommendation: The patient will have 24/7 access to pain and symptom management from the Core Team or the on-call providers. This may occur in-person or via telemedicine (e.g., telephone support, virtual care).

Solutions: Current Initiatives
- HCC Policies and Procedures to support:
  - Pharmacological and non-pharmacological pain and symptom management / administration,
  - Pain and symptom assessment tools, and
  - Families in providing and storing medications to relieve pain / other symptoms.
- SE Health PSW PC module to continue training PSWs in supporting non-pharmacological techniques to manage pain and other bothersome symptoms.

Solutions: Promising Practices
- Some First Nations have collaborated with external health care organizations to support 24/7 access to pain and symptoms management.
- Some communities are using symptom response kits.

Solutions: Proposed Solutions
- Collaborate with NIHB to support the use of symptom response kits to all First Nations. Educate First Nations around the use of these kits.
- Collaborate with NIHB to create a standardized list of essential supplies/equipment required for palliative/EoL care. Create a process that ensures timely access to these supplies/equipment.
- Have a standardized phone line where clients/families have 24/7 access to prescriber / PC specialists.
- Have the Indigenous PCC assist in coordinating extended services in palliative / EoL care as a method to ensure the availability of an interdisciplinary PC team.

Recommendation: The patient and their family will have access to emotional, psychological and spiritual care to address their needs in a culturally safe manner.

Solutions: Current Initiatives
- Lakehead University has developed culturally appropriate resources to support palliative / EoL services in First Nations.

Solutions: Promising Practices
- First Nations rally around individuals/families in need to support them wholistically.
- Some First Nations have used a basket that contain items to support emotional, psychological, and spiritual care and tailored around the clients/families preference (Traditional and Christian).
- First Nations use Elders, natural caregivers and Traditional knowledge keepers to support emotional, psychological, and spiritual care of clients/families.

Solutions: Proposed Solutions

- Include emotional, psychological and spiritual care as a virtual care option that is available 24/7.
- A community-based EoI/DD can address the emotional, psychological and spiritual care needs of clients/families.
- The PC Coordinator to bridge partnerships and coordinate extended services in palliative / EoL care as a method to ensure that the emotional, psychological and spiritual care needs of clients/families are being met.

Recommendation: The patient and their family/caregivers will have access to practical and social supports that address their needs in a culturally safe manner.

Solutions: Current Initiatives

Solutions: Promising Practices

- In some First Nations, natural caregivers / PSWs provide practical and social support to clients/families.

Solutions: Proposed Solutions

- First Nations can create a respite program for all interested community members and provide necessary education to those respite providers.
- Strengthen partnerships with the provincial system that provide practical and social supports. Clients/families should be referred for services as soon as they are needed.
- The Indigenous PCC to bridge partnerships and coordinate extended services in palliative / EoL care as a method to ensure the practical and social needs of clients/families are being met.
- A community-based EoL/DD can advocate on behalf of family and assist to fill practical / social support gaps when needed.

Recommendation: Planning for end-of-life care will begin as early as possible and when it is acceptable to the patient and their family/caregivers

Solutions: Current Initiatives

- HCC Policies and Procedures to clearly outline the required elements involved in EOL care planning.
- Education provided by Lakehead University, SE FNIM Program, McMaster University to emphasize difficult conversation while also creating opportunities for practical experience.

Solutions: Promising Practices

- First Nations are finding creative ways to support the planning of EoL care such as utilizing established community resources (Mental Health Workers).

Solutions: Proposed Solutions

- Normalize the palliative approach to care within communities through the use of education delivered by the HCC program. A community-based EoL/DD can help revive death as a natural part of the lifecycle and use culturally safe approaches to initiate planning for EOL care.
- The Indigenous PCC to assist in EoL planning and if needed, quick formation of the interdisciplinary team.

Recommendation: The family/caregivers of the patient with life-limiting illness will be supported throughout the person’s illness trajectory, at the end of life, and through death and bereavement

Solutions: Current Initiatives

- Lakehead University extending education to include natural caregivers and building generalist PC competencies in First Nations.

- McMaster University supporting early identification of those who benefit from a palliative approach to care. It is essential that education includes families/caregivers as an extension of the client when delivering PC and that services extend into grief / bereavement.
- SE Health PSW training to continue with PC education and best practices that support clients/families all along the PC continuum.

Solutions: Promising Practices

- HCC Policies and Procedures to include wholistic interventions that support client/families along the entire PC continuum.
- Having Indigenous PCC coordinators \ to assist First Nations in supporting families/clients along the PC continuum.
- Maamwesying North Shore Community Health Services Caregiver Education Project.

Solutions: Proposed Solutions

- Develop 27/7 virtual care solutions to support the wholistic needs of clients/families.
- A community-based EoL/DD can help to support clients/families along the PC continuum.
- Indigenous PCC to assist in supporting / mentoring First Nations as they strive to support clients and families through the PC continuum.
- Expand reach of Maamwesying North Shore Community Health Services Caregiver Education through train the trainer program development

Recommendation: The palliative needs of the patient living in a long-term care home will be supported by the home in which they reside.

Solutions: Current Initiatives

Solutions: Promising Practices

- Some First Nations have a long-term care (LTC) home in the community or have established partnerships with nearby to support palliative / EoL care.

Solutions: Proposed Solutions

- Collaborate with existing ISC LTC initiatives (Wholistic Continuum of Care Project) that aim to work with communities to co-design First Nations led solutions in regards to LTC.

Recommendation: The First Nation, Inuit, Métis or urban Indigenous patient and their families/caregivers will receive palliative care that uses a grassroots, participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.

Solutions: Current Initiatives

- Lakehead / McMaster University and SE FNIM Program tailor education to support cultural safety, through an Indigenous lens.
- ISC, HCC Ontario Region is supporting SE FNIM Program to develop *Community Voices-* that is inclusive of palliative and EoL service delivery solutions that are flexible and responsive to the individual needs of each First Nation across Ontario.

Solutions: Promising Practices

- First Nations recognize the need for a PC Strategy, with at least one community developing their own model of care.
- First Nations are developing creative strategies that are inclusive of cultural safety and a collaborative approach to support all aspects of PC service delivery.

Solutions: Proposed Solutions

- Pilot the solutions identified in this table in First Nations to supplement / strengthen the provision of palliative and EoL services.

Recommendation: The palliative care needs of the patient who is homeless or vulnerably housed will be identified as early as possible and care will be provided wherever the patient is.

Solutions: Current Initiatives

- The creation of hospice-like spaces.

Solutions: Promising Practices

- First Nations try to find solutions to support EoL clients to die at home, creating make-shift spaces to deliver services.

Solutions: Proposed Solutions

- All First Nations have hospice-like spaces, either within or less than 30 minutes away from the community.
- First Nations that run LTC homes can have one respite bed used specifically for those in their last days/hours of life.

Conclusion

Ontario First Nations Home and Community Care teams are creatively providing the best palliative and EOL care they can, however existing gaps often impact their ability to ensure equitable, accessible and culturally safe PC for community members. *Community Voices* provides a roadmap for key strategic investments to support Home and Community Care Programs in the delivery of quality, timely palliative and EOL care. A critical gap for communities is knowing who to call for what supports when someone wishes to pass in their home community. The concept of a 1-800 number, one place to call, was identified as a potential solution. A team of Indigenous Palliative Care Coordinators could provide 24/7 support to navigate existing pathways and supports and overcome existing barriers and challenges through advocacy and new and innovative solutions (e.g. virtual care, symptom management kits). Support to pilot these roles, embedded in second level services supports for the coordinators should be considered and designed/delivered in collaboration with the PC Coordinator and communities. A process for sharing of community wise and best practices should also be considered to facilitate the replication of promising practices.

Community Voices have guided solutions and recommendations that chart a path forward for culturally safe palliative and EOL services in First Nations across Ontario. However, many of the solutions to address the provision of palliative and EoL care that are presented throughout the report will require partnerships and strategic multi-sectoral collaboration that extend beyond the Home and Community Care Program. Palliative care is everyone’s business and support to communities to establish these partnerships and collaborations will be an essential step forward for Ontario First Nations.

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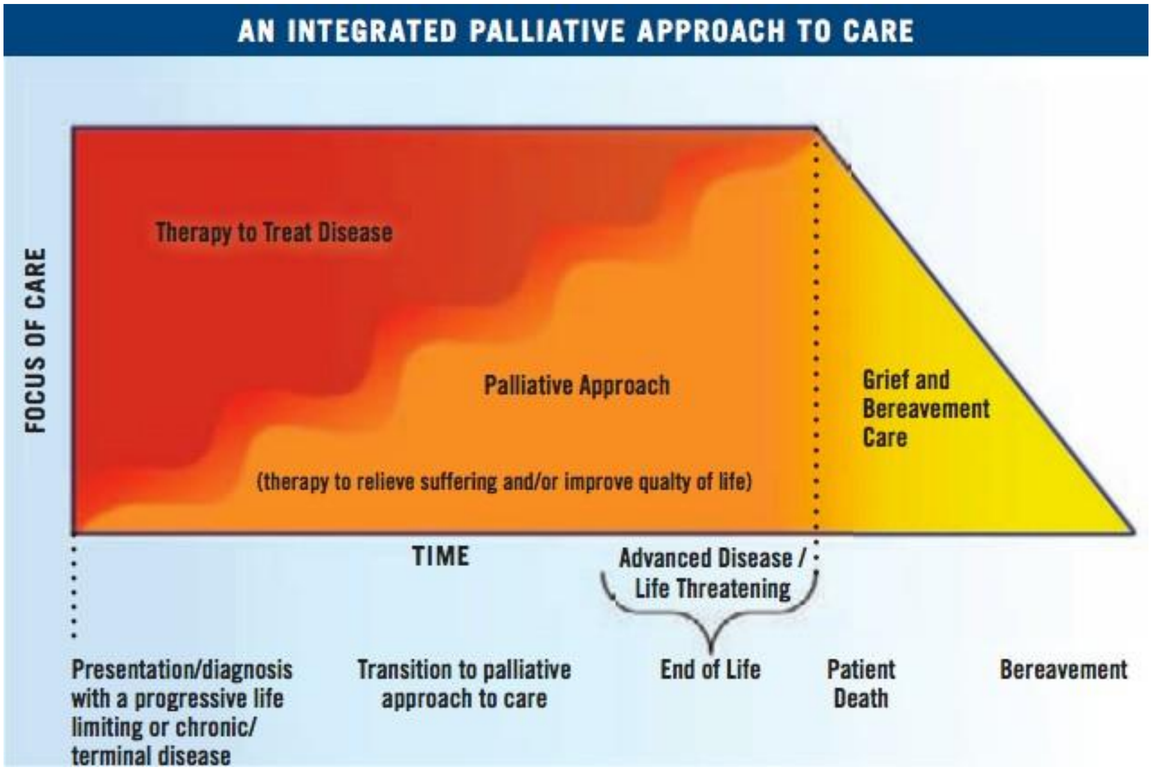
Appendix A: The Integrated Palliative Care Continuum



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Appendix B: Canadian Competency-Based Palliative Care Education and Training Options

Palliative Care Education and Training Options

There are a number of competency-based PC training options available for health care providers, Natural Caregivers, and family members.

- Lakehead University, Centre for Education and Research on Aging and Health (CERAH) https://cerah.lakeheadu.ca/wp-content/uploads/2021/01/PCFLWIC-Booklet-Final-APR51.pdf

CERAH developed an eight module, 15 hour in-person course *Palliative Care for Front--line Workers in Indigenous Communities.*

- Pallium Canada --- LEAP Program (pallium.ca)

Pallium Canada is a national, non-profit organization focused on building professional and community capacity. The LEAP (Learning Essential Approaches to Palliative Care) program, is available as a 2-day in-person course or as an on-line course through Pallium Canada, for frontline health care workers.

- SE Health (https://fnim.sehc.com/se-learning/essential-learning/@yourside-colleague-courses/palliative-care-course)

SE Health is a not for profit organization that offers a Palliative/End-of-Life Care in Indigenous Communities online course, as well as a Natural Caregivers course, available at no charge to all First Nations communities.

- Hospice Palliative Care Ontario (HPCO) (hpco.ca)

HPCO offers Ontario specific information regarding available palliative care services. Free access to HCPO First Nations Caregiver Modules (covers 15 topic areas) (http://caregiversupport.hpco.ca/ocpfn/)

- Canadian Virtual Hospice (virtualhospice.ca)

Canadian Virtual Hospice provides online support and personalized information about palliative and end-of-life care to clients, family members, health care providers, researchers and educators.

- Canadian Hospice Palliative Care Association (chpca.ca)

CHPCA is the national voice for hospice palliative care in Canada and represents provincial/territorial programs. Educational resources are available online to support clients, family members, and health care providers.

Appendix C: Summary of Developing a Palliative Care Program in First Nations

I. Developing Palliative Care Programs in First Nations Communities:

A Workbook (2015), is available online complete with tools/resources; power point presentation, and external partner guide. https://eolfn.lakeheadu.ca/develop-palliative-care-programs-workbook

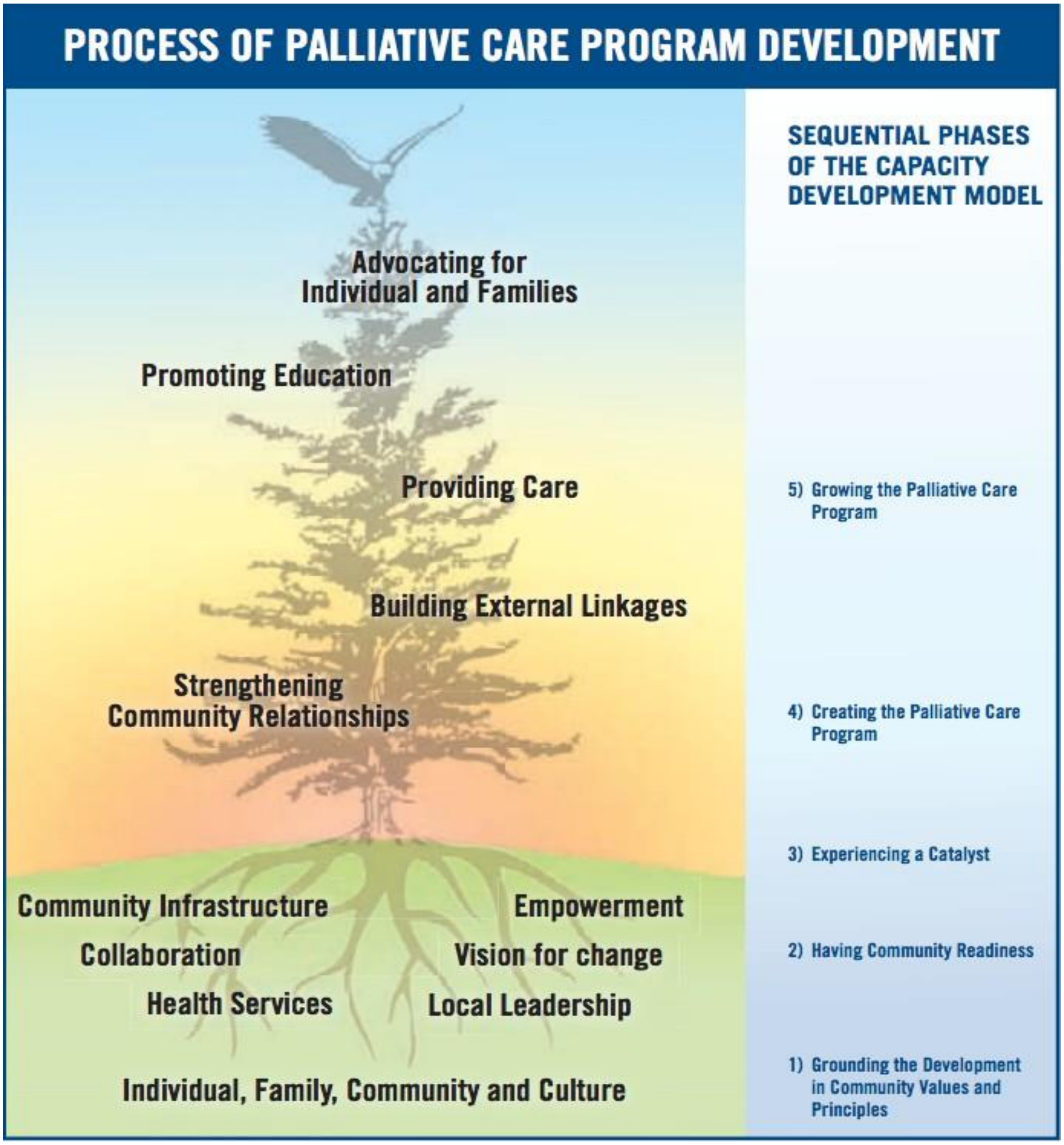
The workbook is based on a five-year project, funded by the Canadian Institutes of Health Research that aimed to improve end-of-life care in four communities in Ontario and Manitoba. It introduces an integrated palliative approach to care that can be incorporated at different stages of a person's chronic illness, the approach covers the transition from curative therapy to palliative care and includes end-of-life care, grief, and bereavement (see page X).

This community development approach is flexible, it is based on community readiness and moves forward at a pace the community is comfortable with. Progress on each phase is continuous and ongoing, the palliative care approach is ultimately integrated into existing programs, such as the local HCC program.

The process of development of a palliative care program is summarized in five phases of capacity development: (see Appendix B)

1. **Grounding the development in community values and principles** (with roots in individual, family, community and culture).
2. **Having community readiness** (based on community infrastructure, local health services, collaboration, vision for change, community empowerment, and strong local leadership).
3. **Experiencing a catalyst** (change initiated by a local leader or local event).
4. **Creating the palliative care program** (identify a local advisory committee including health care providers, leadership, and Elders; conduct a community needs assessment; develop a work plan including education and evaluation).
5. **Growing the palliative care program** (strengthening community relationships [increase community awareness and identify community members that can contribute to the program: Elders, natural caregivers, knowledge carriers]; building external linkages with palliative care experts and resources; providing care using a palliative approach to clients of the HCC program in the last year of life; promoting palliative care education to providers; advocating for individual and families for access to quality palliative care in the community.

Appendix D: Process of Palliative Care Program Development in First Nations



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Appendix E: Palliative Care Standards

Palliative Care Standards, developed by Health Quality Ontario (HQO) and the Ontario Palliative Care Network (OPCN) in 2018 to support:

-Clients, families, and caregivers to know what to ask for in their care.

-Health care workers to know what best practice work in palliative care.

-Health care organizations in an effort toward continuous quality improvement.

https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf

Each standard has quality indicators to promote measurement and continuous quality improvement.

Standards of Palliative Care

1. Identification and assessment of needs, early using a wholistic approach.
2. Timely access to palliative care support, 24 hours a day 7 days a week.
3. Advanced care planning that includes identification of their future substitute decision-maker.
4. Goals of care that are value-based and informed are identified with the team.
5. Individualized, person-centred care plans are developed and reviewed regularly.
6. Management of pain and other symptoms are managed effectively and timely.
7. Psychosocial support is provided to address mental, emotional, social, cultural, and spiritual needs.
8. Education for clients and their families provided about available resources and supports.
9. Families and caregivers are offered ongoing assessment of their needs and given access to resources, respite care, and grief and bereavement support.
10. Transitions in care are coordinated effectively, if required.
11. Setting of care and preferred place of death are discussed and shared with team.
12. Interdisciplinary team provides care and includes volunteers.
13. Education regarding palliative care is delivered to team including volunteers.

Appendix F: Palliative Care Delivery Framework

The Palliative Care Delivery Framework (2019), was developed by the Ontario Palliative Care Network (OPCN) to help front-line health care workers put the HQO Standards (2018) into practice in an equitable manner that helps to ensure wholistic, proactive, timely and continuous care and support. Recommendations are offered to guide and improve PC. A patient pathway helps to illustrate key interactions and decision points, the pathway can be viewed in the pdf document listed below.

https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/2021-01/OPCNHSDFRecommendations.pdf

Recommendations for the Delivery of Palliative Care

1. The patient who would benefit from PC will be identified early in their illness.
2. At any point from when the patient's illness is identified through end-of-life and bereavement, there will always be a designated care coordinator.
3. All patients and family/caregivers will have 24/7 access to an interdisciplinary palliative care team.
4. The Core Team will collaborate with the patient (or Substitute Decision-Maker) and their family/caregivers to regularly assess their needs, and to develop and document a care plan that is based on the patient's wishes, values and beliefs, and their identified goals of care, and to obtain consent for the plan.
5. The patient will have 24/7 access to pain and symptom management from the Core Team or the on-call providers. This may occur in-person or via telemedicine (e.g., telephone support, virtual care, etc.).
6. The patient and their family will have access to emotional, psychological and spiritual care to address their needs in a culturally safe manner.
7. The patient and their family/caregivers will have access to practical and social supports that addresses their needs in a culturally safe manner.
8. Planning for end-of-life care will begin as early as possible and when it is acceptable to the patient and their family/caregivers.
9. The family/caregivers of the patient with a life-limiting illness will be supported throughout the person's illness trajectory, at the end of life, and through death and bereavement.
10. The PC needs of the patient living in a long-term care home will be supported by the home in which they reside.
11. **The First Nations, Inuit, Metis or urban Indigenous patient and their family/caregivers will receive PC that uses a grassroots, participatory and collaborative approach and incorporates cultural knowledge into all aspects of care.**
12. French language services will be highly visible and easily accessible to the patient and family/caregivers. Health care providers must offer these services, guided by the Active Offer Principle, without waiting to be asked.
13. The PC needs of the patient who is homeless or vulnerably housed will be identified as early as possible and care provided wherever the patient is.

Appendix G: Exploratory Survey on End-of-Life Services

The End-of-Life Survey is presented in a condensed version, in the interest of space.

Exploratory Survey: End-of-Life Services, Ontario First Nations

Disclaimer: We acknowledge and respect that not everyone is comfortable with Westernized language used to describe when an individual makes his/her way to the spirit world. The use of the words death, die, or dying used within this survey are not meant to be disrespectful, but are used to ensure clarity.

The words client and patient are used interchangeably throughout the survey and is defined as a person who is receiving support or services from the Home and Community Care Program.

The information you share today about your community will help us to develop an end-of-life services model that can support you and others in your community in providing services to individuals that want to die at home.

The survey will take approximately 20 minutes, depending on the length of your responses. The questions are a combination of multiple choice, yes/no and short answer questions. The survey is organized into 5 sections: Community Information, Home Care Program and Team, Key Role and Current Level of Services, Enablers to Palliative and End-of-Life Care and Physical Resources.

You will be given an opportunity at the end of the survey to provide your contact information and will be asked if you are interested in us contacting you for either a follow-up interview or to clarify your answers from today's survey. Leaving your contact information will be your entry into a draw for a $100.00 Visa gift card. You will be entered into the draw regardless of your decision to participate in the interview or clarification of today's survey.

Section A: Community Information

What is the name of your community? What is
your role?
Using the definitions provided, do you work in a rural, isolated or remote community? What is the
population of your community?
Does your community have a nursing station of a health center? How far
away is the nearest hospital by vehicle?
Is there continuous movement of membership in your community? For example, do community members frequently
move back and forth from the community to an urban location?
Do you provide health services to off-reserve members?

Section B: Home & Community Care (HCC) Program & Team

Approximately how many clients are receiving services from the Home and Community Care (HCC) Program? Please provide a number for each of the questions #10 to #15 below
How many staff are working in HCC? ______________________________
How many PSWs do you have working on the HCC team? ____________________
How many nurses do you have working on the HCC team? ____________________
How many CHRs do you have working on the HCC team? ____________________
How many homemakers do you have working on the HCC team?________________
How many managers/coordinators do you have working on the HCC team? ____________
Are any staff rotated in and out of the community? (For example, some communities have staff that have a scheduled rotation of 2 weeks in the community followed by 2 weeks out of the community) If yes, what is staff rotation schedule?

Definition - End-of-Life Care: "refers to care for people and their families when a person is imminently dying…..in the last hours, days or weeks of life" (Prince, 2017, p. 3)
Does HCC provide end-of-life services?
Do you know how many years your community has been coordinating end-of-life care?
Do you know approximately how many deaths have occurred in the community in the last 12 months? Yes, please provide approximate number ____________________
Have you noticed that more people are choosing to die in the community since the pandemic?

Definition -- Terminal Illness: An illness that is not curable that will ultimately result in death, whether or not, life prolonging measures are taken (McCartney & Trau, 1990). An individual diagnosed with a terminal illness normally has a life expectancy of 6 months or less (Hui et al., 2014).
Do clients who have been diagnosed with a terminal illness come back to community with the intention to die at home, but end up going to the hospital (or another location) to die when care needs become too heavy?

Definition -- Medical Assistance in Dying (MAiD): MAiD is an end-of-life option where a physician or nurse practitioner will prescribe and administer medications to the client causing death OR prescribes and provides medication to the client, so the client may self-administer the medication in which causes their own death. Even if MAiD is chosen, the individual and family should continue to receive palliative care that extends beyond death. Are clients at the end-of-life given information by HCC about MAiD as an option?
No, please explain why not?
Have you experienced a request for MAiD from a HCC client?
Have there been any instances of MAiD being used in your community over the last year?
Yes, can you tell us how many times MAiD has been used over the last year in your community?

Definition -- Palliative Care: "refers to an approach that improves the quality of life of patients and their families facing the problem associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (Prince, 2017, p. 3).
Does H&CC provide palliative care services?
What is the H&CC team's availability for clients that have palliative and end-of-life needs?

Section C: Key Roles and Current Level of Services

These next questions are designed to give us a better understanding of what the key roles are within the community that provide palliative and end-of-life care.

Definition -- Prescriber: A prescriber has the ability to order the use of a medication or other treatment. Examples include a physicians or nurse practitioner

Does the community have regular, consistent access to a prescriber who is comfortable in providing care to clients until the end-of-life?
If yes, how often is access to the prescriber available?
If the community only has access to one prescriber, is there coverage when that prescriber has to be away unexpectedly or takes scheduled time off?

Does the community have regular, consistent access to a pharmacy? If yes, how often is access to the pharmacy available?
When ordering medications for clients who are receiving palliative and end-of-life care, is there a delay in receiving medications? If yes, approximately how much of a delay is there?

Does the community have regular, consistent access to Traditional-based healers?

Is there a good and established transition in place for community members coming back to the community after being in the hospital?

Definition -- Hospice: Hospice is referred to as a location that provides services to individuals who are in their last week's/days/hours of life (actively dying).

Is there a hospice in your community (or less than 30 minutes) that provides end-of-life care regularly to community members who are actively dying?

Definition -- Terminal Illness: An illness that is not curable that will ultimately result in death, whether or not, life prolonging measures are taken (McCartney & Trau, 1990). An individual diagnosed with a terminal illness normally has a life expectancy of 6 months or less (Hui et al., 2014).

Is there a good and established transition between the hospital and community to support those who have been diagnosed with a terminal illness that want to come back to the community to die?

Definition -- Natural Caregivers: A natural caregiver (NC) is a person who provides support and assistance to a family member, friend, neighbor or anyone who needs help. The cared for person may be a child, an adult or an Elder. The NC helps the person do all kinds of tasks and activities. Depending on the individual, the help provided fluctuates and it is always unpaid (SE Health: FNIMP, 2017).

Are there natural caregivers within the community?

Is there an established relationship between these natural caregivers and the H&CC program?
Is there any education or training provided for natural caregivers?

Section D: Enablers to Palliative & End-of-Life Care

There are activities that have been known to promote high-quality end-of-life services. Below is a list of these activities. Please select either yes, no, sometimes, not sure or not applicable based upon what is happening in your community.

In my community, it is common that clients who would benefit from a palliative approach are identified early in the course of their illness.

Please read the statement and select the most accurate response. *It is important in my community that clients who would benefit from a palliative approach are identified early in the course of their illness.*

In my community, it is common for a care-coordinator to be actively involved throughout the duration of a client's illness.

Please read the following statement and select the most accurate response. *It is important in my community that a care-coordinator is actively involved throughout the duration of a client' illness.*

"The **interdisciplinary team** provides care in which several disciplines coordinate assessment and treatment, so that problems can be dealt with comprehensively" (Zeiss & Steffen, 1998).
In my community, it is common for client's receiving end-of-life care and their families to have 24/7 access to an interdisciplinary palliative care team.

Please read the following statement and select the most accurate response. *It is important in my community that clients receiving end-of-life care and their families have 24/7 access to an interdisciplinary palliative care team.*

Palliative Care Specialists: Palliative Care specialists might include physicians, nurses, and social workers who have received extra training and certification in palliative and end-of-life care.

In my community, the HCC team has access to palliative care specialists for consultation as needed.
Please read the following statement and select the most accurate response.
It is important in my community that the H&CC team have access to palliative care specialists for consultation as needed.

In my community, it is common for individuals recently diagnosed with a terminal illness to be assessed by the HCC nurse, including reviewing their goals of care.
Please read the following statement and select the most accurate response. *It is important in my community that individuals diagnosed with a terminal illness are assessed by the H&CC nurse, including a review of that person's goals of care.*

In my community, it is common that clients at the end-of-life are re-assessed by the HCC nurse as their health status changes.
Please read the following statement and select the most accurate response. *It is important in my community that clients at the EoL are re-assessed by the H&CC nurse as their health status changes.*

Definition - Advance Care Planning (ACP)- Defined by Speak Up Ontario (2021):

A process in which a capable adult identifies and confirms their substitute decision maker/s.
The capable adult communicates their wishes, values and beliefs about care to help their SDM make health and personal care decisions for them if they should become mentally incapable of doing so for themselves.

In my community, it is common for clients that are receiving palliative and end-of-life services to have advance care plans that includes the identification of a substitute decision-maker.
Please read the following statement and select the most accurate response. *It is important in my community that clients that are receiving palliative and end-of-life services have participated in advance care plans with their substitute decision-maker.*

In my community, the H&CC staff have the skills, knowledge, and comfort to provide end-of-life care
Please read the statement and select the most accurate response. *It is important that the H&CC staff have the skills, knowledge, and comfort to provide end-of-life care.*

Definition -- Symptom Management: Symptom management does not mean the person does not experience any symptoms. Instead, the goal of symptom management in end-of-life care to ensure comfort, minimize suffering and promote the highest quality of life.

In my community, clients who are at the end-of-life have 24/7 access to pain and symptom management.
Please read the following statement and select the most accurate response. *In my community, it is important that clients who are at the end of life have 24/7 access to pain and symptom management.*

Definition - Emotional Health: "Emotional health is about how we think and feel. It is about our sense of well-being, our ability to cope with life events and how we acknowledge our emotions as well as those of others. It does not mean being happy all the time" (Samaritans, n.d.). Caring for emotional health is an important component of end-of-life care as one may struggle in areas such as self-esteem, disease adjustment, family relationships, communication, or religious beliefs (National Council for Hospice and Specialist Palliative Care Services, 2007; Kelley & Morrison, 2015; Jeffrey, 2003 as cited in Fan et al., 2017, p. 217)

In my community, clients who are at the end-of-life have access to culturally-safe care that addresses their emotional health needs.
Please read the statement and select the most accurate response. *In my community, it is important that clients who are at the end-of-life have access to culturally-safe, emotional care that addresses their needs.*

Definition -- Mental Health: Good mental health is a state of happiness connected to purpose, relationships, connections, self-esteem, the enjoyment of life and the ability to cope with stress (Canadian Mental Health Association, n.d.). Disruptions in mental wellness often occur with the diagnosis of a terminal illness, leading to a decrease in the quality of life (O'Malley et al. 2020).

In my community, clients who are at the end-of-life have access to culturally-safe care that addresses their mental health needs.
Please read the statement and select the most accurate response. *In my community, it is important that clients who are at the end-of-life have access to culturally-safe care that addresses their mental health needs.*

Definition -- Spiritual Care: "Spiritual caregivers provide care for existential (ie. A person pondering their life's purpose), relational (relationships) and religious issues and the emotions related to these issues. Aspects of spiritual care in practice include helping patients find meaning, acceptance or reconciliation, paying attention to the spiritual issues of relatives to the patient, and helping them to say farewell" (Koper et al., 2019, p. 1).

In my community, clients who are at the end-of-life have access to culturally-safe, spiritual care that addresses their needs.
Please read the statement and select the most accurate response. *In my community, it is important that clients who are at the EoL have access to culturally-safe care that addresses their spiritual care needs.*

Definition -- Practical Support: An example of practical support can include helping a client with their activities of daily living such as medication assistance or helping with eating and drinking. An example of social supports can include helping a client with transportation or financial issues.

In my community, clients who are at the end-of-life have access to practical and social supports that address their needs in a culturally safe manner.
Please read the statement and select the most accurate. *In my community, it is important that clients who are at the end of life have access to culturally safe, practical and social supports.*

In my community, families that are providing end-of-life care are supported by HCC throughout the duration of one's life-limiting illness.
Please read the statement and select the most accurate response. *In my community, it is important that families providing EoL care are supported by HCC throughout the duration of one's life-limiting illness.*

Definition -- Bereavement: Bereavement: the experience of the death of a significant loved one or the "time period in which the survivor adjusts to their life without their loved one" (End of Life Nursing Consortium, 2010).

In my community, there are processes to support family that extends through death and bereavement.
Please read the following and select the most accurate response. *In my community, it is important that there are processes in place to support family that extends through death and bereavement.*

In my community, there are established guidelines for HCC staff to provide EoL care.
Please read the following statement and select the most accurate response. *In my community, it is important that there are established policies and practice guidelines for H&CC to provide end-of-life care.*

Definition -- Virtual Care: Virtual Care is a form of health service delivery, information transfer, communication, or education that takes place via telephone, conference call, email, or video conferencing.

In my community, we have access to virtual health care. Yes: what type?
No: Please read the following statement and select the most accurate response. *In my community, we could easily build virtual care into our health services.*

Please read the statement and select the most accurate response. *In my community, it is important that there is access to virtual health care.*

Does your community have reliable access to the internet?
Within your current funding, is your community able to provide EoL services as part of the HCC program? Please read the statement and select the most accurate response. *It is important that my community has funding available to support care until the end-of-life.*

Does your community receive support from provincial palliative care programs in delivering end-of-life care?
Please read the following statement and select the most accurate response. *It is important that my community receive support from provincial palliative care programs in order to provide end-of-life care.*
Does your community have internal, local expertise and knowledge keepers that could help develop an end-of-life program?

Please read the following statement and select the most accurate response. *It is important that an end-of-life program include input from local experts and knowledge keepers in order to be effective.*

Is there an identified leader in end-of-life care within the community?
If yes, what is their role? (HCC nurse, HCC coordinator, PSW, CHR, Natural Caregiver, Other please explain If no, can you think of someone who might take the lead role in end-of-life care? If yes, great can you please identify that person's role?
Please read the following statement and select the most accurate response. *It is important that our community have a leader in end-of-life care in order for these services to be effective.*

How would you characterize the relationship between the HCC program with external health care partners (i.e. Regional hospitals, other health services) Please select the best answer based upon the relationship between your community's H&CC program and external health care partners.
Please read the following statement and select the most accurate response. *It is important that the HCC staff have positive working relationships with external care partners in order to provide end-of-life care.*

Community members are aware that dying at home, in the community is an option.
Please read the following statement and select the most accurate response. *It is important that community members are aware that they have the option to die at home, in the community.*

Do community members who are terminally ill put off making plans for where they would like to die? Please read the following statement and select the most accurate response. *It is important that terminally ill community members make early plans for where they would like to die.*

Is there anything that we have not mentioned that you think assists you to provide end-of-life care?

Is there anything that we have not mentioned that you think are barriers to your community's ability to provide end-of-life care?

Section E: Physical Resources

Participants were given a list of recommended physical resources and asked to identify the resources they have available to their HCC team (Indian Association of Palliative Care, 2007). The list can be viewed within the report in the results section.

Survey Closing
Thank you for your time today in completing this survey. We would like to know if you are interested in participating in a telephone interview to have a more in-depth discussion around your responses?

If we would like to contact you for more information on your responses, where can we reach you?
Would you like to be entered into a draw to win a $100 Visa gift card?

Survey Closing
Thank you for sharing this important information about your community. We value your input and it will help in the development of an end-of-life services model that can support you and others in your community in providing services to

individuals that want to die at home.

Questions
If you have questions regarding this survey, please contact:

First Nations, Inuit
& Métis Program

Doris Warner

Engagement Liaison,

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Appendix H: Interview: Communities Delivering End-of-Life Care

All interview participants, completed the survey. The interview questions, used the survey information to inform the interview. Below is a generic version of the interview questions.

Interview Questions: Communities Delivering End-of-Life Care

Hello, my name is Doris Warner. I am an Engagement Liaison with the SE Health, First Nation, Inuit & Metis Program. Thank you for taking the time to meet with me today. We appreciate that your day is very busy and we don't anticipate it taking more than 30 minutes to complete this interview, which is a follow-up to the online survey about end-of-life services you recently completed. Thank you for indicating on the survey that you would be interested in speaking to us further.

The purpose of our discussion is to explore what the strengths, wise practices, barriers and challenges are in delivering end-of-life services in your community. The information you share today about your community will help us to develop an end-of-life services model that can support you and others in your community in providing services to individuals that want to pass away (die) at home.

[Informed consent]: We also need to let you know that we are recording this interview so we can accurately capture and review your responses. I need to ask if you are okay with this process and give your consent to proceed. Yes / No.
[Disclaimer]: We acknowledge and respect that not everyone is comfortable with Westernized language used to describe when an individual makes his/her way to the spirit world. The use of the words death, die, or dying used within this survey are not meant to be disrespectful, but are used to ensure clarity.
The words client and patient are used interchangeably throughout the survey and is defined as a person who is receiving support or services from the Home & Community Care Program.

Definitions
To be sure that we are gathering accurate information, we have defined palliative and end-of-life care. **Palliative care** is an approach to care, it should begin at the time of diagnosis, regardless of what the diagnosis, age or prognosis is. An example might be a client who has diabetes mellitus type 2 might have neuropathic pain. A health care provider might provide care consistent with a palliative approach that addresses the client symptoms in a wholistic manner. This care is provided even if the client is not expected to pass (die) soon.
As time goes on and the illness progresses, palliative care interventions will increase.
End-of-life care takes place in the last weeks, days and hours of life. At this stage, dying individuals lose their ability to independently function and is more dependent on family/friend/natural caregivers. The client may experience common symptoms that manifest (appear) as death draws near.

We have already been able to gather some basic information in the demographic section that you had shared on the survey. Can you please review and just ensure that the information we have is correct?

DEMOGRAPHICS

Community:

Respondent name & role: **Community population: Number of clients in H&CC: Distance from nearest hospital:**

Classification: Rural / Remote / Isolated

We have kept the questions broad in hopes that we capture the stories of end-of-life care and service delivery in your community.

1. What are the factors that support the delivery of end-of-life care in the community?
a. What happens when a client who is at the end-of-life requires after hours support?
b. You mention on the survey that your community has virtual care services. What are some of the challenges of using virtual care? What are some of the opportunities of virtual care in end-of-life services?
2. What are the challenges and barriers you have faced in providing end-of-life care in the community?

a. You mention on the survey that the community has natural caregivers, but there is no established connection between them and H&CC. Do you think there is an opportunity to engage natural caregivers to assist in end-of-life care? Why or why not?

3. Would you say that those who recently died in the community, died how they had wished to die?

a. Do you feel that you (and other members) of the H&CC program have a good understanding of the dying process and how to manage symptoms (physical, emotional, mental, spiritual) and complications that might arise? Are there any areas that you would like to develop through education and support to assist you to deliver end-of-life care?

4. Why do you think that people who come home with the intention to die in the community end up back in the hospital when care needs become too high? What do you think needs to happen to address this?

a. How involved is H&CC when someone is actively dying in the community? Does H&CC staff go every day? What does this look like?

b. How are families prepared for the increased caregiving needs that will occur as someone is dying?

5. If you could have everything and anything that you need to provide end-of-life care, what would that look like?

a. If you had the ability to consult with someone for practice support when providing end-of-life care, would you use this support? What do you think having practice supports would look like?

b. You mention in the survey that you are not sure if there are polices and guidelines to support end-of-life care in the community. Do you feel that having practice guidelines would assist you to wholistically deliver end-of-life care? Why or why not?

6. Is there anything else you would like to share with us?

Thank you for sharing your valuable knowledge and time with me today. We would like to enter your name into a draw to win a $100.00 gift care. Do I have your permission to do this?

Yes / No

Thank you. If you have anything else that you would like to share, please reach out to me anytime. Take

Care.

First Nations, Inuit
& Métis Program

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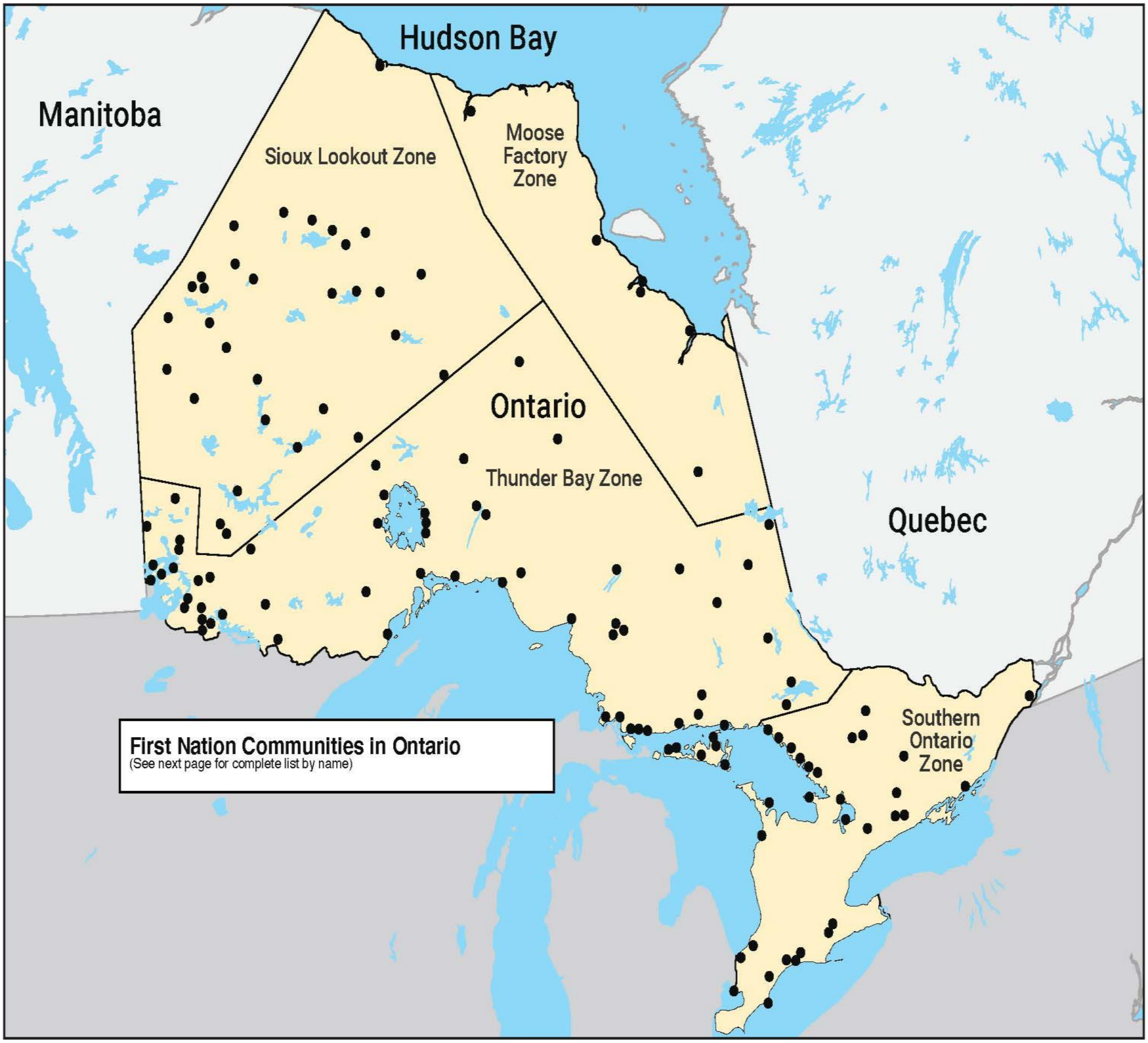
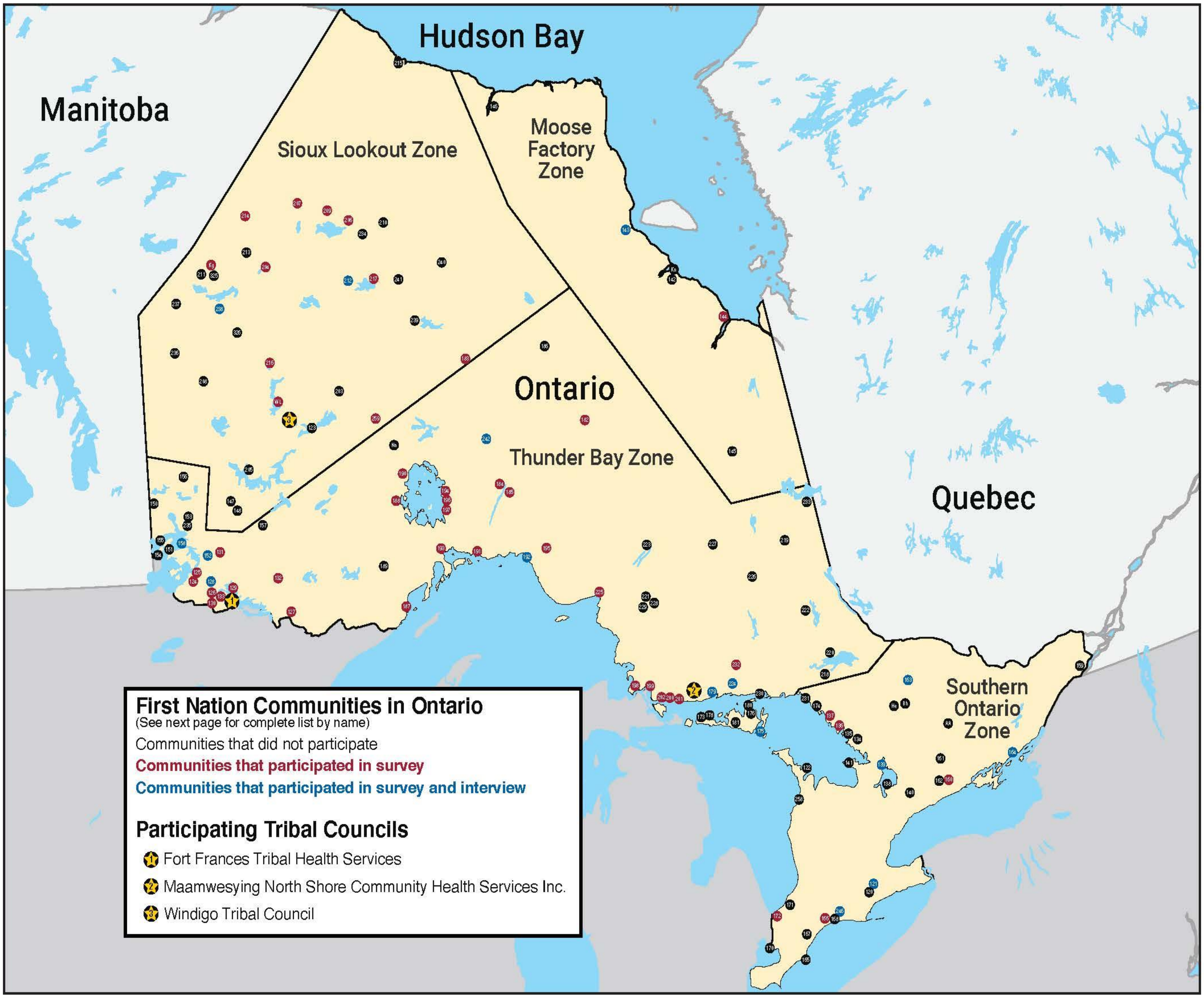
Appendix I: Map Ontario First Nations Communities



First Nation Communities in Ontario

Aamjiwnaang (Chippewas of Sarnia First Nation)	172
Akwesasne	159
Alderville	160
Ardoch Algonquin	AA
Aroland	242
Attawapiskat	143
Aundek Omni Kaning (Sucker Creek)	180
Batchewana	198
Bearskin Lake	207
Beausoleil (Christian Island)	141
Beaverhouse	Bh
Big Grassy	124
Big Island (Anishnaabeg of Naongashiing)	125
Brunswick House	228
Caldwell	165
Cat Lake	216
Chapleau Cree	221
Chapleau Ojibway	229
Chippewas of the Thames	166
Constance Lake	182
Couchiching (Fort Frances)	126
Curve Lake	161
Deer Lake First Nation	237
Dokis (Waabnoong Bemjwang)	218
Eabametoong (Fort Hope)	183
Eagle Lake	148
Flying Post	227
Fort Albany	142
Fort Severn	215
Fort William	187
Garden River	199
Georgina Island (Chippewas of Georgina)	138
Ginoogaming	185
Golden Lake (Algonquins of Pikwakanagan)	163
Grassy Narrows	149
Gull Bay (Kiashke Zaaging Anishinaabek)	188
Henvey Inlet	231
Hiawatha	162
Hornepayne	He
Kasabonika Lake	210
Kashechewan	Kn
Kee-Way-Win	325
Kettle and Stony Point	171
Kingfisher Lake	212
Kitchenuhmaykoosib Inninuwug	209
Koocheching	Kg
Lac Des Milles Lac	189
Lac La Croix	127
Lac Seul	205
Lake Nipigon Ojibway (Animbiigoo Zaagi'igan)	194
Long Lake 58	184
Magnetawan	174
Marten Falls (Ogoki Post)	186
Matachewan	219
Mattagami	226
McDowell Lake	326
Michipicoten	225
Missanabie Cree Nation	223
Mississauga #8	200
Mohawks of the Bay of Quinte-Tyendinaga	164
Moose Cree	144
Moose Deer Point	135
Moravian of the Thames	167
Munsee-Delaware	168
Muskrat Dam First Nation	213
M'Chigeeng	181
Naicatchewenin	128
Namaygoosisagagun	Nn
Nawash	122
Neskantaga (Lansdowne House)	239
New Credit (Mississaugas)	120
Nibinamik (Summer Beaver)	241
Nigigoonsiminikaaning (Red Gut FN)	129
Nipissing	220
North Caribou (Weagamow/Round Lake)	204
North Spirit Lake	238
Northwest Angle No. 33	151
Northwest Angle No. 37 (AnimakeeWa Zhing)	152
Ochiichagwe'babigo'ining (Dalles)	147
Ohsweken	121
Oneida	246
Onigaming	131
Osnaburgh (Mishkeegogamang)	203
Pays Plat	191
Pic Mobert	195
Pic River (Biigtigong Nishnaabeg)	192
Pikangikum	208
Poplar Hill	236
Rainy River	130
Rama (Chippewas of Mnjikaning)	139
Red Rock	193
Rocky Bay (Biinjitiwaabik Zaaging Anishinaabek)	197
Sachigo Lake	214
Sagamok Anishnawbek	179
Sand Point	196
Sandy Lake	211
Saugeen (Savant Lake)	258
Saugeen Nation (Chippewas of Saugeen)	123
Scugog Island	140
Seine River	132
Serpent River	201
Shawanaga	137
Sheguiandah	176
Sheshegwaning	178
Shoal Lake No. 40	155
Shoal Lake No 39 (Iskatewizaagegan)	154
Six Nations	121
Slate Falls (Bamaji Lake)	259
Stanjikoming	133
Taykwa Tagamou Nation (New Post)	145
Temagami	222
Thessalon	202
Wabaseemoong (Whitedog)	150
Wabauskang	156
Wabigoon Lake	157
Wahgoshig	233
Wahnapitae	232
Wahta Mohawks	134
Walpole Island (Bkejwanong First Nation)	170
Wapekeka (Angling Lake)	206
Wasauksing	136
Washagamis Bay (Obashkaandagaang)	235
Wauzhushk Onigum (Rat Portage)	153
Wawakapewin (Long Dog)	234
Webequie	240
Weenusk (Peawanuck)	146
Whitefish Bay (Naotkamegwanning)	158
Whitefish Lake (Atikameksheng Anishnawbek)	224
Whitefish River	230
Whitesand	190
Whitewater Lake	WL
Wikwemikong	175
Wunnumin Lake	217
Zhiibaahaasing (Cockburn Island)	173

Appendix J: Map of Participating Ontario First Nations in Community Voices



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Kitchenuhmaykoosib Inninuwug	**209**
Koocheching	**Kg**
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Lac La Croix	**127**
Lac Seul	205
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Appendix K: Current Initiatives

Indigenous Transition Coordinators

This new role is exclusive to and funded by ISC HCC Ontario Region and works at the zone level. The primary responsibility of this role is system navigation and aims to strengthen linkages between the provincial and federal health systems to optimize care for First Nations that is equitable and culturally safe. This will be achieved by:

- Planning transitions in care for First Nation patients being discharged from a regional facility back home to a First Nation or other community in Ontario.
- Bridge understanding between western and Traditional methods and approaches to treatment and care with a focus on quality.

Lakehead University Center for Education and Research on Aging & Health (CERAH)

ISC HCC, Ontario Region has a longstanding relationship with Lakehead University CERHA, collaborating to improve palliative and EoL service delivery for First Nations across Canada. This collaboration has resulted in the development of PC programs within First Nations and the development of culturally appropriate resources to support the provision of palliative and EoL care in First Nations. The most recent initiative includes a 15-hour training session on PC for front-line workers in Indigenous communities, providing an overview on PC concepts, tools and resources.

SE First Nations, Inuit and Métis Program

ISC HCC, Ontario Region has a longstanding with the SE FNIM Program, collaborating to strengthen health care for First Nations in all aspects, from system design to service delivery. This collaboration has resulted in:

- *PSW Training*: This vocational program aims to build capacity in First Nations through the delivery of blended learning, allowing students in the program to live in their communities while simultaneous pursing culturally safe/relevant education. Within the curriculum, there is a PC module that is heavily focused on non-pharmacological symptom management approaches. Students who complete the program are certified PSWs and often go on to obtain employment within their First Nations.
- *Wound Care Education*: This goal of this program is to provide HCC nurses and PSWs working in Ontario First Nations with foundational knowledge to support evidence-based practices in wound prevention and treatment. As per McManus (2009), "wounds are a symptom of advanced disease, as demonstrated in symptom prevalence studies in PC" (p. 38). The wound care education program is delivered via blended learning, allowing these essential health care providers to learn in their communities, minimizing disruption to health service delivery. To date there has been representation from all geographical areas of Ontario. Building specialized competencies within First Nations minimizes the need for travel outside of communities. This can have a direct impact on improving quality of life for residents of those First Nations, honoring the palliative approach to care.

- *HCC Policies and Procedures*: Currently in development are HCC Policies and Procedures. The goal of this initiative is to guide HCC nurses and PSWs to provide evidence-based, best-practice care to the First Nations they serve. The HCC Policies and Procedures will be inclusive of best practices to support palliative and EoL care in First Nations.
- *Case Management (CM) Training:* Chronic disease management is complex for the client, their family and the health care providers. The two-day, in-person CM Workshop was developed for HCC staff (Nurses and PSWs), to provide an overview of case management as it relates to chronic disease, utilizing a PC approach. Topics covered in the workshop included: case/care management; determinants of health; team building; lateral violence; communication; assessment and documentation; advocacy; referrals; complex case management; and self-care. This training was supplemented with webinars to ensure accessible education opportunities for those in rural/remote areas. In total, there were 161 learners.
- *Chronic Disease Management Training:* The interactive Chronic Disease Management online course and consists of three modules: 1. Introduction to Chronic Disease; 2. Chronic Disease Models and Frameworks; and 3. Chronic Disease Management. The content covers the most common chronic diseases (type 2 diabetes, cardiovascular disease, cancer, and respiratory diseases) and incorporates relevant evidence-based guidelines. The content is presented through an Indigenous lens in a culturally safe manner and is intended for Home and Community Care (HCC) staff including Nurses and Personal Support Workers (PSWs) that work in First Nation communities in Ontario. The majority of the content is applicable to all levels of health care workers; however, there are opportunities for both Nurses and PSWs to work with content that is levelled to their specific competencies. Learners that complete all three modules receive a certificate of completion. The CDM course was launched April 29, 2020 and is available to Ontario learners on the @YSC website. Having a solid foundation in chronic disease management will only improve the palliative approach to care in First Nations.

McMaster University

Primary care is the key to supporting patients and families to live well and die in their communities. With the support of ISC HCC, Ontario Region, McMaster University is planning a large education intervention aimed at improving access to community-based PC for Indigenous communities in Ontario. The intervention, called CAPACITI-FNIM, will include teaching and practical training that will empower existing community primary care providers in delivering home-based palliative approaches to care for First Nations, Inuit and Metis (FNIM) people. This program will increase access to local supports and providers, so if Indigenous People wish to remain at home, the system can fulfil that wish (McMaster University, 2021).

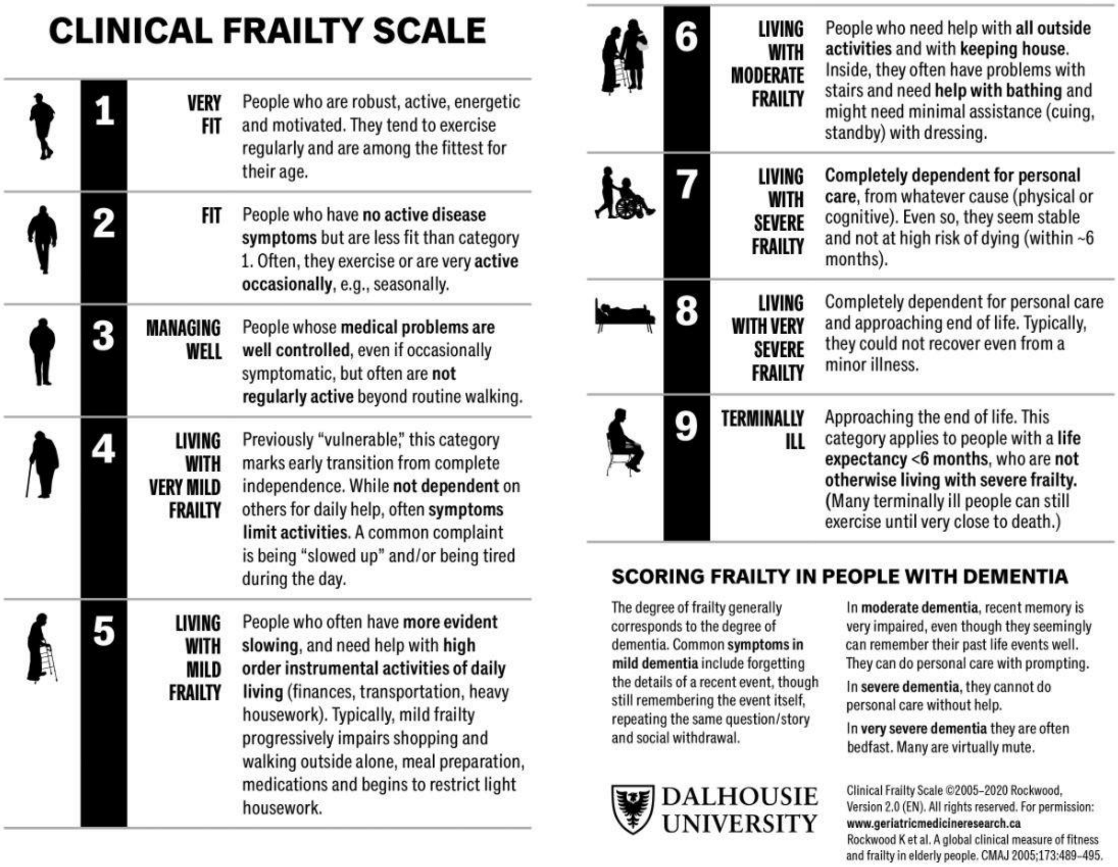
First Nations Digital Health in Ontario (FNDHO)

In November 2018 a Resolution from the All Ontario Chiefs in Assembly (AOCC) to establish an organization (FNDHO) to ensure all First Nations health teams in Ontario can realize the benefits from and receive the required support for digital health. ISC HCC, Ontario Region provides support to FNDHO, a First Nations led organization supporting digital health system transformation for First Nations health teams. Digital health is necessary for health care transformation and is a key focus area to strengthen health care access/equity, including the provision of palliative and EoL services (OPCN, 2019).

Hospice-like Spaces

ISC HCC, Ontario Regions is providing funding over a period of five-years for hospice like spaces. The goal is to develop and enhance the provision of palliative and EoL in First Nations communities in Ontario. As reinforced by *Community Voices*, safe and accessible housing/spaces within First Nations is a longstanding issue that often creates inimitable barriers for First Nations peoples wanting to pass (die) at home. Palliative and EoL frameworks that are inclusive of solutions that address major barriers in infrastructure access, have demonstrated increased levels of success (Morrison, 2017).

Appendix L: Clinical Frailty Scale



CLINICAL FRAILTY SCALE

1	**VERY FIT**	People who are robust, active, energetic and motivated. They tend to exercise regularly and are among the fittest for their age.
2	**FIT**	People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g., seasonally.
3	**MANAGING WELL**	People whose **medical problems are well controlled**, even if occasionally symptomatic, but often are **not regularly active** beyond routine walking.
4	**LIVING WITH VERY MILD FRAILTY**	Previously "vulnerable," this category marks early transition from complete independence. While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being "slowed up" and/or being tired during the day.
5	**LIVING WITH MILD FRAILTY**	People who often have **more evident slowing**, and need help with **high order instrumental activities of daily living** (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework.
6	**LIVING WITH MODERATE FRAILTY**	People who need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.
7	**LIVING WITH SEVERE FRAILTY**	**Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months).
8	**LIVING WITH VERY SEVERE FRAILTY**	Completely dependent for personal care and approaching end of life. Typically, they could not recover even from a minor illness.
9	**TERMINALLY ILL**	Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise living with severe frailty.** (Many terminally ill people can still exercise until very close to death.)

SCORING FRAILTY IN PEOPLE WITH DEMENTIA

The degree of frailty generally corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

In **very severe dementia** they are often bedfast. Many are virtually mute.

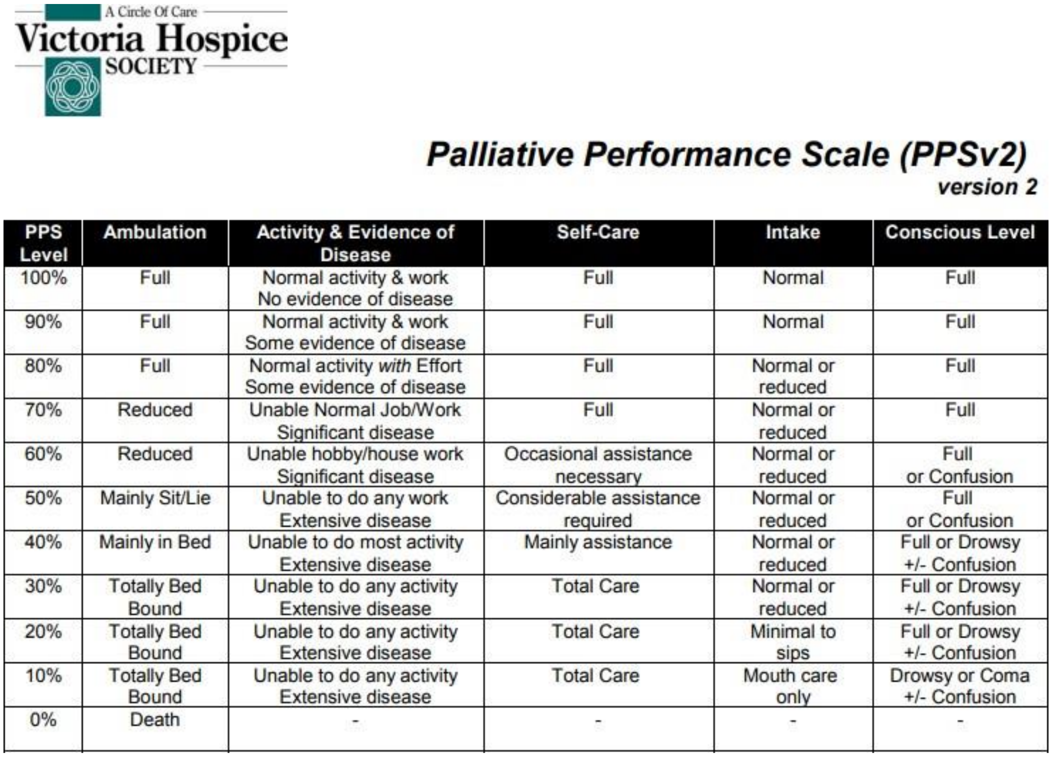
DALHOUSIE UNIVERSITY

Rockwood K et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489–495.

Reference:

Dalhousie University, Geriatric Medicine Research. (2021). Clinical frailty scale (CFS). Retrieved from: https://www.dal.ca/sites/gmr/our-tools/clinical-frailty-scale.html

Appendix M: Palliative Performance Scale Version 2



A Circle Of Care
Victoria Hospice
SOCIETY

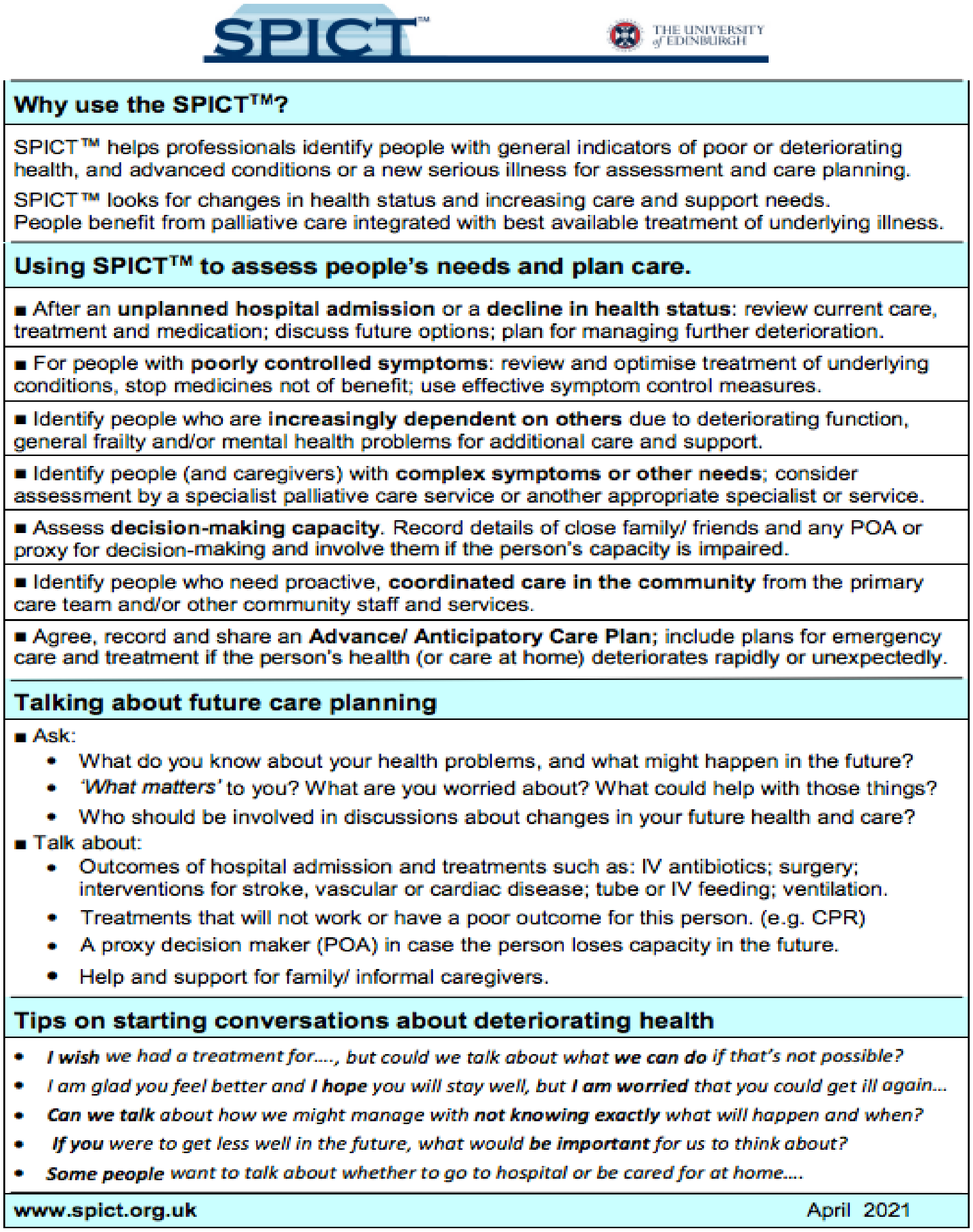
Palliative Performance Scale (PPSv2)
version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Reference:

Victoria Hospice. (2001). Palliative performance scale (PPSv2) version 2. Retrieved from: https://victoriahospice.org/wp-content/uploads/2019/12/PPSv2-English-Sample.pdf

Appendix N: SPICT (Supportive and PC Indicators Tool)



Why use the SPICT™?

SPICT™ helps professionals identify people with general indicators of poor or deteriorating health, and advanced conditions or a new serious illness for assessment and care planning.

SPICT™ looks for changes in health status and increasing care and support needs. People benefit from palliative care integrated with best available treatment of underlying illness.

Using SPICT™ to assess people's needs and plan care.

- After an **unplanned hospital admission** or a **decline in health status**: review current care, treatment and medication; discuss future options; plan for managing further deterioration.
- For people with **poorly controlled symptoms**: review and optimise treatment of underlying conditions, stop medicines not of benefit; use effective symptom control measures.
- Identify people who are **increasingly dependent on others** due to deteriorating function, general frailty and/or mental health problems for additional care and support.
- Identify people (and caregivers) with **complex symptoms or other needs**; consider assessment by a specialist palliative care service or another appropriate specialist or service.
- Assess **decision-making capacity**. Record details of close family/ friends and any POA or proxy for decision-making and involve them if the person's capacity is impaired.
- Identify people who need proactive, **coordinated care in the community** from the primary care team and/or other community staff and services.
- Agree, record and share an **Advance/ Anticipatory Care Plan**; include plans for emergency care and treatment if the person's health (or care at home) deteriorates rapidly or unexpectedly.

Talking about future care planning

- Ask:
  - What do you know about your health problems, and what might happen in the future?
  - *'What matters'* to you? What are you worried about? What could help with those things?
  - Who should be involved in discussions about changes in your future health and care?
- Talk about:
  - Outcomes of hospital admission and treatments such as: IV antibiotics; surgery; interventions for stroke, vascular or cardiac disease; tube or IV feeding; ventilation.
  - Treatments that will not work or have a poor outcome for this person. (e.g. CPR)
  - A proxy decision maker (POA) in case the person loses capacity in the future.
  - Help and support for family/ informal caregivers.

Tips on starting conversations about deteriorating health

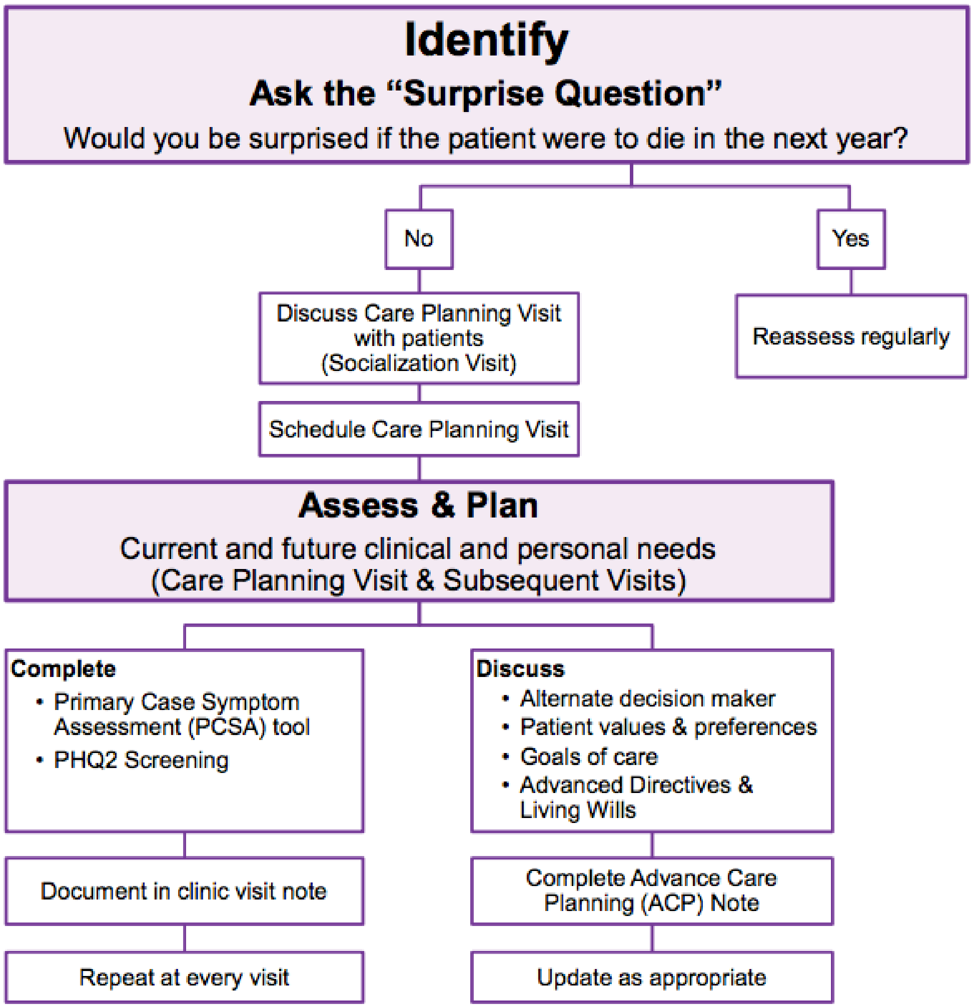
- ***I wish** we had a treatment for…., but could we talk about what **we can do** if that's not possible?*
- *I am glad you feel better and **I hope** you will stay well, but **I am worried** that you could get ill again…*
- ***Can we talk** about how we might manage with **not knowing exactly** what will happen and when?*
- ***If you** were to get less well in the future, what would **be important** for us to think about?*
- ***Some people** want to talk about whether to go to hospital or be cared for at home….*

www.spict.org.uk April 2021

Reference:

University of Edinburgh. (2021). Supportive and palliative care indicators tool (SPICT). Retrieved from https://www.spict.org.uk/the-spict/

Appendix O: Surprise Question Reference:



Mayo Clinic. (2015). Using the "Surprise Question" to trigger patients for palliative measures in community care. Retrieved from: https://media.capc.org/filer_public/86/5e/865e28e3-ba31-4e0a-8783-3a4224b6d15c/mayo_clinic_1_using_the_surprise_squire.pdf

Appendix P: Community Voices Validation Survey Questions

1. The background section of the report covers all the important topics for this project
2. The purpose of this project is clear in the report
3. How we gathered information is clear in the report
4. The results of the report reflects my own experiences
5. The promising practices outlined have the potential to improve equitable access to palliative care for First Nations in Ontario
6. The discussion section of the report adds new insights to palliative care for First Nations in Ontario
7. I see my contributions reflected in the report
8. The report is easy to read
9. The format of the report is well organized
10. Overall, I fell that this report will help with creating positive change in equitable access to palliative care for First Nations in Ontario
11. Do you have any other comments you would like to share about this report?
12. Would you like someone from our team to contact you to discuss this report further?

Questions 1-10 allowed participants to answer on the following scale:

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree