Portrait

OF PALLIATIVE CARE PROVIDED IN FIRST NATIONS COMMUNITIES IN QUEBEC

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FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION

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Note to the reader
The document references the department of Indigenous and Northern Affairs Canada (INAC) and Health Canada. In 2017, the government of Canada announced the dissolution of INAC and the creation of the department of Indigenous Services Canada (ISC), which is now bringing together First Nations and Inuit health services (formerly with the Health Canada), education services, essential social services, child and family services programs, and housing and infrastructure services (formerly with Indigenous and Northern Affairs Canada).

Appreciation
The FNQLHSSC would like to thank the representatives of First Nations communities in Quebec who took the time to complete the questionnaire so eloquently and thoroughly. They contributed to the success of this study, and for that we are extremely grateful.

We would like to express our appreciation for the work of Linda Simon (Simon Management Services), who coordinated the survey and drafted part of this portrait.

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Table of contents

Foreword

Implementation of the *Act respecting end-of-life care*

This project was carried out in 2015 when the Government of Québec was preparing for the implementation of the *Act respecting end-of-life care,* which was to enter into force in December 2015.

This portrait therefore presents the state of affairs prior to the coming into force of this act, which could have a considerable impact on the care and services offered in non-treaty First Nations communities in Quebec.

Although this act is addressed in this document, its application will be subject to further analysis by the FNQLHSSC.

1. Introduction

1.1 BACKGROUND

For a number of years, various studies have been carried out and have brought to light several observations concerning the provision of palliative care in Canada's Aboriginal communities. Already 10 years ago, the summary report *Assessing Continuing Care Requirements in First Nations and Inuit Communities,* produced in collaboration with various Aboriginal and federal organizations, presented recommendations for improving continuing care services. Some of the recommendations were specific to palliative care. The report stated that palliative care is one of the services that must be added to improve care for clients currently receiving continuing care in Aboriginal communities. More specifically, it proposed that palliative care and end-of-life care be recognized as essential components of continuing care and that they receive financial support (Miller and Hollander, 2006). The results also showed that for Aboriginal patients in Quebec, the needs are high but vary widely between communities. Therefore, this study clearly demonstrated the existence of a strong demand for palliative care services as well as significant gaps in their availability (FNQLHSSC, 2006).

In 2009, the summative evaluation of Health Canada's First Nations and Inuit Home and Community Care Program (FNIHCCP) reported similar findings. The evaluation noted that priority should be given to providing services that can address unmet health needs, including palliative care, and gaps in the provision of continuing care. Respondents to this study cited the underfunding of care services as well as the discrepancy between the FNIHCCP and community needs. Several issues were raised, including the shortage of health human resources as well as the lack of specific training in palliative care, jurisdictional issues, links to the provincial health care system that vary from region to region, the situation of remoteness or isolation of certain communities, the lack of data, cultural particularities and housing. The lack of palliative care was the most frequently cited gap in the program.

The need to provide palliative care in Aboriginal communities has therefore been widely reported and is now considered a well-founded need. The range and intensity of services need to be reconsidered in light of the development of the FNIHCCP and the increased capacity of communities to manage health and social services. In recent years, Aboriginal authorities have called for action to be taken in this direction.

In Canada

The topic of palliative care in Aboriginal communities was very much on the political radar in 2013, both nationally and regionally. In July 2013, at the Annual General Assembly of the Assembly of First Nations (AFN), the Chiefs unanimously adopted a resolution mandating the AFN to take steps and lobby the federal government to have palliative care prioritized and deemed an essential service element in First Nations communities (*Resolution No. 07/2013 – Increase in funding for palliative care in First Nations communities*).

In September 2013, the FNIHCCP First Nations working group met with the group behind "The Way Forward" project to discuss the draft of their national framework for an integrated palliative approach to care delivery.

In Quebec

In December 2013, the FNQLHSSC board of directors added an organizational priority to produce a portrait of the palliative care available in non-treaty First Nations communities in Quebec.

On June 10, 2014, the Government of Québec approved Bill 52: *An Act respecting end-of-life care*. This Act specifies the rights related to end-of-life care, the specific rules that apply to the various health care providers (institutions, palliative care homes, private practices, etc.), as well as the organization of and framework for end-of-life care. It also allows people who are terminally ill to obtain medical aid in dying and describes the conditions under which they may receive it. At the time this act was developed, First Nations were not invited to comment at the special consultations held in September and October 2013. To date, the impact of this Act on First Nations and Aboriginal communities in Quebec is still unknown.

This portrait was therefore produced through a lens of further documenting the palliative care situation in non-treaty First Nations communities in Quebec, with the aim of submitting specific recommendations for these communities.

1.2 SITUATIONAL ANALYSIS

Access to palliative care

The 2008 *Quebec First Nations Regional Health Survey* (RHS) demonstrated that palliative care is one of the least accessible forms of home-care support. Specifically, the RHS revealed that "only 9.6% of those who mention needing palliative care do receive some" (FNQLHSSC, 2008, p. 27). This is the lowest proportion of people who have access to a service deemed necessary by the respondent.

Funding for palliative care

First Nations communities in Quebec administer the FNIHCCP, funded by Health Canada. The funding formula for this program is based solely on the provision of essential services and does not include complementary services. Since the program considers home palliative care a complementary service, communities may provide this type of care only when essential services have been provided and funds remain.

To receive the funding and ensure that the communities meet the program criteria, Health Canada requires each community to have a service delivery plan. The document should describe how essential services are provided and how support services desired by the community are delivered based on the funds available. However, since it is difficult to predict the demand for home-care support in a given year, it is almost impossible to predict a budget surplus that would allow for the provision of palliative care. Finally, if a community is under a funding model that affords them greater flexibility, they can reallocate funds from another program to the home-care support program and provide home-based palliative care. The provision of palliative care in communities therefore differs according to several factors, including the social, economic, geographic and demographic context.

Provision of palliative care

In March 2015, the non-treaty First Nations communities in Quebec, including the Naskapis, were surveyed to analyze the situation regarding palliative care offered in the First Nations communities in Quebec. The purpose of this approach was to identify needs, determine the effects of the lack of access to palliative care on the population and explore possibilities for sustainable development of care and services. This became even more pressing with the passage of Bill 52, *An Act respecting end-of-life care* in Quebec.

It should be noted that the portrait is intended to report on the situation of non-treaty First Nations communities only, because treaty communities have a special status in relation to the provincial and federal governments. In Quebec, for example, the three treaty Aboriginal groups have a different reality than the one presented in this portrait.

1.3 DATA COLLECTION

A consultant was given a mandate to collect data, with the following key objectives:

1. Develop and administer a questionnaire to gather information from various care providers involved in delivering palliative care in communities

2. Paint a picture of the situation (community and regional levels) and demonstrate the needs, effects of and opportunities for development and funding of care and services

The communities were invited to complete a questionnaire and return it within a prescribed timeframe. The consultant could also complete the questionnaire with the respondents by telephone. A total of 18 communities responded to the invitation for a total of 19 completed questionnaires.[1] The response rate of the communities is therefore 62%; 18 communities out of a possible 29.[2]

1.4 THE QUESTIONNAIRE

The questionnaire focused on the following aspects:

- The needs of patients, their families and the communities
- The palliative care and services offered in the communities
- The reasons preventing the communities from offering palliative care
- The different barriers facing patients and care providers from First Nations communities
- Partnerships
- The application of the *Act respecting end-of-life care*

1.5 THE PORTRAIT

This portrait was drafted by combining the information taken from the report of the consultant who collected the data, the aggregate data compiled and provided by Health Canada for the Quebec region, and the other references and sources listed in the bibliography.

1 One community submitted two completed questionnaires to cover all the services.

2 The questionnaire was sent to 31 communities, but 2 of them said they could not participate: one of them was a treaty community and the other had no residents.

2. Review of literature

2.1 GENERAL LITERATURE

Palliative care provides relief from pain and other distressing symptoms to improve the quality of life of patients and their families, and integrates the physical, psychological and spiritual aspects of patient care. It affirms the right to life and treats death as a normal process. It does not try to hasten or postpone death. It provides a support system to help patients live as actively as possible until their death and to help families cope with the loved one's death and then with bereavement. Palliative care uses a multidisciplinary approach to meet the needs of patients and their families. It aims to enhance quality of life and can also have a positive effect on the course of the disease. It is applicable early in the course of illness, along with other life-prolonging therapies, and includes the necessary investigations to better understand and manage potential distressing complications (World Health Organization, 2013).

Palliative care

Palliative care is an approach that improves the quality of life of patients (children and adults) and their families facing problems associated with life-threatening illness. It prevents and relieves suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual in nature.

(World Health Organization, 2015)

End-of-life care

This is palliative care provided to dying patients and is the final step on the continuum of palliative care provided to patients.

(Ordre des infirmières et infirmiers du Québec, 2013)

In Canada, a small proportion of the population will require complex, intensive, or tertiary (i.e., ultra-specialized) palliative care delivered by teams of palliative care experts in an institutional setting (hospices or acute care hospitals). However, anyone with fragile health or a chronic disease may need palliative care services (Canadian Hospice Palliative Care Association, 2015).

> **Only 10% of people die suddenly. The other 90% of us will require care and support at the end of life. Only a small proportion of Canadians – about 15% – will need the kind of complex (tertiary) hospice palliative care services provided by specialists in residential hospices and palliative care units. For the rest of us, our needs can be met by integrating a palliative approach into the care we receive in whatever setting we are in, such as at home, in a long-term care facility, in hospital – even in a shelter or prison (Canadian Hospice Palliative Care Association, 2015, p. 9).**

Today, seniors or people with incurable illness may live for many years with fragile health. However, they may also die suddenly, which is why it is difficult to determine the most appropriate palliative care services for each situation. Given our uncertainty about when death will occur, many people will never receive palliative care, as they will not have been identified as being at risk of dying (Canadian Hospice Palliative Care Association, 2015).

The Canadian Hospice Palliative Care Association and its partners advocate for early integration of palliative care into the service delivery program for chronic and other diseases. An integrated care approach gives patients and their families access to all aspects of palliative care at the appropriate time in their lives or during illness in any care setting, which may include open and sensitive communication about the patient's illness and condition, advance care planning, psychosocial and spiritual support, and management of pain and symptoms, which are offered to the patient and their family and adapted as the disease progresses.

In 2011, the Parliamentary Committee on Palliative and Compassionate Care published the report *Not to be Forgotten: Care of Vulnerable Canadians.* In this report, the committee makes recommendations for improving palliative care in Canada. The Committee's fifth recommendation is specifically for First Nations, Métis and Inuit communities:

> **We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve (Parliamentary Committee on Palliative and Compassionate Care, 2011, p. 39).**

The Parliamentary Committee also recommends that the federal government fund research programs to build the capacity of Aboriginal communities and improve the quality of palliative care delivery for Aboriginal peoples. Funding for such programs should make it possible to develop:

- Models of palliative care adapted to First Nations communities
- Education and training programs adapted to First Nations culture
- Strategies for communication and collaboration between outside experts or specialists and local service providers

2.2 FIRST NATIONS STUDIES

The literature on Aboriginal palliative care shows that First Nations people in Canada want to receive home-based palliative care in their community (Hotson et al., 2004; Prince and Kelley, 2006; Kelly and Minty, 2007; McGrath, 2007; Kelley and Prince, 2014). "This population includes people of all ages with any diagnosis who would benefit from a palliative approach to care, especially in the last year of life, as well as the family and community caregivers of that person. When individuals wish to die at home, palliative care extends to include end-of-life care" (Kelley et al., 2015, p. 2).

Three main findings can be drawn from recent studies on the provision of palliative care in remote and rural Aboriginal communities in Canada, the United States, New Zealand and Australia. These studies reveal that, in general, Aboriginal people prefer to die at home, that resources are insufficient to meet their needs, and that there is a need for culturally appropriate palliative care inside and outside the community (O'Brien, V., 2012). Most Aboriginal people would prefer to die at home but cannot. "Dying at home is not only the preferred option for most First Nations people; there is also a strong economic rationale for providing palliative care in First Nations communities. Today, First Nations people are dying in the hospital, which is the most expensive setting of care and not an efficient use of health services" (Kelley et al., 2015, p. 2).

Based on Kelly's review of the literature (2007), many traditional Aboriginal perspectives differ from the viewpoints of other Canadians. These differences may affect decision-making and the provision of palliative care, because ideas and beliefs such as those surrounding end of life may not only differ from those of Western culture but also from one Aboriginal community to another (Kelly and Minty, 2007). Kelly is also involved in another study "to understand cross-cultural hospital-based end-of-life care from the perspective of bereaved First Nations family members . . . [who] describ[e] palliative care as a community and extended family experience" (Kelly, L., 2009, p. 394). Study respondents expressed the need for rooms and services that can accommodate a larger number of visitors per patient. Other important elements that came up in the study included direct and respectful communication and acknowledgement of the role of health care providers in patient care. Although participants emphasize that relationships between patients, their families and health care providers are generally positive, care becomes a greater challenge when the patient's death is imminent. Special attention must be paid to some components of palliative care in order to choose culturally appropriate strategies for interventions. Participants in Kelly's study mentioned that care and service delivery and communication strategies need to be developed to adequately address the needs of Aboriginal clients.

It is important to mention that in addition to specific palliative care studies, other studies addressing different aspects of health care delivery to Aboriginal seniors have been completed. In general, the authors mention the importance of providing culturally safe care.

Colonization and residential school experiences, along with continuing experiences of racism in Canadian society, have created a significant mistrust of mainstream institutions . . . . many seniors delay seeing a health care professional about their symptoms until they are seriously ill because they are afraid their diagnosis will mean they will be sent away for care and never return (Health Council of Canada, 2013, p. 9).

There are many consequences to not providing culturally safe care and services. For example, a senior Aboriginal person may stop going to their appointments or following their treatment plan. In addition, care providers with little or no information about the past or present personal and community lives of Aboriginal people may compromise patient health by inaccurately assessing " . . . seniors' ability to care for themselves, and their access to services and resources" (Health Council of Canada, 2013, p. 9). Frail individuals may therefore be returned to their community without any verification of the home care and support offered by the community that may allow them to return home safely.

In order to guide health professionals in their work with Aboriginal clients, in 2005, the FNQLHSSC published a document presenting the overall health status of First Nations people as well as the cultural traits and values that may differ between

Aboriginal and non-Aboriginal people.[3] More recently, in 2012, the Health Council of Canada published a document about creating cultural safety for Aboriginal people in urban health care. The following boxes present some elements from those two publications. This information evokes general characteristics that do not reflect the cultural nuances of each nation or community but serve to demonstrate that the competency of care providers to ensure cultural safety is paramount to the health status of Aboriginal people.[4] Here are the definitions presented by the Health Council of Canada to provide a better understanding of the concepts used.

Cultural competency

". . . [C]ultural competency is about creating a health care environment that is free of racism and stereotypes, where Aboriginal people are treated with empathy, dignity, and respect."

Cultural safety

"Cultural safety . . . is based on understanding the power differentials inherent in health service delivery, the institutional discrimination, and the need to fix these inequities through education and system change . . . ."

Culturally safe care

"Culturally safe care . . . involves building trust with Aboriginal patients and recognizing the role of socioeconomic conditions, history, and politics in health [. It] requires communicating respect for a patient's beliefs, behaviours, and values . . . ." (Health Council of Canada, 2012, p. 5)

These elements are important, because "Aboriginal people are more likely to use health care services and follow treatment advice when they trust their health care providers" (Health Council of Canada, 2012, p. 6). This publication also provides suggestions for how to ensure health systems are structured to support cultural competency and cultural safety. Health systems that have the characteristics identified by the Health Council of Canada are likely to provide their employees with cultural competency and thus ensure cultural safety for their Aboriginal clients. The characteristics are as follows:

- Ensure that Aboriginal people participate in the decision-making process for issues that concern them
- Ensure that Aboriginal people have access to the tools needed to properly manage their health and well-being
- Have staff who are knowledgeable about Aboriginal resources and needs and who incorporate this information into their practices by changing how they approach Aboriginal clients (Health Council of Canada, 2012)

To improve the quality of care and increase access to health services for Aboriginal people, health care providers must improve their knowledge and understanding of Aboriginal culture, history and contemporary reality. For example, here is a non-exhaustive list of values shared by Aboriginal cultural groups that sometimes differ or even oppose Western values.

3 First Nations of Quebec and Labrador Health and Social Services Commission (2005), *Adapter nos interventions à la réalité autochtone,* available for consultation in person only.

4 These tables can provide guidance to health professionals wishing to adapt their interventions to Aboriginal clientele. However, it is recommended that they deepen their knowledge about the local Aboriginal culture in order to adapt their interventions as appropriately as possible.

Presentation of Aboriginal Values

CONCEPTS	ABORIGINAL VALUES
Family	• Includes the extended family (parents, children, aunts, uncles, cousins, grandparents). • The extended family and the community are involved in the children's upbringing.
Time	• The present moment is important. • The notion of time is not attached to the hour but rather to the moments of the day.
Spirituality	• Spirituality is a link that exists between individuals and natural forces and is a way of life. • Religious acts are spontaneous and can occur at any time (e.g., prayer before meetings).
Elders	• Great respect is given to Elders, who have acquired a great deal of knowledge.
Health	• It's the balance between the different spheres of life (psychological, spiritual, emotional and physical). It's the overall consequence of the action of all the vital functions and of the harmony between them.
Illness	• It's the result of an imbalance in the sick person's life. This imbalance can be psychological, spiritual, emotional or physical.
Treatment	• If a plant's properties have been praised by oral tradition, treatment by traditional methods is suitable. • Traditional medicine can be combined with modern medicine.
Diagnosis	• The diagnosis will very often be shared with the client's close family members.
Informed consent	• A concept that is likely to arouse suspicion based on many peoples' past experiences with imposed medical interventions.

* Table adapted from the FNQLHSSC, 2005.

2.2.1 EXAMPLES OF RESEARCH DONE IN FIRST NATIONS COMMUNITIES

Little research has been done by First Nations people in First Nations communities, but some has been done in Ontario, Manitoba and British Columbia.

Ontario and Manitoba

One research project, funded by the Canadian Institutes of Health Research (2010–2015), was carried out by a team from Lakehead University in Thunder Bay. This research was conducted in collaboration with four First Nations communities in Ontario and Manitoba: Naotkamegwanning First Nation, Fort William First Nation, Six Nations of the Grand River Territory and Peguis First Nation.

The goal of the research was to improve end-of-life care in First Nations communities by creating palliative care programs and teams in the communities. It produced recommendations to improve

the quality of end-of-life care in First Nations communities and access to this care (strategic implications of the research project on improving end-of-life care in First Nations communities).

According to the recommendations, in order for a pan-Canadian palliative care strategy to adequately and fairly respond to the needs of First Nations, the federal government must review its programs' services and equipment so that they may be adapted to reflect real needs. The recommendations also state that the government should support local First Nations leaders and provide them with the necessary resources to help develop an approach that integrates palliative care with health and social services in communities. Local palliative care programs need to be developed and telemedicine made accessible in all First Nations communities to help First Nations care providers do their day-to-day work in the communities. It is recommended that Health Canada review its approval process for Non-Insured Health Benefits (NIHB) in order to implement Jordan's Principle and introduce a quick approval process for end-of-life clients. (Lakehead University, 2014).

The results of the project included assessments in the four First Nations communities, the creation of palliative care teams and the establishment of a framework to guide the development of policies and programs for palliative care in the communities.

In parallel with this research, a book on palliative care adapted to the reality of First Nations people, *Caring for the Terminally Ill: Honouring the Choices of the People,* was published in 2014 in Ontario. The book was designed to support First Nations people living with terminal illness in rural and remote communities and their caregivers. The Canadian Hospice Palliative Care Association encourages this type of small-scale project.

> **Ideally, the shift to an integrated palliative approach to care will happen at all levels in the healthcare system[—]the federal, provincial/territorial or regional health planning levels, including regions where First Nation, Inuit and Métis peoples are responsible for directing, managing and delivering a range of health services, and at the local or care setting level. However, front-line organizations do not need to wait for federal, provincial/territorial or regional action. An integrated palliative approach can start anywhere[—]and should start everywhere[—]in the system (Canadian Hospice Palliative Care Association, 2015, p. 31).**

Although this book was designed to provide information to Northern Ontario First Nations communities, other First Nations communities can use it and adapt it by including elements of local culture and traditions.

British Columbia

Another research project called "Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nations Communities" was started as an initiative of Northern Health Authority's Northwest Hospice and Palliative Care Advisory Committee (Verde, M., et al., 2010). As the title indicates, the purpose of this research was to identify barriers that limited First Nations access to local and urban palliative care services. Considerable barriers were identified, and the following table presents the recommendations

made to overcome them. These recommendations are possible solutions that can be used to establish a partnership between stakeholders, so that solutions can be developed jointly by considering each stakeholder's roles and responsibilities.

Recommendations to overcome barriers

CATEGORY	RECOMMENDATIONS
Planning	• Plan an assessment of palliative care needs.
	• Develop palliative care community plans to ensure sustainability.
	• Invite First Nations stakeholders to decision-making groups for urban facilities so that Aboriginal groups and cultural issues are considered when they plan their services.
Training	• Incorporate general training on Aboriginal cultures into the British Columbia health care network.
	• Implement training that is specific to the local First Nations culture in each area/territory in northwestern British Columbia.
	• Support First Nations member training in palliative care to increase comfort levels in caring for a loved one in their final stages of life/illness.
	• Support First Nations member training in traditional health practices.
Support for clients and their families	• Allocate funding to support families who are required to travel to escort or visit loved ones in treatment or in hospital.
Service delivery	• Allocate funding to increase the capacities of communities to provide palliative care and have access to support from experts 24/7 as needed.
	• Develop formal service protocols between First Nations communities and service providers in each area/territory to facilitate access to first-line workers.
	• Strengthen the Aboriginal Health Improvement Committee.

** Table adapted from Northern Health and BC Cancer Agency, 2010.*

This research also aimed to build support networks between First Nations communities and hospitals by identifying solutions that could reduce barriers to accessing services. A framework for palliative care training was established to build the capacity of First Nations workers to provide palliative care. This framework included an overview of training needs, a section on urban health care providers, a section on community health care providers and a section on families and friends who provide care (Verde, M., et coll., 2010, p. 5).

3. Results of the study

As mentioned, the FNQLHSSC coordinated a portrait of palliative care, the first step of which was to collect data on community care and services. The purpose of this study was to collect information from health care providers and seniors' residence managers in non-treaty First Nations communities in Quebec (including Naskapis). Of the 31 communities solicited, only 2 declined the invitation to participate, one being treaty and the other having no residents in the community. Finally, 19 completed questionnaires were received for 18 participating communities, as one community submitted 2 questionnaires to cover all the services they offered.

3.1 PROFILE OF PARTICIPATING COMMUNITIES

Questionnaires were returned by communities with the following profiles, and for the purposes of the study, the geographic zones defined by Indigenous and Northern Affairs Canada (INAC) were used.

Geographic zones[5] according to the INAC definition

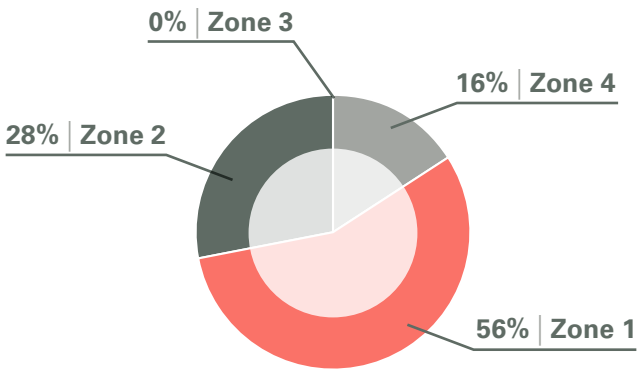
Zone 1: The First Nations community is located less than 50 km from a service centre with year-round road access.

Zone 2: The First Nations community is located between 50 km and 350 km from a service centre with year-round road access.

Zone 3: The First Nations community is located over 350 km from a service centre with year-round road access.

Zone 4: The First Nations community has no year-round road access to a service centre and, as a result, incurs higher transportation costs.

Here is the percentage of communities that participated in the study broken down by geographic zone.



5 It is important to note that the definition of service centre refers to the closest municipality where members of the community must go to access suppliers, banks and government services. In reality, many Aboriginal patients travel to health facilities located in large urban centres in Quebec or outside the province of Quebec when care and services are not available locally or in the language understood by the patient.

The following table presents the rate of study participation by population living in a community.

Percentage of communities by number of residents

POPULATION IN COMMUNITY	% OF COMMUNITIES
0 to 1,000	44
1,001 to 2,000	28
2,001 to 3,000	17
More than 3,000	11

Source: INAC website

3.2 THE NEEDS OF END-OF-LIFE CLIENTS AND THEIR FAMILIES

The questionnaire included questions about the care and service needs of end-of-life clients and their families. The responses provided identified common needs for end-of-life clients and families in different communities.

The following table presents the responses of all participating communities regarding the number of clients per year who would require palliative care services.

Number of clients who would require palliative care services

NUMBER OF PATIENTS PER YEAR	% OF COMMUNITIES
1 to 2	44
3 to 6	22
+ 6	22
Information not provided	11

Overall data from Health Canada's FNIHCCP report an average of 36 end-of-life clients per year, for the period from 2008 to 2014, for all 27 non-treaty communities providing services through this program. However, this data represents only clients who are enrolled in the program as end-of-life clients. For example, clients who have been enrolled in the program for other reasons (e.g., acute care, long-term care or rehabilitation) may have received end-of-life care and may not be included in the statistics if information about the type of client has not been updated as their health status had changed or for any other reason. It is therefore difficult to know the actual number of people at the end of life in the communities, and the results of the study indicate that the needs are higher. In fact, according to the responses of the participating communities, the number of clients requiring palliative care appears to be between 37 and 56 per year.

Families may also have needs in terms of support and accompaniment when a loved one is dying or following the death of a loved one. The following table presents the responses of all participating communities regarding the number of families per year that would require support services.

Number of families per year in need of support services

NUMBER OF FAMILIES PER YEAR	% OF COMMUNITIES
1 to 2	39
3 to 6	11
+ 6	22
Information not provided	28

It should be noted that the FNIHCCP does not include data on the services and care provided to the families of a person receiving palliative care. The services offered to families vary and may include, among other things, support and education for caregivers, respite for families and individual or group counselling before and after a loved one's death. Moreover, in general, [Translation] " . . . respite appears to be considered the service most needed by loved ones, followed by nursing and medical care at home and domestic help" (Shang, M. and A. Jancarik, 2013, p. 22). In addition, several studies have shown that caregivers of a person at the end of life are more likely to have a weakened mental health status compared to the general population (Shang, M. and A. Jancarik, 2013, p. 22). There can be a great need for care and support for a family since it is known that the First Nations family network is very broad and includes, among others, aunts, uncles, cousins and grandparents (FNQLHSSC, 2003).

The following sections provide more details about how the information gathered was compiled as part of the study on the needs of First Nations clients in Quebec and their families.

3.2.1 CLIENT NEEDS

Respondents identified the following needs to ensure a quality end of life for clients.

Client needs

TYPE OF CLIENT NEED	COLLECTION OF RESPONSES OBTAINED
Environment	• Being able to stay in or return to their environment (i.e., their community or home) • Having access to a familiar environment
Choice	• Having the choice to die at home, in a palliative care home or at a hospital • Having the choice to receive end-of-life care and palliative care
Care	• Receiving the care needed, especially for pain management • Having access to medical staff (physicians, nurses, psychologists, etc.) including home visits and 24/7 availability
Support	• Support to help the client navigate the health system • Support staff and volunteers available 24/7 • Meal service • Funding to pay for prescription drugs not covered by Health Canada • Support programs for family members (travel assistance and accommodation)
Culture	• Services in Aboriginal language • Access to spiritual resources • Respect for the patient's culture and religion
Equipment	• Access to specialized and adequate equipment for an end-of-life patient: hospital bed, therapeutic mattress, oxygen equipment, occupational therapy equipment • (i.e., walker, wheelchair, bath bench, support bars, raised toilet seat, etc.)
Information and training	• Information to understand the various stages at the end of life • Access to staff trained specifically for end-of-life clients
Family	• Having a respite service for their family • Being close to family (presence of relatives) • Dying with dignity surrounded by friends and family • Knowing that their family members will get help and support after their death

3.2.2 FAMILY NEEDS

Respondents identified the following needs for families of end-of-life patients.

Family needs

TYPE OF FAMILY NEED	COLLECTION OF RESPONSES OBTAINED
Support	• Psychosocial, emotional, cultural and spiritual support • Support from experienced volunteers or caregivers • Having the support needed to keep the end-of-life patient at home or in the community • Support to cope with grief • Funding to pay for prescription drugs not covered by Health Canada • Support programs for family members (travel assistance and accommodation)
Services	• Respite services • Babysitting services for short periods • Having 24/7 access to medical and professional staff (nurses, physicians, social workers, etc.) • Having a list of available resources • Having the necessary services to keep the end-of-life patient at home or in the community
Education and information	• Education and information for: - Adapting the home for the patient's care - Taking care of a sick person (meals, housework, etc.) - Administering medication - Providing care to a sick person (e.g., symptom identification, skin care, pain management, etc.) • Information on the various stages at the end of life • Information on available care and services (offered by the community or another service provider)
Culture	• Having services in a familiar language (English, French or an Indigenous language) • Access to spiritual resources • Access to culturally appropriate services

In concluding this section about needs, it is relevant to mention that the studies presented in the literature review point to a need to develop a "philosophy, definition, and, community-based process for providing palliative care in First Nations communities that is distinct from a westernized, medicalized or urban model of palliative care" (Kelley et al., 2015, p. 3). Such a process must be carried out to meet the specific needs of First Nations and must consider the following:

- Indigenous ways of viewing health, illness, birth and death differ across communities and linguistic groups
- Local management and implementation of a community capacity building approach that emphasizes the engagement of community members, and incorporates community culture, strengths, and resources
- The vision and goals of *The Way Forward National Framework* (Quality End-of-Life Care Coalition and the Canadian Hospice Palliative Care Association 2014), which promotes an integrated palliative approach to care for clients, their families and community care. This approach promotes autonomy and choice of setting of care (home, hospital, hospice, long-term care facility), meets the needs of an aging First Nations population with a high burden of chronic disease, and promotes the need for culturally safe care for First Nations people (Kelley et al., 2015, p. 3).

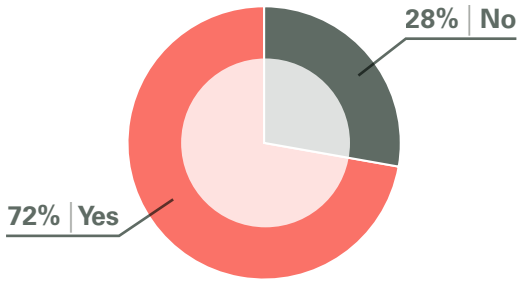
From a broad perspective, the needs expressed elsewhere in Canada are the same as those in Quebec with a few exceptions, and the definition of a model separate from the Western model of palliative care is desirable.

3.3 THE PROVISION OF PALLIATIVE CARE IN COMMUNITIES

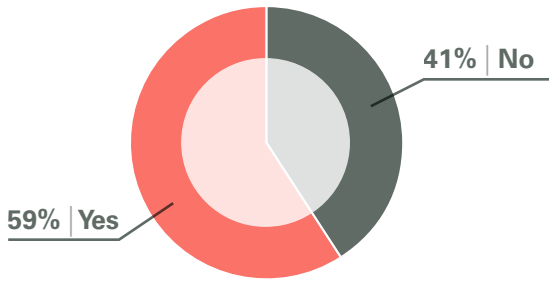
One section of the questionnaire specifically targeted communities that reported providing palliative care. The results of the study reveal that 72% of communities[6] say they offer palliative care, while 28% say they do not offer palliative care. However, 2013–2014 data from Health Canada's FNIHCCP reveals that 59% of communities provide end-of-life services for which they do not obtain additional funding.

Provision of palliative care in non-treaty First Nations communities in Quebec

Result of the study



Data from the FNIHCC – Quebec Region (Health Canada)



6 Thirteen communities say that they offer palliative care services, while five say that they do not offer them.

The study highlighted issues relating to the reliability of the data collected by Health Canada on palliative care. These issues can be explained by the fact that palliative care is not funded by the FNIHCCP, and by the fact that clients can receive several categories of care depending on how their health condition progresses. Therefore, the data may not accurately represent the patient's condition if changes in health status are not recorded in the system. This situation is very likely to occur given that the definition of a person at the end of life is that of a person "whose health condition is not responsive to curative treatment [and whose lifespan is] expected to be less than six (6) months" (Health Canada, 2014, p. 7). However, it is possible that a person requiring palliative care does not meet this definition. The following table presents the client categories as defined in the FNIHCCP.

Client information worksheet – Client type[1]

CLIENT TYPE	DEFINITION
Acute	Outcomes are predictable and recovery is expected in a short timeframe. OR Need immediate or urgent care (within three months) to improve or stabilize a medical or post-surgical condition. If in the program for more than three months you must discharge and change client type.
End of life	Client whose health condition is not responsive to curative treatment. Lifespan expected to be less than six months.
Rehabilitation	Client with activity limitations and/or temporary or permanent impairments. There is potential for significant improvement in functional status.
Long term supportive	Client with multiple, complex health conditions who is at risk for institutionalization. Condition may be unstable and/or medically fragile.
Maintenance	Client whose chronic health condition or functional limitation is stable. Additional resources are needed for assistance with personal care or activities of daily living.
Other	Since April 2014, do not use this code.

These definitions show that clients receiving palliative care can be recorded as acute or long-term supportive clients without meeting the end-of-life definition, and no other data in the system used by the FNIHCCP makes it possible to target clients receiving palliative care. That may explain the difference between the responses received and the data from Health Canada.

3.3.1 INFORMATION ON AVAILABLE SERVICES

The responses helped create a list of the most common care and services provided to patients and their families. The following table presents them starting with the most frequently mentioned care and services.

Care and services most frequently offered by communities that provide palliative care

PATIENT CARE AND SERVICES	FAMILY SUPPORT SERVICES
Care plan	Psychosocial support
Psychosocial support	Respite services
Home nurses	Spiritual support
Physician visits	Training
Management of pain and symptoms	Volunteer visits
Spiritual support	Nutritional support
Nutritional support	Sharing circle
Volunteer visits	
Sharing circle	

The following table presents a non-exhaustive list of the possible stakeholders, services and programs that may be involved in providing palliative care in First Nations communities in Quebec. The table does not show the services offered in each community, since the services available differs in each of them. However, it helps to appreciate the amount of services, programs and people involved in providing care and services in the community.

SERVICES RESPONSIBLE FOR PROVIDING CARE AND SERVICES	PROGRAMS	STAFF INVOLVED IN DELIVERING SERVICES	NUMBER OF HOURS OF CARE PROVIDED
Health centres Social services Seniors' residences Recreation services Nursing services Hospitals Families Provincial health and social services centres	FNIHCCP (Health Canada) Assisted Living (AANDC) Mental health Family support services NIHB First-line Nursing services Traditional medicine Occupational therapy Palliative care services	Nursing manager Nurse – home-care support Nurse Nursing assistant Visiting homemaker Physician Psychologist Social worker Case manager Housekeeper Nutritionist Culture and language coordinator Volunteer Translator	Variable According to each patient's needs 4 hours per month for nursing care None (because there is no local program)

Communities stated that there is no funding for palliative care and that they had to use health transfer funds or other programs to meet the needs of their members. A seniors' residence mentioned that they were eligible for funding from INAC for up to two and a half hours of personal care, but said it would be inhumane to take seniors out of their homes to send them to another facility at this vulnerable time of their lives. The community therefore absorbs these costs. The following section presents in more detail examples of organization of services as described by the survey respondents and demonstrates the variety of structures that have been put in place in the First Nations communities in Quebec to provide service to their population.

3.3.2 ORGANIZATION OF SERVICES

In many communities, services are structured based on a needs assessment conducted using the province's multiclientele assessment tool. An intervention is planned by the nurse and the home and community care coordinator. A multidisciplinary meeting is often organized to manage cases, and hours of care are determined according to needs. The client and the family may be consulted. Services are then provided according to the care plan (services plan) by community care and social services. Some communities offer nursing services outside of working hours. They carry out a needs assessment when the situation changes.

In order to demonstrate the diversity of the current service structures, the following section presents examples based on the communities' geographic location.

Examples from communities located near a service centre (zone 1)

In a community located near a service centre, services are structured according to a client's need for home or institutional care. The head nurse assesses needs and provides the necessary resources to meet the client's biological, psychological and cultural needs. In this community, a nurse manages palliative care at home or in an institution, and there are two replacement care providers. There is also an end-of-life support program, which includes people in institutions. Staff are trained to provide palliative care. Interdisciplinary meetings are held at least three times a year or as needed.

In another community, people have access to a 24/7 personal support worker as well as to a head nurse and a nursing assistant who are available during the day and evening. A nurse is on call at night and, when needed, goes to the bedside of palliative care clients. The CLSC provides equipment and support as needed. The main issue for the seniors' residence in this community is obtaining a physician and a palliative care protocol.

In another community, most end-of-life clients are enrolled in the palliative care program established by the CSSS. The care is aimed at ensuring the well-being of clients, their families and their caregivers. The palliative care team consists of a physician, a nurse and a social worker. They work as an interdisciplinary team and meet up or speak regularly to ensure the best possible client follow-up. A physician and a nurse are on call 24/7. Services are based on the client's needs and health status and the care provided by caregivers. Social workers can provide bathing and dressing services as well as support services, depending on what the team decides. It is also possible to obtain respite services for the family and to admit the client to a palliative care centre where palliative care is largely provided by centre staff and the CLSC.

The home care program provides palliative care in this community. When a patient reaches the palliative care stage, nurses increase their home visits and, when required, they go on-call at all times. One of the nurse's main roles is to teach family and loved ones how to provide basic care to the patient. The family provides most of the care, and the nurse establishes a care plan, guides care and supports the family.

For this community, procedures have been established for palliative care: for admission to home-based palliative care services, the multiclientele assessment tool, a drug list and a signed authorization must be used to share information if there is no family physician to write a prescription. The family and nursing staff sign an agreement. This agreement provides for one daily visit or, as needed, a therapeutic care plan by home and community care providers, and consultation with a nutritionist. When the prognosis is three months or less, the visits are more frequent, care is more intensive and it may be provided 24/7 if necessary by five nurses who take shifts.

Examples from communities located far from a service centre (zone 2)

For this community located far from a service centre, if it is possible to send a client home to receive palliative care, the nurse who liaises with the hospital makes the necessary arrangements regarding the availability of palliative care, the paperwork, nursing care, home care and personal care. He also ensures that the home is ready for the client. The needs of clients are supported by health transfer funds.

Another community says that they start by meeting with the family to determine what care can be provided at home and in the community as needed. The communication is between the nurse, the attendant and the family. The professional services required are determined using the multiclientele assessment tool, and a therapeutic care plan is established.

The local hospital sends requests for services to the health centre of another community. The client and family are made aware of available resources: nurses, personal care workers, housekeepers, social workers and family physicians. The distribution of human resources, documents for the family and equipment is the responsibility of the head nurse in charge of home and community care.

Examples from isolated communities (zone 4)

In this community, there is no established structure and no palliative care available at this time. The home-based palliative care offered consists in providing nursing services every two to three days depending on the family's needs.

For another community, there is a nursing station where two nurses and one head nurse work full-time. Nursing services are available 24/7. There are approximately 300 people in the community, and those aged 0 to 30 are the most in need of these services. Since 2010, there have been only three cases that required palliative care. There is no structure or facility for palliative care. Nurses provide support to the families, manage pain and see to the client's comfort.

3.3.3 CARE PLAN

The care plan describes the assessment of a person's health goals and needs and the care that will be provided to meet those needs and achieve those goals.

Study results indicate that 13 communities report providing palliative care, of which 69% reported using a care plan for clients receiving palliative care and related services.

3.3.4 NUMBER OF CLIENTS BASED ON SERVICES PROVIDED

The following table shows the services provided and the number of clients receiving them.

TYPE OF SERVICE	% OF COMMUNITIES PROVIDING THE SERVICE	TOTAL NUMBER OF CLIENTS RECEIVING THE SERVICE/YEAR (QUEBEC REGION)
A. FOR CLIENTS		
Advance care planning	77	24
Psychosocial support	85	25
Home care nursing	85	25
Management of pain and symptoms	62	15
Nutritional support	54	14
Physician visits	77	21
Spiritual support	43	5
Volunteer visits	31	9
Other: Sharing circle	31	12
Equipment delivery (e.g., custom beds)	8	8
TYPE OF SERVICE	**% OF COMMUNITIES PROVIDING THE SERVICE**	**TOTAL NUMBER OF CLIENTS RECEIVING THE SERVICE/YEAR (QUEBEC REGION)**
B. FOR FAMILIES		
Psychosocial support	54	25
Nutritional support	15	2
Respite services	38	12
Spiritual support	23	6
Volunteer visits	23	8
Training and teaching	31	6
Other: Sharing circle	8	3

3.3.5 CARE PROVIDER NEEDS

According to the results of the questionnaires completed by the communities providing palliative care, the main needs of care providers are:

1. General training on palliative care, death and bereavement
2. Specific training on palliative care by function, i.e., nurses, personal support workers, auxiliary staff, etc.
3. Frequent access to a physician or hospital
4. Equipment such as electric beds and commode chairs
5. Supplies such as quilts and gel cushions
6. Support services

Communities providing palliative care reported the following needs by category:

CATEGORIES	COLLECTION OF RESPONSES OBTAINED
Training (need cited most often)	• Training for nurses: therapeutic approach and pain management and refresher courses to stay up to date • Training for caregivers (home and personal care workers): therapeutic approach and mobility assistance in a safe and suitable environment and refresher courses to stay up to date • Training for care providers: general training on all aspects of palliative care • Training for the organization's volunteers so that they can meet the needs of the community and refresher courses to stay up to date • Training for all seniors' residence staff on palliative care and refresher courses to stay up to date • Training on wound care, pain management for palliative care, periods of bereavement, family and caregiver support and relationships, basic knowledge on palliative care • More documentation and training in English for support workers • Training to cope with the loss of a child and bereavement • Bilingual brochures on palliative care to provide information on the different stages and what can be done to provide support and ensure comfort
Access to medical services	• Physician affiliated with the seniors' residence • Physician, psychologist, social worker, nutritionist and volunteers who can go to the client's home • Creation of an official corridor of services with the hospital and liaison between the CLSC, the family, the heath centre and the pharmacy • Prescriptions and medical protocols
Equipment	• Equipment such as portable patient lifts for home care, adjustable electric beds, oxygen concentrators, therapeutic surfaces like ROHO cushions, gel cushions and air mattresses, light beds, chairs, mobile tables (for beds), urinals and basins, and material like quilts, moisturizing cream, diapers and nutritional drinks (e.g., Ensure) • Budget to set up the home with help from an occupational therapist and to purchase materials and customized beds • Less bureaucracy for NIHB would facilitate situations requiring palliative care
Support services	• Having a team of caregivers for hygiene and comfort care • Psychosocial support provided to families, support providers and workers • Being able to hire a nursing assistant to provide respite to the nurse who provides home care or to relay the nursing staff to prevent burnout • Multidisciplinary team consisting of a social worker, a nurse and caregivers who work with the family and the client to provide support and respite services

3.3.6 CULTURALLY SAFE SERVICES

Of the communities that provide palliative care, 77% stated that their services were culturally safe. Here are some examples of culturally safe practices.

Spiritual support

- Organization of prayer evenings
- Access to traditional healers or Elders with whom nurses collaborate to provide palliative care
- Sharing circles
- End-of-life ceremonies
- Understanding of customs and traditions
- Traditional medicine sessions provided by traditional healers (e.g., purifications)

Palliative care and services

- Adaptation of services according to the person and their wishes to die, pain management, medications, etc.
- Adaptation of the environment to allow the patient at the end of life to be surrounded by members of their family and the community
- Acceptance of the integration of ritual and spiritual practices into care

Traditional medicine

- Traditional medicine pilot project

3.4 COMMUNITIES NOT OFFERING PALLIATIVE CARE

Communities reporting that they did not offer palliative care (just over a quarter of communities participating in the study) were asked to answer questions on the reasons why as well as the external services used to meet the needs of the people in their community.

3.4.1 REASONS PREVENTING COMMUNITIES FROM PROVIDING PALLIATIVE CARE

As is often mentioned, the communities are different and situations vary from one to another. The communities said they did not provide palliative care for the following reasons.

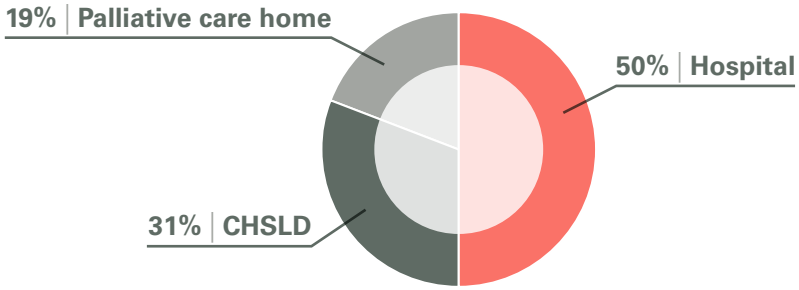
REASONS	EXCERPTS FROM ANSWERS
Lack of human resources	• Our nurses cannot provide 24/7 palliative care, because we do not have emergency services on evenings and weekends in the community. • Our limited staff of three nurses makes it impossible for us to assign a full-time nurse to a client requiring palliative care.
Financial constraints	• No facility built to provide services. • We also do not have a care facility to treat cases in the community.
Program constraints	• Health Canada's mandate focuses on prevention and awareness, but does not yet include palliative care. • Staff hours, including for home and community nurses, are from 8 a.m. to 4 p.m., Monday to Friday. We are closed on statutory holidays and for two weeks over the holiday season (the weeks surrounding Christmas and New Year's Day). • The reality of our program does not allow us to provide services outside normal working hours and on weekends. • Home care services are limited: 40 hours a week for home support and 2 hours a day, 5 days a week for nursing care.
Staff not trained to provide the service	• None of the health care providers have the training required to provide the service.
Lack of policies and procedures to guide the provision of care and services	• Nursing must be included in a palliative care program. • No policies or procedures have been established for the provision of these services.
No demand for service	• Clients do not ask for services that our health centre is unable to provide, as there is a small hospital 15 minutes from the community. • There are not many people who need palliative care.

It should be noted that no statistical data has been collected to know the number of people affected when the service is not offered since the current system does not collect this data. However, in the questionnaire, the communities reported having an average of one to three cases per year.

3.4.2 WHERE DO CLIENTS GO?

As shown in the diagram below, 50% of respondents said that their clients went to the hospital, 31% to a residential and long-term care centre (CHSLD), and 19% to a palliative care home.

Out-of-community institutions frequented by palliative care patients



3.4.3 CULTURALLY SAFE ENVIRONMENTS

Of the respondents, 67% did not believe that services were culturally safe in provincial institutions. Some said that they did not have access to this information, because the institutions were located outside their community, or that they had not had any trouble to date.

In some circumstances, communities have been successful enough at raising awareness in the local hospital to allow visits to larger numbers of family members, but in many cases cultural traditions and purification rituals are not accepted. However, a community was able to provide cultural awareness training to the staff at the hospital where its clients are going. This hospital accepts spiritual ceremonies in the palliative care wing. However, according to the majority of respondents, clients and their families do not feel culturally safe in these environments, and some respondents added that language is also a problem.

3.4.4 FUNDING

Who funds these palliative care services outside the community? Respondents indicated that funding is provided by the Quebec health network when clients go to the network's facilities. As a result, the provincial network funds palliative care delivered outside First Nations communities.

Funding is provided for an escort through the Non-Insured Health Benefits Program. Some communities have programs that provide financial assistance for the transportation of families.

3.4.5 BARRIERS TO OVERCOME OUTSIDE THE COMMUNITY

The following table presents a list of barriers for clients and their families mentioned by community respondents.

BARRIERS FOR CLIENTS AND THEIR FAMILIES	EXAMPLES GIVEN BY RESPONDENTS
Language	• Lack of psychosocial support in English. • No resources in First Nations languages (many clients still speak them). • Services in neighbouring institutions are provided mainly in French. • Language is the main barrier for families when they are in the hospital to spend time with the patient.
Isolation (remoteness)	• Clients are far away from their families. • Clients separated from their families feel isolated and distressed. • It is very important that patients feel the spiritual circle of support from their family, which is possible only when the patient is at home and feels this connection with their family and the community.
Lack of support	• Provincial institutions do not provide the same support as in the community. • No financial support or limitations on support for family members staying at the patient's bedside (transportation and accommodations). • Little or no social services for low-income families.
Racism	• Forms of racism. • General ignorance about First Nations culture. • Prejudice and racism are common. • General ignorance about the legacy of the Indian Residential Schools. • Care providers are indifferent to the emotional and personal difficulties that grieving families may be experiencing.
Culture	• Patients lack culturally appropriate palliative care when they are in an institution. • Little sensitivity for certain rituals surrounding well-being such as purification, drumming and prayers. • It is impossible to organize family visits, because there are too many family members. • Few opportunities to respect cultural ways of doing things.
Institution limits	• Palliative care facilities are sometimes too small. • The number of visits is limited in a CSSS, and visiting hours are very strict.

3.5 MAJOR BARRIERS TO THE CONTINUUM OF SERVICES

The major barriers that communities must overcome with respect to the services offered by the home and community care program and outside of organizations or institutions such as the CLSC or palliative care homes are as follows. All respondents were invited to complete this section.

BARRIERS	EXCERPTS FROM THE ANSWERS OBTAINED
Communication	• Hospitals do not tend to communicate with nurses providing home and community care, even when clients sign consent to disclose information. Medication changes and treatment plans are not communicated quickly. We must be very perseverant with them and the CLSC when we want to get reports. • It is difficult to establish a connection (we are the eternally forgotten).
Programs and financial restrictions	• Home and community care services cannot exceed the maximum limits of the program. The additional hours of care required are taken on by the heath centre to ensure the continuum of care. • The continuum of care is interrupted at the palliative care stage. It is very difficult to explain to the family why we cannot continue to manage care. • Our inability to respect the wishes of families who want to bring clients back to the community due to a lack of resources (the number of nurses at the centre compared to the care required 24/7) and lack of homes and palliative care homes to receive them. • We simply do not have the number of patients to justify these services beyond what is currently available.
Cultural differences	• We want to convince external partners to respect our cultural differences.
Distance	• Lack of palliative care homes and centres to receive patients.

3.6 EXTERNAL PARTNERS

Some communities, especially those that are more remote and isolated, do not have an external partnership. The following table summarizes the responses received regarding external partners and the services they provide.

PARTNERSHIP	SERVICES PROVIDED	POSITION TYPE	HOURS OF CARE
CSSS	• Medical services	Physician and nurse	24 hours a day as needed
	• Palliative care program	Physician, nurse and auxiliary workers	24 hours a day as needed
	• Palliative care, chemotherapy, radiology	Physician, nurse, auxiliary workers and social workers	As applicable
	• Pain management • Appointment service	Family physician Nurse Pharmacist	Determined by the home care nurse (maximum of 120 hours)
NIHB under Health Canada	• Medical supplies and certain equipment	NIHB staff	N/A
INAC	• Assisted living	Support workers for home care	As needed, determined by an assessment
CLSC	• Nursing care services	Nurse for palliative care at the seniors' residence	24 hours a day as needed
Church	• Spiritual support	Priests or pastors	As needed
Palliative care home	• Volunteers • Spots for admissions or respite services • Pain management • Respite services • Psychosocial support	Residence staff	As needed

PARTNERSHIP	SERVICES PROVIDED	POSITION TYPE	HOURS OF CARE
Hospital	• The physician sees the client before they leave to determine which medications to prescribe to manage the pain. • A decision to not resuscitate is requested by the nurse before the client leaves.	Nursing staff Psychosocial support worker Support worker for home care	According to client and family needs
	• Management of pain and symptoms when families are too tired to continue to accompany the patient into death or feel safer for the patient to be in the hospital. • Psychosocial support.	Hospital staff (physicians, nurses, orderlies, care workers, social worker, rehabilitation worker)	As needed
	• When palliative care patients are sent to the hospital, they often die in the emergency room. Sometimes they fail to get a room or a palliative care room on time.	Hospital staff	24 hours a day or as needed
Cultural services	• Traditional medicine program • Accompaniment in mourning, spiritual and emotional support for staff, client, family and caregivers. • Sharing circle • Volunteers	Elders Traditional healers Nurse Volunteers Housekeeper Personal support	According to client and family needs
Tribal council	• Social services • Domestic services	Domestic services	Based on an assessment
CHSLD	• Psychological support	CHSLD staff	As needed

4. Comments on the Act respecting end-of-life care

Many of the opinions and perceptions of the communities regarding the effect of Bill 52 focused on the idea that First Nations communities in Quebec should be able to benefit at home from the same services and care provided in institutions such as palliative care homes. On-reserve seniors' residences must also be able to provide these services on-site and receive training, medical equipment and adequate funding to do so. To support the need for palliative care in communities, respondents cited one of the guiding principles of this policy: keeping users in their natural environment is a choice for those who want it.

Communities suggested that this legislation provide a rationale for what should be in place to adequately meet the needs of end-of-life clients and their families. According to the respondents [Translation] "if the conditions are clearly defined and if it is possible to obtain the resources required for labour, equipment, medication and transportation without having to fight, the bill should have a positive impact."

Lack of funding for end-of-life palliative care prevents communities from providing desired services to clients and limits the means to provide appropriate care for clients and their families. Many families have few financial resources, which makes it difficult to organize services for those families where a loved one may be in a provincial facility. Communities agree that end-of-life palliative care should be recognized as an essential service by Health Canada's home care program rather than as an additional service in the event of a budget surplus.

A few respondents were concerned that First Nations communities were not consulted on this bill, as is the case with other legislation. This act was imposed without regard to whether it was culturally acceptable to First Nations people. Some suggested adding a provision to the Act to respect the rituals surrounding death, the cultural approach to death as well as customs and traditional values (caregivers and traditional healers). The use of traditional or cultural ceremonies in palliative care is becoming a reality for many First Nations patients.

Another issue raised was the patient's right to choose traditional medicines or remedies instead of Western medicine. Some communities said that even if doctors have difficulty accepting it, especially if it is likely that the patient will not get a favourable result, community nurses must respect the choice of the client and their family.

Finally, some said that a provincial accreditation will be required and that communities will need funding and training to deliver the services. The collaboration of the First Nations governments, Health Canada, the FNQLHSSC and the Government of Quebec can greatly accelerate local access to these services.

The adoption of this act illustrates the gap that exists between the services received by First Nations communities and those of the Quebec population. Fortunately, Bill 52 provides Quebec residents with quality end-of-life services. However, since First Nations communities are under federal jurisdiction, the same legislation, the same rights and the same services that end-of-life people receive in the province are not being offered. First Nations people have the right to die with dignity and to choose to die at home.

A questionnaire respondent

5. Conclusion

For First Nations people, palliative care is like a chronic disease with no service delivery system and no direct funding. People living in First Nations communities do not have access to culturally appropriate and quality palliative care services at home and in the community. The First Nations and Inuit Health Branch's Home and Community Care Program does not fund palliative care services, and home care services in the province do not consistently serve First Nations communities. As there is a lack of home care services, First Nations people cannot choose to die at home when they wish.

The 2008 FNQLHSSC *Quebec First Nations Regional Health Survey* states: "As a lot of First Nations communities do not have long-term care facilities, individuals needing care are often sent to provincial facilities, often far from their communities. Based on the results of this survey, nearly one in 10 adults (9.1%) has seen a member of their immediate family be sent to a long-term health care facility outside their community" (Chapter 17, Home care, p. 10). In addition, chronic diseases and neurological injuries are the two most important causes of placement in long-term care facilities outside communities. According to a study by Hotson, MacDonald, and Martin (2004), many First Nations in remote and isolated communities are dying in urban hospitals and long-term care centres without their families, communities and culture.

Communities that responded to the questionnaire said that there is no funding for palliative care and that they should use health transfer funding or other programs to meet the needs of their members. Communities that are isolated have a much harder time providing palliative care services, because they do not have the resources or access to external services to help them provide end-of-life services.

The need for palliative care for First Nations people is increasing due to an aging population and the heavy burden of chronic and terminal illness among the population. The 2008 FNQLHSSC *Quebec First Nations Regional Health Survey* revealed that 58% of adults surveyed had health problems. Many First Nations people wanted the opportunity to die in the community where they have always lived. However, people in these communities have limited access to formalized and culturally appropriate palliative care programs.

First Nations communities in Quebec must be able to benefit from the same services and care at home as those provided in institutions such as palliative care homes. On-reserve seniors' residences must also be able to provide these services on-site and receive training, medical equipment and adequate funding to do so. First Nations people are entitled to the same quality of end-of-life services and the same choices as other residents of Quebec under Bill 52.

End-of-life palliative care should be recognized as an essential service by Health Canada's home care program rather than as an additional service in the event of a budget surplus. In addition, palliative care (such as care planning and psychosocial support) should be part of chronic disease management and seniors' care.

According to the results of the questionnaires answered by the communities, the main needs are:

1. Respect for the wishes of the client and their family regarding end-of-life services, and respect for the right to choose
2. Strengthening community capacity, which would integrate a palliative approach to all community health and social services and create programs using existing services and new partnerships
3. Specific training programs provided locally or through telehealth, videoconferences or webinars by function (nurses, personal care workers, auxiliary workers, social workers, etc.)
4. Education and information on palliative care for communities
5. Frequent access to a physician or hospital, perhaps using telehealth to access a central palliative care team that would assist the local team in providing care
6. Priority of Health Canada's Non-Insured Health Benefits Program or partnerships with the CLSC or the CSSS for equipment such as electric beds, commode chairs and bedside tables in the client's last year of life
7. Immediate availability of necessary supplies such as quilts and gel cushions without the bureaucratic delays of the Non-Insured Health Benefits Program
8. Direct funding for the provision of palliative care services by nurses (or nursing overtime), nursing assistants or auxiliary workers so that services are provided 24 hours a day as planned or as needed
9. Partnerships with the provincial health network to ensure access to a physician directly in the community or through telehealth who will prepare prescriptions, authorize protocols and participate in the development of the care plan
10. Appropriate support (transportation, accommodation, etc.) for the family of clients who need to go outside their community to receive palliative care
11. Access to cultural services, such as traditional healers and purification rituals for clients who wish to obtain these services within or outside the community
12. Culturally safe environment for clients receiving services from outside the community through cultural sensitivity training for provincial staff
13. Consultation before the passage of legislation affecting First Nations communities

Strengthening the capacity of First Nations communities to provide a palliative approach to home and community care requires:

- Development of a local program and case management
- Palliative care education for health care providers and families in First Nations communities
- Creation of new partnerships for the delivery of palliative care services with federal and provincial health care services such as hospitals, home care and respite services
- Injection of funds to fill gaps in palliative care services and equipment for people during their last year of life

Most importantly, communities want to provide their members with culturally safe care and comfort care in the home environment, in their own language and in the company of the spiritual family support circle they wish to receive in the end of life.

6. Recommendations

The results of the questionnaire indicate significant gaps and other unmet needs for palliative care for First Nations in Quebec, as well as a fragmentation in service delivery that makes the continuum of services difficult. In order to better meet the needs of Aboriginal clients requiring palliative care, the portrait highlights the following recommendations.

Promoting accessibility and quality of patient care and services

- Recognize palliative care as an essential service in the FNIHCCP to ensure the delivery of palliative care as required by people's health condition, including end-of-life care (and including medical aid in dying for communities that wish to offer it)
- Ensure that the provincial *Act respecting end-of-life care* is applicable to on-reserve First Nations people and that resources and services comparable to those throughout the province are available

Respect for patient decisions

- Put in place means to promote accessibility, continuity and quality of support services and patient care, while respecting the needs of patients, their choices and the expectations of their loved ones

Approach to culturally adapted palliative care

- Develop a culturally appropriate approach to the delivery of palliative care in First Nations communities
- Collaborate with the province to provide training and awareness to stakeholders in the Quebec network on First Nations culture
- Strengthen the sharing of knowledge and information on the provision of palliative care to First Nations

Organization of services

- Allow flexibility in the organization of care and services required in the provision of palliative care
- Establish partnership mechanisms with specialized external resources (hospitals, long-term care centres, palliative care homes, etc.)

Caregiver support

- Put in place the means to preserve the ability of caregivers to maintain an interpersonal relationship with the sick person

Training staff and caregivers

- Support access to basic training and continuing education for all people who come into contact with the individuals in the end of life
- Establish collaborative agreements with the relevant provincial authorities for training staff and caregivers

References

Parliamentary Committee on Palliative and Compassionate Care (page consulted on September 10, 2015). *Not to be Forgotten: Care of Vulnerable Canadians,* https://www.mcgill.ca/palliativecare/files/palliativecare/parliamentary_report_eng_dec_2011.pdf

Canadian Hospice Palliative Care Association (2015). *The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care,* http://hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf

First Nations of Quebec and Labrador Health and Social Services Commission (2005). *Adapter nos interventions à la réalité autochtone,* Québec.

First Nations of Quebec and Labrador Health and Social Services Commission (2006). *Assessing Continuing Care Requirements in First Nations and Inuit Communities,* Wendake.

First Nations of Quebec and Labrador Health and Social Services Commission (2008). *Quebec First Nations Regional Health Survey,* Wendake.

First Nations of Quebec and Labrador Health and Social Services Commission (2008). "Home Care," in the *Quebec First Nations Regional Health Survey,* Québec.

First Nations of Quebec and Labrador Health and Social Services Commission (2015). *Annual Report 2014–2015,* Québec.

Health Canada (2014). e-SDRT User Guide – Updated 2013/2014 – Appendix C – Code Lists and Definitions. First Nations and Inuit Home and Community Care Program, Ottawa.

Health Canada (page consulted on February 11, 2016). *Summative Evaluation of The First Nations and Inuit Home and Community Care,* online: https://www.canada.ca/en/indigenous-services-canada/services/first-nations-inuit-health/reports-publications/health-care-services/summative-evaluation-first-nations-inuit-home-community-care.html.ons

Health Council of Canada (2012). *Empathy, Dignity and Respect: Creating Cultural Safety for Aboriginal People in Urban Health Care,* Health Council of Canada, Toronto.

Health Council of Canada (2013). *Canada's Most Vulnerable – Improving Health Care for First Nations, Inuit and Métis Seniors,* Health Council of Canada, Toronto.

Hotson, K.E., S.M. MacDonald, and B.D. Martin (2004). "Understanding Death and Dying in Select First Nations Communities in Northern Manitoba: Issues of Culture and Remote Service Delivery in Palliative Care," *International Journal of Circumpolar Health.*

iPANEL (2012). *Initiative for a Palliative Approach in Nursing: Evidence and Leadership.* Online: www.ipanel.ca.

Kelley, M.L., and H. Prince (2014). *Recommendations to Improve Quality and Access to End-of-Life Care in First Nations Communities: Policy Implications from the "Improving End-of-Life Care in First Nations Communities,"* research project, Lakehead University, Thunder Bay, Ontario.

Kelley, M.L., et al. (2015). *A Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities,* Lakehead University, Thunder Bay, Ontario.

Kelly, L., and A. Minty (2007). *End-of-Life Issues for Aboriginal Patients: A Literature Review,* Canadian Family Physician.

Kelly, L., et al. (2009). *Palliative Care of First Nations People – A Qualitative Study of Bereaved Family Members,* Canadian Family Physician.

Lakehead University (2010). "Improving End-of-Life Care in First Nations Communities," research project, Centre for Education and Research on Aging & Health (CERAH), Lakehead University, Thunder Bay, Ontario.

McGrath, P. (2007). "'I don't want to be in that big city; this is my country here': research findings on Aboriginal peoples' preference to die at home," in *Australian Journal of Rural Health,* 15(4):264-8.

Miller, J.A., and M. Hollander, (2006). *Assessing Continuing Care Requirements in First Nations and Inuit Communities,* summary report for Health Canada – FNIHB, Victoria.

O'Brien, V. (2012). *Person-Centred Palliative Care: A First Nations Perspective,* graduate thesis, McMaster University.

Ontario Working Group on Palliative Care (page consulted in April 2015). *Caring for the Terminally Ill: Honouring the Choices of the People,* online: http://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/Honouring-the-Choices-of-the-People-August-2014.pdf.

Ordre des infirmières et infirmiers du Québec, (2013). *Mémoire – Projet de loi no 52, Loi concernant les soins de fin de vie,* brief presented to the Committee on Health and Social Services, Westmount.

Prince, H., and M.L. Kelley, (2006). *Palliative Care in First Nations Communities: The Perspective and Experiences of Aboriginal Elders and the Educational Needs of Their Community Caregivers,* written for the Kenora Chiefs Advisory, Lakehead University.

Shang, M., and A. Jancarik (2013). *Soins palliatifs et de fin de vie – Volet 1: Recension des écrits,* Agence de la santé et des services sociaux de la Montérégie, Longueuil.

Verde, M., et al. (2010). *Addressing Barriers to Palliative Care Services in Northwest BC First Nations Communities,* Northern Health and BC Cancer Agency.

World Health Organization (page consulted in March 2015). *Palliative Care,* online: http://www.who.int/cancer/palliative/en/.

World Health Organization (page consulted on February 12, 2016). *Palliative Care – Fact Sheet No. 402,* online: http://www.who.int/news-room/fact-sheets/detail/palliative-care.

APPENDIX 1

QUESTIONNAIRE AND PRESENTATION LETTER

FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION

CSSSPNQL • FNQLHSSC

March 10, 2015

To: Directors of Health and Social Services

Directors of First Nations Elders' Residences

Re: Questionnaire on Palliative Care Services - Study on Palliative Care Services among First Nations of Quebec

To whom it may concern,

Palliative care in the Aboriginal communities was an issue that generated a great deal of political attention in 2013 at the national and regional levels. In July 2013, at the Annual General Assembly of the Assembly of First Nations (AFN), the Chiefs unanimously adopted a resolution mandating the AFN to carry out actions, including lobbying, to get the federal government to recognize palliative care as a priority and an essential element making up the services provided to the First Nations communities. In December 2013, the FNQLHSSC Board of Directors added producing a portrait of the palliative care offered in the First Nations communities of Quebec as one of the organization's priorities.

On June 10, 2014, the Quebec government passed Bill 52: Act respecting end-of-life care without consultation with First Nations communities. This act sets out the end-of-life rights of people and the special rules applicable to the different end-of-life care providers (institutions, palliative care centres, private facilities, etc.) in order to specify the framework and organization of care services.

Simon Management Services has been hired by the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) to survey the Quebec FN communities on the situation of palliative care, and the possible effects of Bill 52. The ultimate goal of this project is to analyze the situation concerning the palliative care offered in First Nations communities (Quebec) in order to know the situation concerning the needs, to identify the effects that inaccessibility to palliative care has on the population, to look at possible effects of Bill 52, and to provide an immediate portrait on which further work can be done to develop sustainable care and services.

This letter contains a questionnaire to be completed by those responsible for providing palliative care services in each First Nation community, and/or residential facility. There is a glossary provided in back of the questionnaire to provide background on some of the terms used.

The questionnaire is to be completed by the Health Director and/or Residence Director. It is also possible for the consultant, Linda Simon, to complete the questionnaire over the phone with those responsible for these services. You may call 450-479-1941 to set up an appointment to do this.

However, you must please ensure that the questionnaire is completed and returned by email to Linda Simon at Linda.Simon2@sympatico.ca no later than the end of the day, Friday, March 13th so that a Report can be prepared for March 31st. We appreciate your cooperation with the dates, understanding full well how busy communities are with end of year activities.

We thank you for your understanding of the urgency of this study,

Véronique Rankin
FNQLHSSC Continuing Care Program Agent
418-842-1540 ext. 230

Linda Simon
Consultant for FNQLHSSC
450-479-6787

QUESTIONNAIRE ON PALLIATIVE CARE SERVICES

Organization Completing the Questionnaire

Organization:	
Name of Person Completing Questionnaire:	
Position/Title:	Email:
Address:	
Telephone:	Fax:

Please take some time (approximately 20 to 30 minutes) to complete this questionnaire. Your responses will provide important information that will help our organizations on planning better ways to support health and well-being in first nations communities and to defend our interests regarding the application of bill 52.

1. Does your community provide palliative care services?

☐ Yes ☐ No

If YES, please respond to PART ONE. If NO, please respond to PART TWO (Question 9, 10 & 11)

PART ONE – PLEASE RESPOND ONLY IF YOU ANSWERED YES TO QUESTION 1:

COMMUNITY PALLIATIVE CARE SERVICES

2. a) List the services responsible for providing palliative care services in your community, the program(s) (funding sources) used to provide palliative care services and the positions involved in delivering these services (example Nurse, Cultural Support Worker, HCC Personal Support Worker, etc).

Service responsible (ex: Health, Social Service, etc.)	**Program(s)** (Ex. HCCP, Assisted Living Program, regional agencies programs, etc.) *Note: If no funding is available, please state reason and how you are able to manage to provide palliative care services.*	**Position(s) (worker)** (ex. Nurse, housekeeper, Profesionnal, etc.)	**Number of Care hours/ month**

*You may attach informatics systems reports to complete the information.

3. **State how the palliative care services are structured and organized (ex. Structure, operations, health resource allocation, etc.).**

_____

_____

_____

_____

_____

4. **Is a Plan of Care developed and used for your clients receiving palliative care and/or services?**

☐ Yes ☐ No

5. **How many clients and families do you service each year for palliative care and what are the services provided?**

Please indicate how many clients you served last year for palliative care.

Services:	How many clients/year
• Advance care planning	_____
• Psychosocial support to the client	_____
• Nursing services in the home	_____
• Pain and symptom management	_____
• Nutritional support	_____
• Visits by physician	_____
• Spiritual support	_____
• Volunteer visiting	_____
• Other: _____	_____

Please indicate how many families you served last year for palliative care support.

Services:	How many families/year
• Psychosocial support to the family	_____
• Nutritional support	_____
• Respite services for natural caregivers (family)	_____
• Spiritual support	_____
• Volunteer visiting	_____
• Training	_____
• Other: _____	_____

*You may attach informatics systems reports to complete the information.

6. What are some specific needs of interveners working with palliative care situations in your community? (Training, equipment, professional support, etc.)

_____

_____

_____

_____

_____

7. Do you provide culturally-safe services?

☐ Yes ☐ No

If so, please describe services:

_____

_____

_____

_____

PARTNERSHIPS

8. List any outside partnerships in service delivery of palliative care in your community.

Partners (ex: Agency, hospice, etc.)	**Service(s)** (Ex. Pain and symptom management, psychological support, cultural support, etc.)	**Position(s) (worker)** (ex. Nurse, housekeeper, Profesionnal, etc.)	**Number of Care hours**

*You may attach informatics systems reports to complete the information.

SECTION 2 – RESPOND TO THESE QUESTIONS ONLY IF YOU ANSWERED NO TO QUESTION 1

9. Why does your community not provide palliative care services?

_____

_____

_____

_____

_____

10. If your community cannot provide palliative care services, what the client does?

a. Where do clients go for palliative care? (Please check off all applicable cases)

- ☐ Hospital
- ☐ Provincial Long-term Care Facility
- ☐ Hospice
- ☐ Other: _____

b. Are they able to access culturally-safe services in these environments?

☐ Yes ☐ No

Please explain.

_____

_____

_____

_____

c. Who is funding these palliative care services out of the community?

_____

_____

_____

_____

d. What barriers are faced by clients who must go outside the community for palliative care services?

_____

_____

_____

_____

e. What barriers are faced by the families of those clients who must go outside the community for palliative care services?

_____

_____

_____

_____

f. How many clients and families must go outside for palliative care services each year?

_____

11. List any major obstacles for your community with respect to a continuum of services through Home and Community Care and outside agencies or establishments such as CLSC or hospices?

_____

_____

_____

_____

PART THREE: GENERAL QUESTIONS (PLEASE RESPOND WHETHER YOU HAVE SERVICES IN THE COMMUNITY OR NOT)

12. How many people in your community need palliative care services each year? _____

13. How many families in your community need palliative care support services each year?
_____

14. What are the needs of community clients who seek quality of life at the end of life?

_____

_____

_____

_____

15. What are the needs of community families who are faced with end of life situations?

_____

_____

_____

_____

16. List the most important barriers that should be addressed in providing palliative care services in First Nations communities?

a. First Nation Communities in General:

_____

_____

_____

_____

b. Your own Community in Particular:

_____

_____

_____

_____

17. Passed in June 2014, Bill 52 outlines the conditions under which end-of-life care must be given. The purpose of this bill is to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy and to recognize the primacy of wishes expressed freely and clearly with respect to end-of-life care. The bill specifies rights with respect to end-of-life care, in particular by affirming the right of everyone to end-of-life care that is appropriate to their needs.

Could you please comment on the impact this bill could possibly have on the provision of palliative care services in your community?

_____

_____

_____

_____

18. Do you have any comments and/or information you would like to add regarding the palliative care services and/or the bill 52.

_____

_____

_____

_____

We thank you for your participation!

Glossary

The following is a guide to the meaning of some terms that are used in the questionnaire.

TERM	MEANING FOR PURPOSES OF THIS QUESTIONNAIRE
Advance care planning	A process people can use to: think about their values and what is important to them with regard to their health care choices; explore medical information that is relevant to their health; communicate their wishes and values to their loved ones, substitute decision-maker and health care team; and record their health care choices and decisions in the event they can no longer speak for themselves. The process may involve discussions with their health care providers and people who are significant in their lives. Advance care planning may result in the creation of an advance directive or "living will", which is a person's formal or informal instruction about their future care and choice of treatment options.
Caregiver	Anyone who provides care. Formal caregivers are members of an organization and accountable to defined norms and professional standards of practice. They may be professionals, support workers, or volunteers. They are sometimes called "providers." Family caregivers are not members of an organization. They are family members and other significant people (as identified by the care recipient) who provide unpaid care and assistance to individuals living with a debilitating physical, mental or cognitive condition. Family caregivers usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards or practice.
Chronic Disease	A chronic disease is one that may develop slowly, last a long time, be incurable, and be progressive and/or life-limiting. Examples of life-limiting chronic diseases include cardiovascular disease, chronic kidney disease, congestive heart failure, diabetes, dementia, emphysema, multiple sclerosis, amyotrophic lateral sclerosis and some forms of cancer. The disease and its treatment may cause symptoms such as fatigue, pain and sleep problems; they can also limit people's activities, cause them psychological distress and have a negative effect on their quality of life. A chronic disease can't be cured but its symptoms can be managed.

TERM	MEANING FOR PURPOSES OF THIS QUESTIONNAIRE
Frailty	Frailty is a nonspecific state of vulnerability caused by changes to a number of physiological systems which may be related to a variety of physical, psychological, cognitive and social factors. Together, these changes lead to reduced function and strength, and affect the person's resilience and ability to cope with any stress, such as an infection or disease or personal loss. Frailty is most commonly seen in the elderly but can also occur in adults and children who are seriously or chronically ill. Someone who is frail is at high risk of physical and cognitive decline, disability and death. Frailty can cause pain and discomfort. It can also limit people's activities, cause them psychological distress and have a negative effect on their quality of life.
Goals of Care	Describes people's goals for their care and should include treatment of the disease and/or symptom management. In some cases, it includes limits on the interventions that people want, such as "do not resuscitate" orders.
Integrated Palliative Care Approach	Care that focuses on meeting a person's and their family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management.
Multidisciplinary Team	Caregivers with different training and skills who work together to develop a team and implement a person's plan of care. Membership varies depending on the services required to address the person's and family's identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers, psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.
Pain and Symptom Management	Pain and other symptoms that cause discomfort (e.g., shortness of breath, fatigue, changes in mood or functional ability, psychosocial or spiritual distress) can be caused by underlying diseases. They can also be caused by the treatments for those diseases, the side effects of treatments and the process of aging. Many different techniques can be used to manage symptoms, including medication, exercise (physiotherapy), breathing, meditation, the use of heat and cold, biofeedback processes, diet, repositioning, counselling and psychosocial and spiritual support.
Plan of Care	The written plan that describes the person's assessed health needs and goals, and the care that will be provided to meet those needs and goals.

APPENDIX 2

RELEVANT DOCUMENTS AND INFORMATION REGARDING NON-INSURED HEALTH BENEFITS FOR FIRST NATIONS AND INUIT PALLIATIVE CARE CLIENTS

Health Canada
Santé Canada

NIHB Drug Exception Centre
First Nations and Inuit Health Branch
Health Canada
1902D, Jeanne Mance Building
200 Eglantine Driveway, Tunney's Pasture
Ottawa, ON K1A 0K9

Fax Toll Free: 1-877-789-4379

{Create Date}

Case Number: {Case Number}

Dear Prescriber,

The NIHB Drug Exception Centre has received a request for one of your patients for a drug not listed on the NIHB Drug Benefit List.

To ensure that drugs which are medically necessary are not denied to First Nation's clients, some prescription drugs which are not listed may be provided as exceptions, with prior approval.

Please complete the attached 'Exception Drug Request Form' as soon as possible and return it to this office. The request will be reviewed by our Medical Consultant for consideration as an exception. Exceptions are granted on a 'case by case' basis.

Should you have any questions or concerns regarding this case, please call the Supervisor of the Drug Exception Centre at (613) 954-8780.

Thank you for your cooperation.

Sincerely,

Manager,
NIHB Drug Exception Centre

EXCEPTION DRUGS REQUEST FORM | {Case Number} | **PROTECTED B WHEN COMPLETED**

SECTION I: PRESCRIBER/PATIENT INFORMATION

Prescriber Name: {Prescriber Name} **Prescriber #: {Prescriber ID}**
Prescriber Address:
Prescriber Phone: {Prescriber Phone #} **Fax: {Prescriber Fax #}** **Date (dd/mm/yyyy):{Create Date}**

Patient's Surname: {Client Surname} **Given Name(s): {Client Given Name}**
DOB (dd/mm/yyyy): {Client DOB} **Gender: {Client Gender}**
Case #: {Case Number}

Drug Requested: {Item Name} **DIN: {DIN - Item #}**

SECTION 2: TO BE COMPLETED BY PRESCRIBER

You have requested a medication that falls within the NIHB Palliative Care Formulary. If this medication is used for palliative care, please fill out part A. If this medication is used for other purposes, please fill out part B.

PART A - PALLIATIVE CARE FORMULARY
The patient

☐ **has been diagnosed with a terminal illness or disease which is expected to be the primary cause of death within six months or less**

Please note that patients admitted to a provincially funded hospital or long-term care facility are eligible to receive NIHB drug coverage only if medication is not covered by the province.
Once approved, the patient will be eligible for all medications on the Palliative Care Formulary for six months without the need for further prior approval.

Atropine injection	**Ketamine injection**	**Morphine Infusion**
Diazepam injection & rectal gel	**Lomotil tablets**	**Nabilone capsules**
Fentanyl citrate Infusion	**Lorazepam injection**	**Nutritional Supplements (Ensure, Boost)**
Fentanyl patches	**Metadol tablets & oral liquid**	**Ondansetron injection**
Furosemide injection	**Methotrimeprazine injection**	**Phenobarbital injection**
Glycopyrrolate injection	**Methylnaltrexone injection**	**Phenytoin sodium injection**
Granisetron injection	**Metoclopramide injection**	**Ranitidine injection**
Hydromorphone Infusion	**Midazolam injection**	**Scopolamine injection & patches**
Hyoscine butylbromide injection	**Moi-Stir Spray**	**Sterile syringe preparation fee**

A comprehensive list of products listed on the Palliative Care formulary may be found at:
https://www.canada.ca/en/health-canada/services/publications/health-system-services/non-insured-health-benefits-drug-benefit-list/app-c.html

PLEASE NOTE: During the six month coverage period, a maximum 30 day supply will be reimbursed at any one time. If coverage is required beyond the initial six months, an additional six months may be granted upon receipt of another Palliative Care Application Form.

PART B - OTHER EXCEPTIONAL CIRCUMSTANCES

☐ **Please explain:**
_____
_____

Comments/Specialist Name (if applicable):

Prescriber Signature: _____ **Date:** _____

FAX TOLL FREE: 1-877-789-4379 or Mail To:

NIHB Drug Exception Centre
First Nations and Inuit Health Branch
Health Canada
1902D, Jeanne Mance Building
200 Eglantine Driveway, Tunney's Pasture
Ottawa, ON K1A 0K9

Medical Confidential

Vision

First Nations individuals, families and communities are healthy, have equitable access to quality care and services, and are self-determining and culturally empowered.

Mission

To accompany Quebec First Nations in achieving their health, wellness, culture and self-determination goals.

FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION