END OF LIFE CARE FOR INUIT LIVING IN NUNAVIK, QUEBEC

A report written for the Nunavik Regional Board of Health
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EXECUTIVE SUMMARY:

End of life (EOL) care planning and policy for cancer patients, the chronically ill as well as the elderly is becoming increasingly relevant for Inuit communities: community members are living longer and experiencing an increase in rates of certain cancers and chronic disease (CPAC, 2014; Wallace, 2014). Researchers have underlined the need to develop and validate conceptual plans and policies for palliative care for Indigenous peoples in a "bottom-up" inclusive approach with the community (Kelley, Williams, DeMiglio & Mettam, 2011). Studies have called for an incorporation of the view of Indigenous elders in the planning and provision of EOL care (Kalbfleisch, 2007) as the lack of Indigenous voices in EOL care remains a major issue (Loppie & Wien, 2005). Such findings indicate a need for clear policies and guidelines to facilitate home care and community EOL programs. Through questions and observations we sought to identify the existing strengths and resources within Inuit communities as they provided EOL care to community members. Focused ethnography allowed us to combine semi-structured interviews, informal dialogues and participant observations in diverse communities to gather information. Recognizing the expertise in the participants with whom we had spoken, we then solicited individuals engaged in EOL care provision to review the interpretation of our findings.

We had conversations concerning EOL care for Nunavimmiut in the context of four Nunavik communities, the Quebec Module du Nord and the McGill University Health Center. In 2014-2015, 103 participants contributed to the study through recorded interviews and informal dialogues specifically related to EOL care provision. Resultant themes included the following: a) trajectories of patient care; b) the contexts of care, specifically, the challenges and variables to care and recommendations to improve care; c) communication; d) the role of interpreters in EOL care; d) considerations concerning Law 2; and e) bereavement and grief in EOL care.

Variables in CLSC care	Variables in family/community care	Variables in hospital care
Relationship/communication with patient/family	Psychosocial support: functioning/ communication/coping skills	Clarity of communication with patients and health professionals
Access to palliative care resources	Family level of knowledge/preparedness	Involvement of liaison nurses, interpreters, escorts, family
Duration of care	Duration and intensity of care	Degree of cultural awareness
Psychosocial support	Suitability of home environment	Complexity of treatment options
Capacity/preparedness of family/community	Involvement of extended family and community	Continuity of patient care
Amount of moral distress	Degree of trust in nurse/physician/interpreter	Psychosocial state of patients and caregivers
Investment of time and training in Inuit health care providers	Existing responsibilities and obligations	Displacement and homesickness of patient

As indicated in the above table, the capacity to provide EOL care depends on a number of intersecting variables in home, CLSC and hospital contexts. To address these variables in the development of EOL care, Nunavimmiut and Qallunaat participants drew on professional experiences to make recommendations that they believed would lead to a sustainable model for EOL care for Nunavik patients. Several of these recommendations are linked to changes that are already underway in communities and institutions; while others had not yet been implemented. Most participants agreed that a combination of Inuit and Qallunaat areas of practice and expertise is needed for developing EOL care in Nunavik. The Inuit communities appear to be at a disadvantage, however, as their cultural and traditional expertise has largely gone unexamined and thus has not been accorded the stamp of "evidence-based practice," which is so necessary to attain funding for program development and personnel. We conclude our report with several key areas summarizing how to proceed in providing EOL care in Nunavik. These are summarized in the table below:

1-12 months →

- Palliative care resources and training for nurses and physicians
- Support for existing bereavement care initiatives in communities
- Training and recognition of interpreters
- Education in Law 2 and the Supreme Court decision
- Home services and inpatient facilities for elders

12-24 months →

- Education in disease progression and EOL care
- Psychosocial support services for patients and families through the identification of existing cultural and spiritual practices
- Nursing staff support in Nunavik and Montreal
- Family education and respite services

2-10 years →

- The North and South gap: re-examining the public health approach to EOL care
- A sustainable approach to EOL care

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1. PROJECT OBJECTIVES AND RATIONALE

The aim of our study was to better understand the EOL (EOL) services offered in Nunavik and to identify whether there were ways to improve the quality of EOL care for patients and families. We interviewed patients and family members, healthcare providers, community members, and others who were involved in EOL care. Areas of inquiry included homecare, hospital and health center care, communication, resources, and training. We sought input on how EOL care was provided, whether or not the services were accessible and comfortable for patients and their family members, and how EOL services provided by families, communities and health care providers could be supported.

In April 2014, the Canadian Partnership Against Cancer (CPAC) published a document entitled "Inuit Cancer Control in Canada, Baseline Report." This document outlined the national picture of Inuit patients and cancer, barriers in health care service delivery, and the patient experience of care in the context of health care systems and communities. Information was obtained through contractors, health care surveys and environmental scans. We have endeavoured to build on this investigation in our study and to develop a nuanced understanding of the unique challenges and strengths within Nunavik communities concerning EOL care for cancer patients, the chronically ill as well as the elderly.

2. METHODOLOGY

We considered several options in choosing how to best accomplish the above-mentioned objectives. In light of the many cultural, geographical, historical and time considerations in both community and institutional settings, we chose to conduct our study as follows:

Theoretical perspective:
A community capacity theoretical perspective was drawn upon to orient the questions of this study (NSW Health Department, 2001; Simmons, Reynolds & Swinburn, 2011). Recognizing that communities in Nunavik had been providing EOL care to family members in their homes long before health care centers had been established in the Nunavik region, we furthered our understanding of the measures that communities already had in place. We sought to verify what kind of support communities were seeking from hospitals in the South and from health centers in Nunavik concerning EOL care for family members, and to determine how ongoing collaborations might build on the existing capacities of families and communities.

Method:
Focused ethnography (Knoblauch, 2005) was used as a means through which to gather information. Information was attained through field visits, observations and structured and unstructured dialogues. We contextualized what we had found with information from existing health reports, video documentaries, newspapers such as Nunatsiaq online, books, art, museum exhibitions, and academic articles. Between June 2014 and November 2015, we met with people in health centers, homes, schools, municipal offices, churches, and community organizations.

We visited four Nunavik communities, two located on the Hudson coast and two on the Ungava coast; visits ranged from 1-6 weeks with a total of 14 weeks onsite. We also conducted onsite interviews with nurses, physicians, interpreters and spiritual advisors in Montreal. Some participants agreed to have their interviews recorded; others deferred and so the interviewer took notes based on the dialogue.

Data analysis and validation

We performed a thematic analysis of our data, seeking to understand what EOL care measures were already in place in the three different contexts of our study: Community care, CLSC care in Nunavik and Montreal hospital care. We also sought variables under which these measures could succeed, as well as challenges and barriers to providing EOL care in each of these settings. We developed four additional themes from observations and participant dialogue: 1) communication related to EOL care, 2) the work of interpreters, 3) bereavement, and 4) reflections on recent provincial and national discourse concerning physician asssisted suicide and euthanasia. To validate the accuracy of our interpretation of our interpretations, representatives from family and community-based EOL care and institutional care were invited to read portions of this manuscript and provide their commentary. These comments were then integrated into the final version of this report.

3. PORTRAIT OF PARTICIPANTS

3.1 Origins

We interviewed a total of 103 persons, asking questions concerning a variety of subjects related to EOL care in family and institutional settings (See appendix A for interview guide). Themes included the following: a) trajectories of patient care; b) the contexts of care, specifically, the challenges and variables to care and recommendations to improve care; c) communication; d) the role of interpreters in EOL care; d) considerations concerning Law 2; and e) bereavement and grief in EOL care.

Forty-six participants were located on the Ungava coast. Of this number, 17 were of Inuit origin and 29 were Qallunaat (an Inuit designation for persons of non-Inuit decent). Forty persons came from the Hudson coast. Twenty-eight were of Inuit origin and 12 were Qallunaat. 18 persons were interviewed in Montreal. Fourteen participants were of Southern origin and four were originally from Nunavik and now relocated in the South. In addition to these formal discussions, we engaged in impromptu and informal dialogues with Nunavik community members during onsite visits in four communities in Nunavik. Two of these communities were located on the Hudson coast and two communities were located on the Ungava coast.

3.2 Role in provision of EOL care

Table 1 reflects the roles that had led individuals to express an interest in discussing EOL care services in Nunavik. Nurses and interpreters were most consistently on the frontlines in meeting with patients and families and provided key insights into the complexity and nuances of direct patient care. Equally significant were the number of participants who spoke from the perspective of their professional role, as well as that of family members or friends of those who had received EOL care. They drew on these memories to illustrate or elaborate upon the nuances concerning

Role in EOL care	# of participants
Nurse	25
Interpreter	16
CLSC/Hospital administration	13
Social services	12
Physician	7
Spiritual advisor, pastor	5
Child educator	5
Local governance	6
Mortician, grief counsellor	6
Wellness worker	4
Community or family member	3
Family worker, helper	2
TOTAL:	**103**
***Family, community member, cancer survivor**	*26*

Table 1: Participant profile

the provision of EOL care in Nunavik. Their dual role is noted in italics in Table 1. A few participants had themselves been diagnosed with cancer that was now in remission. They shared their experience in negotiating the trajectories that many patients face. The willingness of these many participants to share their personal and witnessed experiences concerning diagnosis, treatment, and EOL care was invaluable in capturing the complexities of EOL care in Nunavik.

Hospital administrators who had direct contact with medical and social services providers, either as supervisors or trainers, were also consulted for this study. Their contributions were valuable in addressing questions of training and resources. Social service workers included social workers, community workers, school counsellors and those with other counselling roles. These individuals provided key insights into the psychosocial needs of families and communities as related to death and dying. All physicians with whom we spoke had provided EOL care to Inuit patients. As the persons designated to communicate diagnosis and EOL care options, these individuals largely focused on the communication process of care. We met with spiritual advisors working for the hospitals as well as pastors from Inuit communities. They spoke of their experiences with Inuit patients and families in Southern hospital settings. Child educators included both Inuit and non-Inuit teachers. Their input was critical in understanding how bereavement care - and lack thereof - impacts children on emotional, behavioural and intellectual levels.

Local governance refers to persons working for municipalities in community organization and planning. These individuals were generous with their time in addressing questions concerning collaboration and community engagement in care. All but one mortician and grief counsellor whom we interviewed were women volunteers in Inuit communities. These women provided their historical account concerning mourning and burial practices as well as insight into bereavement and burial practices today. Wellness workers described their efforts in carrying out community-based support to families at the time of mourning. Family helpers provided direct services to home care patients and spoke of their process, challenges and rewards, in providing this care.

Further, our ethnographic approach allowed us time and space for informal encounters with community members. This was key to engaging with community members who were not professionally engaged in EOL care. These persons are not included in Table 1.

4. CONTEXTUAL FACTORS: NUNVIK INUIT

The EOL process is deeply personal for patient and family. Life stories woven by the threads of relationship, culture, geography, ethnicity, spirituality, history, politics, land, and myths come to their conclusion when a patient dies. At times this end is peaceful, at times distressful. This first section provides an overview of the contextual factors in providing EOL care that study participants had raised as being relevant and thus informed the evolution of our questions concerning care in the context of communities.

4.1 Demographic contextual factors

The following draws upon the 2011 National Household Survey by Statistics Canada[1]:

Ethnic origin: Out of a total population in Nunavik of 12,055, 94% report Aboriginal origins (10,880). 90% of these have Inuit heritage, with 21% claiming mixed origins, primarily European or North American. Thus, when we speak of EOL care in Nunavik, we are primarily speaking of an Inuit population.

Age: 37% of Inuit in Nunavik are 14 years of age or younger. Less than 5% of the population is over 60 years of age.

Language: The population of Nunavik mainly speaks Inuktitut as their mother tongue (95%). 20% have no knowledge of French or English while 75% have a working knowledge of English. 23% of the population has, at minimum, conversational capacities in French. As will be discussed, this poses a unique set of challenges for the largely Francophone health care workers and for their Inuit interpreters.

Religion: EOL rituals and beliefs are often rooted in religious beliefs and practices. In the case of Nunavik, 94% of the Inuit community claims an association to Christianity with the large majority indicating ties to the Anglican Church and others affiliated to Full Gospel/Pentecostal churches. The remaining 6% claim no religious affiliation.

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[1] We are drawing on Statistics Canada for this study, recognizing the limitations in providing a completely accurate portrait of Nunavik community households. Please see our reference list for options for further study.

Education: Patient families and government sanctioned health care providers provide EOL care in Nunavik communities. Licensed health care providers are almost exclusively non-Inuit from the South. These positions require a postsecondary education; only 16% of the Inuit population between the ages of 25 and 65 possess a high school diploma and 2% have a bachelor's level degree or above. 22% have a trade or apprenticeship degree or diploma.

Death/ Incidence rate	**Nunavik**	**Quebec**
Life expectancy at birth	75.2	81.2
Life expectancy at age 65	22.8	20.1
Infant mortality (per 1,000 live births)	20.8	4.7
All cancers (per 100,000)	238.1	183.4
Lung cancer (per 100,000)	117.9	56.4
Circulatory diseases (per 100,000)	122.9	142.9
Ischaemic (coronary) heart diseases (per 100,000)	76.4	77.5
Respiratory diseases (per 100,000)	176.1	47.2
Colon cancer (incidence)	*54.4*	*52.4*
Breast cancer (incidence)	*89.2*	*100.6*
Unintentional injuries (per 100,000)	69.1	23.4
Suicides and self-inflicted injury (per 100,000)	106.2	14.0
Premature mortality (per 100,000)	545.0	251.1

Table 2 Mortality Rates

Housing: Those providing EOL care in the home will most likely be living in a home rented by the government as home ownership is rare (3%) and unusually expensive due to the cost of importing materials and paying for heat, water and sewage. In 2011, 42 % of these rental homes were reported as unsuitable for living; that is, they had an inadequate number of rooms for the residents (based age, gender and number of occupants). 36% of these homes were in need of major repairs.

Mortality rates:
In 2013, Statistics Canada published a health profile of Quebec and its regions (Statistics Canada, 2013). Compared to the Quebec population at large, Nunavik residents have a shorter overall life expectancy (see Table 2). This is in part due to high infant mortality rates and the alarming numbers of accidental and suicidal deaths in the region. Notably, however, Nunavik residents have a longer overall life expectancy once they have reached age 65 then their Quebec counterparts. According to the report, this difference is attributed to the male population who have an average life expectancy of 20.8 years after reaching age 65, compared to the larger Quebec population who are expected to live 18.3 years more. On the other hand, Nunavik women average 17.9 years beyond 65, compared to Quebec-wide statistics where women

average 21.6 years of life beyond the age of 65. This has significant ramifications for end of life care as these figures indicate that women, the traditional care-givers in Inuit society are often no longer present to care for their spouses as they are nearing the end of life. Nunavimmiut also have higher rates of mortality due to lung cancer and respiratory diseases. However, circulatory disease, coronary heart disease and incidences of colon and breast cancer are equal to or below the provincial-wide average.

4.2 Geographic and historic contextual factors

Geography has played an important role in the development of Inuit identity. Both voluntary and involuntary migration patterns mark family and community histories. Migration trajectories affect where people choose to die, the persons who are available to provide this care, and the presence of loved ones at the time of death.

4.2.1 Voluntary migration

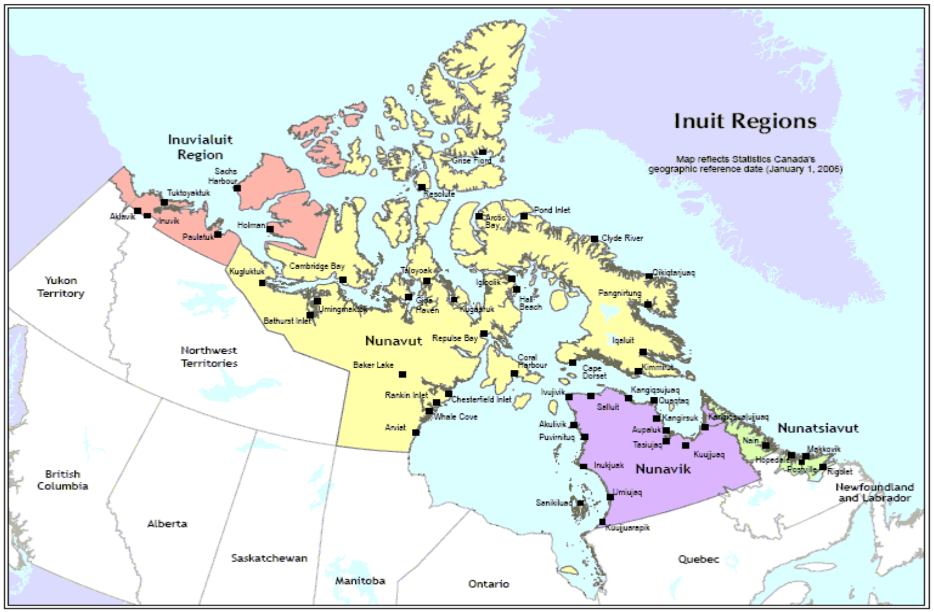
The Inuit of Nunavik are descendants of early nomadic groups who travelled from territories in Russia, Greenland and Alaska. These journeys began about 1000 years ago when Inuit in small clans of 20-30 persons began their migration across what would eventually become Arctic Canada. Prior to their migration, other groups such as the Dorset and the Thule populations had inhabited the territory. Evidence of their presence in Nunavik dates back to 2000 BC (see Abbott, Mastroianni & Sturges, 2003).

> We are in a unique bubble in terms of how our history has shaped today's society. I hope that it never bursts (Interpreter)

Today Canada has four Inuit regions (see Figure 2): Inuvialut (North West Territories), Nunatsiavut (Labrador), Nunavik (Quebec), and Nunavut (its own territory). Inuktitut dialects differ among and within regions, as different vocabulary, pronunciation and terminology developed and migrated with nomadic families and clans. Some Inuit now situated in Nunavik were born in Nunatsiavut or Nunavut and have close family ties in these regions. However, as Figure 2 indicates, Inuit patients are assigned hospitals according to their region of residence as opposed to proximity to a health care center. Thus, an Inuk from Northern Nunavik who may have family ties in Nunavut and not Nunavik will nevertheless be transferred to Kuujjuaq or Montreal for end of life care needs.

4.2.2 Settlement and displacement

The strength of the relational fabric within a community is in part based on the amount of voluntary settlement and involuntary displacements experienced by its families. In the early 1900's, certain Nunavik families had voluntarily settled near fur trading posts and whale hunting sites as their hunting and sewing products were traded for products such as iron, needles, flour, black tea, sugar and canvas (see Abbott, Mastroianni & Sturges, 2003). In many instances, families kept ties to seasonal family camps outside of the community. To this day, families return to these familiar sites that have been known as home for generations in their family, places where hunting, fishing and berry harvesting are plentiful. Inuit attachment to the land remains strong and, according to the Nunavimmiut with whom we spoke, the majority of Inuit prefer to be in this environment of family, community and landscape when they die. Likewise, Nunavimmiut spoke of how families and communities go to great lengths to ensure that members are buried on the land. This includes efforts to repatriate the bodies of those who have lived



Source: 2006 Census of Canada. Produced by the Geography Division, Statistics Canada, 2007.

Figure 1: Inuit Regions of Canada

Figure 2: Inuit patient trajectories (Map created by Inuit Tapiriit Kanatami)

outside of communities for most of their lives, or who had been already buried in the South despite family wishes.

Many Nunavimmiut have histories in which involuntary displacement and resettlement occurred. Participants also spoke of how the residential school movement served to displace two generations of Inuit youth; these children were sent to schools outside of their communities and returned as strangers to their own families and communities (see www.legacyofhope.ca). The tuberculosis epidemic in the 1950's also contributed to unexpected and immediate separations between family members as those diagnosed with the illness were sent to sanatoriums in the South (see Grygier, 1994). There are records of cases in which these family members disappeared and had no contact again with their loved ones. Nunavimmiut described how these involuntary displacements severely disrupted the capacity to develop attachments among family members, a consequence that has led to fragile family structures for many today.

Involuntary displacements also occurred when federal and provincial governments sought to localize populations into centers to facilitate air transportation, education, and health care delivery. Participants described incidents in which families lost their dogs as their primary means of transportation either due to disease or the dogs' execution by local law enforcement officers. Some participants perceived the killing of dogs as a deliberate attempt to establish a fixed Canadian presence in Arctic lands by reducing Inuit movement and by creating a dependency on government allowance and provisions. Though the Quebec government has consistently denied these allegations, the government acknowledged the harmfulness of this mass killing and paid 3 million dollars to be used in the promotion of Inuit culture (see Nunatsiaq news, August 8, 2011).

Participants spoke of this relocation and resettlement, stating that families and clans who, a) had their own dialects and cultural traditions concerning clothing, food preparation, and communication, and b) had existing structures of power and control, now were expected to create a 'community.' Families were divided between communities as husbands and wives chose which sibling or parent to follow. Community members described how, as a consequence, internal differences and friction arose when clans were brought together involuntarily. They indicated that this discord at times continues to affect care giving in community contexts.

4.3 Social and spiritual contextual factors

4.3.1 Spirituality and worldviews

Participants spoke of former shamanic practices, now apparently obsolete, in which either good or evil would prevail. Good shamans found food sources and healed illness and disease. Evil shamans worked against a person's survival. In the 1800's, European missionaries introduced Christianity as an exclusive religion. By the early 20th century, they had definitively turned to Christianity, thereby eradicating centuries of shamanic practices (see Flaherty, et al. 2011;

> A lot of the elders would know we're all going to die. Death is all in every one of us, so they're, they're open to talk about it. (Family member)

Laugrand & Oosten, 2010). Participants spoke of heaven and hell continuing to be widely accepted as afterlife destinations and of God choosing when a person is born and when a person will die. Suicide, however, is largely perceived as contrary to God's timing and will and participants indicated that early traditions taught that these persons would go to hell. This teaching is no longer accepted by the mainstream. Concerning the divine will, many participants remarked that when people are given a terminal diagnosis, they die fairly quickly. Some suggest that the cause of this is the perception that death is now God's will.

Worldviews concerning death are also shaped by Inuit proximity to the land. One participant spoke of how hunting and fishing practices bring children and adults into a regular encounter with death, comparing this habitual experience to persons in the South who buy meat in a grocery store. Several Nunavimmiut spoke of how natural death is understood to be part of the cycle of life, something to be accepted rather than feared or avoided.

Traces of historical Inuit worldviews are evident in Inuit forms of spirituality (see Laugrand & Oosten, 2010). Natural phenomenon such as animals, mountains and lights are understood by some to be infused with spiritual presence, though this is up for debate among community members. Likewise, in certain traumatic forms of death, the spirits of the dead are understood to remain on earth, either until they are released through prayer, or are released when the grieving stops their mourning and they move on with their lives.

Participants also identified that naming practices often shaped grief and bereavement in families and communities. In Nunavik, newborns are often given the name of respected persons or loved ones who had recently died. It is felt that in a sense, the person who had died lives on through this newborn, not as a reincarnation but as a presence or influence. They explained that contrary to the perception of reincarnation that is often attributed to this practice (see Mills and Slobodin, 1994), they believe the soul of the dead has moved to heaven or hell. However, the strengths, characteristics and attributes of the deceased will now be transmitted to the newborn. For example, some infants and children may be called "mother, brother or grandmother" by the parent if the child has been named after this deceased relative. It is not unusual for children to have more than five names, though not all given as namesakes. Participants have stated that on one hand, this facilitates the grieving process as deceased remain present in the minds and hearts of their loved ones in this manner. On the other hand, some explained parents who are expected by others to name a newborn after one who has deceased are not always comfortable with this practice.

4.3.2 Caring traditions

Survival in Arctic conditions historically depended on the ability of families and clans to locate them close to an ever-moving food source. This frequent movement impacted how EOL care was provided. An elder explained that when

> The Inuit practice (of caregiving) is very strong. If you care for that person and the passing of life, your heart is going to be peaceful. If you don't care for the person, your heart is going to suffer. (Inuit elder)

families could afford to stop, they remained in one place and provided consistent care for the dying. This ability to stop depended on their proximity to a consistent food source, the size of a family or clan, and their proximity to each other. Daughters and sons lived in the same tent as a dying parent. According to participants, in rare circumstances, the old and infirm were left behind if they could not keep up with movement of a family.

Community members indicated that traditional teachings held that those who provided end of life care to their parents would be at peace with themselves as their lives continued (see Weetaluktuk et al., 2008). Those who did not care for their parents were taught that they would experience distress, even after death had occurred. This teaching continues in many communities to this day.

Figure 3: Remnants of an historical grave

Community elders and spiritual leaders explained that historically, once death had occurred, bodies were placed under an oblong pile of rocks as the frozen tundra prevented bodies from being buried. Included were a person's key possessions such as hunting, carving, cooking and sewing tools. The rocks covering the body prevented predatory birds and mammals from preying on the deceased. In parts of Nunavik, these graves are now preserved and protected with fencing.

In Nunavik communities, extended family and community members continue traditions in which immediate care-givers keep vigil during the last days of a patient's life. More recently, members of the women's auxiliary, a church-based volunteer group, assist in cleaning, cooking, keeping vigil, recruiting volunteers, if needed, and in washing bodies after death. These practices remain active.

The development of health centers and hospitals in communities has had two paradoxical effects on EOL care provision. On the one hand, people have more treatment options and are living longer. They also have more support in terms of medical knowledge, interventions, and supplies to ensure the comfort of patients dying in the home. On the other hand, certain communities note a decrease in family and community-based EOL care practices and a larger reliance on Southern health care practices. Participants attribute this to various factors: a) positive perceptions of Westernized medicine based on patient accounts of healing and relief from suffering, and b) a lack of formal recognition for what families and communities have traditionally offered and continue to offer in terms of home care thus at times leading to patient and family perceptions that Western medicine is "better."

4.3.3 Social change and upheaval

The complexities of social change and consequent disruption are too complex for a full discussion in the context of this report. What may be important to note is that both Inuit and Qallunaat participants routinely described how the large majority of Nunavik families were struggling with a wide range of physical, social and psychological issues that made extended EOL care giving in home environments difficult if not impossible. These struggles were attributed to the effects of years of colonialism as well as to the rapid historical and social changes that stripped away relational resources and coping skills in individuals, families and communities. Intergenerational forms of abuse, addictions and violence against self and others is of concern to many. Significantly, participants in communities and health care institutions consistently indicated that services to address this suffering, both governmental and Inuit-initiated, are widely underfunded and understaffed.

5. TRAJECTORIES OF CARE

5.1 Potential care trajectories

Figure 3 illustrates the diverse trajectories of patient care that family members and medical personnel described. In a typical scenario, a patient will have come to the local health center in their community, known as the CLSC (*Centre local de services communautaires*), where a nurse or, if present, a physician, will have conducted an initial assessment based on the presenting symptoms. If further evaluation or treatment is needed, the patient would have been referred to the Tulattavik Health Center (on the Ungava coast), the Inuulitsivik health center (on the Hudson coast) or to a hospital site within the McGill University Health Center (in Montreal). The arrows represent the potential directions that patients follow in receiving care. As the arrows indicate, it is not unusual for patients to alternate between North and South as their disease progresses. Assessment refers to consultation with a doctor or nurse to determine prognosis and follow-up care. Admission refers to a patient remaining in hospital for one or more nights to receive further assessment or treatment.

Each of the northern inpatient health centers have one room designated for palliative care. In Puvirnituq, rooms that are used for surgery and acute care are transformed into longer term patient rooms if needed.

If a patient’s health declines in the community resulting in the need for inpatient care, the nurse will call the community physician or the physician on call. A nurse from the inpatient health center, and if needed, the physician, will fly to the community by medivac to accompany the patient back to the inpatient health center for evaluation. The patient may then be transferred to Montreal by one of the two Northern airlines, Air Inuit and First Air. In addition, the ‘Challenger,’ a fully equipped air ambulance with an onboard intensive care unit is available in cases of emergency, though it can only depart from Puvirnituq, Kuujjuarapik and Kuujjuaq.

Those with whom we spoke stated that EOL care planning would be set into motion under the following conditions: a) the physicians had stated that they could not treat the condition (e.g., an advanced form of cancer), and b) treatment to extend life or make what remained of life more comfortable was available (e.g., kidney dialysis, palliative radiation) but would need to be provided in a hospital center, often far from the patient's community. The location in which EOL care could be provided to Nunavimmiut was determined by several factors, including: a) the potential medical complications and the capacity for families and communities to deal with these; b) whether there was a palliative care protocol in place for the patient; c) whether there were adequate numbers of family members and health care professionals available to provide EOL care; d) whether there were beds available in the inpatient health centers in the North; e) whether the patient could tolerate air transportation.

When it is determined that a patient requires palliative care, the transfer back to the North occurs fairly quickly; if the patient is stable, usually within a week. The liaison nurses at the Quebec Northern Module located in Montreal facilitate the transfer and the transfer of documents concerning prescriptions and treatment recommendations.

5.2 Case scenario

Drawing on details frequently mentioned by participants, the case example below presents a fictional account based on a compilation of patient stories. This case portrays how trajectories of care unfold when there are no major complications related to communication or transportation to interfere with the process.

Mr. J, aged 54 arrived at the community CLSC care center with complaints of stomach pain and vomiting. Following an assessment by a nurse and a consultation with the community primary care physician who was visiting from Puvirnituq, he was referred to Montreal for tests. The patient had a history of cancer and recurrence was a concern.

The patient and escort (his daughter) were provided tickets to fly from their community to Puvirnituq where they transferred planes to come to Montreal. At the airport, a driver from the Module du Nord, Québecois (MNQ) transferred Mr. J and his daughter to the patient residence where they were provided with a room with two beds and meals in a common area. He was also assigned a liaison nurse who was responsible for facilitating communication between Mr. J, the specialists in Montreal, the Northern physician who was assigned to visit his community, and the community health care center nurses. The liaison nurse provided him with a card outlining his appointments and their location for the following day.

The next day, Mr. J and his daughter arrived for his medical exams. As Mr. J only spoke Inuktitut and his daughter was not confident in translating medical terminology, an interpreter was present. Within days Mr. J was told that the cancer had metastasized in his brain and was inoperable. He was referred to the palliative care center at the MUHC for an assessment and treatment recommendations. His daughter remained with him, communicating by phone with her family in the North. A meeting was set up in the local CLSC to meet with the physician nurse, social worker and family members to communicate the diagnosis and their desire for treatment.

Shortly after, Mr. J's wife, two biological daughters, an adopted son, a son-in-law and a niece were called into the local CLSC to meet with the physician who had spoken earlier with the oncologist in Montreal. They were accompanied by the local nurse and social worker. The visiting physician explained the results of the tests and provided recommendations concerning *palliative care. The family was given choices regarding care in the home, the hospital in Puvirnituq (accessible only by plane) or that he remain in Montreal. After a brief discussion amongst themselves, the family chose home care. A nurse then visited the home in the patient's community to assess the suitability of the home environment for providing EOL care. There was room in the common living space for a bed and commode. His wife committed herself as primary care-giver, and thus Mr. J. and his daughter were provided tickets to return home two days later.*

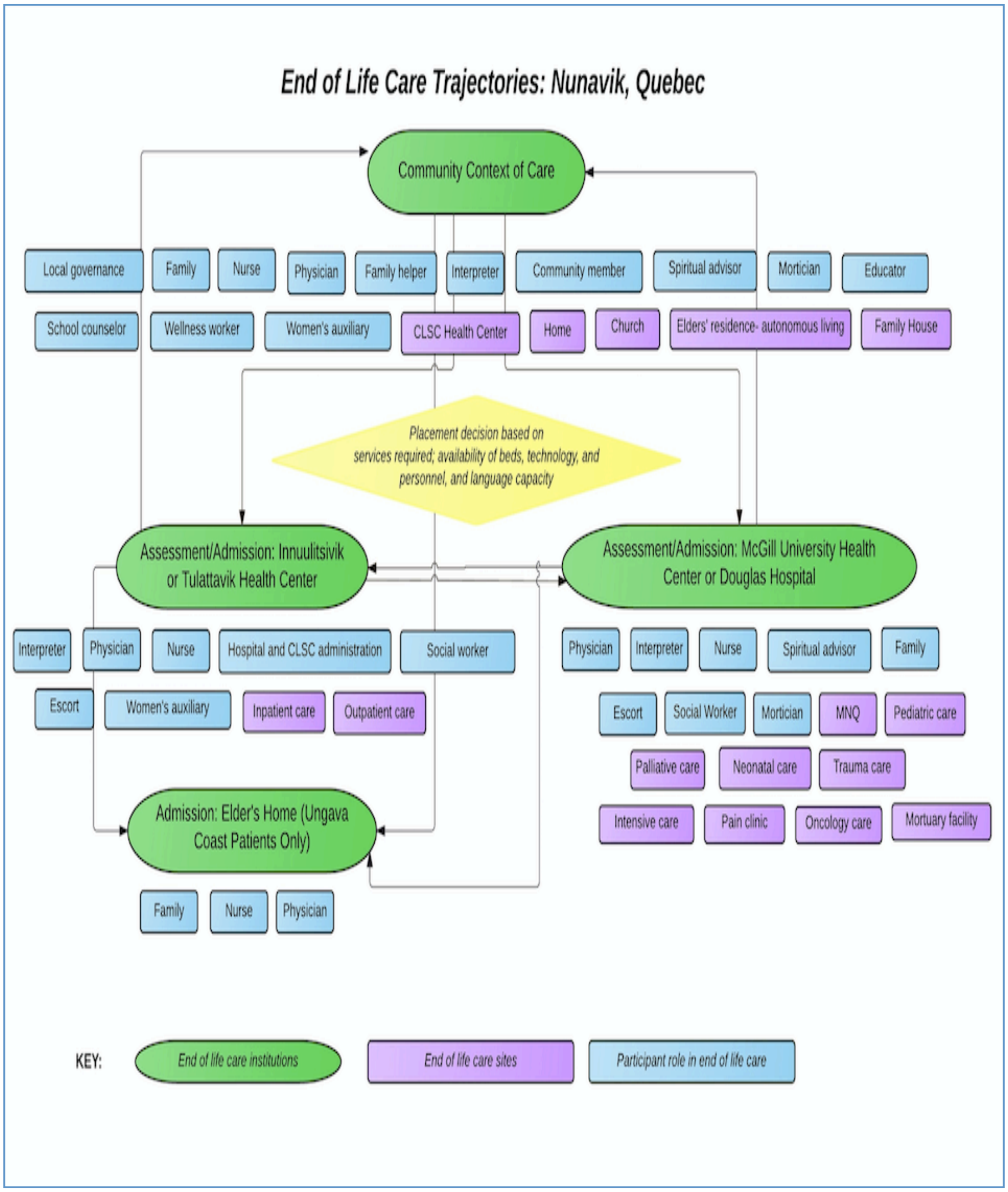


Figure 4: Patient trajectories, sites and care providers

Upon returning, Mr. J's condition remained somewhat stable for 4 weeks. He was able to move around with little assistance. On the 5th week, his condition rapidly deteriorated. As his daughter stated, "it was like he gave up." He stopped eating and remained in bed. His wife *began providing around the clock care. A nurse stopped by to demonstrate how to give morphine injections. The auxiliary committee from the church prepared food to bring to the home as the aroma of cooking in the house had made Mr. J nauseated.*

Mr. J's daughters stopped in each afternoon to do some cleaning and see how their father was doing, but childcare responsibilities kept them from being able to spend the night. Mrs. J. became increasingly exhausted, perhaps a combination of the around the clock hours she kept in providing care and the grief that she experienced. The family requested that Mr. J. be transferred to Puvirnituq where he could receive 24 hour nursing care. His wife accompanied him. Within 3 days, Mr. J died. His body was transferred back to his home. For two days, community members passed by to sit with the family. Relatives flew in from distant communities for the funeral. Once this waiting period had ended, Mr. J.'s body was transferred to the church for a funeral service, then to the cemetery where a song and prayer was offered around his grave.

5.3 Complications related to North/South care

Overall participants describe patient care as satisfactory regarding communication between Northern health care institutions and Southern hospitals. The greatest obstacles to treatment, however, were communication breakdowns and missed appointments as a result of communication and psychosocial difficulties. According to one Southern liaison nurse, about 60% of her patients and escorts were able to negotiate the system without complications; a large part of her job consisted of reorganizing and rescheduling appointments for the 40% who had difficulty. Health care workers and the families of patients cited the following obstacles to families and health care providers negotiating Northern and Southern EOL care:

1. *Keeping of appointments*

Patients risked missing appointments if a guide or interpreter was not available to assist them in negotiating Montreal's medical facilities and registration requirements. Nunavik patients in Montreal did not have patient navigators in the hospital, nor did they have adequate access to psychosocial services to address the concerns that at times prevented them from following through with their appointments. Furthermore, some were not aware of the work it entailed for nurses to schedule and reschedule appointments. Missed flights or appointments with the specialists, or inadequate follow through on protocols for preparation for medical procedures delayed their care by weeks or months.

2. *Family distance*

In the instances of patients who had been given a terminal diagnosis, the Nunavik Regional Health Board paid for the plane flights and the accommodations of two escorts from the North. Any additional family members were required to find their own way, a costly endeavor. As a result, the patient and escorts who were in Montreal for EOL care were isolated from their primary support systems in family and community. Geographic distance also played a factor when patients went back home after a period of hospitalization. When a patient returned to the North appearing significantly worse than when he/she had left, it could have a shocking impact on family and community members who were not prepared to see the patient in a weakened state.

3. *Preparedness of escorts and interpreters*

Patient EOL care largely depended on the reliability and competency of escorts and interpreters. When those who were assigned to the patient were present and capable of responding to the physical, linguistic, and emotional needs of the patient, the patient's experience was significantly altered for the better. If the escorts were not consistently present, the patient's experience would be more isolated and, at times, overwhelming.

4. *Organization of plane transportation*

Terminal patients who are transferred to and from Montreal depend on air and sometimes ambulance transportation. When the patient is on a stretcher, seven plane seats are required, along with space for an escort and often a nurse. Lack of available space on a plane can delay the return of a palliative care patient to the North. In one case, a patient who was near death had his flight back delayed 5 days due to complications related to adequate preparation, lack of personnel and lack of flight availability.

> Ben souvent… ils ont leur traitement…pis ils sont trop instables pour être transférés à Kuujjuaq pis on veut pas qu'ils meurent dans l'avion non plus… ils n'ont pas le temps de revenir chez eux. (Physician)

5. *Patient transfers and health worker judgement calls*

Physicians reported that there had been needless transfers between North and South. Related to EOL care specifically, this occurred when patients had been sent back to the South for tests or treatment because Northern physicians or families were unaware that a terminal diagnosis had been given or because patient and family had denied the reality of the terminal diagnosis. Nurses and physicians also described the difficult task of determining when to order tests, a costly and time-intensive procedure if these tests had to be done in Montreal, and when to wait for the symptoms to abate on their own. In a few cases, patients and families recounted incidences in which complaints had not been taken seriously, which then delayed the diagnosis and treatment of cancer. One cancer patient in particular had been accused of fabricating symptoms in order to gain a free trip to the South. She had to wait for this physician to go on vacation before she could get a consultation from another physician referring her to the South for care.

6. *Patient reticence*

Patients at times resisted recommended transfers for care. Participants explained that sometimes patients feared that if they were sent to Montreal, Kuujjuaq or Puvirnituq for care, they would not be well enough to return home. In contrast, on occasion patients sent back to the North for palliative care resisted this transfer back home as it confirmed that nothing more could be done.

6. FAMILY AND COMMUNITY ORGANIZED CARE

Patients transferred back to the North or who have never left their communities are often provided EOL care by family and community. This care is often provided in collaboration with nurses in the local CLSC. Residents of Kuujjuaq appear to be an exception as many described accessing inpatient health center services in the final days of a patient's life. In this next section, we will draw on our discussions with participants to describe who is involved in family and community care, the variables that shape the provision of that care, and the recommendations offered by participants to ensure the future of EOL care in family and community contexts.

6. 1 Family and community services

6.1.1 Family

Care-providers stated that most terminally ill patients preferred to die in their homes where they are surrounded by friends, family and familiar home and community environments. Families and communities would go through great lengths to respect these wishes, often in collaboration with the local health center or regional hospitals. Families often preferred to have the patient at home for the final days of life as their own grieving process was supported when family, friends and neighbours surrounded them during the final days of a patient's life. Women tended to be the primary caregivers for family members who are dying in the home: wives, daughters and granddaughters. Men did become involved as they may have been needed to lift or move the patient and when women were unable to provide needed care.

In Nunavik, the definition of family is widened, creating a broader system of relations through which EOL decisions are made and care-giving responsibilities are assumed. For example, the children of nieces and nephews were also identified as one's grandchildren and could act as key decision-makers and caregivers. Family members who had been separated by adoption as infants or youth would, at times, return and engage in providing EOL care for members of their birth family. It was not unusual for grandparents to have raised a child during formative years of that child's life. In turn, grandchildren and great-grandchildren may have been present during the decision-making and care-giving process.

In addition to private monetary donations and assistance that comes from community members during time of death, the local co-operative organization (store and hotel) will also make donations of food or financial aid to families. The amount varied according to family need.

On a related note, nurses observed that families and neighbours were very comfortable with providing food, keeping vigil, and attending to the social needs of families during a patient's final days. However, when it came to bathing, toileting or turning the patient, there was more reticence. In larger communities, local family helpers or home care nurses engaged by the CLSC would may have assisted the family in providing this intimate care.

6.1.2 Home environments

Housing shortages are rampant in Nunavik. Three or four generations may be living in one dwelling making it difficult to create a space in which to provide palliative care. Persons who receive EOL care in the home were cared for in the common living space or in a bedroom off to the side. If requested, supplies were provided by the local health center such as an electric hospital bed, commodes, pads and so on.

Daily life routines continued in the home during the time of death, a home where three or four generations may have been living in a home or in close proximity to each other. Consequently, children were exposed to the dying process. They learned about death through observation in their own homes or in that of others. Parents in the study identified struggling to answer children's questions concerning death and loss as they stated that these conversations were not encouraged in their own upbringing. Thus, they did not have a model to go by.

> People are more supportive when they know people are dying from old age or cancer… people are more open to receive support, even the family… It's their last stage of living that people tend to help out. The community really comes. They go visit… or they go clean up they family's house.. and some would cook their meals… There's a lot of community connection. (Women's auxiliary member)

Families were compensated for living with elders through a Kativik government housing policy in which those who dwell with an elder pay $100 dollars in rent, vs. the payment of $ 300-550 per month that they would otherwise pay. On the one hand, family members described that this policy provided financial relief for family members who provided EOL care to elders in their homes. On the other hand, some family members expressed concern for the care a parent was receiving. In one case, it became apparent that a family member had agreed to provide care for an elder motivated by financial reasons, not out of desire to care for the patient. The family members living outside of the home felt constrained in their ability to protect this elderly parent.

6.1.3 Women's auxiliary

In many communities, the women's auxiliary committee played a vital role in supporting families during the dying process. As volunteers, these women would cook, clean and prepare food for patients and families, organizing additional support and financial aid as needed through the FM radio station. Its members may have also be invited to pray, read scripture or sing with the family at time of death. This group was also responsible to prepare the deceased for burial and the family for the funeral, though not all members took on this role as some felt they were not capable. The women whose role was that of community morticians had been mentored into this role by the previous generation of women volunteers.

Figure 5: Winter scene in Nunavik community

6.2 Challenges and variables in providing community care

Providing care in community contexts poses a number of challenges. Participants described how at times, family or community members was unable to meet the actual needs of the patient, a reality that was difficult to acknowledge. Participants explained that EOL care commitments were rooted in Inuit values, practices and beliefs and therefore difficult to relinquish. Several variables played a role in a family's ability to provide care. Nunavimmiut who had been engaged in direct patient care or in accompanying children and families described how psychosocial, educational, geographic and medical/physical factors shaped home-based EOL care provision.

There is a belief that you have to take care of your family, what is (happens) in the home stays home and shouldn't really be going out. So even though they are burning out, they don't reach out for help. (Family member)

6.2.1 Psychosocial variables in family care provision

1. *Strength of family bonds and coping skills in families*

EOL care in families required a close level of collaboration and cooperation. Decisions were complex and nuanced, demands could be significant, and grief could be intense. Participants described how strong family bonds and coping skills would enable the family members to deal with the experiences of loss, stress, conflict, difference of opinion, and suffering that is inherent in providing end of life care. However, if there was a history of violence or abuse by the patient toward other family and community members, this would serve to complicate EOL care.

They need to know that it's ok to be scared, that these feelings are normal when they don't understand what is happening to a dying person… rather than pretend he is not there.
(Community member)

2. *Access to resources:*

Participants also spoke of the importance of resources: personnel, financial and space. First, having an adequate number of persons to provide care was a primary concern for family. For example, the time commitment required to provide 24-hour care was significant. A larger family without major child and work responsibilities could be more available to provide care while a smaller family or one that was already spread thin in taking care of children or grandchildren had less available time. The number of persons available to provide care also depended on the nature of the patient's status and reputation in the community. Community members described how a person with a strong, positive reputation in a community was more likely to draw a wider diversity of persons to engage in care than one who may have had a history of abusive and violent behaviour.

Second, those who took time off from work, hunting, or fishing to provide care in the home carry an economic burden as they continue to meet the needs of their own family. Economic implications in EOL care were also felt by family members travelling from other communities to assist in care who would lose their income as well as dispense significantly for a plane ticket. Families who were financially stable and who had external support (e.g., monetary support, gift certificates or respite care providers) were more positioned to continue providing care.

Third, physical space was a key variable in providing care. Factors related to the suitability of the home environment (e.g., number of occupants, presence of stairs, adequate food, and the consistency of municipal services - water delivery and sewage pick up) also affected how comfortably a patient could be kept at home on a long-term basis. Families did not describe this as a concern for shorter term EOL care.

3. *Prior knowledge and personal comfort level in providing EOL care*

The level of knowledge that families brought into EOL care would also impact their ability to provide care. At times, knowledge was transmitted through observation and mentoring as previous members had died in the home. When a member had already observed or participated in the turning, bathing, feeding of a family member, it would be more natural to do this again. It might also have been less shocking to see a family member experience the physical and mental changes accompanying death. Lack of preparedness, prior experience or access to educational resources could create more hesitation in a family to provide care.

As medically-based palliative care interventions were increasingly offered to patients, family members were asked to engage in procedures with which they were unfamiliar. For example, giving a needle to a loved one to reduce pain. The ability of a family to adjust to this external advice depended also on their personal comfort level in providing intimate care and the degree of trust felt for the nurse providing these instructions. In addition, language and terminology played a role as care required access to an interpreter, and freedom that family members felt in asking for clarification or stating opinions.

Key to the family provision of care was the level of advanced care planning that had already occurred among patients, families and health care providers. Family knowledge about the nuances and legalities of life-saving efforts, palliative care options and their awareness of patient wishes affected the level of conflict that existed in making EOL decisions for the patient. One area in which this conflict arose was over the use of morphine. Once again, interpreters often played a key role in transmitting this knowledge accurately between physician and patient.

4. *Patient condition*

Finally, the condition of a patient served as a variable in whether family members were positioned to provide care in the home. Factors included: a) weight of the patient and the ability of family members to lift or turn the person as needed; b) the autonomy of the patient in communication, bathing, eating, toileting and if family members were at ease with providing this intimate care; c) the frequency and duration of direct care needed (e.g., caregivers at times became fatigued in being up day and night and needed to end their commitment to home care); d) the presence of dementia in the patient and the ability to provide a safe and contained home environment; and e) the level of emotional, spiritual or physical distress in the person who was ill and the ability for families and medical staff to control physical or emotional pain in a home context.

Both health care providers and family members stated that it was not unusual for families to commit to providing EOL care though became unable to follow this through to the end. Either the patient's condition deteriorated more rapidly than was expected, or the actual realities of providing care proved to be too difficult. In these situations, health centers become a safety net for patients.

6.3 What can be done? Family and community care

In the face of the above-mentioned factors, many of the participants felt that the traditional practice of families providing EOL care was decreasing. Most agreed, however, that there were steps that could be taken to reverse this trend.

6.3.1 Psychosocial services

Across the spectrum of interviews and informal dialogues, participants described how a fundamental lack of mental health services had a trickle-down effect on family and community capacity to provide both long-term and short-term EOL care. Without support in the following areas it would not be possible for communities to develop a sustainable plan for EOL care provision.

1. Develop culturally-informed bereavement support for children and adults

Participants described different initiatives that were assisting individuals and families in the midst of grief. These practices often incorporated Inuit traditional and faith-based practices. However, existing supports could not meet the level of demand. As Figure 1 demonstrates, deaths caused by accidents and suicides are disproportionately high in Nunavik. Most Nunavimmiut have been marked by the traumatic deaths of family and community members. Participants described how the current lack of services to assist children and adults in their grief and bereavement results in complex grief reactions where feelings of sadness and anger could be overwhelming. They described how, in these instances, children would manifest their distress through acting out or withdrawal. Adolescents and adults would isolate themselves from friends, family or colleagues, or self-medicate through substance use. This unresolved grief would surface when a family member was dying of illness or natural causes. Taking care of a family member could soon become emotionally overwhelming. Participants described that avoidance of the dying might have been the only foreseeable response for some grieving family members. This resulted in increases in the transfers of patients to health facilities.

Participants stated that bereavement initiatives in certain communities could be reaching more families if given funding and recognition.

2. *Generalized psychosocial services*

Several Inuit and Qallunaat participants cited a 20/80 rule when assessing the percentage of stable versus struggling families in Nunavik communities. In their opinion, 80% of families were struggling to meet their basic social and physical needs. This social breakdown of families and community was attributed to a direct consequence of unaddressed suffering. Community members described how many struggle with intergenerational patterns of addiction and abuse. Access to mental health services would increase their capacity to address the conflicts, grief and anxieties that were inevitable in caring for terminally ill family members.

It is important to highlight that participants were not asking for an increase in government-sponsored programs imported from Southern communities, nor were they expecting solutions from the South. Several grassroots initiatives exist to provide mental health and bereavement services to these individuals; however, they struggle with personnel, funding and recognition by the health care system.

6.3.2 Facilities: Respite care, long term care facilities, mortuary facilities

1. *Long-term and respite care*

When family members become fatigued and can no longer care for the ill, patients are transferred to one of the regional inpatient health centers. It is not unusual for these patients to be assigned to beds designated for other patients, thus creating a scenario not unlike "musical chairs," one in which beds are allotted in the hope that the patients will not need the bed too long before another patient demands the space. An increase in health center beds and inpatient elder facilities are needed for the increasing numbers of Nunavik residents for whom institutional care is their only option.

We spoke with several participants who indicated that families need the option of respite care. The municipality in Puvirnituq has organized a respite care facility for families caring for elders and persons with disabilities who are capable of living autonomously. Seven Hudson coast communities access this home, Sailivik, with four respite and four long-term beds. Families can send members there for up to two weeks, every three months. The inpatient CLSC in Puvirnituq also offers beds for respite care for families providing end-of life-care in the home. In both facilities, however, space is inadequate for the level of need. Furthermore, the health center atmosphere is not conducive to palliative care. As one physician noted, "*L'ambiance est facilement teinté par ce qui ce passe du côté des soins aigus*." The respite beds are clearly located in a hospital environment and do not offer the environment of a palliative care or respite facility. The patients are often two per room. They are located in close proximity to those in acute care and are affected by this as the environment can be filled with activity and rest can be difficult.

While the Ungava coast has an elder's home that has been transformed into a CHSLD facility, the Hudson coast offers no such long term, inpatient EOL care services despite its larger population.

2. *Respite care networks*

Respondents also suggested that communities should develop a network of respite care providers who are assigned to homes for several hours at a time so that family members could leave to sleep, buy groceries or seek a change of scenery. Currently, family workers are assigned to homes for much shorter periods of 1-2 hours. Families also requested palliative care rooms in communities, not unlike those offered in Southern palliative care institutions. This would allow patients to remain in their community at the end of life when home facilities are not adequate or when family members find the emotional burden of caring for a dying loved one in the home to be too much.

3. *Mortuary facilities*

Figure 6 Morgue in community

Finally, mortuary facilities are desired in communities that do not have health centers. Each community has a small, refrigerated container that is used to store bodies. However, the refrigeration is not always functional and there is no space for visitation. Women's auxiliary members access CLSC facilities to prepare bodies in some contexts. However, they are not always welcomed in CLSCs. Some would prefer a space where they could prepare the bodies outside of the home and CLSC and where families and community members could come to visit the body and say good-byes before the funeral. A physician spoke to this need, stating that at times the personnel in the CLSC feel torn by the need for the family to have a private space to mourn and their need for space to tend to patients. She explained that an alternative space is needed:

> *Cela aiderait à faire face au malaise qui parfois survient lorsqu'on doit garder le corps du défunt dans le CLSC tout en devant poursuivre nos activités cliniques. Malheureusement, il arrive par moment que la clinique déborde, qu'on a besoin de toutes nos salles de travail, de tout notre personnel. Tout le monde devient alors mal à l'aise, pris entre le désir d'offrir le meilleur environnement pour que la famille puisse se recueillir et celui d'offrir les soins aux malades qui continuent à consulter au CLSC.*

One community church has found a solution to these needs by building a small addition onto the back of their church for this purpose.

6.3.3 Communication of educational materials to families

Both Inuit and Qallunaat participants indicated that communication concerning medical issues is most clear when presented in an oral and visual format. Wordy pamphlets are ineffective tools of communication with Inuit families. Optimally, a trusted nurse or physician is needed to discuss advanced care planning, to prepare families for the dying process, and to demonstrate palliative care techniques such as administering injections, keeping a patient from dehydrating and so on. Given that not all family members are always present during these sessions, families suggested supplementary materials in Inuktitut and English in the form of video or illustrated pamphlets to prepare them for the physical and emotional challenges in providing EOL care.

7. NUNAVIK INPATIENT HEALTH CENTERS AND OUTPATIENT CARE

7.1 Inuulitsivik Health Center

The Inuulitsivik health center is located in Puvirnituq on the Hudson Coast of Nunavik. Professional services include pharmacy, laboratory, radiology, midwifery, audiology, and dentistry. It offers inpatient and outpatient care. Its inpatient unit has 25 beds, 17 of which are designated for acute care, 8 for long-term care. Long-term beds are available for patients with loss of autonomy, those with physical and intellectual disabilities and those requiring EOL care. Three nurses are assigned to each shift in the inpatient facility. Here, the '*préposés aux établissements Nordiques'* also known as Northern Attendants, served as interpreters for patients and families.

The health center oversees the outpatient CLSCs in six communities also located on the Hudson coast or strait: Salluit, Ivujivik, Akuluvik, Inukjuak, Umiujaq, and Kuujjuarpik. Nurses are assigned to communities according to population and need. There is a 2-nurse minimum in each community. Persons in loss of autonomy (PLA) nurses are located in four communities: Salluit, Inukjuak, Puvirnituq and Kuujjuarapik. A liaison nurse works from the hospital center, coordinating patient visits to the South and working on telehealth services. In addition to these onsite professionals, an average of 21 medical specialists rotate through the communities throughout the year. These specialty services include internal medicine, paediatric services, psychiatry, general surgery, pulmonology, and cardiology.

Figure 7: Innuulitsivik Health Center

7.2 Tulattavik Health Center

The Tulattavik Health Center is located in Kuujjuaq on the Ungava coast. It offers inpatient and outpatient care. Radiology, ultrasound, laboratory, dentistry, pharmacy, birthing (midwife), minor surgery, paediatrics and internal medicine are provided onsite. One room has also been transformed into a psychiatric observation room designed to prevent self-injury. The center has 15 inpatient beds, including private and double rooms. These are designated for those with chronic conditions (currently used by elderly patients and youth with disabilities), patients with loss of autonomy, paediatrics, limited intensive care and EOL care.

The Tulattavik Health Center services patients in Kuujjuaq and five communities located on the Ungava coast: Kangiqsualujjuaq, Tasiujaq, Auplaluk, Kangirsuk, Quaqtaq, as well as Kangiqsujuaq on the Hudson strait. Each of these communities has a CLSC with at least two nurses; depending on population size and need, there may be more. Kangiqsualujjuaq, Kangirsuk, Kangiqsujuaq and Kuujjuaq have a PLA nurse assigned to meet with patients in their homes and provide support to families.

7.3 Tusaajiapik elder's home

The Tulattavik Health Center in partnership with the municipality of Kuujjuaq and the Kativik Municipal Housing Board also staffs a residence for elderly and persons with loss of autonomy, many who have unconfirmed diagnoses of dementia. This residence has 12 beds. It is the only residential care facility for Nunavik's ageing population. It opened as an independent living facility, though is now functioning much as a *Centre d'hébergement et de soins de longue durée* (CHSLD), a long-term care facility. At the time of this study, six elders resided here all with mild cognitive condition or dementia. The remainder of the patients had another form of a cognitive or physical disability. Four men were residing in the Tulattavik Health Center while on the waiting list to enter the elder's home. As several residents come from communities outside of Kuujjuaq, two family members are provided flights three times per year to visit residents of the Tusaajiapik elder's residence.

Figure 8: Outpatient CLSC in a Nunavik community

The Ungava coast has two independent care facilities, located in Kangiqsualujjuaq and Kangiqsujuaq, for which elders and persons with disabilities are given priority. The residence in Kangiqsualujjuaq consists of 17 studio apartments and currently also includes residents without a home (due to fire, domestic violence, or for default on rent payments for their homes). The

Kangiqsujuaq residence is divided into two sections, each able to house three persons. One section is reserved for elders and another for persons with disabilities. Each section has a shared kitchen and living room.

Health care centers in each community are equipped with materials that may be needed by families (e.g., pads, beds, wipes, urinals, chairs). If needed, nurses provide training and support to families concerning the administration of medications, whether orally or intravenously. Seven of Nunavik's larger communities have home care nurses who serve as the primary contact for families providing EOL and palliative care. In smaller communities, the nurses assume this care as within the context of their enlarged role mandate. At times, supplemental nursing staff had been sent into communities where work overload did not allow nurses in the community to simultaneously meet the needs of CLSC patients and homebound palliative care patients and their families.
The health care providers in Nunavik assumed a wide variety of responsibilities. Their interaction specific to EOL care is as follows:

1. *Physicians*

Physicians were each assigned communities for whom they served as primary care physicians. Some lived in the community to which they were assigned; others flew in to communities once per month to provide care. After an initial assessment, the physician would refer the patient to specialists in Montreal. These community-based physicians may have been required to inform patients and/or their families of test results if this had not been done in Montreal. They were also directly engaged in EOL care planning discussions with families. Full time physicians were hired in communities when the population reached 900. Physicians varied in the amount of palliative care training that they had received, dependent on program of study and personal interest.

2. *Nurses: Clinical, Enlarged role, and PLA*

Clinical nurses were hired to work in inpatient health care settings, collaborating with onsite physicians in providing care. They were engaged in 24 hour care of patients who had been admitted for EOL care.

The CLSC also had "enlarged role" nurses, meaning those working in centers without inpatient services. Enlarge role nurses worked 9-5 shifts from Monday through Friday (in actuality, their hours often extended beyond this) and rotated the responsibilities of being on call. In small communities, two nurses were present and so they rotated being on 1st or 2nd call and were never fully off duty. Further, working hours may have been significantly extended when providing both routine and emergency after-hour care. On occasion, when a patient required palliative care and the existing caseload of community nurses prevented them from being able to provide the needed services, a surplus nurse had been sent to a community.

> Each time we are here, we push limits to exhaustion, physical and mental… you have to be really balanced and really well with yourself.
> (Nurse)

Enlarged role nurses performed initial evaluations and participated in home care assessments. They would treat terminally ill patients according to the directives of the community physician or Southern specialist. These nurses were responsible for administering palliative care protocols and as such, they offer instructions and materials to families who choose to provide EOL care in the home.

Nurses recently trained had 3.5 weeks theoretical training, 1.5 weeks rotations in the inpatient health center and 1-2 weeks of community training before they assumed their full time position. Until now, training for nurses in palliative care had been minimal. Due to the nature of their work in communities, nurses preferred continuing education in areas of trauma, emergency and paediatric care. However, some nurses had gained a level of expertise in palliative and EOL care while working in the South.

PLA (Patients with loss of autonomy) nurses were engaged in seven communities throughout Nunavik. They supported patients who have experienced either temporary or permanent loss of autonomy and who are being cared for in their homes. Patients needing assistance from PLA nurses included those who had recently undergone surgery, those with intellectual or physical disabilities, and patients needing EOL care. When PLA nurses were present, they assumed the responsibilities of doing home assessments, at times in collaboration with the local social workers. These assessments screened for physical, social and psychological barriers in providing at home care. When caseloads were not overwhelming, the PLA nurse would also conduct home assessments with all community members over the age of 60, examining current states of health in order to anticipate future long-term care needs. Some nurses provided their phone number outside of their scheduled 9-5 working hours in order to remain available for a family providing palliative care.

3. *PLA interpreters*

PLA interpreters assisted in the delivery of home care through interpretation services and through providing guidance to newly arrived PLA nurses concerning the socio-emotional, relational and physical environments of patients. Depending on the community, the interpreter would also assist in the coordination of community family workers and assist with patient record keeping.

4. *Family workers*

Under the supervision of the CLSC nursing staff, Inuit family workers provided home-based patient services such as cleaning, bathing, and cooking depending on the need. Within the context of their job, family workers would also be assigned to assist families in providing EOL care. Services offered by family workers varied considerably between communities as some communities had challenges finding employees to provide this service.

5. *Community living and wellness workers*

Wellness workers were employed in each community to offer health promotion and prevention services. As Inuit community members, their tasks were quite varied from one community to the next depending on the interest of the workers and the needs of the community. Specific to EOL care, wellness workers would visit bereaved families and provide them with food or gift certificates from the local co-op store to the families. Wellness workers also made public health announcements through written materials or FM radio broadcasts. These announcements included information concerning elder awareness day, elder abuse and prevention messages related to specific chronic illnesses.

6. Social workers and social assistants

Social workers (licensed and almost exclusively Qallunaat) and social assistants (Inuit located in the community) would get involved in EOL care through participation in home care assessments, delivering needed equipment and supplies, participating in family consultations and providing support services. Their engagement was limited, however, due to heavy caseloads, more urgent demands in the community and lack of training in psychosocial interventions. Social workers stated that, occasionally, community members would consult them to speak about grief issues. However, they stated that, as they have little time and no training in this area, they were limited in what they could offer. In addition, some noted that social workers were associated with the department of youth protection and the removal of children from their homes. As such, people would often hesitate to confide in them. In Kuujjuaq and Inukjuak, PLA social workers were appointed to work specifically with persons with loss of autonomy. In terms of EOL care, they would manage the budget of clients who were either mandated or who volunteered to have this outside involvement. The latter required collaboration with a curator from Montreal. They also participated in home assessments, responded to emergency food requests and communicated with liaison nurses in Montreal concerning patient care.

7. Northern attendants (interpreters)

Northern attendants (interpreters) performed a variety of tasks in the health centers. They would do intake with patients, read vital signs, sterilize materials, clean, schedule appointments, organize charts and records and provide interpretation services. According to the Northern attendants with whom we spoke, their primary encounters with EOL care occurred when they provided interpretation services between patients/families and physicians/nurses. Of note, they consistently self-identified as "interpreters" and not as "northern attendants." When asked about this, one interpreter stated that the interpreter portion of her job was both the most difficult and most important aspect of her tasks.

> If you can count on each other, if there's a positive morale, if you can work together, that makes a difference
> (Nurse)

8. Escorts:

Escorts accompanied patients to their appointments to inpatient health center and hospital settings located outside of the community (e.g. patients who had experienced loss of autonomy, who had linguistic barriers, or who were physically fragile). Family members who served as escorts were given free transportation and free room and board in the transit housing affiliated to the health center or hospital. If family members could be found to fill this role, another individual would be hired by the health center to accompany the patient. Tasks of escorts included bringing patients to appointments and providing personal care if the person resided in the transitional housing.

7.4 Challenges and variables in CLSC inpatient and outpatient care

Nurses, physicians and northern attendants (interpreters) were the frontline workers in providing EOL care in the CLSCs. These participants discussed how offering EOL care in Northern contexts posed a unique set of challenges and that successful care and communication depended on several factors. As the question of communication is of widespread concern for professionals working in Northern contexts, section 9 is devoted to this subject.

7.4.1 Variables for nurses/physicians

Nurses and physicians have indicated that several factors influence their ability to provide care in general and EOL care services in particular.

1. *Degree of trust*

The trust that had been established between physician and nurse and family/community was critical to EOL care in Nunavik settings. Misunderstandings concerning the progression of a patient's illness, confusion concerning EOL care choices, and general mistrust of Qallunaat could shape the reactions of families to nurses and physicians providing treatment or advice. On the other hand, once that trust had been established, the difference was felt on both sides. One PLA nurse stated that it took three years of living in the community before she felt that she had been accepted into people's homes. As a long term PLA nurse, trust had grown to the extent that families had thanked her in person or on the radio for the care that she had provided.

> Qu'est-ce qu'on donne, qu'est-ce qu'on donne pas…Tout le monde est un petit peu insécure à ce niveau-là. Ce n'est pas quelque chose qu'on maîtrise bien dans le Nord. (Nurse regarding palliative care protocols)

2. *Access to palliative care educational resources*

Access to training, personal consultation and materials also served as a variable in EOL care delivery. In small northern communities, incidences in which palliative care expertise was needed may have been relatively rare, and knowledge that had been acquired could be forgotten. Consequently, physicians and nurses needed resources to meet EOL patient needs on a case-by-case basis. One physician described how he was left to his own devices to determine treatment for the diversity of symptoms that his patients had been suffering with at the end of their lives. Looking back on this experience, he felt that had he access to training resources concerning pain management and controlling side-effects, he could have prevented unnecessary pain and distress for his patients during the dying process.

3. *The duration of care*

As with families, nurses and physicians became fatigued by the round-the-clock care that was often required in providing palliative care. The ability for nurses and physicians to care for patients in the home depended on the personnel resources, especially if a patient required long-term care. Until now, nurses had reported that this event of providing palliative care was rare, though they anticipated that as the population in Nunavik increased, this would change. In cases where the duration of intensive EOL care was lengthy, additional nursing support was provided.

> Here we do it we have with what we can but have a criminal lack of support for the family. (Nurse in Nunavik)

4. The preparedness and capacities of family members

Nurses told us that the more the family was able to directly contribute to the care of the patient in terms of creating a comfortable environment and implementing interventions to alleviate pain, the more comfortable the EOL process was for the patient. To encourage this participation nurses would often come to the homes and invite family involvement in palliative care. Those who did so were met by families with various degrees of preparedness. This included preparedness in terms of knowledge concerning death, dying, EOL care options, the level of organization required to care for a patient, and emotional and physical capacities needed to respond to the patient. This also included differing levels of desire to invite a Qallunaat nurse into the home, especially if the nurse had only recently arrived.

A nurse recounted an incident in which a family member returned to her community for palliative care. This was done at the request of the family following several weeks of hospitalization in the South. The patient's health had deteriorated rapidly during her absence, and had clearly lost much weight and strength. The family was shocked when they first saw her on the stretcher at the airport. Some family members reacted to their distress by directing hostility toward the nurses providing care, one who was new to the community. One nurse described her perceptions about what transpired:

> *Rendu au village les habitants du village ont été très choqués je pense de voir l'était dans lequel la femme était. Ils ne s'attendaient pas à ça. C'est sûr qu'en phase terminale elle avait perdu beaucoup de poids, avait l'air très fatiguée, pas de force, difficulté à bouger. Donc ils ont été très fâchés contre nous, contre l'hôpital de l'avoir abandonné là à ____ (sa communauté) là. Eux auraient aimé comme avoir une salle de soins intensifs chez eux là avec du personnel à temps plein mais dans le fond l'infirmière n'était pas là à temps plein là. Elle allait comme à toutes les heures ou tsé si jamais il y avait quelque chose la famille pouvait l'appeler mais elle ne dormait pas dans la maison là. Tsé fait qu'eux ont très mal réagit avec des bêtises sur la radio contre les infirmières pis des menaces. Tout ça, ça*

> Aimer dans l'amour c'est facile; mais aimer dans la haine, puis la compréhension profonde, c'est un grand défi (Nurse).

> *l'a été très difficile pour le, le staff là de passer au travers ça.*

The nurse who told the story theorized that: a) had the nurses prepared the family for the changes that occurred in this elder, b) had they reminded family members ahead of time of the elder's stated wishes to return home, and c) had they prepared families and communities for the feelings of grief they might feel in seeing this elder, this mutually-distressing experience may have been avoided.

5. *Psychosocial support and coping skills*

Nurses and physicians who worked in Northern contexts were stepping into a socio-historical context outside of their making. Stories of colonial practices such as residential schools, the displacement of families and communities, exploitation in trade and commerce, the devaluation of Inuit knowledge and the introduction of widespread disease resided in the collective memory of communities.

Nurses described how, coming to the North, they had a two-day training specific to preparing for their transition to Nunavik beforehand. On the first day, they were given an overview and history of the geography and culture of Inuit people. The second day, they were educated on which supplies to bring into Northern communities. However, many of the nurses with whom we spoke felt they were not adequately prepared for work in Northern conditions as they were not made aware of the degree of trauma and violence that they then encountered in communities. They did not feel prepared for the fact that they would often be alienated in the communities they entered, and at times met with verbal hostility. And they were not aware of the lack of psychosocial and mental health services in Nunavik communities and the direct impact this would have on their work.

Nurses identified that personal capacities to deal with stress and existing support structures were key in their ability to provide care. Supportive collegial relationships with other care professionals in the CLSC, both Inuit and Qallunaat, were valued. A supervisor who was aware of the realities on the ground and who could provide a forum to support nurses in the stress of their daily roles could also be a protective factor against nurse burnout. Nurses also described how personal self-care strategies - whether stress reduction activities (e.g., several nurses had skidoos or four-wheelers to participate in outdoor activities and enjoyed hiking and fishing) or spirituality (often in the form of personal practices) - were key to their ability to remain in communities. The development of social relationships with colleagues and with Inuit community members outside of the health care system were also protective factors for nurses in CLSC contexts. In addition, a flexible work program that permitted nurses the option of two or three months on duty with one or two months off, as well as independent rather than transitional or shared housing, was cited by nurses as crucial to their self-care.

7.4.2 Variables for Inuit professionals in providing EOL care:

Observations and dialogues with Inuit professionals employed by the CLSC's provided insights into the variables that influence their ability to perform their tasks at large, as well as their engagement with EOL care provision.

1. *The degree of training in bereavement care and in the dying process*

Participants indicated that regular training had a direct impact on the level of comfort they had in working with patients and families. In other words, the process of professionalization was valued. Importantly, as with the Qallunaat employees, the Inuit expressed a significant gap in their training to address the grief and bereavement needs of individuals and families.

2. *Moral distress*

The degree of internal conflict experienced by Inuit professionals was also a variable in their ability to meet the needs of EOL care patients and families. This was especially true for interpreters who found themselves caught between the expectations of physicians and nurses and that of Inuit patients and families. For example, several interpreters recounted their distress when asked to communicate what the physician saw as the expected lifespan of a terminally ill patient. From a cultural level, this communication regarding death had been reserved for specific persons in the community called *Tutsalukkajiit* and was not to be communicated by interpreters. From a spiritual perspective, many believed that only God knew when someone would die, so they should not communicate a terminal prognosis including the months or years a person had left to live. This moral conflict in how to respond posed significant stress and many interpreters felt alone in negotiating these experiences.

It was also difficult for interpreters to discern whether and how to translate a hostile reaction of a patient or family to a nurse or physician. At times, no good option appeared to exist as they felt the need to communicate literally but also respect the feelings of the nurse or physician. Communication concerning the use of morphine in the context of palliative care also served to create internal distress for interpreters who believed personally that this was a form of euthanasia. These communication issues are discussed in more detail in sections 9, 10 and 11 of this report.

3. *Stress reduction strategies and psychosocial support*

As with Qallunaat care providers, coping capacities and psychosocial support were key to the capacity of Inuit professionals to do their work. This group described themselves in a difficult position. Their professional mandate required them to respond to the needs of the family and the community concerning bereavement and EOL care. However, as community members, care providers often had personal relationships with the deceased and the family. Consequently, they would, at times, be grieving themselves. This dual relationship, being a member in the community and yet serving a professional role was thus difficult to navigate.

Self-care practices cited by these professionals included time spent out on the land to engage in camping, fishing, hunting and berry picking, trips to the South for a change of environment. They also included communal practices such as worship time in church and prayer meetings. Finally, social time spent with families and community members was also key to addressing job related stress.

4. *The integration of Inuit knowledge and rhythms*

In addition to the Northern attendants, wellness workers, family workers and préposés aux bénéficiaires supported patients and families providing EOL care. As most of these employees had received little or no formal postsecondary training to prepare them for their tasks, they relied on education and mentoring in their work environments. Community professionals who spoke of feeling competent in their workplace emphasized how it had been important for them to integrate Inuit practices with Southern or First Nations models of healing and care. Some recounted what they had learned from what they saw as helpful (although brief) trainings concerning grief and bereavement such as the *Dialogue for Life* conference held in Montreal. In 2015, an adapted version of this, the *Puttautiit Conference* was held in Puvirnituq. Plans are to offer this conference on an annual basis, rotating between Nunavik's communities.

One of the difficulties recounted by mothers of young children who were employed by health centers was that the training currently offered was contrary to their family's rhythm and needs. Training took them away from their families for five or six days at a time. This was due to the fact that many were regrouped into one community for a weeklong session. Another challenge was the isolation that many faced in returning to their community when they attempted to integrate what they had learned. However, those who had access to the support or mentoring of colleagues and supervisors on a weekly basis described being satisfied with their work.

7.5 What can be done? CLSC care

Health care providers, both Inuit and Qallunaat, drew on their experience of working in the CLSC's in Nunavik communities to discuss changes that would contribute to the development of EOL care services.

7.5.1 Nurses/physicians

1. *Ready access to updated palliative care resources and training*

Depending on community demographics, nurses and physicians would have a few years in between caring for a palliative care patient. Considering the high rate of turnover of medical personnel, the emerging science of palliative care, and the limits of memory, many nurses and physicians suggested they needed access to updated videos, written materials and individual consultation on a case-by-case basis. Individual consultation would ideally be with a palliative care specialist working for the MUHC in Montreal because this is where patients would be sent. Also, this specialist would haveworked in Nunavik, and thus have some understanding of the key contextual factors in which nurses and physicians provide care.

En cas de soin palliatif, c'est jamais juste la patiente. C'est la famille et la patiente.. En phase terminale, tu marches tout le temps sur des œufs. On sait jamais le problème qui va sortir (Nurse)

2. *Palliative care oncall with a 'fly in' team*

Others suggested an oncall 'fly in' team who would provide services in communities when palliative care expertise is needed. Suggestions for this team included a physician, nurse, bereavement counselor, Inuit elder, notary, and legal counsel. These specialists would be flown into communities as the need arose, prepared to implement palliative care protocols with backgroun knowledge of Inuit care contexts. However, health care providersalso expressed concern that this approach would not facilitate trust between specialists and patients and their families. This trust was a critical factor for successful EOL care in community contexts.

3. *Communication guidelines*

Physicians and nurses suggested that guidelines concerning communication with Inuit family and community members would be helpful in providing EOL care. Physicians and nurses negotiated relational and communication territories fraught with complex moral choices and potential misperceptions. Section 9 will provide a more nuanced discussion concerning strategies of communication that have been found to be effective by nurses and physicians.

4. *Access to psychosocial support and services*

Some nursing participants attributed the high turnover of nursing staff to be a direct result of nurses not having a means through which to address the emotional impact of the suffering that they encountered in their work as well as the isolation that they experienced living in remote communities . Nursing participants indicated that there were moments when they needed to reach out to speak with someone. They felt discussion forums or access to individual consultation could fulfill this need. One on occasion, a psychologist was available by telephone for nurses needing to debrief.

5. *Mentoring models of care which draw on modeling rather than telling*

Models of transmitting information which draw on side-by-side mentoring approaches rather than top down teaching tactics were noted by nurses to be effective in enabling family members to care for patients at the end of life. In a mentoring context, family members and préposés aux bénéficiares were invited to participate in care, thus observing washing techniques, the turning of patients, feeding with small portions, speaking to the patient, moistening a patients lips, and so on. Nurses recommended that this mentoring approach be adopted to guide families in caring for members in their homes and inpatient care facilities.

6. *Emergency care and advanced planning wishes are made readily accessible*

Physicians and nurses did not always have ready access to information concerning previous conversations with patients and families concerning EOL care. This may be due to the fact that the conversation happened in a hospital far from the community, that the files were not transmitted or were delayed, or that advanced care planning discussions had never occurred. Ideally, patients over 65 and concerned family members would participate in these dialogues before a crisis occurs. This would prevent

> Sometimes there is a great lack of understanding on the patient's part which contributes to their receiving 'bad care'. There is room for more resources that help to inform or educate the public of how medical interventions actually take place. (Interpreter)

unresolved conflicts and grief clouding the decision-making process.

7.5.2 Inuit professionals

1. Exchange of competencies.

Recognition of existing competencies balanced with ongoing training and mutual-mentoring opportunities has been central to a successful collaboration between Inuit and Qallunaat health care providers. In this light, some Inuit professionals suggested that a mutual educational approach be implemented in Northern communities, one in which Inuit are training Southerners concerning existing community health practices and initiatives, protective factors, cultural norms and successful communication strategies. In exchange, they would receive training concerning medical, social and psychological models that may be adapted to Inuit communities.

2. Access to bereavement care and psychosocial support

Many with whom we spoke recounted their own stories of loss and grief. Some described having found healing while for others their grief remained unresolved. To be present for individuals, communities and families in EOL care, these professionals also expressed the need for psychosocial support from community insiders and outsiders. Who they relied on depended in part on their trust of community members to remain confidential.

3. Training needs

Training requests related to EOL care included: a) training in dementia prevention and intervention; b) increased linguistic and communication resources (elaborated on in section 10 below); and c) exchanges with other Inuit across the circumpolar regions who are also developing EOL care services

4. Public education

An option was raised to use the FM radio to sensitize the public concerning the role of the interpreters in health care provision. This could potentially alleviate some of their stress as patients and families will become more conscious of the challenges that interpreters themselves face. In addition, it was noted that the more the public was informed about disease and interventions, the more they would be prepared for what the interpreter may need to say. This can also be done through radio or Facebook.

8. The MONTREAL CONTEXT OF CARE

8.1 EOL care facilities and providers:

EOL services are provided at the McGill University Health Center (MUHC) in Montreal. Though we did not meet with all departments involved, we spoke with health care providers located in a number of sectors.

> We help people with, "Now that this has happened, what do we do now? What does this all mean? How does this change my life?" (Spiritual advisor)

8.1.1 Pain Management Clinic

The Outpatient Clinic for Pain Management accepts patients from Nunavik. Their interdisciplinary team approach to pain management includes an anaesthesiologist; palliative care physician, radiation-oncologist and a nurse. Assessment includes a physical exam, questionnaires, and a team review of patient records. Referrals are primarily from the oncology department. Three approaches to cancer pain are offered: pharmacology, radiation and injection. This pain clinic only rarely provides EOL care to Nunavik patients, however, given that most terminal patients leave Montreal to die in the north.

8.1.2 Physical, Psychosocial and Spiritual care

The MUHC has one adult palliative care unit where healthcare providers specialize in addressing the physical, social and emotional process of dying. This includes attentiveness to family dynamics and cultural considerations. In addition to the physicians and nurses providing direct medical care, patients and families have access to social workers and therapists (e.g, psychologist and music therapist) and spiritual advisors who assist in addressing psychosocial, relational and spiritual needs. In this context, spiritual advisors often play an advocacy role with families and patients. Further, they offer bereavement support into, such as offering a listening ear, praying, and creating the possibility for families to conduct their own EOL rituals.

8.1.3 Paediatric services: The Northern and Native Child Health Program

Located within the paediatric services of the MUHC, the Northern and Native Child Health Program staffs physicians as well as a nurse practitioner. Working in conjunction with the community liaison nurse at the Module du Nord Québécois (MNQ), the nurse practitioner facilitates the care for Nunavik children, is available to respond to questions, clarifies misunderstandings and refers children and parents to additional services as needed. This nurse practitioner also facilitates communication between specialists in the South and physicians in the North and assists parents in the decision-making process, providing psychosocial support to parents. Nunavik communities are scheduled to receive a weeklong visit from a paediatrician within this program two times per year. Instances of Nunavik children dying from a disease or illness are rare. In the few instances this has occurred, attempts were made to send children home for EOL care.

8.1.4 Module du Nord Québec (MNQ)

The MNQ is a residence for Inuit patients and their families coming from Nunavik. The MNQ operates within the context of the Inuulitsivik health care center. Locally, the director and nursing supervisor are in charge of the liaison nurses and interpreters. Eight interpreters working throughout the service corridors of the MUHC. They work day and evening shifts with one interpreter on call each night to either provide interpretation by phone or to come into the hospital. There are also eight liaison nurses working to coordinate care for patients who arrive in Montreal for inpatient and outpatient care. Nursing tasks include facilitating communication between North and South health care providers, explaining medical procedures to patients and families, ascertaining that patients understand what physicians have communicated, responding to patient and family questions, and advocating for patient care as they negotiate the Southern and Northern health care systems. Attempts are made to match nursing staff with the communities with which they are familiar.

The MNQ also has workers called '*Responsables d'unité de vie'* (RUV). Their job is to monitor the patients entering and leaving the center, coming and going, including those being transferred to their appointments. RUVs inform patients of the rules of the MNQ, provide an identity card, show patients to their rooms and provide meal cards. They also deal with basic care needs (e.g., milk for an infant) and security.

The *preposés en établissement nordique* are Inuit employees who are also available to interpret at the MNQ as needed. They remain onsite at the MNQ with patients and families. They are directly involved in meeting the daily needs of families and patients receiving EOL care in Montreal for short or extended periods of time.

8.1.5 Social services

The MNQ has an Inuit community worker available to meet with patients and families who request additional care and support. In addition, the Children's Unit of the hospital has a parttime social worker working in the Northern and Native Child Health program. Tasks include providing psychosocial support to families, linking families with needed services, coordinating care, and meeting with hospitalized children.

8.1.6 Escort services

Patients are permitted to have an escort accompany them from the North to Montreal if their health is critical or fragile, or if they do not speak English or French. While family members may serve as escorts, this is not always possible and so an outside escort may be hired. For patients with extended stays in Montreal, escorts are requested to remain a minimum of two weeks for long-term needs. Escorts who are not family members are paid $65/day in addition to being provided with airfare, food and lodging.

> You (Nunavimmiut) are very stressed because, "when am I going back home? What is happening to my daughter back home who's in her third trimester of pregnancy?"

8.2 Challenges and variables in providing care in Montreal

Patients, families and health care providers face a variety of challenges when EOL care is provided in Montreal hospital settings. Inuit and Qallunaat participants offered the following perspectives on this care.

8.2.1 Challenges for patients and families

1. *Displacement and homesickness*

Physicians, nurses and family members described how the geographical distance between patients in the South and their family and friends in the North profoundly impacted those receiving care in Montreal. Patients would be alone when a terminal diagnosis was conveyed and thus forced to deal with the distress on their own if family members and decision makers who would otherwise provide support and clarity were absent. One patient described feeling so profoundly disoriented when she heard her diagnosis that she was unable to physically see well enough to find the phone to call her family. For escorts and patients alike, pre-occupations and concerns about loved ones could contribute to both emotional and physical suffering.

2. *Interpreter and escort competency*

When family and friends were absent, patients could heavily rely on interpreters and escorts for emotional care. Patients described how essential it was to be able to trust these individuals and the important role they played during this vulnerable time. Conversely, if these supports did not follow through with their responsibilities (e.g., we heard stories of escorts and interpreters being sent home early for unprofessional behaviour), patients experienced distress.

3. *Psychosocial state of patients and caregivers*

The compounding factors surrounding care during the terminal phase of life significantly impacted the trajectory of EOL experiences. Health care providers and family members described how patients and family members, who already struggled to cope (i.e., addiction, aggression, and withdrawal), were at risk when grieving. For example, a woman spoke of her husband's four-day silence on learning that he had terminal cancer. Her invitation to communicate allowed him to express his own feelings of sadness in not seeing his grandchildren grow up. A social worker spoke of a mother who was often inebriated when visiting her child, relating this to her perception that her grief had overwhelmed her capacities to cope otherwise.

> Je pense que le pire scenario, c'est de mourir à Montréal

4. Continuity of care

Patients were also affected by the relationship that they had established with specialists and nurses. For many, the liaison nurses based in the Montreal hospital centers and the MNQ had been a supportive presence. Continuity of care between North and South health care providers also served as a variable in care as clarity in this communication had been critical for patients and families seeking to make EOL care decisions.

8.2.2 Challenges for health care providers

1. Treatment choices and interventions

> (We) are getting better at helping that person accept that their body is at a point where prolonging it is only going to lead to more suffering. (Physician)

Physicians and nurses discussed how advancements in medical science led to more nuanced and complex treatment choices being offered to patients. It became more difficult to explain the impact of treatments, potential side effects, and quality of life. Presenting these choices was especially difficult with cultural and language differences between patient and physician or nurse. It was also difficult for patients and caregivers to implement complex medication directives where they were required to take different doses at differing frequencies. Nurses also described how complications occurred when patients chose to discontinue medications because their symptoms had abated without telling the nurse.

2. Communication and interpretation

Physicians described much uncertainty around interpretation. They were often unsure if either their words or their patient's words were being fully and accurately translated. They noted, in particular, when emotional reactions in patients were not interpreted back to them, and when interpreter conversations were significantly longer or shorter than the words stated by themselves or patients. They did not always ask about this to the interpreter in order clarify what they perceived. An interpreter in whom they had confidence was considered valuable.

3 Symptom control

A patient's willingness and ability to acknowledge physical or emotional pain greatly impacts health care providers' accuracy in evaluating the need for further medical intervention and psychosocial support. Traditionally, stoic reactions to pain and suffering had been valued in Inuit cultures and thus pain assessment was difficult. Physicians mentioned that, more recently, this was becoming less of an issue.

4. Standardization of charts

Montreal health care providers have found continuity of care complicated by the fact that the Ungava coast communities use different charting formats in patient records than the Hudson coasts. Standardization between coasts would facilitate clarity in communication.

5 *Awareness of Nunavik context*

Health care providers have differing levels of awareness concerning Nunavik cultural and social contexts. Those who have worked in Northern communities or spent more intensive time with Inuit patients, describe having learned through their work. Examples included: a) using relevant visual metaphors when describing illness; b) reducing or consolidating appointments given the impact of North/South travel; and c) defining family based upon Inuit concepts of extended family (e.g., providing more options when legal consent is needed).

8.3 What can be done? Montreal care

Patients and health care providers offered potential solutions to the challenges discussed above. Patient/family recommendations tended to center around concerns about communication and accompaniment. Montreal health care providers addressed communication and structural challenges.

1. Recommendations from families

Family members who are geographically divided between the hospital in the South and community in the North need to consult each other concerning EOL care treatment options. Though the telephone is used, only two people speak at a time. They asked if videoconference technology could be offered to families to facilitate more effective communication.

Patients who had negative experiences with escorts suggested public education via FM radio in their communities in which health centers clearly outlined the requirements of the escorts. Their hope was that this would help ensure only the truly dedicated would decide to accompany patients.

2. *Montreal physician and nurse recommendations*

Recommendations by health care providers were motivated by a combination of humanitarian and financial concerns. For example, a physician, who had been working with Inuit patients in the South for many years, provided a long-term perspective concerning cuts in services for Inuit patients., In his opinion, cuts in services would actually cost the hospitals more money in the long run. Following is a list of suggested changes from Montreal-based physicians and nurses. It should be noted that some of these measures are already underway:

a. Reduce the number of patient appointments in Montreal by: a) engaging Northern physicians to develop follow-up care in tandem with Southern specialists; and b) screening patients more carefully before they are sent to Montreal, especially those whose appointments had been set up months in advance and whose symptoms may have changed. This may include reinstating the role of the medical coordinator in Montreal who had once screened for appointments.
b. Develop a standardized charting system between the Hudson and Ungava coast.
c. Increase involvement of pivot nurses at the MUHC who would be available to respond to questions by patients and family members, and result in less confusion and anxiety related to medical procedures.
d. Add a social worker to work with families at the MNQ to provide psychosocial support and to link families to resources in the community.
e. Provide communication resources and training to Montreal physicians who work regularly with Inuit patients and interpreters. This would potentially reduce confusion leading to family and patient distress or unwanted medical procedures.
f. Provide telecommunication options for patients and families maintaining contact with family members in the North.
g. Add an Inuit patient navigator such as is offered for Cree patients to introduce Inuit patients to the physical and cultural climate of the hospital.
h. Provide mandatory training for escorts hired by the health center to prepare escorts for perform their responsibilities and increase their pay to match the demands they face.

9. COMMUNICATION IN EOL CARE

When medical test results indicated that a patient was in the terminal phase of their illness, family members were often invited to meet with the physician and other health care workers involved (e.g., specialists, nurses, social workers, spiritual advisors, and interpreters) to discuss patient and family wishes concerning EOL care. When these meetings took place in Montreal, the people who had escorted the patient would be present. If the EOL care planning meeting took place in the North, extended family may have been included along with physicians, interpreters, nurses and social workers.

The decision about where the patient would be cared for depended on three primary factors: a) the physical condition of the patient and readiness for transfer, if desired; b) the availability of hospital beds in Montreal, Puvirnituq or Kuujjuaq; and c) the capacity for families to provide care in their homes. To determine family resources, nurses and/or social workers in the community conducted a home care assessment. This assessment identified the physical and psychological state of the patient, the suitability of the physical environment in the home, and the fit between care-provider capacities and patient needs. If the assessment results indicated the physical and relational environments were favourable to home-based care, nurses in the communities would meet with the families to prepare the home for the arrival of the patient.

9.1 Communication: Northern and Southern health care providers

In Northern contexts, nurses and administrative technicians in the health centers coordinated North-South care. They ensured that the necessary pre-travel procedures had been done, arranged for escorts, arranged transportation, and ensured that the necessary documentation accompanied the patient. Liaison nurses in the South: a) ensured that patients attended appointments, b) arranged for interpretation and transportation services in the hospital, c) coordinated flights back to the North, d) arranged for escorts, e) ensured that patient records were sent to the North, and, f) worked with coroners or morticians in the South in the case that the body needed to be transferred. The coordination of all these tasks was fraught with communication challenges.

9.1.1 Challenges in North/South communication

Based on the accounts provided by nurses and physicians, the challenges in communication between North and South were largely related to institutional practices. We met with several professionals who cared deeply about the work that they did and worked long hours to accomplish their tasks. Yet some felt dissatisfied with their job as the working conditions made their tasks difficult to accomplish and they felt that they could not provide the level of patient care that they wished to provide.

1. Technologies

Many nurses and physicians stated that scanning records and sending the information through computers has improved communication concerning patient care between Northern and Southern health care institutions. The challenges that remain were largely related to personnel shortages and turnover. Phone communication between physicians in the North and specialists in the South could be difficult to coordinate as each were pressed for time. As a physician noted, “*ça a l'air d'être le bordel dans le Sud. Ils ont tellement de monde à voir, c'est de plus en plus difficile. On attend longtemps sur la ligne.*”

If a patient has a problem, they come to us because they have no one else to go to… we listen, we give our opinion, but we don’t have the time! (Nurse)

2. *Workload and holistic patient care*

Several physicians and nurses in the North commented on their positive experience with nurses at the MNQ who were readily available and responsive in communication.

However, it was noted that the amount of phone exchanges had decreased as caseloads for the liaison nurses in the South had increased. This resulted in occasional breakdowns in communication such as prescriptions being communicated late, appointments being delayed, specialists in the South not receiving a patient's paperwork from the North, discharge instructions being delayed and patient transfer times between the South and North being extended. As one participant noted, when MNQ nurses had more time, "*c'était beaucoup plus agréable parce que t'avait une information… l'infirmière pouvait communiquer directement. Il y avait vraiment un lien*."

Eight nurses at the MNQ serve as liaisons between hospital centers, the CLSC in the South and their counterparts in the North. As this report was being written, three of these eight nurses were on sick leave and three of the remaining five nurses were agency nurses rotating through the MNQ who had not necessarily established a relationship with patients, families or community nurses. Some attributed this shortage of permanent staff to work-related stress, increase in caseloads for MNQ nurses and consequent reduction in quality of services that they felt they could offer, and reduced work satisfaction. Further, additional psychological/social support for patients and families were noted as a significant need for this population so that these needs would not fall on the nurses, already overloaded with tasks. One nurse estimated that only about 6 out of 10 patients were able to follow their program of care in Montreal and to keep each of their appointments. The remainder required additional interventions from the liaison nurses in order to follow through with their medical intervention. Depending on these psychological/relational needs, patient concerns could consume much of a nurse's day and prevent the completion of assigned tasks, such as the transmission of medical records to communities in a timely manner.

Patients and families also note the increased workload of nurses at the MNQ. One Inuit participant described with empathy how this was clearly evident as the MNQ nurses with whom she met for her consultation were behind on their list of tasks each day and attempting to balance the needs of several patients during their meeting with her. The two nurses who had been assigned to her community were absent for the several weeks while she was in Montreal, one on sick leave.

> Dans les départements qui offrent ce service d'infirmière pivot (Children, Psychiatry) nous voyons beaucoup plus rarement des problèmes de communication. À mon avis, plus de 50% du travail est ainsi simplifié et nous pouvons enfin nous concentrer sur les soins aux patients plutôt que sur les dédales administratifs. Le sentiment du travail bien fait est un élément majeur à la conservation de notre propre santé mentale. (Physician)

Nurses and physicians also indicated that North/South communication was impacted by the high turnover rates of medical staff in community contexts. When Northern nurses are rotating through a community or are themselves extremely busy, they may not always communicate the needed information to each other. Thus patients may be sent to the South without having prepared for their procedure in advance. A patient may be sent back North if accommodations in the hospital cannot be made. In situations where nurses had come to know their patients and communities, the follow-up care was more consistent.

Nurses in Northern communities also spoke of a lack of personnel and an increasing number of urgent cases seen in the clinic. As one nurse stated, "we often have the impression that we are doing crisis management. Nurses described their bearing the burden of this suffering, whether through aggressive reactions of patients and families or when patients required a listening ear during their medical appointments. As on nurse stated, "*It's difficult to do a rigorous follow-up. Everything around planning and paperwork is secondary*." In her experience, patient treatment had been negatively impacted when booking appointments for assessments and treatment in the South were delayed by the urgent care needs in the Northern clinic.

One nurse spoke of the multidisciplinary model of care in the South where physician, nurse, psychologist and social workers came together to provide care. She compared this to Northern communities where there was little, if any, psychological services for patients and families who are going through the dying process. In her words, this reflected "*a criminal lack of support for the family*."

3. *Awareness of Nunavik patient contexts*

A physician's lack of knowledge about Nunavik patient contexts can also contribute to a breakdown in communication. EOL directives are not always clear between the North and South. Nurses and physicians have noted that this may occur for three reasons: a) lack of clear communication by physicians who themselves may be uncomfortable with death; b) a family's difficulty in accepting the news of a terminal diagnosis; and c) confusion caused by the interpretation process between physician and patient. We heard stories of patients being sent down South for medical interventions while the Southern physicians had understood that the patient was in the North receiving terminal care. Confusion also ensued when physicians in the South changed medication regimes without specifying the reason in writing, and patients might not understand the changes. Consequently, directives can be unclear for northern-based nurses to explain or follow. A final communication breakdown centered around physician's lack of awareness concerning the geographic displacements that patients experience each time that they were sent to Montreal. They did not always realize that returning in three months for follow-up care is a time-consuming and costly challenge (e.g., for patients absence from work and family and for health centers flight fees), and poses physical and emotional difficulty for patients. In addition, Montreal-based physicians may not have been aware that urging patients to pursue aggressive and prolonged treatments in the South may not be what the patient desired. As one nurse indicated, patients did not always feel comfortable advocating for themselves in these instances, "to vocalize when enough is enough and choose to stay home."

4. *Timeliness*

At times physicians waited too long to have a conversation with families about EOL care. As a result, patients who would have preferred to die in the North became too sick to be transferred back home by plane. Reasons provided for that hesitation included a physician's lack of awareness of the complexity of transfer, their reticence to speak openly of death to their patients, their discomfort in working with interpreters or absence of having an interpreter, or their busy schedules. In one such case, nurses in the hospital and MNQ advocated for the patient and family, knowing their deep wish was that an elder would die in her home community. They were not sure whether the patient would survive the voyage; she did and was met by a large crowd at the airport.

9.1.2 Improving communication

Participants had several ideas about how communication could be improved. We have listed the most common responses here.

1. *Add liaison nurses to the MNQ and pivot nurses to departments in MUHC institutions*

Some MUHC departments serve large numbers of Nunavik patients. Pivot nurses would facilitate communications with patients, families and escorts while in Montreal. An increase in liaison nurses would improve the quality and satisfaction of communication in North/South care settings.

2. *Increase social work personnel at the MNQ*

The position of a full time social worker at the MNQ had been cut under former management. Participants have noted that current plans for the MNQ include a room to isolate patients, escorts or family members if alcohol use resulted in aggressive behaviour. However, some believed that without simultaneous psychosocial support, such as that which had been previously offered by a social worker, patients would be more quickly overwhelmed and rely on familiar coping mechanism.

3. *Provide a feedback forum for nurses*

Nurses on the frontline of care have indicated that they do not have adequate opportunities to discuss the realities that they face on the job. Several nurses spoke of how the daily crises that they address kept them from taking the initiative to advocate for themselves. They would welcome a forum where their suggestions could be received by administrators and policy-makers in both hospital and community municipal contexts. In their experience, when supervisors and administrators had solicited accounts of their experiences and responded with concrete action or provided clear reasons for non-action, this had been deeply appreciated.

4. *Increase Northern personnel: nurses and mental health workers*

All professionals with whom we spoke recognized the difficulties of recruitment and retention in Northern communities. Nevertheless, they ask that this increase in nursing staff remain an objective of the health administration.

5. *Provide geographic, historic, and linguistic contextual information to physicians*

It was noted that the National Collaborating Center for Aboriginal Health had also highlighted a lack of Indigenous cultural care resources in Quebec. In response, participants suggested the following: a) Pivot nurses or interpreters become actively engaged in communicating cultural factors in care for Inuit patients to physicians, b) Physicians receive a short written text outlining cultural considerations, c) Medical schools become active in providing training to physicians Canada’s Indigenous populations.

6. *Shared methods of record keeping between Hudson and Ungava coast*

Physicians and nurses noted that each coast had its own norms and systems of providing medical care. Nonetheless, they suggest that, when possible, record keeping should be streamlined.

7. *Arrange for teleconferences earlier in the patient process*

It was suggested that if families and health care providers communicated about EOL care needs before transfers back to the North had been confirmed, the family could have more time to begin preparing (emotionally and physically) for different EOL care possibilities. They could then become more actively included in decision-making, an important factor in their own grief process.

9.2 Communication within patients' families

Both Inuit and Qallunaat participants spoke of their experiences in communication with Inuit family members in the context of EOL care. One of the biggest challenges is whether to tell a patient about a terminal prognosis.

1. *To tell…*

Some patients and family members described having had open discussions with each other about cancer diagnosis, even when a terminal prognosis had been given. This openness was stated to be reflective of what several participants had described as an acceptance of death as being part of the rhythm of life. In light of this acceptance, most elders clearly stated their desire to die in their home communities. One participant described how her father's open discussion about his terminal diagnosis had been critical in helping the family to accept his death from cancer.

> I'm sick again. I want to be able to die at my house. I don't want to be stuck in the hospital, being fed by and trying to be kept (alive) by, equipment… I know I'm going, We're all going to die so I would like to die at my house. (Daughter's account of father's words)

In another case, an Inuk man whose wife had died of cancer had been engaged in his wife's care to the end. He described how their open communication with each other about her death had also helped him prepare. They had shared their life memories together before she died, including positive events and regrets. He also stated that his ability to accept his wife's death was rooted in a dream in which his wife told him that she would soon go far away.

2. *Or not to tell…*

Some family members expressed not wanting their loved ones to know of a cancer diagnosis or to hear the message from a doctor stating no more curing measures can be taken. As one family member

> If I have a cancer, don't tell me, I don't want to know. (Patient to nurse)

stated, "*you tell everything but not the 'certain word*,'" a reference to cancer. She described how Inuit are concerned that the individual would give up and die sooner than they would otherwise, stating: "*some people, if you tell them right away, their strength is sunk*." Anecdotal evidence provided by health care providers suggested that this may be in fact the case, especially for elders. As a physician explained, some have seen enough pain and suffering and want to die; others want to remain alive for their family. A nurse described how patients themselves had told the physician that they did not want to know if they had cancer.

This "not to tell" decision also came from patients themselves. Physicians and nurses described instances in which patients had not communicated their desire to discontinue treatment to their families. In other instances, they had not told family members that a physician had said that there was no more medical care that could be offered.

3. *Self-care*

Physicians and nurses commented on how their Inuit patients engaged in dialogue riddled with laughter and teasing in hospital settings, even during tough circumstances. This levity was interpreted by an experienced nurse as a coping mechanism as patients and families found strength through humour.

Some patients also exercised self-care in requesting interpreters to accompany them to appointments, even though they spoke conversational French or English. As one nurse explained, the presence of the interpreter in these cases served three functions: a) to have someone by their side when family and friends were in distant communities; b) to explain unknown anatomical or medical terms; and c) to have the interpreter ask questions that may be too intimidating to ask directly to a physician. One interpreter stated that many people were "*scared*" to ask questions on their own. Depending on their relationship and availability, interpreters at times also functioned as patient navigators and patient advocates.

Yes I speak English but I don't understand. (Patient to nurse)

9.3 Communication: Qallunaat physician and nurse and Inuit patient/family

The communication between Qallunaat and Inuit concerning EOL care diagnoses and EOL decision-making took place in the context of significant linguistic and cultural differences. Nonetheless, those who had successful moments in these dialogues drew on shared human values and forms of communication to establish trust and clarity in dialogue. Below we will discuss some of the communication challenges faced by Southern-based health care providers and the strategies that they used to address these.

9.3.1 Communication challenges of physicians/nurses

Conversations about EOL care were layered with nuances. Patients were asked to make choices about complex treatment options concerning care. As a physician explained:

> *C'est souvent pas clair pour les gens, c'est difficile à expliquer...toutes les nuances qu'on peut faire. .. On l'envoie-tu à Montréal ? On l'envoie-tu dans l'hôpital à Kuujjuaq ? Est-ce qu'on donne les traitements intraveineux ? Est-ce qu'on fait des rayons-X ? Est-ce qu'on donne juste des pilules par la bouche ?*

Participants explained that each of these questions described by a physician were themselves loaded with more questions: If a patient stays in Montreal, who will be the escort? What work and family responsibilities was each leaving behind? What are the side effects of intravenous treatments? How and where are they administered? Patients and physicians were often communicating this information through interpreters, information, which could often be emotionally loaded for patients and family members,.

It's understandable that people have a hard time recognizing that a reasonable choice is not being treated for something for which there exists a treatment. It's just the treatment might be worse than the disease. (Physician)

1. *Communication regarding EOL care options*

It could be difficult for physicians to explain to families that the most heroic life-saving efforts are not necessarily the best option for the patient. As one participant stated, patient impressions of health care may have been rooted in television shows in which dramatic efforts led to miraculous results.

> *"We see a lot of stuff on TV that you know we can fix anything today, right?... And so (from the parent's perspective) we put a child on a plane so that he can get here to get that help. And now, after all of this…what went wrong with that? And so usually in those cases when they get here, what we're doing is we're waiting for them to be here so that they can give us permission to allow the patient to die."*

A physician described a conversation with a family whose response to whether to hospitalize their grandfather was, "*of course we want him to live*." The physicians found it difficult to communicate what he felt was going to happen: "*I think he's going to die anyway and he'll suffer for 20 days in the ICU (intensive care unit) and then he'll die. Or he'll die here (at home) in dignity surrounded by family*." The physician was concerned that the directness of this message would be misunderstood or experienced as aggressive.

One physician explained that accepting that nothing more can be done can be difficult for families, and resistance to this can actually result in patients dying in the South. The physician elaborated:

> *We have to try to decide; is it worthwhile to go through the usual procedures and keep the patient in Montreal for long periods of time or should we just say that the quality*

> *of life, if not maybe length of life, might actually be better if we didn't do any of this (chemotherapy or radiation) and let them go back up North?.... It's hard to convince patients before they have the twelfth CT scan that yeah clinically speaking your disease is progressing, we don't need another x-ray to say that your disease is progressing …and you've already had four lines of chemotherapy. So the place to be is at home and the focus of care should be staying at home and being as comfortable as you can be at home, rather than going back down South, waiting in the transit (MNQ), being hospitalized, seeing umpteenth physicians that you haven't seen before, falling between the cracks and ending up with a strong possibility of dying down South.*

Inuit and Qallunaat alike described how focus on the present moment rather than the future have previously contributed to lack of EOL care planning for Nunavik patients and families. This tendency was identified as being rooted in historical practices in which the life and survival of families revolved around the hunting, gathering, and food preparation of the day. As one Inuk participant explained, care went into planning for the next season, but thinking further ahead was not perceived as useful in a nomadic culture. Physicians described that was at times interpreted as resistance or apathy toward advanced care planning or EOL dialogues. As noted by one health care professional, "*Habituellement la discussion de fin de vie se fait surtout quand ça commence à aller mal parce quand c'est trop longtemps d'avance les gens ne voient pas le besoin*."

People are not happy about the services, and they kind of want to vent and try to put down your professional qualities or competency.
(Nurse)

However, community members also described how families prepared for and accepted the emotional and physical realities of dying and how this was made easier if a patient accepted that the end of their life was near. A community member found that when this acceptance is present, families "*have been very openly candid about what is physically happening to their loved one as that loved one lives his/her last days*." In these instances, she described a grieving process that can begin while the family member is still alive.

How do we deal with the psychosocial part of their (patient's) feelings is something that we are not necessarily trained as nurses. They say that we can have different hats. But in reality, that does not mean that you are comfortable with all of those hats.
(Nurse)

2. *Communication and patient mistrust*

Patient mistrust could impact communication between nurse or physician and patient or family in community and Montreal settings. A nurse told us about a patient who, rather than speaking to her directly, went public (on the radio and Facebook) to vent frustration about the services that she felt she as nurse was doing her best to provide. Another nurse described a family's mistrust of her concerning a patient in critical condition with respiratory problems. The family had come to the hospital to visit on several occasions and there was a high likelihood that the patient would die. The patient was in pain and morphine was recommended. The family did not trust treatment recommendations. From the nurse's perspective, this lack of trust and ability to address this had consequences for the patient: "*The family refused the morphine. Some accused the hospital of fucking with her. We put the oxygen mask on. The family did not want this. Some felt like we did not care…I saw that person die. In the end, it was horrible… She could have died much more peacefully*." This accusation by family members of nurses not caring was not an uncommon experience for the nurses with whom we spoke.

3. *Communication and unresolved grief*

Nurses were on the frontlines in supporting patients and families in EOL care provision. As such, they were recipients of unresolved emotional suffering that may be triggered by the dying families. An Inuk community member described that when a family has experienced suicide or another kind of violent death, "*they have more bitterness and uneasiness with themselves…this can be toxic*." This "toxicity" could come out in anger expressed against health care providers.

In one instance, a nurse had been sent to a community to accompany a family and patient at end of life. The nurses in the CLSC were already occupied with their regular patients and urgent cases. This newcomer nurse became a verbal target of family hostility when their grief transformed in anger. As she had no relationship with the family and had not had the training to address family reactions, she herself was left feeling threatened and fearful and uncertain as to how to respond. Eventually, a community leader was asked to intervene and the situation became regulated. As her colleague reflected on what happened she concluded the following:

> *Les gens autour avec leur tristesse qui s'est transformée en rage… faut toujours trouver un coupable quelque part dans ce temps là quand on a de la peine."* In thinking of how to prevent this from happening again, she remarked, *" Peut-être ça va mieux, une équipe plus solide pour essayer de dire 'bon là vous êtes*

It must be kept in mind that expressing in Inuktitut is really not the same as expressing in English and that it can happen that one concept requiring 10 sentences to explain in English can also be accomplished in Inuktitut by using just 2 sentences. (Interpreter)

> *fâchés; vous avez de la peine. On comprend mais c'est la dame qui a demandé d'être ici nous on n'a pas forcé rien c'était son désir de voir sa communauté une dernière fois.*

4. *Nurse isolation and fatigue*

Nurses working in a community did not always have a strong collegial relationship with each other. Further, they may not have remained in a community long enough to feel at home there. In an unfamiliar culture and in a challenging work environment, nurses stated that fatigue and isolation could result in a lower degree of patience or empathy for patients and families. One nurse pointed out that their stress as nurses was even greater when they were carrying the additional workload of fellow employees who did not arrive for work that day.

5. *Uncertainty about interpreters*

Another difficulty in physician- patient communication concerns interpretation services. This in part was due to lack of understanding about linguistic differences between languages and lack of clarity concerning a specific interpreter's approach to patients. A physician put it this way:

> *I was invariably relying on translators. Even with our best translators, particularly in that context of death and dying, I was always very leery to what was actually being said… When you are telling the truth (about a terminal prognosis) through someone else, the way the truth is told is different.*

6. *Knowledge of patient, family and community*

The more knowledgeable one was of family and community, the more accurately they could evaluate and support a family's EOL care potential. A nurse provided the following illustration of the difference in home care planning when a nurse knew the families in a community:

> *This whole concept of quality of care, it's all about your relationship. I was talking to two nurses who remarked, "We've never been here before we don't really know the population; we've just arrived and umm, we'll look into it." So they don't know. As opposed to the nurse in (another) community who said "oh yeah I know this family, he's got three sons, but he's actually living with his grandson. I'm going to go to the house and see what the reality is in terms of where he's going back to and if I can actually make this happen (palliative home care) for this guy or not." She knows the patient, she knows the family and she knows that she's looking for the reality.*

It takes longer time to explain to patients, to, and to make sure that they really understand … to make sure that they have given consent; and that it's a "consentement libre et éclairé.." (Nurse)

Notably, most nurses and physicians in Northern communities had never visited the homes of the patients that they saw. Though due to the relationships they have with interpreters, they may have come to know about a family's relational and physical environment.

9.3.2 Communication strategies of physicians and nurse with patients and families

Physicians and nurses offered several strategies that they had drawn upon to improve communication with Nunavimmiut patients and families. We have listed them here.

1. *Time, time, take time*

Throughout our dialogues with nurses and physicians, the notion of "time" continued to surface. EOL conversations could not be hurried. Nurses and physicians routinely described taking up to two hours to meet with patients and family members and described how this time taken served to empower the family.

2. *Keep sentences short*

Interpreters indicate that the shorter the phrases they are given, the more able they are to communicate all of the information clearly to the patient.

3. *Explain why*

Some health care workers suggested that one way to address potential mistrust with patients and families is to explain why questions are being asked. This may avoid the patient feeling intruded upon.

The first thing you need to treat is to treat the person spiritually and mentally instead of with the Tylenol. (Nurse)

4. *Use visual illustrations*

Several Qallunaat and Inuit practitioners commented on the fact that the use of visual illustrations was most effective in communication about the body, disease and medical procedures.

5. *Shift the power dynamic when possible*

Some Qallunaat were conscious about what they saw as colonial practices and sought to acknowledge Inuit expertise in their interactions with patients and families about health. One nurse did this by inviting interpreters and families to share of their anatomical knowledge as Inuit hunters, another by making a point to validate the care that family members were already providing. One participant spoke of her personal journey as a Qallunaat, one in which she shifted from identifying with her assigned position of authority to that of engaging with family and community. She felt the insights gained in doing so had been invaluable.

6. *Welcome patient request for interpreters*

In some cases, an interpreter is desired for both language interpretation as well as to serve as cultural mediators and given emotional support.

7. *Model through example*

As Inuit have historically learned through observation and as didactic teaching can feel patronizing, many

I realized early on in my career that I was not the boss of anything. (Social worker) health care providers spoke of mentoring caregiving techniques with patients or families.

8. Invite family

A nurse related how she approached palliative care by prioritizing relationship building with families in the home. It could be intimidating to nurses to have family members in a room when providing treatment to patients and to step into the cultural world of the patient. Nevertheless, nurses perceived that it was meaningful for family members to be invited into direct caregiving, feeling that the patient, even if not completely conscious, sensed the family's presence.

9. Explain difficult news to the interpreter ahead of time

Some physicians empathized with how difficult it can be for an interpreter to communicate news that they may personally be affected by to patients. Giving some time to the interpreter to process what would be communicated ahead of time would potentially allow interpreters to tend to their own emotional reactions and thereby communicate more clearly to the patient.

10. Explain the rationale of statement to interpreter

When communicating something that could be received as painful or controversial, physicians and nurses found it helpful to explain the reason for their words to the interpreter. This allowed the interpreter to communicate the intent or spirit of the message, which was key to reaching a mutual understanding.

11. Use a telephone

Using a telephone to provide interpretation services was at times necessary. When no interpreter was available in person , it was suggested that Qallunaat keep dialogues short and have several meetings, if possible, rather than one extended discussion.

12. Let patients know that even doctors cannot know the time of death

Some physicians, recognizing the worldviews of the population with whom they worked, chose to contextualize their messages concerning terminal illness with the words that even doctors cannot accurately predict when patients would die. This appeared to address some of the misgivings of family members or patients when doctors spoke too confidently.

13. Look at the patient, not the interpreter when speaking

A natural tendency is to speak to the person who understands what is being communicated verbally, the interpreter. Nonetheless, the patient and family are receiving many non-verbal forms of communication which affect the development of trust with the physician or nurse. Thus, addressing the interpreter verbally while looking at the patient and family members is most effective in communication.

14. Invite input from interpreters

Interpreters discussed that it may be useful to have a feedback loop where they could teach physicians and nurses about how to communicate difficult messages, about cultural knowledge and offer guidance concerning community contextual factors.

15. Be clear concerning the potential impact of extraordinary life-sustaining treatment

Several physicians emphasized the importance of explicitly delineating what "heroic measures" could actually look like, such as that of cutting into a person's chest to revive a patient. They also recommended being clear about the potential consequences of these measures on long-term physical health and emotional wellbeing.

16. Let go and let it be

Southern health care providers noted that it was not always the patient who was having difficulty letting go; sometimes the physicians had difficulty accepting that more treatment was not serving the patient and family. This acceptance ran counter to their perceived mandate of saving lives and was therefore difficult to accept.

17. Recheck comprehension

Several physicians described a feedback system in which they asked questions to their patients at the end of family discussions to verify what the patient had heard and understood. They found it useful to be as specific and concrete as possible.

18. Learn some words in Inuktitut

Many nurses and physicians described using some words in Inuktitut with patients, such as basic greetings. They felt this sent a humanizing message to patients.

> Là, vous êtes fâchés; vous avez de la peine. On comprend mais… (Nurse)

19. Attend funerals when appropriate

Until now, funeral attendance has been open to the entire community. Attendance has been recognized as a gesture of support that has served to build relationships of trust in the community.

20. Speak up about aggression

Some nurses found it helpful to assert their own expectation of being respected in the face of aggression. Health administrators have asked mayors and municipal governments to intervene when patient or community member choices had a detrimental impact on nurse's ability to provide care.

> Compared to other professionals around them who are getting regular professional support, interpreters don't receive regular training or have the structure to professionalize.
> No one has wanted to step forward to advocate for this. (Interpreter)

21. Training regarding accompaniment of Nunavimmiut

Training needs are best explained in the words of a physician*: "Je pense que toute la partie soins de base médicale, le laboratoire, le contrôle de la douleur, donner des médicaments ça c'est fait correct mais tout l'accompagnement pis s'asseoir pis comment tu te sens, comment tu vis ça, pis y-a-t-il des choses qu'on peut améliorer. Ça c'est un*

gros zéro,"
Developing psychosocial support for families could serve to enhance the communication process concerning EOL care as emotional barriers to communication will be addressed.

22. Educate communities about medical procedures through public health announcements
Participants suggested that education concerning EOL care could be done through Facebook, Taqramiut Nipingat Radio (broadcasting in all 14 communities), or through video or brochures (emphasizing illustrations) in health centers.

10. THE UNIQUE ROLE OF INTERPRETERS IN COMMUNITY CONTEXTS

Interpreters played a unique role in EOL care conversations among patients, families, nurses and physicians. As interpreters shared their experiences, it became apparent that the pressures they experience and challenges they face were significant. In light of this, interpreters were unanimous in stating that regular training and support was needed to fulfill their responsibilities.

Cultural and historic considerations for interpreters

Participants described how in Inuit tradition and history, certain positions were reserved for those who had either attained a certain level of status or had experience in clans or communities. Historically, certain individuals were assigned the role of the messenger (*Tutsalukkaijiit*). Their role was to communicate the painful news of death or loss to the families when someone had died. People assigned this task had a degree of life experience and were often respected in the community.

Likewise traditional health care workers, those who tended to birth, death, or illness in communities, were persons, usually women, who had been mentored by the previous generation. Their ability to respond to the complex physical and emotional needs of families depended on what they had learned through observing and assisting the more knowledgeable mentor.

Interpreters were located at a unique juncture between historical and contemporary models of care. Often interpreters were hired because they spoke the language, not because they knew how to interpret. No prerequisite training was required or offered. As they acquired the competency to address the challenges of their job, they relied on others who had experience interpreting. Interpreters were working in a health context where roles were divided according to supervisor expectations, and where professional recognition was weighed by formal education rather than work experience.

> I have to defend the nurse, defend the client. Sometimes were are in the middle, its hard…The patient has to respect the nurse, the nurse has to respect the patient, the interpreter has to respect both. (Interpreter)

In Nunavik's inpatient centers (e.g., hospitals and the elder's home), the interpreters were the PAB's (préposés aux bénéficiaires) whose tasks include cleaning, sterilizing, and the feeding and washing of patients. As they were bilingual, these PAB's were also given the task of interpretation. In the community CLSCs, interpreters were hired in the larger context of their role as Northern Attendants. They performed a variety of tasks that included patient intakes and vital signs, sterilization of equipment, cleaning, responding to phone calls, setting up appointments, and charting. Notably, the Northern Attendants identified themselves as interpreters, not as Northern Attendants, perhaps indicating the weight that they placed on this aspect of their position. Though some Northern Attendants we spoke with had been provided sporadic interpreter training throughout the years, they were unanimous in stating that linguistic resources and training in communication skills were critical to their ability to fulfill their role adequately.

10.1 Challenges in interpretation

The interpreters with whom we spoke described two major challenges: a) feeling caught between patient wishes and physicians and nurses expectations; and b) communicating bad news to patients and families, especially if it was about people they knew personally.

We know people from here. I felt heartbroken. I almost cried. (Interpreter re: translating difficult news)

10.1.1 Conflicts

Interpreters were in the unique position of representing patient to physician and nurse and physician and nurse back to patient. This could be a depersonalizing experience if they felt they themselves were not being recognized as individuals with their own emotions, ideas and opinions. Interpreters described their perceptions of being disrespected as persons in four specific contexts: a) when asked to perform tasks for which they had not been adequately prepared; b) when pressured to accomplish more than they had time to do, including moving too quickly from one emotionally loaded conversation to another; c) when they were the recipient of nurse/physician frustration, for example, interpreters felt blamed at times when patients did not arrive for appointments; and d) when patients took frustrations out on them. At times, this frustration was directed toward them as interpreters; other times this was directed toward a physician or nurse. In the latter case, the interpreter felt pressured by the patient to align with the patient. Interpreters also spoke of their struggle to decide how much of these emotional reactions to translate between parties.

10.1.2 Close relations and bad news

When I don't understand the body parts, its kind of hard for me… the big words they have. (Interpreter)

When a medical prognosis was poor, interpreting for family members, friends or colleagues became a difficult experience. Because of their linguistic abilities, it was not unusual for the interpreters to be requested to be the hospital escort and interpreter for family members or friends. For routine medical procedures, this was not problematic. However, when asked to communicate a terminal prognosis, the interpreters could experience their own personal grief reactions. With family members, interpreters described wondering how much to disclose to the patient about their diagnosis. This decision appeared to be based on what they were able and ready to accept themselves and on selecting the information that they felt would communicate the most hope to the patient.

10.1.3 Linguistic challenges

The most common language used between interpreter and physician and nurse is English. However, the first language for interpreters is Inuktitut and for most nurses and physicians, French. This posed a unique set of challenges for discussions about EOL care. Explaining a disease trajectory or a discussion of EOL care choices filled with complexity and subtle nuances are difficult to communicate under any circumstances, more so when attempting to do so in a second language.

There was no uniformity among Nunavik communities in terms of linguistic resources available to interpreters. Some communities had English-French dictionaries, some had USB keys with access to diagrams and terminology, and some had basic books with diagrams labelled in English or French while others had a three-dimensional model of the body to bring into the consultation room. Though several interpreters had identified that visual illustrations were more effective for communication of information than through written texts alone, there was no visual glossary or text which illustrated anatomy or common disease trajectories in all languages (French, English and the Hudson coast and Ungava coast Inuktitut dialects). Furthermore, not all interpreters were literate in all languages.

Many interpreters described having learned anatomy from school and from hunting. This served them well. A physician remarked on the extent of this knowledge in the Inuit community in which she was located; "*J'ai constaté que les Inuit en general ont une excellente comprehension de leur anatomie. Ils font souvent référence à l'anatomie des animaux qu'ils chassent et semblent avoir développés une compréhension assez juste de leur corps*." In speaking of the interpreters she continued, " *Ils semblent avoir un 6e sens pour savoir quand quelqu'un ne va pas bien. De nombreuses fois ce sont les interprètes qui ont identifié la maladie avant que moi, comme médecin, j'en fasse le diagnostic*." Even with this extensive knowledge, the interpreters were consistent in identifying their need for more translation materials concerning complex procedures and nuanced dialogues. They described how significant errors could be made without this.

10.1.4 Confidentiality

One challenge that interpreters face is they often know the patients on a personal level, whether as family members, friends or community acquaintances. Cultural communication norms in communities often included sharing information about one's health

I thought I was going to be ok
but when we entered the house
I got very sensitive so I was
having a hard time to translate.
(Interpreter)

with each other. Patients and family members may have gone on the radio to share their illness. Consequently some interpreters described how professional expectations concerning patient confidentiality were contrary to community norms in communication.

Further, some had difficulty with confidentiality because of the emotional challenges they faced when translating conversations such as news of an accident or suicide, a terminal prognosis, or a family discussion concerning palliative care options. In these moments, they received the direct and raw reaction of the patients and families which they then had to translate to the physicians and nurses. Interpreters described how this created a need to speak with someone as a way of coping, an option that they did not always have without breaking someone's confidentiality. As one interpreter remarked:

> *It can be a very lonely experience for some interpreters in Nunavik. Sometimes they end up ostracized by people who let their emotions take over and lash out at the nearest and easiest target, the interpreter. Fortunately, there is more awareness of the importance of remembering that the interpreter is only filling the vital role for communications of these grave situations in EOL care.*

10.1.5 Staff turnover

There is a high turnover of nurses and physicians in Nunavik communities. A long-term relationship between interpreter and nurse/physician was regarded by all as a precious commodity, one that contributed to job satisfaction on both sides. These teams appeared to have developed a mutual trust that came with time, knowledge of each other's strengths and weaknesses, and an ability to adjust accordingly. On the other hand, newly formed teams were more likely to experience misunderstandings and the consequences of this. One example provided by an interpreter was that of a newly arrived homecare nurse who came to assist the local PLA nurse with a palliative care patient. This new nurse insisted that the PLA interpreter accompany her on the home visit instead of letting the interpreter leave work to support a family attending a patient's death.

10.1.6 Reliability of colleagues

Interpreters were also impacted by the reliability, trust and the continuity that they experienced with their own colleagues. As interpreters live in small communities, personal conflicts outside of work affected the interpreters job and vice versa. Some interpreters had significant incidences of absenteeism, leaving those who were remaining to assume extra responsibilities. One interpreter called these days with lack of personnel as, "*we are going crazy over here days*."

We have feelings too. We are not robots!" Sometimes we want to say that… One day we will. (Interpreters)

10.2 Strategies used by interpreters to address job stress

On a personal level, interpreters drew on several strategies to address job-related stressors. For many, their religious faith served as a source of strength. Others took time to continue with land-based traditions such as making time for hunting, berry picking, camping and fishing. Others spoke of relying on nurses and fellow interpreters to speak to when they were stressed.

Regarding linguistic and communication challenges, the interpreters with whom we spoke described a variety of strategies. As the examples below illustrate, some followed their own intuitive leanings in decisions concerning patient communication.

10.2.1 Strategies re: EOL communication

As mentioned, interpreters were breaching cultural and religious norms when requested to communicate a terminal prognosis to a patient and family. Though interpreters differed widely on how to respond, some explained their conflict by the following: a) only designated/respected persons in a community transmit news related to death; b) it is ok to not speak directly of death even if this information is known, trusting that the patient will sense when it is their time to pass on; and c) only God knows when it is time to go; humans cannot predict this.

Interpreters struggled to address the incongruence between community norms of communication and the physician who asked them to translate something like, "*so and so has 3-6 months to live*." Interpreters described choosing different strategies to address this incongruence depending on the following factors: a) their personal relationship with the patient/family or physician and nurse; b) their level of confidence and/or experience; c) what they imagined themselves wanting in the patient's place; d) the maturity of the family; e) the location of the patient on their illness trajectory; and f) a patient or family's stated preference. Some patients preferred a direct message; others preferred to not know their terminal prognosis.

Interpreters adapted one or a combination of the following roles

1. *Literal translator:*

Some interpreters adopted a strategy of separating personal life from professional role. These interpreters considered themselves more as translators and less as cultural brokers. They saw their role as neutral, one in which they communicated every word and response as close to their understanding of what the physician and nurse and patient/family had expressed. One interpreter gave the following example of what she said in providing a literal translation of a doctor's prognosis:

We will make you more comfortable so that you will not suffer… the doctors are trying to help. (Interpreter)

> *They asked me to tell you; it's going to be hard to tell you, the doctors don't know everything…. He doesn't even know the date that you will be dying; he asked me to tell you that even in three months and before that you might pass away… he knows very well with the body parts, he found something, a cancer.*

2. *Mediator and advocate*

Other interpreters saw their role as one of mediator and advocate. Recognizing that cultural differences existed between the doctors/nurses from the South and the Inuit patients whose voice they represented, they mediated between the two. They attempted to reassure patients regarding the intentions of physicians.

This group was more likely to advocate for patients, asking questions that they thought patients were afraid to ask and seeking clarification when they were not sure if the patient fully understood what was being communicated. They were more likely to make decisions concerning the parts of a dialogue that they perceived to be beneficial and which they considered as harmful and made interpretation choices accordingly. For example, one interpreter emphasized that she always asked patients returning from the South, "*Were you explained as to what your sickness is? Do you know what the diagnosis is? Do you know what the medication is for*?" If they were uncertain, she would track down this information. She added that she would never interpret that there is no cure as "*only God knows this*." However, if it was clear by their symptoms they were going to die, she explained to patients: "*We will make you more comfortable so that you will not suffer… the doctors are trying to help… you can lengthen the time, you can still have a liveable functional life even though you are given that time*."

Several interpreters chose to not communicate the duration of time remaining that a physician had given a patient, concerned that this would harm the patient who would lose the will to live and die sooner than necessary. One interpreter had been mentored to never interpret a message word for word and did not use the "cancer" word as she believed people see a coffin when they heard this word. In its place, she said things like, "*they have found something….you will live… you're going to have to be sent down for further tests and that there is treatment to be done…. even though they say you have three months to live, they are going by what they know, but they can always be wrong.*" She explained *"We never say its bad. I just say, 'its life like this*.'"

Even though they say you have three months to live, they are going by what they know, but they can always be wrong. (Interpreter)

It should be noted that these choices to not directly communicate cancer or a terminal diagnosis were contextualized in the belief that internally, Inuit know when they are ill, when that illness becomes terminal, and that they will come to accept their impending death when they are ready. They did not need to be told.

I have to add some words that even they (doctors) didn't say. (Interpreter)

3. *Cultural broker*

Interpreters also functioned as cultural brokers, at times explaining the medical culture of the doctors and nurses to patients, and at times representing the Inuit cultural perspective to doctors and nurses. One interpreter described how she would encourage her patients to trust the physicians while simultaneously toning down the directness of their message. She explained:

> *At first I always try to say, 'The doctors, they know everything. They know very well with the body.' It's hard to say it; I have to add some words that even they didn't say. I have to add sometimes, not to let them (patient) gets shocked, cause the way they (doctors) are just saying it (terminal diagnosis). Us, we are different...For Inuit people, we are more calm.*

…because when you know the people, you know how they can take good news and bad news, or their will to live. (Interpreter)

The interpreter went on to explain how she would explain a terminal diagnosis more tentatively adding the word 'maybe.' This manner of communication is congruent with how several interpreters spoke during the interview for this report, making statements with inflections at the end as though it were a question, stating 'maybe' before responding to something that they were actually definitive about.

Another participant described how many interpreters are afraid to say something to physicians when they disagree with a manner in which a message is being communicated. She herself had sat down with physicians and nurses who were speaking about cancer and EOL and told them, "*When you ask me to interpret for you, don't say this in such a way, because right now some people, they know enough English to understand.*" She then explained why, "*I'm telling the doctors because it's to protect not just me but the patient… Because when you know the people, you know how they can take good news and bad news, or their will to live. You kind of have that idea of how people are when you live with them."*

She emphasized to physicians that in the first meeting with the patient, it was especially important to not use the word cancer.

4. *Avoidance*

In cases in which interpreters were dealing with the imminent death of close friends and family members, some spoke openly of adapting a strategy of avoiding the dialogue about the terminal diagnosis. In one instance this occurred even when the interpreter was asked by the patient to communicate the exact message of the physician.

10.2.2 Linguistic strategies

We are a forgotten breed. We're always needed but do not have the resources to do our job. (Interpreter)

When confronted with terms, expressions, or procedures that they were unfamiliar with, the capacity of an interpreter to seek outside resources depended first on their awareness that they did not understand what had been communicated and secondly on their capacity to ask for or seek clarification and assistance. They described diverse strategies in dealing with their predicament such as: a) asking the nurse/physician for clarification; b) waiting to interpret until being certain that everything that was stated is understood; c) consulting with former and current interpreters; d) asking their own parents for translation of terms; e) calling community physicians by phone for advice; and f) drawing illustrations to portray what they could not explain through words.

10.3 Training needs

A few northern interpreters had received training in areas such as administration, medical procedures and anatomy, time management, communication and active listening. However, these trainings appeared to have been few and far between when they had occurred.

10.3.1 Linguistic

Interpreters were unanimous in describing that they felt inadequately trained to fulfill their responsibilities, asking for resources and regular training in translation concerning anatomy and medical procedures. In terms of anatomy and medical procedures, interpreters indicated that it would be useful to have visual resources, some asking for a book with drawings not unlike, "*The Terminology on Human Anatomy*," a document emerging from collaboration between Nunavut's departments of Culture and Heritage and Department of Health. This book would have to be translated for both the Hudson and Ungava coast dialects. Some preferred a three-dimensional model of the body with removable parts as this allowed them to explain procedures and the interrelation between body systems more easily. One interpreter described how helpful it was for her to compare illustrations of what an organ had looked like when it was diseased versus when it was healthy. She requested that physicians provide these explanations and images so that she can more clearly communicate the message from physician to patient.

10.3.2 Communication

Interpreters also requested training in areas of communication. Communication regarding diagnosis and prognosis, treatment options, and EOL care decisions were emotionally loaded for all parties. As a bridge between patient/family and physician and nurse, they were not always certain of how to best represent the other.

1. *Addressing emotional responses of patients and families*

As with nurses, the interpreters spoke of finding themselves needing to respond to the emotional reactions of clients and families. They were often the only ones present to process emotionally loaded conversations. Interpreters would receive the grief, denial or anger reactions of patients and family members and often felt obligated to respond in a humane and compassionate though firm manner. It was not unusual for patients or families to say

> The patients always complain to us, and the doctors and nurses, they complain to us too. We are all in the middle. And we can't say anything. "Stop complaining!" We can't say that because we are working. (Interpreter)

things to interpreters that they did not want translated but rather, to have their sentiments affirmed by the interpreter. Interpreters had no training in how to respond to these emotions or reactions, however, and several with whom we spoke felt this lack of training significantly. Their difficulties in knowing how to respond were heightened by the fact that many themselves had their own unresolved histories of suffering and residual emotional areas of pain that were triggered in their work.

2. Dual roles and addressing conflict

When interpreters described feeling caught in the conflicts between nurses or physicians and patients or families they sometimes used hand gestures to portray the image of feeling pulled or torn between loyalties to community and to colleagues. Several interpreters asked for training in knowing how to respond to this conflict loaded communication. On the one hand, the interpreters were part of the community whom they were representing. From what they described, it was not unusual for patients to assume that they would share the same feelings of anger or indignation when this was felt toward nurses or physicians. One nurse provided further insight into this dilemma describing how patients and families are not sworn to the same confidentiality rules as the interpreters. This places interpreters in community contexts in a vulnerable position as they are not permitted to defend themselves should they be the target of criticism for not taking sides in a conflict.

On the other hand, interpreters described having experienced nurses and physicians as human beings with their own emotions and needs, not only as health care providers performing a task. This perspective had deepened the awareness of interpreters, making it difficult to know how to respond when patient statements reflected hostility and misunderstanding of their colleagues from the South. Likewise, interpreters felt caught if critical statements were directed from physicians or nurses toward community members, usually in the absence of a patient.

3. Knowing how to decide what to say and what not to say

Interpreters stated it would be "very helpful" to have training in knowing how to proceed when their values contradicted that of the physician or nurse. Presently, when caught in these value tensions they drew on the advice of others in the community, medical profession or their own intuitions. As they explained their choice, it was clear that they were engaging in a logical decision-making process. Older interpreters felt confident in their choices regarding communication when value conflicts were present; younger interpreters expressed more uncertainty in their decision-making process. However, when asked if it would be helpful to have a decision-making model through which to make these ethical decisions, interpreters with diverse levels of experience responded affirmatively.

> When I tried interpreting for the sick one; "You "Why did you tell him, why did you tell him he's dying soon, why did you have to say that?" This gave me a shock. (Interpreter)

11. CONSIDERATIONS CONCERNING BILL 52/LAW 2

No one with whom we spoke in the Inuit communities was familiar with Quebec's Bill 52 passed in June 2014, nor Law 2 which was to be implement in November of 2015.[2] During the course of this study, in February 2015,, the Supreme Court of Canada ruled in *Carter vs. Canada* to decriminalize physician-assisted dying. However, neither the Inuit newspaper nor the Nunatsiaq Newsreported on the federal decision or provincial debates. While Nunavik participants we spoke with had heard media networks such as the CBC refer to "doctor-assisted suicide," and community members mentioned seeing television documentaries from other countries concerning "euthanasia" and "assisted suicide," none drew on local issues as a point of reference for our conversation. Physicians and nurses in the North were not engaged in a dialogue concerning the application of this eventual provincial law into Northern communities and seemed to be considering this for the first time in the course of our interviews. In contrast, health care providers in the South with whom we spoke had been engaged in dialogue and debate concerning Bill 52 for several months. The following discussion will shed some light on the complexities that need to be addressed when implementing Law 2 in Nunavik communities.

11.1 Contextual factors for Bill 52/Law 2 in Nunavik

As indicated in the introduction, the passage of Law 2 in Quebec has unique implications for Nunavik, this due to its unique spiritual, historical, cultural and social context. Spiritually, most Inuit in Nunavik have an affiliation with the Anglican Church. Many believe that, just as God gives life, it is only God who knows when life will come to an end. Any interference in the process of dying or attempting to predict when someone will die can be perceived as human intrusion into the divine realm. Community members stated that previously, church leaders were strong in their condemnation of those who committed suicide. Burial and mourning practices were altered to erase the memory of the person who took their life with burials taking place as soon as possible and the usual three-day period for mourning circumvented. Even conversations about this person were considered taboo in certain communities. One participant stated that her church had buried those who had committed suicide in a vertical position in the ground rather than horizontally. Over the past 20 years, the church has taken a more compassionate approach, recognizing the suffering of families that have lost members to suicide and welcoming traditional mourning practices.

> In many instances I would find it a terrifying prospect to have that conversation, feeling so unsure about the quality of communication. (Physician)

A 2015 Health Canada report states that the Inuit youth in Canada have the highest rates of suicide in the country (11 times the national average) and are among the highest rates in the world. Suicide is a serious concern for families and communities in Nunavik, at personal, social, political and cultural levels. Though Quebec has chosen language in Law 2 that does not mention "assisted suicide" or "euthanasia," these are terms used in popular discourse in Nunavik, this based on debates and documentaries in mainstream television. Consequently, discussion about

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[2] On December 1, 2015 – nine days before Law 2 was to take effect - the Quebec Superior Court ruled that Law 2 is incompatible with the federal Criminal Code. The Supreme Court of Canada has given the federal government until Feb 2016 to amend the Criminal Code to allow for assisted-suicide.

palliative sedation and medical aid in dying – the terms used in Law 2 - raise associations to "suicide" in many people's minds. The strong and at times overwhelming emotional reaction makes it impossible for some to discuss medical aid in dying in any form.

A few Inuit community members spoke of hearing stories of elderly or ill family members that had either been left behind by their families when they weakened or who chose to remain behind when they could no longer keep moving and the family needed to continue walking for its own survival purposes. These participants indicated, however, that this had never been widely practiced. Most participants spoke of traditions in which the elders and infirm were cared for by families and communities with stories of voluntary or involuntary abandonment something that a few of our participants had heard spoken about by parents or grandparents but appeared to be a taboo practice. Inuit cultural values emphasize mutual care of the weak and infirm in family community contexts and several participants described examples of families that went to great lengths to provide this.

11.2 Views on palliative sedation and medical aid in dying

Bill 52 was accepted in June 2014 by the Quebec National Assembly as "An act respecting end of life care." A year later, Bill 52 became Law 2. The Act provides the following definitions which were drawn on to guide this inquiry:

Palliative care is defined in the act as "the total and active care delivered by an interdisciplinary team to patients suffering from a disease with reserved prognosis, in order to relieve their suffering, without delaying or hastening death, maintain the best quality of life possible and provide them and their close relations the support that they need."
Continuous palliative sedation refers to care that is offered as part of palliative care and consists in administering medications or substances to a patient at end of life to relieve their suffering by rendering them unconscious without interruption until death ensues.
Medical aid in dying refers to care consisting in the administering by a physician of medications or substances to a patient at end of life, at the patient's request, in order to relieve their suffering by hastening death.
It should be noted that the law also includes its own definition of "EOL care" by which it refers only to medical aid in dying or palliative care. For the purposes of our study, we have defined end-of life-care much more broadly to include all care provided to persons at the end of their lives.

> There is a slippery slope of Bill 52 as a way of saving the government money. (Physician)

11.2.1 Medical community perspectives on the implementation of Law 2

The questions that we asked both Inuit and Qallunaat participants were based on Bill 52, the jurisdiction of which was the entire province of Quebec (not only Nunavik). Specifically, we asked participants about whether someone would receive medical aid in dying if the following conditions (as per the Bill) were met: a) *They were 18 years or over, and capable of giving consent to care; b) suffered from an advanced state of irreversible decline in capability; and c) suffered from constant and unbearable physical or psychological pain which could not be* *relieved in a manner the person deemed tolerable.* We also asked families about their experiences of nurses and physicians administering medication to patients at the end of life and what their understanding of this had been.

Physicians and nurses with varying levels of experience in Nunavik expressed serious concerns about broaching a discussion of medical aid in dying or palliative sedation with patients and families with whom they worked. They were unanimous in their belief that the religious orientation of the Inuit would prevent patients from ever requesting either option. As one nurse emphasized when asked if patients ever ask for aid in dying in the North, "People are very pro-life, very pro-life, very very very pro-life." Reflecting on this, one participant countered this perception concerning a pro-life stance that it was a common mistake made by nurses and doctors. While pro-life refers to a religious attitude concerning a specific debate in society (i.e., abortion), Inuit are not part of these debates. There is no public debate and named position on these issues in Nunavik, even though people have different opinions.

Physicians attributed patient and family trust/mistrust and linguistic barriers as determinants in how conversations concerning EOL care took place. Many recounted stories of having been perceived as devaluing the life of the Inuit when EOL choices needed to be made from a medical perspective. They perceived that family perceptions concerning palliative sedation, withdrawal of care and euthanasia would add to controversy concerning Bill 52/Law 2. This would likely alienate medical caregivers from communities even further. A physician gave an example of a family to whom she recommended disconnection of an elderly person from a ventilator. It had been clear to her that he would not survive and, from her perspective, this would allow him to die with dignity in a manner that remaining attached to machines would not. In spite of her efforts, she felt that the conversation ended badly as the family mistrusted her assessment and intentions and believed that she wanted to 'pull the plug,' which in their mind appeared to equate to euthanasia, rather than done to save his life.

A nurse raised the complexity of negotiating EOL decisions with families whose decision makers (spouse, children or grandchildren) did not trust each other. While part of the family may support a patients wish to receive pain medication at the end of life, others may attribute harmful intentions to these members and therefore block this attempt. One nurse described working with a patient who had two sets of children from two different partners. The first set of children supported the administration of morphine to ease his pain; the second set did not. According to this nurse, the man ended up dying in a considerable amount of pain. She described how another patient expressed hesitation in accepting morphine as his wife and

> What they (family) came away with… was the sense that I was a disrespectful white doctor who wanted to 'pull the plug' on their family member rather than providing him with the best possible care, because there's a lot of mistrust there. (Physician)

children would potentially accuse him of what he labelled as an act of “euthanasia,” a direct contradiction to family values concerning life and death.

A concern was raised by a physician that medical aid in dying and palliative sedation were themselves a slippery slope in a context of Nunavik. In the North, current and historical colonial practices had already threatened the survival of Inuit individuals and communities and health care costs were already significantly heightened. Trusting the government to protect, value and respect the inherent dignity of Inuit lives appeared to be naïve in this physician’s opinion who advised that engaging communities in this dialogue would require utmost clarity and caution. This was not a discussion to broach without extensive preparation.

Accurate pain assessment creates an additional complication in providing palliative care. Nurses and physicians have indicated that Inuit patients may have difficulty in admitting pain to the nurse or physician, in which case family members and interpreters are key in providing this information.

Several clinicians highlighted the importance of having a full-time Montreal pivot nurse who would work exclusively with Nunavik cancer and palliative patients. As misinterpretation and confusion was already a concern, this nurse would be critical in the interpretation of medical facts and assist families in the nuanced decisions that needed to be made. The cultural and linguistic differences make this a hazardous territory to navigate. A pivot nurse would be able to establish continuity and trust when nurses and physicians changed roles.

On a practical level, lack of continuity of care and individual physician values were also raised as a concern in the administration of Law 2. Certain communities have only one physician assigned to them, a physician who may come biweekly or monthly. This physician may be the one having the conversation with families concerning palliative sedation or medical aid in dying but may be away when the actual intervention is expected to occur. The rotating physician may not have the relationship of trust so critical in these moments to families or communities. Further, physicians or nurses in small communities may object to implementing Law 2. In these cases, arrangements would need to be made to accommodate family and patient wishes.

Physicians stated that palliative sedation was already being practiced in Nunavik. For example, morphine was prescribed to patients to ease their suffering in their final days, at times rendering the patient unconscious. As the following accounts by Inuit participants indicate, these practices were controversial in family and community contexts.

> My father says that it was the morphine that killed his uncle. (Family member)

11.2.2 Inuit community on Law 2 and the Supreme Court ruling

Once again, it is important to highlight the critical role that interpreters have in providing EOL care. Not only are they the only professional translation services available in these instances, but some are perceived as a more trustworthy representation of the medical profession than the doctors or nurses themselves. As a result, contrary to what physicians and nurses had recounted, interpreters recounted instances in which patients had requested aid in dying. Having seen examples of assisted dying on TV, they asked for this for themselves. Though infrequent, this request had been made not when the physical suffering had been too great, but either a) when patients knew their lives were ending and did not want to be a burden on their families during the dying process; or b) when a patient had alienated himself from his community due to acts of violence and had no one to care for him. For the interpreters, these were not arguments for the implementation of Law 2 but rather meant that adequate support measures must be put into place so that these individuals receive the care that they needed. The findings in this section are based on conversation with family and community members living in Nunavik who had been invited to offer their thoughts concerning perceptions of death and choices concerning how people choose to die.

> The patient is not going to get better and better. He is just going to get worse and worse. If he won't wake up anymore, it means that he is in strong pain. If it's starting to be like this, will you want for him to have an injection so that he will die faster? If you refuse, it's ok. (Interpreter recollection of physician's statement to family)

Many Nunavimmiut describe predictable death (as opposed to accidental and traumatic deaths) as being part of the cycle of life and therefore accepted as such. As one person stated, "death is one's destiny." Relatedly, some had been taught that they could alter their destiny through behaviours, such as listening to elders, scriptures and by being a good person. Likewise, destructive choices, such as destroying Inuksuks, could potentially shorten one's life. In this light, once a person believes that it is their time, they may die before measures can be taken to arrange for home care or to develop a palliative care protocol for the patient. When asked whether patients *would like* to have the option of palliative sedation or medical aid in dying, Nunavimmiut cited personal or anecdotal examples of when someone had been given a medication that helped them die more quickly. Some spoke of patients who were offered morphine to ease pain at the end of their lives and others of family members who made this choice for their loved ones when they were not capable to communicate for themselves. Though not legally permitted, a community member spoke of her perception that medical aid in dying would be requested by families whose members were no longer conscious. Other community members stated medications other than morphine that were prescribed to ease suffering and shortened a patient's life span, though no one could not recall the name of the medication.

> People don't like people to suicide. (Community member's response to medical aid in dying)

Reactions to these interventions varied from beliefs that Inuit peoples had been killed by physicians, to moral disagreement in interfering with life, to the belief that people should have the option to have medical aid in dying if suffering is great. A nurse spoke of the "myth of morphine": confusion that family members have concerning morphine, its potential to shorten life and their perception that this is why it is prescribed. She recalled overhearing an Inuit family member stating: "*The fucking morphine is just killing them; it's not doing no good. It's just to let them die. They (doctors, nurses) want them to die faster*."
Those who had accepted the administration of medications at the end of life for family members were at times conflicted by this ethical decision and confused about what they had given consent to. Had they just interfered with the length of life of their loved one? One woman described her own suffering when faced with a choice to administer morphine to ease the pain of a dying family member, an act which she perceived as potentially hastening death and thus to interfere with God's will. She consented as she did not want her loved one to suffer in pain.

Regarding the question of whether people *should have the right* to palliative sedation or medical aid in dying, Nunavimmiut were diverse in their response. Many stated that the timing of death is up to God and should not be interfered with, citing examples of people who had been given a short time to live and who ended up living many years longer than expected.

Some believed that Inuit communities would like to have this option when suffering is significant. One individual recalled seeing a lung cancer patient in his final days. Her memory of the patient hooked to an oxygen tank that did not provide him sufficient air, gasping to breathe, and consequently panicking had deeply impacted her. This memory illustrated why she thought that local families would accept knowing their options concerning the recent Supreme Court decision opening the door to physician-assisted suicide.

The eyes of one interpreter filled with tears when asked about Bill 52. She stated that medical aid in dying already takes place in Nunavik. She stated that she had, on numerous occasions, seen Inuit patients offered assistance to die by their doctors at the end of their life. She said that they were administered an injection, and it hurt her to see this. For her, life was precious from the beginning until the end. When asked if she knew what medication they were given, she responded "no."

11.3 What can be done? Law 2

The findings mentioned above indicate that:

1) Community members are forming perceptions of medical aid in dying and of palliative sedation based on four primary factors: a) their experience of interventions given at the end of life to family members; b) interpretations provided by friends, family and community members concerning other patient experiences; c) what is seen on television concerning the worldwide debate; and d) what the news has reported concerning the 2015 Canadian Supreme Court decision (Carter vs. Canada). Importantly, different terminology is being used on national and international stages, terms such as euthanasia,

right to die, and doctor assisted suicide potentially elicits painful associations to Nunavik's colonial history and to its current struggles with its high rates of suicide.

2) What physicians and nurses identify in term of actions and intentions related to palliative sedation and what family and community identify as their experience can contradict each other significantly.
3) Discussions concerning palliative sedation and medical aid in dying are loaded with moral tensions for the medical profession and Inuit community.

To move forward in addressing the requirements of Law 2 in Nunavik contexts, it would be important to establish an advisory committee with substantial membership representing the various aspects of the Nunavik community. Due to the complex historical and cultural context in which this discussion occurs, as well as the climate of mistrust that exists between many Inuit families and the medical profession, further guidance from leaders in the community would be needed before establishing policies related to Law 2 in Nunavik. Areas for an advisory committee to consider may include: a) a detailed understanding of how palliative sedation and medical aid in dying are perceived in Nunavik communities; b) which cultural and communication issues are relevant to the training of nurses and physicians in Law 2; c) how to address the perceptions and misperceptions concerning palliative sedation that already exist in community contexts; d) how health care centers maintain confidentiality in a process where transparency is key to addressing community mistrust; e) how interpreters can be best trained for these nuanced dialogues, both linguistically and emotionally; and f) whether (and how) to add regional criteria to the current provincial guidelines established by the government; for example, the current law requires the signature of two physicians requesting medical aid in dying. This number is based on an assumption that physicians should have more authority than local caregivers or elders in determining eligibility. Should these physicians be required to consult with local advisory members before providing final approval? These questions arise from concerns of the participants in this report. An advisory committee based in part in the community would be needed to ensure these issues are elaborated further.

12. BEREAVEMENT AND GRIEF

> So that was like, 5 griefs in a row that included the whole community in their grief, not just the family. Since it was happening a lot, it was getting harder and harder. We are still grieving from that person who passed away, then all of the sudden, someone passes away again. (Wellness worker)

Throughout the course of this study, participants shared their own grief experiences in the context of family and community. We have chosen to include some of these narratives as they provide further insight into the emotional and social contexts within which many Nunavimmiut are providing EOL care. If the adage is true, that residual emotions from former grief experiences surface when a new loss is felt, it is not surprising that some families find themselves struggling to draw on their emotional reserves of strength to provide palliative care in the home.

12.1 Grieving and diagnosis

The diagnosis of cancer may initiate a profound sense of grief in patients and families, a grief that may often go unspoken. A woman described the three days of silence that she experienced with her partner who had just been diagnosed with cancer before she dared to ask him if she had upset him. His response was one that no, he was not angry, but he was sad that he would not see his grandchildren grow up. Immediately following his diagnosis, he had begun his grief process.

Another community member spoke of the grief journey that she and her siblings had begun when they heard their parent had entered a terminal phase of cancer. She observed those around her sharing a similar path, “*But I know for sure that they grieve, the last of her presence, the active mother or the grandmother, they start to grieve that already... And they’re grieving her losing her autonomy, the harm of the sickness or illness.”* In her account, this ability to prepare for the death of her parent had been central to a grief experience that was not experienced in a traumatic way.

12.2 Grief upon grief

The uniqueness of the Nunavimmiut grief experience lies in the fact that each family in the community will have likely have recently experienced an accident or suicide in their circle of family and friends. As mentioned in the introduction, Nunavik residents are 7.5 times more likely to end their life through self-inflicted injury and 3 times more likely to die from unintentional injuries than in the rest of Quebec. One mother spoke of her son, who, in the span of secondary school alone had lost 5 peers to suicide.

When death is due to sickness, this is accepted because we have to die somehow. When its due accident or suicide, “there is a big grieving, a long time healing.” (Interpreter)

Many suggested that a large majority of the families living in Nunavik who choose to give EOL care in their homes will be doing so in the context of a complex network of grief. Within the context of terminal illness, ageing and EOL care, grief was not experienced as an isolated event but as one of a series of grief experiences. As one interpreter stated, “*people do not have time to grieve. There are too many deaths. It’s like an onion, layer upon layer*.” Another participant recalled how the deaths of a sister, father and mother within a period of months had led to a “*never-ending” experience of grief that “was like forever*.” As communities had originally been formed by a few family clans, the likelihood that they were related to someone in the community who had recently died through suicide or accident was unusually high. This phenomenon led to what one interpreter referred to as “*a big grieving, a long-time healing*” as family and community members were trying to cope with multiple losses. Another community member spoke of this accumulation of grief and lack of resources to aid those who were suffering stating, “*people go a little crazy after a while*.”

Participants spoke of two types of traumatic forms of grief would accumulate and potentially intrude on the bereavement experiences of those providing EOL care: 1) the collective/intergenerational grief related to historical experience of loss; and 2) the personal grief related to the experience of loved ones dying by suicide or accident.

In terms of collective or generational grief, participants spoke of the dehumanizing of Nunavimmiut through forced geographical displacements of families, the separation and permanent disappearance of family members due to residential schools and hospitalizations during the tuberculosis epidemic, and the mass slaughter of sled dogs by the RCMP. On September 16, 2015, a CBC news headline read, *"Nunavummiut are soaked in unresolved grief*." An expert testifying at a coroner's inquest described how "*lingering pain and anger*" related to intergenerational trauma was one cause of the high rates of suicide in Inuit communities in neighbouring Nunavut. Provincial borders do not prevent this reality from being true in Nunavik as well.

> I was grieving over a sister, than my father died a month later. I didn't have time to finish grieving, than my mother died. It was never-ending. It was like forever. (Community member)

When family members had died by suicide, participants spoke of intense feelings of helplessness, guilt, anger, and sadness that left people paralysed and disengaged in their interactions with others, often for years. In instances when children had committed suicide, parents often stated that they were blindsided as these children may have shown no recognizable symptoms of distress. Alcohol was often a factor in accidental and suicidal deaths, a concern which those in leadership in community municipalities spoke about openly. The factor of alcohol led to a lack of predictability in suicidal and accidental death, creating anxiety in parents and family members who feared losing a child, sibling, parent or spouse to suicide.

> People needing to survive on the land had been told don't grieve too long or you stop the fire of living.
> (Community member)

Though not labelled as cause for bereavement, woven within participant dialogues were accounts of parental abandonment, neglect or abuse and consequent displacement of a child. An Inuit educator observed that as this suffering had not resulted in death, the accompanying states of grief and loss were often not recognized or acknowledged for what they were. Rather, focus was often placed on the resultant maladaptive behaviours that resulted from these losses and separations. Notably, an unusually high percentage of children had been relocated to different communities due to abuse, neglect or violence that they had experienced in their families. Added to this were the children and youth who had experienced the loss related to accidental death and suicide in their immediate circles of peers. As another area of bereavement, children were present in the home when adult caregivers were providing EOL care for aunts, uncles and grandparents. The amount of support that these children receive to engage in their own bereavement process depended on the capacity of their adult caregivers, often experiencing their own grief, to guide them.

> You blame yourself, you blame the community, you blame anyone because you don't know what happened.
> (Mother)

If caregivers were not capable to help children grieve, there were few support services in place. Teachers and parents described how parents of children who struggled with loss manifested their suffering through angry, acting out on the one hand or silent and withdrawn behaviour on the other. Teachers described spending inordinate amounts of time doing behavioural management in the classroom, relating this in part to the unresolved grief and trauma that children were dealing with. Teachers may not have been informed if the child had experienced a significant loss in their immediate or extended families. This left them in the dark and unable to support children at these times. Social workers engaged with children in the communities were overwhelmed with caseloads of children experiencing neglect or abuse and described having little, if any time to offer. School counsellors expressed being at a loss in how to help these children. The Kativik School Board appears to be working on providing additional training and resources.

12.3 Beliefs and practices regarding grief

Complicating the ability of some individuals and families to process the multiple losses they had,were the taboos and norms that had been passed along from one generation to the next concerning what is legitimate to express in times of loss. One participant summarized how beliefs concerning the expression of grief are shifting for many Nunavimmiut, speaking of the "*in-between generation*" in which persons were transitioning between the old and new ways of coping with loss. The new way allowed for more expression of emotion and conversation. The scope of this project did not permit us to provide an in-depth exploration concerning the old and new ways of coping. However, some consistent themes emerged in our conversations with Nunavimmiut which may be of use for those engaged in bereavement care.

12.3.1 Grief in nomadic vs. community life

One participant spoke of how, in nomadic times, grief was a "luxury," one that could not be felt for long. Families were so focused on survival that they had to keep moving, literally and emotionally. Unlike in large communities where others may have stepped in to fill these roles for a period of time, families often travelled in small groups where the participation of all was needed for survival. By one account grieving could prohibit the will to live.

In nomadic times, a family member who lost a loved one had to turn to the tasks of the day (whether hunting, cooking, sewing, fishing, establishing shelter) to care for the remainder of the family. Inuit living as nomads did not always have the option of a common burial ground. Due to the frozen conditions of the ground year around, the deceased were buried under a pile of rocks near the location they had passed away.

Let yourself grieve, don't stop crying or you'll be crying for 10 years if you never let the grieving part pass. (Community member)

The stoic means of coping with death is gradually shifting. As someone explained: "*Today, we say when you are grieving someone, feel the pain, acknowledge it; let somebody know that you are hurting*." Communities now come together to offer physical and emotional support. They have churches for communal prayers and rituals, and cemeteries as a shared burial site. Families are given permission to express loss and emotion through physical touch and tears. Some explained that one reason that families value having patients in the home and community before dying as that period just before and after death are vital in the family grief process. In these times, individual and collective expressions of grief are acceptable. People are encouraged to come together to grieve. Following the funeral, life returns to its rhythm and family members are often left to their own devices. Some are unable to cope and rely on vices that numb the pain. Others find healing in the church; others in participating in land-based traditions. As a community member observed: "*a lot of them… after something tragic happens in their family or they've lost a family member, they go to church a lot.. praying and singing releases their loss… and a lot of them go to the land. When they are on the land, they do a lot of healing.. just being in a tent, remembering their memories of their loved one*." A community member described an encounter with winds and stormy waves as part of her bereavement process: "*I was out fishing and it was very windy, a lot of waves and just being there. That's how I feel, anger disappointment. I felt it in nature. This is*

You can even have a relationship with someone who passed away, even though they are not there. (Community member) *how I feel. It was refreshing*." This sensory experience in nature appeared to have provided a place for her to feel her emotions.

12.3.2 Grief and letting go of the deceased

Participants described how prior to the influence of Christianity, there were teachings in Inuit culture of places where people went to die that closely resembled the heaven and hell later taught by the church. Most with whom we spoke described beliefs about heaven and hell. One person shared how this belief provided comfort to her kids: "*My girls say, "my daddy's up in heaven with God and God is holding onto him.' I say 'that's true. Your dad is looking down on you and smiling.*'" In this light, several Nunavimmiut spoke of beliefs concerning the potential dangers of extended grieving for the deceased and for the living. Some believe that if they grieve too long, the soul of the person for whom they grieve would not be free ti go to heaven. As one participant explained: "*There is a myth about people who grieve too long… 'that I'm trying to get to heaven and will not make it to heaven because you're crying too much,' the person's tears will make the stairs slippery*." She stated that beliefs such as these keep people from healing. Another belief shared by some was that grieving the deceased too long would potentially result in the bereaved joining that person in death. Another woman described how she had felt guilty for not having been her grandfather's caregiver until his death and for grieving him for too long. She described: "*Here in the community, they say when somebody passes away, for them to rest in peace, you have to just them go. But for some, it's very hard to just let someone you love go... you don't need to let go of someone who passed away*." A First Nation's bereavement counsellor had comforted her in giving her permission to continue to think of her grandfather, and she now felt his presence, even though he had died.

Ça prend une maudite bonne interprète pour traduire des choses… puis là, un moment donné je lui ai dit, 'ça se peut-tu là qu'elle manque son mari qui est mort…pis là un moment donné, elle se mise à pleurer, pis pendant une demi-heure là elle a pleuré pis là ça sortait là… puis après je ne l'ai plus revu. (Long-term nurse)

Community members remained divided on whether extended periods of sadness in relation to the deceased were acceptable or not. For some, unexpressed emotion was a causative factor contributing to the increased rates of cancer in Nunavik. As one participant stated: "*The body becomes too toxic if you keep the emotions inside. It becomes cancerous."* Several persons spoke of the potential emotional and physical impact of denying or keeping grief inside. In the words of a parent who had lost his child: "*If I have it in my heart and don't express it, it's going to poison me. That's the secret of keeping poison out of my heart.*"

Nurses observed that internalized and unresolved grief was the cause for many visits to the health center. What manifests as a physical symptom (e.g., stomach pain, headache, or another body pain) may have been an indicator of emotional suffering rather than of a traceable physical illness. Examples given included suffering within an ongoing abusive relationships, sadness over the loss of loved ones, and the unresolved guilt and loss over the suicide of a child. As one nurse stated, “*Il y a beaucoup de bobos là qu’on pourrait écrire, mal à l’âme.*” She gave an example of a young woman who had come to the clinic experiencing chest pain. No physical cause could be found. The nurse suspected the pain was related to unresolved grief concerning the many family members that she had lost.

12.4 Institutional and community reponses to death

12.4.1 Grief and death in Montreal

The funeral director in Montreal,estimated that a small percentage of families choose to go to the funeral home. Here the bodies of the deceased are embalmed before being placed on a plane and sent to the North. A mortician who has been working with Nunavik families for 27 years provided his own reflections as to what he often observed in Inuit family members who came to visit the funeral home. His narrative spoke poignantly of the experience of families who are alone and away from family and community at time of death. He used the French term, “*désemparé*” a word which communicates a sense of being in distress, distraught, and helpless, as he compared this population to the other clients he receives. Unaccompanied and alone at the funeral home, Nunavimmiut had come to see the body and to make decisions concerning preparations for the body to be sent back to the North. Decisions included clothing for the deceased, whether to upgrade the casket from the grey, pressed wood casket paid for by the government (400 dollars more for an actual wooden casket), and whether to add fresh flowers. Once these decisions had been made, the body of the deceased was brought to the airport and flown back to the community. For scheduling reasons, the family members usually took a different flight.

Someone drives them (family of deceased) here and then they are lost. … They have no support… They don’t know who to trust. (Montreal mortician)

As noted earlier, Nunavik has a high infant mortality rate; five times higher than the rest of Quebec. When these deaths occur in the neonatal unit of the hospital in Montreal, efforts were made to accommodate the family. A spiritual advisor was available to walk through the process with the families. Some families asked for sacraments for the sick, prayers, blessings and songs. Parents and extended family were invited to hold, bathe, dress, and care for the infant once the network of tubes and IV’s had been removed. Some family members chose to make an imprint on a card of the infant’s foot or hand that they took with them.

12.4.2 Community engagement

As mentioned above, extended families and communities would come together to accompany, cook, clean and other tasks during the days immediately preceding or following death. When possible, family members located in other communities would fly in as well. Depending on the number of family members available and on the needs that present themselves, local volunteers from the women's auxiliary were also likely to become involved with the family (see Section 6). Their engagement with the bereavement process itself depended on their relationship to the family, the place of dying and the expectations of the community. Some would keep vigil during the night or offer to sing and pray with the family during or after the dying process.

Until now, this group of volunteers from the women's auxiliary had also taken sole responsibility for washing the deceased and preparing them for burial. However, in one community the auxiliary members had started to coordinate efforts with the CLSC so that they would not be not responsible for preparing the bodies of those who had died a traumatic death (e.g., accident, murder or suicide). This burden had become too emotionally heavy.

Funerals usually occurred within two or three days of the person dying. These ceremonies closely replicated a Sunday church service, with hymns sung and a message given by the local pastor. Depending on the deceased, their family, and community, there were no set expectations in terms of if and when there was visitation for the family, whether there was a viewing of the body or open casket, or whether there were eulogies offered during the church service. All were invited to support the family in their bereavement. Schools, municipal offices, and businesses, including grocery stores, have been closed for a funeral. The funeral would usually take place in the local Anglican church and be followed by a short burial service in the cemetery. As all communities now had earth-moving equipment, bodies were placed year round in simple wooden coffins in the ground and covered with flowers, usually artificial, as these were the only ones available to those living in the North.

Importantly, the experience of bereavement was altered when the police required an autopsy to be done on a body. A nurse described the potential impact of this on families when she spoke of the anger and anguish of a mother whose son had died in an accident. Upon her arrival at the health center she had not been permitted to touch or embrace him.

Give us an opportunity to say what we want to say. It's a big release to know that people know. When you are in it, you think you are ok, but when you look at how your life is, you see that its not. (Community member)

12.4.3 Community/institutional organized initiatives

Nunavik communities and health centers have recently embarked on initiatives to provide bereavement care to communities. The following four examples come from participants and organizers who had been engaged in these initiatives:

1. *The Residential Health Support Workers*

A group located in Kuujjuaq, The Residential Health Support Workers had, as its first mandate within the context Canada's Truth and Reconciliation process, the task to facilitate healing for Nunavimmiut who had been placed in residential schools. This acknowledgement of the ongoing bereavement faced by those who had been separated from their families, some placed into abusive environments, had been healing for many.

A woman who had participated in the Truth and Reconciliation hearings described the impact for her:

> *All the stuff was just coming out. I felt, 'I am not the only one.' It's hard to express what you went through but when someone else is saying it for you….*
> *We have been hurt. Someone is listening. Give us an opportunity to say what we want to say. It's a big release to know that people know.*
> *When you are in it, you think you are ok, but when you look at how your life is, you see that it's not.*

The mandate of the Kuujjuaq team eventually expanded to working with families who had recently experienced a traumatic death by accident, murder or suicide. This team went into communities within a couple of weeks after a funeral, recognizing that these families were at risk once the communal grief process had ended and the shock had diminished. They provided an assessment of family members, provided means through which family members could express their grief and loss and, if needed, signaled ongoing risk to community social support structures.

On peut renforcir des initiatives pour accompagner les gens en deuil et favoriser ainsi les résolutions saines et, peut-être, prévenir les multiples couches de deuils non-résolus.
(Physician)

2. *Puttautiit conference*

We also spoke with representatives as they were organizing Dialogue for Life, an event that took place for the first time in Puvirnituq in 2015. Patterned after the Dialogue for Life conference held annually in Montreal, this 5-day session gathered individuals engaged in communities to train them in suicide prevention. One component of this training included education and support concerning grief and bereavement. Long-term goals were to rotate this conference through Nunavik communities on an annual basis.

3. *Maison Monbourquette training*

In 2013, a group of wellness workers came together in a community for training concerning grief and bereavement. They met over a period of five days during which they learned about grief reactions and accompaniment in the bereavement process. Originally intended to be a series of trainings with ongoing support, this initiative came to an end due to lack of funding.

4. *Kativik school board*

We also spoke with school counsellors who had received their first training in suicide prevention and bereavement. This training had included models that were drawn from First Nation's communities, as well as books that could be offered to children who were experiencing loss. One of these resources had been written from an Inuit perspective and presented in Inuktitut.

12.3.6 Individual engagement with bereavement

It is important to emphasise that within communities, there were many unofficial and unidentified individuals who were providing bereavement care services. We did not have time to thoroughly assess these initiatives in community contexts. A more thorough assessment would clarify the capacities already existing within communities that might serve as models in program development. The following three examples illustrate individuals who, outside of their job mandate, had recognized and responded to the needs in their communities.

1. *At school*

We spoke with school administrators who welcomed students to stop in if they needed a break from the social or intellectual demands of the class. Some students spoke of their loss, others remained in silence. Teachers welcomed students time after school, and at times in their homes to provide a healing relational space for youth.

2. *Out on the land*

We spoke with a community member who had been hired by the school to take kids out on the land to learn traditional skills when the formal structure of school was not conducive to their emotional or learning needs. Some of these youth had experienced multiple traumas and loss. Another community member described how she accessed the land as a healing space for adults who had suffered loss. She found that these environments permitted a fuller expression of emotion and grief. Memories would surface in this context, both positive and painful, allowing people to access their grief. In addition, this outdoor environment permitted a sensory encounter from within which emotions anger or sadness could be expressed.

3. *In the work place*

Another example in which individuals engaged in bereavement care emerged in a conversation with a hospital chef. This individual described the values that he tried to instill in his young employees, many who were struggling with multiple forms of loss. As he described his encounters and approach, it was clear that the environment that he had created in the work place instilled a sense of meaning and hope in youth. Due to his success, those working in the justice system would solicit him to hire youth at risk.

12.5 Improving grief and bereavement care

Ideas to improve grief and bereavement care came from both Inuit and Qallunaat participants. They emphasized the importance of helping communities recognize the multiple layers of loss, addressing suffering in its various forms, and providing interventions that allowed Nunavimmiut to envision a future.

12.5.1 Incorporating community initiatives in care

Many indicated that the Southern model of healing, such as dialogues in a psychologist's office, would not be welcomed by many in the communities. Rather, Inuit trained professionals who integrated home-based and land-based interventions were needed.

1. *Training opportunities*

Many of those who were engaged in providing bereavement care in communities spoke of the need to receive regular training in order to respond to the overwhelming needs with which they were faced. Continuity was emphasized as key to this training, in part because this provided the context for ongoing support, a form of self-care for those taking the training; and in part because the needs that they faced were nuanced and widespread. One period of training was not sufficient.

Inuit professionals indicated that they were someone insular in their work in local and provincial contexts. Little was known for example, about how communities in Alaska or Greenland were addressing these same issues. They emphasized the importance of building these circumpolar networks as a means through which to develop training in Nunavik communities.

2. *Funding and personnel*

Some community-based workers initiating grass-roots interventions were active in accessing the training and literature that they needed to provide services to individuals and families. In these instances, the problem lay, not in knowledge acquisition, but in being able to develop their services to meet the many needs of their communities. With increased funding, they would be able to expand as needed.

12.5.2. Bereavement care services for individuals and families

Several participants emphasised that unresolved grief manifested in coping behaviours that they felt needed to be incorporated into any approaches to bereavement care in communities.

1. *Anger symptoms*

When he heard about this research into EOL care in community contexts and our desire to identify how to support communities, a man had an immediate, spontaneous reply, "*we need to deal with our anger*." He elaborated that many persons reacted to their loss and suffering with anger. They did not have other tools to deal with the extreme distress that they experienced. This account was corroborated by others who described men and women being emotionally paralysed or frozen in a state of anger in reaction to death and loss. They stated that men had a greater risk of transforming this anger into violent behaviours and women into withdrawal from family and community.

We need to deal with anger (Community member).

2. *Substance abuse symptoms*

Participants spoke of family members turning to alcohol or drugs, not only as a means of self-medicating in suffering, but also as a way of connecting to sadness. They described how in not having anyone to speak with, the emotions had become frozen. Alcohol allowed access, though not healing, to this pain. Substance abuse is widespread in Nunavik. Those with whom we spoke largely agreed that unresolved intergenerational and personal bereavement experiences are ongoing and major causes of substance use. Few intervention programs exist in Nunavik to work with these individuals

3. *Grief and bereavement services*

Community members described how they or family members lost years of their lives as they struggled merely to survive in the depth of their grief. To cope, one family had reached out to someone whom they trusted though did not work in mental health services. This person's normalizing of the family's prolonged feelings of anger and sadness had been key to their healing. A family member emphasized the need for other families to have options of bereavement care services during their time of grief.

> I lost 4 years of my life, just grieving, not knowing what to do. That's a big loss. (Community member)

One participant cautioned against providing only minimal services to individuals and families. She expressed concern about current interventions that encouraged individuals to express their anger and sadness as a form of catharsis and did not take the additional time to help them develop a vision for their own future. From her observation, people's identities would then become wrapped around their grief; they were not yet free to resume living. They had not had the opportunity to complete their healing as the financial resources allotted to their care were limited.

13. PROJECT LIMITATIONS

As with any project, we faced time and resource constraints. As a result, this report is limited in the following areas:

1. *Prevention and intervention services needed to support an aging population*

Many elderly are faced with slow decline in physical and mental capacities which can begin long before palliative care is needed. This population may be restricted to their homes long before health care providers feel EOL interventions are necessary. We have not captured this trajectory in this report.

2. *Children's perspectives*

We did not speak with children as part of this study. Our limited sense of children's experience of death and dying comes through the perspectives of a small number of parents and teachers with whom we spoke. Children's experiences of death and dying in their own homes, communities or in a distant city requires future study, as does their needs concerning bereavement.

3. *Adequately representing the entire territory of Nunavik*

Each village in Nunavik has its own unique realities and capacities. We were only able to visit four villages. Though we hope that we have presented an adequate picture for moving forward in planning EOL care in all Nunavik communities, we recognize that the portrait that we provide may also be incomplete.

14. WHAT'S NEXT?

In order to translate the results of this study into concrete action, we have summarized some of the 'recommendations' offered by participants. This list is not exhaustive and we encourage readers to refer to the more detailed lists earlier in this report.

14.1 The next 12 months

14.1.1 Palliative care resources and training for nurses and physicians

On an immediate level, these findings confirm the importance of current initiatives to train physicians and nurses in providing palliative care to Nunavik patients. These efforts appear to be well underway, including video-conferencing, written materials and phone consultations as means through which to acquire the needed expertise.

14.1.2 Education in Law 2 and the Supreme Court decision

These findings also confirm the importance of current initiatives to educate physicians and nurses concerning Law 2 and the Supreme Court ruling with the consequent laws. Results of this study suggest that physicians and nurses practicing in the North may be themselves uncertain concerning the legalities of what is permitted. Furthermore, most of the communities in the North receive their news from a national radio station and are thus drawing on information provided by the federal government as they consider options available to themselves and their families. Physicians and nurses will be on the frontlines discussing this with patients.

As interpreters, social workers, mayors, pastors and municipality members and elders in each community are key to communicating and clarifying misperceptions concerning euthanasia and assisted suicide, their expertise is critical to understanding how to educate communities on their rights and treatment options. They will know how proactive a position to take and how to approach this with patients who may request medical aid in dying. The interpreters are responsible for direct communication with families. The mayors, pastors and municipality members have the authority and capacity to address potential conflicts between family members or between families and Qallunaat health care providers.

These dialogues concerning the legalities of the provincial and federal laws in terms of euthanasia and assisted suicide are filled with nuance. A literal translation would be difficult for an interpreter. If we add to that the contextual factors (i.e., mistrust of physicians and nurses, confusion between suicide and medical aid in dying, and family member's varying coping skills in the face of loss), it becomes clear that engaging with interpreters and community leaders is key to moving forward.

14.1.2 Training and recognition of interpreters

As this report indicates, the interpreters are an important gateway in communication between physicians and nurses, patients and families. Interpreters have expressed not having the adequate resources with which to address the psychosocial needs of families who may be responding to difficult messages from physician and nurses or to needs of family members. They also have requested visual and written materials so that they may more accurately translate human anatomy and medical procedures. Interpreters have expressed feeling devalued by the fact that the expertise that they develop on the job is not matched with adequate compensation or recognition. Considering their level of knowledge and the significant stress of their position, this should be re-examined.

14.1.3 Support for existing bereavement care initiatives in communities

Several initiatives have begun in Nunavik to address the bereavement care needs of Nunavik children, youth and families. Many of these are land-based interventions, others drawing on faith communities, some drawing on a rich tradition of creative expression, while others building on community support practices. Many also incorporate models of bereavement and grief support learned outside of the community. Identifying and supporting these community-based programs may complement existing initiatives such as the Puttautiit conference (mentioned in section 12).

14.1.4 Home services and inpatient facilities for elders

As elders 65 years of age and older are living longer than before, local nurses are not always able to keep up with their assessments, preventative care and medical interventions. Further, facilities to house elders, whether for respite or long-term care, are inadequate, leading to EOL care patients staying in acute care beds and thus causing shortages for acute care patients. Addressing home services and inpatient facilities for elders is of immediate concern.

14.2 The following 12-24 months

14.2.1 Education in disease progression and EOL care

As elders are living longer, dementia in various forms has become an increasing concern. Prevention approaches, specialists who can provide accurate diagnoses, and care facilities will be needed for these populations. In addition, patients and family members may not have the linguistic or technological capacities to seek information once a terminal diagnosis has been given. Though community-based wellness workers are engaged in increasing health awareness, they are not always able to do public health announcements or educate community members concerning EOL care. Short videos in health centers, grocery stores and municipal offices as well as Nunavik-wide FM radio announcements may increase people's knowledge, thereby preparing them for addressing EOL care needs when the time arises.

14.2.2 Psychosocial support services for patients and families through the identification of existing cultural and spiritual practices

When conversing with Qallunaat and Inuit participants concerning EOL care, the conversation frequently turned to the emotional and psychological coping capacities of patients and families who were confronted with the end of life realities, decision-making and care. Many noted that they did not see families as being able to continue providing care if psychosocial support and mental health services were not developed in communities or offered to patients when in Montreal. Once again, this would be most effective if offered in collaboration with community-based initiatives in Nunavik contexts. Likewise, in Montreal contexts, nurses have identified patients and family members having difficulty coping under times of stress related to illness, diagnosis and separation from family; the MNQ, local CLSCs and hospitals often do not have the personnel to listen and to provide stress-reducing alternatives.

14.2.3 Nursing staff support in Nunavik and Montreal

Nurses face overwhelming challenges. As frontline workers, they are recipients of the immediate consequences of the social suffering of Nunavik patients through an ever-revolving door of patients, during CLSC business hours and during after hour emergency care. Nurses in the North and South have described their fatigue related to the direct services they provide as well as the decline they perceive in the overall functioning of many Nunavik children and families. In light of this, high patient caseloads and inadequate support places nurses at risk for burnout. Several have suggested that reducing nurse caseloads, increasing nurse support in the North, and increasing the hours of pivot nurses in Montreal contexts would improve the quality of care and help retain nurses.

14.2.4 Family education and respite services

Families who desire to keep patients in the home often end up unable to sustain this level of care. This may be due to fatigue or lack of preparedness and accompaniment. Some have suggested illustrated or video resources for patients and families, and consultations with nurses in which the potential changes in the patient and the extent of care required by the family is clearly delineated. Respite rooms in communities or respite care providers on home visit for extended periods may permit families to provide more extended care. Until now, the church-based women’s auxiliary has been able to support families for short periods; however, members state that they are themselves ageing and there are few younger members joining.

14.3 Long term vision: 2-10 years

EOL care in Nunavik is at an important crossroads: should the health care system assume responsibility for dying persons, or should it work in collaboration with communities to develop EOL care services? Participants from Inuit communities and Southern institutions have largely expressed a desire for the latter.

14.3.1 The North and South gap: re-examining the public health approach to EOL care

> *All health care professionals can promote improved aboriginal health in Canada. This can happen daily for those caring for patients of all ages in a wide variety of settings, including rural communities, urban environments, or tertiary care centres. We also need to advocate in key areas to promote aboriginal health. These include helping all Canadians to*

> *understand the history of aboriginal peoples, with the negative legacy of colonization and the residential school system; the role of the social determinants of health; and the urgent need for increased education and employment. We must also advocate for more aboriginal health care professionals; multidisciplinary teams; increased aboriginal self-government, with control of programs including health and education; improved care for patients, families, and communities through adequate funding and relevant programs that are developed with aboriginal input and are appropriately evaluated; and research directed by or undertaken in partnership with aboriginal peoples. This is a long list but all these issues are important, interrelated, and need to be championed…. In the past too much research focused on disease and dysfunction, which only served to emphasize the negative and did not add useful information to develop practical solutions.*
> *(Macaulay, 2009).*

Through these words, Macaulay proposes an agenda for the improvement of Indigenous health in Canada, one which is marked by collaboration with, and advocacy for Indigenous communities. This is not an easy task. In 1998, O'Neil (1998) wrote that the development of Inuit-run health organizations in Canada is difficult to accomplish as local level, socially-oriented health ideologies are hampered by a "dominant capitalist framework." As a result of this dominant framework, "a profound separation of knowledge and power between Inuit patients and non-Inuit health care providers has resulted" (O'Neil 1998). Furthermore, he stated that barriers existed within communities themselves: Inuit employees were distant from training centers; there was a lack of commitment by federal funding agencies to provide training that adapted to Inuit realities; many Inuit preferred job opportunities close to home; and some were discouraged by their families to work in the health sector (O'Neil, 1998). This analysis, though dated nearly 20 years, is still pertinent today. Nevertheless, participants from Northern and Southern institutions and communities provided several examples of collaboration and shared decision making in end-of-life care and many communities have already developed support services for those going through the dying process.

Some communities have family houses[3] that are run and managed by community members and that offer spaces and programming for the promotion of health and well being in children, families and elderly. Church volunteers are also actively engaged in providing EOL care and supporting families during this process. The hunter's support group seeks to address gaps in terms of food. Another men's group had organized to make needed home repairs. Community individuals offered grief support to children and adults in the face of death. Churches offered public spaces for grief and bereavement. Some schools are bringing in health professionals to encourage students to pursue careers in these fields. Community individuals offered grief support to children and adults in the face of death. Had we had the resources to investigate further, certainly more of these community practices would have become evident.

14.3.2 A sustainable approach to EOL care

1. *Collaboration between health care centers and municipalities*

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[3] There are currently only two or three family houses currently operating in the region, most in their exploratory stage of development. Some believe that in the future, they have the potential to engage in supporting families offering EOL care.

Collaborations between federal, provincial, regional and local funding bodies are key to sustainable EOL care. Participants provided examples of where these collaborations have been successful, such as in the building of more residential space for elders or for those needing respite as well as the development of family houses. This collaboration is a solid foundation upon which to develop a shared vision for EOL care in community contexts.

2. *Education and recognition*

Significant barriers to developing sustainable care is that of formal education requirements and the barriers that student's encounter in seeking to meet these in a completely foreign environment in the South. Some have suggested building collaborative training relationships with Arctic College in Iqaluit as students are entering their studies. This would perhaps serve as a bridge for students who are not ready to live so far from home and their culture. Others have suggested education centers in the North in which students come together to receive courses through long-distance learning.

Some interpreters have requested that the current system of compensation and professionalization needs to be reconsidered to include Inuit cultural forms of knowledge acquisition; particularly, training that is attained through observation and experience. If the goal is to empower communities to sustain or increase their engagement in providing EOL care, it will be prudent to re-examine how interpreters, family workers/assistants, and paid escorts are recruited, retained and professionalized and how formalized the process needs to be.

3. *Men ageing alone*

According to the 2001 Statistics Canada report mentioned earlier, men over the age of 65 are expected to live an average of 5 years longer than their wives, men until the age of 87, and women until the age of 82. As on home care nurse explained, this has important ramifications in considering EOL care for men as their traditional roles did not include domestic tasks such as cooking, shopping, and cleaning and some are left not knowing how to care for themselves in their homes.

CONCLUSION: EOL CARE IN NUNAVIK

Through this report and the dialogues that are represented within, we have sought to provide a portrait of EOL care services in Nunavik community and Montreal contexts. Woven into the narratives are Nunavik-specific demographic, geographic, historical, social and spiritual contextual factors and how they shape the provision of EOL care in community and institutional contexts. We have shared participant descriptions concerning family and community-based services, CLSC services and Montreal hospital contexts of care. Participant perspectives concerning strengths, challenges, and variables in care provision, as well as participant recommendations for how to improve upon these have been discussed in detail. As Quebec and Canada at large are presently at a critical juncture concerning the development of laws related to patient's rights to seek physician intervention in dying, we have also added information gleaned through our interviews that may inform how this dialogue may be approached in Nunavik.

Three key themes emerged in our interviews which we felt necessitated special attention: bereavement and grief, the role of interpreters and challenges in communication on diverse levels of service provision. As these themes were central to an understanding of the challenges faced by health care providers as well as patients and families, we chose to represent these reflections of participants in a more focused manner.

The fact that many persons chose to participate in this study clearly indicates that EOL care needs are of vital importance to many individuals and families for whom cancer, disease and ageing have presented a unique set of challenges. We hope that this report serves as a springboard for institutions and community leaders seeking to provide a coordinated approach to future care.

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Canadian Virtual Hospice
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Lakehead University: End of Life First Nations Workbook:
http://eolfn.lakeheadu.ca/eolfn-workbook
Legacy of Hope Foundation: Raising Awareness of the Legacy of Residential Schools
http://weweresofaraway.ca/
Pallium Canada
http://development.pallium.ca/
Saint Elizabeth First Nations, Inuit and Métis Program
https://www.saintelizabeth.com/FNIM/Home.aspx

Inuit and Indigenous Advocacy and Educational Organizations
Avataq Cultural Institute
http://www.avataq.qc.ca
Inuit Tapiriit Kanatami (ITK)
https://www.itk.ca/about-itk
Makivik Organization
http://www.makivik.org
National Collaborating Center for Aboriginal Health (Canada)
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http://www.inuitcircumpolar.com/
Nunivaat: Nunavik Statistics Program
http://www.nunivaat.org/
Nunavik publications
http://publicationsnunavik.com/books/

16 APPENDIX

16.1 Appendix A: Interview Guide

McGill

EOL Care for Inuit Patients in Nunavik, Quebec

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McGill University Health Center
Co-investigators: Dr. Mary Ellen Macdonald, Faculty of Dentistry, McGill University; and
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Semi Structured Interview Guide-November 2013

A. PATIENTS

Target participants

- Inuit patients who have been determined to be at EOL by MUHC treating physician and/or community physician.

Questions

1. **Knowledge and understanding of, and experience with, EOL (EOL) care for patients**
    - **a.** Can you tell us the story of your illness? What is your health situation now? When were you diagnosed? Who cared for you during the different phases of your illness? Where did you receive treatment?
    - **b.** What is most important for you at this stage in your illness?
    - **c.** Do you think other things might be more important for you later?
    - **d.** If so, what kinds of things?
2. **Decision making and information sharing during EOL care**
    - **a.** Tell us about how you came to return home at this stage in your illness.
    - **b.** How did you get information about your illness?

c. What information about your illness did you get? From who? When? Was it too much or too little information? Who was there when you were given the information? Who did you talk with?
d. How can these kinds of discussion be made better?
e. Were there any difficulties you had to face? What can be made better? What services would you have liked to have had?

3. **Description of EOL services for patients in/from Nunavik** (This section will be read/administered together with section 4 below, which addresses home care).

    a. You are being cared for at home/in the health center. Was this your choice? Tell us how this has been for you? What works well? What could be improved?
    b. Who is involved in providing your care?
    c. How could your experience be made better?

4. **Home care for patients at their EOL in Nunavik**

    a. Tell us about your experience with homecare.
    b. What do you think/feel about home homecare for Inuit patients?
    c. Who is involved in providing care for you at home?
    d. What is working well for you? What is not working well with your home care??
    e. What are the benefits of receiving care at home? What could be made better?

5. **Symptom management**

    a. We would like to hear more about your illness. What symptoms have you experienced lately?
    b. What symptoms have been most difficult for you?
    c. How were your symptoms taken care of?
    d. What helped the most?
    e. Are there particular challenges you faced as you handle your symptoms? How could these challenges be addressed?

6. **Support, Training and Education**

    a. What are your hopes and expectations at this time?
    b. How do you deal with difficult feelings (like sadness or anger) when they surface?
    c. Is there any support that could be offered to patients like you that would be helpful?
    d. Is there any kind of support, training and education that could help those taking care of you?

B. FAMILY

Target participants

- Parents

- Grandparents
- Siblings- brother, sister, foster brother/sister
- Aunts, uncles, cousins
- Neighbors

Priority will be to interview those family members who were close to the patient and had spent time with the patient (also to interview family members of patients who are deceased).

Questions

1. **Knowledge and understanding of, and experience with, EOL (EOL) care patients**

    a. Can you tell us the story of your family member's illness? What is their health situation now? When were they diagnosed? Who cared for them during the different phases of their illness? Where did they receive treatment?
    b. Where do you think you would want to die if YOU were ill?
    c. What is most important for YOUR family when providing care?
    d. Are there specific things about the Inuit traditions and culture that Quallanut health professionals should know in order to provide best possible care?

2. **Decision making and information sharing during EOL care**

    a. Tell us about your family's experience getting information and making decisions for your loved one?
    b. How was the family involved in the decision for their loved one to return home?
    c. Who was involved?
    d. How/where/when did this happen?
    e. Were you satisfied with all the information you received? Did you contact anyone else for help or information? How can this process be made better for Inuit families?
    f. What were the main problems you faced as you looked for information, discussed and planned for EOL care for your loved one?

3. **Description of EOL services for patients in/from Nunavik** (This section will be read/administered together with section 4 below, which addresses home care).

    a. What services did you receive while caring for your loved one?
    b. Who was/is involved in caring for your loved one?
    c. Which service providers have/did you interact with during this time?

4. **Home care for patients at their EOL in Nunavik**

    a. Tell us about your experience caring for your loved one at home (E.g., *Activities, tasks.)*
    b. How do you feel/think about homecare?
    c. Who was/is involved in caring for your loved one at home? (e.g., Service providers, community members.)
    d. How much time per day did you spend caring for your loved one?

- **e.** What tasks did you not feel comfortable doing/didn't like doing (i.e. washing, giving medication)? Why did you not feel comfortable? Who do you think should be taking care of these kinds of tasks?
- **f.** What were the main problems and challenges caring for your loved one at home? What were the rewards?
- **g.** Were you satisfied with the services provided?

5. Symptom management

- **a.** Tell us about the illness and the symptoms that your loved one experienced.
- **b.** What symptoms were most distressing for you to see?
- **c.** How were your loved one's symptoms taken care of?
- **d.** What helped the most?
- **e.** Are there any challenges that Inuit patients' and their families experience with taking care of a patient's symptoms? How can these challenges be addressed, if at all?

6. Support, Training and Education

- **a.** What are/were your hopes and expectations for yourselves and loved ones during this experience? Did they change?
- **b.** What kind of support, education and training would be most helpful to yourself, your family or your loved one at this time?

C. COMMUNITY MEMBER (*Elder, minister, key informant)*

Target participants

- Elders
- Youth leaders
- Women's groups; men's groups
- Community groups, church groups or volunteers supporting patients at their EOL;
- Ministers, church leaders

Questions

1. **Knowledge and understanding of, and experience with, EOL (EOL) care for patients**

    - **a.** What are your thoughts about terminal illnesses (i.e. illnesses that kill people, like cancer)? Do Inuit have any particular beliefs about terminal illnesses? Please tell us about death and dying from an Inuit perspective.
    - **b.** The purpose of EOL care is to keep the patient comfortable and pain free when it is clear they are dying. Doctors and nurses do not try to stop the patient from dying at this stage. What do you think of this?
    - **c.** Tell us of your experience with, or observations about EOL care in your community.
    - **d.** Where do you think Inuit patients should be at this time – at home? In the health center? Down south?
    - **e.** What are the priorities for dying patients and their families at this time?

2. **Decision making and information sharing during EOL care**

    - **a.** What are the important decisions that patients and families need to make at EOL? How should decisions about EOL care be made?
    - **b.** What kind of information do patients and family members need? With whom should it be discussed? *Patient? Family? Who else?*
    - **c.** Are there any special considerations for Inuit patients and their families as they discuss and make decisions for EOL care?
    - **d.** How could patients and families be better supported in decision making?

3. **Description of EOL services for patients in/from Nunavik** (This section will be read/administered together with section 4 below, which addresses home care).

    - **a.** What do you think is the right way for a community member to be taken care of at the EOL in your community?
    - **b.** Who is involved in providing EOL care in the community? What are their roles and responsibilities? What is missing in the current care being provided? What could make it difficult for a person to receive EOL care in the community?

4. **Home care for patients at their EOL in Nunavik**

a. Inuit choose to die at home where they can be close their families and friends. Is this true? Tell us what you know about home care for dying people in your community.
b. Who is involved in providing home care in the community?
c. What are their roles and responsibilities? What could interfere with a person receiving home care at the EOL?
d. If you were terminally ill, where do you think you would want to die?

5. **Symptom management**

a. What do people in your community believe and say about patients at the EOL and those caring for them at home?
b. What do people believe about pain and the use of drugs such as morphine in the Inuit community?
c. Describe Inuit beliefs or customs that influence a person's wellbeing at the end of their life.

6. **Support, Training and Education**

a. What kind of help should be available and given to an Inuit patient and/or their family at the end of their life?
b. Many people see dying as a spiritual experience. How can the medical staff and other professionals involved be helpful with this?

D. COMMUNITY SERVICE PROVIDERS (*Care worker, interpreter, spiritual advisor)*

Target participants

- Community care worker: hired to support patient at home
- Community care workers: working with and supporting nurses and social workers
- Interpreter
- Spiritual Advisor
- Employees: Staff or community members who are hired to support professionals or whose job is to provide some kind of support to patients and families at EOL.

Questions

1. **Knowledge and understanding of, and experience with, EOL (EOL) care for patients**

a. Tell us what you know about EOL care in Nunavik.
b. Please tell us about death and dying from an Inuit perspective.
c. How have you participated in EOL care for patients in your community? What currently works well?
d. What are your goals with EOL care for community members?
e. What are the most important things for an Inuit patient and families during this time?

2. **Decision making and information sharing during EOL care**

    - **a.** Tell us about your experience/role in sharing information, discussing with health professionals and making decisions with patients and families in an EOL situation. What are the main issues and challenges facing the patient and family in decision making?
    - **b.** Are there any special considerations for Inuit patients and their families as they make decisions for EOL care?
    - **c.** What are your main problems as you assist patients and their families discuss EOL care?
    - **d.** How could you be better supported as you discuss with families?

3. **Description of EOL services for patients in/from Nunavik** (This section will be read/administered together with section 4 below, which addresses home care).

    - **a.** How did/do you participate in caring for patients at their EOL?
    - **b.** Who is involved in caring for people who are dying in the community? What are their roles? What is missing in the current care being provided? What makes it more difficult to provide care for those who are dying in the community?

4. **Home care for patients at their EOL in Nunavik**

    - **a.** How did/do you participate in home care for patients at their EOL?
    - **b.** What are your responsibilities?
    - **c.** How much time do you spend providing care for each patient? (*Daily/weekly)*
    - **d.** Did you work with other people when you were providing home care?
    - **e.** If so, what were their roles and responsibilities?
    - **f.** In your opinion, what is currently working well? What could be improved?
    - **g.** What are your main challenges as you care for patients?

5. **Symptom management**

    - **a.** Describe your participation in providing symptom relief, especially pain relief, to patients in an EOL situation. What works well?
    - **b.** What do Inuit think about pain medication – such as morphine?
    - **c.** What are the challenges Inuit patients and their families' face with symptom and pain control? How can they be addressed?

6. **Support, Training and Education**

    - **a.** What were the patients' and their families' hopes and expectations at this time? Did you help/assist with their hopes and expectations? How?
    - **b.** Have you received any special EOL training or education concerning that would help you care for patients?

c. What kind of training/education or support would be most helpful to you or to others that you work with?

E. HEALTH SERVICE PROVIDER (*Nurse, physician, social worker, counselor)*

Target participants

- Nurse in communities.
- Nurse in the Health Centers in Nunavik.
- Community physician.
- Urban link- oncologist or physician in urban Centre supporting Nunavik Centre or team. Liaison nurses for patients from Nunavik. Nurses from MUHC involved in providing pall care to patients from Nunavik (Pall care consult team nurse).
- Social workers & community care workers in Nunavik, hospital administrators and public health officials.

Questions

1. **Knowledge and understanding of, and experience with, EOL (EOL) care for patients**

   a. Tell us what you know about terminal illness in your community.
   b. Who receives EOL care in the community?
   c. Where is it/can it be offered?
   d. How is it put into place?
   e. Describe to us your most recent experience providing EOL care for community members.
   f. What are the goals of EOL care in Nunavik?
   g. What are the main challenges and issues in providing care to Inuit patients? What are the successes?
   h. What are the priorities for Inuit patients and their families at this time?

2. **Decision making and information sharing during EOL care**

   a. How are discussions about EOL care initiated?
   b. How are decisions and plans made with patients & their families? Who participates in discussions and planning?
   c. Describe any protocols, practice, systems or tools that guide/facilitate discussions.
   d. How might Inuit cases differ from other cases you have worked with?
   e. Are there any special considerations or accommodations for Inuit patients & families during the planning and decision making process?
   f. What are the main problems for health providers as they plan for EOL care with patients and their families?
   g. How could health providers be better supported as they discuss with families?

3. **Description of EOL services for patients in/from Nunavik** (This section will be read/administered together with section 4 below, which addresses home care).

- **a.** Describe the services for EOL care that are provided in your community?
- **b.** Who are the service providers and healthcare professionals involved in providing care? What are their roles and responsibilities?
- **c.** Are there any community members and groups involved? What is missing in the current care being provided?

4. Home care for patients at their EOL in Nunavik

- **a.** How is home care planned and organized? Describe the provisions for services associated with home care in your community.
- **b.** Who are the service providers and healthcare professionals involved in providing homecare? What are their roles and responsibilities?
- **c.** Are there any community members and groups involved in providing care?
- **d.** What are the particular challenges in providing home care to Inuit patients? What are the benefits of homecare? In your opinion, what is currently working well? What could be improved?

5. Symptom management

- **a.** Describe any standard protocols in use in your community for symptom management (pain, anxiety, respiratory distress, constipation).
- **b.** Tell us about your experience managing patients' symptoms.
- **c.** Are there certain medications (e.g,. morphine) that have particular cultural significance?
- **d.** What works well?
- **e.** Describe particularly challenging situations related to symptom management you encountered while providing EOL care in your community.
- **f.** How were these situations resolved? Could they have been prevented? What are the more common issues in symptom management in your community?

6. Support, Training and Education

- **a.** Have any of the health providers and service providers in your community received specialized training/education in palliative care?
- **b.** If a healthcare provider or service provider requires advice or support to care for a patient, where would they seek it?
- **c.** What kind of training or support would be most helpful to the professionals involved in providing EOL care?

F. INTERVIEW GUIDE FOR HEALTH CARE PROFESSIONALS: Bill 52 in Nunavik

HCP knowledge

1. Have any of your terminally ill (or other?) patients ever expressed a wish to die with the help of a health care professional or otherwise?

2. Have you heard of Bill 52?

If not:

Bill 52 was presented in the summer 2013 session of the Quebec Legislature by Junior Health Minister Veronique Hivon. While the bill has not yet been adopted, public consultations are planned for September and Hivon wants the bill adopted before the Christmas 2013 adjournment.

The purpose of this bill is to regulate the provision of EOL care by health care providers to patients in Quebec. Bill 52 establishes specific requirements for certain types of EOL care, namely terminal palliative sedation and medical aid in dying (MAD). It prescribes criteria that must be met for a person to obtain MAD and the requirements to be complied with before a physician may administer it.

The bill defines neither terminal palliative sedation nor medically assisted death, though working definitions of the following are provided below:

Palliative sedation: (also known as terminal sedation, continuous deep sedation, or sedation for intractable distress in the dying/of a dying patient) is the palliative practice of relieving distress in a terminally ill person in the last hours or days of a dying patient's life, usually by means of a continuous intravenous or subcutaneous infusion of a sedative drug. This is an option of last resort for patients whose symptoms cannot be controlled by any other means. This should be differentiated from euthanasia, as the goal of palliative sedation is to control symptoms through sedation but not shorten the patient's life, while in euthanasia the goal is to shorten life to cease suffering.

Medical Aid in Dying: Medically assisted dying refers to an appropriately-regulated process where doctors provide qualifying patients with a prescription for medication that will cause them to die quickly in order to stop suffering.
In jurisdictions such as Oregon and Washington where medically assisted dying is legal, patients seeking to end their lives still need to take the medication themselves.

   a. If so, have any formal or informal meetings or discussions about the implementation of the Bill happened yet in Kuujjuaq that you are aware of?
   b. What has the general consensus been in these discussions?
   c. What are some of the broader sentiments/concerns relating to Bill 52 that you have heard among health care professionals, if any?

3. Do you see a need for the implementation of Bill 52 across Nunavik?

4. What are your personal feelings on participating in a medically assisted death? Should medical professionals be obligated to provide medically assisted death?

Perception of Community Attitudes

5. Have community leaders been consulted on the possible implementation of Bill 52 in Nunavik?

6. If not, how do you think they might respond?

7. Are there any special protocols or permissions that might be required before Bill 52 is implemented in Inuit or Aboriginal communities?

Implementation in the Context of Nunavik

8. Bill 52 requires that all institutions offer EOL care, include a clinical program for EOL care, and adopt a policy with respect to end-of -life care (III:8-10). Do you think these regulations can be adhered to in Nunavik?
    a. If not, why not?

9. The bill also allows that EOL care be offered in a health care institutions or at home (II:5). Which of the two options are more feasible in your opinion?

10. Are you aware of the distinction that Bill 52 draws between terminal palliative sedation and medically assisted death?
    a. If so, do you think either of these approaches is more appropriate or feasible given the local context of Nunavik?

11. Under the regulations stipulated by Bill 52, the treating doctor, plus a second doctor, must agree that MAD is the best course for the patient (following the patient's clear and repeated expression of their desire to die). Given this constraint, is medical aid to die feasible in Nunavik's communities?

12. Bill 52 stipulates that only a patient who meets the following criteria may obtain medical aid in dying:

    i. *Be of full age, be capable of giving consent to the care and be an insured person within the meaning of the Health Insurance Act (Chapter A-29).*
    ii. *Suffer from an advanced state of irreversible decline in capability; and*
    iii. *Suffer from constant and unbearable physical or psychological pain which cannot be relieved in a manner the person finds tolerable (IV:26).*

Given high rates of mental illness, distress, and suicide among Inuit residing in Nunavik, would you consider providing MAD to a patient who reported unbearable psychological pain, but who was otherwise healthy?

13. What are some of the other barriers you have identified to the implementation of Bill 52 here? Infrastructural barriers? Social or emotional barriers?

14. What are the methods that might be used to perform MAD here, if it were feasible?

15. Is there a kind of revised protocol you would anticipate following to ensure that MAD was available to patients in Nunavik?

    a. If so, what kind of permissions would be required?

16. 2 Appendix B: Consent Forms: English, French, Inuktitut

Institut de recherche
Centre universitaire de santé McGill
Research Institute
McGill University Health Centre

June 2014
EOL care for the Inuit Patients in Nunavik, Quebec

STATEMENT OF CONSENT

You are being invited to be a research participant. This research is designed to look at the EOL care in Nunavik. We are seeking your participation in this interview as a community representative, as a patient or his/her family member, as a health service provider involved in the delivery of EOL care. You have the right to know about the purpose and procedures that are to be used in this research study.

Before you agree to take part in this study, it is important that you read the information in this consent form. If you prefer, we will read it out loud for you. You should ask as many questions as you need to in order to understand what you will be asked to do. You do not have to take part in this study if you do not want to.

Purpose of study:
The aim of our survey is to better understand the EOL services offered in Nunavik, and to identify ways to improve the quality of life for patients and their family members. We are interviewing community representatives, patients and their family members, healthcare professionals and associated staff who are involved in giving these services. What we want to discuss include decision making; homecare; communication; education; hopes/expectations. Also, we would like to get a clear outline of the human resources and equipment required to provide these services. We welcome input on how EOL care is used; whether or not the services are accessible and comfortable for patients and the family members; do we need to offer different care strategies, and whether EOL services need improvement, and if so, how to improve the delivery and utilization of EOL care. Not all of these issues correspond to your own situation and we will adjust our questions accordingly.

Procedures:
If you agree to participate we will conduct a face-to-face interview and your verbal answers to our questions will be recorded and later transcribed and analyzed. The length of the interview will depend on the information you provide and may take up anywhere from 30 to 60 minutes.

Voluntary participation/withdrawal:

Your participation in this study is voluntary. You may choose to participate now and decide to stop your participation at any time. Your decision to participate or not will have no impact on your care now or later.
If you withdraw from this study, any information collected up to the point of withdrawal for the purpose of this research may still be used in order to protect the scientific integrity of the study.

Costs and compensation:
You will not be compensated for your participation in this study. There will be no costs to you for participating in this study.

Confidentiality:
While you take part in this research study, the researcher in charge and study staff will collect and store personal identifiable information about you in a file for the purpose of the research study. Only information necessary for the research study will be collected.
All the information collected about you during the study will remain confidential within the limits of the Law. To protect your identity, your name and identifying information will be replaced with a code (numbers and or letters); the link between the code and your identity will be held by the researcher in charge of the study. No information that discloses your identity will be allowed to leave the institution.
Your study information will be kept for 10 years by the researcher in charge of the study.
The study information may also be used to help in the development of future studies.
The study information could be printed/published in medical journals or shared with other people at scientific meetings, but your identity will never be revealed.

Investigator Compensation

This survey is conducted on behalf of the Nunavik Regional Board of Health and Social Services and is funded by the Fond de recherche du Québec. The funds are being deposited into a research and development account.

Contact information or questions:
If you have any questions about the study you can communicate with the researcher in charge of the study Dr. Paul Brassard at 514-340-7563.

For any questions concerning your rights as a person taking part in this study or if you have comments or wish to file a complaint you can communicate with Dr. Nathalie Boulanger, chief of Medicine in Nunavik at (819) 964-2222.

STATEMENT OF CONSENT

EOL care for the Inuit Patients in Nunavik, Quebec

I have read/understood the above information and my questions were answered to my satisfaction. A copy of this signed consent form will be given to me. My participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my care now or later. I do not give up any of my legal rights by signing this consent form. I agree to participate in this study.

*Signature:*____*Date:*__________________

Name of Participant: ____

Consent form administered and explained in person by:

*Signature:*____*Date:*__________________

Name of Investigator: ____

Research Number _____________

Institut de recherche
Centre universitaire de santé McGill

Research Institute
McGill University Health Centre

Juin 2014

CONSENTEMENT

Vous êtes invité(e) à participer à une recherche qui porte sur les soins de fin de vie au Nunavik. Nous sollicitons votre participation à un entretien car vous êtes un représentant communautaire, un patient ou un membre de sa famille ou un professionnel de la santé chargé de prodiguer des soins de fin de vie. Vous avez le droit de connaître l'objectif et les procédures applicables à la présente recherche.

Avant d'accepter de participer à cette étude, il est important que vous lisiez les informations qui figurent dans le présent formulaire de consentement. Si vous le préférez, nous pouvons vous le lire à haute voix. Vous devez poser toutes les questions qui vous viennent à l'esprit afin de bien comprendre ce que l'on attend de vous. Vous n'êtes pas obligé(e) de participer à cette étude si vous ne le souhaitez pas.

Objectif de l'étude :

L'objectif de notre étude est de mieux comprendre les services et soins de fin de vie offerts au Nunavik et d'identifier les moyens qu'il conviendrait de mettre en œuvre pour améliorer la qualité de vie des patients et des membres de leurs familles. Nous souhaitons interroger des représentants communautaires, des patients et des membres de leurs familles, des professionnels de santé et des membres du personnel médical participant à la prestation de ces services. Nous souhaitons en particulier les interroger sur la prise de décisions, les soins prodigués à domicile, la communication, l'éducation et les espoirs/attentes. Nous aimerions également nous faire une idée plus précise des ressources humaines et équipements nécessaires pour offrir ce type de services. Nous souhaitons plus particulièrement recueillir des informations sur la manière dont les soins de fin de vie sont utilisés et chercher à savoir s'ils sont accessibles et apportent du confort aux patients et aux membres de leurs familles, si différentes stratégies de soins sont nécessaires, si les services de fin de vie doivent être améliorés et, le cas échéant, déterminer les moyens qu'il convient de mettre en œuvre pour améliorer la prestation et l'utilisation des soins de fin de vie. Toutes ces questions ne s'appliquent pas à votre situation personnelle et nous les ajusterons en conséquence.

Procédures :

Si vous acceptez de participer, nous mènerons des entretiens en tête-à-tête et les réponses orales que vous apporterez à nos questions seront enregistrées puis transcrites et analysées. La durée de l'entretien dépendra des informations que vous fournirez et pourra être comprise entre 30 et 60 minutes.

***Participation volontaire/retrait* :**

Votre participation à cette étude est volontaire. Vous pouvez choisir de participer aujourd'hui et décider d'interrompre votre participation à tout moment. Votre décision de participer ou non n'aura aucun impact sur vos soins actuels ou les soins qui vous seront prodigués plus tard.
Si vous vous retirez de cette étude, toutes les données recueillies jusqu'au moment de votre retrait pour les besoins de cette recherche pourront être utilisées de manière à préserver l'intégrité scientifique de l'étude.

***Coûts et indemnisation* :**

Vous ne serez pas indemnisé(e) pour votre participation à cette étude. Votre participation à cette étude ne vous coûtera rien.

***Confidentialité* :**

Dans le cadre de votre participation à cette étude de recherche, le chercheur responsable et le personnel de l'étude recueilleront et conserveront dans un dossier des données personnelles identifiables à votre sujet pour les besoins de cette étude. Seules les informations nécessaires à cette étude seront recueillies.
Toutes les informations recueillies à votre sujet pendant l'étude resteront confidentielles, dans les limites prévues par la loi. Pour protéger votre identité, votre nom et les données permettant de vous identifier seront remplacés par un code (composé de chiffres et (ou) de lettres); le lien entre le code et votre identité sera conservé par le chercheur responsable de l'étude. Aucune donnée permettant de divulguer votre identité ne pourra quitter cet établissement.
Les données vous concernant relatives à cette étude seront conservées pendant 10 ans par le chercheur responsable de l'étude.
Les données de l'étude pourront également être utilisées pour l'élaboration de futures études.
Les données de l'étude pourront être imprimées/publiées dans des revues médicales ou communiquées à d'autres personnes dans le cadre de congrès scientifiques, mais votre identité ne sera jamais divulguée.

Indemnisation du chercheur

Cette étude est menée au nom de la Régie régionale de la santé et des services sociaux du Nunavik et financée par le Fonds de recherche du Québec. Les sommes correspondantes sont déposées dans un compte de recherche et développement.

***Coordonnées ou questions* :**

Si vous avez des questions au sujet de cette étude, vous pouvez vous mettre en rapport avec le chercheur responsable de l'étude, le Dr Paul Brassard, au 514-340-7563.

Pour toute question concernant vos droits en tant que participant à cette étude ou si vous avez des remarques ou souhaitiez déposer une plainte, veuillez vous adresser au Dr Nathalie Boulanger, chef du département de médecine générale au Nunavik, au (819)964-2222.

Juin 2014

CONSENTEMENT

J'ai lu/compris les informations présentées ci-dessus et obtenu des réponses satisfaisantes à mes questions. Un exemplaire du présent formulaire de consentement signé me sera remis. Ma participation est volontaire et je peux me retirer de l'étude à tout moment sans avoir à me justifier et sans que cela n'affecte mes soins actuels ou futurs. Je ne renonce à aucun de mes droits juridiques en signant le présent formulaire de consentement. J'accepte de participer à cette étude.

Signature : ____
*Date :*_____________________

Nom du participant : ____

Ce formulaire de consentement a été présenté et expliqué en personne par :

Signature : ____*Date*
*:*______________________

Nom du chercheur : ____

Numéro de la recherche ____________

Institut de recherche
Centre universitaire de santé McGill

Research Institute
McGill University Health Centre

ᔫᓂ 2014
ᐃᓅᒍᓐᓀᑐᖃᕐᓂᐸᑦ ᐃᓄᒻᒥᒃ ᐋᓐᓂᐊᕕᓕᐊᕐᓯᒪᔪᒥᒃ ᑲᒪᒍᓯᖅ ᓄᓇᕕᒻᒥ, ᑯᐯᒻᒥ

ᐊᖏᕈᑎᒃ

ᖃᐅᔨᓴᕐᓂᒧᑦ ᐃᓕᐅᖁᔭᐅᓯᒪᕗᑎᑦ. ᖃᐅᔨᓴᕐᓂᐊᕋᑦᑕ ᓄᓇᕕᒻᒥ ᐃᓅᒍᓐᓀᓯᒪᔪᑦ ᖃᓄᖅ ᑲᒪᒋᔭᐅᓲᒍᒻᒪᖔᑕ. ᐊᐱᕐᓯᑕᐅᖃᑕᐅᖁᔭᐅᑦᓯᑎᑦ ᓄᓇᓕᒻᒥᒃ ᑭᒡᒐᑐᕐᓗᑎᑦ, ᐊᑐᕐᑎᐅᒍᕕᑦ ᐃᓅᒍᓐᓀᑐᕕᓂᕐᒧᓘᓐᓃᑦ ᐃᓚᒋᔭᐅᒍᕕᑦ, ᖃᓄᐃᙱᓯᐊᕐᓂᓕᕆᓂᕐᒥᒃ ᐱᒍᑦᔨᔨᐅᒍᕕᑦ ᑲᒪᖃᑕᐅᓲᒍᓗᑎᑦ ᐃᓅᒍᓐᓀᑐᕕᓂᐅᔪᖃᕐᐸᑦ. ᐱᒍᓐᓇᐅᑎᖃᕐᑐᑎᑦ ᖃᐅᔨᒪᒋᐊᖃᕐᓂᒥᒃ ᐱᑦᔪᑎᐅᔪᓂᒃ ᖃᓄᐃᓘᑭᓯᕐᓂᓗ ᐊᑐᕐᑕᐅᓛᕐᑐᓂᒃ ᑕᒪᓐᓇ ᖃᐅᔨᓴᕐᑕᐅᑎᓪᓗᒍ.

ᖃᐅᔨᓴᕐᓂᒧᑦ ᐃᓚᐅᖃᑕᐅᒍᒪᐅᑎᒥᒃ ᐊᖏᕈᑎᖃᓚᐅᕐᓇᒃ, ᐊᑐᐊᕐᓯᖄᕆᐊᖃᕐᑐᑎᑦ ᑐᑭᓯᒪᔭᐅᒥᐊᓕᓐᓂᒃ ᐊᖏᕈᑎᐅᑉ ᐅᖃᐅᓯᕐᑕᖏᓐᓂᒃ. ᒍᒪᒍᕕᑦ, ᐊᑐᐊᕐᓯᕕᒥᕐᖄᕈᓐᓇᑕᒥᑦ ᑖᒃᑯᓂᖓ. ᐊᐱᕐᓲᑎᑦᓴᓕᒫᑦᓯᐊᓃᕕᑦ ᐊᐱᕐᓲᑎᖃᕈᓐᓇᑐᑎᑦ ᑐᑭᓯᒪᑦᓯᐊᓂᐊᕋᕕᑦ ᓯᖁᔭᐅᓂᕐᓃᕕᑦ. ᖃᐅᔨᓴᕐᑐᓄᑦ ᐃᓚᐅᒍᒪᙱᑯᕕᑦ ᐃᓚᐅᙱᑑᒍᓐᓇᑐᑎᑦ.

ᖃᐅᔨᕐᓂᐅᑉ ᐱᑦᔪᑎᖓ:

ᖃᐅᔨᓴᕐᓂᕗᑦ ᐱᑦᔪᑎᖃᕐᑐᖅ ᑐᑭᓯᒥᐊᓪᓚᕈᒪᒐᑦᑕ ᐃᓅᒍᓐᓀᑐᖃᑐᐊᕐᒪᑦ ᐱᒍᑦᔨᐅᑎᐅᓲᓂᒃ ᓄᓇᕕᒻᒥ, ᓇᓗᓀᕐᓯᒍᒪᑦᓯᑕᓗ ᐋᓐᓂᐊᕕᓕᐊᕐᓯᒪᔪᑦ ᐃᓚᖏᓪᓗ ᐃᓅᓯᖅᑯᑦ ᖃᓄᖅ ᐃᓯᕐᓇᓯᐊᓇᐊᓪᓚᑎᒍᓐᓇᒪᖔᑦᑎᒥᑦ. ᐊᐱᕐᓯᖃᑦᑕᓛᖓᔪᒍᑦ ᓄᓇᓕᒻᒥᐅᓂᒃ, ᐋᓐᓂᐊᕕᓕᐊᕐᓯᒪᔪᓂᒃ ᐃᓚᖏᓐᓂ, ᖃᓄᐃᙱᓯᐊᕐᓂᓕᕆᕕᓐᓂ ᐱᓇᓱᑦᑎᓂᒃ ᐱᓇᓱᖅᑎᖏᓐᓂᓗ ᑕᒪᑐᒥᖓ ᐱᒍᑦᔨᐅᑎᖃᓲᓂᒃ. ᐅᖃᐅᓯᖃᕈᒪᔪᒍᑦ ᑐᑭᑖᕋᓯᐊᕐᓂᐅᓲᒥᒃ; ᐊᓇᕐᕋᓯᒪᔪᓂᒃ ᑲᒪᓂᖅ; ᑐᓴᐅᒪᖃᑦᑕᐅᑎᓂᕐᒥᒃ; ᐃᓕᓐᓂᐊᓂᕐᒥᒃ; ᓂᕆᐅᒋᔭᐅᔭᓂᓪᓗ. ᑐᑭᓯᑦᓯᐊᕈᒪᑦᓯᑕᓗ ᖃᓄᐃᓪᓗᐊᑐᓂᒃ ᐱᓇᓱᑦᑎᓴᓪᓚᒪᖔᑦᑕ ᖃᓄᐃᑦᑐᓂᓪᓗ ᐱᐅᒃᑯᑎᑦᓴᖃᕆᐊᖃᒪᖔᑦᑕ ᑕᒪᑐᒥᖓ ᐱᒍᑦᔨᐅᑎᑦᓴᑎᓐᓂᒃ. ᑐᓴᕐᑎᑕᐅᒍᒪᔪᒍᑦ ᖃᓄᖅ ᐃᓱᒪᒋᔭᖃᕐᒪᖔᑦᓯ ᐃᓅᒍᓐᓀᓯᒪᔪᑦ ᖃᒪᒋᔭᐅᓂᕆᓲᙱᓐᓂᒃ; ᐱᒍᑦᔨᒍᑕᐅᓲᒍᒻᒪᖔᑦ ᐃᓯᕐᓇᓯᐅᑦᓯᐊᒪᖔᑦ ᐊᑐᕐᑎᓄᑦ ᐃᓚᖏᓐᓄᓗ; ᐊᑦᔨᒌᙱᑐᓂᒃ ᐱᒍᑦᔨᐅᑎᓂᒃ ᒪᓂᒪᑎᑦᓯᔪᑦᓴᐅᕕᑕ, ᐃᓅᒍᓐᓀᓯᒪᔪᓂᒃ ᑲᒪᒍᓯᐅᓲᑦ ᐱᐅᓯᒋᐊᕐᑕᐅᒋᐊᖃᕐᐸᑦ, ᒋᐊᖃᕐᐸᑕ, ᖃᓄᖅ ᐱᐅᓯᒋᐊᕐᑕᐅᒋᐊᖃᕐᐸᑦ ᐱᒍᑦᔨᐅᐲᑦ ᐊᑐᕐᑕᐅᓂᕆᓲᖓᓗ ᐃᓅᒍᓐᓀᑐᖃᕐᓂᐸᑦ ᑲᒪᒍᓲᑦ. ᑕᒪᒃᑯᐊᓕᒫᑦ ᐃᓚᓐᓄᓚᖔᖏᑐᐃᓐᓇᕆᐊᓛᑦ, ᐊᐱᕐᓲᑎᕗᓪᓗ ᐊᓯᑦᔨᒋᐊᕈᓐᓇᒥᓴᕗᑦ ᒋᐊᖃᕈᑦᑎᒥᑦ. .

ᖃᓄᐃᓘᑭᓲᑦ::

ᐃᓚᐅᒍᒪᓐᓂᕈᕕᑦ ᑲᑎᓗᑕ ᐊᐱᕐᓯᑕᐅᒍᓐᓇᑐᑎᑦ ᓂᐱᓕᐅᕐᑕᐅᒐᔭᕋᕕᑦ ᓯᑯᑦᓴᔭᕐᒫᑕᐅᓛᕐᑐᓂᒃ ᕿᒥᕿᔭᑦᓴᐅᓗᑎᒃ. 30-ᒥᓂᑦᓂᒃ 60-ᒥᓂᑦᓂᓘᓐᓃᑦ ᓯᕕᑐᓂᖃᕈᓐᓇᑐᖅ ᐊᐱᕐᓯᑕᐅᓂᖅ ᑭᐅᒍᑎᑉᐱᑦ ᑕᑭᔫᓂᖕᒥᑦ ᒪᓕᓪᓗᒥ.

ᐃᓚᐅᒍᒪᓂᖅ ᐃᓱᒣᓐᓇᕿᐅᑎᒥᓗᒍ / ᐃᓚᐅᒍᒪᒍᓐᓀᓂᕐᓘᓐᓃᑦ:

ᐃᓚᐅᒍᒪᓃᑦ ᒪᓕᓪᓗᒍ ᖃᐅᔨᓴᕐᑕᐅᖃᑕᐅᒍᓐᓇᑐᑎᑦ. ᑕᒐᑕᒐ ᐃᓚᐅᒍᓐᓇᑐᑎᑦ ᖃᖓᑐᐃᓐᓇᓯᐊᖅ ᐃᓚᐅᒍᒪᒍᓐᓀᕈᓐᓇᓗᑎᑦ. ᐃᓚᐅᒍᒪᓯᒪᓃᑦ ᐃᓚᐅᒍᒪᒍᓐᓀᓯᒪᓃᓪᓘᓃᑦ ᓱᕐᕃᓂᖃᓛᖕᖏᑐᖅ ᖃᓄᖅ ᑲᒪᒋᔭᐅᓂᕆᓲᕐᓂᒃ ᑕᒐᑕᒐ ᓯᕗᓂᑦᑎᓂᓪᓘᓃᑦ.
ᐃᓚᐅᒍᒪᒍᓐᓀᓂᕈᕕᑦ ᖃᐅᔨᓴᕐᓂᒧᑦ; ᐃᓚᐅᒍᒪᒍᓐᓀᓃᑦ ᑎᑭᓪᓗᒍ ᑭᐅᒍᑎᕕᓂᑎᑦ ᐊᑐᕐᑕᐅᔪᑦᓴᐅᓛᕐᑐᑦ ᖃᐅᔨᓴᐅᑎᓅᕐᑕᐅᒥᐊᖃᕐᒪᑕ.

ᐊᑮᑦ ᐅᑎᕐᑕᐅᓂᕐᓗ:

ᐊᑭᓕᕐᑕᐅᓛᖕᖏᑐᑎᑦ ᖃᐅᔨᓴᕐᓂᒧᑦ ᐃᓚᐅᓂᕐᓄᑦ. ᐊᑭᓖᒥᐊᖃᕐᓇᓗ ᐃᓚᐅᓂᕐᓄᑦ ᖃᐅᔨᓴᕐᓂᒧᑦ.

ᑭᓇᒃᑯᑐᐃᓐᓇᓂᒃ ᖃᐅᔨᑎᑦᓯᒍᑕᐅᒥᐊᖃᖕᖏᓂᖏᑦ:

ᖃᐅᔨᓴᕐᑕᐅᖃᑕᐅᓗᑎᑦ, ᖃᐅᔨᓴᕐᑎ ᐱᓇᓱᖃᑕᐅᔪᐃᓪᓗ ᑲᑎᕐᓱᐃᓛᕐᑐᑦ ᓇᓗᓀᒃᑯᑕᕆᒥᐊᓕᒥᓂᒃ ᐃᓕᓐᓈᓕᖓᔪᓂᒃ ᑕᒪᓐᓇ ᖃᐅᔨᓴᕐᓂᖅ ᐱᓪᓗᒍ. ᖃᐅᔨᓴᕐᑐᓄᑦ ᑐᑭᓯᒪᐅᑎᑦᓴᑦ ᑲᑎᕐᓯᑕᑑᓛᕐᑐᑦ. ᑭᐅᒍᑎᕕᓂᓕᒫᑎᑦ ᑭᓇᒃᑯᑐᐃᓐᓇᓂᒃ ᖃᐅᔨᑎᑦᓯᒍᑕᐅᓛᖕᖏᑐᑦ ᐱᖁᔦᑦ ᒪᓕᓪᓗᒋᑦ. ᑭᓇᐅᓃᑦ, ᐊᑏᑦ ᓇᓗᓀᒃᑯᑕᕆᒥᐊᓕᑎᓪᓗ ᓴᐳᑦᔨᓯᒪᑦᓯᐊᕈᒪᑦᓯᒥᑦ, ᓇᓗᓀᒃᑯᑕᖃᕐᑎᓛᕐᑕᕗᑦ (ᑭᑎᑦᔪᑎᓂᒃ ᐁ, ᐯ, ᑌ-ᓂᓪᓘᓃᑦ); ᖃᐅᔨᓴᕐᑎᓂᒃ ᐊᑕᐅᑦᓯᑰᕐᑎᓯᔨ ᓇᓗᓀᒃᑯᑕᓂᒃ ᓇᓗᓀᕐᓯᔨᐅᓛᕐᑐᖅ. ᑭᓇᐅᓂᕐᓃᕕᑦ ᖃᐅᔨᒍᑎᑦᓴᐅᒐᔭᕐᑐᑦ ᐱᓇᓱᕝᕕᑕ ᐊᓯᐊᓅᕐᑕᐅᓛᖕᖏᑐᑦ.
ᐊᕐᑫᒍᓂ ᖁᓕᓐᓂ ᑭᐅᒍᑎᕕᓂᑎᑦ ᐱᐅᓕᐊᕐᑕᐅᓛᕐᑐᑦ ᖃᐅᔨᓴᕐᓂᒥᒃ ᐊᑕᐅᑦᓯᑰᕐᑎᓯᔨᒧᑦ.
ᑭᐅᒍᑎᕕᓂᑎᑦ ᐃᑲᔪᕐᓯᒍᑎᑦᓴᐅᒍᓐᓇᒥᔪᑦ ᖃᐅᔨᓴᕐᓂᐅᕙᓐᓂᐊᑐᓄᑦ.
ᑭᐅᒍᑎᕕᓂᑎᑦ ᐊᑐᐊᑫᑦᓴᖑᕐᑎᑕᐅᒍᓐᓇᑐᑦ ᐋᓐᓂᐊᓯᐅᕐᕖᑦ ᐊᑐᐊᑫᑦᓴᖏᓐᓅᑕᐅᓗᑎᒃ ᐊᑐᐊᑫᑦᓴᐅᓂᐊᕐᓗᑎᓪᓘᓃᑦ ᖃᐅᔨᓴᕐᓂᒥᒃ ᑲᑎᒪᓂᖃᓕᕐᐸᑦ, ᑭᓯᐊᓂ ᑭᓇᐅᓃᑦ ᓇᓗᓀᕐᑕᐅᓂᐅᔭᖕᖏᑐᖅ.

ᖃᐅᔨᓴᕐᑎᓂᒃ ᐊᑭᓖᒍᑎᑦᓴᑦ

ᖃᐅᔨᓴᕐᑎᓯᓛᕐᑐᑦ ᓄᓇᕕᒻᒥ ᐃᓗᓯᓕᕆᓂᕐᒥᒃ ᑲᑎᒪᔩᑦ ᑮᓇᐅᔭᖃᕐᑎᓯᑎᓪᓗᒋᑦ *Fond de recherche du Québec*. ᑮᓇᐅᔦᑦ ᑲᑎᕐᓱᐃᕕᑦᑎᓅᕐᑕᐅᓛᕐᑐᑦ ᖃᐅᔨᓴᕈᑎᑦᓴᓂᒃ.

ᖃᐅᔨᒥᐊᕐᑐᕕᑦᓴᑦ ᐊᐱᕐᓲᑎᑦᓴᓘᓐᓃᑦ:

ᐊᐱᕐᓲᑎᑦᓴᖃᕈᕕᑦ ᖃᐅᔨᓴᕐᓂᒎᓕᖓᔪᓂᒃ ᑐᓴᕆᐊᕐᕕᖃᕈᓐᓇᑐᑎᑦ ᖃᐅᔨᓴᕐᓂᒥᒃ ᐊᑕᐅᑦᓯᑰᕐᑎᓯᔨᒥᒃ ᐅᖄᓚᕕᒥᓗᒍ *Dr. Paul Brassard* 514-340-7563.

ᐊᐱᕐᓲᑎᑦᓴᖃᕈᕕᑦ ᐱᒍᓐᓇᐅᑎᑎᑦ ᐱᓪᓗᒥᑦ ᖃᐅᔨᓴᕐᓂᒧᑦ ᐃᓚᐅᓗᑎᑦ ᐅᖃᐅᓯᑦᓴᖃᕈᕕᓪᓘᓃᑦ ᐅᓐᓂᓘᑎᑦᓴᖃᕈᕕᓪᓘᓃᑦ ᐅᖄᕕᖃᕈᓐᓇᑐᑎᑦ, ᓄᓇᕕᒻᒥ ᐋᓐᓂᐊᓯᐅᕐᓂᓕᕆᔨᒥᒃ *Dr. Nathalie Boulanger* (819)964-2222.

ᐊᖕᒋᕈᑎᒃ

ᐃᓅᒍᓐᓀᑐᕐᑲᕐᓂᐸᑦ ᐃᓄᒻᒥᒃ ᐋᓐᓂᐊᕕᓕᐊᕐᓯᒪᔪᒥᒃ ᑲᒪᒍᓯᖅ ᓄᓇᕕᒻᒥ, ᑯᐯᒻᒥ

ᑐᑭᓯᕗᖕᒐ ᑐᑭᓯᒪᔭᐅᒥᐊᓕᓐᓂᒃ ᐊᐱᕐᓲᑎᑦᓴᑲᓗ ᑭᐅᔭᐅᑦᓯᐊᓱᑎᒃ. ᑖᒃᑯᐊ ᐊᖕᒋᕈᑏᑦ ᐊᑦᔨᖕᒋᓐᓂᒃ ᐱᑎᑕᐅᓛᕐᕐᑯᖕᒐ. ᐃᓚᐅᒍᒪᓂᕐᓄᑦ ᐃᓚᐅᓯᒪᔪᖕᒐ ᕐᑲᖕᒐᑐᐃᓐᓇᓯᐊᕐᓗ ᐃᓚᐅᒍᒪᒍᓐᓀᕈᓐᓇᓯᖕᒐ ᕐᑲᐅᔨᓴᕐᓂᒧᑦ ᐱᑦᔪᑎᑦᓴᕐᑲᖕᖕᒋᑲᓗᐊᕈᒪ, ᑲᒪᒋᔭᐅᒍᑎᒃᑲ ᑲᒪᒋᔭᐅᒍᑎᒋᕙᓐᓂᐊᑕᒃᑲᓘᓐᓃᑦ ᓱᕐᕋᑕᐅᑎᓐᓇᒥᑦ. ᑖᑦᓱᒥᖕᒐ ᐊᖕᒋᕈᑎᒥᒃ ᐊᑎᓕᐅᕐᕕᕐᑲᕋᓗᐊᕈᒪ ᐱᕐᑯᔭᑎᒍᑦ ᐱᒍᓐᓇᐅᑎᒃᑲ ᓴᒃᑯᓂᐊᖕᖕᒋᓚᒃᑲ. ᕐᑲᐅᔨᓴᕐᓂᒧᑦ ᐃᓚᐅᓚᖕᒐᓗᖕᒐ ᐊᖕᒋᕐᐳᖕᒐ.

ᐊᑎᕋ:____
ᐅᓪᓗᖕᒐ:___________________

ᐊᑎᖕᒐ ᐃᓚᐅᔩᑉ: ____

ᐊᖕᒋᕈᑎᒃ ᐊᐅᓚᑕᐅᔪᖅ ᑐᑭᓯᑎᑦᓯᒍᑕᐅᑦᓱᓂᓗ ᐃᓚᐅᓚᖕᒐᔪᒥᒃ ᑕᒃᑯᒧᑦ:

ᐊᑎᕋ:____ᐅᓪᓗᖕᒐ:___________________

ᕐᑲᐅᔨᓴᕐᑎᐅᑉ ᐊᑎᖕᒐ: ____

ᕐᑲᐅᔨᓴᕈᑎᐅᑉ ᑭᑎᑦᔪᑎᖕᒐ ____________