

**ADDRESSING BARRIERS TO PALLIATIVE CARE SERVICES IN
NORTHWEST BC FIRST NATIONS COMMUNITIES**

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Executive Summary

The following report summarizes the information from the research project entitled “Addressing Barriers to Palliative Care Services in Northwest British Columbia First Nation Communities”. The project was started as an initiative of Northern Health Authority’s Northwest Hospice and Palliative Care Advisory Committee. A community based research team was then assembled that included a local community college instructor, a Palliative Care Nurse Consultant, a Northern Health research staff member, and a Research Scientist from the BCCA Socio-Behavioral Research Unit. This project was funded by a Canadian Institutes of Health Research grant awarded to a research team including a member of the BCCA Socio-Behavioral Research Unit.

Health research has shown that many First Nations people in Canada have limited access to the mainstream health care system. One of the main reasons for this limited access is that the culture of the mainstream health system is vastly different from the culture of First Nations people. As a result of limited access there are a number of negative health consequences for First Nations resulting in overall lower health status indicators as compared with the general population of Canada. Palliative care is one area of health care in which First Nations people face numerous barriers. Although the majority of First Nations people would prefer to pass away in their home communities, most Aboriginal communities do not have the health personnel or supplies to accommodate a community member’s death at home. For those who do require palliative care services, most will be moved to an urban facility which creates a tremendous hardship on the patients and the family.

The main purpose of the current research was to identify barriers that limited First Nations access to local and urban palliative care services. The research design included a two-phase data gathering process. First we conducted in-depth discussions with a wide range of stakeholders from the First Nations reserve community of Moricetown, BC, and from health services providers from the closest hospital in Smithers, BC. To assess whether the information could be generalized to other regional First Nations groups, we developed a survey based on the information gathered from the focus groups. This survey was administered in five additional NW BC First Nations communities.

In addition to identifying a range of barriers, a major goal of the current research was to continue to build the support networks between First Nation communities and Northern Health’s Hospice and Palliative Care Program. We sought to accomplish this by first working with First Nation communities to identify solutions that may reduce access barriers. We could then identify linkages to the Palliative Care Program that might enhance service support. We intend to present the research findings to the community of Moricetown and to Northern Health Administrators who will then have the opportunity to work together to develop palliative care capacities in First Nation communities.

Project Deliverable

The current research project had one key deliverable. We had proposed to develop a training framework that First Nation communities could use to build their palliative care capacities. The survey results were used in conjunction with the focus group results as a basis for the development of a training framework in the third phase of the project. The training framework is based on identified barriers as well as one of the author's extensive experiences with palliative care in Northern Health (Lynn Shervill). It includes training not only of First Nations community health workers, but also mainstream Northern Health workers and First Nations community members.

Methods

Phase 1

In the first phase, we facilitated four focus group discussions over a period of two months. In total, there were fifty participants including:

- General community members of Moricetown
- Elders of Moricetown
- Political representatives of Moricetown
- Nurses working in Moricetown
- Other health personnel working in Moricetown
- Nurses, doctors and administrators working at the hospital in Smithers

The data from the focus groups was then transcribed and analyzed for further use in the second phase of research.

Phase 2

The results from the focus groups were used to develop a survey which could be implemented in an interview format. In the spirit of cooperation, we were able to secure the efforts of the Hospital Aboriginal Liaison Workers throughout the Northwest Coast area to administer the surveys in the following First Nation areas:

- Carrier/Sekani
- Gitksan
- Haida
- Haisla
- Tsimshian

A total of 29 surveys with First Nations community members were completed.

Phase 3

The focus group and survey results were used to develop the project deliverable: the training framework. The framework is presented in Appendix A.

Results

Phase 1 - Community Member Focus Groups

Two groups of Moricetown community members indicated that while community members had a rich and vibrant traditional history of providing palliative care, interaction with Western culture has impacted much of the community's capacity to provide that

care today. In conjunction with limited local palliative care services, almost every person requiring palliative care must travel to one of the local hospitals where they pass away. Community members shared a collective disappointment that they were not included in the decision making processes for delivery of services such as palliative care. Many also thought that not having a local care facility was a barrier.

Once a community member is moved from home to an urban facility, there is a host of barriers to local families providing support to their dying loved one. The main barriers for the families appear to be financial ones based on the limited resources of the patient travel department and lack of regular employment in the community. The main barriers for the patient appeared to be language difficulties, understanding medical terminology, and loneliness.

Perhaps the most contentious area of concern may also be the source of the most improvement. Many participants indicated that nurses and doctors who work at urban facilities have been more accommodating of First Nations practices during times of crisis. Although inconsistent among staff, accommodations such as large meeting areas for family and complementary tea service were recognized as important for facilitating First Nations people's satisfaction and comfort in the hospital setting. In terms of decision making, most also reported that doctors and nurses were very accommodating of the family decision making approach of First Nations.

Community Member Recommendations:

- Have Elders teach the youth about culture as it pertains to traditional health care.
- Have more local involvement with the local and regional planning of palliative care.
- Have more people be available to support the dying in a traditional manner.
- Provide 24 hour coverage at the health centre.
- Have traditional services and cultural liaison services that can be mobilized quickly.
- Have local health workers proficient in local language.
- Community health workers need to be proactive in meeting community health needs.

Phase 1 - Moricetown Health Service Providers Focus Group

Local health service providers were mostly aware of the local traditions and honored them as much as possible. The main barrier to providing local palliative care identified from their perspective was simply the lack of funding for twenty-four hour care. In most cases, their schedule is nine to five which is inadequate to provide palliative care.

Where home care has been attempted, health care personnel identified a regular progression of emotion in the families which culminates in intense fear of losing their loved one. In almost all cases, this results in the families asking for the patient to be moved to an urban facility where they pass away. Once in the hospital system, coordinating services between the hospital and the Moricetown health workers was reported as difficult and frustrating at times. There also needs to be communication in each patient encounter to clarify roles of professional caregivers and family caregivers at the bedside. Standards of care need to be met yet family members need to feel comfortable and respected in providing care in traditional ways.

Moricetown Health Service Worker Recommendations:

- Provide training to local people to cope with a dying person at home.
- Provide education to youth about traditional medicines and practices around death.
- Fund 24 hour support and link with Northern Health and FNIHB.
- Provide support to families based on their need.
- Address the desire to extend life for Elders.
- Produce worker guidelines on how to culturally support FN patients and families.
- Do a feasibility assessment for in-community palliative care facility.
- Include more Elders on the Aboriginal Health Improvement Committee.
- Get more community input on programs.
- Establish pro-active community services for the elderly at home and in urban facilities.

Phase 1 - Doctors and Nurses from Smithers Hospital Focus Group

The urban service providers as a group were not very knowledgeable about local First Nations and their cultural traditions. In addition, they were confused by the jurisdictional issues around providing palliative care in First Nation communities. They were, however, cognizant that very few First Nation people enroll in the Palliative Care Program and that most are moved to hospital shortly before passing on. Most were also aware that Moricetown had neither the facilities nor staff to provide palliative care.

Most staff was aware of the need for cultural sensitivity but most agreed that it needs to be balanced with the amount of staff and other resources. Some nurses indicated that high levels of stress and burnout are a real concern and that they can have negative effects on staff behaving in a culturally sensitive manner.

Smithers Hospital Nurses and Doctor Recommendations:

- Provide cultural competency training to mainstream health care professionals.
- Provide culturally sensitive training materials to palliative care workers.
- Address the issue of lack of trust around the planning and delivery of services.
- Be careful not to make assumptions and impose solutions.
- Continue with Aboriginal Health Improvement Committees.
- Establish a key contact/liaison in each community around the palliative care program.
- Provide a range of options for palliation based on support available and patient personal beliefs.
- Hire more First Nation workers so local people feel more comfortable.
- Address the lack of 24/7 coverage in Moricetown by examining service delivery boundaries.
- Work with community contacts to ensure programs are working.

Phase 2 - Surveys

Main findings for the survey are as listed below:

- Two thirds of respondents would prefer to pass away at home.
- Local health care service providers respect the family planning process

- Main barriers to culturally appropriate local services were language differences, lack of traditional foods, lack of youth involvement, lack of training for the death process, lack of 24 hour care, and lack of a palliative care facility.
- Ratings of local palliative care services were mixed.
- Sixty-nine percent of respondents would recommend local palliative care services to others.
- Urban palliative care services were generally perceived as adequate.
- Urban facility nurses were seen as culturally sensitive.
- Urban health providers are respectful of the family decision making,
- The main barriers to culturally appropriate service in urban facilities were language differences, lack of traditional foods, lack of traditional ceremonies, high cost to support family in urban setting, a lack of knowledge of First Nation cultures on part of health provider, lack of training to health providers about First Nations traditions on dying, a lack of respect for Elders, and end of life facilities cannot accommodate large families.
- Ratings of urban facilities were again mixed.
- Forty-five percent of respondents indicated that they would recommend urban services to others.
- The main recommendations to improve local services are to have local workers culturally trained in palliative care, train local youth, have local workers who speak the language, have community education around death, and to have a local facility for palliation.
- Main recommendation to improve urban services were to train care providers about traditional medicine and practices, improve coordination between community and urban facilities, hire more local people to work in hospital, and to have planning groups be more inclusive.

Phase 3 - Deliverable

One of the research team members prepared a Palliative Care Training Framework that can be used by First Nation communities to develop or enhance their palliative care capacities. The training framework included an overview of training needs, a section for urban health care providers, a section for community health care providers, and a section for family/friends as care providers.

Discussion

Based on the research, there are considerable barriers to First Nation people accessing palliative care services. There was a strong concordance between the results of the focus groups and the results from the survey suggesting many of the barriers are common across the NW.

The following is a list of approaches that the investigative team believes would be fruitful to pursue given the recommendations of participants in the research:

- Develop plan to assess the palliative care needs of each community and match with a sustainable palliative care community plan.
- Incorporate First Nation cultural training throughout the health system in BC (i.e., PHSA training).

- Implement additional cultural sensitivity training that is specific to the local First Nations in each area/territory in NW BC.
- Continue to improve culturally sensitive environments in urban facilities by including First Nations stakeholders in planning and decision-making groups.
- Allocate funding to increase the capacity of First Nation communities to provide adequate palliative care services through training of local providers and having access to 24/7 specialty palliative care services as needed.
- Allocate funding to support families who are required to travel to see loved ones.
- Support community member training in palliative care to increase comfort levels in caring for someone in their final stages of life.
- Support community training of youth in traditional health practices
- Develop formal coordinated service protocols between First Nation communities and Northern Health service providers that are easily accessed by front-line staff.
- Strengthen the Aboriginal Health Improvement Committee.

These approaches need to be pursued in partnerships between all stakeholders such that solutions are not imposed externally and to develop acceptable and appropriate accountabilities and responsibilities among stakeholders.

Conclusions

The current research shows a definite gap between First Nation people and the rest of the population when it comes to accessing to palliative care services. Numerous barriers were identified from a wide variety of perspectives in focus groups and complemented by a regionally implemented survey. Participants in both stages of research also suggested a number of potential solutions, some that were placed in the training framework, and others that became the basis of suggested approaches to improving access to and cultural sensitivity of services.

While we were able to attain some valuable information and gather some meaningful recommendations during this research process, it is clear that much more work needs to be done. Palliative awareness for many First Nation communities is just beginning and we need to support all communities in enhancing capacity at the local level. To ensure that services are meaningful, full inclusion of First Nation communities in any service planning is necessary.

1. Introduction

Research has shown that many Aboriginal people living in rural and remote communities would prefer to spend their last days in their community and pass away at home. However, due to lack of local services to support this, many elders must be transferred to a hospital for care in their final days. For some Aboriginal people this brings hardship. A transfer to the hospital means being far from home and family. It also requires coping with death in a foreign cultural environment. The purpose of this research is to identify ways to improve palliative care (end-of-life care) for First Nations people and communities.

An informal study conducted locally showed that to support more Aboriginal people to die at home there is a need for special equipment, training of local health workers in palliative care, and strategies to overcome distance and transfer of care issues. Specifically, the goals of this research project are to build upon the research already done and:

- improve our understanding of the **cultural barriers** around palliative care service delivery; and
- identify **possible solutions** to improve access to and cultural sensitivity of palliative care services.

In order to assess palliative care views across several traditional territories and articulate a palliative care training framework, the current research utilized a three-phase design (see Appendix B for project proposal). In the first phase, focus groups were conducted in the community of Moricetown, British Columbia. There were four focus groups in total. Focus group participants included local governance and health care workers, community citizens, and health care workers from the hospital in Smithers. The second phase involved developing a questionnaire based on the results of the focus groups in Moricetown/Smithers and then having Aboriginal Hospital Liaison Workers administer the questionnaire to twenty-nine members of the various First Nations on the Northwest coast of BC. In the third phase, and based on the analysis of both sets of data, we developed a training framework for implementing palliative care training for First Nation communities (See Appendix A). We hope the information from the research will allow service providers and First Nations communities to work together to overcome the multiple barriers limiting access to palliative care. We are also working to support mainstream health care workers to provide culturally appropriate services to First Nations people.

The current research project was conducted by a community-based research team including a local community college instructor (Mitch Verde), a Northern Health Research and Evaluation Department staff member (Jeanette Foreman), a Palliative Care Nurse Consultant (Lynn Shervill), and a research scientist from BC Cancer Agency (Amanda Ward). Funding for the research is from the national Canadian Institutes for Health Research.

The research project received ethical approval from Northern Health's Research Review Committee and the UBC Research Ethics Board (See Appendix C & D for ethics approvals).

The methods and results for the three phases of research are presented below.

2. Phase 1 - Focus Groups

2.1 Focus Group Methods

The first step in the research process involved conducting a total of four small group discussions (focus groups) held in Moricetown and Smithers between April and June 2009. The focus groups were facilitated by the researchers (Mitch Verde and Jeanette Foreman), the research assistant (Ramona Naziel), and a contract facilitator (Shelley Worthington). To ensure participants felt free to express their opinions on palliative care services, the groups were facilitated by those not involved in direct service provision.

We asked all groups questions in four main areas:

- i. Knowledge or awareness of traditional cultural practices in the physical, emotional and spiritual care of the dying and their families;
- ii. Community-based palliative care – whether adequate and culturally sensitive;
- iii. Hospital-based palliative care – whether adequate and culturally sensitive; and
- iv. What is needed to improve cultural sensitivity of and access to palliative care.

There was a general process for the focus groups. Participants were contacted beforehand and asked to participate in the focus groups. After the participant arrived at the focus group, they were given the informed consent form (See Appendix D) and it was carefully explained.

Once the participants had read and signed the consent forms, the focus groups would begin. The focus groups took between one to one and a half hours to complete. For the community member focus groups the facilitator informed participants that a counsellor would be available should any part of the discussion raise grieving issues.

Two focus groups were held with elders from Moricetown Reserve with the assistance of a Wet'suwet'en translator. One focus group was held with health workers in Moricetown (Aboriginal and non-Aboriginal) and one with health workers in Smithers.

For each focus group, the group facilitators followed Focus Group Protocols (See Appendix E for focus group protocols) consisting of a set of predetermined question. Responses from participants were recorded as notes and by a digital recorder. The digital recordings were later used for transcription and were the basis for data analysis.

Community member participants were given a \$25 honorarium. All other participants took part during work hours and thus were not given honorariums.

The three Northern investigators (MV, JF, and LS) reviewed the transcripts independently and did simple theme analysis. The group then shared their independent results and agreed on several key themes. The data were then re-analyzed according to the agreed upon themes and documented by Jeanette Foreman. The final analysis was approved by all investigators on the team.

2.2 Focus Group Participants

Each focus group included a small group of volunteer participants who had previous experience with palliative care either in a current or traditional sense. The Research Assistant (Ramona Naziel) hand-delivered invitations to community elders. This practice is consistent with traditional practices in inviting community members to events in Wet'suwet'en culture. Lynn Shervill invited Moricetown Band and First Nations Inuit Health staff to participate by e-mail and phone. Lynn Shervill also invited urban health to participate by e-mail and he put up posters in the Bulkley Valley District Hospital (Smithers).

The four groups represented convenience samples. Some saturation of data was observed in the community member focus groups. Because the focus groups included the majority of eligible participants, additional focus groups were not feasible. The community member focus groups were large (about 18 participants each) based on the invitation strategy implemented. We did not anticipate such a high response rate but were pleased with the level of community member participation and quality of data obtained. Further, the mainstream focus group methodology that encourages participation of 5-12 people can be considered less culturally-appropriate and could have been perceived as exclusionary in the context. In the community member focus groups community leaders were most often likely to speak according to local custom, and much of the dialogue required live translation for the facilitators. Only the English translation material was transcribed.

The total number of participants are shown below.

Group	# of Participants
Moricetown health workers	6
Moricetown (Wet' suwet'en) elders	36
Smithers health workers	8
Total	50

2.3 Focus Group Results

Below is a summary of the information we gathered from analysis of the recorded focus groups. The results were different for each group based on their unique perspectives. Therefore, we present the results separately for the elders, Moricetown health workers, and Smithers health workers. Combined, the perspectives provide a broad understanding of the barriers. They also point to potential steps to improve health services by ensuring concerns of all stakeholders can be addressed.

2.3.1 Traditional Practices in Support of the Dying

Elders Focus Group

- **Traditional Wet’suwet’en practices in support of the dying and their family members** that are preserved today include support provided by the *father clan*. This support includes going to the home of the sick person, providing food, and assisting with personal care and household matters. Emotional and spiritual comfort is provided by simply being present and having a calming influence. Sometimes visitors will say prayers, sing and play music.
- The father clan members provide support around decision-making if needed. Discussion often occurs to clarify the seriousness of a situation and to address any personal matters that need to be taken care of in the event of death.
- Some elders told us a traditional practice is to try to meet the needs expressed by the dying person, to support them in accepting death if don’t want to die and to support them in giving a sort of verbal will.

“...if someone is dying and I am a father clan member, I would go and I would support the family, making sure that they have everything that they needed, and if they have misunderstandings, that they understood everything that was happening. And if its long-term, I know I’ve had to explain that it’s a long-term disease, and sometimes if it’s an accident, that’s harder to deal with because nobody knows what happened yet. So, to deal with the grief, you have to be there and you have to be very calm. You have to be able to give spiritual help. [through prayers and music]... sometimes you have to give support to the person that’s dying, because they don’t understand, they don’t want to die. You have to meet that person’s needs, because sometimes they need to talk about what they want done after they die – it’s like a verbal will. I’ve had to do that so many times.”

- High respect is paid for last wishes and family and friends will do anything in their power to honour last wishes. For example, if the dying person requests to eat a particular food, this will be sought out for the person.

“The other thing that traditionally we do is, if a person who is going to die, if they request special food, if they request something special that they want to eat, then you have to do anything within your power to find that food... I remember my late Auntie... she was in the hospital in Vancouver...she said, Oh, I wish I had some moose soup with a little rice in it. Well, my brother had moose meat in the freezer, and he took off right away and within three hours, he was back with the broth and everything in it that she wanted. A Thermos bottle full, and she just drank the whole thing. That’s the sort of thing I’m talking about. Especially when they’re away from home – this is something she would get if she was at home, but she was in a strange hospital, and she requested that. That happens with everybody. If there’s something that they want, then you have to make sure you go out and get it.”

- One elder mentioned that people would know when a dying person was passing into the next life because they would talk of the people who passed on before them, and they would talk about what needs to be carried out before they die.
- **Traditional Wet'suwet'en medicines and treatments** for pain include porcupine, soap berries, and use of heated rocks. Some other medicines (not necessarily just near death) include balsam and red willow inner bark mixture for cough syrup, root of water lily for tuberculosis, devil's club for multi-purpose detoxification and "spring cleaning", and potash compresses for rheumatism. White aspen and rotten eggs were also used for medicine.
- In general, medicines would only be taken if they were from their own culture (e.g., a Wet'suwet'en person would not take a Gitksan medicine).
- People were encouraged to hold a belief in the supernatural power of medicines in order for them to be effective. The process of digging out medicine from the land involved sacred steps of preparation with a respect and belief in power of the place and the medicine. Only what was needed was taken from the land.
- **Traditional practices after death** include praying and singing with the body, washing the body, and dressing the body with clean clothes at the place of death. The body would be kept and people would be present with the body for three days and then it would be buried on the fourth day.

"Right in the house, like where the person died, they bathed the body. That was part of the culture. And then they were dressed in their clothes. The father clan did all this work, and they would then make the coffin and then – it used to be that nobody's body was kept for any longer than three days. On the fourth day, there was always a funeral."

- Now, however, there is a mixture of traditional Wet'suwet'en, Christian, and secular European-Canadian practices with respect to handling of the body after death. The body is now usually prepared by funeral service providers, and the body may be buried up to eight days after death.
- Last rites at the hospital is common although religion plays less of a role in decision making than in the last few decades.
- Traditionally the **father clan** is responsible for the work related to planning and carrying out the funeral.
- The reserve used to have strong religious influence around death-related practices from the Catholic Church but that has waned over time. As well, traditional spiritual leaders have also dwindled. Some can be accessed from other communities but they aren't often contacted by members of the Moricetown community.

[Question: Does the church dictate end-of-life care?] "No, it doesn't. Because we're not that strong Catholic anymore." "But the priest does come in and give them their last rites." "Last rites, yeah. But that's about it, they don't -" "But there's other spiritual people – like, we've lost most of them now, we only have a

couple left. They go into the hospital - Burns Lake still does that when they have a member in the hospital – they sit and pray over them, and then they sing hymns to put them at rest. And it's still happening in the hospital today in Smithers.” ... “No, the Catholic Church doesn't have strong control anymore. Back in the 1950s and 60s, we were very strong Catholics.”

- Several elders expressed **concern about the loss of tradition, language, leadership and respect for elders.**
- Elders were highly valued for their wisdom in the past. Younger members of the clan would even pack elders on their backs and carry them around if necessary.
- One elder objected to the “boxing in” and “institutionalization” of palliative care. Prior to contact people accepted death. It wasn't something that was feared. It was the “next gift”, a happy time to go on to the next life. It was a rite of passage and something people were ready for. Concern was expressed that this has been changed over time, and that introduction of new foods and contaminants with colonization has resulted in deaths associated with more suffering.

“I think in our terms, in our language, in our feelings prior to contact, people accepted death, it wasn't something we were afraid of. It was the next gift. It was the next step into another life, and it wasn't so filled with sorrow, it was a happy time, that they're on to their next life. And so, that's why it was also a rite of passage - rites of passage led you to that gate – it became something that we were ready for.”

Moricetown Health Workers Focus Group

- Moricetown health workers were familiar with many of the traditional end-of-life care practices. For example, they noted that support was provided by the father clan, respect was shown for the wishes of the family, and that around the time of death people gather to talk, pray and sing. They noted that visiting was a common way to provide comfort.
- They noted that sometimes sage, sweetgrass, and “grandmother mushroom” is burned.
- In the past, the traditional practice was for family members or other people to wash and dress the body but not any longer. Now it is left to the funeral home.
- It was noted that a “Settlement Feast” is often held after the funeral to pay back expenses and to reimburse people for helping with care. A traditional “Headstone Feast” is held one year after the death of a clan member.
- Sometimes a person would stay with the widow(er) for a year after death. This person would be a relative or friend that was special to the family.
- The health workers also noted traditional foods include fish, moose, and soap berries.

Smithers Health Workers Focus Group

- Some providers have knowledge of the history of the First Nations people in the area but many are not aware of specific traditions around death and care of the dying. They noted that there are several language and cultural groups in the area and that it is difficult for health workers, particularly those from outside the region, to be aware of and understand all the different practices.

“They tend to have several family members in the room during the death process, and they’re very involved. ... they have practices where certain elders are with them and they do bedside care and things like that that they want to be very involved. It’s quite different from just regular palliative care for nursing, because they definitely want to be very involved in the nursing care at the bedside, so we have to allow that and have them involved with things. And to decide where the nurses should be doing stuff where the family would like to do things. And then, around the time of death as well, they often have many rituals around how much time they spend with a loved one once they pass away.”

- Some providers have observed certain traditions being practiced but are not aware of their meaning. For example, one provider was aware of a practice where when the body goes home from funeral house they will follow it in a procession.
- One provider noted that some but not all First Nations families will rub oolican fish oil, use sweet grass, or do smudges on the body.
- Another provider noted that local First Nations do not think a pregnant woman should be around a dead body (e.g., at the morgue or at a wake) as it is “bad luck” for the baby.

2.3.2 Views of Community-Based Palliative Care on Reserve

Elders Focus Group

- The elders expressed several general concerns about care in the community, not specifically palliative care (which currently is not available).
- A key concern elders is that there are not enough services available in the community and the health staff are not there to provide weekend or after hours care (i.e., 24 hour 7 days a week care).
- Elders noted that a lot of cuts have been made to services that they valued.

“You know, you get sick, they should be there to take you to the hospital, or give you advice. They don’t. I’d like to see better treatment than that. And they cut back on all their medication years ago. They give you a Tylenol No. 3. Cough medicine, they don’t give that anymore, they cut everything out, even ointments. What’s the use to have a health station if they’re gonna cut back on it?”... “No, they’re renovating that bloody health station three times in 10 years, and that’s a lot of money to renovate. They buy cars left and right, and any equipment they want, they just get it. And that’s not the way to look after people. You know, in the 1940s, [name withheld], she was a nurse. She was walking. Only one nurse for

the whole village. She took care of the whole village... Take somebody to hospital if it's serious. Now you got three or four nurses up there, nobody can take care of anything, or do anything for you. It has to be a little better service than that."

- There is also concern that specialized services are not readily accessible (e.g., for a person with heart condition or a person with special therapy needs).
- A lack of access to traditional medicine at the health centre was noted. There is interest in seeing more traditional medicines and approaches being used and elders would like to see greater understanding of the medicines among health workers.
- Elders expressed that they feel they have a lack of input into what programs are offered at the local health centre.
- Some reported that local home care providers do not explain fully to elders what their medications are for (some are on 5-7 medications). When health workers don't know the language or traditional medicines it sometimes leads to an inability to show sensitivity to the elders. It was expressed that elders would prefer health staff speak directly to them rather than using answering machines.

Moricetown Health Workers Focus Group

- The Moricetown health workers have observed that elders are very precious to the community and it is hard for families to let go of them. They want to extend their life if possible.

"My dad knew he was dying and he said "I don't wanna die in hospital". But, we made our decision, and we don't want him to die at home, neither. But, we thought we knew he was dying, and maybe he can get help, extend his life a little longer. I personally would respect his wishes if I had to do it all over again. That's where he wanted to die, at home."

- Health care providers respect the person and their families' wishes as far as possible. They note that each person is unique and have varying degrees of adherence to tradition. How they interact with each is based on the individual.
- The health workers report that they have good equipment access and can draw on resources from the east and west except for hospital beds which are not currently funded by FNIH and have to be requested for a specific individual, not the community. There is also lack of storage space and limited resources for equipment management.
- Providers are either local First Nations, First Nations from other communities in Canada or are non-First Nations and have been acculturated by being in the community for a long time. Those from outside the community do their best to learn the traditions and processes but sometimes fear they will "do something wrong" (e.g., in the Feast Hall).

- The health centre services operate on typical business hours of 9am-5pm with no after-hours service availability. Some providers who are members of the community and live on the reserve are sometimes called for help on weekends.
- The perception is that a major barrier to provision of palliative care in the home on reserve is that there is a lot of fear among family members in taking on this responsibility. Training and support can be provided to informal caregivers but you must also address the fear that most people have.

"I still feel that people are very afraid. It's very frightening to see someone die especially knowing they are taking their last breaths and people panic. They not only panic here they panic everywhere."

Smithers Health Workers Focus Group

- Smithers health care providers realized that very few First Nations patients had been referred to the palliative home care program. They noted it was a huge gap that people were not dying in Moricetown. However, they also remarked that few people – First Nations or not – were getting referrals for palliative home care. The majority of people die in hospital.

"We don't get a lot of people being signed up to the palliative program that are First Nations. It's very, very, very few. We have no control over who gets signed up. We don't bring people in or – So, for some reason, they're not being signed up like others are in white culture, or whatever. So, why that is, is a question for me."

"One of the things that kind of – I know that since [there has been a dedicated palliative care nurse consultant] he's done a lot of coordinating, but I can't actually think of very many people at all that we've made arrangements for palliative care. (agreement). Like, there's a lot of homecare nursing-type follow-up.." "Wound care, yes – palliative care, no." ... "...but it's like – People don't die in Moricetown? It's kind of interesting when you think about it – it's a huge hole ..."

- It was suggested lack of access to the palliative care program may be due to lack of awareness of the program. Provision of written material may not be sufficient to raise awareness.
- They noted another possible reason that no First Nations people are referred to the palliative home care program is that people from the reserve do not talk about cancer and dying – these are difficult subjects to bring out in the open.
- One provider with a friend on the reserve thought that people may not be comfortable with the palliative care program because it doesn't employ "brown people".

- The providers noted that the Northern Health home care service boundaries currently do not currently encompass Moricetown. However, providers thought services boundaries are negotiable and could encompass Moricetown. At the same time, there was concern that boundaries do not stretch so much that there is pressure on existing staff to provide a level of service that is not possible to maintain. This concern may be minimized by providers giving appropriate training to families who tend to do well with training.
- One provider suggested that it is important to determine first whether First Nations people really want the kind of home-based palliative care now provided by Northern Health and physicians through the palliative home care program. It is important to understand their cultural preferences based on their “world view” or spiritual understandings around death. It was suggested that once an understanding and articulation of preferences is obtained, it could then be determined who can best provide the desired services. It may be there is not really a role for Smithers health workers to be involved in providing home-based care since so many services are provided through federal and band services and it may be more appropriate for those providers to be involved in improving home-based services. The missing pieces include 24-hour nursing and physician care.

“Well, I think that there’s a huge, bigger picture... if people aren’t signing up for palliative care, is it because that isn’t what they need or what they’re looking for, or are they actually needing something they’re not getting. And I suspect it’s probably not what they’re needing or looking for in a sense. I mean, for one thing, people will often sign up for the palliative care program because it gets their medications paid for. Well, if that’s already taken care of, you know, no problem. I mean, that’s one of the things. There’s home care and ambulance and the possibility of house calls and whatnot. And again, I mean house calls if you’re going to be dying in the hospital – I just have a feeling that it’s possible, or that a person has to look at, whether the enrolment in palliative care is not there because people are being missed, or because it’s not what they’re looking for and need.”

- It was also expressed that each individual’s preference for home- or hospital-based care should be respected, not solely what the cultural group prefers.
- Providers experience frustrations in trying to transfer patients from hospital to home or one hospital to another. There are procedures that need to be followed, certain pieces of information required, and the right contacts must be made. Not all staff may be aware of the steps or find them straightforward.

“One of the frustrations I felt too, was – okay, somebody I’m managing at home and wants to die at home, but the time comes and they end up in the hospital. I have phoned, let’s say a follow-up case manager, and I would say, Look, is it possible to make arrangements for this person just to transfer to the

hospital...And she would say, Well, you know, we don't have the – You have to go through the channels, and why couldn't we just say, if somebody was dying, could just come through this hospital and go through Hazelton without a border? ...could that be from hospital to hospital, facility to facility, could that just be possible for this person? Say if they're dying in a few days?"

- Providers indicated that family decision making is respected. They did add, however, there are issues around family and dynamics that sometimes make it complicated in practice. This includes knowing which relations should be contacted and who should not within a large complex social structure of family, community and clan.
- Some providers are frustrated in that they sometimes cannot connect with family members when a patient is alive and alert and could be transferred to home but then when a patient is comatose and cannot be transferred the whole family is there at the hospital.
- There is concern that the houses in Moricetown are all two level and aren't physically suitable for providing palliative care.
- Providers noted that it also takes people who are at home and not working and a healthy social network at home to be able to provide palliation in the home and that is not always present due to the socio-economic conditions that exist on reserve. One provider thought perhaps the loss of the ability to care for a dying person at home was representative of the cultural loss associated with colonization since prior to contact this would have been managed. At the same time, it was noted that few people in Canada die at home so this shift in culture toward hospital-based care is common to all ethnic groups.

2.3.3 Views of Hospital-Based Palliative Care in Urban Centres

Elders Focus Group

- Elders value prevention and traditional medicine for the purpose of prevention. However, some value modern facilities for palliative care. Some would prefer to die in a nearby hospital where care is readily available, since it is not available on the reserve. Also, since the practice of the father clan coming to support them while they are in hospital exists, they feel that they would have what they would need for a comfortable death in hospital.

"We don't have a place to put a dying person – a hospice centre or certain house that we can bring them back to. And sometimes, it's better to die in the hospital if you have a disease, a cancer, that's spreading to other people. Myself, I would like to die in a modern facility with access to everything. ...I'll take my chances at the hospital, because we don't have the facilities here. And the care is always there, and people from the clan, your brothers and sisters, your father clan, they all bring things in the hospital for you to feel better. We already have that in

place, so – ”

- Transfers to distant hospitals are more problematic since elders and family members do not get the support they need.

That's a real problem. When somebody is sent somewhere else, they're not cared for properly. Like, my uncle, [name withheld], they sent him from Smithers. They couldn't find a hospital to send him to, so they finally sent him to Victoria. And, his wife and his daughter were able to go. And, he died there. That was something that his wife told me was it was really hard for them in Victoria because they didn't know anybody, after he passed on. And, when he passed away, just [the wife and daughter] were there, and ...a cousin at a later time, but they didn't have the family, the extended family, that would have been at the hospital here to look after the family. And they felt themselves that they had nobody to turn to. When our people die like that in the hospital, they're not cared for in a traditional manner whatsoever.

- The elders report respect is shown for cultural and religious beliefs for the most part in urban centres. However, there is inconsistency among staff in respect shown for customs. Hazelton hospital tends to have more responsive staff than Smithers hospital. The elders expressed most prefer care in Hazelton where there are more Aboriginal service providers and staff show a more caring attitude.

*“What I noticed in Hazelton versus Smithers, in Hazelton, they are very, very caring, whereas Smithers, I see we're limited. When we have too many people, the staff, they yell at people in the hallways. I seen that. My dad stayed in Hazelton. He had all the care he needed. I saw the difference versus Smithers and Hazelton....
But, really, in Hazelton, you have at least five to six First Nations working in the hospital, and they are trained LPNs. A few of them are registered nurses. In most of their palliative care, they have an elder sitting on the panel – because, when I was there last, two weeks ago, there was a meeting for palliative care for the community, especially. The lady's that were CHR were there and they mentioned that they do come in and have meetings with the doctors and the nurses, and it's the chiefs that hold some of the meetings, because they're worried about their people. And we need to start doing that for our people from this area, and from Fort Babine, because most of our people that go into hospital are from that area.”*

- Elders report that care providers do a good job of respecting individual wishes of patients in hospital. Hospital staff and doctors are showing increasing cultural sensitivity, and a willingness to learn and understand.
- Providers do contact family members as necessary so that families can make decisions for patients when needed. If the family cannot decide, the father clan will

join together to make the decision. Life support decisions are made by the family and the preference is to have it that way because the “family knows what’s important”.

“The doctor gives the individual family a choice when they’re at the hospital, and the family gets together ... They have one contact person in individual families. And somebody that could understand the doctors and also understand their own traditions. That’s how they work it.”

- Generally the wishes of patients are respected by providers and formal do-not-resuscitate (DNR) forms are offered to patients. The preference among most elders is for a natural death rather than use of life support.

“Most of our people do not want to be. They’d rather die naturally, instead of trying to live off a machine. A lot of them that have died this past five years, I know for a fact that they have all said no, we don’t want that, that’s not our ways, we would rather die naturally than to try for the doctors to revive you - once you’re gone, you’re gone. They prefer that. If you damage something more, trying to revive an elder. ... Especially what we don’t see - what our people understand in terms of spirit and how we prepare ourselves to leave this world, we connect with that, and if we feel like we’re being offered these machines to keep us alive, it can impede that projection of ascension to the spirit world, and that’s not to be messed with.”

- There is concern that physicians don’t explain things well, they just write prescriptions. However, it is difficult to access a new doctor unless one is accepting new patients.
- Language is a barrier and sometimes procedures are not explained or translated so the elder patient knows what is going on.

“I hear this a lot from our elders here, is that when they take blood tests, they take so much blood but they don’t understand, that person in the hospital doesn’t explain to them what it is or what they’re gonna do with the blood.”

- The elders noted that sometimes care providers don’t allow access to the body after death. They don’t allow time to pray with the body as is the custom.

“When [name withheld] passed away, they just came along and the doctor and nurse told us you have only five minutes, maybe 10 minutes, to stay with him, they have to take him away right away. I didn’t figure it was right – they should give you the rights – Aboriginal rights – which way you want to do - pray with them until they take them away. That’s how I see it.... He was gonna be cremated. So they don’t wait ____.... Even an hour is good.”

- There is concern about discrimination against Aboriginal people regarding medicines and interventions to save lives. Elders questioned why just generic drugs are provided to Aboriginal patients when non-Aboriginal people receive name-brand drugs. Also, they thought that perhaps fewer interventions are offered to elderly Aboriginal patients as though their lives are not as worth saving.
- Some elders reported they found care providers do not allow traditional medicines in hospital, not even when close to time of death and nothing else can be done. However, one person reported a case of one elder dying peacefully with the Western doctor's medicine and another reported that herbal medicine was allowed as long as it didn't interact with prescribed medicines.
- Sometimes elders must be transferred to a hospital when there is no other option. Band cuts to travel escort funding means elders or ill people have to go away without physical assistance, may have to navigate new places without assistance, and are without translation help. Hotel arrangements must be negotiated and the mileage rate was reduced. This is especially hard for elders.
- When elders die in urban centre a long way from home it can be very isolating and they do not have traditional family support which involves visits by large numbers of family. This also poses hardship.

"When you lose that contact, your sickness gets worse. You know, like your loneliness gets worse."

- The elders appear to know the Northern Health Aboriginal Hospital Liaison Worker in Smithers and her role.

"I think everybody knows that [name of liaison worker] is working for the Friendship Centre and that she is the Aboriginal hospital liaison worker, I think is what her position is. Everybody knows that, she's there to help us whenever we need help. It's important too that she speaks our language. That is important that they speak the language. She doesn't just work with Wet'suwet'en here, she works with the Nadleh Whut'en, and she works with people from Tahltan – all of the native people that live in the area. So you have to be aware of all these different cultures. And we even have Eskimos living in Smithers."

Moricetown Health Workers Focus Group

- Moricetown health workers have observed that mainstream health care providers in urban centres such as Smithers and elsewhere respect the person and their families' wishes, particularly with respect to life support.
- They have witnessed that elders are very precious to the community and it is hard for families to let go of them. They want to extend their life if possible. There does tend to be a lot of flexibility and individual choice around cultural practice. The

community is not homogenous and therefore it is important to inquire with each patient what their preferences are.

- Traditional food can be brought in to the hospital but it isn't typically prepared by hospital staff as part of the regular menu or as a menu option.
- The hospital staff will place First Nations people in a private room to accommodate large numbers of relatives visiting and this is appreciated. However, there is a concern that nurses avoid providing care to First Nations patients when there are a lot of people in room. The patients may not be getting needed care and checks.
- They feel the cultural sensitivity of mainstream workers toward First Nations patients, anyone of minority culture, as well as elders, depends on the individual – some providers are culturally-sensitive, some aren't. Sensitivity is inconsistent. Hospital staff may see the “seedier” side of things from some people in the emergency department and then “paint all First Nations people with the same brush” (i.e., stereotype).
- Health workers have observed that urban providers don't draw on community supports to provide care to First Nations patients (e.g., translators are not requested to help explain things to a patient to get their cooperation). These supports are readily available, it just takes a phone call to the Moricetown health centre and supports are mobilized. They are concerned that elders will not ask for things like pain killers due to pride and because it is hard to ask a stranger. Health workers would like to see the supports used more often.
- There is the feeling that the local community is not involved in the overall planning of services, that urban providers lack knowledge of the community, and that they do no outreach to the community. There is also instability of urban nursing staff which makes relationship building difficult. However, it was noted that this was beginning to be addressed through the Aboriginal Health Improvement Committee.
- Health workers are aware of the Aboriginal Hospital Patient Liaison Worker but their perception is that the liaison is for “mostly in town” (i.e., Smithers).

Smithers Health Workers Focus Group

- Smithers health workers noted care for First Nations patients can be complex because the Smithers hospital is a referral centre for different First Nations groups and service referrals aren't always straight-forward. For example, one area of difficulty is serving residents of Fort Babine. Their Carrier Sekani leadership and health administration is in Burns Lake but their service travel pattern is to Smithers. The Aboriginal liaison worker for Carrier Sekani is in Burns Lake. The discharge planner at the Smithers hospital only has access to the Smithers liaison worker but that worker is not responsible for Fort Babine.
- There are different languages, different traditions, and different territories that also make patient care complex.

“So, when we think about different cultures of First Nations, and territories, there are overlapping cultures, overlapping territories, and that creates more confusion,

especially for us as service providers.”

- Jurisdictional issues also make it difficult to figure out service delivery solutions due to complexity and uncertainty as to who is responsible for what, and who has money for what. Nothing is clearly defined. Claims on territorial boundaries among First Nations are overlapping even among First Nations people, therefore it is even more difficult for non-First Nations to understand.

“...well, it comes up all the time, because First Nations people are trying to figure out where they fit in to work with us, and we want to work with them, and we’re all trying to figure it out, not only on a community level, but it’s also on a government level, and it’s different levels that they’re being funded with, and everybody is trying to figure it out together, so there’s nothing that’s really definite”

- Providers indicated there is difficulty coordinating transfers of care back to home once in hospital. There may be paperwork or administrative reasons or difficulty connecting with the right people. A patient may have a complex web of relationships to family, community, and to clan. Some may have left the reserve but toward the end of life need they may want to reconnect to their reserve home and let people know they are dying. Health workers don’t know what connections to facilitate for family and community support.

“Two times I just tried to make arrangements for them to go back, but it usually never works out and they ended up in the hospital, and that’s the last place. That’s a bit frustrating.”

- Workers expressed that they have been “pushed away” by the First Nations community because the communities have seen so many health workers come and go. It takes time to develop relationships and them to be open to you. One worker noted that by speaking to the elders even just a few words in their Aboriginal language facilitates openness and friendliness.
- Compassion is shown by most providers to families in hospital, including First Nations families, by providing a “tea cart” for family members when a person is about to pass away. This is not done as a part of policy, but individual nursing practice. There is some concern that when this is expected it becomes a problem because it is not always possible due to workload.
- Providers feel the large room in Smithers hospital with a microwave and television works well for First Nations palliative patients as well as for non-First Nations patients (it accommodates lots of visitors).
- Health care providers feel that First Nations people don’t necessarily want to be at home when they have serious health issues or are dying, they want to be in hospital. A sort of “love-hate” relationship with the Smithers hospital was described, however. People may be choosing to die in hospital for greater security despite the fact they don’t want to be there.

- The perception shared by one worker from a friend is that Hazleton hospital is preferred by Moricetown residents because there are more “brown faces” working in Hazleton compared to Smithers. People like being able to rely on the hospital services, but tend to be more comfortable in a hospital environment that is more consistent with their culture.
- Health workers acknowledge they have a lack of cultural knowledge and this impacts their care. They may not have received their training in province and haven’t had opportunity to learn this otherwise.
- Providers expressed willingness to be culturally sensitive but also commented on pressures to keep the acute care facility running smoothly. Many do try to be culturally sensitive and do a juggling act to balance the need to operate the facility to accommodate emergency care (e.g., one provider reported moving a dead body from a trauma bay to another area so family could spend more time to “say goodbye”).
- Some providers experience frustration at being expected to accommodate family members during busy times – like bringing tea or locating cups, finding paper and pencil for kids to be entertained, interacting with family spread out all over the hospital from the emergency room to the third floor.
- Nurses reported that First Nations family members want to be very involved and hands-on in providing care at the bedside and try to respect that. Some reported that some family members do not want to provide hands-on care, but just want to be present.
- Some providers experience frustration with their coworkers – they want to see them being more culturally sensitive and patient with First Nations patients and families. However, these coworkers are reported to have the attitude: “we have standard healthcare, it should be the same for everyone” and therefore do not try to support First Nations cultural practices.

2.3.4 Potential Solutions to Improve Palliative Care

Suggestions made for improving palliative care access and cultural sensitivity of care included the following from each group:

Elders Focus Group

Education in Traditional Practices

- Younger community members and community health workers could go to the Friday program where culture is remembered. Elders would like to see local people taught to be health care providers and then also learn traditional approaches.
- Ask those with knowledge to pass it down to others, perhaps with the assistance of a translator. Elders would like to see younger people taught how to make traditional medicines (find it, bless it, prepare it). A community-inclusive and wholistic process could be implemented where people use the language, get out for exercise, and learn about the medicines. (They cautioned about need to acquire ability to take traditional medicine in appropriate, graduated, doses, not just full dose at death).

Planning of Services

- Involve the Community Health Representative and Chief in meetings about palliative care services. The Chief could be invited to sit on the board of hospital. Elders would like to see all clans represented on any committees or task forces, not just one family. They recommend those elders who know both English and Wet'suwet'en be on such groups.

Delivery of Services

- Recommend more people be available to support the dying and fulfillment of last death wishes (e.g., having traditional foods and medicines before death; things carried out by family members).
- Provide 24 hour/7 days a week coverage at the health centre. Have traditional services and cultural liaison services at the hospital that can be mobilized quickly for cases when someone will die in a short period of time.
- Encourage local home care workers to explain medication purposes and appropriate use. Ensure health workers speak the language so that a sense of things taking time is conveyed, rather than being abrupt.
- Health workers need to “be aggressive” in getting needed services to community members and such that no one has to wait around for service calls that could come at any time.

Moricetown Health Workers Focus Group

Education in Traditional Practices and Home-Based Palliative Care

- Provide training local people to cope with dying person at home and address people's fear associated with caring for someone near death. Provide education around the health care system trend that emphasizes reduced use of hospitals and more use of community-based care. Training could be offered through venues such as health fairs, tagged onto other workshops & events (e.g., diabetic clinics), and by putting up a palliative care display at the health centre.
- Provide education to youth in the community about traditional medicines and practices around death, and incorporate with other language and culture training (e.g., sessions where go out onto land, identify plants, dig up medicines, prepare them, etc.)

Delivery of Services

- Enhance local capacity for provision of palliative care in the home. Fund human resources to ensure nursing staff availability outside 9-5pm & on weekends (i.e., 24/7 support). Ensure access to hospital beds to allow palliative care at home. Establish working relationships with NH and FNIH for equipment and service to allow for palliation at home. Seek Band Council support.
- Have support for families with less tradition to be able to rely on tradition in times of palliation and on short notice. Address the desire to extend life for elders and to accept interventions that may prolong life but not quality of life.
- Produce a written booklet or guidelines on how to culturally support Aboriginal patients and families for mainstream health workers. Produce simple resources or protocols for hospital staff, especially new staff and staff from outside area to know

who to contact in community for support of care for community members and inter-agency communication/guidelines (e.g., patient travel coverage; community contacts). (Moricetown health workers expressed interest in leading this out).

Planning of Services

- Look into the possibility of a new home on the reserve for palliation. Look into the possibility of an “all-native home” in the North since smaller communities don’t have enough demand to justify their own.
- Establish more permanent or stable representation from elders and communities on planning committees for urban palliative care. Work with the Aboriginal Health Improvement Committee to better establish the group, address high turnover in membership and incorporate elders.
- Work on getting more community input on programs not through a community health survey, but a summer student who will go door-to-door.
- Establish more pro-active community services for the elderly such as outreach visiting and transportation to special events for isolated elders in homes on reserve and in the urban long-term care facilities.

Smithers Health Workers Focus Group

Cultural Sensitivity Education

- Provide cultural competency training to mainstream health care professionals. Providers expressed interest in understanding the First Nations “cosmology” around death, the culture and belief systems.
- Ensure written materials and training to local home care providers in palliative care be culturally sensitive. Use pictures, full explanations, practice of skills and demonstration of skills to ensure it is effective and appropriate.

Planning of Services

- Address the issue of lack of trust around the planning and delivery of services. Effort must be made to establish mutual trust.
- Be careful not to impose solutions and things set up with the assumption that home palliative services as they look now are what people want to happen in First Nations communities.
- Continue with Aboriginal Health Improvement Committees.
- Establish a key contact/liaison in each community around the palliative care program. These contacts would then educate the community about the program discuss issues with the community and interact with relevant stakeholders.

Delivery of Services

- Provide options for palliation to individuals and allow individual circumstances around family support networks and personal beliefs lead to choices to palliate at home or not. Options for palliative care need to be offered in such a way that they aren’t set in stone. People can be offered it and advised they can change their mind.
- Hire more First Nations health workers so First Nations people feel more comfortable at home and in hospital.

- Address the lack of 24/7 coverage. Renegotiate home care boundaries but first put all the pieces in place. Avoid setting up unrealistic expectations for service. Increase nursing staff to provide service in homes if care is going to be shifted to that setting.

“So, if we decide okay, we’re going to offer, or we’re going to kind of encourage people, suggest that dying at home is what they should want and have, and so then we make this referral to Homecare nursing in Moricetown, and there’s no coverage on the weekends, and there’s – dayshift – there’s service provision, right? Yeah, they’re the pieces we want to put in place.”

- Work with community contacts to ensure programs are working.

2.3.5 Comparison of Barriers With Solutions

The participants of our four focus groups offered a wealth of information to enable improvement in palliative care services for First Nations people in Northern BC. Through analysis and synthesis of the transcripts we identified some of the traditional beliefs and practices of the Wet’suwet’en First Nations people around care of the dying, barriers to the provision of palliative care in reserve community homes and barriers to the provision of culturally sensitive palliative care in all settings.

The tables below outline the key barriers (cultural and structural) that were identified by focus group participants as well as potential solutions.

Elders Focus Group	
<i>Key Barrier</i>	<i>Proposed Solution</i>
Lack of 24/7 coverage at community health centre	Provide staffing for after hours
Lack of knowledge of culture, medicines and language among youth and health workers	Provide cultural training in community and to health workers
Lack of input in planning of services	Include elders from all clans on planning committees
Lack of communication or explanations around health care provided & language issues	Have health care providers who can use the language, take time to explain things (e.g., medicine purpose)
Tendency to “box in” or “institutionalize” palliative care	Allow more traditional and natural views of death to re-emerge as well as provide services needed in this day and age due to contemporary causes of death among First Nations people
Moricetown Health Workers Focus Group	
<i>Key Barrier</i>	<i>Proposed Solution</i>
Lack of 24/7 coverage at	Fund staff to provide after hours coverage

community health centre	
Lack of hospital beds	Coordinate with Northern Health and FNHI for access to beds and other needed equipment for home palliative care service
Lack of local facility for palliation or long-term care centres for First Nations elders	Look into possibility of local house for palliation; look into possibility of Northern "all native" long-term care facility
Lack of knowledge & fear	Provide training and support to community members around care of the dying and address issues of fear; train health workers in the culture
Lack of use of supports to facilitate appropriate care of patients in hospital	Develop manual for mainstream health workers to explain transportation and coverage procedures; Ensure nurses understand that care still needed even when family also providing bedside assistance
Lack of regular contact and planning with Northern Health	Ensure continued development of Aboriginal Health Improvement Committee and representation to address issues in an ongoing way

Smithers Health Workers Focus Group	
<i>Key Barrier</i>	<i>Proposed Solution</i>
Complexity understanding people from several different cultural and language groups	Have liaison from each community around palliative care, cultural practices, for translation; Provide cultural competence training to health workers that is region-specific
Jurisdictional confusion	[Potential solutions not offered]
Having to juggle hospital efficiency & cultural sensitivity	Provide cultural competence training; Work with community liaisons to plan service approaches
Lack of 24/7 coverage in community by home care staff and physicians and lack of family supports for home-based care	Extend home care boundaries; Ensure enough nurses/physicians to provide coverage; Provide culturally-appropriate training to local health workers; Provide support to families
Difficulty in making transfers from hospital to hospital or hospital to home	[No solutions proposed for this barrier]
Lack of comfort with hospital workers where there are few First Nations health workers	Hire more First Nations health workers; Provide cultural competence training to all health workers
Lack of awareness and understanding of home-based	Provide information about the program but not just printed material; work with liaisons

palliative care	from each community
Lack of trust	Take steps to ensure mutual trust before imposing “external” solutions; offer options to patients with flexibility to choose and change their minds

3. Phase 2 - Survey

3.1 Survey Methodology

Aboriginal Hospital Liaison Workers or health worker contacts were asked by the investigative team to conduct community member interviews between the dates of February 2010 and April 2010. In order to promote consistency during the interview process, each interviewer underwent the same orientation process before conducting interviews.

Aboriginal Liaison interviewers in seven communities (Burns Lake, Hazelton, Queen Charlotte City, Kitimat, Masset, Skidegate, Terrace) were asked to interview 5-10 members of First Nations reserve communities they serve. Each interview lasted approximately one hour. The reserve communities represent the following northwest BC First Nations cultural groups:

- Carrier-Sekani
- Haida
- Haisla
- Tsimshian
- Nisga’a
- Gitx’san

The Liaisons employed by Northern Health were not reimbursed for data collection. Liaisons not employed by Northern Health were provided \$25 per interview conducted on their own time. All survey participants were given a \$10 honorarium.

The survey questions were similar to the focus group questions, and the focus group results were used to develop appropriate response categories.

The survey asked questions in the following areas:

- a) demographics
- b) traditional practices around death and dying
- c) preferences for end-of-life care
- d) opinions on barriers to culturally appropriate palliative care services in the local community (i.e., on reserve)
- e) satisfaction with/opinions on palliative care services in urban centres

- f) opinions on barriers to culturally-appropriate palliative care services in urban centres
- g) potential solutions to improve health services in the community and urban centres
- h) comments

Please see Appendix G for the survey consent form and Appendix H for a copy of the survey.

Data were entered into Excel spreadsheet by a data entry clerk and imported into SPSS 15.0 for analysis by Jeanette Foreman.

3.2 Survey Participants

Not all interviewers were able to complete 5-10 surveys within the time frame of the research grant. A total of 29 community member surveys were received from five different contacts as shown in the table below.

Community Contact From:	Number of Surveys Recieved
Burns Lake	6
Kitimat	8
Prince Rupert	3
Skidegate	7
Hazleton	5
<i>TOTAL</i>	29

Surveys were received from community members from the following major cultural groups, providing a wide representation from across the Northwest:

- Carrier-Sekani
- Gitxsan
- Haida
- Haisla
- Tsimshian
- Wet'suwet'en

It is important to note that each individual may have been from one or more First Nations cultural groups by background and some were maternally or paternally descended from additional First Nations groups from North America.

The detailed demographic profile for the 29 community members interviewed is as follows:

Sex:

22 Females (76%)

6 Males (21%)

(1 = missing (3%))

More women than men participated in the survey (76% females).

Age Group:

		Frequency	Percent
Age (years)	20-40	6	20.7
	41-50	6	20.7
	51-60	2	6.9
	61+	14	48.3
	Total	28	96.6
Missing		1	3.4
Total		29	100.0

Almost half of the participants were 61 years or older (n=14).

Ethnic Background:

Twenty-six participants responded to the questions regarding their First Nations (or other) heritage. Three did not report their ethnic heritage.

- 26 (100%) reported having First Nations heritage.
- 24 (83%) participants reported having First Nations heritage on both their mother's and father's sides.
- 13 participants had the same First Nation's heritage on both their father and mother's sides (e.g., both parents of Haisla background).
- 8 reported being of mixed First Nations background (e.g., Gitksan father and Tsimshian mother).
- 1 participant reported $\frac{3}{4}$ First Nations, and $\frac{1}{4}$ European background.
- 2 participants reported having First Nations background not from northwest BC (groups not reported to preserve confidentiality). All other participants were of northwest BC First Nations background.

Years Lived in Community:

Participants tended to be long-term residents of their First Nations community.

- 59% lived in their community 41 or more years.
- 14% lived in their community 11-20 years.
- 21% lived in their community 21-40 years.
- 6.9% lived in their community less than 10 years.

		Frequency	Percent
Years	0-10	2	6.9
	11-20	6	20.7
	21-40	4	13.8
	41+	17	58.6
	Total	24	100.0

Experience Providing End of Life Care to Friends or Relatives:

Almost all participants reported that they had provided end-of-life care to a friend or relative (25/29 or 86%). The number of friends or relatives cared for ranged from 1-30.

- Fifteen participants reported caring for three or fewer friends or relatives.
- Six participants reported caring for between 5-15 friends or relatives.
- Two participants reporting caring for 30 friends or relatives.

3.3 Survey Results

3.3.1 Traditional Practices Around Death and Dying

Survey participants were asked to provide some information on traditional practices around care of the dying and how death and burial was handled. The objective was to gain an understanding of traditional practices and how they might interact with modern healthcare and burial practices – either positively or negatively. The idea was that this would allow for a greater understanding regarding First Nations community member satisfaction or dissatisfaction with services, and be used to inform how services can be made to be more compatible with traditional practices.

Participants were asked to provide information regarding traditional (a) family support practices; (b) spiritual practices; (c) ways of providing emotional comfort; (d) medicines or treatments for pain or other purposes; (e) care and preparation of the body and spirit or soul after death; (f) funeral or ceremonial practices.

The responses reflected a mix of both pre-contact and post-contact practices of the past, with some participants clarifying whether the practice was pre- or post-contact. On a whole, it appears that practices now and in the recent past are somewhat syncretised – or a blend of pre-contact traditional First Nations practices and traditional post-contact Christian-European practices.

Since participants come from different cultural groups, the results are presented below for each area of traditional practice and by each cultural group. Responses were open ended,

so the results were analyzed qualitatively and a summary is presented for each. Due to low number of responses and inability to probe for details and meanings of certain practices, the information is somewhat limited.

Traditional Practices...

	Gitksan	Haida	Haisla	Tsimshian	Carrier-Sekani
Family support	Father clan provides support. Family house group clan provides support.	Clan & family provide support. Opposite clan plays large role.	No clan system. Family helps. Formerly verbal wills.	Clan & family provide support.	Father clan helps. Own clan prepares food, drinks, helps with visitation. Helpers are hired.
Spiritual	Ministers or pastors, other Christians, come to pray.	Prayers, song, whole community involved. Elders support.	Traditional way was to sit and be quiet and wait for death. Prayers with minister introduced by Christians.	Church support. Ceremonies, washing & cleansing of patient.	First Nations healers, Catholic priest support. Prayers, Carrier hymns.
Emotional	Visiting, singing, praying.	Community support, foods, singing, visiting, prayer circle.	Tons of family & support, food, singing, hymns, visiting.	Visiting, food.	Family visits, gospel singing, food, grooming, prayer.
Medicines	Plant roots ingested or smudged.	Plants, roots, bark, heated rocks. Cedar, devil's club tea.	Medicine tea, Devil's club tea, Yew wood tea (cancer). Alder bark +hemlock pitch for burns, elderberry bush poultice (poisons), Owk-su-lee root pinned on clothing (prevention/ward off bad spirits).	Devil's club (pain).	Indian tea/medicine to drink. No specific compounds mentioned.
Care after Death	Washing body, prayers & singing, feasting. Father Clan buy clothes	Opposite clan washes & dresses body. Prayer &	No crying while passing so don't hold person back. No crying	Prayers. Wash and dress body. Now undertakers usually prepare	Prayers & goodbye. Not touching body after death.

	Gitksan	Haida	Haisla	Tsimshian	Carrier-Sekani
	and casket, dig grave. Undertaker dresses in clothes. Chiefs talk and minister prays.	singing. Keeping a clear mind.	or touching body after death (10 - 30 min after so spirit doesn't get lost with sound of crying). Wash & dress body (male-male; female-female). Mourning songs after death. Clan takes care of family of deceased (cook/clean).	body.	Catholic last sacrament, anointing, rosary, cross.
Funeral/Ceremonial	Mother clan (house members) decides everything and hires father clan members. Father clan does night watch, transporting. If a chief dies, chiefs and house members from other clans sing their mourning songs during wake period.	Opposite clan guards and transports body. Opposite clan takes care of most details.	Wake time 3 days, now 4 or 5. Guarding of body. Relative with truck usually transports due to expense of funeral home hearse. Family burial plot. One year mourning.	Memorial service before burial. Grave digging to dry grave and ground.	7 day wake in case deceased awakes. Father clan for potlatch, clothing, casket, digging, burial.

3.3.2 Preferences for End-of-Life Care

Participants were asked, when the time comes, whether they would prefer to pass away in their home community or in an urban facility (e.g., hospital or care home). Roughly two-thirds preferred to pass away in their home community and one-third said they preferred to pass away in an urban facility.

	Frequency	Percent
Missing	1	3.4
Home Community	20	69.0

	Urban Facility	8	27.6
	Total	29	100.0

Participants were also asked who they would like to have their end-of-life care provided by. The numbers of participants preferring care provided by family, traditional healers, community-based service providers (e.g., home support workers), or formally trained care providers (e.g., doctors, nurses) are shown in descending order the table below.

Wish care to be provided by	Yes	Percent
Family	24	82.8%
Community-Based Service Providers	15	51.7%
Formally-Trained Care Providers	13	44.8%
Traditional Healers	6	20.7%

Other preferences (n=5) for care-givers specified were:

- father clan (n=2)
- nurse hired through insurance (n= 1)
- hospital (n=1)
- friends (n=1)

3.3.3 Opinions on Palliative Care Services in the Local Community

Participants were asked to rate their level of agreement with several statements about palliative care services in their community. The statements and the number of participants selecting each rating are shown in the table below.

Where a majority of respondents “strongly agreed” or “agreed”, or where a majority of respondents “disagreed” or “strongly disagreed” the results are shaded lightly to show the slightly dominant pattern of results around the neutral. Where there was a clearer majority, the responses are shaded darker (i.e., more than 50% or 15 or more).

Q. #		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
15.	Palliative care services in this community are adequate to meet community needs.	3	7	10	5	4	29
16.	Doctors who provide palliative care in this community are sensitive to local culture.	1	9	10	5	4	29

Q. #		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
17.	Nurses who provide palliative care in this community are sensitive to local culture.	3	11	11	2	2	29
18.	Nurses are adequately trained to provide palliative care in this community.	2	9	10	4	4	29
19.	Home support workers are adequately trained to provide palliative care in this community.	3	10	6	6	4	29
20.	The local palliative care services respect the family planning in the overall palliative care process.	7	15	3	2	2	29

Overall, a large number of respondents were neutral with respect to the questions. It may be that respondents did not have strong opinions one way or the other, their experiences are mixed, or they did not feel they could “judge” these areas.

Slightly more respondents agreed than disagreed:

- nurses providing palliative care are sensitive to local culture;
- nurses providing palliative care are adequately trained; and
- home support workers are adequately trained to provide palliative care in the community.

Slightly more respondents disagreed than agreed that:

- doctors providing palliative care are sensitive to local culture.

The strongest response pattern for all participants was with respect to the question about respecting the family planning in the overall palliative care process. The majority of respondents agreed or strongly agreed that services respect the family planning (22/29).

3.3.4 Opinions on Barriers to Culturally-Appropriate Palliative Care Services in the Local Community

Potential factors that may limit access to culturally-appropriate palliative care service in the community, based on our focus group results, was listed and participants were asked to rate the degree to which the factor was a barrier. The number of participants selecting each rating is shown in the table below. The rating chosen by the largest number of

participants is shaded light aqua. If this number was over half of respondents it was shaded dark aqua.

Q. #		Not a barrier at all	Some what of a barrier	A definite barrier	A very large barrier	Don't know/not sure	Missing
21	Local care providers do not speak the original language .	3	10	7	9	0	0
22	Traditional foods are not available in the community.	3	8	12	4	0	2
23	Traditional services or ceremonies are not able to be performed freely.	4	11	5	4	3	1
24	Traditional spiritual practices are not available in the community.	11	4	7	3	3	1
25	Younger family members do not know or value the local cultural traditions and practices around death and dying.	1	7	8	12	0	1
26	Our community does not teach the traditional ways around death and dying to our younger generations.	4	2	8	12	2	1
27	Local care providers do not know the traditions and practices around death and dying.	3	11	5	9	0	1
28	There is a lack of training for local providers in traditional ways around death and dying.	1	3	7	14	3	1
29	Formal religious practices have taken the place of traditional practices around death and dying in the community.	6	3	10	7	2	1
30	There is a lack of support of elders from family members in the community.	11	5	4	6	2	1
31	There is a lack of 24 hour community health worker services .	4	1	7	15	1	1

Q. #		Not a barrier at all	Some what of a barrier	A definite barrier	A very large barrier	Don't know/not sure	Missing
32	There is a lack of 24-hour palliative care nurse or physician support for the community.	2	2	10	14	0	1
33	There is a lack of local end-of-life care facilities in the community	3	1	6	18	0	1

The largest barriers were “structural” barriers. The largest majority of participants identified the following as large barriers to culturally appropriate care:

- Lack of 24 hour community health worker services
- Lack of 24-hour access to palliative care nurse or physician support
- Lack of local-end-of-life care facilities

The largest “cultural” barriers, where the majority of respondents indicated it was a very large barrier, included:

- Younger family members **do not know or value** the local cultural traditions and practices around death and dying
- Our community **does not teach the traditional ways** around death and dying to our younger generations.
- There is a **lack of training** for local providers in traditional ways around death and dying.

Overall Ratings of Local Palliative Care:

Participants were asked to rate the quality of palliative care services provided by providers in the community (where 1 = very poor and 10 = excellent). Twenty-eight participants responded.

- The ratings ranged from 1-8.
- The mean rating was 5.1 (st. deviation 2.4).
- The median rating was 5 (i.e., half below 5, half above 5).
- The modal rating was 8 (i.e., most common rating was 8; 7/24 selected this rating).

See Figure 1.

Quality of Local Palliative Care Services Ratings

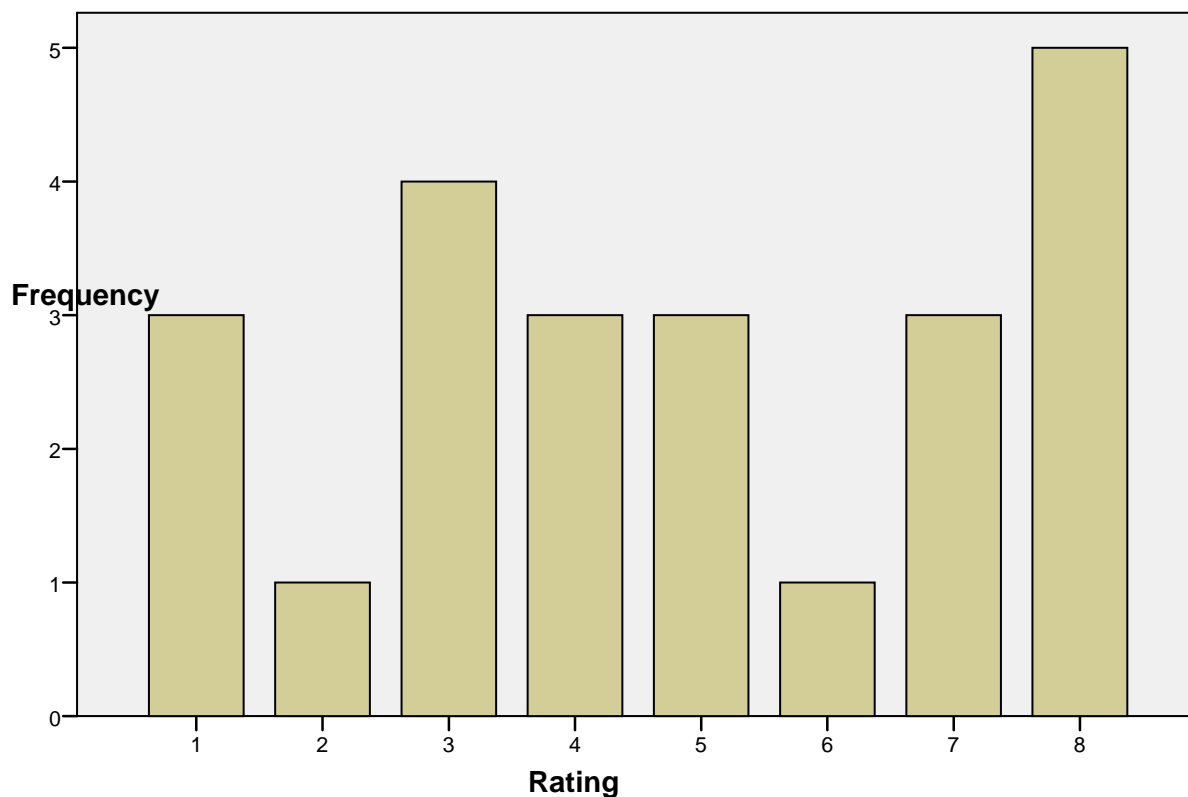


Figure 1. Participant ratings of community end-of-life services on a scale of 1-10 (1= very poor; 10 = excellent).

Thus there was a high degree of variability among responses. Examining the data by community group did not suggest quality was perceived as better in some communities and not others. Ratings varied within community as well.

Whether Participants Would Recommend Community Services to Others:

Participants were asked whether they would recommend the local palliative care services to fellow community members. The majority would, but almost a third would not.

- 20/29 (69% of all survey participants) said they would recommend the services to others
- 7/22 (24.1%) said they would not

		Frequency	Percent
Recommend Services?	Missing	2	6.9
	No	7	24.1
	Yes	20	69.0
Total		29	100.0

3.3.5 Opinions on Palliative Care Services in Urban Centres

Participants were asked to state their level of agreement regarding statements about end-of-life care in urban centres (e.g., hospitals or care homes). The statements and number of participants selecting each rating are shown in the table below.

Q.#		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Missing
36.	Palliative care services in surrounding urban communities are adequate to meet community needs .	2	10	7	8	1	1
37.	Doctors who provide palliative care in urban centers are sensitive to local culture.	1	7	10	5	5	1
38.	Nurses who provide palliative care in urban centers are sensitive to local culture.	3	6	9	6	4	1
39.	The urban palliative care services respect the family planning in the overall palliative care process.	6	9	8	4	2	1

3.3.6 Opinions on Barriers to Culturally-Appropriate Palliative Care Services in Urban Centres

Potential factors that may limit access to culturally-appropriate palliative care service in urban centres, based on our focus group results, was listed and participants were asked to rate the degree to which the factor was a barrier. The number of participants selecting each rating is shown in the table below. The rating chosen by the largest number of participants is shaded lightly. Where more than 50% of participants selected a rating the response is shaded darkly.

		Not a barrier at all	Some-what of a barrier	A definite barrier	A very large barrier	Don't Know/ Not Sure	Missing
40.	Urban care providers do not speak the native language .	2	6	5	15	1	0
41.	Traditional foods are not served in the urban centres.	2	3	6	18	0	0
42.	Traditional services or ceremonies are not able to be performed freely in urban centres.	4	3	7	14	1	0
43.	Out-of-pocket costs for transportation, hotel and meals associated with stays at urban centres are too high.	1	1	5	22	0	0
44.	Traditional spiritual practices are not able to be performed freely in urban centres.	3	2	7	13	3	1
45.	Urban care providers do not know the traditions and practices around death and dying.	1	4	8	15	1	0
46.	There is a lack of training for urban providers in traditional ways around death and dying.	0	3	6	16	4	0
47.	There is a lack of respect for elders of diverse background in urban centres.	3	3	6	12	4	1
48.	Urban end-of-life facilities do not accommodate large numbers of visitors in patient rooms.	3	4	3	18	0	0

All factors were seen as significant barriers. The largest barriers noted, in order of participant ratings were identified as:

- Too high out-of-pocket costs associated with stays in urban centres
- Traditional foods not served in urban centres

- Urban facilities do not accommodate large numbers of visitors in patient rooms
- Lack of training for urban providers in traditional ways around death and dying
- Urban care providers do not speak the native language
- Urban care providers do not know the traditions and practices around death and dying

Overall Ratings of Urban Palliative Care:

Participants were asked to rate the quality of palliative care services provided by providers in the community (where 1 = very poor and 10 = excellent). Overall the ratings were slightly higher than for local services.

- The ratings ranged from 1-10.
- The mean rating was 5.5 (st. deviation 2.5).
- The median rating was 5.5 (i.e., half below 5.5, half above 5.5).
- The modal rating was 8 (i.e., most common rating was 8; 7/29 selected this rating).

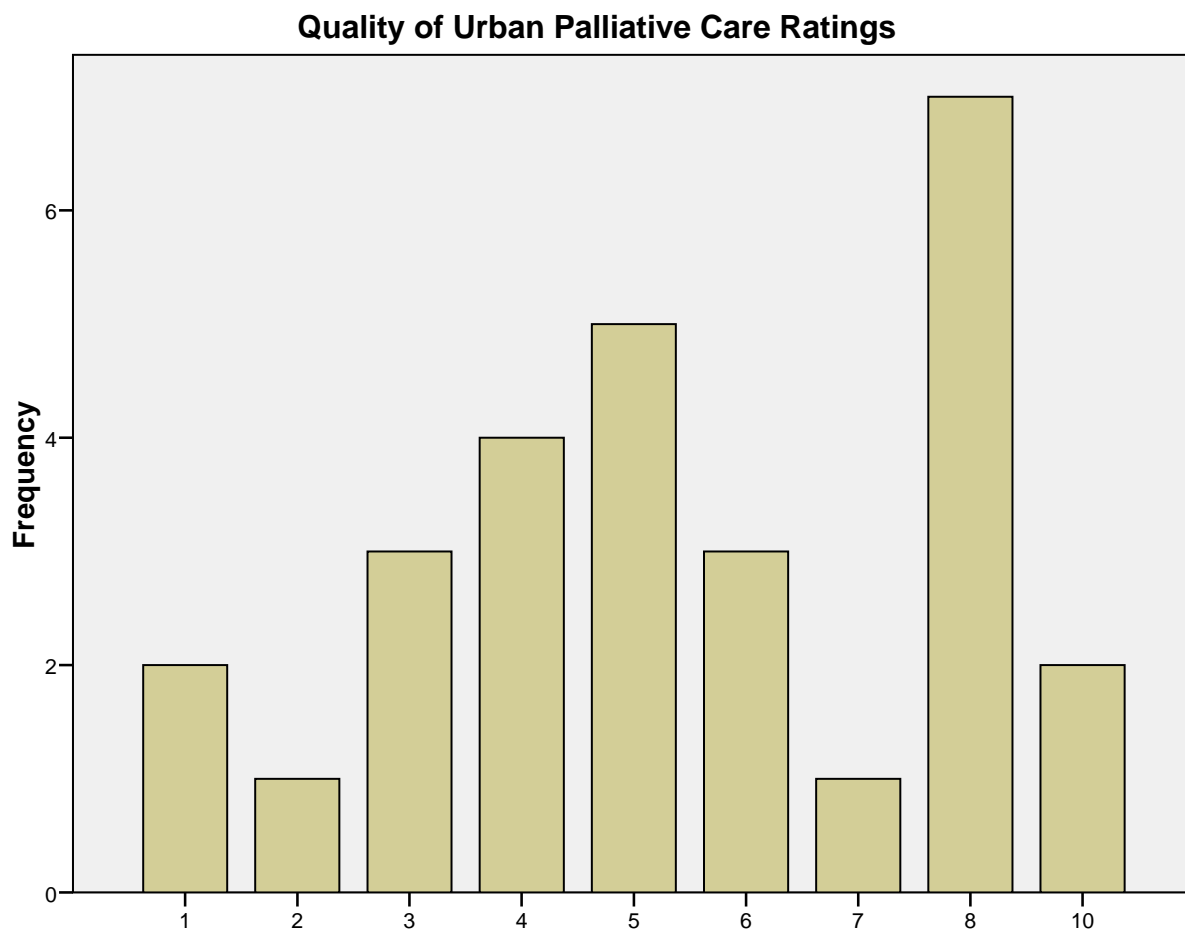


Figure 2. Participant ratings of urban end-of-life services on a scale of 1-10 (1= very poor; 10 = excellent).

Whether Participants Would Recommend Urban Services to Others:

Participants were asked whether they would recommend the urban palliative care services to fellow community members. About half would and half would not.

- 13/29 said they would recommend the services to others (45% of all survey participants)
- 14/29 said they would not (48.2%)
- 1/29 was unsure (3.4%)

		Frequency	Percent
Recommend Services?	Missing	1	3.5
	No	14	48.2
	Yes	13	44.8
	Unsure	1	3.5
Total		29	100.0

3.3.7 Potential Solutions to Improve Health Services in the Community and in Urban Centres

Participants were asked to identify what they regarded as the three issues of greatest concern to them regarding provision of services in (a) the local community and (b) urban centres. The question was left open-ended and thus a qualitative analysis of the responses was conducted by grouping according to similar themes and then ranking them numerically. The most significant issues are noted in the table below.

<i>Top Concerns – Local Care</i>	<i>Top Concerns - Urban Care</i>
To have local workers trained in palliative care (n=8)	Interactions with staff where they are not respectful of culture or courteous or not supportive (n=10)
To have local facility, home, or beds so people don't have to be "shipped out" for palliative care (n=7)	Affordable accommodations/housing for family (n= 7)
Provider respect for culture & training in culture (n=4)	Space in rooms to accommodate family (n=5)
Expenses for family in supporting loved one cared for outside home community (n=4)	Lack of traditional foods (n=4)
Training/support of family	Difficulty of not being surrounded by loved

Top Concerns – Local Care	Top Concerns - Urban Care
members/community to provide care (n=3)	ones (n=3)
Availability & support for use of medical equipment locally (beds, catheters) (n=3)	Transportation issues (n=3)
Lack of space for large families (n=3)	Desire for Aboriginal Liaison (n=2)
Pain management (n=2)	Place for kids while parents visiting (n=1)
Alcohol use while visiting patient – ban it (n=1)	Too medical (n=1)
Counselling service (n=1)	Visiting hours too restricted (n=1)
Transportation to & from community (n=1)	
Language (n=1)	
Food (n=1)	
If no hope, patient should not be sent out (n=1)	
Total n = 28	Total n = 26

Based on suggestions received in the focus groups, participants were then provided a list of potential approaches to improve access to culturally-appropriate, high quality end-of-life services. They were asked to indicate their level of agreement with these possible approaches. The results are presented in the table below. The most common rating is shaded lightly. Where there was over 50% of participants selecting a level of agreement, the response is shaded darkly.

	Approaches To Improve Local Services	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Missing
53.	Train local providers in traditional practices & medicines & their meaning.	16	9	3	0	1	0
54	Train local youth in traditional practices.	17	10	1	0	0	1
55	Hire local workers who can speak the native language.	13	11	5	0	0	0
56	Host a community workshop to explain the physical process of death and Western palliative care approaches (e.g., pain medicine).	23	4	2	0	0	0
57	Build a local facility where local people can receive end-of-life care.	24	4	1	0	1	0

Overall, survey participants were in high agreement with all the suggestions for improving access to local, culturally-appropriate palliative care services.

- Only one respondent strongly disagreed with the idea of training local providers in traditional practices and medicines and their meaning.
- One respondent also strongly disagreed with building a local end-of-life care facility.

Participants were asked what additional suggestions they had for improving local services. This was an open ended question so responses were grouped according to theme and are presented below in order of most to least common suggestion. Fourteen participants made comments.

- Local palliative care/respice facility (n = 5)
- spiritual practices in care for dying (n = 3)
- housing/accommodations for families coming from out of town or more “at home” feel so visitors feel more comfortable (n=2)
- playroom for kids (1)
- more respect, compassion (n=1)
- more use of traditional foods consistent with health status (e.g., fish soup vs salmon steak) (n=1)
- die in own home (n=1)

	Approaches To Improve Urban Services	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Missing
59	Train urban providers in traditional practices & medicines & their meaning.	13	11	3	1	1	0
60	Improve coordination between community and urban providers.	17	11	1	0	0	0
61	Hire more local people to provide service in the hospital.	17	10	2	0	0	0
62	Include representatives from each community on the Northern Health Aboriginal Health Improvement Committees or other relevant planning groups.	21	8	0	0	0	0

Overall, survey participants were in high agreement with all the suggestions for improving access to urban, culturally-appropriate palliative care services.

- Two respondents disagreed that urban providers should be trained in traditional practices and medicines and their meaning.

Participants were asked what additional suggestions they had for improving urban services. Participants were asked what additional suggestions they had for improving local services. This was an open ended question so responses were grouped according to theme and are presented below in order of most to least common suggestion. Eighteen participants made comments.

- more training of providers in traditions and family in care that can be provided to relative in hospital (n=5)
- more dialogue/communication/planning/cooperation between providers and family around patient care (n=4)
- visitor/family accommodations – free or at reasonable rates, made more comfortable for them (n= 3)
- more funding (n=2)
- First Nations liaisons or representatives working with the terminally ill (n=2)
- dedicated palliative care room that is roomy (n=1)
- mental health counseling for First Nations to address pain buried for years (n=1)

3.3.8 Additional Comments

Participants were invited to share any additional thoughts they had about end-of-life services for First Nations people in Northern BC. This was an open ended question so responses were grouped according to theme and are presented below in order of most to least common suggestion. Fifteen participants made comments.

- listen to the patient, respect the patient & their wishes, support the patient (n=6)
- have bigger family and patient rooms in facilities (n=2)
- have a 24-hour access to care services (n=1)
- use liaison workers to keep communication between family and patient (n=1)
- provide financial help to bring remains of loved one back home plus home where family can make themselves comfortable and cook their traditional foods (n=1)
- caregivers would gain in their spiritual lives and need to respect the knowledge ways of the First Nations – “we are all connected” (n=1)

4. Phase 3 – Training Framework

Based on the focus group and survey results, a training framework was developed. The complete framework and rationale appears in Appendix A. The framework was developed to facilitate action toward improving First Nations access to and cultural sensitivity of palliative care services both in local communities as well as towns and cities where people are often transferred for care (i.e., urban settings).

5. General Discussion

For many First Nation people who have interacted with their local and urban palliative care systems, despair and confusion are often part of the process. This research study assessed some of the First Nation barriers to palliative care at the local and urban levels using focus group and survey methods. Based on the information gathered, we also provided a training framework in which the local residents can tailor to their culture and resources.

The present research study was a three stage process with each component building off of the previous step. In the first step, we conducted focus groups in Moricetown and Smithers to assess barriers to local and urban palliative care services for local First Nation residents. Information from the focus groups was used in the second stage to prepare a questionnaire and administer it to twenty-four participants from several different North-west coast First Nations.

Consistent with earlier research was the observation that a majority of people would prefer to pass away in their home community if the resources were adequate. Almost two thirds of survey respondents indicated that their home community was a preferred place to pass on. Over eighty percent of survey respondents also indicated that family would be the preferred palliative care providers suggesting that in terms of their practical wishes, a home based palliative care system is a viable option. Most of the survey respondents also agreed that local palliative care facilities would reduce community barriers to palliative care.

Although a preference for many First Nation people, most participants identified a lack of palliative care resources in their home communities. Compounded by an overall weakening of the First Nation traditional cultural approaches to palliative care, many people see local palliative care service as a remote possibility. Furthermore, the lack of continuity of care between local and urban health service providers creates an environment which often creates fear, confusion, and hardship for many First Nation clients and family members.

One of the major issues for First Nation people is that services in their communities are often limited and are not practical for palliation at home. Participants suggested locally conducted palliative care training could be offered to bring some awareness and

understanding to the process of dying. Further to training, most participants were supportive of expanding local palliative care services. Strong points identified included expanding local services to twenty-four hours, developing local care facilities, hiring more First Nation people in local communities and urban centers, and including more people in planning services.

To complement the western approach to palliative care training, most of the participants suggested that there needed to be more involvement with the young people in cultural training as it pertains to palliative care.

In terms of the actual palliative care services offered, there were again some differences and some similarities in the two sets of data. One difference was that there was a high amount of neutral answers chosen on the survey scales. This difference may be due to actual differences in knowledge between the participants in the survey and focus groups or it may be due to differences in the information gathering procedures. Although the data did seem to differ in this regard, other similarities suggest that overall there were more commonalities than differences. One area of congruency was the participant observations that there is a lack of formal management processes between rural and urban health care providers. A solution from many participants suggested that better coordination between health care providers could result in a major improvement to providing palliative care to First Nations people.

Increasing participant hope that services could improve was the observations by many participants that services have been improving over time. Elders from the focus groups and Moricetown health workers noted that they have witnessed increasing willingness and effort on the part of mainstream health workers to understand First Nations cultures and to be respectful in practice. The relatively positive attitude towards acknowledged accommodations for First Nation kinship systems during times of crisis suggest that some urban facilities are striving to provide a more culturally comfortable setting. Further to making accommodations for First Nation families, virtually everyone reported that the wishes of individuals and families are respected by healthcare providers around life support and other critical end-of-life decisions. The role of the Aboriginal hospital liaison was also recognized as valuable although her work appears to be largely based in town and in the hospital.

Although access to palliative care has been improving at some levels, other barriers seem to have been getting worse over time. Many participants identified a lack of adequate support to families who are required to travel to visit their relatives who have been moved to urban facilities. For many people, a lack of or reductions to overall patient travel funding for First Nation groups has correspondingly resulted in reduced access to escort funding, as well as food and accommodation funding.

The consistency of identified barriers was reflected in the consistency of solutions by the participants in both data gathering stages. Almost everyone recognized the value of education. Different types of education for different groups were stressed. All recognized the value in planning together, particularly through the Northern Health

Aboriginal Health Improvement Committees which exist in each Health Service Delivery Area (HSDA) and each cluster within the HSDAs. Numerous specific and practical suggestions were made to improve coordination and access to services as well as to enhance cultural sensitivity.

Either explicitly or not, most expressed that each individual is unique, and that each person may make a choice to die at home or in hospital, depending on their circumstances as well as their cultural and religious beliefs. Thus an approach that optimizes choice and flexibility in options throughout the dying process is preferred. Moreover, everyone wished to see improvements in the cultural sensitivity of care provided in home and hospital.

Study Limitations

Due to the variability in traditional and western palliative care resources available to the different First Nations, the findings from the focus groups may not be readily generalized to all First Nation groups. Our intent was to address this limitation by implementing a survey across the various Northwest Coast First Nations. Due to the lower than expected responses to the survey, we were unable to compare results by community reliably. Primarily group results are presented. Also, the overall results must be interpreted with caution due to the overall low number of respondents. We view these results as preliminary. Where response patterns are strongest are the areas where most likely a larger sample would yield similar results. However, we can only view these findings as tentative unless similar findings are obtained from another research project with larger numbers of community members. Further exploration of barriers and solutions is required in each local community.

6. Conclusions

The present research contributes to the knowledge regarding cultural barriers to palliative care in several ways. First, by using a two step data gathering procedure, we were able to extend our research population across the North coast of BC. Although small samples for the survey merit caution in interpretations, there was some strong consistency with the focus group in some areas. This is important as any steps to address barriers should account for need and efficacy of system enhancement.

A second way that this research contributes is that there was an emphasis on investigating barriers to palliative care from several different stakeholder perspectives. The perspectives of community members, as well as local and urban service providers resulted in a wealth of information. The strength of this approach was a clearer

understanding of the practical, cultural, and financial influences on how First Nation people access palliative care services.

A third and more practical contribution of this research is the development of a training framework that can be implemented based on the local First Nation cultures and availability of resources. This framework does not intend to impose cultural perspectives, western or other First Nation, on any one First Nation group. In the spirit of community based research, we are hoping to encourage each community to take full ownership of the home-based palliative care programs. As a result of the current research there are also viable suggestions to improve the working relationships between the local community care providers and their urban counterparts.

There are many positive implications from the present study, however, and there will need to be much effort from all parties involved to improve access and strengthen culturally-sensitive approaches to care. The First Nation communities will need to continue to strengthen their cultural traditions in palliative care, particularly passing on the training to their younger people. To complement the local strengths, palliative care training needs to be made available to local community members. Additional funding is required in order to increase local community health services to twenty-four hour care. Finally, there needs to be better coordination between local service providers and urban services providers. There is some reason to be optimistic about First Nations gaining better access to palliative care services based on current trends toward cultural competence and sensitivity training. Consistent with these trends, our goal is to assist the health care system and First Nation family systems in honouring the request of many local community Elders and others who are experiencing a terminal illness. For many, we can collectively honour their wishes by providing an environment that will allow them to pass away in their home communities.

7. Acknowledgements

We would like to thank everyone who participated in the focus groups, and the Moricetown members who provided the lunch to Elders who participated. We would like to extend a big thank you to Ramona Naziel, our Research Assistant from Moricetown. We also would like to thank the Moricetown Band, Northern Health, and BC Cancer Agency managers for their support of this research project. We would like to thank all of the Aboriginal Hospital Liaison Workers and interviewers for their assistance on the survey part of the project. We also would like to acknowledge the investigator group from the BC Cancer Agency who allocated their Canadian Institutes for Health Research funding to this specific project.

Appendix A: Training Framework

OVERVIEW OF TRAINING NEEDS

The research project entitled Addressing Barriers to Palliative Care Services in Northwest BC First Nations Communities has identified several areas where training and education would enhance the delivery of hospice/palliative care to the Aboriginal population of this part of the province.

Four focus groups and a multi-subject questionnaire were used to gather information, opinions and suggestions about the current state and potential of hospice/palliative care delivery from Haida Gwaii to Burns Lake. Subject areas included traditional practices around death and dying, preferences for end-of-life care, opinions on palliative care services -- and barriers to those services -- in Aboriginal communities and urban health facilities and, finally, suggested solutions to some of the identified barriers. The need for training in cultural competence and the knowledge and skills associated with the delivery of quality palliative care were referred to often.

Enhancing cultural awareness, sensitivity and competence was a major theme arising from this research. For instance, more than 50 per cent of questionnaire respondents saw language difficulties, a lack of knowledge about traditional foods and end-of-life traditions, and the failure to provide adequate family space as “very large barriers” to palliative care delivery in urban care facilities. Another barrier cited by both focus group and questionnaire participants involved a lack of training for younger members of Aboriginal communities in traditional end-of-life care practices. In the solutions section of the research, the most often cited suggestions for improvement involved the need for training in cultural competence.

This emphasis on the importance of cultural competence is echoed in other research involving the Indigenous people of Northwest B.C. Tobin et. al. (*Appropriate Engagement and Nutrition Education on Reserve*, Journal of Aboriginal Health, Jan. 2010, Vol 6, Issue 1) state “... even the most state-of-the-art initiatives are destined to fail if they are perceived to be disrespectful of, and insensitive to, local First Nations culture and ways of knowing.”

And Richard Gremm, a former social worker at Prince George Regional Hospital, states in his Master’s thesis *Learning From Healing The Healers* (UNBC 2007): “Health care providers should consider that current practices in health care that fail to accommodate First Nations cultural practices may be experienced by them as a continuation of the cultural oppression that they experienced when the Government of Canada outlawed the balhats (potlatches).”

Community-based training in the knowledge and skills required to deliver quality palliative care was another major suggestion emerging from the research. In fact, of the 24 questionnaire respondents, 19 “strongly agreed” with the suggestion for “a community workshop to explain the physical process of death and Western palliative care approaches (eg. – pain medicine).”

In order to address these training needs, and thus break down some of the access barriers, the researchers have identified three training target groups. The first group – urban care providers – are defined as those Euro-Canadian health care providers (doctors, nurses, social workers, physiotherapists, discharge planners, lab techs) working in the hospitals and clinics outside of but near the Aboriginal communities -- places like Smithers, Terrace, Prince Rupert, Vanderhoof and Prince George.

The second target group is composed of professional health care providers, both Indigenous and Euro-Canadian, working in the Aboriginal communities. These would, for example, include nurses, social workers, counsellors, home support workers and dental assistants.

The third target group is family care givers and friends, the mostly Aboriginal people who would be providing around-the-clock care in the home of the palliative patient. More than one research participant stated that while their loved ones indicated a desire to die at home, they ended up dying in hospital because family and friends were uncomfortable with the process of dying and unfamiliar with the kind of care required.

In what follows the researchers have made some suggestions as to training for these three groups of care givers. However, it should be said that the specifics of such training – enrolment criteria, course preparation, delivery methodology, instructors – should be a collaborative undertaking involving, at the least, representatives from the Aboriginal Health community (eg. – Aboriginal Health Improvement Committees, community health clinics, band councils), Northern Health’s Hospice Palliative Care Program, and the Provincial Health Services Authority’s Indigenous Cultural Competence program.

URBAN CARE PROVIDERS (mainly non-Aboriginal)

The BC Provincial Health Services Authority has prepared a comprehensive, on-line cultural competence course for health care providers working with Aboriginal clients and their families. This course, entitled Indigenous Cultural Competence (ICC), takes approximately eight hours to complete and provides detailed information on the *Social/Historical Context for Aboriginal People, Enhancing Self Awareness and Cultural Competency and Skill Development for Cultural Competency*. It employs a variety of teaching methodologies including a journal, on-line discussion groups, teleconferences, videos, referral to additional resources and a pre- and post-course quiz. Much of the course material is delivered by Aboriginal people and a course facilitator engages in regular communication with students. An IT tech is available on short notice if any technical glitches crop up.

While this course uses examples of cultural practices, values and beliefs from a variety of Aboriginal groups in British Columbia, it does not purport to provide a comprehensive overview of any one of them. In fact, it stresses that cultural practices, language, values and beliefs vary widely between and within the different Aboriginal groups residing in the province. As such, it is recommended local health managers in the NW Health Service Delivery Areas work with the Aboriginal Health Improvement Committees to provide training on the cultural practices of specific Aboriginal groups as a supplement to the PHSA course. One way to do this would be to employ the Aboriginal Hospital Liaison Workers in the northwest to provide this kind of group-specific awareness training. The training would be informed by the results of this research project (focus groups and questionnaires) as well as by the liaison workers' own knowledge of local practices. For example, the responsibilities of the father clan and the mother clan in end-of-life care and support differ greatly between various Aboriginal groups. Knowing what applies locally could be extremely helpful to the urban professional care giver trying to design a care plan for an Aboriginal palliative patient and that patient's family. The use of traditional medicines, the importance of traditional foods, beliefs around the meaning of death, after-death traditions and ceremonies, use of translators, and the role of mechanical life support are other subjects of local importance cited by participants.

In terms of enhancing hospice/palliative care knowledge and skill levels among urban professional care providers, there are several options. The Hospice/Palliative Care Nurse Consultant employed by Northern Health is mandated to provide education focused on all aspects of end-of-life care. The nurse's mandate also provides for consultations on difficult symptom management problems. Victoria Hospice provides excellent, five-day courses on medical and psychosocial care of the dying. Another source of expert palliative care mentoring is available through NH home care nurses. Unfortunately, in many cases, their service area does not encompass some of the more remote Aboriginal communities (eg. – Moricetown is outside the service area for Smithers-based home care nurses).

COMMUNITY HEALTH CARE PROVIDERS (Aboriginal and non-Aboriginal)

Again, the PHSA on-line ICC course would be an appropriate educational tool for professional care providers such as nurses, social workers, counsellors, dental workers and home support workers in Aboriginal communities. The skills and knowledge around cultural competence contained within the course are a valuable asset to any care giver's practice.

If we hope to shift at least some of the hospice/palliative care for Aboriginal people from urban health care facilities to their communities and their homes, education around hospice/palliative care delivery is required for community health care providers. This is a point repeated several times by questionnaire and focus group participants and addresses earlier research findings (Hotson et al, 2004; Verde & Shervill 2008) that indicate that while most Aboriginal people would prefer to die at home, the vast majority die in hospital. It should be said here that education and training is only part of the problem. Elders cited a shortage of qualified care givers, especially those who can speak the local language, and a lack of after-hours and weekend health care coverage. Earlier research also pointed to geographical and resources barriers.

Several Power Point presentations, prepared by the NH hospice/palliative care consultation team, are available for training purposes. They include lecture material and case studies covering such topics as pain management, drug calculations, nausea and vomiting, shortness of breath, respiratory congestion, nutrition and hydration at the end of life, psychosocial care and self care. Training for palliative care givers from beginners to experts is also available through Life & Death Matters, a BC-based training company. Information on various national, provincial and local health authority resources and programs dealing with hospice/palliative care could form the basis of a separate presentation. Examples include the Canadian Hospice/Palliative Care Association, Virtual Hospice (Canadian internet-based resource tool), federal Compassionate Benefits programs, First Nations Inuit Health Branch (Non-Insured Health Benefits Program with palliative pharmacy) BC Hospice Palliative Care Association, the BC Benefits Program and Northern Health's Hospice/Palliative Care Program.

FAMILY CARE GIVERS, FRIENDS (mostly Aboriginal)

For those Aboriginal people who have expressed a desire to die at home, much of the care giving would fall on the shoulders of family and friends. According to many participants in this research, the care giving role is one with which they have no experience and one that scares them. A lack of knowledge and training is compounded by a lack of available community experts who can be summoned to deal with symptom management crises in a timely manner. Thus, even when there is an

expressed desire to die at home, the patient's family may prefer that end-of-life care be provided in the urban hospital setting where there is 24/7, expert care available.

There are, however, excellent resources available for family caregivers. One of the primary mandates of the NH Hospice/Palliative Care Nurse Consultant is education. Another of the nurse consultant's mandates is to provide consultations. Thus, a community-based RN or health worker, working in conjunction with family and friends, has access to expert training and advice on how to deal with various symptom management problems encountered in the palliative patient. In addition, books such as *A Care Giver's Guide* from the Canadian Hospice/Palliative Care Association, provides the non-professional care giver with easily accessible information on what to expect as their loved one nears the end of life and on many aspects of actual end-of-life care. Some elders also suggested in-house training (from the elders) for Aboriginal young people in the gathering, preparation and use of traditional medicines.

CONCLUSION

This research project, Addressing Barriers to Palliative Care Services in Northwest BC First Nations Communities, and others (Gremm 2007) have demonstrated a real need for two distinct types of training; ***cultural sensitivity, awareness and competence***, and training in the ***knowledge and skills associated with quality palliative care***. It is the sincere hope of the "Barriers" researchers that we can work collaboratively with various community, regional and provincial health organizations to ensure this training is provided in a comprehensive and timely manner.

In his 2009 Aboriginal Health Report, BC's Provincial Health Officer stated that the province's Indigenous people have a shorter life expectancy and higher rates of preventable deaths, infant mortality, suicide and chronic disease than other residents of the province. For some BC residents, this is not "The Best Place on Earth" ... yet.

Appendix B: Research Study Proposal

Identifying Cultural Barriers to Accessing Palliative Care Services

A Community Based Approach to Assessment and Improvement

Project Description

A research project will be undertaken to identify cultural barriers that discourage First Nation people who live in a rural setting from accessing formal palliative care services. Identifying these barriers will assist the different levels of palliative service providers to better understand and as a result, to improve palliative care services to rural Aboriginal communities in British Columbia.

Statement of Problem

Although some cultural barriers have been identified for different aspects of First Nation health care use, information regarding palliative care services in rural First Nation communities remains limited.

Some local research has indicated that although a majority of rural First Nation people would prefer to die at home, the majority of them die in hospitals outside of their home communities. Furthermore, when rural Aboriginal residents choose to die in their home communities, palliative care services do not usually meet the standards offered in larger regional communities. A number of reasons have been identified for the lower standards of service provision and collectively, these barriers contribute to the discrepancy between preferences for end of life settings and actual outcomes for residents of rural Native communities.

Acknowledging practical barriers to providing high standards of palliative care such as a lack of formal training and inadequate equipment and technology is only part of the challenge to improving First Nation access to palliative care services. Identifying and understanding how cultural perspectives and cultural concerns about existing palliative care services also impact the choices of First Nation people when assessing alternatives to where they would prefer to die.

Project Details

Goals and Objectives:

To identify cultural barriers to rural First Nation people accessing locally or regionally provided palliative care services.

To better understand the relationship between cultural barriers and other types of barriers to First Nation people accessing locally or regionally provided palliative care services.

To assist one partner First Nation group in improving access to local palliative care services.

To assist all participating First Nation communities by providing them with a comprehensive list of cultural barriers identified in survey and focus groups.

To assist all community participants with priority training related to providing local palliative care services.

Groups Involved:

One group is a yet to be identified First Nation group that resides in a rural setting. This group will be the basis for the focus group component of the research project.

The second group will be made up of all interested First Nation groups in the regional area. The second group will be the basis for the questionnaire component of the research project.

Method:

To get an in-depth look at cultural and related barriers by conducting focus groups with members of one First Nation group. The questions for the focus group will be developed in advance and will be consistent with questions on the questionnaire component of the project. In addition to some quantitative type questions, there will be a strong emphasis on qualitative open-ended questions and responses.

The focus groups will be conducted locally with assistance from the local health care organization.

To get a broad perspective of cultural barriers across the regional health service area, a questionnaire will be developed and distributed to interested rural aboriginal health service providers for distribution to its members. The questionnaire will be based on

already identified cultural barriers as well as giving respondents the opportunity to identify additional cultural barriers.

Completed questionnaires will be returned to Northern Health Hospice and Advisory Committee for analysis and data compilation. Results will be distributed to all participants and the funding agency.

Project Staffing:

Project Directors: Lynn Shervill; Mitch Verde

There will be two project directors who will be responsible for the overall organization of the proposed research project. Duties will include:

Development of partnerships with all relevant First Nation groups.

Coordination of development of research materials

Implementation and maintenance of research process

Coordinating the analysis of research data

Compiling research results

Developing summary of research project

Distributing summary to all relevant agencies

Facilitating process of infrastructure support

Coordinate distribution of project funds

Focus Group Facilitators: Yet to be identified

There will be one main contact from the First Nation's community health service Provider who will be responsible for coordinating the focus group/s in their local communities.

Questionnaire Distribution Coordinators: Established Contact List

There will be one main contact from each interested First Nation group who will be responsible for distributing and collecting completed questionnaires.

Trainers: Yet to be identified

In order to improve standards of rural palliative care in the main community partner, training will be provided in priority areas such as pain assessment and pain management. There will be an emphasis on understanding and incorporating cultural issues into mainstream provision of palliative care services.

Required Resources

The large majority of human resources for the coordination and implementation of the project is on a volunteer basis. The followings are a list of resources and the agencies that will be responsible for certain activities or resource provision.

Project materials including paper and photocopying will be supplied by the Northern Health Authority.

Data compilation and non-computerized analysis provided by project Directors.

Computerized analysis of data will be provided by Northern Health Authority.

Budget:

Focus Group supplies- Materials - Food	Four Sessions	\$ 400.00
Trainers - Travel - Accommodations - Meals - Materials Training Fee	Four Workshops	\$4,000.00
Infrastructure support	Two Beds used for training purposes and also for long-term program support	\$5,600.00

The grand total for the project is \$10,000.

Evaluation Plan

The proposed research project will be evaluated at three levels. The first level will be a collective assessment of whether the research methodology including questionnaire and survey group was a sound approach to reaching the project goals. At the end of the project, we hope to assess whether the research process yielded meaningful information by gathering valid data about the cultural barriers to First Nation people accessing Palliative care services. Although this evaluation will consist of several subjective viewpoints, viewpoints will be logically related to relevant contexts such as experience in the field of palliative care.

A second evaluative process will consist of a more formal process of evaluating the success of priority training portion of the project. This will consist of a short questionnaire to service providers and volunteers who participate in the training portion of the research.

A final and practical evaluation of the research process will be the development of a relevant and usable summary of the project that can be used to improve access to palliative care services in rural First Nation communities. Although the utility of the summary will can only be identified over a longer term, can be somewhat objective and may be based on anecdotal evidence, we believe that any knowledge can assist local First Nation groups in promoting improvement of their local palliative care services.

Appendix C: UBC Ethics Approval

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BC Cancer Agency

University of British Columbia - British Columbia Cancer Agency Research Ethics Board (UBC/BCCA REB)

UBC/BCCA Research Ethics Board
 Patient Medical Building (6th Floor)
 314 - 710 West Broadway
 Vancouver, BC V5Z 1V5
 Tel: (604) 877-8224 Fax: (604) 706-7102
 Email: ethics@bccancer.bc.ca
 Website: <http://www.bccancer.bc.ca>
 Research Ethics
 FRSU: 00000000000000000000

Certificate of Expedited Approval

PRINCIPAL INVESTIGATOR:		INSTITUTION / DEPARTMENT:		REC NUMBER:	
Mara Barmann		BCCA/Cancer Rehabilitation BCCA		H05 05759	
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:					
N/A					
Other location where the research will be conducted: N/A					
This protocol will be conducted in Anker PC. Study participants are community members of Men of color and Brothers, we encourage this certificate if required due we go to					
PRINCIPAL INVESTIGATOR FOR EACH ADDITIONAL PARTICIPATING BCCA CENTRE:					
Vancouver:	N/A	Vancouver Island:	N/A		
Fraser Valley:	N/A	Southern Interior:	N/A		
Abbotsford Centre:	N/A				
SPONSORING AGENCIES AND COORDINATING GROUPS:					
Canadian Institutes of Health Research (CIHR) - Palliative Care in Cross-cultural context a NCI for equitable and quality cancer care for culturally diverse populations. OCT 65760 P60 603					
PROJECT TITLE:					
Addressing Barriers to Palliative Care Services in NW BC First Nations Communities					

The UBC/BCCA Research Ethics Board Chair, Vice-Chair or second Vice-Chair, has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants approval.

EXPIRY DATE OF THIS APPROVAL: May 7, 2016

DATE DOCUMENT(S) APPROVED: May 7, 2016

Document Name	Version	Date
Protocol		
Barriers to Palliative Care in NW BC Communities	V1	March 17, 2015
Consent Form	V1	March 17, 2015
ICENQ V1	V1	March 17, 2015
ICURBAN V1	V1	March 17, 2015
ICURIC V1	V1	March 17, 2015
ICURIN V1	V1	March 17, 2015
Questionnaire, Questionnaire Cover Letter, Tests	V1	March 17, 2015
Survey V1	V1	March 17, 2015
ICOR (Initial Questionnaire) V1	V1	March 17, 2015
ICOR (Follow-up Questionnaire) V1	V1	March 17, 2015
Other Documents:		
NI Letter Support		
ICOR (Initial Questionnaire)	N/A	April 1, 2016
ICOR (Follow-up Questionnaire)	N/A	April 1, 2016

REB COMMENTS:

UBC/BCCA Research Ethics Board Chair, Vice-Chair or second Vice-Chair, has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants approval.

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UBC/BCCA Research Ethics Board

UBC/BCCA Research Ethics Board

Appendix D: Northern Health Ethics Approval



northern health

Northern Health Corporate Office
601-288 Victoria Street, Prince George, BC V2L 5D6
Telephone (250) 563-2948 Fax (250) 563-2141 www.northernhealth.ca

March 27, 2009

File #RRC-2009-0007

Mitch Verde
Box 275
New Aiyemh BC V6J 1A0

Dear Mitch:

RE: Addressing Barriers to Palliative Care Services in NW BC First Nations Communities

On behalf of the Northern Health Research Review Committee, I would like to thank you for your submission titled *Addressing Barriers to Palliative Care Services in NW BC First Nations Communities*.

Your study has now met the requirements of the Northern Health Research Review Committee and you may proceed.

Enjoy your work! We look forward to hearing about your findings.

Sincerely,

A handwritten signature in black ink that reads "Suzanne Johnston".

Suzanne Johnston, Chair, NH Research Review Committee
Vice President, Academic Affairs and Chief Nursing Officer

SJew

CC: Angela Szabo
File

Appendix E Informed Consent Forms for Focus Groups

ADDRESSING BARRIERS TO PALLIATIVE CARE SERVICES

IN NORTHWEST BC FIRST NATIONS COMMUNITIES

FIRST NATION COMMUNITY MEMBERS

AND LOCAL COMMUNITY HEALTH CARE PROVIDERS

INFORMED CONSENT FORM FOR FOCUS GROUP PARTICIPANTS

Please consider this information carefully before deciding whether to participate in this research. This research is a collaborative effort between Northern Health Northwest Hospice & Palliative Care Advisory Committee, BC Cancer Agency, and participants from the community of Moricetown.

Purpose of the research: To examine how cultural barriers might affect access to palliative care for First Nation people. Palliative care is defined as: “A combination of active and compassionate therapies that are intended to comfort and support individuals and their friends and families who are living with or dying from a progressive life threatening illness, or who are bereaved.”

Participation: To fulfill the purpose of the research, research organizers decided to conduct focus groups with a cross section of the community who had experience with palliative care. Potential participants were identified by community contacts based on the participant’s experience with the palliative care system or their cultural knowledge.

What you will do in this research: Participating in a group of between 6-10 people, or smaller, you will be asked to respond to questions about palliative care. The information will be recorded with summary notes by the interviewer and tape recorded for later analysis.

Access to Responses: After the project is completed, a summary of the responses will be developed and a report will be generated. This report will be shared with the appropriate agencies to assist with overall program

improvement. Each participant can request a copy of the report and one will be mailed to him or her.

Time required: The focus group discussion will take between 1-2 hours.

Risks: One possible risk associated with participating in this study is that participants may re-experience distressing emotions that they had during the loss of a loved one. To address this possibility, we have arranged for a grief counselor to be available at any time during or after the focus group. We are also distributing a list of counseling resources that can be accessed by community members at a later date if they require additional assistance.

Benefits: The anticipated benefits for the research are to potentially improve access to palliative care services for the First Nation population. Research results will be shared with appropriate health care agencies, which can use the information to improve First Nation access to local palliative care services.

Compensation: Each community participant will receive \$25 for participating in the focus group. Each community health worker, if on volunteered time, will receive \$25 for participating in the focus group.

Confidentiality: Your participation in this study will remain confidential, and your personal identity will not be stored with your opinions. The signed consent forms will be stored in a locked cabinet until it is deemed they are no longer needed and will be shredded. Any dissemination of the results of this research will not be associated with your name in any way. Transcribers of the tape recording will have signed an oath of confidentiality prior to listening to the tapes. Tapes will be kept in a locked cabinet on the property of the Northern Health Authority until they are deemed no longer needed and will be destroyed after three years.

Participation and withdrawal: Your participation in this study is completely voluntary, and you may withdraw at any time without penalty. You may withdraw by informing the researcher that you no longer wish to

participate and no questions will be asked regarding your decision to withdraw.

Contact: If you have questions about this research, please contact one of the following principle investigators.

<p>Mitch Verde – NH NW Hospice Pall. Care Adv. Comm. Box 275 New Aiyansh, BC V0J 1A0</p>	<p>Lynn Shervill Box 370 Smithers, BC, V0J 2N0 250-877-4410</p>	<p>Jeanette Foreman Bag 5000, Smithers, BC, V0J 2N0 250-847-6428</p>
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In the event that you have expressed concerns about the research project and have not received an adequate response from one of the principle investigators, please contact the Office of the Vice President, Academic Affairs, Northern Health (kim.bain@northernhealth.ca or call 250-565-2941).”

Agreement:

The nature and purpose of this research have been sufficiently explained and I agree to participate in this study. I understand that I am free to withdraw at any time without penalty and without having to justify my reason.

Signature: _____

Date: _____

Name (print): _____

Appendix F (1). Focus Group Protocol for Local Palliative Care Providers

ADDRESSING BARRIERS TO PALLIATIVE CARE SERVICES IN NORTHWEST BC FIRST NATIONS COMMUNITIES “Perspective from Local Palliative Care Providers”

PROTOCOLS FOR COMMUNITY FOCUS GROUPS

Aim and Objectives: To investigate community palliative care provider perspectives on the effect that cultural barriers have on accessing palliative care services. The information collected through focus groups and interviews will be used (a) to compare perspective with that of First Nation participants and with acute care providers, (b) to improve the cultural sensitivity of service delivery, and (c) to develop a knowledge sharing framework with palliative care providers.

General Protocols

1. Participation in the focus groups is voluntary and all participants must sign a consent form. Selection of participants would be made cooperatively by the local Advisory Committee, Project Staff, and Project Administrators.
2. The Interviewer will interview participants either in small groups or individually depending upon their wishes and situations.
3. Focus groups and interviews will be recorded through summary notes and, with the signed consent of participants, tape recorded.
4. Focus groups will take approximately 1 to 2 hours.
5. If on volunteered time, Participants will receive \$25 as a financial remuneration for taking part in the focus group or interview.

Focus Group/Interview Guide

Instructions: Prior to interviewing, the Principal Interviewer will review the purpose of the group and terms of participation. The participants will then sign the Consent for Focus Group Interview.

General Areas of Interest

1. To identify the traditional practices for providing local palliative care?
2. To identify the level of palliative care services that is currently provided to the community?
3. To assess whether the services provided are adequate to meet the expectations of the community, particularly in respect to cultural issues (beliefs, values, and customs) sensitivity?

4. To identify steps that can be taken to improve the palliative care services?

Focus Groups Discussion Topics

1. Service provider awareness of traditional palliative care practices
 - Are service providers aware of any traditional practices used by First Nation people in the care for the terminally ill, prior to contact?
 - Are they aware of any specific spiritual practices that were undertaken prior to contact?
 - Are they aware of any specific medicinal treatments that were used prior to contact?
 - Are they aware of any specific ways in which the emotions of the person dying or caregivers were addressed?

2. Current service provision
 - How do service providers feel about their provision of local palliative care services?
 - Do they think the services are adequate?
 - Do they think that the local services are culturally sensitive?
 - Do local residents prefer quality or quantity of life (life support)?
 - Do local services take into account the religious beliefs of families?
 - Are local families aware of and making use of Aboriginal Hospital Liaison Workers?
 - Do they think the decision making role of the family is respected in the palliative care process?
 - Are life support decisions made jointly with the family?
 - Is there timely access to the deceased body for family or cultural reasons?
 - In the event that death is close at hand and little to nothing can be done by medical personnel, does the treatment process change to allow more family involvement?

3. Community Program
 - Does the community have meaningful input into the planning and provision palliative care services?
 - Do the service providers feel that community should be more involved in how services are delivered, particularly in terms of culture?

4. Urban Palliative Care Services
 - How do local services providers feel about the provision of palliative care in urban settings?
 - Do they think that the urban services are culturally sensitive?
 - Is the role of the family respected in the urban palliative care process?

5. Previously Identified Barriers in First Nation Populations
 - Language barriers
 - Lack of facilities and equipment

- Isolation of elders
 - Reduced quality of life away from family
 - Loss of contribution to culture when away
 - Lack of cultural competence
 - Lack access to traditional services
 - Lack of traditional foods
 - Lack of spiritual support
 - Funding issues for certain equipment and services
 - Facility management inconsistent with cultural processes
6. Solutions for improving access to the local palliative care services
- What are some immediate changes or steps that you would recommend for the provision of local palliative care services?
 - Traditional practices
 - Community services: Cultural and family considerations
 - Community program: Meaningful input from community
 - Urban palliative care: Cultural and family considerations
 - Addressing specific barriers
 - What are some of the long-term changes or steps that you would recommend for the provision of local palliative care services?
 - Traditional practices
 - Community services: Cultural and family considerations
 - Community program: Meaningful input from community
 - Urban palliative care: Cultural and family considerations
 - Addressing specific barriers

Wrap Up: Thank you from the project organizers and closing prayer.

Appendix F(2). Focus Group Protocol for Urban PC Providers

Cultural Barriers to First Nations Accessing Palliative Care Perspective from Urban Acute Care Providers PROTOCOLS FOR FOCUS GROUPS AND INTERVIEWS

Aim and Objectives: To investigate urban palliative care provider perspectives on the effect that cultural barriers have on accessing palliative care services. The information collected through focus groups and interviews will be used (a) to compare perspective with that of First Nation participants and those of rural palliative care providers, (b) to improve the cultural sensitivity of service delivery, and (c) to develop a knowledge sharing framework with palliative care providers.

General Protocols

1. Participation in the focus groups is voluntary and all participants must sign a consent form. Selection of participants would be made cooperatively by the local Advisory Committee, Project Staff, and Project Administrators.
2. The Interviewer will interview participants either in small groups or individually depending upon their wishes and situations.
3. Focus groups and interviews will be recorded through summary notes and, with the signed consent of participants, tape recorded.
4. Focus groups will take approximately 1 to 2 hours.
5. Participants will receive a \$25 financial remuneration for taking part in the focus group or interview.

Focus Group/Interview Guide

Instructions: Prior to interviewing, the Principal Interviewer will review the purpose of the group and terms of participation. The participants will then sign the Consent for Focus Group Interview.

General Questions

5. What level of palliative care services are provided to the community in question?
6. Are the services provided adequate to meet the expectations of the community, particularly in respect to cultural (beliefs, values, and customs) sensitivity?
7. What steps can be taken to improve the palliative care services?

Suggested Focus Groups Discussion Topics

2. Service provider awareness of traditional or cultural palliative care practices
 - Are service providers aware of any traditional practices used by First Nation people in the care for the terminally ill prior to contact?

- Are they aware of any specific spiritual practices that were undertaken prior to contact?
 - Are they aware of any specific medicinal treatments that were used prior to contact?
 - Are they aware of any specific ways in which the emotions of the person dying or caregivers were addressed in any way?
3. Current service provision
- How do service providers feel about their provision of urban palliative care services?
 - Do they think the services are adequate?
 - Do they think that the local services are culturally sensitive?
 - Do they think the role of the family is respected in the palliative care process?
4. Community Involvement
- Does the community have meaningful input into the planning and provision palliative care services in urban centers?
 - Do the service providers feel that community should be more involved in how services are delivered, particularly in terms of culture?
7. Barriers previously identified that can be used for exploration in current group
- Lack of facilities and equipment
 - Isolation of elders
 - Reduced quality of life away from family
 - Loss of contribution to culture when away
 - Lack of cultural competence
 - Lack access to traditional services
 - Lack of traditional foods
 - Lack of spiritual support
 - Funding issues for certain equipment and services
 - Facility management inconsistent with cultural processes

Appendix F. (3). Focus Group Protocol for Community Members

Cultural Barriers to First Nations Accessing Palliative Care First Nation Perspectives

PROTOCOLS FOR FOCUS GROUPS AND INTERVIEWS

Aim and Objectives: To investigate First Nation perspectives on the effect that cultural barriers have on accessing palliative care services. The information collected through focus groups and interviews will be used (a) to describe the process from the perspective of First Nation participants and compare with local and urban palliative care service providers, (b) to improve the cultural sensitivity of service delivery, and (c) to develop a knowledge sharing framework with palliative care providers.

General Protocols

1. Participation in the focus groups is voluntary and all participants must sign a consent form. Selection of participants would be made cooperatively by the local Advisory Committee, Project Staff, and Project Administrators.
2. The Interviewer will interview participants either in small groups or individually depending upon their wishes and situations.
3. Focus groups and interviews will be recorded through summary notes and, with the signed consent of participants, tape recorded.
4. Focus groups will take approximately 1 to 2 hours.
5. Participants will receive a \$25 financial remuneration for taking part in the focus group or interview.

Focus Group/Interview Guide

Instructions: Prior to interviewing, the Principal Interviewer will review the purpose of the group and terms of participation. The participants will then sign the Consent for Focus Group Interview.

General Questions

8. Who provides palliative care services to your community?
9. Are the services provided adequate to meet the expectations of the community, particularly in respect to cultural (beliefs, values, and customs) sensitivity?
10. What steps can be taken to improve the palliative care services?

Suggested Focus Groups Discussion Topics

1. Traditional or cultural palliative care practices
 - How did First Nation people care for the terminally ill prior to contact?
 - Were there specific spiritual practices that were undertaken?
 - Were there specific medicinal treatments that were used?
 - Were the emotions of the person dying and caregivers addressed in any way?

4. Current service provision
 - How do participants feel about the local provision of palliative care services?
 - Are they aware of the local services?
 - Do they think that the local services are culturally sensitive?
 - Is the role of the family respected in the palliative care process?

5. Community Program
 - What are the ways that the community contributes to the planning and provision of palliative care services?
 - Do the participants feel they could be more involved in how services are delivered, particularly in terms of culture?

6. Urban palliative care services
 - How do participants feel about the provision of palliative care in urban settings?
 - Do they think that the urban services are culturally sensitive?
 - Is the role of the family respected in the urban palliative care process?

8. Barriers previously identified that can be used for exploration in current group
 - Lack of facilities and equipment
 - Isolation of elders
 - Reduced quality of life away from family
 - Loss of contribution to culture when away
 - Lack of cultural competence
 - Lack access to traditional services
 - Lack of traditional foods
 - Lack of spiritual support
 - Funding issues for certain equipment and services
 - Facility management inconsistent with cultural processes

Appendix G: Informed Consent for Survey

RESEARCH SPONSORS

Northern Health's Northwest Hospice & PC Advisory Committee

Northern Health's Research and Evaluation Department

BC Cancer Agency

RESEARCH APPROVAL RECEIVED FROM

**Northern Health Research Review Committee
600-299 Victoria Street, Prince George BC, V2L-5B8**

**UBC Research Ethics Review Board
Fairmont Medical Building, 614-750 West Broadway
Vancouver BC, V5Z-1H5**

PARTICIPANT INFORMATION and CONSENT FORM Addressing Barriers to Palliative Care Services in Northwest BC First Nation Communities

Principal Investigator:

Mitch Verde, MSc: Northern Health Northwest Hospice & Palliative Care
Advisory Committee

Contact Information:

Address: Box 275 New Aiyansh BC, V0J-1A0

Phone: 250-633-2099

Email: mverde@telus.net

Co-Investigators:

Lynn Shervill, RN: Northern Health Hospice Palliative Care Program

Jeanette Foreman, BA Honors, MPH Candidate. Research and Evaluation
Department, Northern Health Authority

Amanda Ward, PhD: Research Scientist, BC Cancer Agency

In signing this consent form you will be agreeing to participate in the Addressing Barriers to Palliative Care Services in Northwest BC First Nation Communities

**ADDRESSING BARRIERS TO PALLIATIVE CARE SERVICES IN
NORTHWEST BC FIRST NATIONS COMMUNITIES
INTERVIEW/QUESTIONNAIRE
INFORMED CONSENT FORM**

Please consider this information carefully before deciding whether to participate in this research.

This research is a collaborative effort between Northern Health Authority's Northwest Palliative Care Advisory Committee, BC Cancer Agency, and First Nations in Northwest BC.

Purpose of the research: To examine how cultural barriers affect palliative care for First Nation population. Palliative care is defined as: "A combination of active and compassionate therapies that are intended to comfort and support individuals and their friends and families who are living with or dying from a progressive life threatening illness, or who are bereaved." Sometimes palliative care is called "end of life care".

Study Procedures: As a participant in this research project, you will be interviewed by a research assistant in a structured interview format. Your responses will be recorded on a questionnaire form by the research assistant. You will be required to give your personal opinion, where possible, in several topic areas. For some items on the questionnaire, you will be required to provide your opinion on a scale. Once completed, the questionnaires will be collected and sent to Northern Health's Northwest Research and Evaluation Department in Smithers BC for analysis. For the purposes of analysis and reporting, all participant names will remain confidential. All of the participant names will be removed from the questionnaires and a number will be assigned to each questionnaire. Therefore, responses to the questionnaire will not be associated with a name but with a number to preserve confidentiality and allow all participants to remain anonymous. All information collected will remain in a locked cabinet at Northern Health's Northwest Research and Evaluation Department in Smithers BC. After three years, the information will be destroyed.

Participation: You were identified as a potential participant by community contacts based on your experience with the palliative care system or your cultural knowledge.

Access to Report: After the project is completed, a summary of the responses will be developed and a report will be generated. This report will be shared with the appropriate agencies to assist with overall program improvement. You will be able to access the report at your local health center.

Time required: Participation will take approximately one hour to complete.

Risks: One possible risk associated with participating in this study is that participants may re-experience distressing emotions that they had during the loss of a loved one. To address this possibility, the interviewer has ensured that support services are available to participants during or after the interview and can refer you if necessary.

Benefits: The anticipated benefits for the research are to potentially improve access to palliative care services for the First Nation population in Northwest British Columbia. Research results will be shared with appropriate health care agencies, which can use the information to improve First Nation access to local palliative care services.

Compensation: Participants will be compensated \$10 for participating in this research study.

Confidentiality: Your participation in this study will remain confidential, and your personal information will not be stored with your questionnaire data. The consent forms will be stored in a location separate from the completed questionnaires and your responses on the questionnaire will not be linked with your name in any way. Only group results will be reported. Raw data will be stored for a period of three years on Northern Health property and then destroyed.

Participation and withdrawal: Your participation in this study is completely voluntary, and you may withdraw at any time. You may withdraw by informing the researcher that you no longer wish to participate and no questions will be asked regarding your decision. If you decide to withdraw, you have the right to keep all of your information as well as the compensation for participating.

Contact: If you have questions about this research, please contact one of the following principle investigators.

<p>Mitch Verde, NH NWHPC Advisory Committee Box 275 New Aiyansh, BC V0J 1A0 250-633-2099 mverde@telus.net</p>	<p>Lynn Shervill Box 370, Smithers, BC, V0J 2N0 Ph. 250-877-4410 lshervill@creekstonepress.com</p>	<p>Jeanette Foreman Bag 5000, Smithers, BC, V0J 2N0 Ph. 250-847-6428 jeanette.foreman@northernhealth.ca</p>	<p>Amanda Ward Suite 660 – 750 W. Broadway St., Vancouver, BC, V5Z 1H5 Ph. – 604-877-6000 L. 3288 Award2@bccancer.bc.ca</p>
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In the event that you have expressed concerns about the research project and have not received an adequate response from one of the principle investigators, please contact the Office of the Vice President, Academic Affairs, Northern Health (Administrative Assistant: kim.bain@northernhealth.ca or call 250-565-2941).

Agreement:

The nature and purpose of this research have been sufficiently explained and I agree to participate in this study. I understand that I am free to withdraw at any time without having to justify my reason.

Signature: _____

Date:

Name (print): _____

If this consent process has been completed with the aid of an interpreter/translator, please indicate the language and the type of assistance.

Language: _____

Type of Assistance: Please check the appropriate box

The consent form was read to the subject, and the person signing below attests that the study was accurately explained to, and apparently understood by, the subject.

The person signing below acted as an interpreter/translator for the subject, during the consent process.

Signature of Interpreter

Printed Name

Date

Appendix H: Survey



Health Questionnaire ADDRESSING BARRIERS TO PALLIATIVE CARE SERVICES IN NORTHERN BC FIRST NATIONS COMMUNITIES

Thank you for taking part in our questionnaire. For the questions below, please select your response from the options available or provide comments as indicated.

There are no right or wrong answers. Your opinions are important for making improvements to services. We value your input.

Definitions

Palliative care is care for dying individuals and their families and friends. It is formally defined as: "A combination of active and compassionate therapies that are intended to comfort and support individuals and their friends and families who are living with or dying from a progressive life threatening illness, or who are bereaved." It is sometimes referred to as **end-of-life-care**.

For the purposes of the questionnaire, "**local community**" means your reserve community. "**Urban centre**" means a town or city with a hospital or long-term care home.

A. Demographic Information

The following questions are about you and your background. Please circle the appropriate response or fill in the blank:

1. Your Age Group:

20-40 41-50 51-60 61+

2. Your Gender:

Female Male

4. Your First Nations (or other) heritage:

Mother's Side: _____

Father's Side: _____

3. Your Community: _____

5. How many years you have lived in the community:

0-10 11-20 21-40 41+

6. Have you ever been involved in providing end-of-life care to a friend or relative?

No Yes (If yes, approximately how many people? ____)

B. Traditional Cultural Practices Around Death and Dying

Please list any of your local traditional practices around end-of- life care. (If necessary please use additional paper.)

7. Traditional Family Support Practices (for example, tribal support or clan support system that determines who has a role in providing care and support at end-of-life):

8. Traditional Spiritual Support Practices (for example, prayers or ceremonies):

9. **Traditional Ways of Providing Emotional Comfort (for example, visiting, singing, providing specific foods or other comforts):**

10. **Traditional Medicine or Treatments for Pain or Other Purposes (for example, specific herbs, plants or trees, heated rocks, massages):**

11. **Care and Preparation of the Body and Spirit or Soul after Death (for example, washing body, saying prayers or singing, not touching the body):**

12. **Traditional Funeral or Ceremonial Practices (for example, specified “wake” time period, guarding or transporting the body practices, choosing burial):**

C. Your Preferences for End-of-Life Care

13. **When the time comes, if possible, I would prefer to (Choose one):**

pass away in my home community
 pass away in an urban facility (e.g., hospital or care home)

14. **When the time comes, if possible, I would prefer to have care provided by (Choose all that apply):**

my family
 traditional healers

_____ community-based service providers (e.g., home support worker)

_____ formally trained care providers (e.g., doctors, nurses)

_____ other (please specify: _____)

D. Your Opinions on Palliative Care Services in Your Local Community

The following questions are asking your opinions about palliative care services in your community.

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
15.	Palliative care services in this community are adequate to meet community needs.	1	2	3	4	5
16.	Doctors who provide palliative care in this community are sensitive to local culture.	1	2	3	4	5
17.	Nurses who provide palliative care in this community are sensitive to local culture.	1	2	3	4	5
18.	Nurses are adequately trained to provide palliative care in this community.	1	2	3	4	5
19.	Home support workers are adequately trained to provide palliative care in this community.	1	2	3	4	5
20.	The local palliative care services respect the family planning in the overall palliative care process.	1	2	3	4	5

E. Your Opinions on Barriers to Culturally-Appropriate Palliative Care Services in the Local Community

Below are a list of potential factors that may limit access to culturally-appropriate palliative care services in your community. Please indicate how large of a barrier you think this is in your community.

		Not a barrier at all	Some what of a barrier	A definite barrier	A very large barrier	Don't know/not sure
21	Local care providers do not speak the original language.	1	2	3	4	5
22	Traditional foods are not available in the community.	1	2	3	4	5
23	Traditional services or ceremonies are not able to be performed freely.	1	2	3	4	5
24	Traditional spiritual practices are not available in the community.	1	2	3	4	5
25	Younger family members do not know or value the local cultural traditions and practices around death and dying.	1	2	3	4	5
26	Our community does not teach the traditional ways around death and dying to our younger generations.	1	2	3	4	5
27	Local care providers do not know the traditions and practices around death and dying.	1	2	3	4	5
28	There is a lack of training for local providers in traditional ways around death and dying.	1	2	3	4	5
29	Formal religious practices have taken the place of traditional practices around death and dying in the community.	1	2	3	4	5
30	There is a lack of support of elders from family members in the community.	1	2	3	4	5

31	There is a lack of 24 hour community health worker services.	1	2	3	4	5
32	There is a lack of 24-hour palliative care nurse or physician support for the community.	1	2	3	4	5
33	There is a lack of local end-of-life care facilities in the community	1	2	3	4	5

34. Overall, on a scale of 1 to 10, how would you rate the quality of the palliative care services provided by providers in your community (where 1 = very poor and 10 = excellent).

35. Would you recommend the services to fellow community members?
(please circle)
Yes No

F. Your Opinions on Palliative Care Services in Urban Centres

The following questions are asking your opinions about care in urban centres (for example, hospitals or care homes).

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
36.	Palliative care services in surrounding urban communities are adequate to meet community needs.	1	2	3	4	5
37.	Doctors who provide palliative care in urban centers are sensitive to local culture.	1	2	3	4	5
38.	Nurses who provide palliative care in urban centers are sensitive to local culture.	1	2	3	4	5
39.	The urban palliative	1	2	3	4	5

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
	care services respect the family planning in the overall palliative care process.					

G. Your Opinions on Barriers to Culturally-Appropriate Palliative Care Services in Urban Centres

Below are a list of potential factors that may limit access to culturally-appropriate end-of-life care services in urban centres. Please indicate how large of a barrier you think this is in urban centres.

		Not a barrier at all	Some-what of a barrier	A definite barrier	A very large barrier	Don't Know/ Not Sure
40	Urban care providers do not speak the native language.	1	2	3	4	5
41	Traditional foods are not served in the urban centres.	1	2	3	4	5
42	Traditional services or ceremonies are not able to be performed freely in urban centres.	1	2	3	4	5
43	Out-of-pocket costs for transportation, hotel and meals associated with stays at urban centres are too high.	1	2	3	4	5
44	Traditional spiritual practices are not able to be performed freely in urban centres.	1	2	3	4	5
45	Urban care providers do not know the traditions and practices around death and dying.	1	2	3	4	5
46	There is a lack of training for urban providers in traditional ways around death and dying.	1	2	3	4	5
47	There is a lack of respect for elders of diverse background	1	2	3	4	5

		Not a barrier at all	Some-what of a barrier	A definite barrier	A very large barrier	Don't Know/ Not Sure
	in urban centres.					
48	Urban end-of-life facilities do not accommodate large numbers of visitors in patient rooms.	1	2	3	4	5

49. Overall, on a scale of 1 to 10, how would you rate the quality of the palliative care services provided by urban care providers (where 1 = very poor and 10 = excellent).

50. Would you recommend the services to fellow community members?
(please circle)
Yes No

H. Potential Solutions to Improve Health Services in the Community and in Urban Centres

51. Please indicate, if possible, the three issues of greatest concern regarding the provision of palliative care services in this community.

1. _____
2. _____
3. _____

52. Please indicate, if possible, the three issues of greatest concern regarding the provision of palliative care services in urban centres.

1. _____
2. _____
3. _____

Here is a list of potential approaches to improve access to culturally-appropriate, high quality end-of-life services. Please indicate your level of agreement with these possible approaches.

	Approaches To Improve Local Services	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
53.	Train local providers in traditional practices & medicines & their meaning.	1	2	3	4	5
54	Train local youth in traditional practices.	1	2	3	4	5
55	Hire local workers who can speak the native language.	1	2	3	4	5
56	Host a community workshop to explain the physical process of death and Western palliative care approaches (e.g., pain medicine).	1	2	3	4	5
57	Build a local facility where local people can receive end-of-life care.	1	2	3	4	5

58. Do you have other ideas to improve local end-of-life services? (list suggestions)

	Approaches To Improve	Strong	Agree	Neutra	Disagr	Strong
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	Urban Services	ly Agree		l	ee	ly Disagr ee
59	Train urban providers in traditional practices & medicines & their meaning.	1	2	3	4	5
60	Improve coordination between community and urban providers.	1	2	3	4	5
61	Hire more local people to provide service in the hospital.	1	2	3	4	5
62	Include representatives from each community on the Northern Health Aboriginal Health Improvement Committees or other relevant planning groups.	1	2	3	4	5

63. Do you have other ideas to improve urban end-of-life services?

H. Additional Comments

Please share any additional thoughts you may have about end-of-life services for First Nations people in Northern BC.

**THAT'S ALL OF THE QUESTIONS.
THANK YOU VERY MUCH FOR YOUR TIME.**

FOR COMPLETION BY THE INTERVIEWER ONLY

Participant Identification Number: _____

Date of Completion (Month/Day/Year): _____

Name of Interviewer: _____