

Provision of Palliative and End-of-Life Care Services to Ontario First Nations Communities: An Environmental Scan of Ontario Health Care Provider Organizations

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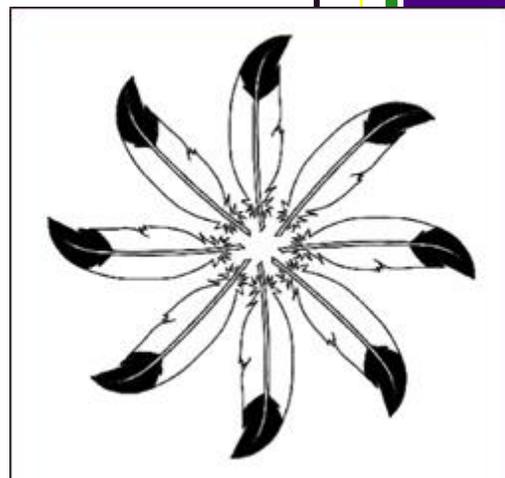


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For more information about this research, please contact:

Holly Prince, HBSW, MSW

Aboriginal Project Manager

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

(807) 766-7274 or

Email at hprince@lakeheadu.ca

Dr. Mary Lou Kelley, MSW, PhD

Principal Investigator,

School of Social Work, Lakehead University

(807) 766-7270 or

E-mail at mlkelley@lakeheadu.ca

2.0 EXECUTIVE SUMMARY

The purpose of this research was to identify direct care services that the Ontario government provides to individuals who are designated as palliative and live in First Nations communities (on-reserve). The research also sought to document some innovative practices in Ontario for providing access to palliative care services in First Nations communities, specifically exploring: the policies and practices that determine the service arrangements for palliative care patients who reside in First Nations communities, how this provision of care is initiated and managed by service agencies, and how off-reserve and on-reserve service agencies coordinate service provision.

This report presents the research findings based on the analysis of data gathered from 27 survey participants and 17 interview participants from across Ontario in November 2011-April 2012. Survey and interview participants represented the following groups: Leads from the regional End-of-Life Care Networks (EOLCNs), Aboriginal Health Leads from the Local Health Integration Networks (LHINs), and also key informants from health service delivery programs in Ontario.

The findings are organized under three themes: regions' awareness and knowledge of palliative care programs provided in First Nations communities; palliative care innovative practices in First Nations communities in Ontario; and barrier and strengths in the delivery of palliative care services to Ontario First Nations communities.

Three initiatives were identified as successful, interesting, and collaborative examples of practices that could be shared with other LHIN areas and First Nations communities across the province. These three practices include a Memorandum of Understanding between a Community Care Access Centre (CCAC) and a First Nations community, a First Nations palliative care education program, and a palliative care outreach team that provides service in a First Nations community (on-reserve). The description of these three initiatives is provided as innovative practices that could be adopted by other First Nations communities to enhance and build palliative care capacity across Ontario.

Based on the study findings, the report makes 6 recommendations to begin to address the palliative care needs of First Nations people:

1. The LHINs and EOLCNs work together in collaboration with First Nations communities in conducting needs assessments to identify community needs and current palliative care services provided in First Nations communities.
2. The LHINs take leadership to clarify their mandate in planning for the provision of palliative care services in First Nations communities.
3. The LHINs work out collaborative agreements with federal government and other service providers as necessary to meet the identified needs for palliative care services on First Nations

communities. Formal memorandums of understanding will help to provide role clarity, responsibility, as well as accountability for all parties.

4. The LHINs Aboriginal Health Networks/Circles and EOLCNs jointly work together at the local level to ensure that Aboriginal Hospice Palliative Care is addressed as a priority and efforts are made to build local capacity in First Nations communities.
5. The LHINs and EOLCNs work together in collaboration with First Nations communities to facilitate the sharing of innovative practices for providing palliative care in First Nations communities that incorporate Aboriginal service providers, appropriate traditions, and cultural practices at end of life.
6. The LHINs and EOLCNs work together in collaboration with First Nations communities to offer culturally relevant palliative care education, training, coaching, and mentorship of Aboriginal service providers. Members from the First Nations community should be involved in the design, planning, and implementation of the program curriculum and materials to ensure the inclusion of appropriate cultural traditions, content, and competencies.

3.0 METHODOLOGY

The purpose of this research was to conduct a provincial scan to identify direct care services that the Ontario government provides to individuals who are designated as palliative and live in First Nations communities (on-reserve). The intent was to identify innovative practices in Ontario for providing access to palliative care services in First Nations communities, specifically exploring: the policies and practices that determine the service arrangements for palliative care patients who reside in First Nations communities, how this provision of care is initiated and managed by service agencies, and how off-reserve and on-reserve service agencies coordinate service provision.

Data collection for the environmental scan involved a three-phase process. In the first stage, the research team identified a list of key informants based on their role within their respective organizations that could potentially provide preliminary information via a survey. The focus was obtaining participation from the Leads of the regional End-of-Life Care Networks (EOLCN) as well as the Aboriginal Health Leads from the Local Health Integration Networks (LHIN). These individuals were recognized as having the ability to most accurately report and comment on their regions' experiences related to the provision of palliative care services in First Nations communities.

The Chief Executive Officers (CEO's) of each of the 14 LHINs were contacted individually to invite the LHINs in Ontario to participate as key informants in this provincial scan and to ask for their assistance in identifying the most appropriate person to complete a survey. As each LHIN area was only requested to submit one completed questionnaire, it was also encouraged that the individual completing the questionnaire consult with other LHIN staff as appropriate. A copy of the survey instrument was attached for the CEO's information to assist in identifying the most appropriate key informant.

In November - December 2011, the survey was sent electronically to all 14 identified LHIN key informants as well as 13 Leads of the regional End-of-Life Care Networks. One EOLCN did not have a Director or Lead at the time, therefore, the survey was not sent out to this network. The survey consisted of questions that were divided between two categories: health systems planning and health services provision (see Appendix A). At the end of the survey, individuals were also asked to share any relevant documentation that may assist in addressing the research objectives and/or to provide the names of other key informants who should be contacted. Additionally, through their involvement in the survey, participants were also asked to volunteer for a follow-up interview if required.

In the second phase of data collection, individual interviews were conducted in February – March 2012, to follow-up with those participants from the EOLCNs and the LHINs who reported on the questionnaire that palliative care services were provided to the First Nations communities in their region. This stage was specifically designed to identify potential innovative practices in Ontario for further investigation. Follow-up questions with participants included:

- Of these palliative care services that you listed in the survey that are provided to First Nations communities, could you recommend a program(s) that exhibits a successful, interesting, and

collaborative example of practices that might be shared with other LHIN areas and First Nations communities across the province?

- Why are you recommending this program(s) in particular? (e.g., positive attributes or characteristics, unique partnerships, successful outcomes etc.)
- Could you please provide me with contact information to speak with someone directly to find out more details about this recommended program(s)? (e.g. name, organization, email address, and phone number)

In the third phase of data collection, the research team selected three innovative practices that were identified as being successful, interesting, and collaborative examples that might be shared with other LHIN areas and First Nations communities across the province. Interviews were then scheduled in April 2012 with key informants who could elaborate on these practices. In selecting the three innovative practices, the Research Team considered a wide range of service deliverables, including education, infrastructure, clinical care models, policy, and procedures. Researchers used the following criteria in the final selection of the three innovative practices:

- Geographical representation of both Northern Ontario and Southern Ontario
- Must be in progress and not in the planning stage, with some demonstrated outcomes of success
- Must be a service that is delivered and not focused on research or assessment
- Funded by the Ontario Ministry of Health and Long-term Care

4.0 RESULTS

These results, which incorporate findings of both the surveys and interviews, are organized under three themes: LHIN regions' awareness and knowledge of palliative care programs provided in First Nations communities in their area; palliative care innovative practices in First Nations communities; and strengths and barriers in the delivery of palliative care services to Ontario First Nations communities.

4.1 LHIN Regions' Awareness and Knowledge of Palliative Care Services Provided in First Nations Communities in their Area

All thirteen Leads from a regional End-of-Life Care Network (EOLCN) as well as all fourteen Aboriginal Health Leads from a Local Health Integration Network (LHIN) responded to the survey, achieving a 100% response rate. Out of the 14 regions in Ontario, ten Aboriginal Health Leads from a LHIN indicated that they had a First Nations community within their LHIN area. One-hundred and thirty seven First Nations communities were reported across the province. The following data is therefore based on a total sample size of ten LHIN regions.

In exploring health systems planning, seven out of the ten LHINs indicated that they engaged in health system planning with First Nations communities to provide services that would benefit individuals who require palliative care. However, only one LHIN reported that they have the mandate for hospice palliative care systems planning for the First Nations communities in their area. Four LHINs indicated that they did not have a mandate while the remaining five did not know.

Four of the ten EOLCNs indicated that they did undertake hospice palliative care systems planning for First Nations communities in their area, while another five indicated that they did not.

Eight of the ten EOLCNs indicated that they currently collaborate with their local LHIN on hospice palliative care system planning. Seven of the LHINs concurred with this statement.

Six of the ten EOLCNs indicated that provincially funded health services are provided in First Nations communities to individuals who require palliative care, while another one indicated "No" and another two indicated that they "Did Not Know." One EOLCN did not respond to this question. There was variation in the responses from the EOLCN and LHIN key informants on this issue. Five LHINs indicated that provincially funded health services are provided in First Nations communities to individuals who require palliative care, while one indicated "No" and another four indicated that they "Did Not Know."

Participants from both the ten LHINs and the EOLCNs were provided with a list of provincially funded palliative care health services and asked which are provided in First Nations communities for individuals who require palliative care in their region. The responses varied among LHINs and between LHINs and EOLCNs within the same region. Table 1 summarizes the overall findings according to service category and not by each LHIN area.

Table 1: Provincially funded palliative care health services provided in First Nations communities (on-reserve)

Provincially funded palliative care health services provided in First Nations communities (on-reserve)	# of LHINs stating services are provided on-reserve in their region (N=10)	# of EOLCNs stating services are provided on-reserve in their region (N=10)
CCAC services (case management, nursing, personal support worker, other professional services)	7	7
Regional cancer centre services	1	3
Palliative care teams	4	3
Pain and symptom management consultant	5	5
Grief and bereavement	2	4
Hospice volunteer visiting program	0	4
Palliative care education	5	6
Community health centres	1	0
Other	1	1

When asked if access to these provincially funded health services differs from one First Nations community to another within their LHIN area, two EOLCNs responded that it did differ, two responded that it did not differ, and two did not know. On the other hand, one LHIN indicated that it did differ; three indicated that it did not differ, and four did not know. In the category of other, examples were community health centres and other health care providers working in the community.

The final question in the survey attempted to determine how palliative care services were funded in a First Nations community. A mix of responses were received and summarized in Table 2.

Table 2: Funding sources for palliative care health services provided on-reserve

Funding sources for palliative care services provided on-reserve	LHIN Responses (N=10)	Network Responses (N=10)
Federal Government	1	1
Ontario Ministry of Health (directly)	1	0
LHIN	2	2
Transfer of funds from a provincial service provider to the First Nations	1	1
Special one-time research funding (foundation, research grant, government)	1	1
Combination of provincial and federal sources	4	2
Other	4	4

In the other category, four participants indicated that they did not know who provided funding for palliative care services on-reserve.

4.2 Palliative Care Innovative Practices in First Nations Communities

Phase-two followed up with ten survey participants who reported that palliative care services were provided to First Nations communities within their LHIN area and also agreed to a follow-up interview.

Most interview participants provided an overview of their regional palliative care services and confirmed that these services are normally “offered” to First Nations communities, but are not dedicated programs in First Nations communities. Several participants stated that palliative care services are provided in First Nations communities only by request and referral, particularly in the case of CCAC services. In remote communities, the distance and travel barriers prohibited routine service intervention.

However, participants identified a number of successful, interesting, and collaborative examples of practices in their area. For phase-three, three initiatives were selected for more extensive research based on the selection criteria previously described. Interviews with key informants from these initiatives provided a thorough overview of each innovative practice, including a better understanding of relevant:

- Policies and procedures - the policies and practices that determine the service arrangements for palliative care patients who reside in First Nations communities,
- Provisions of care/service - how this provision of care is initiated and managed by service agencies, and
- Coordination of the service - how off-reserve and on-reserve service agencies coordinate service provision.

These three examples of innovative practices are described below.

4.2.1 Innovative Practice #1: CCAC Memorandum of Understanding with a First Nations Community

Policies and Practices:

The Hamilton Niagara Haldimand Brant (HNHB) CCAC and the Six Nations of the Grand River Territory Home and Community Care Program (HCC) developed a Memorandum of Understanding (MOU). This document took close to 10 years to develop but was finalized and signed in 2011. While this memorandum is not palliative care specific, it does acknowledge and include a provision for palliative care services to people living in Six Nations. The MOU is to allow CCAC and Home and Community Care staff to communicate proposed substantive changes in service to one another. The goals are to enhance information sharing, smooth transitions for clients, and to ensure a vehicle for client/family complaints to be identified and resolved in a timely manner. It is agreed that this MOU may be reviewed/revised annually, or from time to time as necessary, to ensure optimum client service delivery.

Provision of Care

The MOU provides a framework which details the collaborative partnership and information sharing and which assists in outlining expectations and accountabilities for in-home community services to the client. This MOU formalizes agreements and accountabilities and has helped to define what each organization provides. CCAC provides acute care and palliative care nursing, while Home and Community Care provides chronic care and Personal Support Workers. The organizations share therapies and equipment. They share similar training and assessment tools across the 2 organizations (e.g., have trained HCC nurses on use of the RAI assessment tool). Having regular joint rounds offers the opportunity to review client needs and create collaborative care plans. This has strengthened partnerships with Case Managers in the First Nation community. In-service training was provided to HCC on the use of a palliative care kit which resulted in better coordination following hospital discharge and more integrated care.

The kit consists of a plan of treatment, expected death in the home protocol, ambulance Do Not Resuscitate Confirmation Forms (DNRC), and a death certificate.

Coordination of Service

The MOU describes three levels of collaboration between the two parties. These collaborative processes offer a mechanism for ongoing communication and resolution of local issues. The MOU has been recognized by the Ontario Association of Community Care Access Centres (OACCAC) as a positive proactive concept.

1. The first level of collaboration is Interdisciplinary Team Meetings which occur every Thursday from 2:00 to 3:00 p.m. at Six Nations or at the CCAC Brantford site, which is closest to the community. Teleconferencing is an option and available. Time and place are negotiable and must be agreeable to both parties. The Community Case Manager assigned to Six Nations is the CCAC's representative at these meetings.

The typical attendance at these meetings includes:

- HNHB CCAC Case Manager assigned to Six Nations
- Six Nations Case Managers
- CCAC Contact Nursing Provider for Six Nations
- Six Nations Therapy Manager (Ad Hoc)
- HNHB Client Services Manager and Six Nations Manager (Ad Hoc)

Specific to palliative care, on the second week of each month (Thursdays), the HNHB Palliative Care Case Manager will attend if there is a caseload of palliative clients to discuss. On Week 4 of each month the HNHB CCAC Children's Health Case Manager will attend if there are active cases on the caseload.

2. The second level of collaboration is a one-hour quarterly Directors meeting at Six Nations or at the HNHB CCAC Brantford office. Minutes are recorded and distributed by the hosting Administrative Assistant. The HNHB CCAC Administrative Assistant to the Director arranges these meetings. Participants are:
 - Director, Client Services HNHB CCAC
 - Director, Six Nations Long Term Care Home and Community Services
 - Manager, Six Nations Long Term Care Home and Community Services
 - Client Services Manager, Brant Branch HNHB CCAC
3. The third level of collaboration is a bi-annual one-hour Directors and Senior Directors meeting at Six Nations or at the HNHB CCAC Brantford office. Minutes are recorded and

distributed by hosting Administrative Assistants. The HNHB CCAC Administrative Assistant to the Director arranges these meeting. Participants are:

- Senior Director, Client Services HNHB CCAC
- Director, Client Services HNHB CCAC
- Director, Six Nations Long Term Care Home and Community Services
- Client Services Manager, Brant Branch HNHB CCAC
- Manager, Six Nations Long Term Care Home and Community Services

4.2.2 Innovative Practice #2: Palliative Care Education for Front-line Workers in First Nations Communities

Policies and Practices

The Centre for Education and Research on Aging & Health (CERAH) is located at Lakehead University in Thunder Bay, Ontario, and has been funded since 1993 by the Ontario Ministry of Health and Long-Term Care to deliver palliative care education to physicians and interdisciplinary community care providers. Each year, CERAH dedicates a portion of their provincial funding to provide education for health care providers in First Nations communities.

The need for the curriculum evolved from a program of research on palliative care in First Nations (2005-2009) that was funded by the Ontario Ministry of Health and Long-Term Care and the Northern Cancer Research Foundation (2008). At the time of development of this curriculum there was no palliative care education designed specifically for First Nations community caregivers. Thus, this curriculum was developed through a partnership between CERAH, the Kenora Chiefs Advisory, Kenora, Ontario, and the Gizhewaadiziwin Health Access Centre, Fort Frances, Ontario.

The curriculum is based on the needs identified in a palliative care assessment conducted in thirteen First Nations during 2005. The purpose of the curriculum was to teach palliative care knowledge and skills to First Nations people who provide healthcare and social services to individuals with life-limiting illness in thirteen Ontario First Nations communities in the Kenora and Rainy River Districts (Treaty #3 area). The ultimate goal was to improve the care of individuals at the end of life in their home community.

The Kenora Chiefs Advisory (KCA) is an alliance of independent, participating First Nations within Northwestern Ontario where the Chiefs from each of the seven communities constitute a board of directors and govern KCA. These Chiefs are accountable to the First Nations that they represent. KCA's mandate is to provide programs and services to the First Nations in the fields of health, education, and social services in a holistic, traditional way ensuring the survival of the Anishinabe way in the present and future generations. The Kenora Chiefs Advisory, based on the

approval of the board of directors, has been working with CERAH since 2005 on palliative care education and community development research through their Long-term Care (LTC) Program.

The Gizhewaadiziwin Access Centre is a community based, Aboriginal controlled, Primary Care service which combines western curative care with traditional Ojibway healing philosophies and practices. The Access Centre provides clinical, social, health promotion and preventive services, as well as access to traditional Ojibway healers. As part of the education and community development research, six First Nations in the Rainy River area participated in the research.

Provision of Service

Education is provided at the request of First Nations communities. This 15-hour palliative care education curriculum consists of 7 modules designed to educate the front-line staff from First Nations communities about the basics of palliative care. The modules can be offered as individual sessions over a period of several weeks or condensed into two full days of learning.

The curriculum uses the holistic teaching concepts of the medicine wheel combined with the holistic focus of palliative care. The format of the program can accommodate learning on-site within different organizations or communities. Although the curriculum can also be delivered using distance education, it is strongly recommended that it be delivered on-site in the First Nations community. The curriculum utilizes a resource called “Caring for the Terminally Ill: Honouring the Choices of the People” to enhance the material covered in this program. This resource was developed by palliative care experts and cultural Knowledge Carriers in the Treaty #3 area as a resource for families caring for dying people.

(http://cerah.lakeheadu.ca/uploads/Caring_for_the_Terminally_Ill.pdf)

The curriculum has been pilot tested, evaluated, and revised several times. This developmental process has been extremely important in making this program uniquely relevant to First Nations communities. The strength of the program is that it is adapted community-by-community to meet local needs. Experiential evidence indicates the ideal number of participants per session is 20, a number which provides opportunity for participant interaction, but maintains a safe, supportive environment.

The program includes the following modules:

- Module 1: Creating Context
- Module 2: Last Hours of Living
- Module 3: Pain
- Module 4: Community Care Teams
- Module 5: Working with Families
- Module 6: Grief and Bereavement
- Module 7: Helping Relationships and Self-Care

Coordination of Service

The facilitation team for each educational course is selected based on the needs of the community. All of the facilitators have expertise in palliative care and an understanding of cross-cultural care delivery. The usual facilitation team includes an individual with clinical experience in pain and symptom management; a social worker with experience in grief, bereavement, and psychosocial care; and a third social worker with an understanding of the cultural identity, beliefs and values of First Nations communities. In addition, one or two local cultural guides or Elders from the community also participate in the education to provide local context. These cultural guides or Elders are provided with an honorarium or gift depending on local cultural protocols.

Organizing the sessions requires a significant amount of communication with the local community to agree on the schedule, the details of time and place and participants. Therefore, planning the course can often take 6 to 8 weeks because it is tailored to each area and is not a standardized approach. An outline is sent of the course in advance, which details the learning objectives. The cost of the program may be subsidized by CERAH if participants meet the requirements for inclusion in the Ministry of Health funding. Where this is not the case, communities will pay for the education on a contract basis.

A limitation of making the education assessable to all interested First Nations communities is a lack of funding when communities do not qualify for the Ministry of Health program. In addition, revising the curriculum is ongoing and requires human resources. Some of the other challenges that have been identified include the delivery of the content to ensure that the literacy level is appropriate for the participants, which can range from grade 8 to university level.

This curriculum has been delivered multiple times to over 25 First Nations communities in the Northwest LHIN and HNHB LHIN areas as well as to a group of medical interpreters who provide service to residents in the Nishnawbe Aski Nation (NAN). In addition, it was also delivered to a group of service providers in the Northwest Territories. Participant evaluations indicate the benefits as it provides a holistic learning environment by combining First Nations beliefs, practices, and culture with mainstream westernized medicine and practices. Specifically, it utilizes the knowledge and wisdom of local Elders and cultural guides, along with circles and group sharing which are reflective of First Nations culture; provides practical and useful information by knowledgeable facilitators; provides an opportunity for cross cultural knowledge sharing between First Nations health care providers and non-First Nations health care providers; and improves individuals' abilities to work through their own losses. It is anticipated that this program will offer tremendous opportunity for growth across the province and country. With the possibility to offer train-the-trainer sessions, broader access to the program can be achieved and replicated.

4.2.3 Innovative Practice #3: Palliative Care Outreach Team

Policies and Practices

A palliative care outreach team hosted by the Stedman Hospice provides specialized outreach services to Six Nations clients who require home based palliative care. The team consists of a palliative care physician expert, a clinical nurse specialist and psychosocial/ bereavement workers who make home visits to support individuals who wish to die at home. In addition, the outreach team physician also goes to Six Nations 1-2 days a week to offer a palliative care clinic.

The palliative care clinic has been in operation since 1979 building a long standing relationship with members of Six Nations. The physician connects with other members of the team as required including working collaboratively with Six Nations primary care physicians and nursing staff. Having access to the outreach team also provides access to the wellness program, the residential end of life beds at the hospice and bereavement support if needed.

The strength of the team is the rapport and trust that they have established with the patients, families and other care providers in Six Nations to best understand and provide what is needed in the care plan. This relationship building with the community has been a long-standing development and is not something that typically happens quickly. Strong communication across the entire team is also considered a strength. There is a mutual respect for everyone who is a member of the team and the members trust one another's roles.

One barrier is the lack of community awareness of the team. New referrals are usually initiated by word of mouth from other members in the community. Given this lack of awareness, there is probably a greater need for palliative care services than is currently known. However a new link with the Brantford Cancer Clinic is also identifying patients earlier so it is anticipated that there will be increased referrals to these services.

There are definite opportunities for further development of this type of palliative care service and for an expansion to include other First Nations communities across the province. The biggest foreseeable challenge would be engaging physicians as they are considered the core of the team. It is also important to establish other supportive team positions so as to not over-burden the physicians.

Building trust within the First Nations community and involving their local team members is also critical. Offering mentorship and educational opportunities to support and build capacity in First Nations so that they can develop services on their own is important. The Brantford team has had many successes in engaging and mentoring Six Nations' nurses and physicians.

Provision of Care

Building confidence and trust is essential to the provision of palliative care. There is a widespread respect for the First Nations care providers and they are fully integrated into the team. All members of the team are viewed as equal and there is no hierarchy in roles, even in relation to the physician role. Building confidence and trust is also extremely important between the team members and the patients and families.

Standards of medical best-practices guide all of the palliative care provided to First Nations patients; however, the traditional culture and beliefs of the patient and their family are integrated into the patient care plan when requested. Family members are also invited to participate in providing care when desired. Consistent with cultural practices, anywhere from 2-15 people can be in the room with a patient at the end of life when care is provided in the home.

Referrals to the team can come from anyone; however, it is often one neighbour telling another neighbour about the service. The reputation of the team and the relationship of the team members with the community are critical to the acceptance of the outreach team's services.

Coordination of Service

The outreach program encourages early identification and referral to the program; as early as the time of a diagnosis of a life-threatening and/or life-limiting illness. When a referral is made to the program, a member of the team connects with the family to do an assessment. This can be done at the palliative care clinic, or as a home visit. Depending on the circumstances the person may begin the program by attending the Day Wellness program. As their illness progresses, additional services are added as needed, including access to the entire outreach team. Therefore, Day Wellness patients can be registered with the outreach program for years, since it is beneficial to work with patients long before they are imminently dying.

If the referral is not originally made by the family physician, the physician is contacted and involved very early. The team then provides information and care planning recommendations to the family physician. The family physician or other consulting physicians, for example the oncologist, are provided the option to share in the ongoing care of the patient along with the palliative outreach team.

The outreach team meets each Friday for clinical rounds to review and discuss the care plans of the patients. These meetings include all members of the team which could include: the physician(s), the nurse, the psychosocial/bereavement workers, the residential care coordinator of the hospice, the case managers from CCAC who are dedicated to Six Nations, representatives from the nursing agency, and representatives from the pharmacy. These weekly clinical rounds provide an opportunity to monitor patients, discuss, and modify their care plans. The goal is to

proactively attend to patients' needs, avoid crisis, emergency room visits, and hospital admissions.

4.3 Barriers and Strengths to Providing Palliative Care Services to Ontario First Nations Communities

Mandate

The survey indicated there is an overall lack of awareness and understanding regarding current palliative care services provided in First Nations communities. Many responses indicated confusion about whether their organization had a mandate to provide palliative care services in First Nations communities. One respondent noted that clarity is needed to resolve federal and provincial jurisdictional issues and that a tri-partite agreement between federal, provincial, and First Nations communities is needed to formally decide who does what.

Other participants noted that LHINs are legislated to work with the Aboriginal communities. LHINs have Aboriginal engagement funding which helps to support Aboriginal health circles or forums which in turn serve to advise the LHINs on these matters. Several EOLCNs also reported having Aboriginal representation on their Advisory Committees and/or had a specific Aboriginal Hospice Palliative Care Service Committee advising the Network. Despite this, participants from both the LHINs and the EOLCNs expressed that their knowledge of Aboriginal palliative care was limited and that other Aboriginal key informants needed to be involved for accuracy of information.

Palliative Care Education

In most cases, First Nations community members are invited to participate in mainstream palliative care education programs held off-reserve and it was reported that many members attend. Some respondents stated that this is because First Nations community members have no alternative, not because it is the preference. Some palliative care education is provided in First Nations communities by request and is often done in conjunction with First Nations leaders in the community.

Service Provision

It was rare to find a grief and bereavement or hospice volunteer visiting program that was offered in First Nations communities. In most cases, an invitation to attend integrated grief and bereavement group sessions off-reserve was extended to members of First Nations communities. In most cases, grief and bereavement counseling is provided by spiritual leaders in the First Nations community. In one instance, a request for a grief and bereavement educational session in the First Nations community led to a coping with grief workshop at the community health centre. Palliative pain and symptom management is offered in First Nations whenever and wherever possible. In some cases, program funding restrictions also limited this regular intervention due to the high cost of travel.

Several statements acknowledged that service providers try to respond to needs as presented and that they also try to work collaboratively with members in the First Nations community as much as possible. However, there were many relevant issues and challenges noted in their ability to provide services:

- The vast geography and isolation of some First Nations communities, therefore access is a huge issue;
- The need for cultural responsiveness to be built into these mainstream services to make them relevant and applicable;
- The desire for Elders to remain at home and maintain cultural traditions – question of how to best do this;
- The hope of First Nations to build their own capacity under the direction of First Nations communities; and
- The occasional reluctance of First Nations communities to accept provincial intervention, which is interpreted as a weakening of traditional federal agreements and responsibilities.

The follow-up interviews indicated many LHIN and EOLCN Leads were unable to provide any additional information. Participants expressed frustration in their lack of ability to provide any further details and with their own lack of knowledge in this area. Our study appeared to raise awareness that more involvement is required to develop palliative care services. It was evident that palliative services for First Nations vary greatly across the province. However, this interview phase of the study was effective in obtaining information regarding innovative palliative care services that were being provided in First Nations communities. In particular, these interviews identified programs that participants recognized as successful, interesting, and collaborative example of practices that might be shared with other LHIN areas and First Nations communities across the province.

Participants also noted that this study prompted LHINs and EOLCN s to ask important questions about palliative care in their First Nations communities. In response to the survey, one LHIN area undertook a needs assessment to find out what services are provided since there was such a poor understanding of the current situation. In another LHIN area, our study prompted the planning of a joint meeting with Aboriginal leaders to discuss potential next steps. Participants expressed that they were interested in fostering conversations with their First Nations communities, in a non-paternalistic dialogue and discussion, of these important issues.

This interview phase of the study also stimulated greater collaboration between LHIN and EOLCN Leads to discuss the palliative needs of First Nations communities. The study process served to encourage and engage relationship building where it had not previously occurred. In three cases, the LHIN lead and the EOLCN lead requested a joint interview discussion to collaboratively contribute information and potentially identify next steps for their local area. These collaborations were unexpected and yet very encouraging.

5.0 CONCLUSIONS

The research provided a beginning understanding of the direct care services that the Ontario government provides to individuals who are designated as palliative and live in First Nations communities. Utilizing a three-phased approach to data collection, we have been able to summarize the current provincial situation and reveal many strengths and challenges. A key finding was the overall lack of awareness and understanding regarding current palliative care services provided in First Nations communities. Confusion about jurisdiction and mandate for providing palliative care in First Nations communities was also evident. These are barriers to improving access and quality of care for First Nations communities.

This work is important for the progress of palliative care in First Nations communities since it not only identified a number of innovative practices that can be shared across the province, it also stimulated greater attention to First Nations palliative care issues. In much of Ontario, leadership is lacking federally, provincially, regionally, and locally to examine some of the issues identified through this research. Clear leadership is critical since currently there appears to be an overall lack of clarity regarding existing palliative care services provided to First Nations communities. In many cases there was even confusion in terms of whose mandate it was to provide palliative care services in First Nations communities.

The research also revealed a gap in knowledge about local Aboriginal hospice palliative care services. While Aboriginal Health Networks or Circles exist in most LHIN areas and are mandated as advisory bodies to the LHINs, regarding a broad array of Aboriginal health issues, these groups may or may not address issues of palliative care. EOLCNs exist in each LHIN area, mandated by the provincial government to be hospice palliative care advisory bodies; however, EOLCNs may or may not address Aboriginal issues. It appears that no organization is consistently taking responsibility for examining or addressing the issues of palliative care in First Nations communities.

This research demonstrates that in most cases First Nations community members are able to utilize mainstream palliative care programs held off-reserve as needed. However, while many First Nations members use these services, they indicate that this is because they have no alternative – not because it is the preference. The innovative practices identified in this report show that local community capacity building in First Nations communities can be achieved through establishing closer working relationships, trust building, as well as training and mentorship opportunities with expert palliative care providers.

6.0 RECOMMENDATIONS

To support the advancement of palliative care in First Nations communities the following recommendations are offered which coincide with the findings of this research.

It is recommended that:

- 6.1 The LHINs and EOLCNs work together, in collaboration with First Nations communities, in conducting needs assessments to identify community needs and current palliative care services provided in First Nations communities.
- 6.2 The LHINs take leadership to clarify their mandate in planning for the provision of palliative care services in First Nations communities.
- 6.3 The LHINs work out collaborative agreements with the federal government, and other service providers as necessary, to meet the identified needs for palliative care services in First Nations communities. Formal memorandums of understanding will help to provide role clarity, responsibility, as well as accountability for all parties.
- 6.4 The LHINs Aboriginal Health Networks/Circles and regional EOLCNs work jointly together at the local level to ensure that Aboriginal Hospice Palliative Care is addressed as a priority and efforts are made to build local capacity in First Nations communities.
- 6.5 The LHINs and EOLCNs work together, in collaboration with First Nations communities, to facilitate the sharing of innovative practices for providing palliative care in First Nations communities that incorporate Aboriginal service providers, appropriate traditions, and cultural practices at end of life.
- 6.6 The LHINs and EOLCNs work together, in collaboration with First Nations communities, to offer culturally relevant palliative care education, training, coaching, and mentorship of Aboriginal service providers. Members from the First Nations community should be involved in the design, planning, and implementation of the program curriculum and materials to ensure the inclusion of appropriate cultural traditions, content, and competencies.

APPENDIX A: PHASE ONE ELECTRONIC SURVEY

Provision of Palliative and End-of-Life Services to Ontario First Nations Communities by Ontario Health
Care Provider Organizations:
An Environmental Scan

Dear Potential Participant,

You are invited to participate in a five-year research titled *“Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development.”* This research is being conducted by a research team led by Dr. Mary Lou Kelley of Lakehead University, Thunder Bay, Ontario and Dr. Kevin Brazil, McMaster University, Hamilton, Ontario and is funded by the Canadian Institutes of Health Research. The overall goal of this research is to improve end-of-life care in First Nations communities.

As part of this study, we are conducting a provincial scan to identify direct care services that the Ontario government provides to individuals who are designated as palliative and live in First Nations communities (on reserve). We want to identify best practices in Ontario for providing access to palliative care services in First Nations communities, specifically exploring: the policies and practices that determine the service arrangements for palliative care patients who reside in First Nations communities; how this provision of care is initiated and managed by service agencies and how off-reserve and on-reserve service agencies coordinate service provision.

You are being invited to participate as you have been identified as a key informant based on your role within your organization. As either a lead from a regional End-of-Life Network or an Aboriginal Health Lead from a Local Health Integration Networks, we think you could most accurately report and comment on your regions' experiences related to the provision of palliative care on First Nations communities. Survey participants will receive the results of this research.

Your participation will involve completing an online survey which will take approximately 15 minutes of your time. By completing and submitting this online survey, you are indicating that you have read and understood this information letter and you are providing your consent to participate. The survey provides the opportunity to volunteer to participate in a follow up interview which will take approximately 1 hour. At the end of the interview, you will be asked for any relevant documentation that may assist in addressing the research objectives.

Your participation in all aspects of this research is voluntary and you may refuse to participate in any part of the study or withdraw from the study at any time. During data collection, you may decline to answer any questions. Interviews will be audiotaped, however, you may decline to be audiotaped, and that will be respected. It is not anticipated that there are risks to your safety by participating in this research. All data that you provide will be confidentially and securely stored at Lakehead University for five years, accessed only by the researchers and staff involved in the research.

The findings from this study will be summarized in a report, presented at conferences, or published in a journal so that others may learn from it. In all cases, findings will be reported in non-identifying and summary format, conforming to the guidelines for research ethics at Lakehead University. No individual participants will be identified by name in published results without their explicit consent. However, since your name and job title is available to the public and since we will report the findings by region, we cannot guarantee your anonymity.

If you have any questions concerning the research, please feel free to contact Dr. Mary Lou Kelley, School of Social Work, Lakehead University at (807) 766-7270 or by e-mail at mlkelley@lakeheadu.ca or the Research Ethics Board, Lakehead University at (807) 343-8934.

Thank you for your time and consideration.

Dr. Mary Lou Kelley
Principle Investigator
School of Social Work, Lakehead University

Consent

Do you consent to participate?

Yes, I agree to participate

No, I do not agree to participate at this time.

LHIN or EOLC Network Name:

Are there any First Nations communities (reserves) located within your LHIN area?

Yes

No

Health System Planning

1. How many First Nations communities or reserves are located within your LHIN region (please indicate number): _____
2. Does your LHIN engage in health system planning with First Nations communities or reserves to provide services that would benefit individuals who require palliative care (please choose one answer)?
 - a) Yes
 - b) No
 - c) Don't know
3. Does your LHIN have the mandate for Hospice Palliative Care Systems Planning for the First Nations communities or reserves in your area (please choose one answer)?
 - a) Yes
 - b) No
 - c) Don't know

If yes, please provide the name and contact information (telephone and email address) of the person responsible for this planning: _____

4. Does the HPC/EOLC Network in your region undertake Hospice Palliative Care Systems Planning for First Nations communities or reserves in your area?
- a) Yes
 - b) No
 - c) Don't know

If yes, please provide the name and contact information (telephone and email address) of the person responsible for this planning: _____

5. Does the LHIN and the HPC/EOLC Network in your region collaborate on Hospice Palliative Care System planning?
- a) Yes
 - b) No
 - c) Don't know

Health Services Provision

6. In your LHIN area, are provincially funded health services provided on-reserve to individuals who require palliative care?
- a) Yes
 - b) No
 - c) Don't know
7. Please estimate how many First Nations communities or reserves are receiving provincially funded health services for individuals who require palliative care in your area (please indicate number):
8. Which of the following provincially funded health services are provided on-reserve for individuals who require palliative care? (please check all that apply)
- a) CCAC services (case management, nursing, personal support worker, other professional services)
 - b) Regional Cancer Centre services
 - c) Palliative care teams
 - d) Pain and symptom management consultant
 - e) Grief and bereavement
 - f) Hospice volunteer visiting program
 - g) Palliative care education
 - h) Other:

9. Does access to these provincially funded health services differ from one on-reserve First Nations Community to another within your LHIN area?

Yes

- a) No
 - b) Don't know
 - c) Not applicable (there is only one First Nations community reserve within this LHIN area)
10. Where palliative care services are provided on a First Nations community or reserve, how are these funded? (please check all that apply)
- a) Federal Government
 - b) Ontario Ministry of Health (directly)
 - c) LHIN
 - d) Transfer of funds from a provincial service provider to the First Nation
 - e) Special one-time research funding (foundation, research grant, government)
 - f) Combination of provincial and federal sources
 - g) Other: please specify

11. May we contact you for a follow-up teleconference interview scheduled at your convenience to discuss this issue in greater detail? (please choose one answer)

- a) Yes
- b) No

If yes, please provide your full contact information in order to reach you to set up an appropriate interview time (Name, Position, Organization, LHIN area, Phone, Email):

12. Is there anyone else that you would recommend that we speak with in order to better understand provincially funded health services provided to individuals who are designated as palliative and live in a First Nations community or reserve in your LHIN area?

- a) Yes
- b) No

If yes, please provide contact information (Name, Position, Organization, LHIN area, Phone, Email):

Thank you for your time and participation in this survey