

Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care

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Background: The Indigenous people of Canada include First Nations, Inuit and Metis. This research focused on four diverse First Nations communities located in Ontario and Manitoba. First Nations communities have well-established culturally-based social processes for supporting their community members experiencing dying, loss, grief and bereavement. However, communities do not have formalized local palliative care (PC) programs and have limited access to medical services, especially pain and symptom management.

Methods: Researchers conducted participatory action research (PAR) in partnership with four First Nations communities to create local PC programs. A conceptual framework for community capacity development (Kelley model) and an integrative framework for PC research with First Nations communities guided the research over 6 years. Based on a community assessment, Elders and Knowledge Carriers, community leaders and First Nations health care providers created PC programs grounded in the unique social, spiritual and cultural practices of each community, and integrated them into local health services. Maintaining local control, community members engaged external health care organizations to address gaps in health services. Strategies such as journey mapping clarified roles and strengthened partnerships between community and external health care providers. Finally, community members advocated for needed funding, medication and equipment to provide palliative home care. The research team provided mentorship, facilitation, support, education and resources to the community leaders and documented and evaluated their capacity development process.

Results: Our findings contribute to PC practice, policy and research. Four unique PC programs were created that offered First Nations people the choice to receive PC at home, supported by family, community and culture. A workbook of culturally relevant resources was developed for use by interested First Nations communities across Canada, including resources for program development, direct care, education, and engaging external partners. Policy recommendations and a policy framework to guide PC program development in First Nations communities were created. All research outcomes were published on a website and disseminated nationally and internationally. Our work also contributes to furthering discussions of research methods that can advance public health and PC initiatives. We demonstrated the achievements of

PAR methods in strengthening community action, developing the personal skills of community health care providers and creating more supportive environments for First Nations people who wish to die at home. The Kelley model was adapted for use by First Nations communities. We also identified keys to success for capacity development.

Conclusions: This research provides a Canadian example of implementing a public health approach to PC in an Indigenous context using PAR. It provides evidence of the effectiveness of a community capacity development as a strategy and illustrates how to implement it. This approach, fully grounded in local culture and context, has potential to be adapted to Indigenous communities elsewhere in Canada and internationally.

Keywords: Palliative care (PC); participatory action research (PAR); Indigenous; community capacity development; public health

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Introduction

Palliative care (PC) integrates physical, psychological, social and spiritual care elements to improve the quality of life for people living with a life-limiting illness and their families (1,2). It honors the connections and relationships that people have with family members, community members, and care providers, and views the family as the unit of care. Culture plays a key role since it incorporates the social practices and beliefs of any group of people (3).

There is growing international interest to improve access to PC for Indigenous people. Research on Indigenous PC is emerging from Australia, New Zealand, Canada and the United States (4-6). The Indigenous people of Canada include First Nations, Inuit and Metis. This Canadian research focused on developing culturally appropriate PC programs in four First Nations communities.

There are 618 First Nations communities in Canada with approximately 474,000 inhabitants (7,8). Many First Nations communities are small and located in rural or remote regions (8). The aging of Canadian First Nations populations, and their increasing rates of chronic illness and terminal disease, make providing PC for this population a growing social obligation (9). The responsibility for funding Indigenous health rests with the federal government under the Canadian constitution; however, First Nations people also access provincially funded hospitals and health services outside their communities (10,11).

While there is diversity between and within First Nations communities, there are common themes pertaining to end of life. Communities view death as a natural part of the life cycle and care is provided by family and community (12-15).

For most First Nations people, the dying experience is sacred and needs to be prepared for according to their beliefs (12). There are established traditions for providing psychological and spiritual support, and long standing social processes for supporting people experiencing dying, loss, grief and bereavement. Further, connection to the land is important, especially to the traditional territories where people grew up and have familial connections (16,17).

While social, cultural and spiritual support is available in First Nations communities, people lack access to PC programs, especially pain and symptom management (9). Absence of social policy to address this issue, and dissension between levels of governments about jurisdictional responsibility for funding, have resulted in a service gap for PC in First Nations communities (6). Additional PC barriers include limited local health services, staff and resources, and lack of training in PC (6). The federal government funds only basic home and community care services (e.g., nursing, personal support) through the First Nations Inuit Home and Community Care Program (HCCP) (18). The limited funding allows services only during the day (Monday to Friday, 8:30 to 4:30), and PC is not funded as a unique service element. Most communities have visiting physicians who come weekly or monthly, depending on the population and location of the community. Many communities have no health services available on evenings and weekends.

Consequently, First Nations people frequently leave their communities to access service that is geographically distant and often culturally unsafe due to differences in language, values, beliefs and expectations (16,19-23). Receiving care outside the community creates alienation and social

isolation for First Nations individuals who are separated from their language, culture, Elders, Knowledge Carriers, family and support people (14,16,17,23,24). Although people want to die at home, many die in urban hospitals and long-term care homes (19,20).

Dying outside the community negatively impacts families and community members. It may prevent transmission of culture from one generation to the next (3). Further, dying is a time when the community traditionally gathers to support the family, and these community relationships foster collective resilience. Caregiving provides a shared purpose that builds social and cultural capital (25). Over time, lack of end-of-life caregiving can have a disempowering effect, undermining the community's collective confidence to care for their loved ones (19). It may also interrupt the community's collective ability to grieve since social networks promote belonging and emotional healing (26).

Given the issues described for First Nations people, it is increasingly recognized that PC should be developed at the local level. Program models need to be locally relevant and accessible (6,17), and need to be developed in conjunction with community leaders, Indigenous health care providers and the Indigenous community (3,27-32). While the challenges are similar, the solutions need to be community specific (14). Community capacity development, as an approach that is bottom-up and inside out, provides an appropriate conceptual framework for this work.

Community capacity development is consistent with a public health approach—also known as health promoting PC—that approaches end-of-life issues from a social, cultural and community lens (33). Applying the public health approach to First Nations PC has not been done to the knowledge of the authors. It requires: (I) implementing culturally appropriate PC services at the local community level; (II) developing supportive government policies that promote cross-jurisdictional partnerships and funding for required services, medication and equipment to support community-based programs; and (III) providing education of policy makers, health care providers and community caregivers. Generating the knowledge required to implement health promoting PC in First Nations communities provided the rationale for this research.

Methods

Overview of the research

This 6-year [2010–2016] research project was entitled

“Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development” (EOLFN). The overarching goal was to improve end-of-life care in four First Nations communities through developing PC programs and creating a culturally appropriate theory of change to guide program and policy development. Objectives were to:

- (I) Document Indigenous understandings of PC as a foundation for developing PC programs;
- (II) Generate a culturally appropriate theory of change in First Nations communities based on Kelley's community capacity development model;
- (III) Create an evidence-based tool kit of strategies and interventions to implement PC programs in First Nations communities;
- (IV) Empower First Nations health care providers to be catalysts for community change in developing PC and supportive policy frameworks;
- (V) Improve capacity within First Nations communities by developing PC teams and programs and strengthening linkages to regional PC resources.

Theoretical perspective

The EOLFN research adopted community capacity development as its theoretical perspective. Capacities are the collective capabilities found within and among people, organizations, and community networks and society (34). From this perspective, communities are seen to have the capacity to tackle their problems through collective problem-solving. The method of promoting change is to enhance local capacity and not impose solutions from outside (35). Through this research, researchers worked with First Nations communities to mobilize community PC capacity. Kelley's Developing Rural Palliative Care (DRPC) model offered the conceptual framework for this research (36).

Kelley's DRPC model

Kelley's four phase community capacity development model conceptualizes a process of change that builds on existing community capacity and context. Change evolves through four phases: (I) having necessary antecedent community conditions; (II) experiencing a catalyst for change; (III) creating a PC team; and (IV) growing the PC program. The four phases represent a sequential, yet gradual transformative process that ultimately provides clinical care, education and advocacy. Each phase has tasks that must be

Table 1 Demographic characteristics of the EOLFN Partner Communities[†]

Community attribute	Naoakamegwaning First Nation	Fort William First Nation	Peguis First Nation	Six Nations of the Grand River
Population [‡]	675	878	3,558	11,634
Cultural identity	Ojibway	Ojibway	Ojibway and Cree	Haudenosaunee
Proximity to an urban centre with hospital/specialized health services	100 kilometers (Kenora, ON) 537 kilometers (Thunder Bay, ON)	2 kilometers (Thunder Bay, ON)	190 kilometers (Winnipeg, MB)	25 kilometers (Hamilton, ON) 19.3 kilometers (Brantford, ON)
Level of local health infrastructure	Minimal & need to travel an hour for services	Good & easy access to hospital & services in Thunder Bay	Good & easy access to Percy Moore hospital located in Hodgson MB (15.7 km). Hub for smaller surrounding First Nations	Excellent & easy access to hospitals and hospices in Hamilton and Brantford

[†], these were the community attributes at the time the needs assessments were being planned and conducted [2008]; [‡], population is defined as the number of people living in the community; total populations (i.e., total number of community members, including those who reside outside of the First Nations community) were: Naoakamegwaning, 1,142; Fort William, 1,854; Peguis, 8,558; Six Nations, 23,289.

accomplished, culminating in the delivery of a PC program that is mobilized through strong linkages both within the community and to external resources.

The model incorporates the following principles of community capacity development: change is incremental and dynamic; change takes time; development builds on existing resources and is essentially about developing people; development needs to be “bottom-up”, not imposed from outside; and development is ongoing (36). This validated model is recognized as a guide to program and policy development for rural PC (37-39). In the EOLFN research, this model was adapted to guide creation of a culturally appropriate theory of change for First Nations communities. All aspects of program development were controlled by community members, ensuring the PC program was embedded in the unique social and cultural context of the community.

Ethics

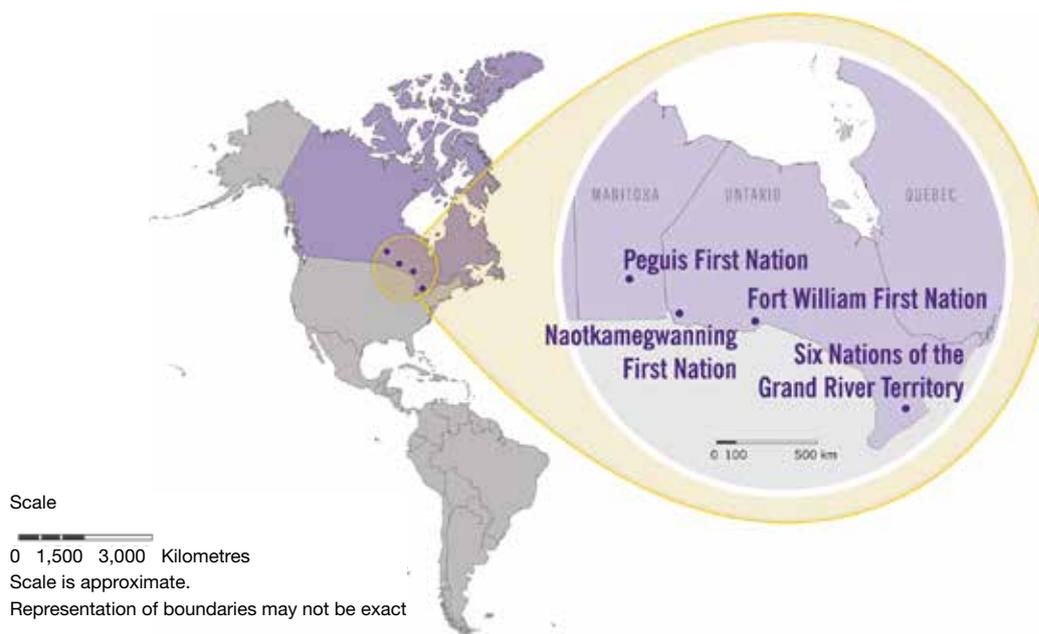
The research was approved by the Research Ethics Board of Lakehead University (REB #020 10-11), McMaster University (REB #10-578), Six Nations of the Grand River Territory and the Chief and Councils of Fort William, Naoakamegwaning, and Peguis First Nations. All participants in the project provided informed consent. Research was conducted following national guidelines

for health research with Indigenous people (40), and the principles of Ownership, Control, Access and Possession (OCAP[®]) which are sanctioned by the First Nations Information Governance Centre (FNIGC) to ensure self-determination in research concerning First Nations (41).

Design

This research followed Prince and Kelley's Integrative Framework for Conducting Research with First Nations communities which consists of five components: community capacity development, cultural competence and safety, participatory action research (PAR), ethics and partnerships (9). A comparative case study design was adopted using four First Nations communities as study sites (42). The four sites varied widely on relevant dimensions since maximum variation strengthens findings and applicability of results. Differences included: rurality, proximity to an urban health service centre, level of community infrastructure, local health services, population size, cultural identity and provincial health policy environment (see *Table 1*). *Figure 1* depicts the communities' geographic locations.

The method was PAR, which generates practical and theoretical knowledge using a social change process (43). The goal is to create social change for participants' benefit. This paradigm differs from conventional research paradigms in three ways: in its understanding and use of knowledge; its



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Figure 1 Geographical location of the EOLFN partner communities.

relationship with research participants; and the introduction of change into the research process (44,45). In this research, data were collected through multiple methods: surveys, interviews, focus groups, observations, and workshops. All instruments were reviewed by First Nations' community advisory committees to ensure cultural appropriateness and adapted as requested. For example, in one community there were changes in language, replacing the words palliative and dying with the words seriously ill and preparing for the journey. Data were collected by facilitators chosen by the advisory committees and paid using research funds.

The activities of the research are outlined in *Table 2*. Activities evolved incrementally and dynamically over the 6 years, from working inside the community (creating local PC programs) to working regionally and nationally on creating partnerships, reorienting health services and changing policy (funding and resources). Consistent with case study design and PAR, each community evolved in a unique way. As needed, the researchers provided mentorship, facilitation, support, education and resources to the community leaders and documented and evaluated their capacity development process (see *Table 2*).

During the research, each community developed their own PC program that was grounded in their unique social, spiritual and cultural practices, and integrated the

program into existing health services. Each community created an advisory committee that ensured development was consistent with their vision, community capacity and context. Comprehensive assessments were conducted in each community to understand beliefs and experiences with death and dying, and identify PC education and service needs. These assessments gathered quantitative and qualitative data in two phases. Key informant surveys were followed by interviews and focus groups to provide elaboration and clarification (see *Table 3* for participants). The survey and interview/focus group guides are attached as a Supplementary file 1 to this article. A video overviewing the research process is included as *Figure S1*.

Guided by the Kelley model and using the assessment findings, multiple clinical, educational, administrative and policy interventions were created and implemented. The research team documented the community development process in each community, generated a workbook of research informed strategies, evaluated use of the Kelley model and identified keys to success.

Results

The results are presented in three sections. Section 1 summarizes the community assessment findings which

Table 2 Activities of the EOLFN research over the 6 years

Locus of the work (time frame)	Objectives	Strategies
Working inside the First Nations community (year 1–5)	Community engagement	Identify community lead and create community advisory committee to conduct community assessment with recommendations (assess community values and beliefs about death and dying, knowledge and experience of PC, educational and service needs)
	Create community vision for PC	Develop leadership team to implement PC program development
	Create PC program guidelines based on social, spiritual and cultural norms and existing community resources	Assess existing community capacity for PC (resources, strengths, gaps and challenges)
Working outside the community with regional health care providers (year 2–5)	Reorienting external health services to support delivery First Nations communities	Provide PC education for First Nations health care providers
		Engage and educate regional health services as partners to: offer additional services, improve communication and coordination and discharge planning, and provide more culturally safe care
		Implement journey mapping [†] to create a PC pathway for First Nations people
Working with relevant governments and health care decision makers (year 3–5)	Advocating for required policy changes, funding and resources from all levels of government	Implement memoranda of understandings with external service providers
		Conduct provincial environmental scan of policy barriers for providing PC services in First Nations communities
		Advocate for additional funding for communities to implement local PC programs
Working within the research team: community leads and researchers (year 2–6)	Creating resources and to guide practice and policy	Educate health care decision makers on the policy barriers, issues and potential solutions
		Create a workbook to guide First Nations communities
		Create two policy documents to guide funders and program planners
Working within the project team: community leads and researchers (year 3–6)	Disseminating results to First Nations communities and health care decision makers provincially, federally and internationally	Create a facilitator guide for external partners who wish to support program development in First Nations communities
		Create open access website www.eolfn.lakeheadu.ca
		Organize a national “Improving End-of-Life Care in First Nations Communities Stakeholder Alliance” with over 100 individuals and organizations (held meeting, webinars)
Working within the project team: community leads and researchers (year 3–6)	Disseminating results to researchers	Present project process and outcomes to indigenous groups, First Nations health service providers, government funders and researchers
		Present research outcomes at regional, provincial, national and international research conferences
		Develop publications for refereed journals to share research outcomes and build international evidence for method (46-49)

[†], journey mapping is a culturally appropriate adaptation of value stream mapping used for quality improvement in health services (46). The research team created a journey mapping toolkit providing detailed guidelines to replicate the journey mapping process in other First Nations communities it is available on the EOLFN website: <http://eolfn.lakeheadu.ca/wp-content/uploads/2015/12/1-Example-EOLFN-Journey-Mapping-Guide.pdf>. PC, palliative care.

Table 3 Characteristics of the survey and focus group samples in the community assessments

Method	Key informant group [†]	Number of participants
Surveys	Community members	94
Interviews/focus groups	Community members	82
	Elders/knowledge carriers	68
	External health care providers	35

[†], community member: a member of one of the participating First Nations communities, including community leadership, family caregivers, internal health care providers (a member of the community who also provides health services in the community); Elder/Knowledge Carrier: a member of the community having status as being knowledgeable either due to age or immersion into the traditional cultural practices of the community; external health care provider: a non-community member who provides health care services to members of one of the First Nations community partners (either inside or outside of the First Nations community).

Table 4 Community assessment data illustrating the importance of dying at home

Key informant sample group [†]	Illustrative quote
Community member	<p><i>"I think about my uncle right now and he had cancer and, he just kept going and going, and going because I think his hope was that he would be at home to die, and he didn't go into the hospital for a very long time in the end, maybe a week eh, and then he died. He struggled every day to stay home because he wanted to really be at home to die, but it was just that last week he had to go in, and that's where he died, but to me and even, in this time of his death, I really believe that it was a very hard thing for him to go there and be in that environment, to leave the world because I think his hope was he would be at home to leave the world."</i></p> <p><i>"One of the things that there is such a great need in the community for end-of-life care and it brings a community together. Not being able to have that love on at home because of barriers can really pull family, not only the family, the community apart. That's why it's so important to bring them home where they belong."</i></p>
Elder/knowledge carrier	<p><i>"You hear everyone say well they passed away at home in their bed, and that just makes you feel so good ... that was nice, they, it happened the way they wanted it, but some of us don't have that choice, we're taken away too soon."</i></p>
Internal First Nations health care provider	<p><i>"There are people that are very sick in our community and we want to help them, and we know that is their wish to stay at home for as long as possible and that is what we want to do."</i></p>

[†], community member: a member of one of the participating First Nations communities, including community leadership, family caregivers, internal health care providers (a member of the community who also provides health services in the community); elder/knowledge carrier: a member of the community having status as being knowledgeable either due to age or immersion into the traditional cultural practices of the community; internal First Nations health care provider: community member who also provides health services within one of the four First Nations community partners.

motivated the action research. Sections 2 and 3 present the research outcomes to guide PC program development and policy and planning.

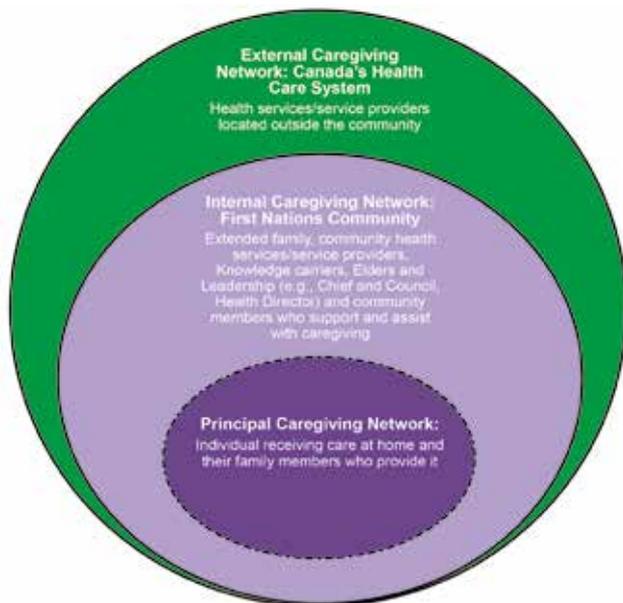
Section 1: Community assessments

A thematic analysis (50) integrating the findings of the four community assessments is presented below. Individual community reports can be accessed on the project website (51-54).

PC and community caregiving

Most (87%) survey respondents (n=94) indicated that community members would prefer to receive their PC at home in the First Nations communities, if local services were available and appropriate to their needs. *Table 4* provides quotes illustrating the importance of dying at home.

Most (81%) respondents also indicated they had cared for someone who was dying. Community members felt it is important for families to be involved in providing care for their loved one who is ill, and that community members



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Figure 2 Palliative caregiving in First Nations communities. Note: this model is an adaptation of Circles of Care Model from Abel *et al.* (55). Based on the EOLFN research, the Abel model was adapted for relevance to the First Nations community context. This adapted model depicts the integration of family and community caregivers when someone is dying which is a unique feature of palliative caregiving in First Nations communities that is not depicted in the original model.

should not die alone. Participants described the current state of palliative caregiving in the community below:

“It’s just, probably just the natural ways of the people. Just the way it was I guess a long time ago. People used to help you no matter who he was. If you were on the reserve, people, somebody would get sick, and then people would go down there and the whole family would have support...”—Community Member

“In a First Nation community it’s real extended family who, who have community members there too, and everyone helps and there’s always certain community members that show up and come and stay with the family, give them support, ... they bring in food, the whole community does that, and help. They help guide the family through, a, through this grieving process.”—Community Member

Palliative caregiving in the First Nations community is depicted in *Figure 2*. In the community, a person with a life-limiting illness is normally cared for at home by family members who provide direct care and support (the

principal caregiving network). Family is supported by community members who provide both direct and indirect support to the dying person and their family (the internal caregiving network). The internal community caregiving network includes extended family, natural helping networks, Elders and Knowledge Carriers, paid health care providers and leadership (e.g., Chief and Council and local health service administrators). Internal health care providers have ongoing, trusting relationships with community members and most live in the community. The boundary between the principal caregiving network and the internal community caregiving network is depicted as porous because of the importance of kinship and relationships in First Nations communities, and because people often hold dual roles (e.g., internal health care providers are often family members). Community members described supporting one another through death, dying, grief and bereavement.

Although cultural values and beliefs varied, the importance of culture in caring for community members who are dying was highlighted. Community members felt it is important to recognize death as part of life, and that death should not be feared. They spoke of the importance of traditions at the end of life, and that it is a time to pass on traditions, share stories, and participate in traditional ceremonies. They also described cultural community practices around supporting community members through grieving. The importance of culture is illustrated in the quote below:

“The community will always bring you back to culture. You will need to adapt your service provision to maintain that cultural uniqueness. Each family is unique. They may be traditional and attend the Longhouse or they may be Christian and attend one of the many churches, or they may be a combination of both. Six Nations thought it was important to include the traditional Elders, healer and pastors in a team we could call upon as needed.”—Internal Health Care Provider

Internal health care providers described feeling honored to journey with their clients and felt gifted with their clients’ stories. They explained they found great meaning in their work and grew close to their clients and families. They acknowledged that it is more common and acceptable for health care providers to emotionally bond with their clients in the First Nations community as compared with outside. This is due to the close personal relationships among everyone in the community.

“Cause you say we’re a big reserve and we are, but we’re still all intertwined in some way. Like we may not be relatives, but we grew up, or they know our brother or whatever. But when

Table 5 Summary of community assessment results related to challenges and barriers to community PC

PC resources & supports
Lack of PC services in the community and lack of access to external PC specialists
Lack of support services for families & lack of respite care
Lack of grief supports for families, internal health providers and the community at large
Lack of medical equipment (hospital beds, wheelchairs, pain pumps, oxygen)
Lack of transportation to transport seriously ill community members to medical appointments
Lack of access to medication for pain and symptom management; problems with the safe storage of medications
Inadequate housing and lack of assistive devices (e.g., houses lack proper door width, grab bars, and bathing equipment)
Knowledge, skills & cultural safety
Community members' personal fears around death and dying were identified as barriers
Community members lack knowledge in PC. The identified education needs focused mostly on the medical aspects of death and dying (e.g., illness specific information, care techniques, and what to expect at the end of life) as well as training in advance care planning
External health care providers lack knowledge of how to provide culturally safe care to First Nations people
Service, policy & jurisdictional barriers
Lack of communication/coordination between internal and external service providers
Jurisdictional issues related to First Nations health policy and inadequate budgets for delivering quality programming 24/7 in the communities (lack of services, lack of availability of services, and eligibility criteria for services) prevented community members from receiving care at home in the community

PC, palliative care.

somebody is dying and they need help, our community members will, well we'll help each other." —Community Member

At the outer edge of *Figure 2* is the external caregiving network depicting the health care system outside the community (primarily non-Indigenous). This includes physician services, hospitals, home care and long-term care as well as other specialized services (e.g., PC services, cancer care and PC educators). Data indicated a strong social and cultural barrier exists for community members accessing the external caregiving network. External caregivers lack ongoing, committed, trusting relationships with the community and culturally respectful care practices. The boundary between the community and the external network is depicted as thick to represent this barrier. Supporting data are provided below:

"In the hospital, you got to get out at a certain time, certain number of people, but when you're at home people can come and go in and out. People can sit there and sit with you for hours on end. That is one of the reasons people like being in their household." —Elder/Knowledge Carrier

"When I am near death, wheel me outside. Let me smoke my pipe outside the long-term care facility. Don't worry about the

cold, I am dying. My physical being needs to hold the pipe (its last chance). Don't maul my body! Give my family time. It doesn't matter if you know the exact time of my death." —Community Member

Overall, the assessments revealed that the communities had many strengths and assets that could assist in community members dying at home (e.g., dedicated health care providers and local services, strong natural helping networks, Indigenous understandings of death/dying, traditional caregiving practices).

Challenges and barriers to community PC

The assessments also identified multiple challenges and barriers that would need to be addressed to better support PC in the communities. These are summarized in *Table 5*.

A strong theme emerging from the data was the need for increased PC services in the community, especially for physical care and pain and symptom management. Families that had cared for loved ones described feeling powerless and not adequately supported to bring a family member home; this impacted both the principal and internal caregiving networks (*Figure 2*). Communities were not

Table 6 Community assessment data illustrating the need for community-based PC

Key informant sample group [†]	Illustrative quote
Community member	<i>"Having a palliative care program allows for that community to bring their loved one's home, to die where they were born...Certainly in an aboriginal community that is the one thing that is key, to be born on the territory and to pass away on the territory. Having a palliative care program helps them to feel comfortable leaving the hospital."</i> (community facilitator)
Internal First Nations health care provider	<i>"If the community members themselves, staff and family can keep care of their loved one, then they can come home. If the care that they require is too great for the staff that's here and, or the family then they usually have to stay in the hospital or in Kenora. Sometimes people stay in Kenora at family or friends there, for more service."</i> <i>"Oh, I have a friend, her mother passed away in the hospital and she told me that her mom was trying to come home, but the doctors wouldn't let her come home. And, my friend said that they wished she could of, like had the power to bring her home."</i>

[†], community member: a member of one of the participating First Nations communities, including community leadership, family caregivers, internal health care providers (a member of the community who also provides health services in the community); internal first nations health care provider: community member who also provides health services within one of the four First Nations community partners.

resourced to provide services on evenings and weekends or to provide sufficient hours of care to people with advanced illness. *Table 6* provides quotes illustrating the need for community-based PC.

In summary, the community assessments showed that, consistent with health promoting PC, community involvement and support of families at the end of life was traditional practice. A social and cultural model of care was already in place within the communities. While the social processes for supporting community members through death and dying were well established, the formalized PC services, supports and policies were lacking.

Section 2: Outcomes to guide development of PC programs in First Nations communities

A First Nations' adaptation of Kelley's community capacity development model

An early research outcome was adaption of Kelley's community capacity development model to the First Nations culture and context (see *Figure 3*). Consistent with the original model, PC program development is a bottom-up process which occurs through sequential phases of growing community capacity. The adapted model included a new tree graphic that was created by the project participants in Six Nations of the Grand River Territory and was given to the EOLFN project to use in the project.

The graphic is infused with cultural meaning (see note, *Figure 3*). The adapted model includes modification of the language to be more familiar and accessible for

community use. Two antecedent conditions of community readiness are added, namely, having sufficient community infrastructure (water, housing, transportation etc.) and having strong, consistent community leadership. Whole community collaboration replaces the focus only on health care providers. A new phase of development was added called "Grounding the Development in Community Values and Principles". This emphasizes that the person, family, community and culture (social context) are foundational to the program development process in the First Nations' adapted model.

This First Nations' adaptation of the Kelley model describes each community's incremental progress through the five phases of developing a PC program. Beginning at the bottom, each phase builds on the phase below, although work in each phase must continue (never ending). Program development takes time (months to years). The rate of progress will vary; communities can move forward or backward in the phases depending on their unique antecedent conditions and other situations happening within each community. Ultimately, the PC program becomes integrated into existing health services (e.g., Home and Community Care program, and is not a separate specialty service).

Once program guidelines are created, the program grows through implementing five processes: strengthening community relationships, building external linkages, providing PC in the community, promoting education and advocating for individuals and families. Growing the program happens from the inside out; external partners are engaged only after the community has created the program



"The pine tree symbolizes the Tree of Peace. The branches provide protection and the roots spread outwards in the four directions of the earth. The eagle on top is a spiritual being that warns of impending danger and is a symbol of strength. The eagle watches over all and is a connection to the creator. The colours of the sun can be a sunrise or sunset which gives us hope."

EOLFN Advisory Committee, Six Nations of the Grand River Territory

Figure 3 Process of palliative care development in First Nations communities.

and identified what outside help they want and how they want it. The principles of local control and community empowerment are fundamental to success.

Four customized PC programs in First Nations communities

Through the research, each community developed a unique and customized PC program with guidance from their local PC Leadership Team (composed of Elders, Knowledge Carriers, community members, and local health care providers). The achievements of each community are summarized in *Table 7*. More detailed descriptions of the communities' experiences are available in separate publications (47,49). Examples of two community program descriptions and a table summarizing how one community implemented the five phases of the model are included as supplementary files (Supplementary files 2-4).

The PC programs evolved differently in each community. Overarching keys to success were identified using comparative analysis and factors accounting for the variation among the communities; those are summarized in *Table 8*.

A workbook of resources to guide program development in First Nations communities

Through documenting and evaluating the PC program development in the four communities, "The Developing Palliative Care Programs in First Nations Communities Workbook" was created. The workbook, organized according to the First Nations' adapted model, outlines the capacity development approach and provides practical resources developed in the four communities. There are resources to assess PC capacity in a community and, based on what already exists, to develop or enhance the programs and resources to better support people to live at home until the end of their lives. A summary of the workbook contents is available as a supplementary file to this article (Supplementary file 5). The workbook and resources are also published on an open access website (<http://eolfn.lakeheadu.ca/>).

Based on the activities of the researchers, a facilitator guide called "Supporting the Development of Palliative Care Programs in First Nations Communities" was created to guide external partners who participate in capacity development with First Nations communities (56). The guide summarizes the EOLFN capacity development approach and provides strategies appropriate at each phase of program development. The importance of cultural humility and the need for the "outsider" (external partner) to take direction from the community is emphasized. Partners can provide valuable mentorship, support,

education and create opportunities for new linkages and resources.

Section 3: Outcomes to guide policy and planning

The need for supportive public policy

The research demonstrated the need for creating new public policy that: supports First Nations communities to undertake PC capacity development; enhances funding and resources to implement services; respects community control; and requires collaboration between First Nations, federal and provincial health care systems (51-54). There are currently barriers to collaboration between the federal and provincial health services, and jurisdictional confusion about the mandate to fund and provide PC (57). This research demonstrated the benefits of taking highly localized approaches to PC development, recognizing that needs and solutions are specific to place, context and culture. Programs that are locally developed, controlled and embedded in existing community social support networks are inherently culturally appropriate. Partnerships between federal, provincial and First Nations governments are required.

Policy development process: integrating the capacities of two systems

The guiding principle of two-eyed seeing articulated by Mi'kmaw Elders Albert and Murdena Marshall provided the research with an appropriate vision for policy development. Implementing this principle, one eye sees using Indigenous ways of knowing and the other sees using Western perspectives. Thus, two-eyed seeing is based on a "dynamic, changing, interaction and relational process which generates new ideas, understandings and information" (58,59). For PC, this approach meant integrating knowledge and resources from community and culture, with specialized PC knowledge and resources to support people with serious illness and their families to receive PC at home. It further emphasized that PC capacity development is the outcome of an emergent process to generate new knowledge. This policy making approach and capacity development strategies are illustrated in *Figure 4*.

Policy recommendations and guidelines for program development

Two policy documents were created based on this research. The first, called "*Recommendations to Improve Quality and Access to Palliative Care in First Nations*

Table 7 PC program development initiatives and outcomes in each community

Community	Initiatives/outcomes
Fort William First Nation	<p>Conducted journey mapping workshops to improve system integration and communication protocols between internal and external health services for people wishing to receive PC at home (e.g., hospital, home care programs, regional PC consultant)</p> <p>Created new discharge planning protocol with regional hospital (ultimately led to hiring an Indigenous discharge planner for the hospital)</p> <p>Conducted community education/awareness sessions on PC topics and advance care planning (with community partners)</p> <p>Developed culturally appropriate advance care planning resources (video, print)</p> <p>Created an information booklet of PC resources for community members</p>
Nootkamegwanning First Nation	<p>Developed a local PC program situated within home and community care</p> <p>Advocated for/received enhanced funding (10 months) from the provincial government for increased (24/7) services, PC education and medical equipment in the community</p> <p>Developed and delivered a cultural competency curriculum for external health care providers entering the community</p> <p>Participated in a regional telehealth pilot project in collaboration with external partners (used for care conferencing with regional palliative care specialists)</p> <p>Conducted a series of journey mapping workshops (internal and external health care providers) to improve service integration for clients wishing to receive PC at home</p> <p>Advocated for more PC funding to federal and provincial government ministers/members of parliament</p>
Peguis First Nation	<p>Developed and implemented a PC home support worker role</p> <p>Delivered a train-the-trainer grief and bereavement curriculum to First Nations health care providers (home care, mental health, etc.) to provide better grief support for clients/families</p> <p>Created a memorandum of understanding with the regional health authority (provincial) re: providing PC services in the First Nation community</p> <p>Increased the linkage with nearby federally funded hospital to collaborate with PC nurse/program and initiated a physician home visiting program</p>
Six Nations of the Grand River Territory	<p>Created a memorandum of understanding between internal home and community care program and external home care provider (provincial) to access needed PC services in the First Nation community</p> <p>Developed a local, First Nations, PC team (shared care outreach team)—physician, nurse, social worker, cultural knowledge keeper—to provide palliative home care in the community (provincial funding ongoing)</p> <p>Team received training/mentoring from the regional hospice (external); integrated the team into the regional PC program (external)</p> <p>Created culturally appropriate advanced care planning resources (video and print) and implemented community education in</p> <p>Knowledge Carrier role supported clients, families and staff, e.g., Four Strings Healing Ceremony</p>

PC, palliative care.

Communities” (60), includes four recommendations that are directed at the federal government who have constitutional responsibility to provide and fund First Nations health services. These recommendations could be implemented

immediately though political will. For example, enhanced resources for PC can flow into the Home and Community Care Program already funded in First Nations communities. Funding levels for home care are insufficient to meet the

Table 8 Overarching keys to success in First Nations community capacity development with variations among cases

Overarching keys to success in all four cases (not prioritized)

- Adopt a social model of PC, acknowledge dying as a social and cultural (not medical) event
- Understand unique community culture, values and principles, and ground the program in these
- Focus on the whole community including families, Elders/Knowledge Carriers and volunteers (not only health services)
- Get the “right” people involved on the community advisory committee (formal and informal leaders)—all “insiders” who are respected and influential and can champion change
- Have the vision for change emerge from within the community (internal)—respect diversity among communities in vision and priorities
- Assess local antecedent conditions and build PC program on assets—strengthen antecedent conditions as needed prior to proceeding with PC program development
- Provide culturally appropriate palliative care education to First Nations health care providers and community members
- Promote working together/teamwork within the whole community
- Have a strong local leader in the community as the catalyst for change: passionate, respected and influential, able to mobilize others
- Move through the phases of the model sequentially but flexibly (bottom up)
- Maintain local leadership and control of process
- Focus on changing things the community has control over or can act upon
- Adopt the concept of two-eyed seeing when integrating internal and external caregiving systems (see *Figure 4*)
- Adopt a palliative approach that integrates PC into existing primary care programs (e.g., home and community care programs)
- Reach out to create partnerships with external health services to address unmet local needs—creating program guidelines/care pathways and journey mapping (46) were key strategies (See Supplementary files 2,3,5)
- Promote sustainability by recognizing achievements and building community pride in supporting seriously ill people at home

Variations between the four cases

- Grounding the process in culture, values and principles: in the communities where the advisory committee and project lead most strongly embedded their work in community values and principles, the PC program development was accepted more quickly and fully
- Community characteristics: communities that were smaller and more socially homogeneous communities (culture, values and beliefs) more easily and quickly created a common vision and moved forward together with a common goal and plan
- Sufficient community infrastructure: if a community lacked basic infrastructure such as housing, clean water, communication, transportation to health services, it would be difficult to provide PC at home. All project communities had sufficient infrastructure, but the amount and type varied greatly. “Sufficient” is a qualitative judgement by the local advisory committee
- Community collaboration: existing health and social care programs collaborated closely and worked together beyond their normal roles to provide enhanced PC services. The better the collaboration the better the progress. The number of health care providers was not the most critical factor (the number ranged from 30 to 300 local health care providers)
- Community control of programs/services: where communities had control of their health services, collaborations were more successful, and progress was faster. In communities where health services were contracted to external providers, it was more challenging to create the local PC team. There were organizational barriers to collaboration and team work. Communities focused on education (community and health care providers) and advocacy with external partners for improved services
- Empowerment/support: all advisory committee members and leads were empowered and got ongoing support from community leadership (formal and informal leaders). However, the sources of support varied by community: Elders/Knowledge Carriers, health directors, local Chief and Council or local research ethics board

Table 8 (continued)

Table 8 (continued)

Sufficient health services: project communities varied greatly in the number of services and service providers, but all could mobilize sufficient health services to provide PC at home. "Sufficient" is a qualitative judgement by the local advisory committee. Communities built their PC program on existing resources and customized them during design (all programs were different). If a community lacked any health services, it would be difficult to develop local PC

Vision/motivation for change: communities that were most unhappy with their current access and quality of PC service were most motivated to do the work needed for change. Progress was faster when the vision was strongly embedded within the community (internal). Communities had competing priorities (social problems/flooding) and this impacted the progress of developing PC programs

Local leadership: continuity in leadership was important for progress. Community progress slowed, stalled or regressed with a change in leadership. Leaderships interruptions included maternity leave, personal leave and retirement. All communities experienced leadership interruptions/changes over the six years

The catalyst for change: the catalyst/change agent in all four communities was the lead person who was a local health care provider. The leads were all passionate, respected and influential in their community. The person was more important than the position or job title. Leads did not all have the same position

Community facilitator: the role of the community facilitator was important in community progress. All communities had two or more facilitators over the course of the project. Their skills varied. Strong facilitators maintained momentum and increased progress. Recruiting and retaining local, well qualified facilitators was an ongoing challenge because the position was part time. The project provided training, coaching and mentoring as needed

PC, palliative care.

needs of people with advanced chronic and terminal illness; program funding has not increased (except cost of living increases) since it was developed in 1999 (61).

The second document, called a "*Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities*" (62), targets health care decision makers and program planners at three levels: the First Nations community, provincial health services responsible for PC services and federal health services responsible for First Nations health. It provides ten guidelines for PC program development in First Nations communities based on the principles of capacity development, equity and social justice. The guidelines call for respecting the integrity of each First Nations community, its unique philosophy, and cultural traditions. Delivering services should be done through teamwork/collaboration and partnerships (within the community and between the community and external health services). Consistent with the Indigenous First Nations' model (Figure 3), the PC program provides services, advocacy and education for family and community members and education for the First Nations health care professionals.

Discussion

The following discussion highlights the contributions of this research for PC practice, policy and research. Limitations of the research are also acknowledged.

Contributions to practice and policy

It is well documented in the international literature that despite the growing need, First Nations people experience many barriers to accessing PC. The needs and barriers identified in the EOLFN research were consistent with those identified in an international literature review by Caxaj *et al.* The review concluded by identifying the following three priorities for providing Indigenous PC: (I) family centeredness throughout the PC process; (II) building local capacity to provide more relevant and culturally appropriate PC; and (III) flexibility and multi-sectoral partnerships to address the complexity of day-to-day needs for patients/families (6). The capacity development approach used in the EOLFN project created four community-based PC programs and addressed all those priorities. As a result, seriously ill community members had the choice to receive care in their community. While not all clients died at home, all received PC at home longer than before (47,49).

Through the capacity development process, communities created program models where internal community and external health and PC services worked together to support members in the First Nations community. Strategies such as journey mapping clarified roles and strengthened partnerships between community and external health care providers (46). Building on and reclaiming their historical and cultural traditions of family and community caregiving,

Palliative Care Programs for First Nations Communities: Integrating Two Systems

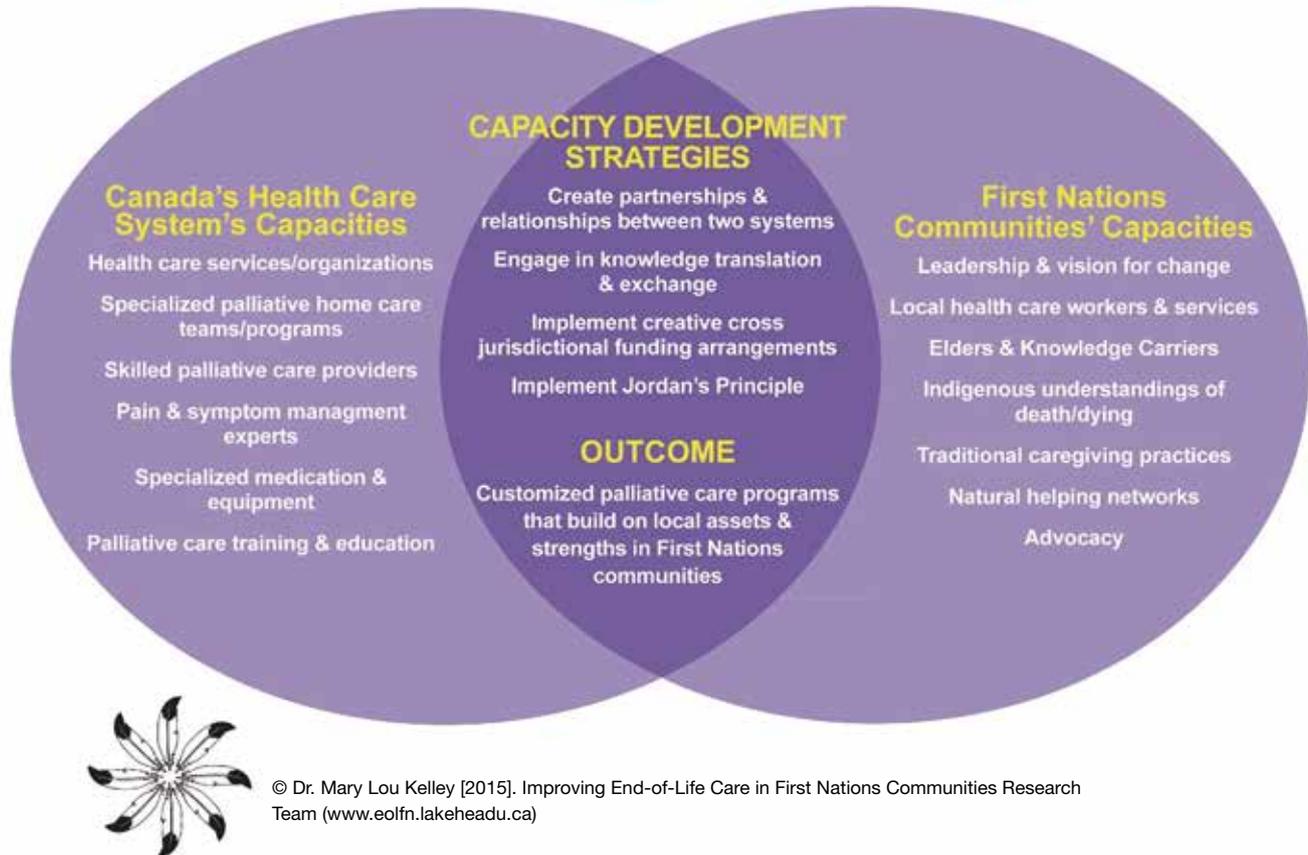


Figure 4 Palliative care programs for First Nations communities: integrating two systems. Note: Jordan's Principle is a needs-based principle that is intended to overcome the jurisdictional and service eligibility barriers to accessing health care services for First Nations people in Canada. It outlines that "the government department of first contact pays for the service", and resolve jurisdictional disputes and payment reimbursement later. Jordan's Principle can be found at: <http://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879>

the four First Nations communities involved in our research have demonstrated that they can mobilize their own capacity to provide PC. The communities have shared all their resources and learnings in the workbook that can be used by other First Nations communities across Canada to develop similar programs (63).

A unique contribution of the research was providing a practical example of how to do community capacity development in a place-based community with a distinct

social and cultural context. The change process was grounded in the social and cultural characteristics of the community and built on local strengths and assets. The catalyst for change was a passionate and dedicated local health care provider who could mobilize community members. Unmet needs were identified internally by the community (not by the external health system) and community-led action was undertaken to address them. External health services reoriented to better support

community care (better discharge planning, better communication and collaboration between internal and external health care providers, and increased cultural understanding by external providers). Community members successfully advocated for needed funding, medication and equipment to provide palliative home care. The role of the researchers was to support, mentor, educate, empower and organize—to provide structure around their process, and provide them resources and tools. The outcome was different in each community, as required to meet their unique needs.

The research also validated the Kelley model for use with First Nations communities. During the EOLFN research, an adaptation of the Kelley model was created to represent a culturally appropriate theory of change for First Nations communities (36). This First Nations application of the Kelley model illustrates that other unique Indigenous groups could adapt and use the Kelley model in their specific context. The model is intended to be adapted to local context.

This research provides an example of health promoting PC (33,64,65) where end of life is viewed from a social, cultural, and community lens. Consistent with health promotion strategies, the EOLFN project used public education, community engagement and development, policy development, and participatory methods of working. The PC programs created in the First Nations communities helped dying people avoid or delay accessing external services (harm reduction) and build on the positive, social and personal assets in communities.

The Ottawa Charter for Health Promotion outlines that successful public health interventions require attention to strengthening community action, developing personal skills, creation of supportive policies and supportive environments, and reorienting health services. Three basic strategies are endorsed: advocate, enable, and mediate (66). An important contribution of the EOLFN research approach is illustrating how all the components of the Ottawa Charter can be implemented. Every one of these components was essential to achieving the desired outcome. In 2017, the Canadian federal government announced more home care funding for First Nations communities, including PC. Some provinces are now engaging more with First Nations communities regarding health services.

The EOLFN community capacity development approach has potential to be used in place-based contexts anywhere across geographies. It overcomes cultural differences by integrating PC into existing social networks and services. This research further illustrates the potential of the Kelley

model for broader use since it guides communities to adapt and customize each phase of PC program development to their unique needs. The process is about building on local capacity, and the strengths that already exist in the community. The EOLFN research illustrates that the original Kelley model can (and should be) adapted by the population that it is going to use it.

Contribution to research

This research illustrates the benefits of PAR as a methodology to create culturally appropriate, community-based PC programs. PAR recognizes the expertise of First Nations community members and promotes integration of community values and practices into PC. Researchers and participants co-create knowledge through a reflective spiral of activity: identifying a problem, planning a change, acting and observing the process and consequences of the change, reflecting on these processes and consequences, and preplanning, acting, observing and reflecting (repeating the cycle) (44). PAR is particularly relevant to facilitating change and development as the research is embedded in social action. In PAR practice and policy are altered through the research (policy change, practice change, and research occur simultaneously).

PAR offers an appropriate methodology for health promoting PC research. Recently, Sallnow and colleagues proposed that, to advance the health promoting PC literature, participatory approaches are needed to complement the traditional approach to public health research which focuses on quantitative, epidemiological, and clinical research (67). The EOLFN research demonstrates the value of PAR methods for community capacity development in PC. PAR is particularly relevant to working with Indigenous communities because data required for the more traditional public health methodologies (e.g., longitudinal population-level PC data) are lacking for Indigenous populations in Canada. Further, ethical issues are high priority when conducting Indigenous health research and the PAR approach is consistent with guidelines created for national use in Canada (40,41).

Our findings also offer new learnings about the role and importance of place (internal and external caregiving networks), leadership, education and sense of community as keys to success. It also provides evidence of the important role of culture as an asset in capacity development. In addition, the research provided insights on the impact that community context (antecedent conditions) has on PC program development. While all communities implemented

the same capacity development process and created a PC program, there were variations in their experience (*Table 8*); those comparative insights can inform further application of the model.

Limitations

There are two limitations to the research. First, the intent of the research was knowledge creation related to developing the PC programs rather than evaluation of program outcomes. Only two communities documented outcomes related to the number of clients and services provided, participant satisfaction and perceived benefits (47,49). The impact of the new program on quality of patient care is not known or how community care compared with usual care outside of the community. Second, this was case study research done in only four communities in Canada. The transferability of research results to other First Nations communities in Canada, or to Indigenous communities internationally, requires further examination. However, the solid theoretical foundation in the Kelley model strengthens the likelihood of theoretical generalizability (68).

Conclusions

This research contributes to the international literature on public health and PC in Indigenous communities. It also provides Canadian evidence of the benefits of community capacity development to create culturally appropriate PC programs. The research adds understanding of how Indigenous communities can mobilize to provide PC and illustrates the appropriateness of using the public health approach where end of life is viewed from a social, cultural and community lens. It also furthers our understanding of the keys to success for community capacity development.

Four First Nations communities developed PC programs that integrated their social and spiritual practices, local health services and specialized PC expertise. This approach, fully grounded in local culture and context, can be adapted to Indigenous communities elsewhere in Canada and internationally. A workbook of culturally appropriate resources was developed that provides resources for PC program development, direct care, PC education, and engaging external partners (63). Policy recommendations and a policy framework to guide PC program development in Indigenous communities were created (60,62). These resources are published on an open access website (www.eolfn.ca) for use by all interested Indigenous people and

others.

Methodologically, this paper contributes to the public health and PC research agenda by demonstrating the achievements of PAR in strengthening community action to create PC programs, developing the personal skills of community health care providers and creating more supportive environments for people who wish to receive PC at home. PAR is a research tool that can be used for implementing health promoting PC across geographies and cultures. The Kelley model, adapted by First Nations communities, was validated for use to guide developing community capacity for PC. The model can now be adapted for use in other geographies and cultures.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The research was approved by the Research Ethics Board of Lakehead University (REB #020 10-11), McMaster University (REB #10-578), Six Nations of the Grand River Territory and the Chief and Councils of Fort William, Nautkamegwanning, and Peguis First Nations. All participants in the project provided informed consent.

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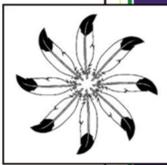
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SURVEY AND INTERVIEW / FOCUS GROUP GUIDES USED IN THE EOLFN COMMUNITY ASSESSMENTS

SUPPLEMENTARY FILE 1



Improving End-of-Life Care in First Nations Communities www.eolfn.lakeheadu.ca

SURVEY

Please answer the following questions as honestly as possible. Place an X or a checkmark in the appropriate box.

- 1. Gender:**
 Male Female
- 2. Age:**
 18 – 30
 31 – 40
 41 – 50
 51 – 60
 61 and over

Your General Knowledge of Palliative Care

- 3. Have you heard of the term Palliative Care?**
 Yes
 No

For the purposes of this survey, the term "palliative care" is defined as the following:
Palliative Care: A term used to describe a variety of services that are brought together to relieve the suffering and improve the quality of life for persons living with or dying from a terminal illness. These services are also available for family members of the individuals.

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

4. Who do you think that palliative care services are intended for? (please choose one answer)

- Everyone at the end of their life regardless of their illness
 Only patients dying of a life threatening disease like cancer or AIDS
 I don't know

5. Where do you think that palliative care is offered? (please check all that apply)

- Long-term facility or nursing home
 Hospital
 Patient's home
 Hotel
 In the Community
 Other _____

6. What services do you think palliative care includes? (please check all that apply)

- Medical services such as pain management
 Psychological support such as dealing with depression and anxiety
 Home-making such as help with household tasks, cooking, cleaning, etc.

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

- Spiritual care such as dealing with beliefs/religious practices/traditional customs
 Personal care such as hairdressing/shaving
 Respite
 Other _____

Your Personal Opinions

7. If you needed information about services for someone who is dying, who would you go to for information? (please check all that apply)

- Family Doctor Community Health Representative
 Community Health Centre Friend/Family Member
 Health Nurse Social Worker/Counsellor
 Hospital Priest/Minister/Pastor
 Pharmacist Traditional Healer/Elder
 Internet Other _____
 Tribal Authority Health Clinic

8. Have you or a family member ever provided care for someone who was dying? (If No, please go to question #9)

- Yes No I don't know

a) Where was this care provided at? (please check all that apply)

- Long term care facility or nursing home

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

- Yes No

14. In your opinion, how important is it to discuss your end-of-life care with a doctor? (please circle one answer)

- Very Important Important Not very important Not at all important Don't Know

15. Have you ever discussed your end-of-life care with a doctor?

- Yes No

16. In your opinion, if services were available and adequate, would more community members choose to die at home?

- Yes
 No
 I don't know

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

Any Additional Comments:

Thank you for your time and participation!!!

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

GUIDE FOR FIRST NATIONS (INTERNAL) HEALTH CARE PROVIDERS

1. Why does your community need palliative care? What events have led your community to want develop a palliative care program?
2. What services do you and/or your organization currently provide in the First Nation community?
3. How are these services accessed by patients and families? What are the eligibility requirements?
4. What organizations are you currently partnered with to provide service?
 - What is the decision making structure with your partners?
 - When and how did these relationships develop?
 - Are there formal service agreements and/or MOU's with these agencies?
 - What resources can be accessed through your partners?
5. Does your community receive palliative care services? If so, from where?
 - Does your community have its own palliative care program?
 - Who provides funding for palliative care services? Does the First Nation band directly receive the funding? If so, from where?
 - Are external agencies funded to provide palliative care services?
 - Are there service overlaps/gaps?
6. What do your health staff know about palliative care? Have they received any special training? If so what, when, and from where?
7. Who has received palliative care training in the community?
8. What do you see as the barriers and opportunities to providing enhanced palliative care and developing a palliative care program in this First Nation community?

- Hospital
 Home
 Other _____

b) Did you use health or community care services to take care of the person who was dying?

- Yes No I don't know

If yes, please name the services that you used _____

c) How satisfied were you with the services that you and your loved one received? (please circle one answer)

- Very Satisfied Satisfied Dissatisfied Very Dissatisfied Don't Know

9. How many hours a week do you think it would take to care for a dying loved one in your home – this would include tasks such as food preparation, housekeeping, shopping and attending appointments?

_____ hours a week

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

17. Which comes closer to the way you feel: (please choose one answer)

- People should start planning for end-of-life care when they are healthy
 People should start planning for end-of-life care when they have a serious illness
 You can't plan for end-of-life care; planning happens when you need it

18. What would be some of the advantages of choosing to die in your community?

19. In your opinion, what additional services or programs are needed to improve the experience and care of people who are dying in your community?

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

INTERVIEW / FOCUS GROUP GUIDES

GUIDE FOR COMMUNITY MEMBERS

1. Within your community, what is the primary diagnosis of terminally ill people?
2. Where do you feel that community members would prefer to die?
3. What would be some of the advantages of dying in this community?
4. What do you feel is the role of the community and family members when someone is dying?
5. What would be some of the challenges/obstacles that would prevent people from choosing to die in this community? What does your community need to allow terminally ill people to return home to die?
6. In your opinion, what can be done to improve the experience and care of people who are dying in your community?
7. Do you think that talking about death and dying is acceptable in your community?
8. What are some of the beliefs and values surrounding death and dying in this community? What are some of practices that are customary when someone is about to die?
9. What are some of your experiences working/providing care in your community for care with people who are dying?
10. Follow-up questions to the survey exploring contradictions will also occur. This will include topics such as: The surveys indicate that people in your community feel that discussing end-of-life care wishes (with family or your doctor) is a very important thing to do but also that it is not being done very often.
 - i. Can you explain this contradiction?
 - ii. Why are these discussions not taking place?
11. Is there anything else that you would like to add on the topic of palliative care in your community?

10. Do you think you could devote this much time to caring for a dying loved one, given your current schedule?

- Yes No

If no, please indicate why not? _____

11. Do you feel that talking about death and dying is acceptable in your community?

- Yes No I don't know

If no, please indicate why not? _____

12. In your opinion, how important is it to discuss your end-of-life care with a family member? (please circle one answer)

- Very Important Important Not very important Not at all important Don't Know

13. Have you ever discussed your end-of-life care with a family member?

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

20. What kinds of education or training do community members need to support people who choose to die at home in your community?

21. If you needed to get services in the home for someone who is dying, where would you go or who would you talk to?

Some questions in this survey were adapted and revised from a Ipsos-Reid survey conducted in 2004. The Glaxo-SmithKline Foundation and the Canadian Hospice Palliative Care Association. (2004). Ipsos-Reid Survey: Hospice palliative care study. Final report, January 2004.

GUIDE FOR ELDERLS AND KNOWLEDGE CARRIERS

1. How can I use this information that you are going to tell me?
2. From your perspective, what is the meaning of health and illness?
3. Is talking about death and dying acceptable in your community?
4. As an outsider coming in to your community, what do I need to know if I were helping or providing care for someone who was dying in your community?
5. What do you feel is the role of the community and family members when someone is dying?
6. What are your beliefs relating to advance health care planning?
7. What does your community need to know or take into consideration when developing a palliative care program?

GUIDE FOR EXTERNAL HEALTH CARE PROVIDERS

1. What services do you and/or your organization currently provide in the First Nation community?
2. How many residents of the (Name of First Nation community) access services from you and/or your organization? (if known)
3. How are these services accessed by patients and families? (may be in a variety of ways; Find out about all the different ways.)
4. What do you see as the barriers and opportunities to providing enhanced palliative care and developing a palliative care program in this First Nation community?
5. What is your and/or your organization's potential contribution to providing palliative care and developing a palliative care program for people who want to die in (name of First Nation community)?



Figure S1 The power to choose: the story of developing palliative care in four First Nations communities (69).

Available online: <http://www.asvide.com/article/view/24557>

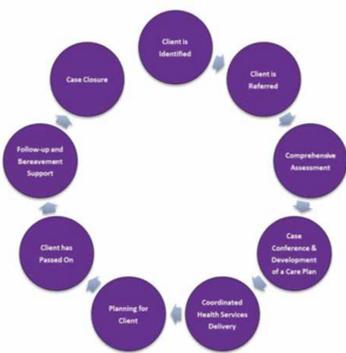
**WISOKOTAATIWIN PROGRAM
GUIDELINES**



**NETAAWGWONEBIIK HEALTH SERVICES
HOME & COMMUNITY CARE
AND LONG-TERM CARE**

807-226-2864
HOURS OF OPERATION
8:30 am – 4:30 pm
Monday - Friday

**WISOKOTAATIWIN PROGRAM
PATH OF CARE FLOW CHART**



- d) Family and staff will be instructed to call HCCP Coordinator for answers to any questions regarding care, changes in health status, or symptom crises; and prior to taking client to emergency or hospital or given other specific instructions.
- Family and staff will be made aware of whom to contact if the HCCP Coordinator is away from the community, on vacation, or sick. This support will be available on a 24/7 basis.
- e) Regular reassessments will be coordinated through the HCCP Coordinator and home care nurse. Adjustments to the care plan will be made as necessary and communicated to members of the circle of care through the In-Home chart, and other communication from the HCCP Coordinator if appropriate.
- f) HCCP Coordinator will call the discharge planner and/or the emergency department, based on type of hospital visit, when the HCCP Coordinator is away from the community, on vacation, or sick. This support will be available on a 24/7 basis.
- g) The HCCP Coordinator will provide the LWDH care planner and WNAC with a list of Wisokotaatiwin Program clients, and the planner will notify the coordinator if any clients are admitted to hospital.
- h) If a client is transferred to hospital, the client will be requested to bring the In-Home chart to the hospital for hospital staff to refer to.
- If this is an Emergency Room visit, a note/fax will be placed in the In-Home chart regarding the presenting problem, the treatment, and any further plan.
 - If this is an admission, the HCCP Coordinator will be involved in discharge planning. A copy of the discharge form will be placed in the In-Home chart which will return home with the client.

Home Support 226-2864

- Services provided are:**
- Minor home repair and exterior maintenance of client's home
 - Installing grab bars and other minor home adaptations, seasonal yard maintenance, for example: grass cutting, snow removal, cutting and piling wood, clearing hazardous walkways, observing and reporting client/home safety concerns, and equipment malfunctions

NETAAWGWONEBIIK HEALTH SERVICES

Administration 226-1026

Health Clerk/Reception 226-5383

- Services provided are:**
- Coordination and scheduling of medical appointments, as requested
 - Coordination of doctor and nurse practitioner appointments, in community
 - Maintenance of Winnipeg and Kenora appointment books
 - Coordination of clinic prescription pickup

Community Health Nurse 226-5383

- Services provided are:**
- Provision of health care services through clinic visits
 - Knowledge of individuals' general health by regular contact with community members
 - Assistance with referrals to outside agencies, as requested
 - Mandated Programs:**
 - Immunization
 - Communicable Disease Program
 - Well Baby Program

Walk-ins if and when time permits

LAKE OF THE WOODS DISTRICT HOSPITAL
(807) 468-9861
21 Sylvan St., Kenora

Palliative Care Coordinator: 468-9861 ext. 2339

- Services provided are:**
- Coordinate palliative care, see patients in hospital
 - Referral by client's physician

Discharge Planning: 468-9861 ext. 2254

- Services provided are:**
- Provide consultation to any in/out patient at LWDH to assist with identification/coordination of services required for safe discharge
 - Referral through any member of interdisciplinary health team or at patient/family request

NORTHWEST COMMUNITY CARE ACCESS CENTRE
(807) 467-4757
Suite 3 - 35 Wolsley St., Kenora

Robin Gould, Manager

- Through personal visits and regular check-ins, we help determine the right care and health supports for people and their families.

- Services provided are:**
- Nurses, occupational therapists, social workers, physiotherapists, speech therapists, and nutritionists
 - Nursing service referrals need to be faxed in from physician or nurse practitioner. All other referrals can come from anyone (the client, family/caregiver, other community service programs)

Disclaimer

This program booklet was developed as a guide to help those preparing for their Journey by the Naotkamegwaning Wisokotaatiwin Program Leadership Committee. Information presented is based on current resources and is not meant to endorse any particular listing.

**WISOKOTAATIWIN PROGRAM
PATH OF CARE**

1. Client Identification

Referrals for the Wisokotaatiwin program may be received from all access points, including existing Naotkamegwaning Home and Community Care program (HCCP) clients, self or family, family physician, Health Centre or other medical clinics, hospital, or any other health care program.

A referral to the program is appropriate if:

- The client could benefit from the services of the program, and
- The client wishes to receive their care at home, and
- The client has an illness from which no recovery is expected, and
- The client has a PPS score of 80% or less with a prognosis of continuing decline to 0% within approximately 1 year.

A Client Introduction pamphlet, a condensed version of this program guideline booklet, regarding the program will be made available to service providers and shared with the client and family. If translation is required and unavailable elsewhere, translation services are available from the community and may be requested by notifying the HCCP Coordinator.

2. Client Referral

Upon receiving consent from the client, a referral can be made to the Home and Community Care Program Coordinator (who is also the coordinator of the Wisokotaatiwin program) by phone at (807) 226-2864 or by faxing the HCCP Program referral form, specifying the Wisokotaatiwin Program (fax number is on the form).

6. Planning for Coming Home (The Passing):

Discussions with the client/family regarding their choices for care are initiated by the physician, or appropriate person, at a PPS score of 30% (or earlier if appropriate) and documented with the date in the In-Home chart.

- If a client is in hospital, a meeting with the client/family is initiated by the discharge planner and the HCCP Coordinator, involving the physician, and Merv Copenace if appropriate. The options for care and services available in hospital and at home are explained. If the decision is to go home, a case conference with the circle-of-care is initiated by the HCCP Coordinator to plan for care at home, including identifying what needs to be in place prior to discharge.
- If the client is at home, the HCCP Coordinator meets with the client/family to discuss "what it means to stay home", and explains what services the program can offer. The decision to remain home initiates a case conference with the circle-of-care to revise the care plan.

In both cases, the care plan will include:

- Explanation of expected physical changes in a culturally sensitive and safe manner;
- Ensuring the family knows who to contact for support; and
- Involvement of a spiritual support person or a traditional healer/support person for client/family support and performance of ceremonies, as requested/required.

Community Health Educator 226-5383 ext. 224

- Services provided are:**
- Identify, prioritize community needs on an ongoing basis
 - Education and promotion of all health initiatives
 - Home visits to all community members on a quarterly basis
 - Coordination of Health related community activities

Mental Health Services 226-1026 ext. 222

- Services provided are:**
- Ongoing counselling to all family units and individuals
 - Referrals to services on and off reserve, when appropriate
 - Home and office visits to community members to provide support as needed

Elder Support Worker 226-1026

- Services provided are:**
- Support and services to Elders
 - Transportation to town and cities

Family Support Worker 226-1026 ext. 248

- Services provided are:**
- Community based support and prevention services for children, youth, and families
 - Family counselling services within the context of mental health

Circle of Hope and Healing 226-1026

- Services provided are:**
- Promotion of the involvement of natural and extended family systems
 - Strategies to promote positive changes in lifestyle through traditions, customs, and language of Naotkamegwaning
 - Respect for the customary way of life, including traditional

JOHNSON'S PHARMACY
(807) 468-7412
116 Main Street S., Kenora

- Services provided are:**
- Accurate and timely prescription filling, including drug interactions, therapy duplication, correct dosing, and appropriate medication use and storage
 - Available in person or by phone for direct patient inquiry or questions from family members
 - Provide blister packaging of medication
 - Member of patient's health care team

PAIN & SYMPTOM MANAGEMENT PROGRAM
1-800-625-5406

Marg Poling, Pain & Symptom Management Consultant

- Services provided are:**
- Expert advice, support, and resources to health care providers on all aspects of palliative care
 - Consulting on issues regarding a specific client
 - Information and education on palliative care
- *Services available Monday-Friday 8:30-4:30**

TELEMEDICINE NURSE, HOSPICE PALLIATIVE CARE
St. Joseph's Care Group, Thunder Bay
(807) 343-2431 ext. 2511

Robin Cano, Telemedicine Nurse Consultant

- Services provided are:**
- Pain and symptom management
 - Assistance discussing and completing advanced directives
 - Client specific caregiver support and education
 - Client specific allied health support and evaluation



Naotkamegwaning Wisokotaatiwin Program Leadership Committee
October 2014

Back Row (left to right): Jyles Copenace, Rachel Prince, Shannon Anderson, Wilma Sietmoen, Maxine Crow

Front Row (left to right): Rose Skead, Lulu Kabestra, Megan Cowley

3. Comprehensive Assessment

Upon receiving a referral, the HCCP Coordinator visits the client, explains the program in detail, and conducts a comprehensive palliative care assessment, utilizing the HCCP Wisokotaatiwin program assessment form.

- If the assessment occurs at home, it will be conducted in conjunction with the home care nurse and the family.
- If the client is in hospital, the assessment will be conducted in coordination with the palliative care nurse and/or other hospital staff and the family.

Consent is obtained from the client to share assessment information with the circle of care (see step 4).

4. Case Conference and Development of Care Plan

- Upon completion of the assessment, and with client consent, the HCCP Coordinator organizes and chairs a case conference with the client/family and invites the following members of the circle of care, as appropriate: home care nurse; personal support worker; physician; homemaker; WNAC nurse practitioner; Community Health Nurse; Community Health Representative; CCAC care coordinator/staff; LWDH discharge planner; palliative care nurse; cross-cultural coordinator; any other appropriate provider (i.e. OT, PT, mental health, spiritual care provider, traditional healer); and anyone else the client wishes.

- If client is at home, the conference will take place in the home or in the community; participants will attend case conference in person or with OTN connection.
- If the client is in hospital, the case conference is planned and occurs several days before discharge. The HCCP Coordinator organizes and chairs the conference in conjunction with hospital discharge planner and appropriate hospital staff.

7. Client Has Passed:

The family is most involved and caregivers take direction from the family. If food and wood are required, the community will provide help with this. Financial support for the family, funeral, food and supplies, are available through the Naotkamegwaning Band Office if required.

8. Follow-up and Bereavement Support:

Traditional and cultural beliefs, values, and customs are honoured and respected.

Services from the Wisokotaatiwin Program will continue after the passing, as appropriate:

- A follow-up bereavement visit from the HCCP Coordinator will occur to assess how the family is doing.
- If additional support is required, referrals can be made to the community mental health coordinator, family support/traditional advisor, elder support, KCA psychologist, WNAC emotional wellness coordinator, or Thunder Bay community wellness team.
- HCCP Coordinator will ensure family has access to traditional support.
- A sharing circle for all members of the circle-of-care will take place, organized by the HCCP Coordinator, and led by both an Elder and a mental health professional.

9. File Closure:

Equipment is returned to the HCCP Coordinator and will arrange returns to appropriate agencies as required.

Each agency is responsible for maintaining and retrieving their own records.

Community Wellness Worker 226-1026 ext. 240

- Services provided are:**
- Assistance to community members requesting traditional healing
 - Quarterly sweat lodge ceremonies
 - counselling services/referrals
 - Transportation to appointments

Suicide Prevention/Black River Camp
226-1026 ext. 244

- Services provided are:**
- Culturally based activities for youth and Elders
 - Black River Youth and Elder engagement camp

Community Transportation Services 226-5383

- Services provided are:**
- Medical Van: transportation to and from appointments in Kenora
 - Alternate Distance Driver: transportation to and from Winnipeg appointments
 - Dialysis Driver: transportation of dialysis patients to and from Kenora

IMPORTANT COMMUNITY SERVICES NUMBERS

- Mino'Giizhigad Elder Centre 226-9665/226-2864
- Naotkamegwaning Housing Manager 226-2736
- Naotkamegwaning FN Administration 226-5411
- Naotkamegwaning Ontario Works 226-1092
- Naotkamegwaning EMS 226-2277
- Community has 911 system

COMMUNITY HEALTH CARE PROFESSIONALS INC.
(807) 467-8393
201 - 115 Chipman St., Kenora

Vicki Barnes, General Manager

- Services provided are:**
- Deliver Home Care and Community Health nursing services in First Nation Communities, including Naotkamegwaning.
 - All of the nurses receive cultural sensitivity training and are able to incorporate the needs of the community and clients into their nursing care, while maintaining all standards of the programs they service, as well as, the professional standards of nursing.
 - Home care services are offered through the First Nation and Inuit Home & Community Care Program.
 - Offer both Registered Nurses and Registered Practical Nurses depending on the needs of the clients they are providing services for.
 - Nursing services include hands on nursing, on call nursing, program supervision, assistance with reports and supervision of unregulated health care providers.
 - The team of professional nurses has a variety of skills and experiences to accommodate the communities and clients they service.

SHOPPER'S HOME HEALTH CARE
(807) 468-4128
605 4th St., Keewatin

BROWN'S FUNERAL HOME
(807) 468-8633
429 2nd Street S., Kenora

MISSION STATEMENT

Wisokotaatiwin will provide coordinated, comprehensive, person-centered and compassionate care to those who are very sick whose wish is to return home to Journey, while supporting individual beliefs and values.

VISION

To have available for Naotkamegwaning First Nation members, coordinated comprehensive services for those wishing to return home to Journey, maintaining use of individual traditions and spiritual beliefs.

TERMS OF REFERENCE

The Wisokotaatiwin Program Team will facilitate the coordination of high-quality service to those who are very sick in our community by:

- Providing a forum to share and collaborate within the team
- Providing education and training to those involved in the person's care
- Providing bereavement and after care to families
- Creating partnerships with external linkages
- Maintaining communication with our networks

- A written plan of care will be developed and shared with all members of the circle of care, by means of the In-Home chart. In the event that care providers are unable to attend the meeting the HCCP Coordinator may also follow up with a phone call to communicate the care plan, if necessary. It may be determined that not all case conference participants are necessarily actively involved in the client's care at the present time, and/or it may be determined that other providers need to be included.

The plan will include goals of care; services to be provided; procurement and storage of medications, including traditional medicines if appropriate; and, equipment procurement; as well as a checklist of possible services designed to address all domains of care. This is to be referred to on an ongoing basis, ensuring clients are assessed for and offered services at the appropriate time.

The plan will also include information for family and staff on whom to contact if there are changes in health status, symptom crises, or questions regarding care occur. This can include but not be limited to CHCP, WNAC, physicians, telemedicine services, and pain and symptom management coordination. If additional members are added to the circle of care, consent is obtained and the care plan is shared with them.

5. Coordinated Health Services Delivery

- Day-to-day communication between the circle-of-care is documented in the logbook placed in the clients home.
- The HCCP Coordinator is the client's care manager.
- Case conferences will be called as necessary; any member of the circle-of-care can call the HCCP Coordinator and request a case conference.

**WISOKOTAATIWIN PROGRAM
LIST OF SERVICES**

HOME & COMMUNITY CARE PROGRAM

Program Coordinator 226-2864

- Services provided are:**
- Intake, assessments, monitoring and support of HCCP and Wisokotaatiwin Program
 - Case conferencing, client advocacy, care plan development and review
 - Referral(s) to organizations/agencies
 - Coordination of client discharge from hospital

Home Care Nurse 226-9665

- Services provided are:**
- Assistance for chronically and acutely ill clients to receive the care they need in their own community

Personal Support Workers 226-9665

- Services provided are:**
- Health monitoring, health teaching, personal care and meal preparation
 - Bathing, grooming, basic foot care, skin care, dressing, medication assistance, toileting, vital signs, respite care

Home Maker 226-2864

- Services provided are:**
- Assistance with activities of daily living and non-medical care
 - Home cleaning tasks, person care and meal preparation, housekeeping, laundry duties, personal care, assistance with hygiene, assistance with transferring and mobility, friendly visits, respite care

COMMUNITY HEALTH CARE PROVIDERS

WAASEGIIZHIG NANAANDAWE'IYEWIGAMIG (WNAC)
Kenora Health Access Centre (807) 467-2666
212 4th Avenue S., Kenora

Nurse Practitioner

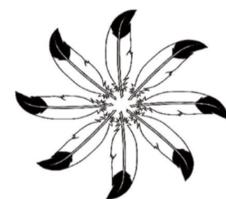
- Services provided are:**
- Weekly clinic in community, broad range of health care services including assessment, diagnosis, and treatment
 - Home visits can be arranged for Wisokotaatiwin clients as required
 - Available to respond to questions regarding care of family or staff

Mental Health & Emotional Services (in community or Kenora)

- Services provided are:**
- Emotional Wellness coordinator
 - Traditional healing programs, access to Elders and traditional health services
 - Diabetes education and foot care
 - Health education and promotion—group education and issue-specific workshops in community

KENORA CHIEFS ADVISORY
(807) 467-8144
3 - 115 Chipman St., Kenora

- Services provided are:**
- Psychologists
 - Social Workers
 - Mental Health team



*Ojibway unity and harmony
with Mother Earth*

SIX NATIONS LONG TERM CARE/ HOME AND COMMUNITY CARE

**PALLIATIVE CARE
PROGRAM GUIDELINES**

519-445-0077
HOURS OF OPERATION
8:30 am—4:30 pm
Monday - Friday

Haudenosaunee Philosophy Statement

Traditional philosophical principles have a crucial relevance to the challenges our people face today. Oshenton karhwahakwen or the words that come before all else are a reminder of the place that we as human beings were meant to occupy in relation to all of Creation; a place of balance and respect. Our worldview comes from the Creation Story, the Original Instructions and is expressed in our annual cycle of ceremonies of thanksgiving. Our worldview teaches us that we exist with purpose, with a sacred intent and a duty to uphold the human responsibility to all of Creation. Our core philosophy is simply expressed as one body, one mind, and one heart. In the Haudenosaunee tradition, acceptance comes from a view of the natural order that accepts and celebrates the co-existence of opposites; our purpose is contained in the quest for balance and harmony, and peace is gained by extending the respect, rights, and responsibility of family relations to other peoples. The values are the state of peacefulness, the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. In the words that come from the Thanksgiving Address "we must see the cycle of life continue" –and ensure the health and wellness of the people.

Mission Statement

Six Nations Health Services is dedicated to ensuring that each individual is respected and treated as a valued human being by providing, promoting and protecting and advocating holistic health home and community care services for current and future generations of the Six Nations Community.

Vision

To provide compassionate, coordinated, and comprehensive end of life care to individuals living in the community of Six Nations.

Terms

The Community Team will help facilitate the coordination of services as follows:

1. Provide a forum for information sharing and promote collaboration amongst team members.
2. Through information sharing, identify issues and/or deficiencies requiring attention and discussion. Team will then troubleshoot together and come up with solutions that work for everyone.
3. Maintain communication with appropriate networks of care and community partners.
4. Support and share educational opportunities for all involved (professionals' education including family and caregiver).
5. Promote the team as a resource to be accessed by the public/promote awareness of the team at the local level (public education).
6. Evaluate the program/process on a continuous basis, in order to make adjustments and improve upon the delivery of end of life care in the community.
7. Inclusion of Haudenosaunee Philosophy and maintaining cultural sensitivity in all decisions for the best interest of the people.

Disclaimer

This palliative care program guideline booklet was developed as a guide to help those preparing for their final days by the Six Nations Palliative Care Leadership Committee. Information presented is based on current resources and is not meant to endorse any particular listing.

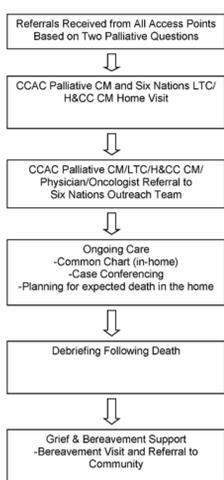
Six Nations Palliative Care Program Path of Care

1. Referrals will be received for the Six Nations Palliative Care Program from all access points including hospitals, families, family health teams, cancer clinics and CCACs. In order for a patient to be followed by the Outreach physician for gain and symptom management, a physician referral is needed. Anyone can refer to the Outreach team for psychosocial/bereavement support and do not need to be followed by a nurse/physician if family physician chooses to maintain primary responsibility of care. Clients will be determined to be palliative based on the response to two palliative care questions:
 - a) Would you be surprised if client were to die within the year = NO
 - b) Does the client have pain and symptom issues related to end of life = YES

Admission to the program does not need to be by physician alone. Any care provider who identifies an individual who could benefit from end of life care can discuss this with the individual and initiate the referral. Clients are admitted directly to CCAC and acute nursing agency (First Nations/Care Partners/Red Cross) and the Six Nations Long Term Care/Home and Community Care Program.

2. An initial home visit is made by the CCAC Palliative Case Manager and the LTC/Home and Community Care Case Manager and whoever else the family wants present. As well as an initial referral could also be made by the Clinical Nurse Specialist and physician if a referral to CCAC has not yet been made.
 - a) A palliative RAI assessment is completed and shared between each Case Manager and the appropriate consent is signed.
 - b) Appropriate palliative services are initiated and equipment put in place. Client and family are given the contact information to ensure that they can access assistance on a 24/7 basis. The end of life checklist is put in the home. Clinical Nurse Specialist and Outreach Physician will make initial visit with patient and family.
 - c) A pamphlet describing the program and related services is given to the client and family by Outreach Team and/or LTC/H&CC CM, whoever makes initial contact. Information on 'who to call' is left with the family i.e. acute nursing agency number.

Six Nations Palliative Care Program Path of Care Flow Chart



Six Nations Palliative Care Program List of Services

CASE MANAGEMENT UNIT

The Case Management Unit consists of 4 Case Managers who provide intake and Referral for the services of the Long Term Care/Home & Community Care program.

The Case Managers conduct an in depth assessment of a community member's health and functional ability and refers to the appropriate service provider on and off the Reserve.

They also attend family meetings, case conferences and hospital discharge meetings to assist Six Nations residents understand the way our services operate and the limitations with our home care services. Once again to ensure client safety when sent back into the community setting.

Services Provided are:

- To provide intake and referrals for all clients
- To conduct needs assessments
- Determine clients plan of care
- To advocate for clients and ensure needs are met
- To liaison for clients with other agencies

REGISTERED NURSE

There are two complex care nurses who perform dual roles of visiting clients in the community who require maintenance care. One of the nurses provides foot/care for clients and provides hands on nursing when required.

Services provided are:

- Provides nursing care to clients' in the community
- General health monitoring
- Advocates for client to access services
- To help improve quality of life

PHYSIOTHERAPY

Physiotherapy promotes wellness, mobility and independent function. Physiotherapists understand how the body moves, what keeps it from moving and how to restore function.

Physiotherapy can help:

- Manage sprains and strains of joints and muscles
- Maintain your independence
- Recover after surgery
- Maximize your mobility
- Manage the physical complications of cancer and its treatment
- Pre- and post natal care and other women's conditions
- Manage conditions such as arthritis, neurological disorders, cardiac and respiratory disorders.

The physiotherapy treatment may include some or all of the components listed below:

- Therapeutic exercises
- Education about your condition
- Hands on manual therapy techniques
- Posture and gait retraining
- Electrical modalities and acupuncture

Physiotherapy services are available on the first floor of the White Pines Wellness Center.

OCCUPATIONAL THERAPY

The Occupational Therapist is available on Mondays and Wednesdays. The OT receives new referrals at that time and makes visits to clients in the community requiring equipment.

The OC provides assessment and treatment related to:

- Environment and safety assessment
- Body mechanics in the home
- Education of lifting and carrying techniques
- Promote independence in the home
- Energy conservation techniques
- Pain management
- Relaxation
- Referral to community resources
- Training in the activities of daily living
- Use of devices and adaptations
- Mental health rehabilitation
- Life skills
- Assists in accessing funding through various programs such as ADP, RPA, and...
- Assesses transfer techniques and mobility issues.

ADULT DAY CENTRE

- Assessment:**
- Clients are assessed by the case manager to determine eligibility
 - Adjuvant to conduct a leisure inventory profile with client and/or family
 - Day center/meal to develop an individual program plan for the client to outline goals and objectives for programming
- Transportation**
- Transportation is arranged by the caregiver or family member for the client

Client cost for the program

- Lunch is available from Meals on Wheels
- Monetary donations accepted
- Drinks and snacks are available
- Special events may carry an additional charge

NUTRITIONIST/DIETITIAN

The Long Term Care Dietitian provides in home visits and office visits to set up meal plans and provide nutritional surveillance to clients requiring assistance with a variety of diagnoses ranging from diabetes to weight loss to renal to palliative. The dietitian also acts as an integral member with Health Promotions.

Services provided are:

- Nutrition/Dietary Counselling—available for one-to-one counselling, with family members or for groups
- Group Presentations—possible target groups: toddlers, preschoolers, teens, adults and seniors. Any nutrition related topic may be covered upon request
- Diabetes Education Program
- In-School Curriculum—Diabetes Awareness and Prevention is taught in all schools twice a year
- Educational Resource—written and audio visual materials are available to the community covering numerous areas

COMMUNITY SUPPORT SERVICES

The Six Nations Community Support Services offers many different services to seniors (65+) and disabled person who are residents and registered band members of the Six Nations of the Grand River

Services provided are: (some services may have a minimal monetary fee)

- Meals on Wheels—delivery of a hot nutritious meal to clients home five days per week
- Transportation—every Monday and Friday transportation (van) to local centers for purposes of shopping and banking. A courier service is available
- Home maintenance and repairs
- Some help-workers—provide light housekeeping services such as vacuuming, mopping floors, laundry, dishwashing and dusting
- Friendly visiting—workers will visit seniors in their homes in order to keep them socially involved in community events and news
- Security—workers will make regular telephone contact to seniors' in their homes
- Diners club—supervised recreational and social group activities (Silver Fox Club) are offered every Tuesday and Thursday at a setting location. Transportation and meals are provided

SPEECH SERVICES

Speech Services helps clients to overcome and prevent communication problems and difficulties with swallowing. Communication difficulties in the areas of language, speech, voice, fluency may involve producing sounds, words and sentences, understanding or listening to the speech of others, and the use of reading and writing skills (literacy).

Services provided are:

- Assessment and management of speech and language, feeding/swallowing difficulties
- Set treatment goals with family and caregivers, determine and provide care plans to meet these goals
- Develop and monitor programs to be carried out by other care providers (including Communicative Disorders Assistants)
- Provide consultation, individual or group therapy in clinic or in the home
- Collaborate with Physicians, Nurses, Dietitians, Teachers, Psychologist, Occupational Therapists, Educational Assistants, Personal Support Workers and other care providers

Caring for People with Communication Disorders

HEALTH ADVOCACY OFFICE

This service provides a holistic assessment in regard to issues such as financial, legal, personal, emotional and/or mental needs of the client.

Services provided are:

- Public presentations and trainings
- Supportive counselling e.g. survivors of heart attacks, strokes and dementia
- Supportive counselling of issues or concerns of Elder abuse
- Palliative care counselling for clients and caregivers
- Counselling related to aging process
- Advice on financial needs
- Navigate for services with health and social issues

PERSONAL SUPPORT SERVICES

Personal support services are provided to all Six Nations band members of all ages based on individual needs per the Case Manager's nursing assessment.

Services provided are:

- **Personal care**—assistance in personal hygiene, bathing, dressing, grooming, toileting and transfer assistance.
- **Meal planning/preparation**—assistance with grocery lists, grocery shopping, planning and preparing meals, special diets
- **Ambulation**—assisting with ambulation in wheelchairs, assistance with walkers, canes, transfers and safety supervision
- **Exercise**—assisting with a planned medical regime under the supervision of a physiotherapist
- **Respite care**—providing care giver relief
- **Home Management**—assisting with light housekeeping
- **Personal business**—assisting with banking, bill paying and sending/receiving mail, accompanying clients to medical appointments
- **Child care**—providing child care while the primary giver is ill/incapacitated/convolescing
- **Advocacy**—assisting with referrals to additional agencies for other services

SUPPORTIVE HOUSING JAY SILVERHEELS COMPLEX

The Jay Silverheels Complex provides supportive care for Oshkwenhones who have experienced a spinal cord injury the opportunity to move back to Six Nations. The potential clients will be able to return to their own community to live in one of the 8 specially equipped apartments located in Oshkwenk. We have designed short term respite to any Six Nations band member. We have designed a spacious environment with the client's needs in mind.

Services provided are:

- Semi-private roll in shower
- Special lifts which run on a ceiling track
- 24 hour personal support workers on site
- Meals provided daily by qualified personnel and served in a spacious dining area

All applicants will go before an Admissions Committee and prioritized according to Supportive Housing criteria.

TRADITIONAL WELLNESS COORDINATOR

The Traditional Wellness Coordinator role is:

- Promote concepts of traditional health
- Organize or assist with implementing traditional teachings and activities
- Resource development
- Assisting the needs of clients referred for care
- Identify & coordinate resource people to assist individuals or families in need of traditional healing
- Networks with culturally knowledgeable people & other Traditional Healing programs.

TRADITIONAL KNOWLEDGE CARRIER

The Haudenosaunee are inseparably connected to the land and its resources. The knowledge, language, stories, and ceremonies are intertwined between the land and the people. Traditional knowledge encompasses all knowledge pertaining to the Haudenosaunee and their territory and has been transmitted from generation to generation.

Knowledge teaches the people how to be responsible for their own lives and develops their sense of relationship to others. The Traditional Knowledge Carrier is an individual who is recognized by their community as having knowledge and understanding of the traditional cultural practice of the community, including the language, spiritual and social practices.

The Traditional Knowledge Carrier works with the people towards the restoration of balance and harmony to the body. The diverse elements of the Haudenosaunee can be acknowledged, learned, and understood by means of the teachings shared by a culturally knowledgeable person.

Six Nations List of Health Services

Ambulance	519-445-4000
Dental Services	519-445-2221
Early Childhood Development	519-445-0339
Family Health Team	519-445-4019
• Primary Health Care	
Health Administration	519-445-2418
• Clinic Nurse	
• Medical Receptionist	
• Medical Transportation	
• Public Health Receptionist	
• School Nurse	
• Sexual Health Nurse	
Health Promotion & Nutrition Services	519-445-2909
• Activity Program	
• Diabetes Education	
• Healthy Lifestyles	
• Nutrition Counselling	
Healthy Babies/ Healthy Children	519-445-1346
Iroquois Lodge	519-445-2224
Long Term Care	519-445-0077
• Adult Day Care	
• Community Support Services	
• Home & Community Care/ Case Management/Equipment	
• Jay Silverheels Complex	
• Personal Support Services	
• Professional Services/Part Time Driver	
Mental Health Team	519-445-2143
• Case Management	
• Early Intervention in Psychosis	
• Mental Health Educator	
• Psychiatric Consultation	
• Rehabilitation Services	
• Release from Custody	
• Supportive Housing	
New Directions Group	519-445-2947
• Addiction Counselling/Bereavement Counselling	
• Addiction Outreach Worker	
• Animal Control	
• Community Health Rep.	
Share-AP	519-445-2228
Six Nations Maternal & Child Centre	519-445-4522
• Aboriginal Midwives	
• Breastfeeding Coordinator	
• Children's Health Services	
• FASD Coordinator	

Contact Information for the Longhouses

Haudenosaunee Resource Center
905-765-1749

Casket Maker

Two Feathers 519-933-6922
Hills Custom Coffins 519-861-0370

Cooks

Janice Henry 905-768-1945
Virgie General 519-445-0904

Clothing

Iroquois 519-445-0414
Martins Crafts 519-445-2558

Moccasins

Deanna Sky 519-445-2472
Wanda Green 519-445-2920

Corn Bread

Sky's Corn 905-768-5050
Hi's Native Food 519-445-2930

Wake Singers

Cam Hill 905-765-1749

Speakers

Onondaga, Mohawk, Seneca
• Pete Sky 519-445-2933
Cayuga, Tuscarora, Oneida
• Leroy Hill 905-765-6966

Contact Information for the Local Churches

- Bethany Baptist 519-445-0561
- Chapel of the Delaware United 905-768-1366
- Faith Victory Tabernacle 519-445-2691
- Grand River United 519-445-0955
- Johnsheild Baptist 519-445-2872
- Medina Baptist 519-445-4396
- Oshkwenk Baptist 519-445-2908
- Six Nations Pentecostal 519-445-4291
- Six Nations Seventh Day Adventist 519-770-4585
- St.Peter's St.Luke's, St.Paul's, Christ Church—Anglican 519-445-2661

Funeral Homes:

- Styres Funeral Chapel. Oshkwenk 519-445-2262
- Hyde & Mott Chapel. Hagersville 905-768-5733
- RHB Anderson Funeral Homes LTD
 - o Tel# 905-768-5733
 - o Fax# 905-768-2724
 - o E-mail: rbanderson@mountaincable.net

Client Rights of Rights

CLIENT RIGHTS

Every Client has the right to:

- Be treated with courtesy and respect
- Have one's own ethnic, cultural spiritual and religious values respected
- Have information about the organization that is providing services and how those services are to be provided
- Give consent to, or refuse service or treatment
- Confidentiality with respect to their personal or medical information
- Raise concerns and recommend changes regarding service delivery
- Have information on where and how to direct grievances or concerns regarding service or service providers
- Participate in the scheduling of visits with case manager to accommodate (when possible) conflicting dates and times
- Have the level of service assessed and adjusted according to treatment plan, with plan towards discharge if possible

CLIENT RESPONSIBILITIES

Every client has the responsibility to:

- Treat service providers with courtesy and respect
- Expect ethnic, cultural and religious values be recognized by service providers
- Provide all required information and sign the needed consents in order to receive services
- Be involved in care planning and follow a mutually agreed upon plan
- Inform care provider of any change in condition or needs (hospital, holiday) as soon as possible
- Accept the scope and limitations of service providers
- Make every effort to be as independent as possible
- Be present and prepared for the service providers' visit
- Give the service provider as much notice as possible when you need to cancel a visit

Statement of Information Practices

Collection of Information

We collect personal health information (PHI) about you directly from you or from a person acting on your behalf. The personal health information that we collect may include: your name, date of birth, address, health history, band number, record of your visits, and the care that you received during those visits. Occasionally, we collect personal health information about you from other sources, if we have obtained your consent to do so or if the law permits.

Uses and Disclosures of Personal Health Information

- Treat and care for you
- Plan, administer and manage our internal operations
- Conduct risk management activities
- Conduct quality improvement activities
- Compile statistics
- Conduct research
- Teach
- Conduct client satisfaction surveys

Your Choices

You may withdraw your consent for some of the above uses and disclosures by contacting us and completing a Withdrawal of Consent Services for PHI Use Form.

Important Information

We take steps to protect your personal health information from theft, loss and unauthorized access, copying, modification, use and disclosure, and disposal. We conduct audits and complete investigations

If you think we have violated your rights, contact the:

Information & Privacy Commissioner/Ontario
2 Bloor Street East, Suite 1400
Toronto, ON M4W 1A8
1-800-389-3333

Dedicated to the memory of Christine Sky,

our Traditional Knowledge Carrier,

who assisted in the development of our resources:

The Journey Back Home

and

For The One's Left Behind

MODEL FOR ABORIGINAL PALLIATIVE CARE

Advocacy

Education

Clinical Care

Building external linkages

Building community relationships

Process of PC Development

Sufficient health services infrastructure Community Empowerment

Collaborative generalist practice Vision for change

Individual and family

The Five Phases of Developing A Palliative Care Program In First Nations Communities: An Overview of the Process from Six Nations of the Grand River Territory

PHASES	ACTIVITIES	TIMELINE	OUTCOMES
1.GROUNDING THE PROGRAM IN COMMUNITY VALUES AND PRINCIPLES -may be different than westernized ,medicalized , or urban models of palliative care -needs to be based on local control and engage community members -builds on each individual community's strengths -build on local community partnerships with regional ,provincial and territorial health care providers	-Coordinate a strategic planning session and bring together community/Traditional leaders, community members, health care providers and external regional, provincial and territorial health care providers. -Determine the community philosophy and the desire for working in a palliative approach to care. -Determine those members who wish to be part of a palliative care committee	<u>YEAR 1</u> Community Engagement and Community Assessment -Identify Elders as knowledgeable informants to share their Indigenous understanding of end of life care through unstructured narrative interviews -Community members asked about their knowledge of palliative care and their previous experiences caring for a dying loved one -A one day community session to discuss how palliative care services are currently provided	You have a sense of community control and community empowerment You have a vision to improve the care of the dying
2. HAVING COMMUNITY READINESS Characteristics: -having enough community	-Determine the Community Lead (should be in a Managerial position in the Health department and who can delegate to task groups) -Organize a meeting of the	<u>YEAR 2</u> Assessing Antecedent Community Conditions -the community will self-assess sufficient	You have sufficient local health care infrastructure You have a collaborative and generalist approach

infrastructure e.g. housing, clean water, transportation, good communication technology -having enough local community health services and health care providers -having health care providers who are able to collaborate within the community as well as outside the community -having a sense of community empowerment to take action and responsibility to solve local problems -having a vision for change which will guide the work of the leaders and community members -having strong local leadership to initiate and guide the community development process	interested members and set up an Advisory Committee who will oversee the work (these members should be at a Senior management level so they can initiate recommendations) --Committee to begin work on the tables for assessing antecedent conditions: - determine what services are already in place and what services are needed. -determine what are the community's strengths and gaps. -determine what are the goals of the community and prioritize them	infrastructure ,collaborative practice, vision for change and a sense of community empowerment -community members will be invited to discuss their perceptions and experiences in providing palliative care ,perceived barriers and supports -health care professionals who serve the community will be interviewed in person or by telephone and asked about services that they currently provide in the community.	to practice
3. EXPERIENCING A CATALYST -this person or event begins the process of community change and mobilizes community members to work towards their vision	The event is highlighted and the committee focuses on making appropriate changes	<u>YEAR 3</u> A series of focus groups held to generate the local vision for change and to explore the vision for a local palliative care program	You have had a catalyst that mobilized the community into action

4.CREATING THE PALLIATIVE CARE PROGRAM -the process is formalized with seven steps: i) hiring a community facilitator ii) creating a timeline iii) understand community needs and perspectives iv) developing the work plan v) forming the Leadership team vi) creating palliative care guidelines vi) addressing the outcomes	-A community needs assessment is completed , the community facilitator collects information by doing focus groups, interviews and helping people do surveys for the needs assessment -Timeline summarizes the present situation including funding and policies. -A report compiling all collected information is completed -The work plan is developed based on the recommendations of the needs assessment -The Leadership team is formalized and work on identified initiatives is to commence. -The Leadership team creates the community's palliative care guidelines and meets monthly to monitor the progress.	<u>YEAR 4</u> Creating the palliative care team -the Community Facilitator begins the "leg-work" she collects information, organizes events, creates resources, writes reports and provides updates to the Advisory committee. -the Leadership team meets monthly to develop the work plan and palliative care guidelines -the Leadership team focuses on monitoring their progress and addressing the issues and barriers they encounter while creating the palliative care program	You have dedicated providers and getting palliative care staff and resources You have physician involvement You are working together as a team with strong relationships, good communication and support
5.GROWING THE PALLIATIVE CARE PROGRAM -extending palliative care out into	-Focus on increasing public awareness of the palliative care program by developing client brochures and posters, being	<u>YEAR 5</u> Implementing and Evaluating all	The team is being strengthened with sharing of knowledge and skills. Linkages are being

the community and putting the program into practice with five strategies: -strengthening community relationships -building external linkages -promoting education -providing care -advocating for individuals and families	present at community events and promoting the program. -Develop Memos of Understanding with external service providers to define the roles with the community. -Organize educational opportunities for all health care providers about the principles and practices of the palliative approach to care. -Following education the health care providers begin providing care and advocating for families	interventions. -Community Launch to talk about the program ,discuss the work plan and get some feedback on the program development process -Promotion of education to local health care providers about the principles and practices of the palliative approach to care. This education would include grief and bereavement, care for the caregiver ,pain and symptom management and family support	created outside the community. As a team you are learning by doing and developing member self-confidence. The community is engaged and you are developing and implementing tools for care.(e.g. in home chart, ESAS) You are care planning You are providing family education and support along with community providers Service delivery is improved by building community relationships Palliative care is being sustained, policy and procedures are being developed.
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Authors: Verna Fruch and Lori Monture, Six Nations of the Grand River Territory

References

69. ML Kelley, Prince H, Nadin S, et al. The power to choose: the story of developing palliative care in four First Nations communities. *Asvide* 2018;5. Available online: <http://www.asvide.com/>