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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 six years. Based on a community assessment, Elders and Knowledge Carriers, community leaders and Indigenous 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 Indigenous 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.

Conclusion:

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.

Key words. palliative care, participatory action research, Indigenous, community capacity development, public health

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 (5,6). 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 (12,13,14,15). 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 dissention between levels of governments about jurisdictional responsibility for PC, 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 (16,19,20,22,23,24). 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 (14,16,17,21,24). 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 (3,27,28,29,30,31,32). 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: 1) implementing culturally appropriate PC services at the local community level 2) developing supportive government policies that promote cross-jurisdictional partnerships and funding for required services, medication and equipment to support community-based programs, and 3) 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 six-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:

1. Document Indigenous understandings of PC as a foundation for developing PC programs.

2. Generate a culturally appropriate theory of change in First Nations communities based on Kelley's community capacity development model.

3. Create an evidence-based tool kit of strategies and interventions to implement PC programs in First Nations communities.

4. Empower First Nations health care providers to be catalysts for community change in developing PC and supportive policy frameworks.

5. 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 Developing Rural Palliative Care (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: 1) having necessary antecedent community conditions; 2) experiencing a catalyst for change; 3) creating a PC team; and 4) 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 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 (37,38,39). 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, Naotkamegwanning, 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, 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 traditions and provincial health policy environment (See Table 1). Figure 1 depicts the communities' geographic locations.

<< Table 1: Community Descriptions>>

<< Figure 1: Community Map >>

The method was participatory action research (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 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 community members 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 committee and paid using research funds.

The activities of the research are outlined in Table 2. Activities evolved incrementally and dynamically over the six 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).

<<Table 2: Research Activities>>

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 Supplementary File 2.

<<Table 3 Participants>>

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 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 (51,52,53,54).

Palliative care 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.

<<Table 4. 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 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 community 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.

<<Figure 2. Palliative Caregiving in First Nations Communities >>

 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 community as compared with outside of the community. 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 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"

(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 Palliative Care

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

<< Table 5. Challenges and Barriers to Community PC>>

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 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.

<< Table 6. 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 Palliative Care 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 was created by the project participants in Six

Nations of the Grand River Territory and differs from the original in several ways.

<< Figure 3: **Process of Palliative Care Development in First Nations**

Communities>>

Visually, the graphic is infused with cultural meaning (See Note, Figure 3). The language is

modified 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 though 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 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 Palliative Care 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 File 3, 4, and 5 respectively).

<< Table 7. Community Initiatives>>

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.

<< Table 8. Overarching Keys to Success in First Nations Community Capacity Development with Variations Among Cases>>

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 6). 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 (51,52,53,54). 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.

<< Figure 4-- Palliative Care Programs for First Nations Communities: Integrating Two Systems >>

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 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

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 (62).

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, 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: 1) family centeredness throughout the PC process 2) building local capacity to provide more relevant and culturally appropriate PC and 3) 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, 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 (64).

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. Provincial health services are now engaging more with communities.)

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).

Conclusion

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.

Author contributions

Conceived and designed the research: MLK, HP, SN, KB, MC, GH, LM, LM, CM, VO, JS. Analysed the data: MLK, HP. Wrote the first draft of the manuscript: MLK. Contributed to the writing of the manuscript: HP, SN. Agree with manuscript results and conclusions: MLK, HP, SN, KB, MC, GH, LM, LM, CM, VO, JS. Jointly developed the structure and arguments for the paper: MLK, HP, SN, KB, MC, GH, LM, LM, CM, VO, JS. All authors reviewed and approved of the final manuscript.

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Table 1. Demographic Characteristics of the EOLFN Partner Communities†

Community Attribute	Naotkamegwanning 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: Naotkamegwanning, 1142; Fort William, 1854; Peguis, 8558, Six Nations, 23,289.

§ More details on the specific services available in each community is available in the community program descriptions in the Workbook located on the project website (http://eolfn.lakeheadu.ca/)

Table 2. Activities of the EOLFN Research over the Six Years

Locus of the Work (Time Frame)	Objectives	Strategies
Working inside the First Nations community (Year 1-5)	• Community engagement • Create community vision for PC • Create PC program guidelines based on social, spiritual and cultural norms and existing community resources • Identify gaps in health services and medical care and needs for external partners	• 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) • Develop Leadership Team to implement PC program development • Assess existing community capacity for PC (resources, strengths, gaps and challenges) • Provide PC education for First Nations health care providers
Working outside the community with regional health care providers (Year 2-5)	• Reorienting external health services to support delivery First Nations communities	• 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 • Implement Memoranda of Understandings with external service providers
Working with relevant governments and health care decision makers	• Advocating for required policy changes, funding and resources from all levels of government	• Conduct provincial environmental scan of policy barriers for providing PC services in First Nations communities

(Year 3-5)		• Advocate for additional funding for communities to implement local PC programs • Educate health care decision makers on the policy barriers, issues and potential solutions
Working within the research team: community leads and researchers (Year 2-6)	• Creating resources and to guide practice and policy	• Create workbook to guide First Nations Communities • Create 2 policy documents to guide funders and program planners • Create a facilitator guide for external partners who wish to support program development in First Nations communities
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 open access website www.eolfn.lakeheadu.ca • Organize national "Improving End of Life Care in First Nations Communities Stakeholder Alliance" with over 100 individuals and organizations (held meeting, webinars) • Present project process and outcomes to Indigenous groups, First Nations' health service providers, government funders and researchers
Working within the project team: community leads and researchers (Year 3-6)	• Disseminating results to 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 (46,47,48,49)

† 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

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	"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." "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 loved on at home because of barriers can really pull and family, not only the family, the community apart. That's why it's so important to bring them home where they belong."
Knowledge Carrier	"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."
Internal First Nations Health Care Provider	"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."

† *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 is also a health care services provider within one of the 4 First Nations community partners

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 programing 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

Table 6: Community Assessment Data Illustrating the Need for Community-Based PC

Key Informant Sample Group[†]	Illustrative Quote
Community Member	"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" (Community Facilitator).
Internal First Nations Health Care Provider	"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". "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".

[†] *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 is also a health care services provider within one of the 4 First Nations community partners

Table 7. PC Program Development Initiatives and Outcomes in Each Community

Community	Initiatives/Outcomes
Fort William First Nation	- 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) - Created new discharge planning protocol with regional hospital (ultimately led to hiring an Indigenous discharge planner for the hospital). - Conducted community education/awareness sessions on PC topics and advance care planning (with community partners) - Developed culturally appropriate advance care planning resources (video, print) - Created an information booklet of PC resources for community members
Naotkamegwanning First Nation	- Developed a local PC program situated within Home and Community Care - Advocated for/received enhanced funding (10 months) from the provincial government for increased (24/7) services, PC education and medical equipment in the community - Developed and delivered a cultural competency curriculum for external health care providers entering the community - Participated in a regional telehealth pilot project in collaboration with external partners (used for care conferencing with regional palliative care specialists) - 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. - Advocated for more PC funding to federal and provincial government Ministers/members of parliament
Peguis First Nation	- Developed and implemented a PC Home Support Worker role - 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 - Created a Memorandum of understanding with the regional health authority (provincial) re: providing PC services in the First Nation community - Increased the linkage with nearby federally funded hospital to collaborate with PC Nurse/Program and initiated a Physician Home Visiting program

Six Nations of the Grand River Territory	• 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
	• 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)
	• Team received training/mentoring from the regional hospice (external); integrated the team into the Regional PC Program (external)
	• Created culturally appropriate Advanced Care Planning resources (video and print) and implemented community education in
	• Knowledge keeper role supported clients, families and staff eg. Four Strings Healing Ceremony

Table 8. Overarching Keys to Success in First Nations Community Capacity Development with Variations Among Cases

Overarching Keys to Success in all 4 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 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 3,4, and 6) • Promote sustainability by recognizing achievements and building community pride in supporting seriously ill people at home
Variations Between the 4 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 will 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 palliative care 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 within the collaborated closely and worked together beyond their normal roles to provide enhanced PC services. The number of health care providers was not the most critical factor; the number ranged from 30 to 300 local health care providers. The better the collaboration the better the progress.
- **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. However, communities then 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, Health Directors, local Chief and Council or local research ethics board.
- **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 all health services, it would be difficult to provide local palliative.
- **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 must address 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. |

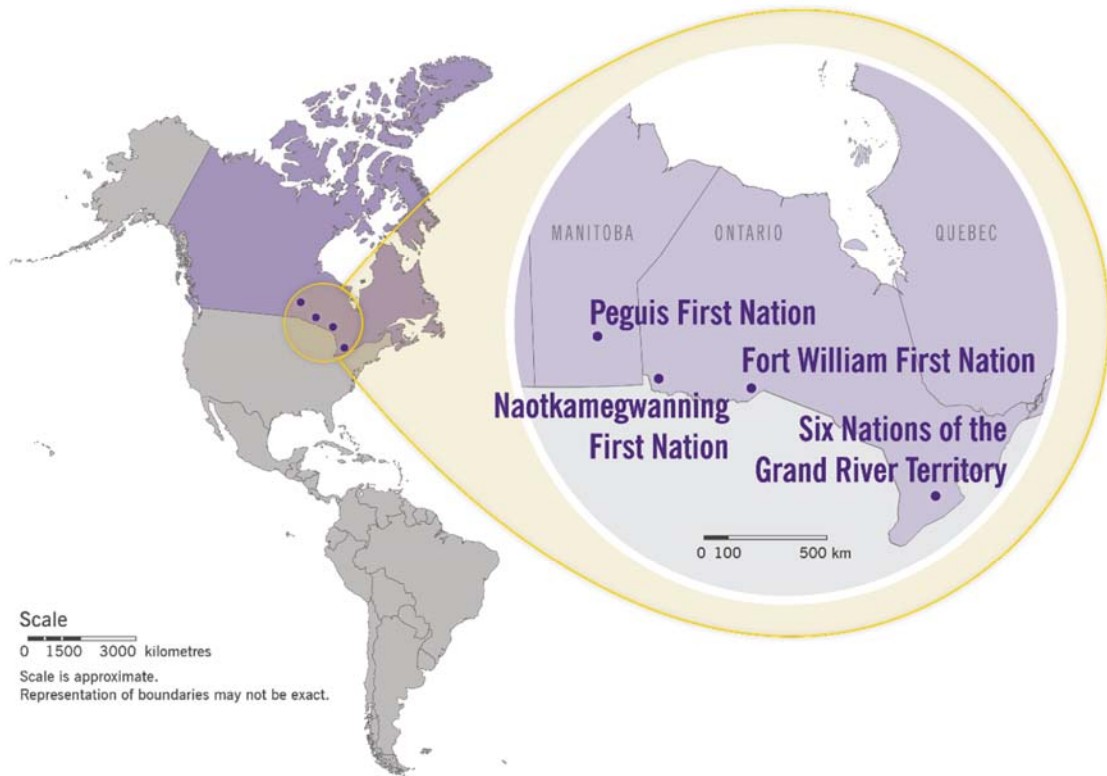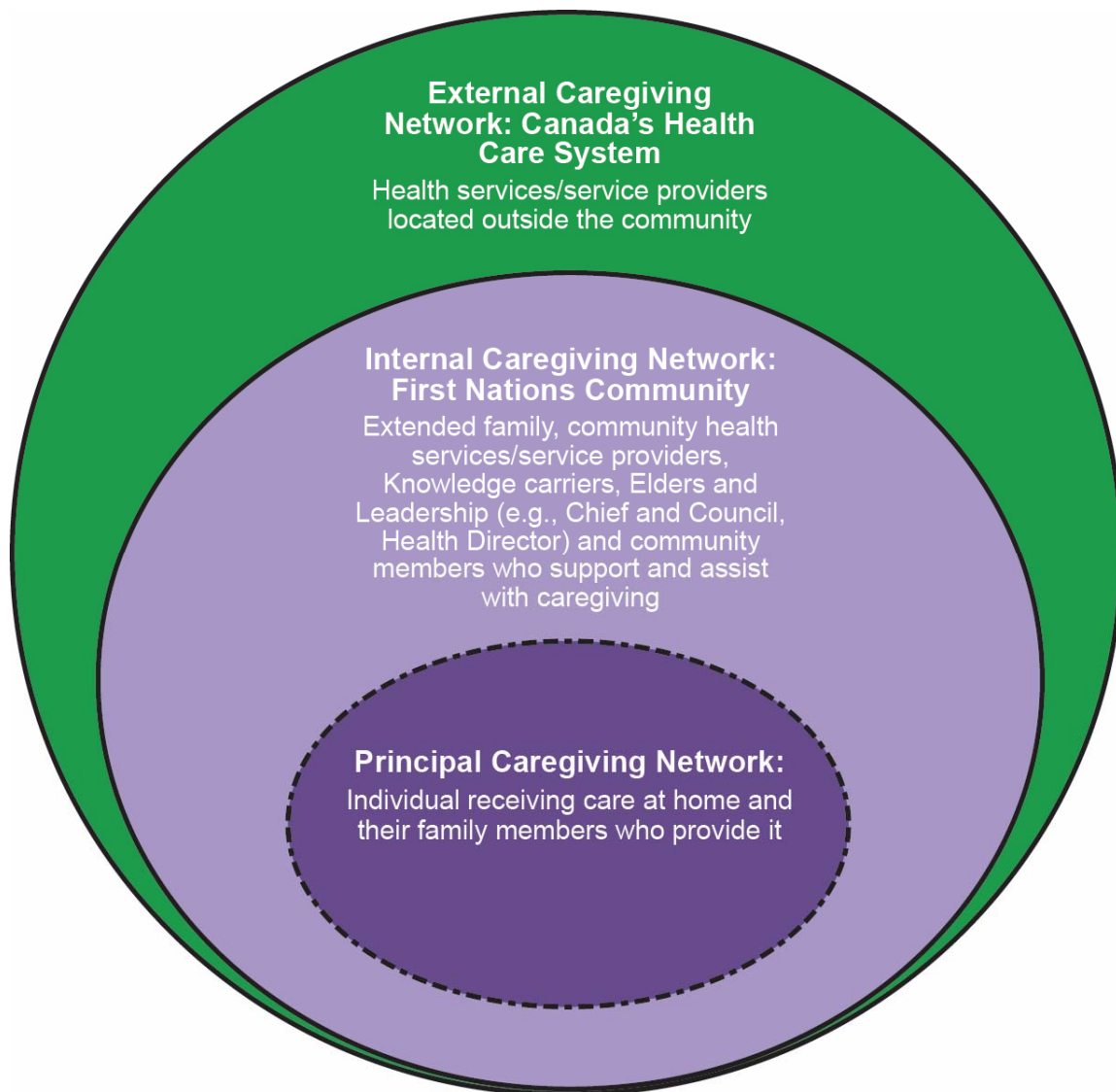**Figure 1. Geographical Location of the EOLFN Partner Communities**

Figure 2. Palliative Caregiving in First Nations Communities.

External Caregiving
Network: Canada's Health
Care System
Health services/service providers
located outside the community

Internal Caregiving Network:
First Nations Community
Extended family, community health
services/service providers,
Knowledge carriers, Elders and
Leadership (e.g., Chief and Council,
Health Director) and community
members who support and assist
with caregiving

Principal Caregiving Network:
Individual receiving care at home and
their family members who provide it

Note: This model is an adaptation of Abel et al.'s Circles of Care Model (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.
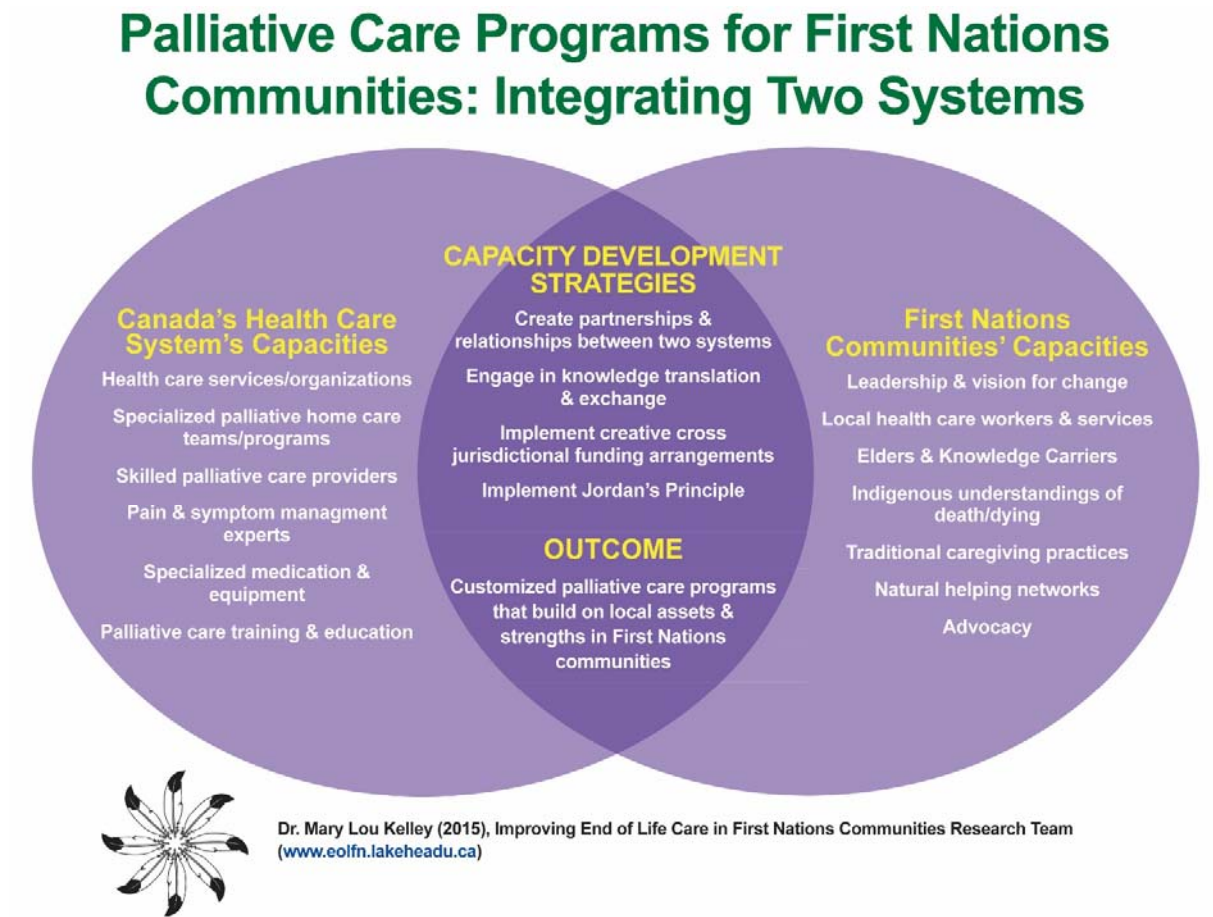
Figure 3. Process of Palliative Care Development in First Nations Communities

PROCESS OF PALLIATIVE CARE PROGRAM DEVELOPMENT

SEQUENTIAL PHASES OF THE CAPACITY DEVELOPMENT MODEL

Advocating for Individual and Families

Promoting Education

Providing Care

Building External Linkages

Strengthening Community Relationships

Community Infrastructure

Collaboration

Health Services

Empowerment

Vision for change

Local Leadership

Individual, Family, Community and Culture

5) Growing the Palliative Care Program

4) Creating the Palliative Care Program

3) Experiencing a Catalyst

2) Having Community Readiness

1) Grounding the Development in Community Values and Principles

"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 4. Palliative Care Programs for First Nations Communities: Integrating Two Systems

Note. Jordan's Principal 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: Jordan's Principle can be found at: http://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879

List of Supplementary Files

1. Instruments used in the community assessments (Survey and Interview and Focus Group Guides).
2. Video: The Power to Choose: The Story of Developing Palliative Care in 4 First Nations Communities. (https://vimeo.com/95293171)
3. Palliative Care Program Guidelines, Example: Naotkamegwanning First Nation
4. Palliative Care Program Guidelines, Example: Six Nations of the Grand River Territory
5. Implementing the Community Development Process – An Overview of the Process of Six Nations of the Grand River Territory
6. Developing Palliative Care Programs in First Nations Communities Workbook Summary