

## Coming Home to Die: Six Nations of the Grand River Territory Develops Community-Based Palliative Care

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### Abstract

This paper describes the development and implementation of a community-based palliative care program in Six Nations of the Grand River Territory, Ontario, Canada. Six Nations' innovative program is grounded in a vision to provide access to quality palliative care at home and incorporate Haudenosaunee traditional teachings. A community-based Project Advisory Committee led the development process, and a Leadership Team of local and regional palliative care partners led implementation. Using participatory action research, academic researchers supported activities and facilitated data collection and evaluation. Outcomes included: creation of a Palliative Shared Care Outreach Team, including a First Nations physician, nurse, and social worker; development of a detailed care pathway for clients who need palliative care; increased home deaths (55) as compared to hospital (22) or hospice (6) deaths; access to palliative care education and mentorship for local healthcare providers; incorporation of traditional teachings to support clients and staff dealing with death, dying, grief, and loss; and creation of a palliative care program booklet for Six Nations Health Services. This unique initiative reduces disparities in access to quality palliative home care and demonstrates that First Nations communities can successfully undertake a process of community capacity development to create unique and culturally responsive palliative care programs. Challenges included overcoming federal and provincial jurisdictional issues in provision of health services through collaborative partnerships at the local and regional level.

### Keywords

Aboriginal, First Nations, Indigenous, end-of-life care, supportive care, palliative care, community capacity development, shared care outreach team, Haudenosaunee traditional teachings

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### **Introduction**

Supporting dying community members and their families in their wish to come home to the Six Nations of the Grand River Territory at the end of life motivated the work being shared. This article reports the experience of Six Nations of the Grand River, Ontario, Canada, in successfully developing and implementing an innovative palliative care program that is uniquely adapted to their community, culture, and regional context. Their palliative care program model is grounded in community values and Indigenous culture, and it successfully supports people to receive their care and die at home if that is their wish.

The palliative care initiative in Six Nations began in 1999 with the establishment of the Home and Community Care (HCC) Program, funded by Health Canada, First Nations and Inuit Health Branch. The program was further developed and formalized (2010–2015) through a collaboration with the Improving End-of-Life Care in First Nations Communities (EOLFN)

research project, based at Lakehead University, Thunder Bay, Ontario (see [www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)). The palliative care initiatives in Six Nations are ongoing and have now been integrated into existing community health services and regional palliative care programs.

This article shares the story of developing palliative care in Six Nations of the Grand River Territory. The story is told from the perspective of the community facilitator, Verna Fruch, and community lead, Lori Monture, in collaboration with two members of the research team (Prince and Kelley). The purpose of the article is to enhance understanding of how other communities can incorporate dying within a First Nations wellness tradition that focuses on providing quality of life to the end of life. Other First Nations communities may be inspired by this example to undertake their own community development process and build local capacity to provide palliative care.

### **The Haudenosaunee Philosophy as the Program Foundation**

*When we are born the Creator gives us that first breath ... and when we die, he takes it back.* (Six Nations Traditional Knowledge Carrier)

This statement provides the cultural foundation for developing the palliative care program in Six Nations of the Grand River. It captures the essence of the traditional philosophical values in the Haudenosaunee (People of the Longhouse) philosophy statement (Six Nations Palliative Care Leadership Committee, 2015). Dying is understood as part of the cycle of life, and people take their place in relation to all of Creation. Acceptance comes from a view of the natural order that accepts and celebrates that we are given life. We exist with purpose and a duty to uphold the human responsibility to all of Creation until the time when the Creator takes back our life.

The Six Nations community desired to return to the traditional acceptance of death and dying as part of the life cycle. It was this desire that motivated local healthcare providers to develop a palliative care program in their community, as illustrated by the comments below:

*Traditionally, our birth was announced to the universe when our mothers went into nature and our birth fluid seeped into the earth, and we were named and celebrated. Now as we make our journey back to the Creator, we have lost that acceptance and we struggle with the natural order. Our community is telling us that we need to regain our acceptance of death and dying, and we need to help each other through this transition and provide supportive care as is done at birth.* (Traditional Knowledge Carrier as told to Six Nations community facilitator)

It is our intention [as healthcare providers] to support our cultural practices to help individuals achieve a sense of peace and well-being while they are preparing for their journey back home.

Sacred knowledge may be different as variances arise from the family, the Longhouse, the Nation and the community (Martin, 2009, p. 2).

### **Palliative Care and End-of-Life Care**

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2015). End-of-life care is the final phase of palliative care when dying is imminent and inevitable (Canadian Hospice Palliative Care Association, 2013), and normally requires enhanced services and support for the person and family.

Historically, palliative care has focused mainly on people with terminal cancer, a focus that has resulted in a misperception by some that palliative care is only appropriate for people suffering from a terminal illness, is only for the last few weeks of life, and is provided mainly by highly specialized teams and programs (WHO, 2004). The Canadian Hospice Palliative Care Association (2013) emphasises that palliative care is appropriate for all people and their families who are living with a life-threatening illness due to any diagnosis, including but not limited to cancer. The palliative approach can be provided concurrently with treatment and chronic disease management (Boland & Johnson, 2013; Coventry, Grande, Richards, & Todd, 2005; Murtagh, Preston, & Higginson, 2004; WHO, 2004).

### **The Need for Palliative Care in First Nations Communities**

The need to develop appropriate palliative care programs for First Nations communities is urgent because the First Nations population is aging with a high burden of chronic and terminal illness. In their population study, Statistics Canada (2011) projected that among those of Aboriginal identity, the number of persons aged 65 and over will more than triple from 4.7% in 2006 to 15% in 2031. Older First Nations people have a higher prevalence of a number of health conditions when compared to the age-adjusted Canadian adult population. These include: arthritis/rheumatism (25% vs. 19.1%), hypertension (20.4% vs. 16.4%), asthma (9.7% vs. 7.8%), and heart disease (7.6% vs. 5.6%; First Nations Information Governance Centre [FNIGC], 2007). Rates of diabetes are reported as being more than 3 times higher than in the Canadian population (20.7% vs. 6.2%) with over three quarters (80.8%) having the Type 2 variant (FNIGC, 2012). The prevalence of chronic illness increases with age, with approximately half of First Nations people aged 60 years or older reporting four or more chronic health conditions (FNIGC, 2012). In sum, palliative care programs in First Nations communities are required to address multiple and complex health issues.

While cancer is a major cause of death among older Canadians, other major causes of death are heart disease, stroke, and respiratory diseases (Wilkins, 2006). These trends are reflected in the First Nations population as well. A recent report that focused on First Nations health status in Alberta noted that ischaemic heart disease, cancer, COPD, and diabetes are among the leading causes of death for seniors 65 and up (Health Canada, 2012). Thus, palliative

care programs for First Nations people must focus on caring for people who are dying primarily of chronic disease. Fortunately, within the last 15 years, the scope of palliative care has evolved to be much broader than cancer care (Ferris et al., 2002).

### **The Six Nations Community and Health Services Context**

Six Nations includes the Mohawk, Cayuga, Onondaga, Seneca, Oneida, and Tuscarora Nations that were unified in 1722 (National Park Service, 2015) under the Great Tree of Peace (Parker, 1912). During the American Revolution, Captain Joseph Brant led many from the Iroquois Confederacy to ally with the British. For their loyalty to the Crown, the Mohawks and such others were deeded a tract of land along the Grand River of approximately 18,000 hectares, bounded by Brant County and Haldimand County (National Park Service, 2015). The main reserve is located approximately 25 km southwest of the city of Hamilton, Ontario. Six Nations has the largest population of all First Nations communities in Canada, and as of December 2013, the total band membership was 25,660, with 12,271 living within the reserve (Six Nations of the Grand River, 2013). Six Nations Health Services employs about 300 staff.

The Six Nations Palliative Care Program is situated within the Long Term Care/Home and Community Care Program. The Palliative Care Program vision includes providing compassionate, coordinated, and comprehensive end-of-life care to individuals living in the community of Six Nations (Six Nations Palliative Care Leadership Committee, 2015). Services include: case management; physiotherapy; occupational therapy; health advocacy; nursing; adult day centre; personal support services, community support services; supportive housing; traditional wellness coordinator; Traditional Knowledge Carrier; family health team; and a medical centre that includes dental and public health staff, a physician, and a pharmacy (<http://eolfn.lakeheadu.ca/develop-palliative-care-programs-workbook>). The program is rooted in the following Haudenosaunee philosophy statement:

Traditional philosophical principles have a crucial relevance to the challenges our people face today. Ohenton karihwatehkwen 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 on 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 coexistence 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 (Six Nations Palliative Care Leadership Committee, 2015, p. 3).

Healthcare providers in Six Nations recognize that offering people the choice to die at home on the territory provides community members familiarity, comfort, and access to culturally appropriate services. Care at home can be provided by people you know, and transportation to external health services is not such a burden. Dying at home helps to retain a person's dignity until the end of life by having frequent access to family, friends, and community members. The community is very important when someone is dying and offers support both to the dying individual and to their family.

### **Home and Community Care Services**

In 1999, the Canadian federal government established the First Nations and Inuit Home and Community Care (HCC) Program, which has been designed to provide basic home and community care services to First Nations and Inuit communities (Health Canada, 2009). The program is funded using a population-based formula that has not been adjusted for increases in population, population aging, or changing health status since 1999. In most First Nations communities, the limited funding allows for services only during the day, Monday to Friday.

The HCC program is funded to provide nine essential service elements: client assessment; managed care; home care nursing; home support personal care; in-home respite; linkages; medical equipment and supplies; capacity to manage program delivery; and record keeping and data collection (Health Canada, 2009). Where communities provide all the essential service elements and if funding remains available within their approved budget, the HCC program allows communities to implement additional supportive service elements. These supportive services may include but are not limited to: home-based palliative care; adult day care; meal programs and rehabilitation and other therapies (Health Canada, 2013). Therefore, First Nations and Inuit Health Branch does not fund palliative care as a unique program; however, the essential services required to provide home-based palliative care are funded (i.e., case management, nursing, personal care).

The implication of this funding situation is that communities that wish to provide palliative care can do so; however, they need to have the required resources within their existing budgets. First Nations communities may also augment their services through the creation of health service partnerships (Health Canada, 2013). Examples of service partnerships that could be created to provide palliative care are with provincially funded hospices, home care programs, or palliative care programs. These were the partnerships formed in Six Nations of the Grand River Territory by the HCC program.

### **Community Capacity Development to Create Palliative Care Programs**

The approach taken by the Six Nations community members to develop their palliative care program was based on a model of rural community capacity development created by Kelley (2007; Kelley, DeMiglio, Williams, Eby, & McIntosh, 2012) and introduced to the community

by the EOLFN research team. Members of the Six Nations community adopted this model as a guide for developing their palliative care program, adapting it to culture and local circumstances.

In this model, developing a community palliative care program is locally initiated and driven. It requires dedication, leadership, and commitment from key community members and local healthcare providers. The process of creating change is from the bottom up and it takes time (years). The program builds on what already exists, strengthening and adapting resources, services, and relationships when required. Change takes place in four incremental phases (see Methods), each phase building on the previous work accomplished. However, it is a dynamic rather than a linear process. Progression through the phases is controlled by community members but is influenced by internal and external barriers, supports, and resources. Efforts to shape and manage these influences are the “work” in capacity development. Key aspects of the process are summarized below.

Prior to beginning, there are some required antecedent conditions for success. Communities need to have sufficient infrastructure, such as health services and providers, to provide palliative care. A shared vision for change in the care of dying people is important, and implementation of the program relies on effective collaboration among community healthcare providers and members. Finally, community members need to feel empowered to take action to achieve their vision, addressing gaps and challenges along the way. Early community work can focus on strengthening antecedent conditions if required.

A local person or event provides a catalyst for change that mobilizes community members into action. The program development process begins with establishing a local committee or resource team. Getting the “right” people involved is critical—people with influence, skills, and access to community resources. The palliative care committee assesses current community capacity and unmet needs and creates a program guide. Implementation involves growing the local palliative care program using five strategies: building community relationships; providing education to local healthcare providers and community members; providing palliative care (learning by doing); creating external linkages with regional palliative care resources; and advocating for quality palliative care.

Six Nations’ experience implementing the community capacity development process is described in the following section.

### **Methods**

Development of the Six Nations Palliative Care Program (2010–2015) evolved from earlier work done both by healthcare providers at Six Nations and by the Lakehead University research team in northwestern Ontario. This earlier work provided a solid foundation for the collaboration between the Six Nations healthcare providers and EOLFN researchers. The focus of the work was developing palliative care at the community level.

## **Foundational Work in Six Nations of the Grand River Territory**

In Six Nations, there was a strong interest in and commitment to supporting community members to come home to die. As a result, an internal palliative care committee was developed during 1999–2003 within the Long Term Care/Home and Community Care program. In 2005, an Indigenous graduate student, Valerie O'Brien, began a study to examine Six Nations' existing palliative care services, including the strengths, barriers, and challenges (O'Brien, 2012). This graduate student's research provided valuable information to the Six Nations healthcare providers by identifying where the current palliative care system needed to be improved. Later, the graduate student was invited to become, and became, a member of the EOLFN research team.

In 2004, the province of Ontario launched an End-of-Life Care Strategy that was implemented by each of the 14 Local Health Integration Networks (LHIN), which are the funders of all provincial health services for the region. Six Nations healthcare providers became actively involved with their LHIN (LHIN 4) and their regional End-of-Life Care Network in an effort to further their efforts in palliative care. The Network formed an Aboriginal Hospice Palliative Care Services Committee to work towards designing and implementing a service delivery model for First Nations communities within the region. Six Nations hosted a LHIN-wide regional planning meeting in December 2010, with the goal of requesting community and healthcare provider input to establish priorities in care provision, and to strengthen the networks involved in providing care to Aboriginal clients. This LHIN-supported regional work served to engage regional healthcare providers and generated a higher level of awareness of the issues and needs related to providing palliative care in First Nations communities. The EOLFN research team was invited to attend and participated in that planning meeting.

This regional work done by Six Nations with the LHIN and End-of-Life Care Network built many important relationships, including one with Stedman Community Hospice/St. Joseph's Healthcare Foundation in nearby Brantford, Ontario. Stedman had a well-established inpatient hospice and was the hub for a regional shared care outreach team that offered palliative home care (<https://www.sjlc.ca/>). To enhance home care, Six Nations also developed a memorandum of understanding with the Brantford Community Care Assess Centre (CCAC) to collaborate on providing palliative home care in Six Nations. The CCAC is funded by the Ontario Ministry of Health to coordinate and fund nursing services, medical equipment, and supplies for all palliative clients who choose end-of-life care in their homes or residential hospices. A CCAC community care coordinator visited Six Nations biweekly to discuss clients in need of palliative home care services with HCC staff. CCAC then provided the necessary acute nursing services, medications, and equipment, and coordinated care provision with HCC providers. These strong relationships and collaborations became critical to the future success of the Six Nations Palliative Care Program.

### **The Research Partnership to Develop Palliative Care in Six Nations**

In 2009, Six Nations partnered with the researchers and three other First Nations communities to apply for a participatory action research (PAR) project that was funded by CIHR from 2010 to 2015. The goal was to develop culturally appropriate palliative care programs using a process of community capacity development in four partnering First Nations communities that would each serve as case studies. Over 5 years, using the EOLFN community capacity development process, each of the four partnering First Nations communities created a unique community-based palliative care program suited to their culture and context. The learnings from the four communities were used to create knowledge, tools, and resources for other First Nations communities.

The overall goal of PAR methodology is to create social change. PAR differs from more conventional research in that the participants (the community) and not the researchers retain control of all aspects of the process. Relationships are collaborative partnerships where researchers and participants bring their expertise together to achieve their common goal (Minkler & Wallerstein, 2002). Using the PAR approach, knowledge about how to build community capacity in palliative care was co-created by the researchers and the Project Advisory Committees in the four communities. Research involved using a reflective spiral of activity involving: identifying a problem, planning a change, enacting the change and observing its consequences, reflecting on these processes and consequences, and preplanning, acting, observing, and reflecting (Kemmis & McTaggart, 2000). In the overall EOLFN project, promising practices drawn from the work have been shared with other First Nations communities through a workbook of research-informed community capacity development strategies (EOLFN [Improving End-of-Life Care in First Nations Communities Research Team], 2015).

It is the process of change that is the essence of the PAR methodology and the community capacity development model. There were four overall phases to the EOLFN research:

1. Conducting a community needs assessment and creating recommendations.
2. Developing work plans to implement identified strategies.
3. Implementing and evaluating each strategy.
4. Disseminating the outcomes to community members, healthcare decision makers, and other First Nations communities.

Throughout this research, the change process and its outcomes were documented. Please visit the project website for further information on the overall project activities ([www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)). The focus of this paper is how Six Nations moved through their process of change and the outcomes specific to their community.

### **Implementing the Research Process**

Approval for the EOLFN research was gained from the Six Nations Research Ethics Board as well as the Lakehead University and McMaster University Research Ethics Boards. The project followed OCAP principles of ownership, control, access, and possession (FNIGC, 2014).

The community established a Project Advisory Committee that consisted of Six Nations health and social care leadership, chosen by the health director. Members included the manager of the Six Nations Long Term Care/Home and Community Care Program; chair of the HCC Palliative Care Committee; the Six Nations community facilitator; executive director of the Family Health Team; and ex officio the director of Six Nations Health Services. Lori Monture, manager of Long Term Care/Home and Community Care, was chosen to be the community lead for the EOLFN project and to chair the Project Advisory Committee. The Project Advisory Committee's role was to oversee and guide all aspects of the research including: assisting with community engagement, identifying appropriate key informants and participants, reviewing preliminary data interpretations, and developing an inclusive dissemination plan. The committee also ensured that any decisions complied with the Six Nations Council Research Ethics Committee and assured that appropriate respect was given to Haudenosaunee culture, language, knowledge, and values. All cultural knowledge shared through the research was shared with permission of the Traditional Knowledge Carriers.

The community lead described how the Project Advisory Committee consulted with the Traditional Knowledge Carriers:

*Initially we asked our traditional wellness coordinator, a staff member of the Home and Community Care Program, to research and consult with the local Traditional Knowledge Carriers on palliative care. Once it was time to share information, she worked with them and they gained "approval" from their peers (who were the Clan Mothers, chiefs, and Faithkeepers as well as other Traditional Knowledge Carriers) on what could be shared. There is an understanding that this is ancient wisdom and is very sacred; we must protect it and use it in a most respectful manner. We would not misuse the information or exploit it, for it to continue to be effective as it was intended to be. We have embraced the Traditional Knowledge Carriers in the work that we do and now they understand that it is important to teach the coming faces and are more willing to share the ceremonies with us. (Manager, Long Term Care/Home and Community Care)*

The EOLFN research team paid for a local community facilitator, selected by the Project Advisory Committee, to assist them to document the process and outcomes of the research. Verna Fruch, a member of Six Nations and an experienced home care case manager, was hired as the community facilitator. With guidance from the research team and direction from the Project Advisory Committee, Verna facilitated the community development process, collected data, and participated in qualitative data analysis by validating transcribed interviews and focus groups, and interpreting community context. She assisted the Project Advisory Committee to organize meetings, take minutes, and disseminate information.

### **Developing Palliative Care in Six Nations**

The priority of the Six Nations Project Advisory Committee was to create a Palliative Shared Care Outreach Team in the community that would be available 24 hours a day, 7 days a

week, and provide medical, spiritual, and cultural support to dying people and their family members. It was perceived by the community that having such a palliative care team would enable people to have the choice to die at home if that was their wish, something that was not currently possible given limited resources. The community needs assessment indicated insufficient nursing services, especially during evenings and weekends. Further, there were needs for more culturally sensitive care that incorporated traditional medicine and culturally appropriate grief support for families and healthcare providers following a death.

To achieve their goals, the Project Advisory Committee created a Leadership Team of 20 internal and external healthcare providers who provided services to people living in Six Nations. This Leadership Team was responsible for the planning, education, and evaluation components of the Palliative Care Program. The team focused on four areas: identifying common issues/concerns and coming up with solutions; promoting educational opportunities for care providers; increasing public awareness of the availability of palliative care in community; and developing a care pathway and other protocols for the clinical teams. A detailed work plan was created that included seven objectives, each with detailed activities, a budget, time frames, and planned outcomes. This work plan guided the Leadership Team's work over the next 3 months.

The initial step in the work plan involved securing funding for a palliative shared care team in Six Nations from the LHIN. Palliative shared care teams are usually composed of a palliative care physician(s), nurses, social workers, and case managers, as well as primary care providers such as family physicians (DeMiglio & Williams, 2012; Seow et al., 2014). Palliative care specialists provide consultation, and there is 24/7 access to specialist clinician support for pain and symptom management, as well as psychosocial/spiritual and bereavement support. A multidisciplinary team approach is used and the family is considered a major part of this team, with a major emphasis on palliative care education (Seow et al., 2014).

With the needs assessment data in hand and the partnerships in place, LHIN funding to create a Palliative Shared Care Outreach Team in Six Nations was secured for 1 year. It was agreed that this funding would flow directly from the LHIN to the Six Nations community who in turn would pay Stedman Community Hospice for their services. A memorandum of understanding was developed between Six Nations and Stedman to detail the working relationship and mutual expectations.

Palliative Shared Care Outreach Team members were recruited next. The Family Health Team physicians at Six Nations agreed to participate in the new Palliative Shared Care Outreach Team and to be mentored by the Stedman Hospice Outreach Team physicians. A key component of the functioning of a palliative shared care team is the role of the palliative physician, and specifically for this team, an Aboriginal physician. A compensation package for the physician's time spent in mentorship and on call was agreed upon. The interested physician also agreed to attend an accredited palliative care education course.

The new positions of clinical nurse specialist and psychosocial spiritual bereavement clinician were filled next by an Aboriginal nurse and a social worker, both well-qualified community members. Their position descriptions were adapted from the regional palliative care

program to encompass the Haudenosaunee philosophy. Members of the new Six Nations palliative care team then began a 1-year mentorship experience with the physicians and staff at Stedman Hospice.

Three months after receiving funding from the LHIN, the Six Nations Palliative Care Program and team began receiving referrals for their community members from the regional palliative care program and, under the mentorship of Stedman Hospice, began providing palliative home care services. More details of the mentorship process and experience are included in the next section.

### **Outcomes**

In May 2013, the first opportunity to bring a community member back to the territory to die occurred, and the newly created palliative care guidelines and client care pathway were put into effect. The experience of caring for this client at home was gratifying for all members of the new palliative care team, and the family was grateful for the professional care that they received. In terms of the research, all activities developed by the local Project Advisory Committee and Leadership Team were successfully implemented. Specific research outcomes included: creation of the Palliative Shared Care Outreach Team, including a First Nations physician, nurse, and social worker; development of a detailed care pathway for clients who need palliative care; increased home deaths as compared to hospital or hospice deaths; increased access to palliative care education and mentorship for local healthcare providers; incorporation of traditional teachings to support clients and staff dealing with death, dying, grief, and loss; and creation of new palliative care program guidelines within Six Nations Health Services.

#### **1. Creation of the Palliative Shared Care Outreach Team**

The Palliative Shared Care Outreach Team consisted of three healthcare professionals: a physician employed by the Six Nations Family Health Team, a clinical nurse specialist, and a psychosocial/spiritual worker employed full time on the team. All were Six Nations community members. The Six Nations community facilitator described the creation of the team as the most significant accomplishment:

*I'd have to say the community outreach team is the most important because ... of being able to bring community members back home and to pass away in their own community.*

The benefits of having the palliative care team are as follows: community members now have access to round-the-clock care; people are assisted with pain management; the team can manage complex care needs; the physician makes home visits; hospital emergency room visits are reduced; the risk of dying in hospital (rather than at home) is lowered; community members are able to die peacefully in their own home; the team links the community to external care providers to ensure client-centred care. Team roles are described in Table 1.

**Table 1**

***Roles and Activities of Palliative Shared Care Outreach Team Members***

Palliative care physician	<ul style="list-style-type: none"> <li>▪ receives referrals from family MD or specialists and collaborates with family MD, CCAC, Cancer Clinic, and community agencies to manage pain and symptoms</li> <li>▪ makes home and hospice visits with clinical nurse specialist and provides psychosocial support on as-needed basis</li> <li>▪ takes part in rotating call for 24-hour coverage of community patients and dedicated palliative beds in local hospital</li> </ul>
Clinical nurse specialist	<ul style="list-style-type: none"> <li>▪ establishes and implements treatment plans for pain and symptom management at home</li> <li>▪ makes daily home visits independently and with MD</li> <li>▪ provides clinical support to families and community nurses</li> <li>▪ facilitates biweekly rounds with the entire team</li> <li>▪ takes part in monthly rotating call for after hours and weekends</li> </ul>
Psychosocial spiritual bereavement clinician	<ul style="list-style-type: none"> <li>▪ provides emotional and spiritual care for individuals/their families</li> <li>▪ assesses, acknowledges, and nurtures those living with advanced illness or on the journey of dying regarding all personal, cultural, financial, legal, and spiritual needs</li> <li>▪ assists in advanced care planning, funeral/memorial service planning</li> <li>▪ offers grief and bereavement follow-up support</li> </ul>

While team members continue to work as part of the regional palliative care program and Stedman Hospice, their activities can be tailored to the needs of the Six Nations program. As of 2015, the Palliative Shared Care Outreach Team was located back to Six Nations. They have completed their training as expert clinicians and gained their credentials as palliative physician, clinical nurse specialist, and master of social work.

**2. Development of a Care Pathway for Clients Who Need Palliative Care**

A care pathway outlines, in writing and in detail, the anticipated care required by a person, and it places the care in the appropriate sequence and time frame; it is then agreed upon by a multidisciplinary team. The Six Nations Leadership Team, consisting of internal and external healthcare professionals, developed a detailed care pathway to guide the provision of palliative care to its clients. Generally, clients are identified as needing palliative care when their life expectancy is less than one year and when they are having pain and symptom issues. A

benefit of following the care pathway is that care needs of the client and family will not be overlooked.

The care pathway specifies who makes referrals to the team and how they are made. It outlines all of the processes for communication and consent with the clients and between healthcare professionals. It indicates how quickly clients are to be seen based on need, describes the activities of home visits by team members, and describes use of the in-home chart. The pathway includes post-death staff debriefings and bereavement visits to the caregivers. The full care pathway is included in the EOLFN (2015) workbook. Table 2 shows two examples from the care pathway.

**Table 2**  
*Examples from the Care Pathway*

Initial client contact	The CCAC palliative case manager or the Home and Community Care case manager (whoever receives the referral first) sets up an initial joint home visit. A palliative care assessment is completed and shared between the two case managers, and a consent form is signed for each agency. All appropriate palliative services are initiated and required medical equipment is put in place. Client and family are given the contact information for each service to ensure they can access assistance on a 24/7 basis. The end-of-life care checklist is put in the home, which includes the telephone number for all services, including the funeral home.
End of life	Expected Death in the Home forms are completed and discussed with the client and family by the CCAC palliative case manager, the acute nursing agency, or the palliative physician or clinical nurse specialist. All nurses have been trained in Pronouncement of Expected Death, and the palliative physician completes the death certificate if the family physician is not available. Case managers notify each member of the clinical team that an in-home death is being planned; thus, no calls are made to the emergency response team. Families are encouraged to call the acute nursing provider who notifies the Palliative Shared Care Outreach Team.

The clinical nurse specialist commented on the value of the home visits in an interview with the Six Nations community facilitator:

*I think the home visits are the most important. That initial home visit because after that, they know who they're talking to and can connect a face with the person they are talking to on the phone. Also bringing the physician to the home is important.*

### 3. Increased Home Deaths Compared to Hospice or Hospital Deaths

Data were collected on the number of referrals and the location of death. Table 3 shows a 170 percent increase in the number of referrals to the palliative care team over the 3 years it has been operating. Table 4 indicates that home deaths far outnumbered hospital deaths over the 3-year period the team has been operating.

**Table 3**

*Number of Palliative Shared Care Outreach Team Referrals (Six Nations and Surrounding Areas)*

Year	Number of Referrals
2012	30
2013	80
2014	81

**Table 4**

*Location of Deaths - Six Nations Palliative Shared Care Outreach Team Clients, 2013–2015*

Location	Number of Deaths
Home	55
Hospital	22
Hospice	6

As more people died at home with access to quality palliative care, members of the community were more willing to be referred. The following example of this was provided by the psychosocial spiritual bereavement clinician, who herself benefited from the palliative care program when a family member was dying.

*And she referred me to ... the nurse who was on call, and it just worked out that Dr. [name] happened to be in the area and she was in my aunt's home within fifteen minutes. They worked together to make sure that my aunt was peaceful and comfortable in the last days of her life. (Family member of dying Six Nations resident)*

### 4. Access to Palliative Care Education and Mentorship for Local Healthcare Providers

Palliative care education for the local healthcare providers in Six Nations was a critical part of capacity development. In addition to 1 year of mentorship with the Stedman Hospice clinicians, the Six Nations team (physician, nurse, psychosocial spiritual clinician) took a 15-

hour inter-professional course, Learning Essential Approaches to Palliative and End-of-Life Care, offered by Pallium (<http://www.pallium.ca>). Other courses offered were Palliative Care for Front Line Workers in First Nations Communities (<http://www.cerah.lakeheadu.ca>), which is a 15-hour introduction to the philosophy and principles of palliative care, and The Fundamentals of Palliative Care Training and CAPCE (Comprehensive Advanced Palliative Care Education), both offered by the Pain and Symptom Management Program consultant in the Brant, Haldimand, Norfolk region.

Personal support workers, homemakers, social workers, and nurses all benefited from this education. Two team members commented specifically on the benefits to them:

*Well, I think my confidence has changed, I feel more assured about what I'm doing.*  
(Clinical nurse specialist)

*Like when I took this job on, my vision was working with our people and our community to develop programs and to meet the needs of our people, and I'm okay being mentored and I accepted that and I respected that, and I really truly appreciate it 'cause I have learned lots.* (Psychosocial spiritual bereavement clinician)

The mentorship of team members with Stedman Hospice was a very positive experience that continued for a year. The following, in the words of the Six Nations community facilitator, describes the mentorship experience between the newly hired members of the Six Nations palliative care team and the Stedman Hospice palliative care providers:

*One of the core values of the Haudenosaunee is the state of peacefulness, understanding the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. This was the personal relationship that existed between the Stedman Hospice and the Six Nations Home and Community Care Program, that of respect. The hospice was more experienced in dealing with end-of-life care and offered their expertise. In turn, Six Nations would offer its cultural perspective so that palliative Aboriginal clients would have culturally sensitive end-of-life care.*

*We saw it as a mutually beneficial partnership. Our new palliative care team would gain valuable expertise by working with clients throughout the entire county and dealing with a varied number of issues. The clinical nurse specialist would begin by visiting with the more experienced nurses from the hospice and would then carry her own caseload, which would include all Aboriginal clients. The psychosocial spiritual bereavement clinician would meet with the other psychosocial support clinicians and learn of the practices of other denominations. She would follow clients through their stay in the hospice, attend the day programs and the support groups offered by the hospice.*

*Throughout the mentorship, the team members would feel the support and be able to consult during regular rounds with the palliative physicians. This partnership would*

*build and maintain the expertise that would be needed to have a fully functioning Shared Care team.*

## **5. Incorporation of Traditional Teachings to Support Clients and Staff Dealing with Death, Dying, Grief, and Loss**

The procedures for Aboriginal clients took consideration of Haudenosaunee teachings and rituals; thus, ceremonies and policies were adapted, such as the medical equipment in the home not being picked up until after the 10-day feast. The community needs assessment clearly showed that the meaning of palliative care for community members may differ from Westernized understandings of palliative care, and that many individuals would need support in understanding and accepting the benefits that a unique palliative care program at Six Nations could offer them.

Throughout their work, palliative care team members were sensitive to individual and cultural wishes as indicated in the following comment:

*I have opened my heart more than my heart has ever been opened in my life because I feel that everybody, when you are dying or your loved one is dying, you are in a very vulnerable state and I feel like it's a gift from my Creator to help, help walk with these people and help them hopefully have a peaceful journey. (Psychosocial spiritual bereavement clinician)*

The role of the Traditional Knowledge Carrier was very important in supporting clients and families. She was recognized by the community as having knowledge and understanding of the traditional cultural practice of the community, including the language as well as spiritual and social practices, and she worked with people towards the restoration of balance and harmony to the body. The role also included explaining the spiritual transitions to end of life and releasing the loved one. The Traditional Knowledge Carrier worked very closely with the Palliative Care Program and team.

Addressing a gap identified in the needs assessment, a traditional grief and bereavement program was developed by the Leadership Team. The Six Nations community facilitator described this new program:

*This initiative brought together family members of clients who received end-of-life care through the SN palliative program. These participants have been on their grief journey for close to a year, and they were to be assisted in their grief with traditional practices and medicines. They attended 10 weekly sessions, which were facilitated by the psychosocial spiritual bereavement clinician and a Traditional Knowledge Carrier. The participants were assisted to understand bereavement and the grief journey, and were presented with traditional teachings with ceremonies and traditional medicines for teas and baths and taught self-care. They were assisted with listening, witnessing, companionship. They were supported and nurtured within a healing sharing circle, and were assisted to realize that we cannot change the past but learn to live in the future. The participants were helped in healing their hurt with sharing of realistic expectations for*

*grief and mourning and encouraging hope, and by giving honour and respect. Five intended outcomes were sought and they included: reawakening the spirit, holistic balance, teachings of self-care, softening the grief, and healing the heart to carry on.*

An additional challenge identified in the needs assessment was the burden of grief and loss carried by the staff working within the palliative care program. Not only did staff develop close worker/client relationships, many of the staff were also family members of their clients. As the palliative care program grew, staff expressed the need for grief support for themselves. The Traditional Knowledge Carrier developed and facilitated a traditional ceremony, called the Four Strings Ceremony, which is described as follows:

*The Four Strings Healing Ceremony begins with a presentation of the traditional teachings surrounding this ceremony, and it will not be described to maintain the sacredness of the teaching. The following are the areas that are dealt with: **The Eyes and Tears**—when someone is in great distress as a result of a death in the family, the eyes are in tears which makes blindness and we are unable to see anything, and the mind is hurt by this. To help and comfort you, we place our fingers on the soft white deer-skin of the fawn and wipe off your tears and remove all your sorrows, and give you encouragement to lift your spirit. You are now able to see your grandchildren, your colleagues, and you will think of your duties to your people, and you will feel and be yourself again as there are many days ahead of you. **The Ears**—when a family loses someone, there is great distress and hearing is lost, the mind is hurt by this and unable to hear people around you because the thoughts are on the great loss in the family. The ears are unplugged with the down of an eagle feather so you may hear more clearly and understand the voices of the people around you. You can continue your duties and your mind will be clear and you will feel good for the days ahead of you. **The Throat**—when a person is in great sorrow, the throat becomes clogged and we are unable to speak or swallow food. It is hard to breathe and this has caused your body to become weak with distress. We unplug your throat by drinking fresh clear water and this gives you comfort and strength. You will forget your sorrow and think only of good things and you will feel good and your mind will be at ease. This will bring you comfort and happiness so that you may continue with your duties for your people for days to come. **The Stomach**—when a person is in great distress as a result of the death of a loved one, this causes a weak mind, the body does not function properly, causes an upset stomach and creates nervous tension, and the body becomes weak. You will take the medicine, which is the strawberry. It will settle your stomach, remove the yellow spots, cleanse you within, give you strength, and protect your spirit. Now you will feel good, be yourself, and you will not feel such great loss. This will comfort you so that you may continue with your duties for the benefit of your people for many days ahead. One then goes home and rests, and takes a cedar or salt bath, and perhaps follows up with a massage, and continues to flush their system and hydrate their bodies. (Traditional Knowledge Carrier)*

## 6. Creation of the Palliative Care Program Booklet

One of the final steps in the intervention was formalization of the palliative care program through creating a written summary of all of the palliative care initiatives that were now integrated into the Long Term Care/Home and Community Care Program. The Palliative Care Program booklet (Six Nations Palliative Care Leadership Committee, 2015), distributed to healthcare providers and community members, opens with the following mission and vision (p. 4):

### 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, 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.

The program booklet proceeds to describe the team, care pathway, and the medical, social, spiritual, and cultural services of the program in detail, including case management, physiotherapy, occupational therapy, health advocacy, registered nursing, adult day centre, personal support services, community support services, supportive housing, traditional wellness coordination, Traditional Knowledge Carrier, Six Nations family health team, psychosocial spiritual supports (longhouse, local churches, funeral homes), screening, and training of staff and volunteers.

Members of the Six Nations community also created resources for clients and their families. These include a culturally appropriate grief support resource called *The Ones Left Behind* (Martin & Skye, 2011) and an advanced care planning guide titled *Journey Back Home* (Martin, 2009), which helps clients to document their end-of-life wishes. The diversity in spirituality among community members and the need to support and respect this diversity is acknowledged in these two documents as follows:

It is our intention to support our cultural practices to help individuals achieve a sense of peace and wellbeing while they are preparing for the loss of their loved one. The sacred knowledge shared with you may be different from what you have learned as the variances arise from the family, the Longhouse, the Nations and the Community (Martin & Skye, 2001, p.2).

*Journey Back Home* (Martin, 2009) was authored by the traditional wellness coordinator and reviewed by Traditional Knowledge Carriers prior to being shared. The guide opens with the following acknowledgement:

On behalf of the Six Nations Long Term Care/Home and Community Care Program, I wish to thank the efforts of Christine Skye [Traditional Knowledge Carrier] and many other people who have shared their knowledge to contribute to the development of the Journey Back Home resource. I also wish to thank our Ancestors for making this resource possible, as it would have never come to be if they did not share and teach their knowledge to others for the future generations. The sacred cultural knowledge within this resource is to help assist our families learn about the journey back home to the Creator. In our state of grief, we recognize that it can be difficult to think or function while we are feeling a great sadness. I hope that this resource will guide and help support the families while they prepare and send their loved ones on their journey. (Traditional wellness coordinator; p. 28)

Overall, the Palliative Care Program booklet and resources represent the achievements of the Leadership Team after many years of work. Members of the palliative care program expressed great pride in seeing the outcome of their work, as illustrated by the comment below:

*I definitely think this is an important service to provide to our patients, to people who are in need of palliative care services, whether it is just pain and symptom management or end-of-life planning. It's nice that we are available 24/7; there is always a nurse and a doctor on call.* (Clinical nurse specialist)

### **Limitations**

The outcomes of this research (i.e., the design of the palliative care program) are embedded in and emerged through the PAR process and the unique context at Six Nations. Thus, the specific palliative care program described in this article cannot be reproduced in other First Nations communities. Contextual variables such as community size, historical background, physical setting, economic status, infrastructure, cultural beliefs, and isolation will influence how each community can develop its palliative care program. Despite this, the achievements of Six Nations of the Grand River Territory can serve to inspire other First Nations communities to implement their own vision for change in care for people who wish to die at home in the First Nations community. It is the community capacity development approach (process of change) described in this article that is applicable to any First Nations community, and by employing it as described, communities can develop their own culturally appropriate palliative care programs that build on local assets and partnerships.

### **Discussion**

Within the overall EOFLN project, the success of the Six Nations community capacity development is impressive. Many factors contributed to it. The motivation, leadership, and vision of the project's community lead were significant, and she was able to mobilize her community. Six Nations also had excellent community resources to build on; it is a large, urban community, with a strong HCC program that was already providing some palliative care services. HCC had

partnerships that could be enhanced with provincial home care and a hospice. The partnership with the EOLFN research team provided timely support and funding for the community facilitator. And finally, there was opportunity in that the province of Ontario was prioritizing the funding of community-based palliative care. This environmental readiness enabled Six Nations to gain provincial funding for their Palliative Shared Care Outreach Team from their LHIN.

In Six Nations the capacity development process required strong commitment from the Project Advisory Committee and Leadership Team over 5 years. There were challenges to be managed. At times, a sense of apathy deterred participation in the project as some service providers felt that nothing concrete would be achieved. There were many competing priorities that required the attention of Six Nations leadership, and palliative care was not always the top priority. It was sometimes difficult to engage participation by community members because of transportation costs to come to meetings. HCC staff lacked coverage for their work when they took time for palliative care planning and education. Delays in getting authorization from political leadership and ethics boards also posed challenges for conducting research activities.

However, receiving timely and ongoing practical benefits of the project will help the Six Nations community members maintain motivation. Also, a strong community engagement through a Project Advisory Committee, decision maker partners, and community facilitator helps sustain interest. Managing environmental impacts is always part of the community capacity development process. In this case, dedication and hard work by the Project Advisory Committee sustained the initiative.

The experience of Six Nations highlights broader policy issues for other First Nations communities who wish to develop palliative care. The EOLFN project found that accessing human resources and equipment is an ongoing issue; jurisdictional issues represent a barrier to funding. Building a team of qualified First Nations healthcare professionals from the community requires education and training. Later, as more and more people chose to return home to die, there was a need for more personal support workers, more nurses and case managers. However, there is no specific funding allotted for end-of-life care in First Nations communities. Both the provincial and federal governments describe themselves as the *payer of last resort* for providing equipment and medication for palliative care. This means that the family, who are often unable to afford this expense, must assume equipment rental costs. Seeking funding from the Non-Insured Health Benefits (NIHB) program is the only option for clients who have no other health insurance coverage. The NIHB approval process can be too lengthy when dealing with end-of-life care.

The new team and program in Six Nations is a work in progress. There is need for continual revision of the team and program to address emerging issues. For example, a recent experience with a client who had end-stage chronic disease highlighted issues in the service partnerships and identified a need for more staff education on pain and symptom management in chronic disease. Discharge planning with families prior to coming home from hospital is often lacking, resulting in families not knowing what to expect in the provision of end-of-life care at

home. There are also specific risk factors to be managed in the use and storage of narcotics for pain relief in the home setting.

The new Palliative Care Program needs to remain culturally flexible and supportive. In the words of the Six Nations community facilitator:

*Each family is unique. They may be traditional and attend the longhouse, or they may be Christian and attend one of the many local churches, or they may be a combination of both. We wanted to accommodate both the traditional Elders/healers and pastors, and coordinate a pastoral team that we could call upon as necessary.*

It is also very important to support staff with post-death debriefings and sacred ceremonies, and to offer bereavement leave to avoid staff burnout. Work has begun on a wellness strategy, and individual wellness plans for all staff.

The Six Nations Palliative Care Program represents the integration of two caregiving systems. From within Six Nations, the desire to return to the traditional Haudenosaunee philosophy, along with strong leadership and a vision for change by local healthcare providers, initiated and drove the process. External to the community, the Ontario healthcare system respectfully engaged with Six Nations and provided funding, education, and mentorship to support local capacity development. These two systems shared in a process of community capacity development that has implications as a promising practice at the policy level.

The program development is still in process. The future of the Six Nations Palliative Shared Care Outreach Team is unknown as the LHIN Regional Palliative Plan may include a shift to having hospices as Centres of Excellence for palliative care. While this proposal would fit well into the memorandum of understanding between Six Nations and Stedman Hospice, the team anxiously awaits the final plan. The palliative care team will continue to be funded by the province at the current level; however, the growing number of people who want to die at home has put great stress on Home and Community Care resources. The jurisdictional issue of who pays for providing palliative home care services needs to be addressed by the provincial and federal governments. This research suggests that much can be accomplished through federal and provincial health partnerships.

### **Conclusion**

The Six Nations Palliative Care Program model is an innovative and promising practice grounded in community values and Indigenous culture, and successfully supports people to receive their care and die at home if that is their wish. Support is provided for people with advanced chronic disease who are in the last year of life, and those with a cancer diagnosis. The program is integrated within Six Nations Health Services and was developed over 5 years by a Project Advisory Committee and Leadership Team who worked with internal and external health services partners and research partners at Lakehead University. The Palliative Care Program

focuses on meeting the end-of-life care needs of people and their families in a way that incorporates Haudenosaunee traditions, yet individualizes all clients and honours their beliefs.

The need to develop appropriate palliative care programs for First Nations communities is urgent because the First Nations population is aging with a high burden of chronic and terminal illnesses. Creation of the palliative care team and program at Six Nations was done using community capacity development. The process described is applicable to any First Nation that has the vision, leadership, and motivation to develop its own palliative care program. Each community program will need to evolve with unique features that reflect the local community needs, existing community resources, and partnerships with provincial healthcare services. In the EOLFN research, these outcomes have been shared with other First Nations communities through a workbook of research-informed community capacity development strategies (EOLFN, 2015) that are drawn from the work of all four communities.

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