

A Literature Review & Environmental Scan of  
The Experiences of First Nations, Inuit, and Métis Peoples  
with Advanced Cancer Illness and at the End of Life

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## Introduction

In 2016, there were just over 1.6 million Indigenous People living in Canada, accounting for 4.9% of the total population. Since 2006, the Indigenous population has grown by 42.5%, more than four times the growth rate of the non-Indigenous population. Indigenous People in Canada represent a population that is not only growing, it is also young. The average age of Indigenous People in the country is 32 years, almost a decade younger than their non-Indigenous counterparts (40 years) (Statistics Canada, 2017). While there is a paucity of data reporting on the national incidence, prevalence, and cancer survival rates among the entire Indigenous population within Canada, both Ontario and British Columbia have recently compiled reports on their Indigenous populations. Two recent reports funded by Cancer Care Ontario (2017) and The BC Cancer Agency (2017), are providing statistics on the rates and prevalence of cancer within Indigenous communities. In Ontario, it was reported that the most common cancers in First Nations People were lung, colorectal, breast, and prostate, accounting for over 50% of all cancers diagnosed. Furthermore, most cancers were diagnosed in people between the ages of 50 and 74 and, First Nations females had higher incidence rates than their non-First Nations counterparts in the province (Chiefs of Ontario, Cancer Care Ontario, Institute for Clinical Evaluative Science, 2017). In British Columbia, similar statistics were found. First Nations People are less likely to survive a cancer diagnosis compared to non-First Nations People and lung cancer rates, while on the decline in the general population, are rising within the First Nations community (McGahan et al., 2017). Both reports also acknowledged there is a complex basis for these disparities in cancer incidence and survival rates within Indigenous populations.

It is well documented that Indigenous People in Canada face a multitude of health disparities and barriers in accessing necessary cancer supports and services (Cavanagh, Wakefield, McLoone, Garvey, & Cohn, 2016). There are gaps in cancer education, prevention, screening, diagnosis, treatment, and end of care services available to Indigenous Peoples. Those who live on-reserve and in geographically isolated areas experience even poorer outcomes when it comes to cancer prevention, treatment, and accessing palliative care services (Beben & Muirhead, 2016; Hammond et al., 2017). Despite the lack of services and supports, Indigenous People consider cancer prevention and treatment to be important health issues and are calling for greater access to care and services within their communities. They recognize the need for continued cancer screening and education but also experience a different reality. Several gaps exist when Indigenous People try to access cancer care in their own communities (Cavanagh et al., 2016). These include: jurisdictional issues, a lack of on-reserve healthcare services, a lack of community health workers or Indigenous health workers, a lack of family or caregiver education and training to offer home care services, and a lack of culturally-safe, relevant supports (Caxaj, Schill, & Janke, 2017; Isaacson, 2018; Lavoie, 2018; McKenna, 2015).

A large component of cancer care includes both end of life care and advance care planning. As people move into the final stages of life, following an advanced cancer diagnosis, palliative care becomes critical. This includes: pain management strategies, care plans, family and caregiver support, home care and preparation emotionally, physically, spiritually, and mentally for transitioning from the physical world (Cueva et al., 2016; Russell, Fred, & Brown, 2018). For Indigenous People there is a desire to receive palliative care services within their homes and communities and have family members providing care directly when possible. Indigenous People

also expressed concerns about medical professionals lacking important cultural knowledge and people not being able to partake in essential end of life cultural and spiritual practices (Daudt, d'Archangelo, & Duquette, 2018). Finally, Indigenous People express how accessing home care supports outside of their communities further isolates them from their communities and families, and their culture and language (Denis & Washington, 2018; Fruch, Monture, Prince, & Kelley, 2016).

This literature and environmental scan identifies the current needs, disparities, and services available to Indigenous People living with cancer, in Canada. Specifically, it will focus on current end of life care service models and policies, as well as advance care planning. This review builds on previous work from 2014, which gathered information on the experiences of Indigenous People with advanced cancer illness and at the end of life. This was used to inform the development of a series of online multimedia and text-based tools to empower Indigenous Peoples living with advanced illness. The purpose of this review is to build onto this previous document, and further identify trends in the experiences of Indigenous Peoples with advanced cancer, their caregivers, their families, and their communities. It focused on adding materials related to: 1) cultural competencies for providing palliative care to Indigenous Peoples and 2) advance care planning specific to Indigenous People. In order to further inform the development of the previously mentioned tools, an environmental scan will outline the resources available to Indigenous People with advanced cancer illness and at the end of life, to support them and their communities.

## Methodology

This review focused on published and online materials pertaining to palliative and end of life experiences of Indigenous People. Primary literature searches were completed using databases such as ArticleFirst, MEDLINE, and PubMed. The following identifiers and descriptions were used in combination with one another: “Indigenous”, “Aboriginal”, “First Nation”, “Métis”, “Inuit”, “Native”, “end of life”, “palliative”, “terminal”, “advanced cancer” and “terminal cancer” “advance care”, “culture”, “culturally relevant”. “culturally safe”, “spiritual”, and “cancer”. Specific healthcare journals were also searched. The journals searched included: *Canadian Journal of Public Health*, *Cancer Causes & Control*, *Palliative Research & Treatment*, *Journal of Palliative Care*, *Palliative & Supportive Care*, *Palliative Medicine*, *International Journal of Palliative Nursing*, *Journal of Pain & Palliative Care*. A general Google search and Google Scholar search were also performed. Finally, the reference pages of several relevant articles were also searched, particularly those that conducted recent meta-analyses or literature reviews of palliative care research in Canadian Indigenous communities.

Search combinations within the above-mentioned databases and Google scholar search engine yielded between 350 and 12,400 results. Article titles and abstracts within the first 10 pages were scanned for relevancy and the titles and abstracts were reviewed to ensure the focus was on Indigenous Peoples’ experiences with palliative or cancer care. Articles that were published before the year 2014 were excluded to ensure the information was current and to prevent the re-examination of materials already included in the literature review conducted that same year. Although the focus was on articles from Canada, relevant articles from countries with similar colonial histories, such as Australia, New Zealand, and the United States, were also included. In total, 38 articles were found and were reviewed. A total of twelve articles were omitted after a more detailed review, as they did not contain relevant information, despite meeting the original search criteria.

In terms of the environmental scan conducted, a review of online materials included a review of websites containing relevant palliative care and Indigenous organizations. Also, a general Google search with the above-mentioned key words was completed (the first five pages were reviewed for each combination). In addition to identifying online resources, the scan also yielded information relevant to the current state assessment.

The websites reviewed for relevant information included:

- Canadian Virtual Hospice;
- Pauktuutit Inuit Women of Canada;
- LivingMyCulture.ca;
- Canadian Cancer Society;
- BC Cancer Agency;
- Speak Up Ontario;
- BC First Nations Health Authority;
- MyHealth.Alberta.ca Network;
- British Columbia Ministry of Health;
- Advance Care Planning Ontario; and
- Cancer Care Ontario.

## **Limitations**

This review was limited to materials accessible online, and as a result, it does not comprehensively reflect the experiences of Indigenous Peoples living with advanced illness, and cancer and/or at the end of life. Although the search aimed to include additional sources of information outside of peer-reviewed academic literature, the limits of published and online accessible materials to reflect the experiences of Indigenous populations must be acknowledged. Often experiences, or initiatives, or needs within communities will not be captured in written work. Lastly, it is important to acknowledge that the search for international materials was not comprehensive, as the search terms were not designed for their inclusion. As a result, only select, relevant international materials identified from the search were included.

## Literature Analysis

Several salient themes identified in the original literature review reemerged in this review. These themes were:

- Indigenous People have varied and unique perspectives on death and dying that are closely linked to their culture, language, traditions, spiritual beliefs, and worldview;
- Families and caregivers play an important role in cancer care, palliative care, advanced care planning, and preparation for death;
- Receiving care at home and/or within one's home community is important;
- There are several barriers to accessing health and home care supports;
- Interactions with healthcare providers must be culturally-safe and rooted in trust;
- Traditional healing and ceremonies are an important component of the palliative care process; and
- Language, culture, and the spiritual needs of the individual are tantamount in the ways in which they access, utilize, and conceptualize palliative healthcare services.

In addition, there were new themes that emerged from this review and will be expanded below. These emergent themes were:

- Indigenous People have always and continue to live in compassionate communities that centre on collectively caring for one another;
- Many Indigenous People and communities view death as a transition rather than an end point, and focus on "preparing the spirit" during palliative care;
- Advance care planning education and support services need to be culturally safe;
- There are several current Indigenous palliative care models that are operating successfully in Indigenous communities; and
- Best practices in Indigenous palliative care models could include digital storytelling and journey mapping processes.

## Compassionate Communities & Communities of Care

Indigenous People have always lived in compassionate communities as they continue to recognize dying as a social experience. Community members hold extensive traditional knowledge and have community-based practices to support the personal, familial, and community experiences surrounding end of life. In this way, they create communities of care amongst each other and have generations of experience supporting one another through palliative care processes. However, western health systems were imposed upon these communities and typically did not support Indigenous social and cultural end of life practices. Colonial policies and colonization disrupted compassionate care within Indigenous communities and created systemic barriers preventing them from healing, treating, and grieving collectively (Hordyk, MacDonald, & Brassard, 2017; Hordyk, MacDonald, & Brassard 2016). One solution for reclaiming compassionate community traditions is for Indigenous communities to develop their own palliative care programs so that people can receive care at home amongst their family, community, and culture. A recent research project "Improving End-of-Life Care in First Nations Communities" (EOLFN) funded by the Canadian Institutes of Health Research [2010–2015] was created in partnership with four First Nations communities, to develop such programs. This



model includes a community capacity development approach to support Indigenous models of care at end of life, that allows communities to develop their own care models (Prince, 2018). These models celebrate cultural capacity in their communities, while enhancing medical palliative care services in a way that respected and integrated with their community cultural practices. They demonstrate how communities can develop palliative care programs by building upon community care culture, values, and principles already in existence (Prince, 2018).

Among the Inuit, compassionate care communities were once sustainable care models with a rich oral history of caregiving traditions in which the sick and elderly were collectively cared for by family and clans who shared social responsibilities. Prior to colonial policies that forcibly relocated Inuit People into permanent settlement sites, the nomadic clans would reorganize themselves so that caregivers could temporarily settle to provide care for the sick and dying. According to one Elder interviewed, *“the Inuit practice (of caregiving) is very strong. If you care for that person and the passing of life, your heart is going to be peaceful. If you don’t care for the person, your heart is going to suffer”* (MacDonald, & Brassard, 2017). Families and community members would gather in the home and sing, cook, talk, story tell, play games, pray, and share in daily household activities. However, today due to gaps in funding, access to equipment, infrastructure, housing issues, and socio-economic factors, many family members are often unable to provide end of life care in their homes (Hospice of Waterloo Region, 2014; MacDonald, & Brassard, 2017). Care models need to acknowledge both the history and the current barriers, and seek ways to work with community members to overcome them (see Appendix B).

### **‘Preparing the Spirit’: Death as a Transition**

Another theme that emerged from this literature review is that conceptualizations of death are cultural, rather than fixed constructs. While mainstream western cultures tend to view death with some sort of finality or as an end point, Indigenous communities may view it as a transition. This shift in perspective also signals a shift in how palliative care supports might also be conceptualized differently for Indigenous People. It also signals how terms such as “end of life” could be viewed as problematic and inappropriate, when people do not view death as “an end.” While Indigenous conceptualizations of death still include elements of creating comfort for the physical body such as managing pain, they also include the notion of beginning a transitional phase of one’s life. This transition is marked by the concept of “preparing the spirit” (Duggleby et al., 2015). Preparing the spirit can mean many things such as viewing death as a transition to the next life, increasing the need to connect to family members and land, and healing and protecting both the self and the spirit through ceremony and prayer. Preparing the spirit has been conceptualized as a tree with the roots being “where we come from,”. The trunk represents the process of “preparing the spirit,” and the branches are “healing”, “connecting”, and “protecting”. The leaves of the tree are “what we want at the end of life” and the other trees in the model reflect the collective nature of these experiences (see Appendix C). Trees have been used as a symbol by many Indigenous Peoples and have many different meanings. However, the use of the tree here shows the connection to the land and nature as well as how all of the noted concepts are important interconnected parts of end of life experiences (Duggleby et al., 2015).

In today's modern healthcare systems there are many barriers Indigenous People face in accessing adequate supports and services so they may undertake this important process. Healthcare practices often run counter to the work that needs to be done to prepare the spirit. These potentially harmful practices include facility rules regarding family visitation hours, restrictions on the number of people allowed in the room at once, and banning certain cultural or personal objects within care facilities that may prevent prayer or ceremony from occurring (Green, Jerzmanowska, Green, & Lobb, 2018). It also creates barriers for patients and families because patients may not want to discuss their illness with strangers or health care providers, and may prefer to use different language to conceptualize dying (i.e. death versus transitioning). They may also refuse medical treatment due to beliefs, and/or they may request traditional or culturally-based treatments and care (Beben & Murihead, 2016; Gott et al., 2017). For example, one American Indian woman refused a left lower extremity amputation, despite the lifesaving potential of the procedure. Through increased dialogue from a culturally safe standpoint, the medical team discovered that in her tradition, she could not go to the spirit world without her whole body. The team was then able to negotiate with the surgeon, pathologist, and hospital to ensure that her amputated leg could be returned to her postoperatively so that it could be buried on sacred land and able to make her final journey (Gebauer et al, 2016).

### **Offering Culturally Safe Advance Care Planning**

There is a need within Canadian healthcare to developing culturally appropriate advance care planning information resources for use in community and hospital settings. Recent research has revealed that there are several key themes impacting the perceptions of advance care planning among the Indigenous population including: possible conflicts with cultural approaches to dying; the importance of family and kin in advance care planning; and appropriate communication between patients and healthcare providers during the process (Caxaj et al., 2017; Hospice of Waterloo Region, 2014; Sinclair, Williams, Knight, & Auret, 2014). Conceptualizations of death are not static and standard across all populations and this also impacts the ways in which people view advance care planning. For example, Indigenous People have the right to identify and prioritize their own advance care directives and identify what it means to prepare their spirit for transitioning. Other more salient end of life concerns might emerge such as preserving their families, the community, and their cultural ways of life, as opposed to merely dealing with material items belonging to the physical world (Isaacson, 2018).

There are several myths and assumptions made by healthcare providers, particularly those that are offering palliative and advance care supports in larger centres, located outside of Indigenous communities. The first myth is that the lack of formal, documented advance care planning within these communities indicates that individuals, families, and communities did not have or share plans with one another or that people have an aversion to discussing their end of life preferences (Caxaj et al., 2017; Denis & Washington, 2018). This is not usually the case. Most Indigenous Peoples and communities acknowledge the importance of making plans however admitted to not knowing the process or, not having access to the appropriate resources to record or document their wishes. Many preferred to use oral means to transmit their advance care directives to their families. Second, there is an assumption that within Indigenous families and communities, people will or should "look after their own," which has resulted in a hands-off approach by palliative care health providers in Indigenous populations (Caxaj et al., 2017). This creates a

paradox, whereby patients and families feel simultaneously ignored and judged (Peltier, 2015). Advance directives and palliative care planning then become processes that feel intrusive, inflexible or like impositions of an individualist framework, on what should be family or community decisions (Caxaj et al., 2017).

Specifically, there is a need for palliative care models and advance care planning service models to *move away* from a cultural competency framework that suggests that providers can “‘master’” a checklist of characteristics associated with a group of people, and *move toward* cultural humility as an alternative framework for assessing culturally appropriate care (Gebauer et al., 2015). Cultural humility is a process in which providers engage in self-reflection and lifelong learning, so they become “flexible and humble enough to assess the cultural dimension of the experiences of each patient” (Gebauer et al., 2015). This approach is context-dependent and therefore, more capable of avoiding the pit-falls of the notion of capturing a pan-Indigenous experience that many programs encounter. Healthcare providers need to respond to the need culturally and linguistically diverse needs of Indigenous People in Canada and provide individuals and families with resources for advance care planning (Caxaj et al., 2017; Denis & Washington, 2018; Schill & Caxaj, 2019). This includes programs that focus on: the development of patient education materials on advance directives to be made available in the community; training of facilitators who are accessible at all healthcare organizations in the community; policies for maintaining, documenting, and using advance care directives; and the use of community-based evaluations to enhance the outcome of each of these efforts (Pecanac, Repenshek, Tennenbaum, & Hammes, 2014).

The most successful palliative and advance care models are those that acknowledge the needs and barriers that Indigenous Peoples have identified. This includes acknowledging that Indigenous People prefer to die close to or at home, wish to involve family, and see the inclusion of cultural practices as essential (Shahid et al., 2018). Several barriers that have been identified through community-based research practices include: inaccessibility, affordability, lack of awareness of services, perceptions of palliative care, and inappropriate services. One of major barriers identified in several studies was the lack of education surrounding what to expect during palliative care and in planning, who to call for support, or the inherent challenges in becoming a caregiver to a family member with palliative care needs (Southwest Ontario Aboriginal Health Access Centre, 2016). Furthermore, there is a lack of staff in communities to meet the demands of palliative care for Indigenous Peoples (Southwest Ontario Aboriginal Health Access Centre, 2016). The staff available are often unable to meet the needs of their patients, as they lack palliative care training, and are unable to cultivate healthy working relationships with family members and care providers. There is also a significant lack of cultural safety for Indigenous patients requiring palliative care (Schill & Caxaj, 2019; Southwest Ontario Aboriginal Health Access Centre, 2016). Some of the best practice models that attempted to address these gaps adopted the following strategies: community engagement and ownership; flexibility in approach; continuing education and training; a whole-of-service approach; and creating local partnerships among multiple agencies (Schill & Caxaj, 2019; Shahid, 2018). When these models were utilized, there was better engagement with Indigenous clients, an increase in number of patient receiving palliative care services, improved outcomes, and a greater understanding of palliative care by patients and their families (Shahid, 2018).

## The Wiisokotaatiwin Pathway to Palliative Care Model

There are many examples of recently implemented and successful palliative care models that have been created within Indigenous communities. They differ considerably from mainstream care models that are usually created outside of the communities and then adapted to try and meet the needs of the people. These models are rarely successful, and they fail to properly identify individual needs and are not able to be adapted to fit the unique issues faced in the community. There may be a lack of on-site health services and jurisdictional issues preventing services from being delivered within the community (Caxaj et al., 2017; Fruch et al., 2016; Kelley et al., 2018). Therefore, trying to implement a mainstream care model that focuses on local hospice support services, for example, will not fit the needs of a community that does not have a hospice to begin with. This lack of care forces people to leave their culture, family and community, to receive the care they need in distant hospitals or long-term care homes (Kelley et al., 2018; Lavoie, Kaufert, Browne, & O’Neil, 2016). The Wiisokotaatiwin pathway to palliative care model was implemented in the rural First Nations community of Naotkamegwanning (see Appendix D). It is a model created by the community, for the community to address the lack of local on-site, palliative care (Nadin, Crow, Prince, & Kelley, 2018). The model operates in a cyclical rather than linear way, so that patients are cared for at the beginning of their diagnosis. The care pathway doesn’t end when the patient passes away and instead shifts its focus on the needs of the families and community and continues to operate until that family feels they no longer need supports. Naotkamegwanning has already completed a highly successful 10-month pilot of the program. The Wiisokotaatiwin Program allowed community members to receive palliative care at home. This improved the client experience and enhanced service integration by ensuring all services and supports were operating closely together with a focus on strong communication with one another, patients, and families while ensuring there were no gaps in services because of funding (see Appendix F).

## Getting Ready to Go Home: A Collective Story of Cancer & Minobimaadiziwin

*Minobimaadiziwin* is an Anishinaabe term encompassing a broad understanding of health. It includes not only physical, but emotional, mental, and spiritual health and focuses on the individual, family, and larger community (Peltier, 2015). Within the context of Indigenous healing in cancer care, the concept of *Minobimaadiziwin* is often detached from the western medical perspective that isolates not only the physical self during treatment, but also the self from the family and community. There are many potential benefits to including Indigenous healing in cancer care and making the concept of *Minobimaadiziwin* a foundational aspect of a care model. One such care model accomplished this by “braiding” together Indigenous ways of knowing and healing with western medicine for patients with cancer (see Appendix F). Five Manitoulin First Nation communities used western medicine specifically, including medications used for physical pain management alongside traditional approaches to focus on the spiritual, emotional, and mental aspects of the self. This model demonstrated that when this braiding occurs, western medicine provides people with choices about pain management and traditional and cultural healing practices allow them to go through the death process with less fear. This is an important part of *Minobimaadiziwin* in staying on the good path going into the Spirit World. Finally, *Minobimaadiziwin* can and should be maintained in the transition from the end of

physical life and beyond. Anishinaabe People refer to this part of the spirit journey as “getting ready to go home.” According to one Elder interviewed: “*palliative care is a Western term. Our term is that they’re getting ready to go home. That time that the person was getting ready to travel home was a time of celebration. It meant visiting. It meant sharing. It meant getting teachings and knowledge. It meant feasting together with that person who’s getting ready to go home*” (Peltier, 2015).

## **Best Practices in Palliative Care Delivery: Journey Mapping & Digital Storytelling**

Finally, in terms of best practices in creating, implementing, and evaluating Indigenous, community-based palliative care programming, there have been several new developments in the research in recent years. One involves the ways in which information is shared and the other offers a promising new evaluation tool. Digital storytelling operates as both a process and a platform for people to share their stories about a wide range of health issues. Digital stories are short, first-person videos that tell a story of great significance to the creator. They also function as effective tools to communicate with the public, share vital health information, personalize often clinical experiences, and increase awareness and education. Digital storytelling has had success when used to allow both cancer patients and healthcare practitioners to educate one another and the public (Williams et al., 2017). These videos have directly impacted screening, prevention practices, and treatment in communities. Indigenous digital stories have the potential for broad uses as culturally appropriate health messaging tools. Culturally, storytelling and teaching through oral language have been a central part of life for many Indigenous People. In this modern context, digital stories allow people to share within their communities through social media and other online platforms. As one Alaskan Native resident stated, “*a lot of natives have a better understanding of cancer from other natives and the wording is so much easier to understand than all the medical language that providers use*” (Cueva et al., 2016).

This has implications in how prevention practices, screening, diagnosis, treatment, pain management, end of life care, and caregiver and family support services are offered in communities. Digital storytelling as tool has been shown to be culturally respectful, enhance learning, increase the comfort in talking about cancer with patients and in communities (specifically as a way to open or begin the conversations), inspire behavioural changes, and is sharable within community groups (Cueva et al., 2016; Williams et al., 2017). Healthcare practitioners are able to learn factual information about how cancer is conceptualized among communities and are better able to offer supports and services. In addition, the participants were able to reflect on their personal experiences and envisioned how they might apply their knowledge within their communities. There is no one-size-fits-all solution to accommodate all palliative care needs. In fact, while there is a need for a national strategy to offer greater palliative supports to all individuals, there is also a need for a flexible care model that recognizes the unique barriers and needs of Indigenous Peoples. Digital storytelling is a vital part of palliative care approaches in Indigenous communities because it helps meet the need for diverse methods to involve underrepresented groups (Cueva et al., 2016; Williams et al., 2017).

The use of journey mapping, when evaluating palliative care models in Indigenous communities, is also a new and innovative technique researchers are currently using. The *journey mapping process* is a method of gathering qualitative data from participants when evaluating program

outcomes. Journey mapping is inspired by “customer journey mapping” and “value stream mapping” processes used in the marketing and manufacturing industries (Koski et al., 2017). Customer journey maps help to understand customers’ interactions with company touchpoints and identify areas for improvement, while value stream mapping has evolved from a manufacturing-based model of flow to a healthcare quality improvement strategy. It has already been used to effectively evaluate palliative care service delivery in several First Nations communities. This tool has highlighted the need to improve quality and access to palliative care at home by better integrating First Nations’ health services and urban non-Indigenous health services. Journey mapping has been adopted as a new format for evaluating palliative care programs in Indigenous communities, as it is consistent with the guiding principles of Indigenous community-based research (Koski, 2017). Implementing the journey mapping process has the following benefits: helps Indigenous People to better understand the policies and procedures (mandates) of the other non-community health organizations involved, identifies gaps and problems in end of life care service delivery, and effectively helps create a palliative care pathway for Indigenous People (Koski et al., 2017).

## Palliative and Advanced Cancer Care Resources Available to Indigenous People & Healthcare Workers

### Cancer Information and Resources

#### 1. Canada Cancer Society: Aboriginal Traditional Healing

The Canadian Cancer Society provides information on accessing traditional healing such as herbs, sweats, ceremonies, and smudging. It also includes information on how to access traditional healers and Elders.

<http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/complementary-therapies/aboriginal-traditional-healing/?region=on>

#### 2. BC Cancer: Indigenous Cancer Control

As part of its Indigenous Cancer Initiative, the British Columbia government is providing access to the following resources for Indigenous People:

- **Cancer and First Nations People in BC: A Community Resource**
- **First Nations Patient Support Book: “Living with Cancer Everyone Deserves Respect”**
- **Métis Nation Patient Support Book: “Living with Cancer Everyone Deserves Respect”**
- **Declaration of Community to Cultural Safety & Humility**
- **Johanna’s Story (Breast Cancer Screening)**
- **Marion’s Story (Cervical Cancer Screening)**
- **“Silent Enemy” (A Comic Book)**

<http://www.bccancer.bc.ca/our-services/services/indigenous-cancer-control>

#### 3. Speak Up Ontario: First Nations Resources

This website provides the following advance care planning resources for First Nations People:

- **“Advance Care Planning in Ontario – Presentation for First Nations Communities” (PowerPoint Presentation)**
- **“Advance Care Planning with First Nations People” (Video)**
- **“First Nations Community Resource – What is Advance Care Planning?” (Brochure)**
- **“First Nations Community Resource – Why Engage in Advance Care Planning?” (Poster)**
- **“First Nations Community Resource – What is a Substitute Decision Maker?” (Brochure)**

<https://www.speakupontario.ca/resources-for-health-care-providers/?cat=null&keyword=&lang%5B%5D=76#directory-anchor>

#### 4. BC First Nations Health Authority - Living with Cancer: Everyone Deserves Support (a Resource Report)

This resource provides information, tools, and resources for Indigenous People living with cancer. It includes information on receiving a diagnosis, family and community support, healing options, treatment planning, palliative and end of life care planning, and wellness planning resources.

<http://www.fnha.ca/wellnessContent/Wellness/Living-With-Cancer.pdf>

#### **5. MyHealth.Alberta.ca Network– Indigenous Cancer Care Experiences: Video Series**

This digital storytelling video series provides first-hand accounts of Indigenous Peoples' experiences with cancer diagnosis, what family members can expect from a diagnosis, receiving care in the community, the challenges of communication with healthcare professionals, cultural wisdom and strength, the use of traditional medicines, companionship and travel, and healthy living.

[https://myhealth.alberta.ca/Alberta/Pages/indigenous-cancer-care-experiences-video-series.aspx?\\_cldee=bWFyaXNzYUB2aXJ0dWFsaG9zcGljZS5jYQ==&recipientid=contact-309ee5578137e811a98f000d3af454d7-e337544dd09240a9a922b77baf1afef0&esid=12c48806-81a4-e811-a96c-000d3af475a9](https://myhealth.alberta.ca/Alberta/Pages/indigenous-cancer-care-experiences-video-series.aspx?_cldee=bWFyaXNzYUB2aXJ0dWFsaG9zcGljZS5jYQ==&recipientid=contact-309ee5578137e811a98f000d3af454d7-e337544dd09240a9a922b77baf1afef0&esid=12c48806-81a4-e811-a96c-000d3af475a9)

#### **6. Living My Culture – Canadian Virtual Hospice**

These videos provide information on quality palliative care that helps people honour their culture, spirituality and traditions. At LivingMyCulture.ca, people from various cultures share their stories and wisdom about living with serious illness, end of life and grief to support others. There are both videos and downloadable print materials for First Nations, Métis, and Inuit People on the following topics:

- Traditions, rituals, and spirituality;
- Expectations of care;
- Care for the patient and family;
- Emotion and support;
- Talking About the illness; and
- After death and ceremonies.

<http://livingmyculture.ca/culture/>

#### **7. Pauktuutit Inuit Women of Canada & Canadian Cancer Society – Inuusinni Aqqusaaqtak: My Journey**

This resource contains two workbooks for Inuit women to education themselves on their journey with cancer. Book one has information about cancer, and book two has space to write about one's own personal cancer journey.

<http://www.cancer.ca/~media/cancer.ca/CW/publications/My%20Journey%20series/My-Journey-series-EN.pdf>



## Palliative and Advanced Care Planning Resources

### 1. British Columbia Ministry of Health – Aboriginal Health: Advance Care Planning: Respecting Aboriginal Ceremonies and Rites

This pamphlet provides information and resources for Indigenous People, so they learn about how to create their own advance care plans. It includes links to a downloadable planning guide as well as information about how to share plans with family and how to include traditional spirituality and ceremonies into their plans.

<https://www.health.gov.bc.ca/library/publications/year/2012/aboriginal-health-advance-care-planning-brochure.pdf>

### 2. Advance Care Planning Canada: First Nations Resources

This website was a collaborative effort from the following organizations: Improving End-of-Life Care in First Nations, The Way Forward Integration Initiative, Quality End-of-Life Care Coalition of Canada, and Canadian Hospice Palliative Care Association. It provides advance care planning education resources for people living in First Nations Communities. There are brochures on what advance care planning is, how to create advance care plans, how advance care planning is different between provinces and territories, and includes downloadable work books and options for hard copies.

<http://www.advancecareplanning.ca/resource/first-nations-acp-resources/>

### 3. Cancer Care Ontario: Palliative Care Toolkit for Aboriginal Communities

This website provides a palliative care toolkit as well as several brochures for Indigenous Canadians including information on:

- **Understanding the diagnosis for parents and caregivers;**
- **Teachings to support grief and loss;**
- **Making decisions and plans;**
- **Taking care of the self and loved ones; and**
- **Resources**

<https://www.speakupontario.ca/resources-for-health-care-providers/?cat=null&keyword=&lang%5B%5D=76#directory-anchor>

## General Cultural Competency Resources Available to Healthcare Workers

### 1. Aboriginal Nurses Association of Canada (ANAC) - Cultural Competency and Cultural Safety in Nursing Education

This framework was developed with a primary audience of nursing education programs and nurse educators. Employers have a responsibility to ensure a “culturally safe” working environment for Aboriginal and non-Aboriginal nurses alike. Furthermore, “cultural safety” is relevant to the clinical context and employers should be encouraged to consider how “cultural safety” can be enacted in the workplace setting.

[https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/first\\_nations\\_framework\\_e.pdf](https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/first_nations_framework_e.pdf)

### 2. Alberta Children’s Hospital, Child & Women’s Health Diversity Program - Enhancing Cultural Competency Resource Kit

This resource kit is intended to assist health professionals in providing culturally-competent care to individuals and families from diverse cultural backgrounds.

[http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/Enhancing\\_Cultural\\_Competency\\_Resource\\_Kit1.pdf](http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/Enhancing_Cultural_Competency_Resource_Kit1.pdf)

### 3. American Medical Association – Office Guide to Communicating with Limited English Proficient Patients

This guide provides information and resources that physicians and healthcare staff can use to provide better care to patients with limited English proficiency (LEP). It offers detailed information on the ways LEP can affect patient care and includes effective strategies to address the language needs of patients in a culturally, linguistically and ethically-appropriate manner.

[http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/lep\\_booklet.pdf](http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/lep_booklet.pdf)

### 4. Canadian Collaborative Mental Health Initiative (CCMHI) – Establishing Collaborative Initiatives Between Mental Health and Primary Care Services for Ethnocultural Populations

This toolkit is designed “to assist service providers and other key stakeholders to work collaboratively to meet the mental health needs of ethnocultural populations.” Highlights include: ten key issues for consideration when planning and implementing an initiative, descriptions of two positive-practice initiatives, and a list of key websites.

[http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/EN\\_Companion-ToolkitforEthnocultural.pdf](http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/EN_Companion-ToolkitforEthnocultural.pdf)

### 5. Canadian Council on Social Determinants of Health - Indigenous Cultural Competency Training Options

The Canadian Council on Social Determinants of Health (CCSDH) has identified cultural competency training options to assist organizations and individuals from different sectors to

better understand Indigenous histories and cultures. These trainings are appropriate for broad audiences and offer accurate and comprehensive information to support cultural competency.

<https://www.ccsa-nccah.ca/docs/other/CCSDH-Cultural-Competency-Training-EN.pdf>

#### **6. Diversity Rx – Improving Health Care for a Diverse World**

This website is designed to improve access to and quality of healthcare for minority, immigrant and Indigenous communities and to support culturally and linguistically responsive health services.

<http://www.diversityrx.org>

#### **7. Indigenous Corporate Training Inc. – Indigenous Cultural Competency Self-Assessment Checklist**

This organization was curious to see if there was a sort of litmus test available for people to measure their Indigenous cultural competency and when they couldn't find one, they decided to create it. The questions that follow are intended to encourage reflection, and hopefully, meaningful discussion with colleagues, friends and family.

<https://www.ictinc.ca/blog/indigenous-cultural-competency-self-assessment-checklist>

#### **8. Indigenous Physicians Association of Canada (IPAC)**

This organization includes several resources for healthcare providers including:

1. First Nations, Inuit, Métis Health Core Competencies: A Curriculum Framework for Continuing Medical Education
2. Promoting Culturally Safe Care for First Nations, Inuit, Métis Patients

<http://www.ipac-amac.ca/resources/>

#### **9. McGill University, Cultural Consultation Service - Cultural Competency Service Clinical Handbook**

This handbook provides detailed information on various aspects of cultural consultation such as the consultation procedure and methods of information intake. Also, the site provides information on the role of the consultant and the culture broker/interpreter.

<https://www.mcgill.ca/tcpsych/publications/report/appendices/handbook>

#### **10. NAHO - Cultural Competency and Safety: A Guide for Health Care Administrators, Providers and Educators**

The National Aboriginal Health Organization (NAHO) created this living document as a general guide or resource for researchers, educators, and health professionals working in Indigenous health. As a general guide, it explains the need for culturally competent and safe care, identifies the stakeholders in this process, and outlines ways organizations can evaluate healthcare programs and policies to ensure that they are culturally safe. Finally, it examines how culturally safe environments in healthcare and education are applied to First Nations,

Inuit and Métis. Additionally, this document provides select resources, contacts and links for further knowledge development.

<http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/culturalCompetency1.pdf>

### **11. National Center for Cultural Competence**

This website provides many educational resources, publications, and self-assessment tools including:

1. Cultural and Linguistic Competence Health Practitioner Assessment
2. Promoting Cultural and Linguistic Competency Self-Assessment Checklist for Personnel Providing Primary Healthcare Services

<https://nccc.georgetown.edu>

### **12. Northern Health Indigenous Health - Cultural Safety Initiative**

This website supports the healthcare system to be culturally safe for Indigenous People. All its programs and initiatives work toward inclusive health services and a healthcare system respectful of Indigenous People in northern BC. The NHIH creates specific cultural safety activities and resources to increase awareness, understanding and capacity within Northern Health to provide culturally safe services.

<https://www.indigenoushealthnh.ca/initiatives/cultural-safety>

### **13. Nova Scotia Department of Health - Culturally Competency Guide for Primary Health Care Professionals in Nova Scotia**

This guide includes tools and resources to assist primary healthcare professionals in providing culturally competent healthcare. Culture is a broad term used in reference to a wide variety of groups. In order to respectfully and effectively address health needs and issues related to race, ethnicity and language, the focus of this guide is on these elements of culture.

[http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/Cultural Competence guide for Primary Health Care Professional s.pdf](http://www.multiculturalmentalhealth.ca/wp-content/uploads/2013/10/Cultural%20Competence%20guide%20for%20Primary%20Health%20Care%20Professional%20s.pdf)

### **14. San'yas Indigenous Cultural Safety Training – Provincial Health Services Authority in BC**

This website includes information about the San'yas: Indigenous Cultural Safety Training Program delivered by the Provincial Health Services Authority of British Columbia. Cultural safety is about fostering a climate where the unique history of Indigenous Peoples is recognized and respected in order to provide appropriate care and services in an equitable and safe way, without discrimination.

<http://www.sanyas.ca>

### 15. SickKids Hospital (Toronto, ON)

SickKids has created a Clinical Cultural Competency Series including 15 open-access multimedia and interactive e-learning modules on various topics (see especially these modules: Cross-cultural Communication, and Parenting Across Cultures). Other SickKids Hospital resources include: About Kids Health, Multilingual Health A–Z.

<http://www.sickkids.ca/tclhinculturalcompetence/index.html>

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## Appendix A: Annotations

Beben, N., & Murihead, A. (2016). Improving cancer control in First Nations, Inuit and Métis communities in Canada. *European Journal of Cancer Care*, 25, 219–221. doi: 10.1111/ecc.12479

This editorial explores the complex significance of Canada's colonial history and how it continues to influence health policies today for Indigenous People. This directly impacts the health and well-being of Indigenous Canadians. For example, cancer incidence and prevalence rates are rising in Indigenous communities and are often experienced with other health issues such as communicable and infectious diseases, making cancer even harder to prevent and treat. The researchers briefly address the lack of resources, education, and access to necessary medical services and facilities at the community level. The authors acknowledge that a lack of culturally relevant services and training within the health community makes it challenging for Indigenous People to navigate the often-complicated nature of receiving a cancer diagnosis. In 2009, the Canadian Partnership Against Cancer, hosted a national forum on First Nations, Inuit and Métis Cancer Control. Through this forum, they created *the First Nations, Inuit and Métis Action Plan on Cancer Control*. This action plan guides work by the Partnership with and for First Nations, Inuit and Métis cancer patients and partners. It outlines the importance of closing gaps around culturally responsive care, addressing language and geographic barriers, and building greater cancer awareness within communities. Currently, the Partnership is documenting best and/or promising practice models of Indigenous health supports working to connect patients with Elders, healers and/or navigators to provide First Nations, Inuit or Métis specific supports.

Cavanagh, B. M., Wakefield, C. E., McLoone, J. K., Garvey, G., & Cohn, R. J. (2016). Cancer survivorship services for Indigenous peoples: Where we stand, where to improve? A systematic review. *Journal of Cancer Survivorship*, 10, 330–341. doi: 10.1007/s11764-015-0479-2

This research article highlights the lack of support programs available to address the needs of cancer survivors from Indigenous populations. This systematic review analyzed the experiences and current support services for Indigenous cancer survivors following the cessation of cancer treatment. Similar to the findings on end of life care for Indigenous patients, several common themes emerged when looking at survivorship. These include: the importance of family support, the negative effect of community stigmatization, fatalistic attitudes towards cancer, and the importance of spirituality in coping with, and understanding, the cancer experience. They also explored the potential barriers to accessing care including the distance to and difficulties visiting cancer treatment facilities, and the negative emotional and psychological experience in seeking follow-up care due to an associated fear of cancer recurrence. The authors concluded that Indigenous cancer survivors would benefit from survivorship programs more specifically tailored to their individual circumstances and should include personalized spiritual care, facilitation of increased involvement of family members, and connection to other Indigenous cancer survivors all based on the individual needs of the patient.

Caxaj, C. S., Schill, K., & Janke, R. (2017). Priorities and challenges for a palliative approach to

care for rural Indigenous populations: A scoping review. *Health & Social Care in the Community*, 26, e329–e336. doi: 10.1111/hsc.12469

These researchers conducted a review of relevant literature to identify key priorities and challenges for Indigenous People accessing rural Indigenous palliative care. They also discuss the impact of socio-economic factors on care including financial strain, overcrowding in homes, and travel expenses. The researches discuss how modifications and renovations to homes as well as home care assistance is not considered when health organizations plan and how they offer palliative services. The assumption that all people are able to modify their homes to meet their end-of-life care needs is one that ignores the realities of Indigenous Peoples, especially on-reserve. There are also several institutional barriers such as jurisdictional issues as the federal government does not consider end of life care programming, a core programming need. This creates gaps and inequities for on-reserve patients and many are transferred to unfamiliar larger urban facilities for palliative care. The results lead to trauma and stress. Finally, the interpersonal dynamics that challenged patient-clinician interactions are examined. Specifically, the article addresses how the assumption that family members will “look after their own,” has resulted in a hands-off approach in palliative care for Indigenous populations. Furthermore, it discusses the common concern for participants related to different expectations of advanced care planning, whereby many families reported this process felt intrusive, inflexible, or like an imposition of an individualist framework on what should be a family decision.

They also highlighted several priorities including the need for family connections throughout the dying process by allowing families to incorporate traditional practices and knowledge into screening, prevention, treatment, advanced care planning, and palliative care. There is a need to build local capacity for palliative care to provide more relevant and culturally appropriate care, greater flexibility, and multi-sectoral partnerships, to address the complexity of day-to-day needs for patients/families. These findings point to several areas for change and action that can improve the relevance, access and comprehensiveness of palliative care programming for rural Indigenous communities in Canada and elsewhere.

Cueva, M., Kuhnley, R., Lanier, A., Dignan, M., Revels, L., Schoenberg, N., & Cueva, K. (2016). Promoting culturally respectful cancer education through digital storytelling. *International Journal of Indigenous Health*, 11, 34–49. doi: 10.18357/ijih111201616013

This article explores the use of digital storytelling courses to educate Community Health Aides/Practitioners (CHA/Ps) who provide healthcare to Alaska Native People living with cancer in rural communities. Indigenous digital stories have the potential for broad uses as culturally appropriate health messaging tools. Culturally, storytelling and teaching through oral language have been a central part of life for many Indigenous People. In the modern context, digital stories allow people to share within their communities through social media and other online platforms. As one participant stated, “*a lot of natives have a better understanding of cancer from other natives and the wording is so much easier to understand than all the medical language that providers use.*” The course objectives were to provide basic cancer information, introduce digital storytelling as a tool for promoting cancer awareness, develop computer literacy skills so patients can continue the use of the digital story platform, and assist cancer patients in using this tool to share their stories.

In terms of cancer education, the practitioners learned factual information about how cancer is conceptualized among the Alaska Native population. This has implications on how prevention practices, screening, diagnosis, treatment, pain management, end-of-life care, and caregiver and family support services are offered in communities. The results from this study found that digital storytelling as a tool, was culturally respectful, enhanced learning, increased the comfort in talking about cancer with patients and in communities (specifically as a way to open or begin the conversations), inspired behavioural changes, and was sharable within communities. In addition, the participants were able to reflect on their personal experiences and envisioned how they might apply their knowledge within their communities. Each course participant also created a personal and authentic digital story, a methodology increasingly embraced by Indigenous communities as a way to combine storytelling traditions with modern technology to promote both individual and community health. As a result of creating a personalized digital story, CHA/Ps reported feeling differently about cancer, noting an increase in cancer knowledge and comfort to talk about cancer with clients and family.

Daudt, H., d'Archangelo, M., & Duquette, D. (2018). Spiritual care training in healthcare: Does it really have an impact? *Palliative and Supportive Care*, 1–9.  
doi: 10.1017/S1478951517001134

Spiritual care is considered an integral part of palliative care however, people with advanced illnesses frequently report that their spiritual needs are not attended to by their medical care team. Many healthcare professionals recognize the importance of spirituality, especially within end-of-life care contexts, yet they feel underprepared to offer quality culturally and spiritually relevant care to their patients. This disconnect prompted the staff at the Victoria Hospice in Victoria, British Columbia to develop and pilot a caregiver education and spiritual information program. The education program (EDUC) advertises a nondenominational approach, which claims to respect the spiritual path of every person, regardless of religious affiliation, if any. The EDUC also attempts to integrate history, science-depth psychology, and spiritual insight with practical tools and clinically tested best practices.

This qualitative study analyzed the feedback of hospice staff and volunteers through in-depth interviews, regarding the impact of the EDUC spiritual care training program on their practices and the quality of care they provide. The results demonstrate that the program had a profound personal impact on attendees and contributed to a slight shift in practice patterns within the organization as a whole. Specifically, the EDUC increased the self-awareness of the attendees in terms of their own cultural and/or spiritual beliefs, increased their understanding and acceptance of other cultures, exposed them to diverse cultural/spiritual beliefs and practices, highlighted that self-care is a professional responsibility, provided new language, tools, and resources, and helped shift the conversation to one that is culturally and spiritually inclusive. This program allowed the staff to recognize that palliative experiences are cultural and spiritual, and that for many, this includes a reclamation of palliative spaces. It also means honouring individual's personal and cultural boundaries. A general agreement of all participants was that a systematic approach to spiritual care training that incorporates the concepts of workplace spirituality and sensitive practice, offers a useful framework for the development and implementation of spiritual care training, that could be used in other institutions.

Denis, M. K., & Washington, K. T. (2018). “Just let me go”: End-of-life planning among Ojibwe elders. *The Gerontologist*, 58, 300-307. doi:10.1093/geront/gnw151

The purpose of the study is to examine how the principles underpinning advance care planning are designed to promote person-centered end of life care and may differ greatly from the values and norms of many American Indian/Alaska Native (AI/AN) communities, contributing to low rates of advance care planning among AI/AN Elders. The goal of examining this tension between Western medical approaches and Indigenous models is to create more culturally appropriate approaches to planning for end of life care. Twenty tribal Elders living on a Great Lakes reservation participated in semi-structured, face-to-face interviews. The Elders were generally open to discussing the care they would want at end of life and expressed their wishes for a peaceful death. Many had already developed funeral and burial or cremation plans. In addition, several salient end of life concerns for the Elders emerged such as preserving their families, the community, and their cultural lifeways. Furthermore, this study examined how the lack of formal advance care planning within these communities did not necessarily mean individuals, families, and communities did not have or share plans with one another, or that people had an aversion to discussing their end of life preferences. In order to increase the use of advance care planning in tribal communities, it is important to acknowledge the spiritual and cultural significance of death and dying for many AI/AN individuals.

Duggleby, W., Kuchera, S., MacLeod, R., Holyoke, P., Scott, T., Holtslander, L.,...Chambers, T. (2015). Indigenous peoples' experiences at the end of life. *Palliative and Supportive Care*, 13, 1721–1733. doi: 10.1017/S147895151500070X

This metaanalysis explores the end of life experiences of Indigenous Peoples in Canada, Australia, New Zealand, and the United States. In the end, 2255 qualitative studies were reviewed and assessed against four inclusion criteria: a) studies on the experiences of Indigenous populations at the end of life; b) studies published in English from any country; c) studies using qualitative and mixed-methods designs; and d) studies published between 1993 and 2013. The results identified an overarching theme of “preparing the spirit” in several contexts such as viewing death as a transition to the next life, increasing the need to connect to family members and land, and healing and protecting the self and the spirit. This study also found very clear barriers within healthcare systems and current healthcare provider practices to “preparing the spirit” including facility rules regarding family visitation hours, number of people allowed in the room, and the inability to bring cultural or personal objects into the physical space.

Fruch, V., Monture, L., Prince, H., Kelley, M. L. (2016). Coming home to die: Six nations of the Grand River Territory develops community-based palliative care. *Journal of Indigenous Health*, 11. doi: 10.18357/jih111201615303

This article explores how a community-based, palliative care model was developed and implemented in six nations in the Grand River Territory region of Ontario. This model focuses on providing quality palliative home-care whenever possible, and incorporates traditional teachings. The model began through the creation of a Project Advisory Committee comprised of healthcare professionals and community members that lead the development process. Eventually, a *Palliative Shared Care Outreach Team* was created including First Nations healthcare

professionals and social workers, to develop services that were offered directly to patients. Through this work, the communities were able to increase the number of home deaths (a community-identified need), improve access to palliative care supports and education, better train local healthcare providers, and provide individual, caregiver, and family supports deeply rooted in traditional knowledge and practices. Finally, a resource booklet was created for the Six Nations Health Services Department to use to further its research and training initiatives. This research aims to enhance the understanding of how other Indigenous communities could incorporate palliative care within an Indigenous wellness framework that focuses on providing quality of life, to the end of life. It demonstrates that First Nations communities are fully capable and highlights their desire to create, implement, oversee, and evaluate their own palliative care services that are culturally responsive and community-driven. The largest challenges encountered during this project were federal and provincial jurisdiction issues regarding who pays for home-care services. This prevented services and programming from being seamlessly integrated into the community and led to difficulties between staff, as well as caregiver burnout.

Gebauer, S., Knox Morley, S., Haozous, E. A., Finlay, E., Camarata, C., Fahy, B.,...Marr, L. (2016). Palliative care for American Indians and Alaska Natives: A review of the literature. *Journal of Palliative Medicine*, 19. doi: 10.1089/jpm.2016.0201

This metanalysis examined the palliative care needs for American Indians and Alaska Natives (AI/AN). The purpose was to summarize what is currently known about end of life care in this population in hopes of improving the delivery of culturally sensitive care for this patient population and to highlight areas where increased study is needed. Only 10 articles met the original criteria for the research, indicating the paucity of data on palliative and end of life care for AI/AN patients and families. Specifically, this study called for care models to *move away* from a cultural competency framework that suggests that providers can “master” a checklist of characteristics associated with a group of people and *move toward* cultural humility, as an alternative framework for assessing culturally appropriate care. Cultural humility is a process in which providers engage in self-reflection and lifelong learning, so they become “flexible and humble enough to assess the cultural dimension of the experiences of each patient.” This approach is context-dependent and therefore, more capable of avoiding the pit-falls of the notion of capturing a pan-Indigenous experience that may programs encounter.

Another important theme was the importance of understanding and valuing the interrelationship between the physical and spiritual worlds when providing end of life care for AI/AN individuals. This may include patients not wanting to discuss their illnesses, using different language to conceptualize dying (i.e. death versus transitioning), refusing medical treatment due to beliefs, and/or requesting traditional or culturally-based treatments and care. For example, one AI patient refused a left lower extremity amputation, despite the lifesaving potential of the procedure. Through increased dialogue from a cultural humility standpoint, the medical team discovered that in her tradition, she could not go to the spirit world without her whole body. The team was then able to negotiate with the surgeon, pathologist, and hospital to ensure that her amputated leg could be returned to her postoperatively so that it could be buried on sacred land and able to make her final journey. Finally, the many ways in which families and caregivers should be included, consulted, respected, informed, and empowered, are also explored in this work.

Gifford, W., Thomas, R., Barton, G., Grandpierre, V., & Graham, I. D. (2018). Breaking the silence to improve cancer survivorship care for First Nations Peoples: A study protocol for an Indigenous knowledge translation strategy. *International Journal of Qualitative Methods*, 17, 1–6. doi: 10.1177/1609406918774133

Knowledge translation is a critical component in offering quality healthcare services to Indigenous People. Currently, there is a large knowledge-to-action gap in cancer survivorship care for Indigenous People, meaning that people are aware of the importance of cancer care, prevention, education, screening, and treatment but are unable to access the supports and services needed. Most approaches supporting cancer survivorship have not been culturally responsive or community-based. This study, however uses the concept of Indigenous knowledge translation (KT) to mobilize community-based knowledge about cancer survivorship into healthcare programs. The objectives of the program are to develop a holistic approach to cancer survivorship using community-based strategies, implement the approach and strategies, evaluate the outcomes and experiences of translating knowledge into health-care practices and community-based programs, and develop and disseminate a model of Indigenous knowledge translation to improve healthcare services.

This study found that conducting culturally appropriate Indigenous KT allows healthcare practitioners and communities to mobilize and translate knowledge of cancer survivorship needs into healthcare practices, approaches, and community-based programs and services. Here, Indigenous People are empowered and educated within their own communities and are able to have agency and control within the cancer care process. Specifically, the research team discusses how KT will lead to increased follow-up for screening and culturally appropriate psychosocial supports and services to improve health outcomes, cancer survival rates, and quality of life. Furthermore, the Indigenous KT process developed from this work is useful as a model for how KT could work in other communities within the cancer care context and/or to meet other emergent health needs.

Gott, M., Frey, R., Wiles, J., Rolleston, A., Teh, R., Moeke-Maxwell, T., & Kerse, N. (2017). End of life care preferences among people of advanced age. *BMC Palliative Care*, 16. doi: 10.1186/s12904-017-0258-0

It is critical to acknowledge that end of life preferences differ significantly among people and that there are no standard criteria that will fit all individuals' end of life support needs. This study focuses on the palliative perspectives and preferences of people in advanced age (over 80 years of age), particularly the preferences of older Indigenous People, including New Zealand Māori. Through the use of an interview-format questionnaire, researchers were able to determine that the preferences of people in advanced age both converged and diverged (based on culture and gender). For example, the top priority for both Māori and non-Māori participants at end of life was 'not being a burden to my family.' Having a home death was not a high priority for either group. In terms of differences, more female Māori participants wanted spiritual practices at end of life than male Māori participants and more male non-Māori participants wanted to be resuscitated than female non-Māori participants.

The results of this study confirm the importance of engaging in open dialogue with all individuals requiring palliative care services and not expecting the preferences, experiences, and wishes of all groups of people to be heterogenous including Indigenous People. In fact, many of the findings run counter to what is considered best practice in palliative care based on other groups examined. For example, having a home death was not one of the top three end of life priorities for the participants in this study however, that is not consistent with palliative care policies in most developed countries where place of death, and particularly home death, is a central concern. The top concern of these participants was not being a burden, something that has received little research or policy attention. Our results also indicate a need to pay attention to diversity in end of life preferences amongst people of advanced age, as well as the socio-cultural context within which preferences are formulated.

Green, A., Jerzmanowska, N., Green, M., & Lobb, E. (2018). 'Death is difficult in any language': A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. *Palliative Medicine*, 32, 1419-1427. doi: 10.1177/02692163187768

These researchers examined the experiences of palliative care health professionals when providing care for patients from culturally and linguistically diverse backgrounds. They conducted a series of focus groups with palliative care staff at a specialist palliative care service facility in Australia. The results found that when engaging with people from culturally and linguistically diverse backgrounds healthcare professionals must: 1) determine the rules of engagement around discussing diagnoses and prognoses; 2) navigate the challenge of language to patient understanding; 3) establish trust; 4) maintain the balance between patient safety and comfort care; 5) provide a quality end of life experience while privileging patient preferences. Specifically, they found that caring for patients at the end of life is difficult regardless of language and culture, that families play a key role in patient care, and that care strategies need to lessen the barriers experienced by culturally and linguistically diverse patients.

Hammond, C., Thomas, R., Gifford, W., Poudrier, J., Hamilton, R., Brooks, C.,... Warner, D. (2017). Cycles of silence: First Nations women overcoming social and historical barriers in supportive cancer care. *Psycho-Oncology*, 26, 191–198. doi: 10.1002/pon.4335

This study explores survivorship experiences of First Nations women with cancer and their caregivers. The research team conducted a participatory, arts-based study using several data collection methods (interviews, sharing sessions, photovoice, and other creative activities) with 58 participants (27 cancer survivors and 31 caregivers) across four communities in the provinces of British Columbia, Ontario, and Quebec. The results revealed that the women in these communities were suffering without support, leading to cycles of silence, and that community-based supports can disrupt these cycles. Specifically, these women identified that suffering without support leads to silencing and that Indigenous Peoples' silence around cancer is much more complex than has been typically conveyed in research. Often it is situated as a “cultural barrier” within global health research literature and as such, is framed as a static communicative-style characteristic of Indigenous cultures. It is assumed that Indigenous women have delayed diagnoses and therefore experience poorer outcomes because they lack knowledge, or are suspicious. However, the patients reported being given fewer opportunities to discuss their



experiences with cancer and limited availability of institutional and/or informal supports. The ‘silence as a cultural barrier’ narrative also suggests that Indigenous Peoples' fears of cancer are largely unfounded and are not in keeping with advancements in cancer survival rates.

Hordyk, S. R., Macdonald., M. E., & Brassard, P. (2017). End-of-life care in Nunavik, Quebec: Inuit experiences, current realities, and ways forward. *Journal of Palliative Medicine*, 20, 647-655. doi: 10.1089/jpm.2016.0256

This study examines the end of life care experiences of Inuit People in Nunavik, Quebec. The objective of the study is to better understand the factors shaping palliative care in Nunavik to support the development of a sustainable model of care. Interviews were conducted with community members, healthcare practitioners, and administrators across Nunavik and in Montreal at an affiliated tertiary care center. Several themes emerged regarding the unique perspectives of Inuit People as the Inuit participants recounted a rich oral history of caregiving traditions in which the sick and elderly were collectively cared for by family and clans who shared social responsibilities. Prior to colonial policies that forcibly relocated Inuit People into permanent settlement sites, the nomadic clans would reorganize themselves so that caregivers could temporarily settle to provide care for the sick and dying. According to one Elder interviewed, “*the Inuit practice (of caregiving) is very strong. If you care for that person and the passing of life, your heart is going to be peaceful. If you don’t care for the person, your heart is going to suffer.*”

The study also found that most patients wish to die at home and that during the final stages, their homes are filled with friends and family from all ages. These gatherings may include singing, cooking, talking, storytelling, playing games, praying, and partaking in daily household activities. A care model focusing on Inuit cultural practices respects these strong communal ways of being and allows family members to work alongside nurses and physicians to provide direct care. However, due to gaps in funding, access to equipment, infrastructure and housing issues, and socio-economic factors many family members often unable to provide end of life care in their homes. Care models need to acknowledge these barriers and seek ways to work with community members to overcome them.

Hordyk, S. R., Macdonald., M. E., & Brassard, P. (2016). *End-of-life care for Inuit living in Nunavik, Quebec*. Prepared for the Nunavik Regional Board of Health. Retrieved from [http://digitool.library.mcgill.ca/R/?func=dbin-jump-full&object\\_id=137708&local\\_base=GEN01-MCG02](http://digitool.library.mcgill.ca/R/?func=dbin-jump-full&object_id=137708&local_base=GEN01-MCG02)

This document outlines the aforementioned ethnographic research on the end of life care planning and policies for cancer patients, the chronically ill, and the elderly in Inuit communities. It identifies the existing strengths and resources within Inuit communities in Nunavik as they provided palliative care to community members. Several themes emerged including the trajectories of patient care, the contexts of care, the challenges and variables to care and recommendations to improve care. Some of the challenges identified were the need for communication between patients/families and caregivers, and the role of interpreters to ensure language barriers and challenges can be addressed. In addition, many recommendations were identified that participants believed would lead to a sustainable model for end of life care for

Nunavik patients. Several of these recommendations are linked to changes that are already underway in communities and institutions, while others had not yet been implemented. These included providing palliative care resources and training for nurses and physicians, support for existing bereavement care initiatives in communities, training and recognition of interpreters, home services and inpatient facilities, education in disease progression and end of life care, psychosocial support services for patients and families including existing cultural and spiritual practices, family education, and respite services.

Hospice of Waterloo Region. (2014). *Waterloo Wellington Aboriginal palliative care assessment final report*. Retrieved from <http://www.hospicewaterloo.ca/wp-content/uploads/2015/05/Final-Report-Aboriginal-Palliative-Care-Needs-Assessment.pdf>

This report presents the findings of a palliative care needs analysis of the Waterloo and Wellington region's Indigenous patients. It highlights the barriers, challenges, and the vision Indigenous communities have for palliative care supports and services for its members. This five-month research project conducted talking circles and individual conversations with Indigenous participants, non-Indigenous palliative care providers (including nurses, a doctor, a social worker), volunteers, and hospice staff in the Waterloo and Wellington region. An Elder's Advisory Group was also created to review existing programming and make recommendations. The Elders recommend that care facilities establish strong representation from the Indigenous community to provide direction at provincial and local levels to guide Indigenous health initiatives in the Waterloo Wellington region. They strongly recommend that the health authority establish a local Indigenous Advisory group. The Elder's Advisory group also recommended the establishment of additional resources for palliative home care services and supports, ensuring that Indigenous People living with a life-threatening illness remain in their home for as long as possible. This requires supports and services which must include financial, social, emotional, spiritual and cultural resources for Indigenous People wishing to be at home, and if possible, allows them to die at home.

They found there were gaps in: awareness about end of life care information, resources, and services within the Indigenous community; access to and utilization of Indigenous Elders and Healers in palliative care services; and access to traditional Medicine and ceremony in hospital settings. Traditional Medicine refers to any ceremony, substance, process, teaching, song, story or symbol that helps to restore balance in human beings and their communities. Furthermore, there was a lack of culturally informed and appropriate grief, loss, and bereavement supports for Indigenous People. All of these gaps make it difficult for healthcare providers and their Indigenous patients to have meaningful dialogue on palliative care and to make care plans that consider and respect cultural values and beliefs. All of the participants identified the importance of building end of life and healthcare services for Indigenous People living in the Waterloo Wellington region through wholistic Indigenous knowledge and practice. Participants identified the challenges faced by urban Indigenous People due to the lack of services and supports that integrate culture or have culturally relevant aspects including wholistic care, Elders and spiritual ceremonies.

Isaacson, M. J. (2018). Addressing palliative and end-of-life care needs with Native American elders. *International Journal of Palliative Nursing*, 24, 160-168.

Access to palliative and end-of-life care, including hospice care, is severely limited for Native Americans. This study explores the experiences with palliative and hospice care of Native American Elders as well as the perspectives of tribal health educators on a Northern Plains reservation in the United States. Through the use of a community-based, participatory approach including talking circles and semi-structured interviews, the participants shared information regarding the cultural relevance of palliative and hospice care in their tribal community. Specifically, monthly talking circles were held over a five-month period. The researchers found that there were gaps in offering cultural and spiritual care to Elders, and a need to improve advance directive education to Elders. Several challenges were also raised relating to infrastructure and jurisdictional issues between tribal governments and the federal Indian Health Service. The participants identified the need for greater cultural awareness and language education for health-care providers and advance directive education.

Kelley, M. K., Prince, H., Nadin, S., Brazil, K., Crow, M., Hanson, G.,...Smith, J. (2018). Developing palliative care programs in Indigenous communities using participatory action research: A Canadian application of the public health approach to palliative care. *Annals of Palliative Medicine*, 7, 2S52-S72. doi: 10.21037/apm.2018.03.06

The overarching goal of this study was to improve end-of-life care in four First Nations communities through developing end of life care programs and creating a culturally appropriate theory of change to guide program and policy development. This research provides an example of health promoting palliative care where end of life is viewed from a social, cultural, and community lens. Like many communities, the four diverse First Nations located in Ontario and Manitoba had pre-existing, well-established culturally-based social processes for supporting their community members experiencing dying, loss, grief and bereavement. These cultural traditions include providing psychological and spiritual support, and long-standing social processes for supporting people experiencing dying, loss, grief, and bereavement. What these communities did lack were formalized local palliative care programs and access to medical services, especially pain and symptom management. In fact, 87% of those community members surveyed preferred to receive their palliative care at home, if local services were available, and it was safe to do so. Another 81% of the respondents indicated they had cared for someone who was dying. Community members also reported that it was important for families to be involved in providing care for their loved one who is ill. Families that had cared for loved ones described feeling powerless and not adequately supported to bring a family member home.

This review identified three priorities for providing Indigenous palliative care: 1) focus on family-centeredness throughout the palliative care process; 2) build local capacity to provide more relevant and culturally appropriate palliative care resources and supports; and 3) create flexible, multi-sectoral partnerships to address the complexity of day-to-day needs for patients and families. The absence of social policy to address these issues and government jurisdictional issues have resulted in a service gap in First Nations communities. Furthermore, there are limited local health services, staff and resources, and a lack of training in end of life care. For example, on reserve, the federal government funds only basic home and community care services on weekdays and visiting physicians only come weekly or monthly, depending on the population

and location of the community. This means there are no health services available on evenings and weekends. Consequently, First Nations People frequently have to leave their communities to access services that are in geographically distant communities (i.e. larger urban centres) and often culturally unsafe due to differences in language, values, beliefs, and expectations.

Koski, J., Kelley, M. L., Nadin, S., Crow, M., Prince, H., Wiersma, E. C., & Mushquash, C. (2017). An analysis of journey mapping to create a palliative care pathway in a Canadian First Nations community: Implications for service integration and policy development. *Palliative Care: Research and Treatment*, 10, 1-16. doi: 10.1177/1178224217719441

The researchers in this study worked alongside members of the Naotkamegwaning First Nation, an Ojibway community, located in Northwestern Ontario. It describes and analyzes a unique *journey mapping process* to improve quality and access to palliative care at home by better integrating First Nations' health services and urban non-Indigenous health services. Journey mapping is inspired by "customer journey mapping" and "value stream mapping" processes used in the marketing and manufacturing industries. Customer journey maps help to understand customers' interactions with company touchpoints and identify areas for improvement, while value stream mapping has evolved from a manufacturing-based model of flow to a healthcare quality improvement strategy. In this research, the term journey mapping was adopted as it was more meaningful and acceptable to First Nations community participants and a new format was created that was more consistent with the guiding principles of Indigenous community-based research.

Four journey mapping workshops were conducted to create a care pathway which was implemented with 6 clients. A follow-up focus group, workshop, and healthcare provider surveys identified the perceived benefits as improved service integration, improved palliative care, relationship building, communication, and partnerships. It concluded that while the journey mapping process was a time commitment, it did increase communication, established partnerships and is a recommended way to create a care pathway. Specifically, all of the respondents (100%) agreed that implementing the journey mapping process had the following benefits: helped them to better understand the policies and procedures (mandates) of the other non-community health organizations involved, identified gaps and problems in end of life care service delivery, and was effective to create a care pathway for palliative care.

Lavoie, J. G. (2018). Medicare and the care of First Nations, Métis and Inuit. *Health Economics, Policy and Law*, 13, 280–298. doi: 10.1017/S1744133117000391

This article provides a general overview of the how the Canada Health Act 1984 (CHA), considered foundational to Canada's publicly funded healthcare system, shapes the ways in which healthcare is and is not adequately delivered to Indigenous People in Canada. The CHA determines how funding is transferred to the provinces and territories, impacting the services that Indigenous Peoples can access both on and off-reserve. In this way it is a decentralized healthcare system, managed independently by Canada's provincial and territorial governments, allowing for regional adaptations to fit varying degrees of urbanity, remoteness, and needs. This paper examines how the CHA is in need of an overhaul to make an explicit commitment to Indigenous health equity; clarify jurisdictional obligations; establish effective mechanisms for

addressing areas of jurisdictional dispute and/or confusion; and explicitly recognize First Nations and Inuit healthcare services as integral, yet distinct systems. Currently, the CHA has not adapted to address the evolving healthcare needs of Indigenous Peoples, the current healthcare gaps that exist, or the increasing movement toward Indigenous community autonomy and self-government. It fails to clarify jurisdictional issues, which leads to barriers to accessing necessary healthcare services resulting in poorer outcomes and premature mortality.

Lavoie, J. G., Kaufert, J., Browne, A. J., & O'Neil, J. (2016). Managing Matajoosh: Determinants of First Nations' cancer care decisions. *BMC Health Services Research*, 16. doi: 10.1186/s12913-016-1665-2

Matajoosh is an Ojibway word for 'cancer', which translates as "worm eating at your insides." Accessing cancer treatment requires First Nation Peoples living in rural and remote communities to either commute to receive care, or to relocate to an urban centre for the length or part of the treatment. Given the rising incidence of cancer within First Nation populations, there is a growing potential for negative health outcomes. This research study focused on the experience of First Nation Peoples' access to cancer care in Manitoba. The researchers conducted a policy analysis of documents and government websites and interviewed individuals who have experienced relocation, as well as family members, healthcare providers, and administrators. It focused on how palliative care is a possible end point in the continuum of care, once treatment options are exhausted, and that in Manitoba, palliative care and especially pain control, is often only available in urban centres, and to a limited extent, in regional centres. Knowing that some patients may opt not to pursue active cancer treatment but also may not wish to pursue palliative care off-reserve, there is a need to offer end of life care services on-reserve. Specifically, one family member shared how her father, who refused to relocate, lived at home with cancer for 5 years, despite a lack of access to services. Rural providers elaborated explaining that a patient's rationale for not pursuing palliative care was often linked to having to leave their community for extended periods of time suggesting that patients were afraid to die away from home.

McGahan, C. E., Linn, K., Guno, P., Johnson, H., Coldman, A. J., & Spinelli, J. J. (2017). Cancer in First Nations people living in British Columbia, Canada: An analysis of incidence and survival from 1993 to 2010. *Cancer Causes & Control*, 28, 1105-1116. doi: 10.1007/s10552-017-0950-7

This study explores the cancer incidence and survival rates in the First Nations population of British Columbia compared to the non-First Nations population. All new cancers diagnosed from 1993 to 2010 were assessed as well as age-standardized incidence rates. The results of this research yielded that incidents of lung cancer are increasing for First Nations and decreasing for non-First Nations, as are colorectal cancers. The incidence rates of almost all other cancers were generally similar or lower in First Nations populations overall and by categories of sex, age, and time period compared to non-First Nations residents. However, survival rates were generally lower for First Nations People, with differences evident for some cancer sites at one year following diagnosis. The study also revealed that First Nations People living in British Columbia face unique cancer issues compared to non-First Nations People.

McKenna, C. (2015). Members of remote Ontario First Nation appeal for cancer facility.

*Windspeaker*, 33, 22. Retrieved from <https://ammsa.com/publications/windspeaker/members-remote-ontario-first-nation-appeal-cancer-facility>

This news article tells the story of how members of Cat Lake First Nation, a northwestern Ontario community, have made a plea to the province for help for their community and other remote communities, to address concerns over the lack of cancer services and supports. This community has seen an increase in fatalities in recent years and community leaders have attributed this to a lack of access to proper screening and treatment. To date, Ontario does have an Aboriginal cancer strategy initiative through the Cancer Care Ontario organization but there is still a desperate need for on-reserve cancer services, especially for remote and geographically isolated communities. As one chief stated “(In remote communities), once you’re diagnosed with cancer, it’s a death sentence for you,” because of the lack of on-site services. Furthermore, this article addressed the increase in cancer rates on-reserve and linked them to possible on-reserve environmental concerns such as ground-water contamination. Cancer Care Ontario’s Aboriginal cancer control department recognizes the need for more action and research to be done in northern communities and is currently working on implementing a separate strategy to meet these needs.

Nadin, S., Crow, M., Prince, H., & Kelley, M. L. (2018). Wiisokotaatiwin: Development and evaluation of a community-based palliative care program in Naotkamegwaning First Nation. *Rural and Remote Health*, 18. <https://doi.org/10.22605/RRH4317>

This study examines how the lack of local on-site, palliative care in most First Nations communities, forces people to leave their culture, family, and community, to receive the care they need in distant hospitals or long-term care homes. This is due to several factors including jurisdictional issues as a result of policy gaps where neither federal nor provincial governments take responsibility for funding palliative care in First Nations communities. Furthermore, there is no Canadian program model for how different levels of government can collaborate to fund and deliver palliative care in First Nations communities. This article describes an innovative, community-based palliative care program (Wiisokotaatiwin) developed in rural Naotkamegwaning. It also serves as an evaluation aimed to: 1) document the program’s pilot implementation; 2) assess progress toward intended program outcomes; and 3) assess the perceived value of the program.

The program met all of the above objectives including a successful 10-month pilot, achievement of program-level outcomes, and progress toward system-level outcomes. All of the clients, families, and healthcare providers interviewed were satisfied with the program and perceived it to be meeting its objectives. The program model was also perceived to be transferrable to other First Nations communities. The results demonstrate how a rural First Nations community can build capacity and develop a palliative care program tailored to their unique culture and context that builds upon, and is integrated into existing services. The Wiisokotaatiwin Program allowed community members to receive their palliative care at home, improved client experience and enhanced service integration. This article provides a First Nations specific model for a palliative care program that overcomes jurisdictional issues at the local level, and a methodology for

developing and evaluating community-based palliative care programs in rural First Nations communities.

Pecanac, K. E., Repenshek, M, F., Tennenbaum, D., & Hammes, B. J. (2014). Respecting Choices© and advance directives in a diverse community. *Journal of Palliative Medicine*, 17. doi: 10.1089/jpm.2013.0047

Respecting Choices© is one of the most successful programs developed to improve the prevalence and utilization of advance directives in the United States. It was developed in La Crosse County, Wisconsin, in response to the need to provide individuals and families with resources for advanced care planning. However, the program has not been tested in racially or ethnically diverse communities and research has shown racial/ethnic minorities are less likely to have advance directives. The Respecting Choices© program includes: the development of patient education materials on advanced directives to be made available in the community; training of facilitators who are accessible at all healthcare organizations in the community; standardization of policies for maintaining, documenting, and using advanced care directives; and the use of performance improvement to enhance the outcome of each of these efforts. The objective of this study was to explore the prevalence and utilization of advance directives comparing Caucasians and racial and ethnic minorities before and after the Respecting Choices© was implemented in a diverse community. The prevalence of advanced care planning increased significantly for racial and ethnic minorities after the implementation of Respecting Choices in their communities (25.8% to 38.4%). While this increase demonstrates a positive change, the lack of racial and ethnic diversity in the community where the program was applied, is a significant limitation.

Peltier, C. M. (2015). *The lived experience of Anishinaabe people with cancer: A focus on Indigenous healing, western medicine, and minobimaadiziwin* (Doctoral dissertation). Laurentian University, Sudbury, ON. Retrieved from [https://zone.biblio.laurentian.ca/bitstream/10219/2879/1/Cindy%20Peltier\\_Thesis\\_Final\\_Version.pdf](https://zone.biblio.laurentian.ca/bitstream/10219/2879/1/Cindy%20Peltier_Thesis_Final_Version.pdf)

This inquiry examines the potential benefits and challenges of including Indigenous healing in cancer care. Using a participatory approach, Peltier investigated how the cancer experience was affected when Anishinaabe People included both Indigenous and Western medicine in treatment and, when they did not. It also examined how Indigenous healing assisted in achieving *Minobimaadiziwin*, an Anishinaabe understanding of health. Interviews were conducted with thirteen adults diagnosed with cancer from five Manitoulin First Nation communities. Seventeen key informant interviews were also conducted with those working from both Indigenous and Western health perspectives. Overall, the researcher found that the participants recognized that *Minobimaadiziwin* could not be realized with Western medicine alone, and must include Indigenous Healing/Traditional Medicine. This allows for the recognition of the spiritual component of life so that a person can approach *Minobimaadiziwin* despite the obstacle of cancer along their path. This is best facilitated by braiding the two types of healing: Western medicine and Indigenous Healing/Traditional Medicine.

Specifically, this study found that Western medicine and the use of medications in pain management, was useful so that people may use traditional approaches to focus on the spiritual, emotional, mental aspects of the self. For some individuals and families, the use of pain

medication can pose a dilemma where providing the pain medication impedes the person's ability to communicate with others. There is a fine line between relieving pain and maintaining the patient's awareness of their surroundings and ability to communicate. However, it also helped to prolong life to allow a person time to deal with unfinished business. The study also found that Western medicine needs to provide people with choices about their lives and allow them to go through the death process with less fear, which is an important part of *Minobimaadiziwin* in staying on that good path into the Spirit World. Finally, the study discusses how *Minobimaadiziwin* can and should be maintained in the transition from the end of physical life and beyond. Anishinaabe People refer to this part of the spirit journey as "getting ready to go home." According to one Elder interviewed: "*palliative care is a Western term. Our term is that they're getting ready to go home. That time that the person was getting ready to travel home was a time of celebration. It meant visiting. It meant sharing. It meant getting teachings and knowledge. It meant feasting together with that person who's getting ready to go home.*"

Prince H. (2018). Celebrating Indigenous communities' compassionate traditions. *Annals of Palliative Medicine*, 7(Suppl 1).doi: 10.21037/apm.2018.s005

This abstract outlines how Indigenous People live in compassionate communities as they have always recognized dying as a social experience. First Nations hold extensive traditional knowledge and have community-based practices to support the personal, familial, and community experiences surrounding end of life. However, western health systems were imposed and typically did not support these social and cultural practices at the end of life. One solution for reclaiming compassionate community traditions is for First Nations communities to develop their own palliative care programs so that people can receive care at home amongst their family, community, and culture. A recent research project "Improving End-of-Life Care in First Nations Communities" (EOLFN) funded by the Canadian Institutes of Health Research [2010–2015] was created in partnership with four First Nations communities to develop such programs. This model includes a community capacity development approach to support Indigenous models of care at end of life, that allows communities to develop their own care models. These models celebrate cultural capacity in their communities while enhancing medical palliative care services in a way that is respected and integrated with their community cultural practices. This demonstrates how communities can develop palliative care programs by building upon already existing community culture, values, and principles.

Russell, B., Fred, D. E., & Brown, C. (2018). Culturally safe end-of-life care for First Nations persons living on reserve. *Rural and Remote Health*, 18. doi: 10.22605/RRH4500

This study explores many aspects of end of life (EOL) care recognizing that it involves not just the final few days of a person's life but also living with a terminal illness over an extended period of time. Importantly, in addition to medical care and relief of physical suffering, it focuses on quality of life, honoring personal healthcare treatment decisions, supporting the family, and acknowledging psychological, cultural, and spiritual concerns for dying people and their families. The goal of this commentary is to raise rehabilitation therapists' awareness of the need for culturally safe EOL care services for First Nations persons who live on reserve, and to identify strategies to help resolve this unmet need. Three key strategies were identified: 1) educating healthcare providers; 2) delivering services using telehealth and social media to



increase accessibility; and 3) sharing information about resources and building community awareness.

Schill, K., & Caxaj, S. (2019). Cultural safety strategies for rural Indigenous palliative care: A scoping review. *BMC Palliative Care*, 18. doi: 10.1186/s12904-019-0404-y

This study identifies culturally safe approaches to palliative care, particularly for rural Indigenous clients. Schill and Caxaj conducted a review of all relevant peer-reviewed and grey literature pertaining to Indigenous palliative care in rural and small-town settings in Canada, United States, New Zealand, and Australia. An audit of all of the provinces indicates that as of 2013 only 4 provinces (Ontario, Quebec, British Columbia and Prince Edward Island) had provincial frameworks for the delivery of palliative care. Alberta publishing their provincial framework in 2014, but there are still several provinces and territories that lack a framework. At the national level, The Parliamentary Committee on Palliative and Compassionate Care (PCPCC) released a report noting that Canada still “falls far short of quality end-of-life care for all,” as evidenced by the statistics that show that only 16 to 30% of those who require palliative are actually receiving it. These gaps in care are especially prevalent in Indigenous communities, particularly those that are geographically isolated and lack on-site palliative services and supports. The PCPCC recommendations include: 1) strengthening capacity in palliative care by building on existing services; 2) strengthening home care services to improve palliative care options and to better support Indigenous Peoples living with chronic illness; 3) taking action to curb the relocation Elders experience at end of life and; 4) develop community-based models that facilitate recognition of the unique cultural values, traditions, and languages of Indigenous Peoples. People prefer to stay close to home when approaching end of life and benefit from a collectivist spirit that may be a key source of support for palliative clients. This indicates the need to build on the strengths and resources available in local communities, such as home care services, long-term care homes, and local hospice volunteers.

Three key challenges to offering palliative care at home or directly in Indigenous Peoples’ communities include: 1) staffing issues, particularly in regards to recruiting/retaining Indigenous healthcare workers; 2) institutional and cultural barriers, which include jurisdictional service gaps, lack of knowledge of local or culturally-relevant supports, rigid Western biomedical parameters for palliative care, and a lack of recognition of a history of colonization that increased the vulnerability of Indigenous seniors and; 3) interpersonal dynamics such as mistrust, mismatched expectations, poor communication or lack of a common language or understandings, stereotypes, and assumptions about Indigenous families. A consistent barrier to access for Indigenous populations stems from tensions between provincial and federal bodies, which has resulted in clients ‘falling through the cracks’ in seeking economic compensation or time-sensitive treatment. In order to offer culturally competent Indigenous palliative care services, several strategies need to be incorporated including: symbolic or small gestures; anticipating barriers to access; deferring to the client, family, and community members; and, collective decision making and family involvement. Culturally safe approaches contribute to institutional or organizational change and decolonized care. Strategies include: involvement of patient and family in service planning; reflection about individual and systemic racism; community ownership of services, and recognizing distinct worldviews that shape care.

Shahid, S., Taylor, E. V., Cheetham, S., Woods, J. A., Aoun, S. M., & Thompson, S. C. (2018). Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: A comprehensive review. *BMC Palliative Care*, 17. doi: 10.1186/s12904-018-0325-1

The objective of this study was to review the relevant research outlining how palliative care service delivery for Indigenous Peoples in Australia, Canada, New Zealand, and the United States is being delivered, and highlight possible areas for improvement. They adopted the Agency for Clinical Innovation's definition of Model of Care (MOC), which is broadly defined as 'the way health services are delivered.' It outlines best practice care and services for a person as they progress through the stages of any condition, injury, or event. In this case, end of life care. It aims to ensure people get the right care, at the right time, by the right team, and in the right place. The results of this review demonstrate that Indigenous People prefer to die close to or at home; wish to involve family; and see the inclusion of cultural practices as essential. Several barriers identified included: inaccessibility, affordability, lack of awareness of services, perceptions of palliative care, and inappropriate services (Shahid, 2018). Some of the best practice models that attempted to address these gaps adopting the following strategies: community engagement and ownership; flexibility in approach; continuing education and training; a whole-of-service approach; and local partnerships among multiple agencies. When these models were utilized they found that there was better engagement with Indigenous clients, an increase in number of palliative care patients, improved outcomes, and understanding about palliative care by patients and their families.

Sinclair, C., Williams, G., Knight, A., & Auret, K. (2014). A public health approach to promoting advance care planning to Aboriginal people in regional communities. *Australian Journal of Rural Health*, 22, 23–28. doi: 10.1111/ajr.12079

This study explored how the Noongar People of Australia perceive advanced care planning. Advanced care planning is a process of identifying and sharing life values and goals, to ensure medical treatment is concordant with a patient's wishes, if they are unable to make or communicate decisions at the time. This study also focused on the need to develop culturally appropriate advanced care planning information resources for use in community and hospital settings. By combining active health promotion with interviews and group discussions, the researchers gained participant feedback from the members of six rural Indigenous communities across the Great Southern region of Western Australia. Community members received information about advanced care plans at community events or home visits, from an Aboriginal health worker and palliative care researcher. Semi-structured interviews and group discussions were then conducted and the research team was able to reflect on these community events and the qualitative feedback. The results indicate that there are several key themes impacting the perceptions of advanced care planning including: cultural approaches to dying; importance of family and kin; and appropriate communication. The participants were satisfied with the information resource and method of community engagement.

Southwest Ontario Aboriginal Health Access Centre. (2016). *Indigenous hospice palliative care planning: Readiness assessment report*. Retrieved from <http://soahac.on.ca/wp-content/uploads/2015/01/Final-V7-SOAHAC-Palliative-Care-Report--July-31-16.pdf>

The Aboriginal Health Committee of the South West Ontario Local Health Integration Network (LHIN) is developing an Aboriginal Hospice Palliative Care planning project to enhance and support the development of an Indigenous informed approach to address the Hospice Palliative Care and End of Life care for Aboriginal and First Nations communities located within the South West LHIN. This research was conducted with more than 25 key informants and two focus groups to address the needs of Indigenous Peoples across Canada who are living with advanced, progressive, chronic, and terminal illnesses. They found most Indigenous Peoples wish to receive palliative care at home or in their community, where they are surrounded by family, friends, culture and spirituality. However, the majority of Indigenous Peoples currently die in urban hospitals or long-term care homes away from their home communities and families. This report also acknowledged that the hospital is the most expensive setting of care and is an inefficient use of health services, as it is estimated to cost over 40% more, than providing care in a hospital-based palliative-care unit. This is more than double the cost of providing care in a hospice bed and over 10 times more than providing at-home care.

The findings also revealed that the diagnostic process for palliative care is flawed, as it does not occur early enough and potential patients must satisfy rigid requirements in order to access care. Patients and their families are extremely unfamiliar with the palliative process and all the agencies involved. There is a lack of education surrounding what to expect, who to call for support, or the inherent challenges in becoming a caregiver to a family member. Furthermore, there is a lack of staff to meet the demands of palliative care to Indigenous Peoples. Staff are not able to meet the needs of the communities, lack palliative care training, and are unable to create good working relationships with family members and care providers. There is also a significant lack of cultural safety for Indigenous palliative care patients. One of the primary recommendations of this report is that the South West LHIN fund an Indigenous Hospice Palliative Care inter-professional team composed of: registered nurses, nurse practitioners, a social worker (with experience in grief and bereavement), a mental health worker, a traditional healer, personal support workers (PSWs), occupational therapists/physiotherapists and physicians. Another key recommendation is that additional Aboriginal Patient Navigators be hired to provide community outreach and case management through the Indigenous Hospice Palliative Care program. Finally, all care models need to establish early relationships with patients diagnosed with chronic diseases, improve advanced care planning education, and ensure that the Indigenous Hospice Palliative Care Model screens patients *into* the program, rather than screening them *out*.

Williams, L., Gott, M., Moeke-Maxwell, T., Black, S., Kothari, S., Pearson, S.,... Hansen, W. (2017). Can digital stories go where palliative care research has never gone before? A descriptive qualitative study exploring the application of an emerging public health research method in an Indigenous palliative care context. *BMC Palliative Care*, 16. doi: 10.1186/s12904-017-0216-x

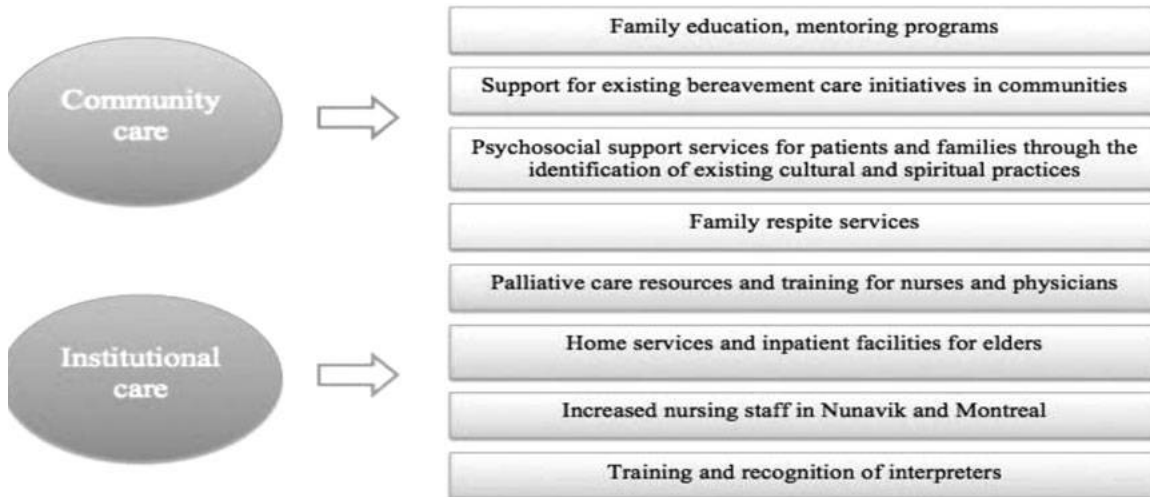
There is no one-size-fits-all solution to accommodate all palliative care needs. In fact, while there is a need for a national strategy to offer greater palliative supports to all individuals, there is also a need for a flexible care model that recognizes the unique barriers and needs of Indigenous Peoples. This study examined the use of digital storytelling (DST) as a potential method for doing community-based participatory research in Maori communities regarding palliative care.

Digital stories are short, first-person videos that tell a story of great significance to the creator. Specifically, this study examined Māori participants' views on DST's usefulness, from an Indigenous perspective, as a research method within the discipline of palliative care. The digital storytelling method was adapted to include Māori cultural protocols. The study followed the principles of Kaupapa Māori research including: 1) giving full recognition to Māori cultural values and systems; 2) challenging dominant Pakeha [western] constructions of research; 3) determining the assumptions, values, key ideas, and priorities of research; 4) ensuring that Māori maintain conceptual, methodological, and interpretive control over research; and 5) following Māori protocol during research processes. There were two main themes identified during analyses: 1) digital storytelling is useful as a research method for Māori reporting on end of life caregiving; and 2) there are issues that hindered this process. Additional subthemes identified focused on: recruitment, the pōwhiri process, (Māori formal welcome of visitors) and technology. The study found that digital storytelling is an emerging method useful for exploring Indigenous palliative care issues. It aligns with a Health Promoting Palliative Care approach that centres on research in Indigenous communities because it helps meet the need for diverse approaches to involve underrepresented groups.

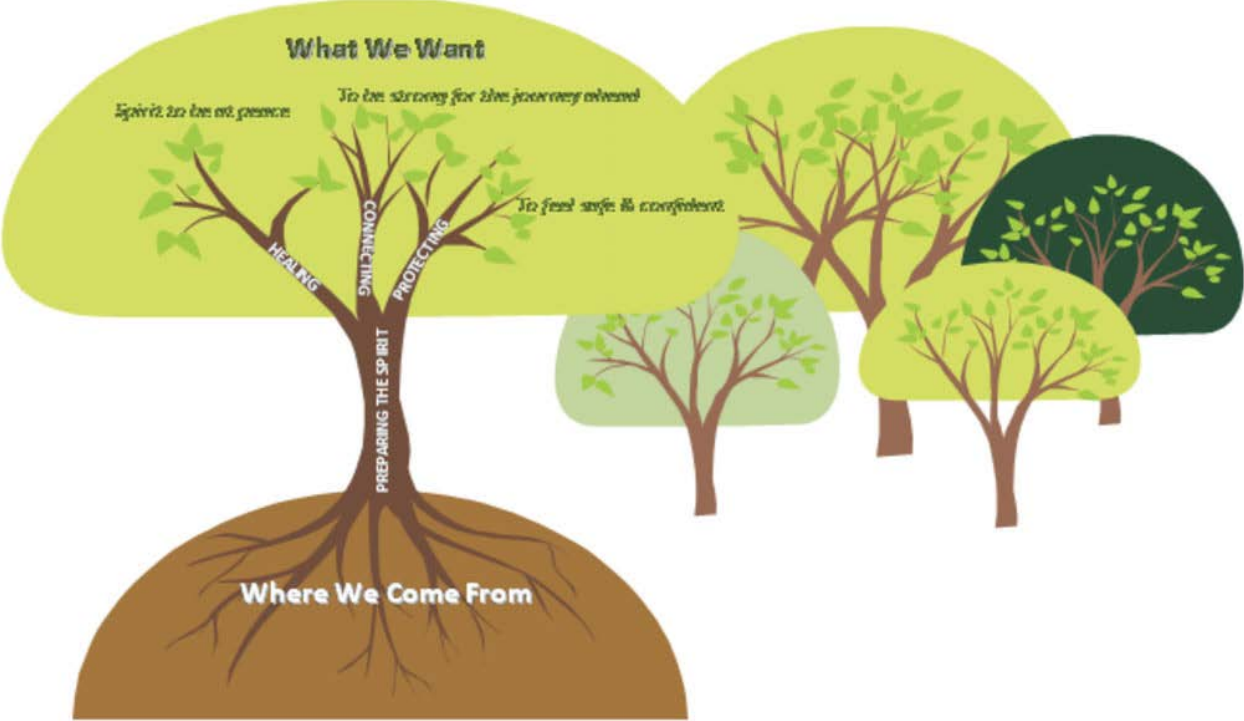
Woods, J. A., Johnson, C. E., Ngo, H. T., Katzenellenbogen, J. M., Murray, K., & Thompson, S. C. (2018). Delay in commencement of palliative care service episodes provided to Indigenous and non-Indigenous patients: Cross-sectional analysis of an Australian multi-jurisdictional dataset. *BMC Palliative Care*, 17. doi: 10.1186/s12904-018-0380-7

This study examines whether the benchmark for timely commencement of palliative care episodes are being met for Indigenous Australians in participating services. The established benchmark is an occurrence of delay greater than one day after being designated 'ready for care' in less than 10% of the instances of designation. The Palliative Care Outcomes Collaboration collects Australia-wide health service data on patient care and has established performance benchmarks for specialist palliative care services. Using multi-jurisdictional Palliative Care Outcomes Collaboration data, this cross-sectional analytical study investigated all episodes of care provided to both Indigenous and non-Indigenous patients over 18 years of age in hospital and community settings over a two-year period. The study found that the benchmark was met for both Indigenous and non-Indigenous patients (delays in 8.3% and 8.4% episodes respectively). However, the likelihood of delay was modestly higher in episodes provided to Indigenous than non-Indigenous patients. Furthermore, excess delays among Indigenous patients were more common for episodes in patients aged under the age of 65 years, and among those residing in regional areas within the country.

## Appendix B: Participant-Identified important elements for end of life care programming for Inuit People in Nunavik



**Appendix C: A Schematic Diagram Conceptualizing the Process of Preparing the Spirit**



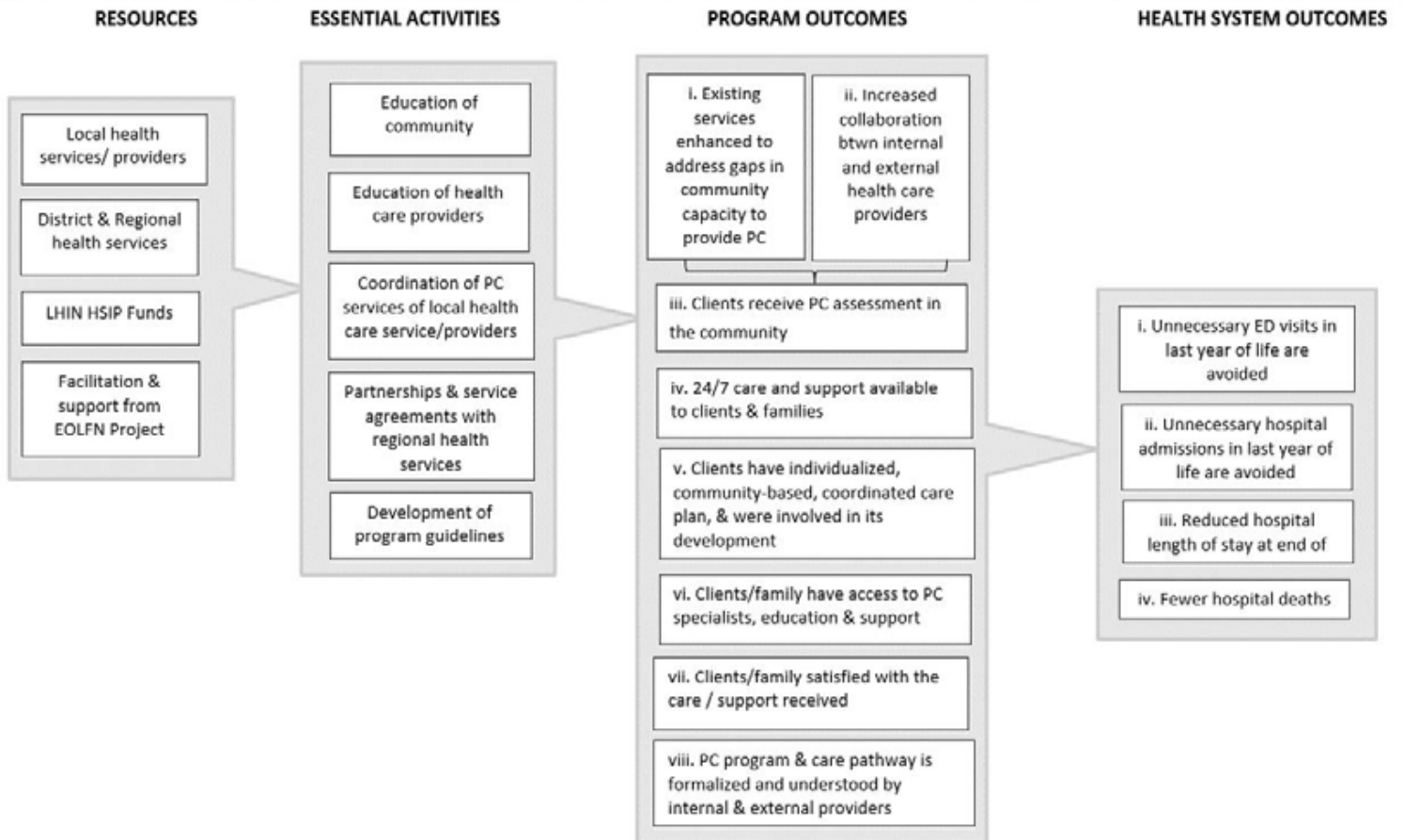
**Appendix D: The 9-stage Wiisokotaatiwin Program Care Pathway**



## Appendix E: The Wiisokotaatiwin Program Logic Model

**AIM:** To enhance / integrate existing services so that people living in Naotkamegwaning have the option to receive palliative care at home.

**Targets:** Naotkamegwaning First Nation community members who have a chronic/terminal illness and are in the last year of life & their families.





# Appendix F: A Collective Story of Cancer and Minobimaadiziwin

