Beginning the journey into the spirit world:

First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

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1. Giving of thanks (acknowledgements)

The Canadian Partnership Against Cancer (the Partnership) is committed to working with First Nations, Inuit and Métis Peoples to support the implementation of distinctions-based, self-determined priorities relevant to cancer care.

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada focuses on the challenges and resiliencies of accessing timely and culturally congruent palliative and end-of-life care for First Nations, Inuit and Métis Peoples.

Production of *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* has been made possible through financial support from Health Canada.

Furthermore, knowledge shared in this report was primarily based on Health Canada's 2020 C*omfort/palliative & EOL care for Indigenous Peoples in Canada: A comprehensive literature review.*

The Partnership gives thanks to the following people who were instrumental in developing knowledge products for this project.

Turtle Island Consulting Services Inc. Project Team

NAME	HERITAGE
Cara Bablitz, BSc, MD, CCFP (PC)	Métis Nation of Alberta
Don Caverley, MSW, LTCOM	Algonquin/Irish; Whitney and Area Algonquins
Natasha Caverley, PhD, CCC	Algonquin/Jamaican/Irish; Whitney and Area Algonquins
Tanya Gadsby, BFA	Māori/Ukrainian/Scottish
Tom Spetter, Visual Arts (Dipl)	Tla-o-qui-aht First Nation
Madeline Walker, PhD	German/English/Mixed European

The Partnership

NAME	HERITAGE
Deborah Dudgeon, MD, FRCPC	Scottish and English
Meaghan Hume, BA, MA	Mixed European
Valerie Kearney, BSc, PMP	European-Canadian
Alice Muirhead, BHSc, MHA	European; English and Scottish
Raquel Shaw Moxam, BHSc, MHA	Jamaican; Canadian

Peer Reviewers

NAME	HERITAGE
Anonymous Reviewers	
Marygalak Ashoona Bergin, BA (Psychology)	Inuk
Shelly Cory, MA	English/Irish/Scottish/French-Canadian
Alexander Kmet, MD, CCFP (FPA) (PC)	Métis Nation of Alberta
Laura McCormick, PSW	Northern European
Sherry Metcalfe	Inuk; family from Nain, Nunatsiavut
Jeffrey Moat, B. Comm, CM	Scottish-Canadian
Amy Montour, BScN, MSc, MD, CCFP (PC)	Haudenosaunee, Six Nations of the Grand River Territory
Tanya Nancarrow, MSc	Cornish/Scottish/Irish
Sophie Pamak, RN, CCHN(C)	Inuk
Elder Ella Paul	Mi'kmaw
Chrystal Toop, RSSW	Anishinaabekwe, Pikwakanagan First Nation
Elyse Tratt	Canadian of French and Unknown Heritage
Lisa Vaughn, RN, MN	Métis Nation of Alberta
Erica Williams	Gitxsan Nation

The Partnership also extends gratitude to Indigenous and non-Indigenous health-care organizations; First Nations, Inuit and Métis Elders, Knowledge Carriers; and community health professionals and researchers who have and continue to be committed to collaboration and engagement alongside our organization on the topic of palliative and end-of-life care. The Partnership appreciates their ongoing commitment to advancing timely, accessible and culturally congruent palliative and end-of-life care strategies and resources across Canada. Thanks for sharing stories, experiences and wisdom with us.

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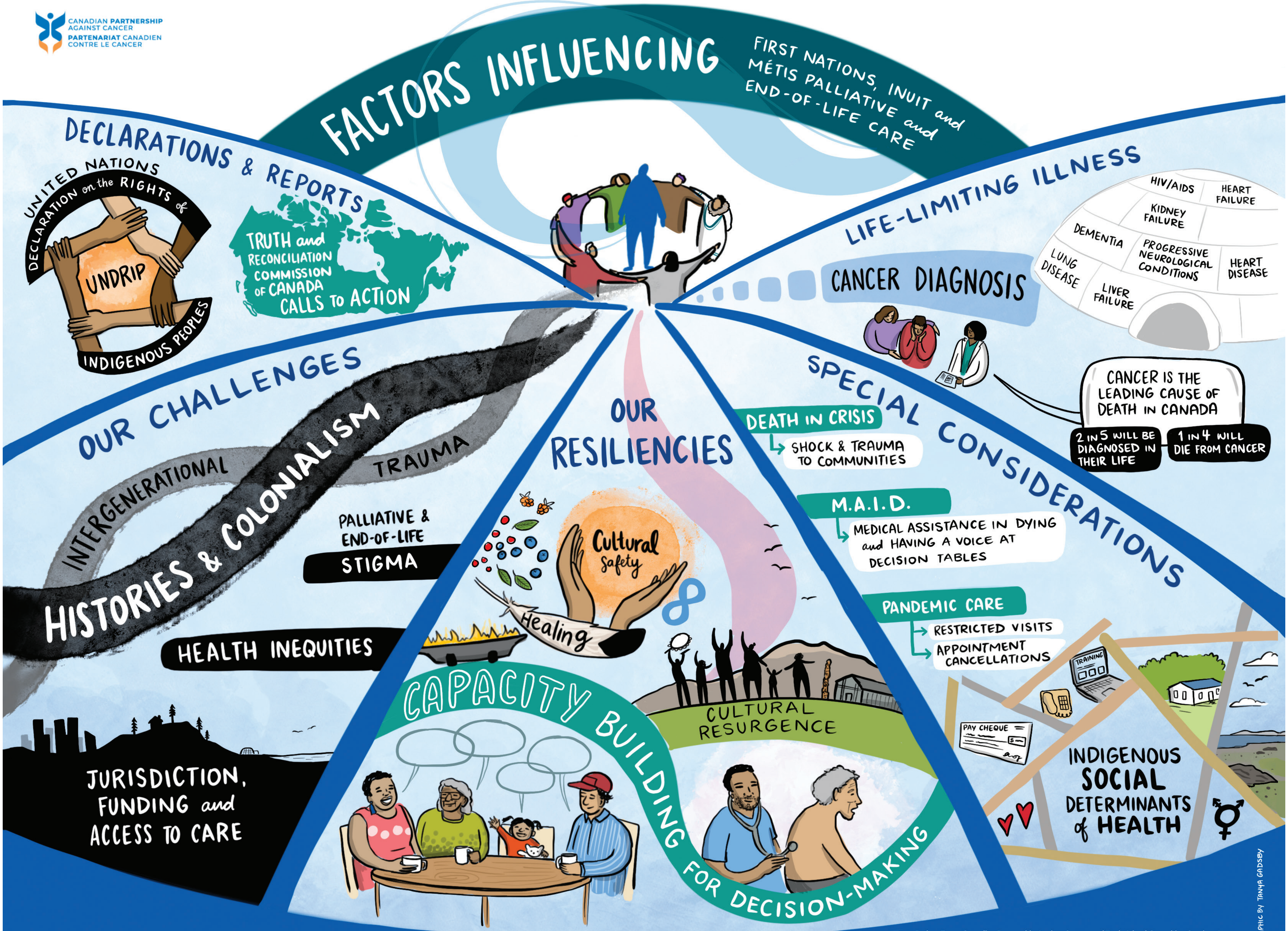

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Peer Reviewers: Anonymous Reviewers, Marygalak Ashoona Bergin, Alexander Kmet, Laura McCormick, Sherry Metcalfe, Jeffrey Moat, Amy Montour, Tanya Nancarrow, Sophie Pamak, Elder Ella Paul, Chrystal Toop, Elyse Tratt, Lisa Vaughn and Erica Williams

2. Overview

Background

The Canadian Partnership Against Cancer (the Partnership) is the steward of the Canadian Strategy for Cancer Control (the Strategy). The Partnership works to implement the Strategy to reduce the burden of cancer on Canadians.

The Partnership is committed to advancing truth and reconciliation which includes achieving health equity for First Nations, Inuit and Métis Peoples. As a result, the Partnership has been working with partners from across what is now called Canada to further actions on cancer care priorities expressed by First Nations, Inuit and Métis Peoples, their families and communities.

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada creates a culturally safer[1] space to amplify First Nations, Inuit and Métis voices on

(1) factors that influence First Nations, Inuit and Métis palliative and end-of-life care; and

(2) promising practices in First Nations, Inuit and Métis palliative and end-of-life care.

Specifically, this report

- **summarizes factors contributing to First Nations, Inuit and Métis palliative and end-of-life care experiences.**
- **identifies areas for action in palliative and end-of-life care based on priorities, gaps, challenges and needs expressed by First Nations, Inuit and Métis Peoples and communities; and**
- **is strengths-based in identifying innovative and Indigenous community-based models of care and person-centred approaches to palliative and end-of-life care promising practices, resources and strategies.**

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[1] Although comparative adjectives (such as “safer”) are generally used with “than” plus the thing being compared (e.g., this report is longer than that report), Indigenous palliative care leaders advise us that care based on the biomedical approach can never be safe; it can only be “safer.” Honouring this perspective, we have chosen to use the grammatical form: “safer” with no comparative.

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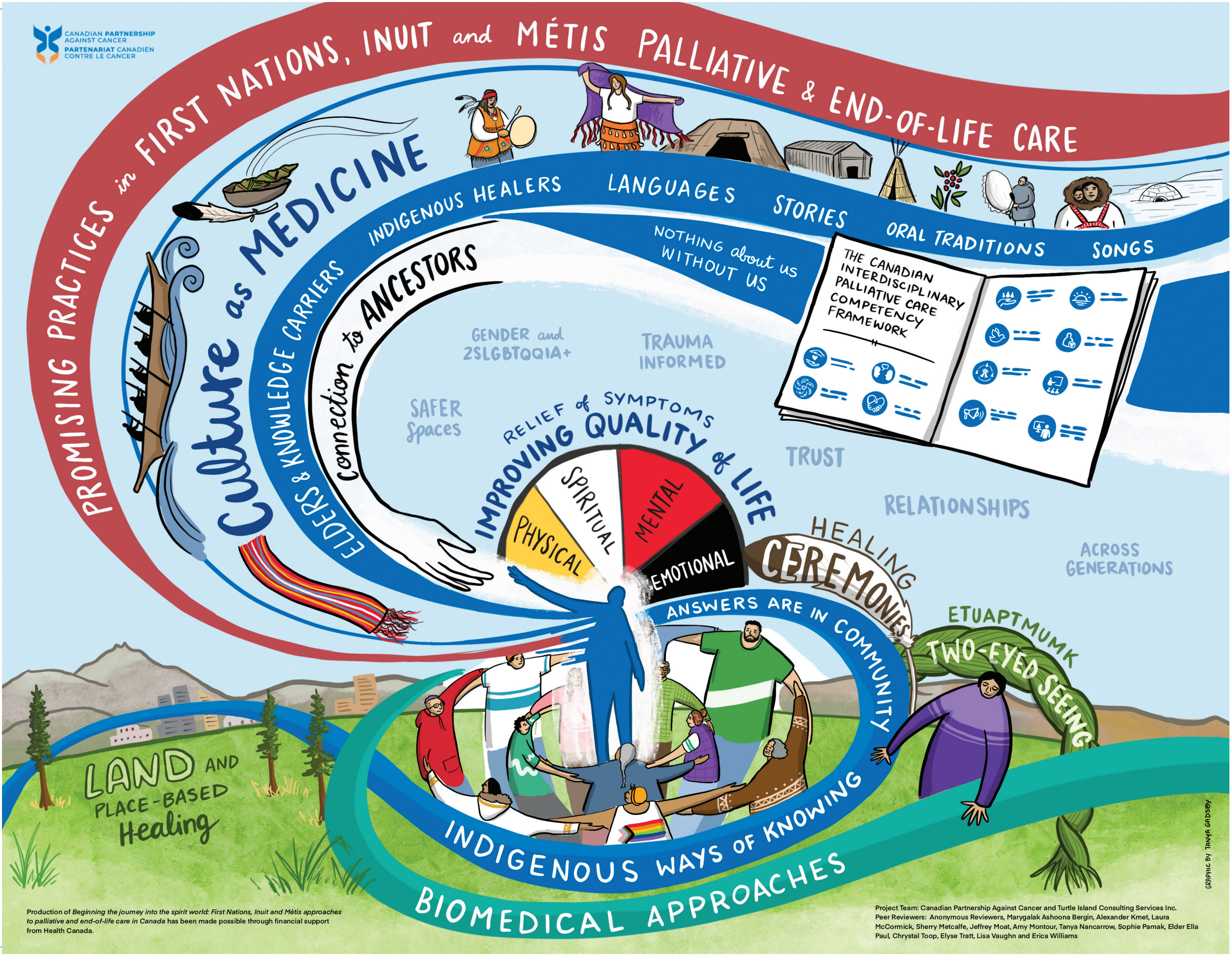

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Indigenous perspectives and considerations on palliative and end-of-life care create pathways towards truth and reconciliation. These pathways enable topics such as identity (loss, healing and reconnection), government laws and policies and the intergenerational effects of these colonial events to be recognized in relation to access to health care and related services and supports for First Nations, Inuit and Métis Peoples, their families and communities. As such, this report is informed by the *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)* and the *Truth and Reconciliation Commission (TRC) of Canada Calls to Action.*

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada is a foundational reference document for readers (health-care providers and professionals, service providers, orders of government and educators) and the Partnership to guide the development and implementation of strategies, programs and resources—supporting the delivery of high-quality culturally congruent palliative and end-of-life care, specific to the priorities and needs of First Nations, Inuit and Métis Peoples, their families and communities.

In particular, knowledge shared in this report can aid readers to adapt, scale and reference strategies, programs and resources that support Indigenous approaches to palliative and end-of-life care.

What are palliative care and end-of-life care?

- *Palliative care* is a process from diagnosis to end-of-life in relieving symptoms (pain and discomfort) and improving the quality of life for people with life-limiting illnesses (for example, cancer, dementia, heart disease, heart failure, HIV/AIDS, kidney failure, liver failure, lung disease, progressive neurological conditions). Palliative care includes physical, emotional, mental and spiritual support and focuses on the whole person and their families. For some First Nations, Inuit and Métis Peoples, families and communities, the term *palliative care* means *comfort care.*[2]
- *End-of-life* care focuses on increasing care and meeting the goals of people within their last hours, days, weeks or months of life. End-of-life care includes supporting their families through the life-limiting illness and after death and is part of palliative care.

Indigenous perspectives and considerations on palliative and end-of-life care

Indigenous Peoples are the fastest growing population in Canada. There is much diversity among First Nations, Inuit and Métis Peoples and communities in languages, lifestyles and teachings. Every Indigenous community across Canada is unique.

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[2] Comfort care provides necessary cultural contexts that acknowledge the role of values, identities, families and communities.

For many First Nations, Inuit and Métis Peoples, their families and communities, dying and death are not just about biomedical and physical processes. It is about an individual's transition to the spirit world—a social and spiritual event to be honoured and celebrated as a collective.

Many factors influence palliative and end-of-life care for Indigenous Peoples.[3, 4, 5] Some of these factors are

- **historical factors**, for example, history of colonization, intergenerational trauma, health inequities and stigma associated with life-limiting illnesses, dying and death;
- **jurisdictional factors**, for example, access to palliative and end-of-life care based on health-care jurisdiction and funding;
- **cross-cultural factors**, for example, cultural resiliency and resurgence; connection or reconnection to land, people, family, place, languages and Indigenous spirituality;
- **capacity building factors**, for example, development of knowledge, skills and abilities to participate in any or all aspects of decision-making in communities, regions, provinces/territories and the country as a whole; includes program planning and development to implementation and evaluation intended to enhance holistic palliative and end-of-life care; and
- **resource factors**, for example, access to the basic needs in life, high-quality health services, resources and supports.

Special considerations in Indigenous approaches to palliative and end-of-life care include Indigenous social determinants of health, medical assistance in dying, pandemic care and death in crisis.

We cannot fully recognize the health inequities for Indigenous Peoples in Canada without understanding how these factors have shaped and continue to shape relationships between institutions such as the health-care system and Indigenous Peoples and their communities. Health inequities, the historical effects of colonization and the residential school system in Canada are interrelated. When groups of individuals are oppressed and marginalized by state policies, laws and organizational systems by devaluing their ways of being and knowing, intergenerational trauma results which disrupts First Nations, Inuit and Métis cultures, languages, values, practices and histories.[6]

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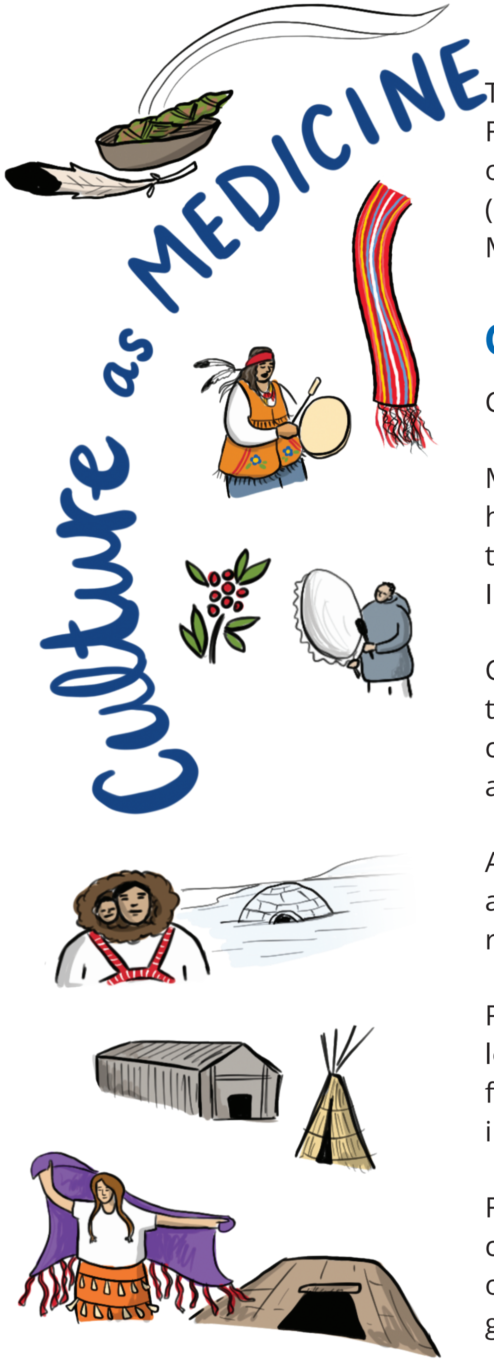
[3] Caxaj CS, Schill K, Janke R. Priorities and challenges for a palliative approach to care for rural Indigenous populations: a scoping review. Health & Social Care in the Community. 2018;26(3):e329—e336.

[4] http://www.cfp.ca/content/cfp/55/4/394.full.pdf

[5] Lemchuk-Favel L. The provision of palliative end-of-life care services in First Nations and Inuit communities. FAV COM; 2016, January.

[6] Johnston G, Vukic A, Parker S. Cultural understanding in the provision of supportive and palliative care: perspectives in relation to an Indigenous population. BMJ Supportive & Palliative Care. 2012;3:61–68.



To support cultural safety, it is important for allies (individuals, groups and organizations working with and alongside First Nations, Inuit and Métis Peoples) to have access to timely, relevant and culturally congruent palliative and end-of-life care strategies, promising practices and resources. It is also beneficial for allies to enhance their competencies (knowledge, skills and abilities), understanding of and interpersonal communications with First Nations, Inuit and Métis Peoples living with life-limiting illnesses, their families and communities.

Culture as medicine

Culture is a complex concept that refers to many aspects of living and being in the world.

Many First Nations, Inuit and Métis communities understand that a way to enhance individual, family and community healing and helping is through culturally congruent practices. When culture is a core component to healing and helping, there are opportunities for programs, policies and broader strategies to honour relationships to land, people and place; Indigenous spirituality and connections with our ancestors; and the role of families, friends and communities.

Culture as medicine recognizes the value of relationships in First Nations, Inuit and Métis communities' cultures and traditions. Indigenous approaches to healing and helping are often linked to land and place through songs, stories, ceremonies, language and writing. As such, land and place are often important dimensions of cultural identity, healing and helping (physical, mental, emotional and spiritual dimensions) for many Indigenous Peoples across Canada.

Also, strengths and ways of knowing are present in First Nations, Inuit and Métis communities in the form of Elders and Knowledge Carriers, Indigenous healers and helpers, community leaders, families and friends who support relational healing and helping.

Relational healing and helping practices in palliative and end-of-life care facilitate healthy ways to experience grief, loss and bereavement. These practices help people and groups to develop a greater sense of connectedness to self, families, friends, community members, communities (as a whole) and Mother Earth, each of which influences how individuals and groups can understand illness, dying, death and loss.

First Nations, Inuit and Métis cultures support resiliency in terms of the ability of people, their families and communities to flourish and adapt to situations and/or environments with minimal negative effects during hardships or crises and/or after a change. From a healing and helping perspective, resilience emphasizes a person's and/or group's ability to effectively draw on strengths and capabilities rather than focus on weaknesses or pathologies.[7, 8]

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[7] Duran E. Healing the soul wound: counseling with American Indians and Other Native Peoples. New York (NY): Teachers College Press; 2006.

[8] Duran E, Duran B. Native American postcolonial psychology. Albany (NY): State University of New York; 1995.

Braiding Indigenous ways of knowing and biomedical approaches in palliative and end-of-life care

Braiding (or harmonizing) Indigenous and non-Indigenous ways of knowing can be used in a way that is mutually respectful and reciprocal. In this context, braiding palliative and end-of-life care can include

- Etuaptmumk/two-eyed seeing,
- care across the generations,
- gender- and 2SLGBTQQIA+[9] -informed care,
- trauma-informed care,
- resilience-informed care, and
- relationships and allyship.

Palliative care competencies and Indigenous promising practices

Working with partners across Canada, including the Palliative and End-of-life Care National Network and Health Canada, the Partnership developed *The Canadian Interdisciplinary Palliative Care Competency Framework* in response to the *Action Plan on Palliative Care* (2019)[10], which called for the development of a pan-Canadian, interdisciplinary palliative care competency framework that documents essential skills, knowledge and abilities for health-care workers.

The Canadian Interdisciplinary Palliative Care Competency Framework outlines a clear and common vision of the minimum standards that people (for example, caregivers, health-care providers) need to demonstrate to deliver high-quality, safe and ethical palliative and end-of-life care programs and services in Canada. There are 12 national palliative and end-of-life care competencies in Canada:

1. Principles of palliative approach to care
2. Cultural safety and humility
3. Communication
4. Optimizing comfort and quality of life
5. Care planning and collaborative practice
6. Last days and hours
7. Loss, grief and bereavement
8. Self-care
9. Professional and ethical practice
10. Education, evaluation, quality improvement and research
11. Advocacy
12. Virtual care

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[9] 2SLGBTQQIA+ refers to two-spirit, lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual and other sexually and gender diverse people.

[10] Health Canada. Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada. Ottawa, ON: Health Canada; 2019

For more information about the palliative care competency framework, visit https://www.partnershipagainstcancer.ca/topics/palliative-care-competency-framework/background.

To meet the current and future needs in palliative and end-of-life care for First Nations, Inuit and Métis Peoples with life-limiting illnesses, their families and communities, it is important to have a set of nationally-recognized competencies and accompanying promising practices and support tools to recruit, develop and retain a skilled group of helpers (in particular, Indigenous skilled helpers) using Indigenous approaches in palliative and end-of-life care.

These above competencies consist of knowledge, skills and abilities that are considered necessary for helper effectiveness in palliative and end-of-life care which are integral to the learning and development in this important health-care area.

Further engagement with First Nations, Inuit and Métis Peoples, governments, communities and organizations is needed to (1) identify gaps and opportunities in service delivery and (2) inform the development of Indigenous core competencies in palliative and end-of-life care.

Conclusion

As Murray Sinclair[11] stated, “The road we travel is equal in importance to the destination we seek. There are no shortcuts. When it comes to truth and reconciliation we are forced to go the distance.”[12]

As a framework for reconciliation, the implementation of the *United Nations Declaration on the Rights of Indigenous Peoples* and the *Truth and Reconciliation Commission of Canada Calls to Action* with Aboriginal title and rights case law positions First Nations, Inuit and Métis Peoples with opportunities to amplify their voices in advocating for and advancing Indigenous approaches to palliative and end-of-life care programs and services across Canada.

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada is intended for readers

- who are interested in developing palliative and end-of-life care programs, resources and strategies specific to the priorities and needs of First Nations, Inuit and Métis Peoples, their families and communities;
- who are interested in applying for funding available through the Partnership on specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care; and
- who are engaged in or would like to engage in Indigenous approaches to palliative and end-of-life care.

The Partnership will also use this report as a main reference document when funding initiatives to ensure alignment with identified palliative and end-of-life care priorities, needs and promising practices specific to First Nations, Inuit and Métis Peoples, their families and communities.

In closing, we hope to build trust by upholding Indigenous cultural values and worldviews while engaging First Nations, Inuit and Métis Peoples, their families and communities as equals to biomedical research and practice. Our purpose is to improve informed decision-making and the quality of Indigenous approaches to palliative and end-of-life care.

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[11] The Honourable Mr. Justice Murray Sinclair is a former member of the Canadian Senate. He is also the former Chair of the Truth and Reconciliation Commission of Canada.

[12] https://nctr.ca/wp-content/uploads/2021/04/NCTR-Memorial-Register-E2.pdf

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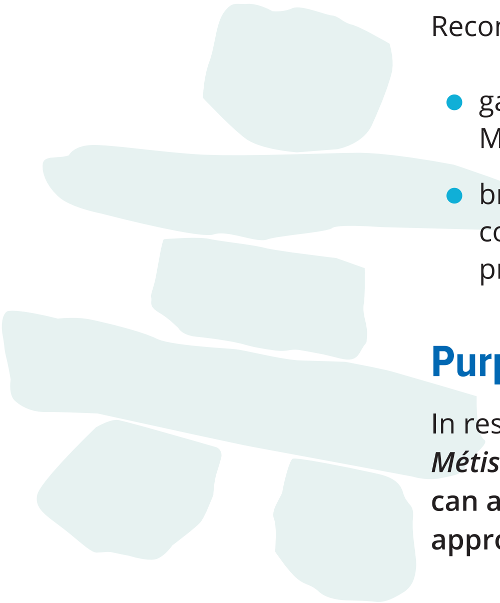
3. Context

In July 2021, the Canadian Partnership Against Cancer (the Partnership) organized a virtual roundtable discussion with First Nations, Inuit and Métis Elders, Knowledge Carriers, community health professionals and researchers—all of whom have experience and knowledge of Indigenous approaches to palliative and end-of-life care. The objectives of the meeting were to

- **identify priorities and needs** of First Nations, Inuit and Métis Peoples caring for family or community members who require palliative and end-of-life care;
- **identify promising practices** in palliative and end-of-life care specific to First Nations, Inuit and Métis Peoples, their families and communities; and
- **discuss opportunities** for the Partnership to support and fund self-determined palliative and end-of-life care priorities of First Nations, Inuit and Métis Peoples, their families and communities.



Recommendations from the July 2021 meeting included

- gathering information on promising practices[13] in palliative and end-of-life care specific to First Nations, Inuit and Métis Peoples, their families and communities across Canada; and
- bringing together foundational information on Indigenous approaches to palliative and end-of-life care to foster collaborations and partnerships within and between Indigenous and non-Indigenous organizations to develop programs, resources and strategies in this important field of health care.

Purpose

In response to the above recommendations, ***Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care*** **in Canada is a foundational background document that readers can adapt, scale and reference in developing strategies, programs and resources that support Indigenous approaches to palliative and end-of-life care**. Accompanying this report are infographics and a presentation deck.

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[13] Promising practices in Indigenous approaches to palliative and end-of-life care include developing strategies, programs and resources.

This report highlights

(1) **factors that influence First Nations, Inuit and Métis palliative and end-of-life care; and**

(2) **promising practices in First Nations, Inuit and Métis palliative and end-of-life care.**

Specifically, this report

- **summarizes factors contributing to First Nations, Inuit and Métis palliative and end-of-life care experiences;**
- **identifies areas for action in palliative and end-of-life care based on priorities, gaps, challenges and needs expressed by First Nations, Inuit and Métis Peoples and communities; and**
- **is strengths-based in identifying innovative and Indigenous community-based models of care and person-centred approaches to palliative and end-of-life care promising practices, resources and strategies.**

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada is a comprehensive foundational resource bridging the history of Indigenous Peoples in Canada with a pathway and set of resources for empowering both Indigenous and non-Indigenous Peoples to grow and develop community-based palliative and end-of-life care services.

Readers

This report is for

- **Health-care organizations and professionals.** People, groups and organizations responsible for the design of strategies, programs and resources in palliative and end-of-life care;[14]
- **Service providers.** Organizations and communities that assist Indigenous Peoples, their families and communities in palliative and end-of-life care, support and information;
- **Orders of government.** Indigenous, provincial/territorial and federal levels of government that engage in setting palliative and end-of-life care policy decision-making, regulating health care and funding priorities in the continuum of care in their respective jurisdiction; and
- **Educators.** People who are involved in developing and/or delivering curricula in palliative and end-of-life care.

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[14] Health-care organizations include community health organizations, not-for-profit organizations specializing in palliative and end-of-life care and disease-specific organizations (such as the Canadian Cancer Society). Health-care professionals include nurses, physicians, mental health workers (such as social workers), personal support workers, dietitians, physiotherapists and volunteers. Some or all of these people and groups often work together as a collaborative team to support people with life-limiting illnesses, their families and communities during palliative care (from diagnosis to end-of-life).

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada is intended for readers

- who are interested in developing palliative and end-of-life care programs, resources and strategies specific to the priorities and needs of First Nations, Inuit and Métis Peoples, their families and communities;
- who are interested in applying for funding available through the Partnership on specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care; and
- who are engaged in or would like to engage in Indigenous approaches to palliative and end-of-life care.

The Partnership will also use this report as a main reference document when funding initiatives to ensure alignment with identified palliative and end-of-life care priorities, needs and promising practices specific to First Nations, Inuit and Métis Peoples, their families and communities. Specifically, this report assists readers and the Partnership to

- minimize or avoid duplication of efforts in planned work in Indigenous approaches to palliative and end-of-life care strategy, program and resource development while identifying future work opportunities by readers who are interested in accessing funding from the Partnership; and
- motivate readers to increase collaborations, networking, and partnerships within and between Indigenous and non-Indigenous organizations in developing integrated and culturally congruent strategies, programs and resources pertaining to specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care.

Intended uses of the report

Readers may be at different stages of cultural awareness (knowing), cultural competencies (applying), cultural safety (acting) and cultural agility (adapting). Some readers may be learning about the living history of Indigenous Peoples in Canada for the first time. Other readers may be at the stage of developing strategies, programs and resources pertaining to specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care. Readers may also be representing Indigenous organizations and communities who are leading Indigenous approaches to palliative and end-of-life care.

For readers who are just beginning to learn about the living history of Indigenous Peoples in Canada or would benefit from a refresher on this topic, you are invited to start at the beginning of this report and read through each section.

For readers who are starting to develop strategies, programs and resources pertaining to specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care, feel free to jump to specific topics and sections of this report. We endeavoured to make each section stand alone in terms of content.

For readers who have already built significant capacity in Indigenous approaches to palliative and end-of-life care, please refer to specific sections of this report. If your organization or community already has strategies, programs and resources pertaining to specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care, feel free to review Section 11 (Palliative care competencies and promising practices) to compare your organizational strategies, programs and resources to each of the 12 palliative care competencies in Canada. Doing so will enable you and your organization to address any competency areas that may have been overlooked.

Next steps

Readers are invited to engage in forward thinking by reflecting on ways to apply and adapt the learnings from this report and the accompanying knowledge products to new or existing palliative and end-of-life care strategies, programs and resources in their organizations and communities, for example,

- designing organizational systems to be inclusive and welcoming to all cultures;
- developing accountabilities for organizations in relation to palliative and end-of-life care specific to First Nations, Inuit and Métis Peoples, their families and communities;
- developing a strategy for evaluating current system services and outcomes which includes identifying gaps and creating system change objectives for Indigenous approaches to palliative and end-of-life care;
- using this report and the accompanying knowledge products as a resource to advocate for funding and resources specific to the priorities and needs of First Nations, Inuit and Métis Peoples, their families and communities;
- using this report and the accompanying knowledge products as a relationship-building tool with local Indigenous communities and opening dialogue with communities who may not have had much of a voice in discussions to date on Indigenous approaches to palliative and end-of-life care;
- using this report and the accompanying knowledge products as a planning document for upcoming funding opportunities that support palliative and end-of-life care priorities and needs of First Nations, Inuit and Métis Peoples, their families and communities;
- informing knowledge translation and continuous learning activities such as palliative and end-of-life care training, group discussions and post-secondary health-care education; and
- developing communities of practice in Indigenous approaches to palliative and end-of-life care.

Co-development of knowledge products

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada was made possible by a collaboration between the Partnership and an Indigenous management consulting company (Turtle Island Consulting Services Inc.). In addition to this report, other knowledge products (presentation materials and infographics) were developed that recognize diverse learning styles[15] that readers can use to find out more about this important topic.

All of the knowledge products developed for this project were peer reviewed by individuals with experience and knowledge of palliative and end-of-life care. The peer reviewers represented voices and perspectives from First Nations, Inuit and Métis Peoples and non-Indigenous allies across Canada which reinforces the "braiding" (harmonizing) approach to palliative and end-of-life care that will be further explored in this report.

The peer reviewers ensured that this report and the accompanying knowledge products were timely, relevant, reader friendly, accessible and culturally congruent in nature.

Indigenous approaches to palliative and end-of-life care are for, by and about First Nations, Inuit and Métis Peoples. They are about healing and helping the whole person (physical, mental, emotional, spiritual), not just the physical self.

The Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care knowledge products were created in a way that involved collaboration and modelled the "nothing about us without us" philosophy. Readers are encouraged to develop and implement palliative and end-of-life care programs using our co-development approach.

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[15] Preferred learning styles include visual, written, auditory and multi-modal.

4. Shared understandings

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada is informed by the following considerations and shared understandings:

- **Braiding (harmonizing).** We acknowledge that Indigenous and non-Indigenous systems of care can work together in palliative and end-of-life care;
- **Cultural assessment.** This assessment should be an expectation for every encounter with people with life-limiting illnesses and for every health-care provider, not just for Indigenous Peoples but for everyone;
- **Culture as medicine.** Culture, Indigenous identities and the reconciliation process are necessary for healing and helping in palliative and end-of-life care. Culture is medicine for someone with life-limiting illness just as antibiotics are medicine for someone with a serious infection;
- **Distinctions-based approach.** This approach recognizes the unique rights, interests and contexts for First Nations, Inuit and Métis Peoples across Canada. It is important to acknowledge that there is much diversity among Indigenous Peoples and communities in terms of languages, lifestyles, histories, values, practices and teachings. This includes diversity of settings in which Indigenous Peoples live (for example, urban, rural, remote, northern, on-reserve communities). There is also diversity in individual communities, particularly in terms of use of Indigenous and non-Indigenous spiritual practices. Therefore, if and where possible, a distinctions-based approach was used in preparing this report to recognize the unique rights, interests and contexts for First Nations, Inuit and Métis Peoples;

Readers are invited to use a distinctions-based approach in their interpretation of this report and any actions taken in developing and implementing strategies, programs and resources in palliative and end-of-life care.

This report is not a "how-to" clinical manual, nor is it intended to be prescriptive as a "one size fits all" for First Nations, Inuit and Métis communities across Canada.

It is important to recognize that there is a vast number of First Nations, Inuit and Métis communities across Canada in urban, rural, remote and northern areas.

Each community may have unique ways to support individuals with life-limiting illnesses in their transition to the spirit world.

Therefore, representation and adaptability of all of the promising practices presented in this report may vary based on the protocols, customs, languages and practices relative to community connections and family lineages.

- **Empowerment and validation.** Knowledge and recognition of Indigenous approaches to palliative and end-of-life care is an empowering and validating way for First Nations, Inuit and Métis Peoples with life-limiting illnesses to transition to the spirit world with support from their families and communities;

As mentioned in Section 5 (Disclaimers), *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* is not an exhaustive list of all First Nations, Inuit and Métis palliative and end-of-life care initiatives used across Canada. Rather, this report provides examples of First Nations, Inuit and Métis palliative and end-of-life care strategies, approaches and promising practices.

- **Indigenous approaches to palliative and end-of-life care.** Palliative and end-of-life care is fundamentally life affirming. It supports communities as much as they support individuals recognizing that one cannot separate individuals or communities from each other. Palliative and end-of-life care encompasses grief and bereavement supports for individuals and their communities including after death;
- **Person-centred approach.** This approach recognizes that the person is placed at the center of palliative and end-of-life care and treated as a person first. The focus is on the person and what they can do, not their life-limiting illness. Support focuses on achieving the care goals of the person with the life-limiting illness and is customized to their needs and unique circumstances;

Helpers using a person-centred approach demonstrate the following three attributes:

(1) genuineness—being real, not hiding behind a false front/persona;

(2) unconditional positive regard—caring for the person with the life-limiting illness by developing an open-minded philosophy and being non-judgmental; and

(3) empathic understanding—being sensitive to the feelings expressed by the person with the life-limiting illness and offering continued support during palliative and end-of-life care.

Nothing about us without us.

This statement signifies that local engagement and consultation with First Nations, Inuit and Métis Peoples and communities is required when developing and implementing palliative and end-of-life care programs.

- **Learning styles.** Recognizing diverse learning styles[16] aids readers to find out more about Indigenous approaches to palliative and end-of-life care. Creative arts are equally important as oral and written forms of knowledge sharing. As such, graphic design images, art, photos and infographics were designed and included in this report and the accompanying knowledge products;
- **Life stories and lived experiences.** Throughout this report, life stories and lived experiences have been shared to engage readers' hearts and minds on themes such as healing, empowerment, reflection, connections to place and community, strength and resiliency, cultural heritage and identities that relate to Indigenous approaches to palliative and end-of-life care;

While great strides have been made to engage Indigenous Peoples in palliative and end-of-life care research and evaluation, much of the research and evaluation on this topic across Canada has focused on perspectives, ways of knowing and lived experiences of First Nations Peoples, their families and communities.

Métis and Inuit voices, experiences and promising practices in palliative and end-of-life care continue to be underrepresented in health research across Canada.[17, 18]

- **Relationship building and allyship.** Readers are invited to take an inclusive and holistic approach to palliative and end-of-life care. This approach involves the respectful consideration of gender and 2SLGBTQQIA+-,[19] trauma- and resilience-informed approaches when *braiding* or harmonizing Indigenous ways of knowing and biomedical strategies in the broader continuum of care for people living with life-limiting illnesses, their families and communities; and
- **Terminology.** Language influences cultural and social attitudes. As communication is important, we invite readers to embrace terminology that braids Indigenous ways of knowing and biomedical terms, thus honouring the spirit and intent of Etuaptmumk/two-eyed seeing (refer to Section 10.2). Also, key terms are provided in Section 7.4 (Terminology) and Section 13 (Key terms) which provide a common understanding of notable terms used throughout this report. Wording related to Indigenous approaches to palliative and end-of-life care were consistent and congruent at the time of publication.

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[16] Preferred learning styles include visual, written, auditory and multi-modal.

[17] Young TK. Review of research on Aboriginal populations in Canada: relevance to their health needs. BMJ (Clinical research ed.). 2003;327(7412):419–422.

[18] Furgal CM, Garvin TD, Jardine CG. Trends in the study of Aboriginal health risks in Canada. International journal of circumpolar health. 2010;69(4):322–332.

[19] 2SLGBTQQIA+ refers to two-spirit, lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual and other sexually and gender diverse people.

5. Disclaimers

- Indigenous approaches to palliative and end-of-life care are supported by appropriate teaching and learning experiences. Therefore, while this report is intended to enrich your learning, the Partnership makes no warranty or representation that reading this report and the accompanying resources on the Partnership's website deems you culturally competent or identifies you as a recognized expert, healer, traditional teacher or Elder.
- From an ethical perspective, experiential teachings and supervision with recognized Elders, Knowledge Carriers and/or healers is needed to continue one's safer[20] and respectful use of Indigenous healing, helping and spiritual practices in palliative and end-of-life care.
- *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* is not intended to be "one size fits all," nor is it an exhaustive list of all First Nations, Inuit and Métis palliative and end-of-life care initiatives used across Canada. Rather, this report provides examples of First Nations, Inuit and Métis palliative and end-of-life care strategies, approaches and promising practices.
- The Partnership recognizes that there is a need for palliative and end-of-life care strategies, programs and resources that acknowledge the unique cultural, jurisdictional topics and issues for First Nations, Inuit and Métis Peoples and communities in Canada.
- Stories in this report were shared with permission from the storytellers and were documented as accurately as possible.
- The views, opinions, conclusions and recommendations expressed in this report are intended to share themes, lessons learned and promising practices that are representative of a variety of Indigenous perspectives across Canada.
- Ethical standards and practices associated with medical assistance in dying remain in the early stages of discussion in the health-care field across Canada. Therefore, further exploration of this topic and its application in cross-cultural settings is needed. Complex planning and guidance from Elders, Healers and Knowledge Carriers in Indigenous communities across Canada are essential.

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[20] Although comparative adjectives (such as "safer") are generally used with "than" plus the thing being compared (e.g., this report is longer than that report), Indigenous palliative care leaders advise us that care based on the biomedical approach can never be safe; it can only be "safer." Honouring this perspective, we have chosen to use the grammatical form: "safer" with no comparative.

- In this report, promising practices and resources (including websites) are current as of the date of publication. Furthermore, there is recognition that promising practices in one community or organization may not be applicable for all communities and/or organizations. Rather, promising practices are based on community or organizational strengths and are grounded in Indigenous ways of knowing and experiences—so they will vary from one community or organization to the next.
- The Partnership accepts no responsibility of liability for any loss or damage that any person may sustain as a result of the information in, or anything done or omitted pursuant, to this report and accompanying resources (presentation deck and infographics).
- The views expressed herein do not necessarily represent the views of Health Canada.

Excerpts from *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* may be reprinted for use in educational settings without prior approval; however, the citation on the cover page must be used when referencing this report. The reproduction of text, photos, infographics and/or illustration for publication or other uses requires written permission from the Partnership.

To request permission, contact the Partnership at info@partnershipagainstcancer.ca

THIS REPORT CONTAINS CONTENT WHICH MAY BE SENSITIVE, TRIGGERING OR DIFFICULT TO DEAL WITH EMOTIONALLY.

If you experience any of these responses, we encourage you to contact a mental health specialist/counsellor, your local Elder or Knowledge Carrier or other support person.

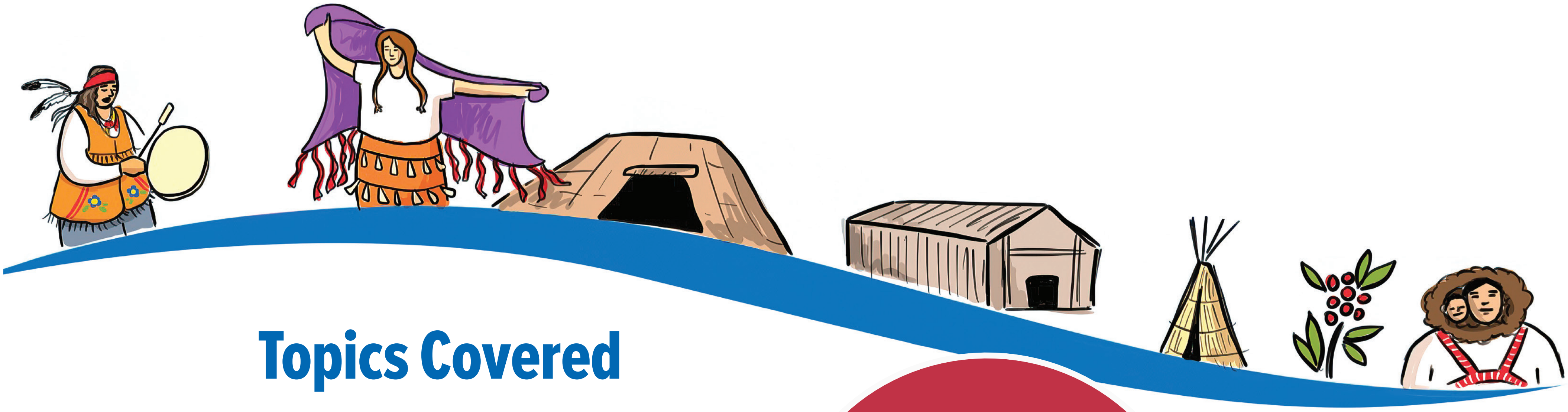
You can also consult

- Talk Suicide Canada: https://talksuicide.ca
- Residential School Survivors and Family Crisis Line: 1-800-721-0066; https://www.irsss.ca/faqs/how-do-i-reach-the-24-hour-crisis-line

It is not our intention to cause any harm or discomfort to readers.

Rather, the Partnership's intent is to provide an inclusive and holistic overview of the challenges and resiliencies in accessing timely and culturally congruent palliative and end-of-life care for First Nations, Inuit and Métis Peoples, their families and communities across Canada.

By understanding these realities, collective work can be carried out towards palliative and end-of-life care.



Topics Covered

Indigenous perspectives and considerations on palliative and end-of-life care

Culture as medicine

Braiding Indigenous ways of knowing and biomedical approaches in palliative and end-of-life care

Palliative care competencies and Indigenous promising practices

6. Foreword

Storytelling involves sharing narratives across the generations which often includes teachings. As a traditional way of gathering and disclosing information, storytellers communicating ways of knowing and learning have a relationship with their listeners by helping them to make sense of events, issues and lived experiences.

To set good intentions in sharing knowledge about challenges and resiliencies in accessing timely and culturally congruent palliative and end-of-life care for First Nations, Inuit and Métis Peoples, the Partnership invited Alexander Kmet, Sherry Metcalfe and Elder Ella Paul to provide introductory remarks, wisdom and insights about this important topic.

> *The wrinkles around her eyes curled to highlight the uncontainable joy of her grin as she mimed shooting a moose one more time. An Elder, from a First Nation community outside of Whitehorse, emphasized the importance of returning home from the hospital into the care of her community, knowing that her advanced cancer would progress without ongoing medical treatment. As a palliative care physician living in the Yukon, I have witnessed firsthand the importance of honouring culture, tradition and connection to both community and the land during the end-of-life journey.*
>
> *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada provides a thoughtful overview of the factors contributing to palliative care experiences of First Nations, Inuit and Métis in Canada by exploring both historical and contemporary factors, including key legislation. Best and promising practices in palliative care, specific to First Nations, Inuit and Métis Peoples are woven throughout.*
>
> *As health-care providers, we have a responsibility to emphasize personhood and dignity in the face of illness, to be with people and hear their stories, and to provide not just physical care for the body, but mental, spiritual and emotional care for the mind, heart and spirit. This is especially true when caring for First Nations, Inuit and Métis Peoples, for whom history and experiences are inextricably linked to health and well-being.*
>
> *Regardless of your experience or role in palliative care, Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada provides insights and teachings that will support you and others in your caregiving journey.*
>
> *Alexander Kmet, Métis physician specializing in Anaesthesia, GP Oncology and Palliative Care Medicine in Whitehorse, Yukon*

Traditionally among Inuit, there is a responsibility to care for family members at end-of-life. Many Inuit wish to return to their community, to be on the land and in the company of family. Unfortunately, for many Inuit, especially those living in Inuit Nunangat, palliative care is not available close to home. To receive care, Inuit must leave their homes for urban centres such as Ottawa or Montréal, where they spend their final days alone. For Inuit living in urban centres, there is often a desire to return home at the end-of-life, to return to Inuit Nunangat, which is often not possible due to a lack of care.

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada paints a picture of how palliative care can be different, how a person's end-of-life wishes can be heard and respected and the impact this can have on their family and community.

First Nations, Inuit and Métis Peoples each have our own histories, practices and current realities. The Canadian Partnership Against Cancer and Turtle Island Consulting Services Inc. worked with First Nations, Inuit and Métis Elders, Knowledge Carriers and health-care providers to ensure these resources reflect these differences and complexities. I am looking forward to sharing these resources with others, and hope that you will too.

Sherry Metcalfe

Palliative care has been part of my life for a long time, starting with my husband who died when he was 29 after living for six years with cancer.

Toward the end of my husband's life things got pretty rough. The doctors were telling me he was dying and that he was getting worse. They were telling him he was getting better and that he would be fine in about three months. I was so excited when my husband told me that. I was so happy I called the doctor and told him how glad I was that something had changed for the better. The doctor got really angry with me. He said, I told you he was dying.

I was only 25 when my husband died, but I felt like an old lady. I felt like I'd already seen everything. People didn't think the way I did about life and death. Since then, I've supported many people during palliative care.

These products will be useful for families because they let you know others have shared your experience. Learning that your family member is sick or close to death is overwhelming and devastating for most people. But if families are provided with support and respect, death can be beautiful. I've seen people who are on the verge of dying, and they're halfway in the spirit world and halfway here. They just glow. There's a glowing about them that you just don't see in most people because they are stepping into the spirit world. Their bodies may be ugly with disease, but their eyes, there's something about them that just glows. If more people could see that they wouldn't be so afraid.

These products will be useful for health-care providers as well. Sometimes it seems like health-care providers get so wrapped up in providing care that they forget about the person. Or they are so overworked and burned out that they lose empathy and patience. I think this report is helpful in that sense. It will build empathy and compassion. Health-care providers and facilities can make a difference in a patient's palliative care experience by supporting smudging or other cultural practices. It's so important to be respectful of the person and their family.

-Ella Paul (Mi'kmaw Elder)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7. Introduction

Voices from the community: A First Nations lens on palliative and end-of-life care

Recently, I was contacted directly about an Indigenous patient who was being transferred home and asked if I could coordinate the care for this patient. In our region, there are specific Indigenous palliative care services, but the local referral forms don't include our program, so it's sometimes difficult to identify patients who require support.

The patient was transferred on a Friday, with no care or medication supports. As soon as we learned of this on Monday, our team quickly mobilized, and the family assured us they could manage the patient's needs until the following day when the nursing services could start. Travelling to the patient's home the next day, we learned that the patient had rapidly deteriorated over the past 24 hours, and their family was now distraught, unequipped to address the situation.

In the home, we assessed the patient, identifying that they hadn't urinated overnight. Fortunately, the nurse had a catheter in the car and a neighbour had lorazepam. The patient had arrived without support or a clear referral, we hadn't known the equipment or medications we would need, and even in this relatively urban area, a prescription would take at least four hours to arrive.

As we worked to address the patient's symptoms, we learned from the family that it was important to the patient that as they were leaving this earth, that they have proper words spoken for them, and ceremony. Unfortunately, I don't speak my language, but an Indigenous colleague who does reassured me over the phone that whatever words I knew, I should give them to the patient, the Creator would understand.

Not having a hospital bed, we lay the patient on the floor, and I lay down beside him. I remembered a hymn, Fishers of Men, that I had learned in the Oneida language as a child. Hearing this, the patient immediately began to settle. His spouse laid by his side, and shortly after he passed.

- Amy Montour (Palliative Care Physician; Haudenosaunee, Six Nations of the Grand River Territory)

The Partnership has been working with partners from across what is now called Canada to advance action on the cancer care priorities of First Nations, Inuit, Métis Peoples, their families and communities.

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada focuses on sharing the challenges and resiliencies in accessing timely and culturally congruent palliative and end-of-life care for First Nations, Inuit and Métis Peoples.

The Partnership hopes this report and accompanying knowledge products contribute toward building and sustaining trust with and alongside Indigenous communities and organizations. We hope to build this trust by upholding Indigenous cultural values and worldviews while engaging First Nations, Inuit and Métis Peoples, their families and communities as equals to biomedical research and practice for the purpose of improving the quality of Indigenous approaches to palliative and end-of-life care.

7.1 What are palliative care and end-of-life care?

Palliative care is a process from diagnosis to end-of-life in relieving symptoms (pain and discomfort) and improving the quality of life for people with life-limiting illnesses (for example, cancer, dementia, heart disease, heart failure, HIV/AIDS, kidney failure, liver failure, lung disease, progressive neurological conditions). Palliative care focuses on the whole person and their families which includes physical, emotional, mental and spiritual support and support of cultural traditions, values, beliefs and wishes.

For some First Nations, Inuit and Métis Peoples, families and communities, the term *palliative care* means *comfort care*. Comfort care provides necessary cultural contexts that acknowledge the role of values, identities, families and communities. With a focus on kindness, compassion and quality of life, comfort care honours the spiritual beliefs, cultural protocols and practices of people living with life-limiting illnesses. In addition to care focusing on the whole person, comfort care supports the whole family and community of people with life-limiting illnesses.[21]

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[21] https://www.cancercareontario.ca/sites/ccocancercare/files/assets/ACCUPalliativeCare.pdf (p. 1).

According to the World Health Organization (WHO),[22] palliative care

- provides relief from pain and other distressing symptoms,
- affirms life,
- regards dying as a normal process,
- neither hastens nor prolongs death,
- integrates the psychological and spiritual aspects of care,
- offers a support system to help patients live actively as long as possible until death,
- is a support system to help the family cope both before and after their loved one's death,
- uses a team approach to address needs of patient and family,
- enhances quality of life, and
- is applicable early in the course of an illness.

End-of-life care focuses on increasing care and meeting the goals of people within their last hours, days, weeks or months of life. End-of-life care includes supporting their families through the life-limiting illness and after death. Overall, end-of-life care is part of palliative care.

7.2 Why are Indigenous approaches to palliative and end-of-life care important?

In Canada, Indigenous Peoples (First Nations, Métis and Inuit) are the fastest growing population. There are approximately 1.7 million First Nations, Inuit and Métis Peoples in Canada with unique languages, cultures, values and practices. The rights of First Nations, Inuit and Métis Peoples and the commitment to full partnerships and relationships are articulated in Section 35 of the *Constitution Act* (1982).[23]

Furthermore, this section of the *Constitution Act* reflects a promise on the part of the Government of Canada and associated entities to respect the distinct rights of First Nations, Inuit and Métis Peoples as well as the treaty obligations that create a framework for First Nations, Inuit and Métis Peoples and non-Indigenous People to work and live together.

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[22] World Health Organization. The determinants of health. Health impact assessment. 2020.

[23] https://www.justice.gc.ca/eng/csj-sjc/principles-principes.html

As a whole, “Indigenous peoples have a unique connection to and constitutionally protected interest in their lands, including decision-making, governance, jurisdiction, legal traditions, and fiscal relations associated with those lands”.[24] This creates a legal and contractual framework in the relationship with First Nations, Inuit and Métis peoples that are unique and require direct focused effort to uphold obligations and respect these rights.

Palliative and end-of-life care research carried out alongside Indigenous communities across Canada demonstrates that Indigenous Peoples commonly hold perspectives and understandings of health, helping, dying and death that differ from other ethnic groups. Health-care services in Canada are generally based on non-Indigenous biomedical values, which can lead to inequities in service delivery and health outcomes for Indigenous Peoples.

An increasing number of Indigenous communities across Canada are caring for more citizens who are aging and/or diagnosed with complex, chronic and/or life-limiting illnesses.[25] The majority of Indigenous Peoples prefer to receive palliative and end-of-life care at home where family, friends, community and cultural practices surround them. However, Indigenous Peoples with life-limiting illnesses (especially from rural, remote and northern communities in Canada) often do not have access to timely and culturally congruent palliative and end-of-life care services, support and resources. Indigenous Peoples with life-limiting illnesses are typically transferred for palliative and end-of-life care to urban hospitals and care facilities for highly specialized medical care, where they are isolated from their support networks (for example, family and friends) and cultural practices (for example, ceremonies and protocols regarding dying and death). As a result of this transition to an unknown environment far from home and community, Indigenous Peoples with life-limiting illnesses face the prospect of being lonely in an environment where their traditions, cultural beliefs and wishes are not known, respected or met and facing language and cultural communication barriers during the most vulnerable time in their lives.[26, 27]

The Partnership supports the self-determined palliative and end-of-life care priorities of First Nations, Inuit and Métis Peoples, their families and communities.

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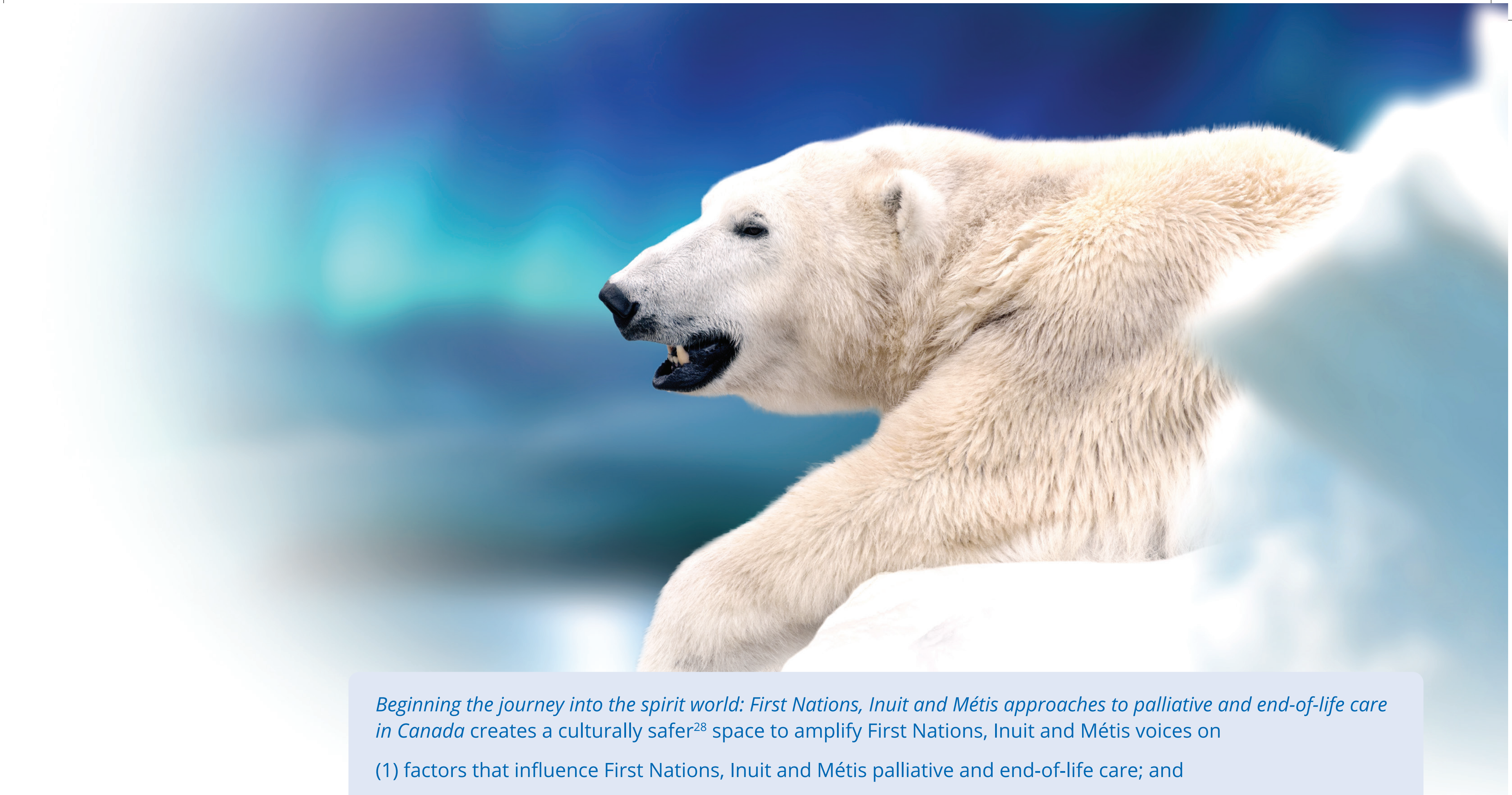
[24] https://www.justice.gc.ca/eng/csj-sjc/principles-principes.html

[25] Caxaj CS, Schill K, Janke R. Priorities and challenges for a palliative approach to care for rural Indigenous populations: a scoping review. Health & Social Care in the Community. 2018;26(3):e329—e336.

[26] https://bit.ly/3KyI7m7

[27] https://www.lco-cdo.org/wp-content/uploads/2019/03/Dying-alone_An-Indigenous-mans-journey-at-EOL_C-Bablitz.pdf



Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada creates a culturally safer[28] space to amplify First Nations, Inuit and Métis voices on

(1) factors that influence First Nations, Inuit and Métis palliative and end-of-life care; and

(2) promising practices in First Nations, Inuit and Métis palliative and end-of-life care.

The Partnership is committed to advancing truth and reconciliation which includes achieving health equity for First Nations, Inuit and Métis Peoples. As a result, the Partnership has been working with partners from across what is now called Canada to advance actions on cancer care priorities expressed by First Nations, Inuit and Métis Peoples, their families and communities.

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[28] Although comparative adjectives (such as “safer”) are generally used with “than” plus the thing being compared (e.g., this report is longer than that report), Indigenous palliative care leaders advise us that care based on the biomedical approach can never be safe; it can only be “safer.” Honouring this perspective, we have chosen to use the grammatical form: “safer” with no comparative.

CANADIAN **PARTNERSHIP**
AGAINST CANCER
PARTENARIAT CANADIEN
CONTRE LE CANCER

2019–2029 Canadian Strategy for Cancer Control (the Strategy)

The Canadian Partnership Against Cancer (the Partnership) is the steward of the Canadian Strategy for Cancer Control (the Strategy). The Partnership works to implement the Strategy to reduce the burden of cancer on Canadians.

In order to advance reconciliation and achieve health equity for First Nations, Inuit and Métis communities, all orders of government, health-care organizations and providers need to work side-by-side with First Nations, Inuit and Métis Peoples and partners to support action on five Peoples-specific, self-determined priorities:

PRIORITY 1: Decrease the risk of people getting cancer

PRIORITY 2: Diagnose cancer faster, accurately and at an earlier stage

PRIORITY 3: Deliver high-quality care in a sustainable, world-class system

PRIORITY 4: Eliminate barriers to people getting the care they need

PRIORITY 5: Deliver information and supports for people living with cancer, families and caregivers[29]

Of note, Priority 5, Action 2 of the Strategy is a call to address the limited and unequal access to palliative and end-of-life care across Canada. In support of this priority and corresponding action item, funds have been allocated to address the specific needs and priorities of First Nations, Inuit and Métis Peoples relative to palliative and end-of-life care.

PRIORITIES SPECIFIC TO FIRST NATIONS, INUIT AND MÉTIS PEOPLES

PRIORITY 6: Culturally appropriate care closer to home

PRIORITY 7: Peoples-specific, self-determined cancer care

PRIORITY 8: First Nations-, Inuit- and Métis-governed research and data systems[30]

For more information, visit https://bit.ly/3kujahb

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[29] https://www.partnershipagainstcancer.ca/wp-content/uploads/2019/06/Canadian-Strategy-Cancer-Control-2019-2029-EN.pdf (p. 6).

[30] https://www.partnershipagainstcancer.ca/wp-content/uploads/2019/06/Canadian-Strategy-Cancer-Control-2019-2029-EN.pdf (p. 7).

7.3 How is this report organized?

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada is organized to apply learnings from Etuaptmumk/two-eyed seeing (refer to Section 10.2) to amplify the voices and ways of knowing of First Nations, Inuit and Métis Peoples on palliative and end-of-life care.

Challenges and resiliencies are described acknowledging the truths of the living histories of Indigenous Peoples across Canada while engaging in reconciliation. Strengths, assets and opportunities are recognized in the form of culture as medicine. This report highlights the importance of relationships to land, people and place; Indigenous spirituality and connections with our ancestors; and the role of community members and community as a whole in palliative and end-of-life care.

As a way of recognizing how the application of Indigenous ways of knowing support timely, accessible and culturally congruent palliative and end-of-life care in Canada, we share notable competencies and promising practices in this report.

7.4 Terminology

Terminology is designed for ease of reading while ensuring the use of consistent and congruent wording related to Indigenous approaches to palliative and end-of-life care:

- The terms “palliative care” and “end-of-life care” will be used alongside one another and referenced as *palliative and end-of-life care* in this report to recognize unique yet harmonizing cross-cultural dimensions of these important key terms for First Nations, Inuit and Métis Peoples.
- Unless specified, the information and resources presented in this report can be applied to all Indigenous Peoples in Canada (First Nations [Status and Non-Status], Inuit and Métis).
- The terms *Aboriginal* and *Indigenous* will be used interchangeably, though the current term we are using in this report (and accompanying knowledge products) is Indigenous.
- The term *person (or people) with a life-limiting illness* refers to people seeking and/or receiving health care and related services which includes (home care) residents and (hospital) patients.
- Gender-inclusive language (for example, they/them) is used throughout this report and accompanying knowledge products to promote gender equality and remove any forms of gender bias and related stereotypes from the discussion on Indigenous approaches to palliative and end-of-life care.
- Health-care providers and professionals, service providers, orders of government, educators and related helpers will be collectively referenced as *readers*.
- *Indigenous approaches to palliative and end-of-life care* refers to both Indigenous-informed healing and helping and Indigenous-led healing and helping.

To aid in the transparency, meaning-making and clarity of terminology in palliative and end-of-life care, we define and describe key terms in Section 13 of this report.

8. Indigenous perspectives and considerations on palliative and end-of-life care

8.1 Overview

Indigenous Peoples are the fastest growing population in Canada. There is much diversity among First Nations, Inuit and Métis Peoples and communities in languages, lifestyles and teachings.

As previously mentioned in this report, the rights of First Nations, Inuit and Métis Peoples and the commitment to full partnerships and relationships are articulated in Section 35 of the *Constitution Act* (1982).[31] Furthermore, this section of the *Constitution Act* reflects a promise on the part of the Government of Canada and associated entities to respect the distinct rights of First Nations, Inuit and Métis Peoples as well as the treaty obligations that create a framework for First Nations, Inuit and Métis Peoples and non-Indigenous People to work and live together.

Increasingly, readers will work alongside people from many different cultures and backgrounds, including First Nations, Inuit and Métis Peoples, their families and communities. Therefore, we need to recognize First Nations, Inuit and Métis perspectives and considerations on palliative and end-of-life care.

To support cultural safety, it is important for allies working with First Nations, Inuit and Métis Peoples to have access to timely, relevant and culturally congruent palliative and end-of-life care strategies, promising practices and resources.

It is also beneficial for readers to enhance their understanding of and their interpersonal communications with First Nations, Inuit and Métis Peoples living with life-limiting illnesses, their families and communities.

8.2 Notable Indigenous declarations and reports

In 2007 and 2015, two notable Indigenous declarations and reports were published that informed discussions and corresponding actions in Canada and internationally with regards to Indigenous rights, well-being, engagement and partnerships.

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[31] https://www.justice.gc.ca/eng/csj-sjc/principles-principes.html

This report on palliative and end-of-life care is informed by the *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)* and the *Truth and Reconciliation Commission (TRC) of Canada Calls to Action.*

8.2.1 *United Nations Declaration on the Rights of Indigenous Peoples*

UNDRIP was adopted by the United Nations General Assembly on September 13, 2007 and by Canada in 2016. This declaration establishes a comprehensive international framework of minimum standards for the survival, dignity and well-being of the Indigenous Peoples of the world. It elaborates on existing human rights standards and fundamental freedoms as they apply to the specific situation of Indigenous Peoples.

Indigenous approaches to palliative and end-of-life care:

Notable articles from the *United Nations Declaration on the Rights of Indigenous Peoples*

The following are notable *UNDRIP* articles that relate to Indigenous approaches to palliative and end-of-life care:

Article 7(1): Indigenous individuals have the rights to life, physical and mental integrity, liberty, and security of person.[32]

Article 21(1): Indigenous peoples have the right, without discrimination, to the improvement of their economic and social conditions, including inter alia, in the areas of education, employment, vocational training and retraining, housing, sanitation, health and social security.[33]

Article 23: Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.[34]

Article 24(2): Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.[35]

For more information, watch *How UNDRIP changes Canada's relationship with Indigenous Peoples* - https://www.youtube.com/watch?v=-Tq7Mnlavqs

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[32] https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf (p. 6).

[33] https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf (p. 9).

[34] https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf (p. 9).

[35] Ibid.

8.2.2 *Truth and Reconciliation Commission of Canada Calls to Action*

From 2008 to 2014, the TRC heard stories of abuse (for example, mental, emotional, sexual, physical) from thousands of residential school survivors. The purpose of the TRC was to document the history and impacts of the residential school system in Canada. The TRC provided former residential school survivors with an opportunity to share their experiences during public and private meetings held across Canada. In June 2015, the Commission released a report based on these hearings, resulting in 94 calls to action. The *TRC calls to action* address the legacy of residential schools and advance the process of Canadian reconciliation.

Indigenous approaches to palliative and end-of-life care:

Notable *Truth and Reconciliation Commission of Canada Calls to Action*

The following are TRC calls to action that the Truth and Reconciliation Commission of Canada specifically asked the Partnership and our colleagues in health institutions across the country to realize:

TRC call to action #22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.[36]

TRC call to action #23. We call upon all levels of government to: i. Increase the number of Aboriginal professionals working in the health-care field. ii. Ensure the retention of Aboriginal health-care providers in Aboriginal communities. iii. Provide cultural competency training for all health-care professionals.[37]

TRC call to action #24. We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.[38]

Reconciliation is not about forgiving and forgetting. Rather, reconciliation is about remembering and changing.

Furthermore, reconciliation is not a final destination: it is a shared journey and process for First Nations, Inuit and Métis Peoples and non-Indigenous Peoples in Canada.

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[36] https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Calls_to_Action_English2.pdf (p. 3).

[37] Ibid.

[38] Ibid.

As people living and working in Canada, we all have individual and collective roles in advancing the TRC calls to action.

For more information about the TRC final report, refer to https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Executive_Summary_English_Web.pdf.

UNDRIP and the *TRC calls to action* shine a light on the importance of understanding the historical, social, cultural and political landscape that shape relationships between Indigenous Peoples and institutions such as the health-care system in Canada. Understanding this landscape and these relationships is crucial to achieving social justice. As orders of governments, health-care organizations, and related leadership and education groups implement the *TRC calls to action* and the *UNDRIP* articles, helpers need to be aware of their roles when working with First Nations, Inuit and Métis Peoples living with life-limiting illnesses, their families and communities:

- **Recognize the effects of historical and intergenerational trauma on Indigenous Peoples—**These effects are often associated with the policies of forced assimilation through the residential school system and other forms of colonization in Canada (for example, *Indian Act* legislation and the reserve system, land appropriation, Indian hospitals,[39] Sixties Scoop[40]);
- **Deconstruct one's understanding of change at the community level—**First Nations, Inuit and Métis communities set the pace and define (or redefine) ways of knowing related to identity/identities; resiliency; palliative and end-of-life care. It is important to recognize that a community's readiness to engage in or lead Indigenous approaches to palliative and end-of-life care will differ within and between First Nations, Inuit and Métis communities;
- **Engage communities—**Take the time needed to grow relationships and sustain trust among individuals, groups and organizations who provide Indigenous approaches to palliative and end-of-life care and related support to individuals with life-limiting illnesses; and
- **Understand processes and protocols for working with and alongside First Nations, Inuit and Métis communities—**Understanding these processes and protocols includes acknowledging, recognizing and understanding cultural practices associated with dying and death.

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[39] As part of the Government of Canada's assimilation policy, the government created segregated Indian hospitals. Indigenous Peoples were sent to under-resourced Indian hospitals from residential schools, northern Canada and northern parts of the prairie provinces. Medical experiments (for example, forced sterilization, forced confinement for tuberculosis treatment) were carried out at the Charles Camsell Hospital. Currently, there is litigation on injustices that occurred at Indian hospitals; https://www.ictinc.ca/blog/a-brief-look-at-indian-hospitals-in-canada-0.

[40] https://indigenousfoundations.arts.ubc.ca/sixties_scoop/ and https://www.sixtiesscoopsettlement.info/.

8.3 Our challenges and resiliencies

Many First Nations, Inuit and Métis Peoples, their families and communities may look at palliative and end-of-life care from worldviews that differ from non-Indigenous Peoples and biomedical perspectives. Many factors impact and influence palliative and end-of-life care for Indigenous Peoples.[41, 42, 43] Some of these factors are historical factors, jurisdictional factors, cross-cultural factors, capacity building factors and resource factors.

8.3.1 History of Indigenous Peoples in Canada

When we reflect on the history of Canada, it is important to view it as a living history in terms of past and current effects of colonization, the residential school system and associated intergenerational implications as reflected in current health care, the legal/justice system and child welfare policies and practices. History did not start with colonial history: Indigenous cultures survived and thrived in what is now called Canada for millennia. Indigenous communities in Canada had a profound relationship with the land which supported livelihoods and spiritual and cultural well-being.[44] However, historical dispossession of lands in Canada occurred through colonial wars and/or formal treaties;[45] the creation and implementation of *Indian Act* legislation and the reserve system;[46] depopulation by epidemics of European diseases (for example, smallpox, influenza, measles);[47] and unilateral appropriation of Indigenous lands, territories and resources.[48, 49, 50, 51, 52]

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[41] Caxaj CS, Schill K, Janke R. Priorities and challenges for a palliative approach to care for rural Indigenous populations: a scoping review. Health & Social Care in the Community. 2018;26(3):e329—e336.

[42] http://www.cfp.ca/content/cfp/55/4/394.full.pdf

[43] Lemchuk-Favel L. The provision of palliative end-of-life care services in First Nations and Inuit communities. FAV COM; 2016, January.

[44] Nelson M, Natcher DC, Hickey CG. Subsistence harvesting and the cultural sustainability of the Little Red River Cree Nation In: David D, editor. Seeing beyond the trees. The social dimensions of Aboriginal forest management. Concord (ON): Captus Press; 2008. p. 29–40.

[45] Weaver JC. The great land rush and the making of the modern world, 1650–1900. Montreal (QC): McGill-Queen's University Press; 2003.

[46] First passed in 1876, the *Indian Act* gave the Government of Canada exclusive authority over those First Nations communities who were recognized as "Indians" living on reserves which were unilaterally created; https://www.rcaanc-cirnac.gc.ca/eng/1536350959665/1539959903708.

[47] Tennant P. Aboriginal peoples and politics: the Indian land question in British Columbia, 1849-1989. Vancouver (BC): UBC Press; 1999.

[48] Bhandar B. Status as property: identity, land and the disposessions of First Nations women in Canada. Dark Matter. 2016;14:1–20.

[49] https://www2.unbc.ca/sites/default/files/sections/neil-hanlon/2009_hanlon_dialoguesfinalreport.pdf

[50] DeCourtney CA, Branch PK, Morgan KM. Gathering information to develop palliative care programs for Alaska's Aboriginal Peoples. Journal of Palliative Care. 2010;26(1):22–31.

[51] Harris C. Making native space: colonialism, resistance, and reserves in British Columbia. Vancouver (BC): UBC Press. 2002.

[52] Macaulay AC. Improving Aboriginal health: how can health care professionals contribute? Canadian Family Physician. 2009, April;55:334–336.

The historical context of harm resulting from colonization continues to affect Indigenous Peoples across the generations. This harm is often called intergenerational trauma. These historical factors influence health decisions that include Indigenous Peoples living with life-limiting illnesses being able to access palliative and end-of-life care programs, services and resources.[53, 54]

Canadian laws and policies have had historical effects on Indigenous Peoples in Canada. Recently, policies, practices, laws and related processes are recognizing and reconciling the effects of colonization.

- ***Royal Proclamation of 1763.*** As settlers occupied British North America, the British government proclaimed that the interests of Aboriginal People and their lands must be protected under the Crown. For example, the *Royal Proclamation of 1763* explains that the Crown is required to have an agreement in place to acquire land from Aboriginal People. To date, this proclamation has and continues to be significant in terms of recognizing Aboriginal title and rights.
- ***Constitution Act, 1867—Section 91(24).*** This specific section of the Act pronounces that the Government of Canada has exclusive legislative authority for Indians and lands reserved for Indians (reserve system).
- ***Constitution Act, 1982—Section 35.*** This specific section of the Act provides constitutional protection to the rights of Aboriginal People in Canada. Examples of Aboriginal rights that Section 35 has been found to protect are fishing, logging, hunting, Aboriginal title (right to land) and the right to enforcement of treaties.
- ***Indian Act.*** First passed in 1876, this statute gave the Government of Canada exclusive authority over Indian People living on reserves. The Act defines who are Indians and their associated rights. The Act previously denied First Nations People the right to vote unless they gave up their Indian status and associated rights. In 1960, First Nations People received the right to vote in federal elections without giving up their Indian status. At present, the *Indian Act* remains in effect. Though amendments were made to the statute from approximately 1881 to 2000, the Act remains fundamentally unchanged since 1876. An amendment in 2000 allows First Nations band members living off reserve to vote in band elections and referendums. The *Indian Act* is administered by the Minister Responsible for Crown-Indigenous Relations and Northern Affairs Canada.[55]
- ***1969 White Paper.*** Former Minister of Indian Affairs, Jean Chretien, prepared this policy document that proposed the elimination of the *Indian Act* and Aboriginal land claims. In addition, the *White Paper* supported the assimilation of First Nations People into the Canadian population as "other visible minorities" rather than being recognized as a distinct racial group. Harold Cardinal and the Indian Chiefs of Alberta countered the 1969 *White*

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[53] de Leeuw S, Lindsay NM, Greenwood, M. Rethinking (once again) determinants of Indigenous Peoples' health. In: Greenwood M, de Leeuw S, Lindsay NM, editors. Determinants of Indigenous Peoples' health: beyond the social. 2nd ed. Toronto (ON): Canadian Scholars' Press; 2018.

[54] Jacklin K, Warry W. Decolonizing First Nations health. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012. p. 374–375.

[55] https://laws-lois.justice.gc.ca/eng/acts/i-5/

Paper by preparing the “Citizens Plus” policy document (*Red Paper*). The *Red Paper* coupled with the *Calder v. British Columbia (1973*) decision were contributing factors for the Liberal Party of Canada (the governing party of Canada during this time) to step away from the policy recommendations described in the *1969 White Paper*.

- ***Calder v. British Columbia (1973).*** This Supreme Court of Canada decision was the first time that Canadian law acknowledged that Aboriginal title to land existed prior to European contact (colonization). Subsequent legal decisions such as Delgamuukw, Nisga’a, Gitxsan, Wet’suwet’en, Haida, Taku River Tlingit, Musqueam, Heiltsuk, Sto:lo, and Tsilhqot’in Nation are making significant contributions in the protection and advancement of Indigenous title and rights—affirming that Indigenous Peoples exist and they have laws and governments.

- ***Bill C-31. Bill C-31*** is the 1985 pre-legislation name of the Act to Amend the *Indian Act.* This legislation removed discriminatory clauses against women and restored status and membership rights. Aboriginal People who have been reinstated as Status Indians under this Act are often referred to as *Bill C-31 Indians.*[56]

- **Powley case.** On September 19, 2003, the Supreme Court of Canada acknowledged the existence of Métis as a distinct Aboriginal People in Canada with existing rights that are protected by the *Constitution Act, 1982—Section 35.*

- **Statement of apology to former students of residential schools.** On June 11, 2008, Prime Minister Stephen Harper officially apologized on behalf of the Government of Canada for the residential school system. For over a century (1840s–1990s), the residential school system took more than 150,000 Indigenous children from their families and communities to non-Indigenous operated residential schools across Canada. The residential school system was intended to isolate Aboriginal children by removing them from their languages, families, communities and cultures—thereby assimilating them into mainstream Canadian culture. In addition to the negative effects of assimilation, there were allegations that many Aboriginal children suffered abuse (psychological, physical and sexual), overcrowding, lack of medical care and poor sanitation during their attendance at residential school. In a move towards reconciliation between Indigenous Peoples (particularly, former residential school survivors) and the Government of Canada, the statement of apology in 2008 was intended to write a new chapter in Canadian history of working together in partnership to ensure that government systems and processes like residential schools are not repeated for future generations.

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[56] https://indigenousfoundations.arts.ubc.ca/bill_c-31/

From 2021 to present, there have been a series of investigations and confirmations of unmarked graves of children who reportedly died at former residential school sites across Canada. There continues to be searches for further unmarked graves at these sites. These discoveries highlight the truths of the residential school experience and the importance of ensuring cultural safety for future generations of First Nations, Inuit and Métis Peoples.[57]

> Those who cannot remember the past are condemned to repeat it.[58]

- ***United Nations Declaration on the Rights of Indigenous People.*** *UNDRIP* was adopted by the General Assembly of the United Nations in September 2007. In May 2016, the Government of Canada announced that Canada is a full supporter, without qualification, of *UNDRIP*. This declaration establishes a comprehensive international framework of minimum standards for the survival, dignity, security and well-being of the Indigenous Peoples of the world, and it elaborates on existing human rights standards and fundamental freedoms as they apply to the specific situation of Indigenous Peoples. The declaration covers a wide range of human rights and fundamental freedoms related to Indigenous Peoples such as the freedom from any discrimination (Article 2); the right to self-determination and to freely determine political status and pursue economic, social and cultural development (Article 3); the right to self-government relating to internal and local affairs (Article 4); and the right to life, physical and mental integrity, liberty and security of person (Article 7). Moreover, states must obtain free, prior and informed consent (FPIC) before adopting and implementing legislative or administrative measures that may affect Indigenous Peoples (Article 19).
- ***Truth and Reconciliation Commission of Canada Calls to Action.*** From 2008 to 2014, the TRC heard stories of abuse (for example, mental, emotional, sexual, physical) from thousands of residential school survivors. The purpose of the TRC was to document the history and impacts of the residential school system in Canada. The TRC provided former residential school survivors with an opportunity to share their experiences during public and private meetings held across Canada. In June 2015, the Commission released a report based on these hearings, resulting in 94 calls to action. The 94 calls to action address the legacy of residential schools and advance the process of Canadian reconciliation. There are individual and collective roles for people living and working in Canada to advance the calls to action.

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[57] https://globalnews.ca/news/8458351/canada-residential-schools-unmarked-graves-indigenous-impact/

[58] https://www.goodreads.com/quotes/634544-those-who-cannot-remember-the-past-are-condemned-to-repeat

8.3.2 Colonization, intergenerational trauma and health inequities

We cannot fully recognize the health inequities for Indigenous Peoples in Canada without understanding how historical, social, cultural and political factors over time have and continue to shape relationships between institutions such as the health-care system and Indigenous Peoples and their communities. Health inequities, the historical effects of colonization and the residential school system in Canada are interrelated. When groups of individuals are oppressed and marginalized by state policies, laws and organizational systems by devaluing their ways of being and knowing, intergenerational trauma results which disrupts First Nations, Inuit and Métis cultures, languages, values, practices and histories.[59]

Did you know? Residential school system in Canada

Indigenous children and youth were forcibly removed from their families and cultures and sent to residential schools.

The residential school system was funded by the government and administered by Christian churches. More than 30 per cent of Indigenous youth (approximately 150,000) were put through this system with the intent to assimilate them into Euro-Canadian society. This was legislated assimilation.

There were approximately 139 residential schools across Canada.

It is challenging at times to know exact histories (truths) of the residential school system because colonial history has often erased or withheld transmission of knowledge (records and other ways of knowing) for hundreds of years.

The last residential school in Canada closed in 1997 in Rankin Inlet (Nunavut).[60] By this time, there was growing awareness among Canadians of the depraved conditions of residential schools.

Thousands of court cases against the Government of Canada by survivors and their families led to the largest class-action lawsuit in Canadian history and the establishment of the Truth and Reconciliation Commission.

To hear stories from residential school survivors, watch *Stolen Children: Residential School Survivors Speak Out (CBC, 2015) - https://www.youtube.com/watch?v=vdR9HcmiXLA.*

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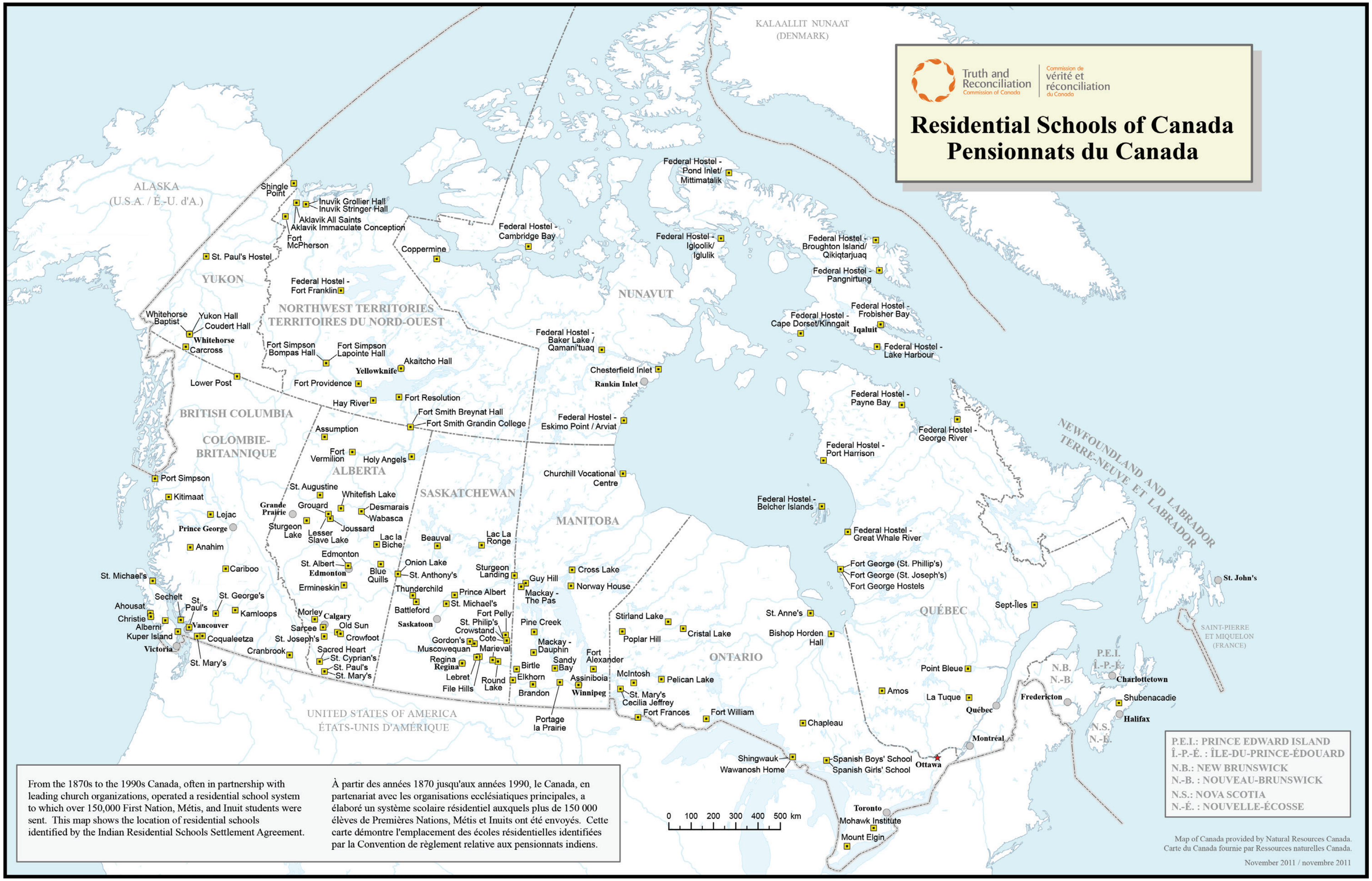
[59] Johnston G, Vukic A, Parker S. Cultural understanding in the provision of supportive and palliative care: perspectives in relation to an Indigenous population. BMJ Supportive & Palliative Care. 2012;3:61–68.

[60] https://www.cbc.ca/news/canada/canada-residential-schools-kamloops-faq-1.6051632

Figure 1. National Centre for Truth and Reconciliation Archives, Residential School Map, T00005, Truth and Reconciliation Commission of Canada.



From the 1870s to the 1990s Canada, often in partnership with leading church organizations, operated a residential school system to which over 150,000 First Nation, Métis, and Inuit students were sent. This map shows the location of residential schools identified by the Indian Residential Schools Settlement Agreement.

À partir des années 1870 jusqu'aux années 1990, le Canada, en partenariat avec les organisations ecclésiatiques principales, a élaboré un système scolaire résidentiel auxquels plus de 150 000 élèves de Premières Nations, Métis, et Inuits ont été envoyés. Cette carte démontre l'emplacement des écoles résidentielles identifiées par la Convention de règlement relative aux pensionnats indiens.

For more information on the historical effects of colonization on Indigenous Peoples in Canada,

- Watch the following excerpt from the 8th Fire with Wab Kinew—"500 years in two minutes": https://www.youtube.com/watch?v=L7LY-fXzhZI
- Participate in the Kairos Blanket Exercise: https://www.kairosblanketexercise.org

The residential school system and the enduring legacies of intergenerational trauma are major factors impacting and influencing Indigenous health, healing and helping. Colonialism creates an oppressive environment whereby Indigenous Peoples are unable or not allowed to express anger and frustration because it is too dangerous or risky. Feelings of alienation and marginalization can turn inward and be directed at oneself and/or one's families and communities.

In the *Evaluation of the health and social services system in Nunavik: The users' perspective* (2021) *report,* interview participants shared how acts of colonization ranging from forced settlement, slaughtering of sled dogs to cultural assimilation and removal of children from their families have individually and collectively affected the health and well-being of Inuit in Nunavik.[61]

There are often feelings of fear and apprehension in accessing palliative care, especially for Indigenous Peoples and their family members who were forcibly removed from their communities, languages and ways of life as part of the residential school system, Indian hospital system and/or the Sixties Scoop. Their fears and apprehensions center on questions such as, Will there be any options in palliative care? Will I be forced to leave my family, community, language and way of life to enter into a biomedical health care setting for palliative care? Will my palliative care choices and decisions actually be heard, respected and supported in the health-care system?

The consequences of Canada's colonized history significantly relate to the health of Indigenous Peoples as evidenced by the high rates of poor mental and physical health (for example, intergenerational trauma, depression, substance misuse, suicide, domestic violence, cancer, kidney failure, liver failure, heart disease, heart failure) compared to non-Indigenous populations in Canada.[62, 63]

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[61] https://nrbhss.ca/sites/default/files/documentations/corporatives/UserPerspective_Report_EN_digital.pdf (p. 72).

[62] Browne AJ, Varcoe C, Lavoie J, Smye V, Wong S, Krause M. et al. Enhancing health care equity with Indigenous populations: evidence-based strategies from an ethnographic study. BMC Health Serv Res. 2016;16(544).

[63] Kim PJ. Social determinants of health inequities in Indigenous Canadians through a life course approach to colonialism and the residential school system. Health Equity. 2019;3(1):378-381.

8.3.3 Access to palliative and end-of-life care—jurisdiction and funding

Access to palliative and end-of-life care is based on health-care jurisdiction and funding as part of intergovernmental relations. The Government of Canada (federal order of government) has responsibility for Indigenous Peoples, while the delivery of health-care services in Canada is primarily a provincial/territorial responsibility. In Canada, palliative and end-of-life care are typically hospital-based and provincially/territorially-organized.

Jurisdiction (law making authority) creates added complexities for First Nations, Inuit and Métis Peoples attempting to access care. It is worth noting that health inequities also exist between First Nations, Inuit and Métis Peoples and communities. While the *Indian Act* limits the health-care rights for (Status/registered) First Nations Peoples, Métis Peoples and Inuit are typically not afforded the same rights to health care as First Nations Peoples.[64, 65] Lack of cultural support and services for urban Indigenous homeless populations means that they are not likely to receive any kind of Indigenous-specific palliative and end-of-life care. Also, in many Inuit regions and communities in Canada, there are little to no palliative and end-of-life care services.[66, 67, 68]

Barriers to access:

Jurisdictional barriers limit access by First Nations, Inuit and Métis Peoples to palliative and end-of-life care.

Jurisdiction in health care and the broader continuum of care has resulted in

(1) undefined roles and responsibilities,

(2) lack of coordination among services across orders of government (for example, Indigenous,[69] federal and provincial/territorial orders of government)[70, 71] and

(3) gaps in jurisdictional responsibility for funding between orders of government.

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[64] Krieg B. Bridging the gap: accessing health care in remote Métis communities. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012.

[65] Lavoie JG, Gervais L. Access to primary health care in rural and remote Aboriginal communities: progress, challenges, and policy directions. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012.

[66] Canadian Partnership Against Cancer. First Nations cancer control in Canada baseline report. Toronto (ON); 2013.

[67] Kaufert JM, Wiebe R, Lavallée M, Kaufert PA. Seeking physical, cultural, ethical, and spiritual "safe space" for a good death: The experience of Indigenous Peoples in accessing hospice care. In: Coward H, Stajduhar KI, editors. Religious understandings of a good death in hospice palliative care. Albany State: University of New York Press; 2012. p. 231-256.

[68] Anderson M, Woticky G. The end of life is an auspicious opportunity for healing: decolonizing death and dying for urban Indigenous People. International Journal of Indigenous Health 2018;13(2):48–60.

[69] Some examples are First Nations governments, Métis settlements and Inuit regional governments or related authorities.

[70] Habjan S, Prince H, Kelley ML. Caregiving for Elders in First Nations communities: social system perspective on barriers and challenges. Canadian Journal of Aging. 2012;31(2):209–222.

[71] https://spcare.bmj.com/content/bmjspcare/3/1/61.full.pdf

Gaps and lack of clarity lead to discontinuity of care between health systems for Indigenous Peoples living with life-limiting illnesses, their families and communities.[72, 73]

The ability to navigate between political and jurisdictional boundaries (for example, Indigenous, provincial/territorial and federal orders of government) is often challenging for Indigenous Peoples living with life-limiting illnesses, their families, communities and health-care providers. They encounter difficulties as they deal with administrative processes that pertain to coordination, communications and decision-making, and follow up and discharge for palliative and end-of-life care. Furthermore, health care is generally divided between primary (community), secondary (hospital), and tertiary (specialized treatment centres) services that often overlap orders of government and agencies (including federal, provincial/territorial, regional, community and First Nations-, Métis-, and Inuit-led organizations).[74]

Voices from the field: Calls to action in access to palliative and end-of-life care for Indigenous Peoples in Canada

In discussions with the Partnership, some Indigenous palliative and end-of-life practitioners shared the following concerns and calls to action:

- There are limitations in the post-secondary education system across Canada, whereby there is limited or no training for emerging health-care professionals to build capacity for providing culturally safer palliative and end-of-life care, including grief and bereavement support.

At the specialist palliative care level, there are too few palliative care physicians with advanced palliative care training across Canada. At a generalist level, studies show that too many graduates of medical and nursing schools (and graduates of other health science schools) enter practice without having core palliative care skills.

- In general, physicians in Canada are exempt from most of the discussions on access (jurisdiction and funding) to palliative and end-of-life care as they are not included in federally-funded systems and are often excluded in First Nations on-reserve discussions on this topic due to the long standing legacy of the federal government not funding physician services. Furthermore, provinces/territories often have limited input into the practice of physicians except through regulatory colleges and/or where doctors are employed in salaried positions. There is a need to hold physicians accountable for culturally appropriate care provided to Indigenous Peoples. The current state of physician services is not meeting the needs of Indigenous Peoples across Canada, particularly in rural, remote and northern regions of the country.

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[72] Giesbrecht M, Crooks VA, Castleden H, Schuurman N, Skinner M, Williams A. Palliating inside the lines: the effects of borders and boundaries on palliative care in rural Canada. Social Science & Medicine. 2016;168:273–282.

[73] https://novascotia.ca/dhw/ccs/documents/Aboriginal-Home-Care-Framework-full.pdf

[74] Canadian Partnership Against Cancer. Inuit cancer control in Canada: baseline report. Toronto (ON); 2014.

- The separation and specialization of work based on biomedical and Western science-based designations (e.g., nurse, medical doctor, social worker, psychologist) is creating unnecessary barriers in access to palliative and end-of-life care as Indigenous Peoples are often unaware of the health-care role differences and are looking for support from whomever is involved.
- Provincial/territorial home care services and federal home care services are often confusing to people with life-limiting illnesses. In some cases, there are multiple providers overlapping each other with poor communication between health-care agencies. This can be overwhelming for people with life-limiting illnesses and their families. We (as a health-care system) decide who goes into a home. Why is the person with the life-limiting illness and their family not allowed to decide who they want in their home/involved in their palliative and end-of-life care?

We can no longer afford to ignore these realities in our health-care system and post-secondary education system in Canada. If we do not call out these disparities, they will not be addressed.

Therefore, more actions are needed across all orders of government to provide access to equitable palliative and end-of-life care for Indigenous Peoples and associated supports and resources for their families and communities.

Coupled with problems arising from jurisdiction is the inadequate availability of sustainable funding support for Indigenous approaches to palliative and end-of-life care which is driven by policies, government mandates (priorities) and laws/regulations.[75] The failure to address social determinants of health for Indigenous Peoples in urban, rural, remote and northern communities,[76] as well as the exclusive use of a biomedical (non-holistic) approach to health care can disempower many Indigenous families and communities and erode their confidence to provide palliative and end-of-life care and engage in traditional healing practices for family members living with life-limiting illnesses.[77] Institutional health-care policies and protocols have posed and continue to pose barriers to traditional practices and cultural grieving processes due to the restrictions on number of visitors, length of visit and the practice of traditional ceremonies, particularly ceremonies for dying and death. These restrictions challenge the valued Indigenous traditions of being surrounded by the entire family and using traditional practices such as preparing special foods, engaging in pipe ceremonies and smudging.[78] Also, access to medications, supplies and home care are not equitable in many rural, remote and northern communities.

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[75] O'Brien V. Person-centered palliative care: a First Nations perspective [thesis]. Hamilton (ON): McMaster University; 2012.

[76] Giesbrecht M, Crooks VA, Castleden H, Schuurman N, Skinner M, Williams A. Palliating inside the lines: the effects of borders and boundaries on palliative care in rural Canada. Social Science & Medicine. 2016;168:273–282.

[77] Habjan S, Prince H, Kelley ML. Caregiving for Elders in First Nations communities: social system perspective on barriers and challenges. Canadian Journal of Aging. 2012;31(2):209–222.

[78] Kelly L, Linkewich B, Cromarthy H, St. Pierre-Hansen N, Antone I, Gilles C. Palliative care of First Nations people: a qualitative study of bereaved family members. Canadian Family Physicians. 2009;55(4):394–395.

Opportunities for access:

With growing recognition of Indigenous title and rights in Canada, there is a need to promote Indigenous models of self-determination with a focus on the negotiation of practical and workable arrangements to implement self-government with jurisdiction and funding associated with health care (including palliative and end-of-life care). To enhance meaningful engagement in authentic intergovernmental relations, all orders of government must actively participate in the form of partnerships and collaborations. They must work alongside Indigenous Peoples with life-limiting illnesses, their families, communities and health-care providers to enhance capacity for palliative and end-of-life care through self-government, self-determination and sustainable community development.

Through reconciliation and decolonization strategies at various levels of the health-care system in Canada, there is growing respect for the integrity of local Indigenous primary care systems which includes traditional systems of care, while ensuring these systems are braided with biomedical health institutions where Indigenous Peoples living with life-limiting illnesses can receive culturally safer palliative and end-of-life care, preferably home-based or community-based.[79]

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[79] Jacklin K, Warry W. Decolonizing First Nations health. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012. p. 374-375.

Promising practice—jurisdiction and funding: First Nations Health Authority

On October 1, 2013, as part of the *BC tripartite framework agreement*, Health Canada transferred its role in the design, management and delivery of First Nations health programming in BC to the new First Nations Health Authority (FNHA).

The FNHA is setting the stage for the transformation of health governance processes and services such as primary care, public health, environmental and community health programs for First Nations Peoples and communities in British Columbia (BC).

With a "made in BC" approach towards First Nations health services, health benefits, policy, planning, engagement, service improvements/integration, investment strategies and partnership implementation in BC regions, it is most likely that other jurisdictions (provinces/territories) and countries are watching and learning how similar governance and organizational models can be adapted in support of Indigenous health and wellness.

From a jurisdiction and funding perspective, Health Canada, the First Nations Health Council and the BC Ministry of Health were all involved in implementing the *BC tripartite framework agreement on First Nation health governance* via the transfer of management, design and delivery of First Nations health and wellness programming to FNHA.

For more information about this historic agreement, visit https://www.fnha.ca/Documents/framework-accord-cadre.pdf.

In May 2018, the *BC tripartite framework agreement* expanded the investments in financial and human resources by Health Canada, the First Nations Health Council and the BC Ministry of Health to support the improvement of mental health and wellness services and corresponding outcomes for First Nations Peoples, families and communities in BC.

The FNHA supports program development, service delivery and research and evaluation that adheres to its Seven Directives: (1) be community-driven, Nation-based; (2) increase First Nations decision-making and control; (3) improve services; (4) foster meaningful collaboration and partnership; (5) develop human and economic capacity; (6) be without prejudice to First Nations interests; and (7) function at a high operational standard.

For more information about the FNHA's 7 Directives, visit https://www.fnha.ca/about/fnha-overview/directives.

Some of the notable drivers that advanced the members of the FNHA in creating and implementing their goals:

- They looked for common ground, areas of mutual interest and win-win situations across all orders of government responsible for and involved in the implementation of First Nations health care and service delivery;
- They commenced their work well in advance of their initial intergovernmental dialogue sessions—understanding cultures, governance, history and worldviews. This learning included having a working knowledge of relevant Supreme Court of Canada judgments that relate to Indigenous title and rights, consultation and accommodation;
- They engaged in intergovernmental relations early and often—as part of the ongoing interpersonal communications and relationship-building process with Indigenous communities, organizations and orders of government in Canada. This process provided opportunities to discuss needs and issues as they arose;
- They acknowledged the past and living history of the orders of government in Canada and the health-care sector; and
- They endeavoured to engage in transparent communication to maintain trust—sharing strengths/opportunities and barriers/challenges.

For more information about the FNHA, visit https://www.fnha.ca.

Funding and decision-making that affect First Nations, Inuit and Métis Peoples, their families and communities are often siloed in different government departments, making it challenging to fully address socio-cultural determinants of health and develop holistic Indigenous approaches to palliative and end-of-life care. The infusion of additional funding and flexible funding models aid in developing, implementing and most importantly, sustaining timely, accessible and culturally congruent palliative and end-of-life care for Indigenous Peoples, their families and communities.

For palliative and end-of-life care to be of high quality, they need to be timely, accessible and culturally congruent for Indigenous Peoples, their families and communities. They must also be culturally safer.

Some examples of cultural safety are being responsive to the needs of Indigenous Peoples across the lifespan and over the generations as well as to the needs of their families and communities and related social support networks/groups, while being flexible in how palliative and end-of-life care is delivered and implemented.

8.3.4 Palliative and end-of-life care stigma

First Nations, Inuit and Métis Peoples may find it difficult to reflect on and discuss palliative and end-of-life care due to fear of hospitals, lack of trust and systemic racism[80] in the health system. Stigma is associated with life-limiting illnesses, dying and death. For some Indigenous communities, there is no word for death or cancer.

Health inequities exist between First Nations, Inuit and Métis Peoples which can intensify stigma associated with palliative and end-of-life care discussions and decision-making.[81, 82, 83, 84, 85] Section 10.5 discusses stigma in the context of advocating for a gender- and 2SLGBTQQIA+-informed approach to palliative and end-of-life care.

Reflections

Developing and sharing toolkits prepared about, by and for First Nations, Inuit and Métis communities can help to reduce the stigma associated with palliative and end-of-life care.

Toolkits may contain a variety of information such as checklists, resources, services, supports for grief, loss, bereavement and survivorship, home support, end-of-life requests and hospice options.[86]

One example is Cancer Care Ontario's Palliative care toolkit for Indigenous communities (Cancer Care Ontario): https://bit.ly/3vXxKmx

8.3.5 Indigenous resilience and cultural resurgence

Indigenous resilience and cultural resurgence are empowering many Indigenous Peoples to reclaim their First Nations, Inuit or Métis identities. Examples of empowerment are connecting or reconnecting to land, people, place and Indigenous spirituality.[87] Also, Indigenous-led or Indigenous-informed education, capacity building programs and supports are on the rise which, in partnership with diverse employers and post-secondary institutions, are

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[80] Barriers in the health-care system include lack of recognition of cultural beliefs and practices associated with dying and death.

[81] Krieg B. Bridging the gap: accessing health care in remote Métis communities, In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012. p. 409-424.

[82] Lavoie JG, Gervais L. Access to primary health care in rural and remote Aboriginal communities: progress, challenges, and policy directions. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012.

[83] Canadian Partnership Against Cancer. First Nations cancer control in Canada baseline report. Toronto (ON); 2013.

[84] Kaufert JM, Wiebe R, Lavallée M, Kaufert PA. Seeking physical, cultural, ethical, and spiritual "safe space" for a good death: the experience of Indigenous Peoples in accessing hospice care. In: Coward H, Stajduhar KI, editors. Religious understandings of a good death in hospice palliative care. Albany State: University of New York Press; 2012. p. 231–256.

[85] Anderson M, Woticky G. The end of life is an auspicious opportunity for healing: decolonizing death and dying for urban Indigenous People. International Journal of Indigenous Health. 2018;13(2):48–60.

[86] https://www.hospicewaterloo.ca/wp-content/uploads/2015/05/Final-Report-Aboriginal-Palliative-Care-Needs-Assessment.pdf

[87] Brant Castellano M. Updating Aboriginal traditions of knowledge. In: Sefa Dei G, Rosenberg B, editors. Indigenous knowledges in global contexts: multiple reading of our world. Toronto (ON): University of Toronto Press; 2000.

strategically integrating and linking skills development with economic diversification in many First Nations, Métis and Inuit communities. Cultural resurgence also includes revitalization of traditional livelihoods, Indigenous languages and community engagement. This resurgence is facilitating opportunities for many Indigenous Peoples to connect or reconnect with their Indigenous identities as sources of resiliency for enhancing self-esteem in the form of renewing purpose and vision in their lives.

Indigenous resilience and cultural resurgence draw on core values and resiliency factors that transcend First Nations, Inuit and Métis worldviews. Examples of values and factors are collectivism and interconnectedness—the relationship between land, identity, people and place and roles of families and communities; balance/harmony between mind, body, spirit and emotions; Aboriginal title and inherent rights (land decisions) and self-determination.[88, 89, 90, 91] However, diversity among Indigenous Peoples and communities in languages, lifestyles and teachings means there is no singular "one size fits all" worldview held by all Indigenous Peoples across Canada.

8.3.6 Indigenous healing, helping and cultural safety

Based on the ground-breaking work of Elaine Papps, Irihapeti Ramsden and Māori experiences in the health-care system,[92] *cultural safety* (kawa whakaruruhau) is defined as "an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the system. It results in an environment free of racism and discrimination, where people feel safe."[93] Furthermore, "cultural safety is based on a framework of two or more cultures interacting in a colonized space - where one culture is legitimized and the other is marginalized. This can happen in hospitals, schools, workplace[s], and in many different service settings."[94]

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[88] Absolon K, Willet C. Putting ourselves forward: location in Aboriginal research. In: Brown L, Strega S, editors. Research as resistance: critical, Indigenous, and anti-oppressive approaches. Canadian Scholar's Press; 2005.

[89] Brant Castellano M. Updating Aboriginal traditions of knowledge. In: Sefa Dei G, Rosenberg B, editors. Indigenous knowledges in global contexts: multiple reading of our world. University of Toronto Press; 2000.

[90] Hart MA. Indigenous worldviews, knowledge, and research: the development of an Indigenous research paradigm. Journal of Indigenous Voices in Social Work. 2010;1(1):1–16.

[91] Simpson L. Anishinaabe ways of knowing. In: Oakes, J, Riew R, Koolage S, Simpson L, Schuster N, editors. Aboriginal health, identity and resources. Native Studies Press; 2000. p. 165-185.

[92] Papps E, Ramsden I. Cultural safety in nursing: the New Zealand experience. International Journal for Quality in Health Care. 1996;8(5):491–497.

[93] https://www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/cultural-safety-and-humility

[94] https://www2.gov.bc.ca/assets/gov/family-and-social-supports/child-care/ics_resource_guide.pdf

In summary, culturally safer practices are actions in colonized spaces (for example, biomedical health-care settings) where First Nations, Inuit and Métis Peoples, their families and communities feel respected, included, welcomed and comfortable being themselves and expressing all aspects of who they are as Indigenous Peoples.

Examining our blind spots: Checking our common assumptions as health-care professionals and helpers

Common blind spots in palliative and end-of-life care that can affect First Nations, Inuit and Métis Peoples, their families and communities are

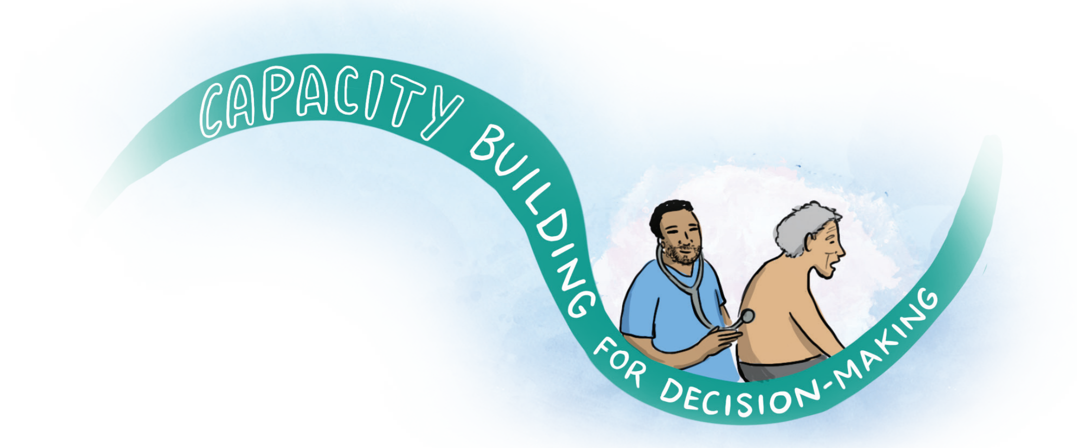
- the melting pot myth—assimilation;
- the colour blind myth—failure to take culture and diversity into account, whereby one denies diversity and related cultural differences typically in the form of statements such as "I don't recognize differences; I treat everyone the same";
- incongruent expectations and assumptions about the helping relationship;
- de-emphasis of macro level social and political systems forces that may impact and influence issues/needs of people with life-limiting illnesses, their families and communities;
- exclusive biomedical focus on palliative and end-of-life care;
- ignorance of one's attitudes, biases and prejudices; covert prejudice—trying to hide negative, stereotyped opinions, but people with life-limiting illnesses notice these cues; and/or cultural ignorance—lack of knowledge as a result of a homogeneous background; and
- institutional racism (for example, human rights discrimination and barriers) which may take the form of actions that diminish, demean or disempower the identity/identities and well-being of people based on individual or collective factors such as ancestry/race, gender, socio-economic status or sexual orientation.

8.3.7 Capacity building

In Canada, Indigenous communities have contributed to successful programs that deliver palliative care to Indigenous peoples.[95]

Capacity building involves developing knowledge, skills and abilities to empower Indigenous Peoples to participate in any or all aspects of decision-making in their communities, regions, provinces/territories and the country as a whole. Capacity building also includes program planning, development, implementation and evaluation intended to enhance holistic palliative and end-of-life care.

For some Indigenous communities, capacity building has been hampered by many challenges, in particular socio-economic barriers (for example, high unemployment rates, low labour force representation, low wage earners, inadequate housing and overcrowding).[96, 97, 98] Despite these barriers, many Indigenous communities have broadened and continue to broaden the scope of capacity building and availability by acknowledging that the answers are in the community. They honour and recognize the strengths, existing roles and capabilities of families and communities, for example, Elders, Knowledge Carriers, Indigenous healers and helpers, community leaders, families and friends. These family and community members are an extended collaborative network of healing and helping support and resources for people living with life-limiting illnesses.[99, 100]



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[95] http://www.cfp.ca/content/cfp/64/9/667.full.pdf (p. 668).

[96] Canadian Partnership Against Cancer. First Nations cancer control in Canada baseline report. Toronto (ON); 2014.

[97] Kaufert JM, Wiebe R, Lavallée M, Kaufert PA. Seeking physical, cultural, ethical, and spiritual "safe space" for a good death: the experience of Indigenous Peoples in accessing hospice care. In: Coward H, Stajduhar KI, editors. Religious understandings of a good death in hospice palliative care. Albany State: University of New York Press; 2012. p. 231–256.

[98] Kelley ML, Prince H. Recommendations to improve quality and access to end-of-life care in First Nations communities: policy implications from the "improving end-of-life care in First Nations communities" research project. Thunder Bay (ON): Lakehead University; 2014.

[99] Hordyk SR, Macdonald ME, Brassard P. End-of-life care in Nunavik, Quebec: Inuit experiences, current realities, and ways forward. Journal of Palliative Medicine. 2017;20(6):647–655.

[100] Kelley ML, Prince H. Recommendations to improve quality and access to end-of-life care in First Nations communities: policy implications from the "improving end-of-life care in First Nations communities" research project. Thunder Bay (ON): Lakehead University; 2014.

Promising practices: Community recommendations for capacity building in palliative and end-of-life care

- Have strong local community leaders as the catalysts for change in making local Indigenous approaches to palliative and end-of-life care a strategic priority as part of the continuum of care for community members across the lifespan and the generations. These leaders are passionate, respected, influential and able to mobilize others.[101]
- Identify, utilize and build on local capacity and resiliencies that already exist within communities to enhance the provision of Indigenous-focused palliative and end-of-life care. [102,103]
- Commit and act to better support self-determination where all orders of government fully involve Indigenous Peoples in the development, design, delivery and evaluation of palliative and end-of-life care policies, programs and services.[104]
- Continue to support partnerships between Indigenous and non-Indigenous community health-care providers and regional palliative and end-of-life care service to improve access and quality of palliative and end-of-life care for Indigenous Peoples.[105]
- Commit to supporting, in the spirit of allyship, Indigenous approaches to community-based palliative and end-of-life care programs and teams in their efforts to identify and address community needs. Advocate for the required resources and supports in Indigenous communities and in the broader health-care system. [106]

Note: Refer to Section 11 for further information on competencies that identify core knowledge, skills and abilities for providing safer, high quality and ethical palliative and end-of-life care.

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[101] Kelley ML, Prince H, Nadin S, Brazil K, Crow M, Hanson G, Maki L, Monture L, Mushquash CJ, O'Brien V, Smith J. Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care. Annuals of Palliative Medicine. 2018;7 (Suppl2):S52–S72.

[102] https://www2.unbc.ca/sites/default/files/sections/neil-hanlon/2009_hanlon_dialoguesfinalreport.pdf

[103] Kelley ML, Prince H, Nadin S, Brazil K, Crow M, Hanson G, Maki L, Monture L, Mushquash CJ, O'Brien V, Smith J. Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care. Annuals of Palliative Medicine. 2018;7 (Suppl2):S52–S72.

[104] Inuit Tairiit Kanatami. 2016–2019 Strategy and Action Plan. Ottawa (ON); 2016.

[105] Kelley ML, Prince H. Six Nations of the Grand River Territory: palliative care needs assessment. Thunder Bay (ON): Lakehead University; 2013.

[106] Kelley ML, Prince H. Six Nations of the Grand River Territory: palliative care needs assessment. Thunder Bay (ON): Lakehead University; 2013.

Promising practice: Natural caregiver education and training program

In 2018, Maamwesying North Shore Community Health Services and the Saint Elizabeth Health First Nations, Inuit and Métis Program partnered to develop a natural caregiver education and training program. This program's purpose is to provide natural caregivers (community-based caregivers and family members) with practical skills-based training that supports their helping roles.[107]

Who are natural caregivers? Natural caregivers are individuals who provide care for family members (for example, Elders, individuals with life-limiting illnesses). The natural caregiver role is typically informal and unpaid though they play an important helping role in keeping community members in their home communities.[108]

Maamwesying North Shore Community Health Services and the Saint Elizabeth Health First Nations, Inuit and Métis Program implemented the natural caregiver education and training program in three phases:

Phase one: Coordinating dialogue sessions to create culturally safer space for natural caregivers to share stories and experiences that could then inform learning priorities, support needs and other related considerations (for example, gaps, challenges, hopes, aspirations and promising practices);

Phase two: Delivering natural caregiver training based on priority needs identified in phase one of the program; and

Phase three: Expanding the development of prepared curricula that address identified needs from phase one and informed by the delivery of training education in phase two. This phase also included advancing a train-the-trainer component to support community-based health care providers with sustained natural caregiver education.[109]

Natural caregiver education and training focuses on traditional teachings, practices and medicines; illnesses and conditions; medication support; palliative care; and self-care. Training sessions are experiential and interactive and involve scenarios, case studies, energizers and collaborative learning.[110]

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[107] SE Health First Nations, Inuit and Métis Program. Caregiver education partnership final report: Maamwesying, North Shore Community Health Services. 2020.

[108] Ibid.

[109] Ibid.

[110] Ibid.

Other lessons learned in advancing the natural caregiver education and training program include

- **developing and sustaining collaborative partnerships** between like-minded Indigenous and non-Indigenous organizations (for example, Saint Elizabeth Health and Maamwesying Community Health) who are jointly committed to building capacity in First Nations, Inuit and Métis communities, improving access to Indigenous-informed palliative care and addressing challenges in health care;
- **having an input and validation process as part of developing and implementing programs.** During the natural caregiver education and training program, the Saint Elizabeth Health First Nations, Inuit and Métis Program reached out to the Maamwesying Senior Patient Advisory Committee to gain input and validation on the proposed education and training program approach in keeping with regional engagement protocols (for example, hosting sharing sessions, choosing preferred session locations, determining the process to validate the program strategy, determining preferred training and education delivery methods and facilitators). This input and validation process ensured there was meaningful involvement of natural caregivers throughout the program (from pre-planning to implementation); and
- **embedding evaluation into program design and implementation.** Continuous improvement and feedback on the program provided opportunities for Maamwesying North Shore Community Health Services and the Saint Elizabeth Health First Nations, Inuit and Métis Program to revise the natural caregiver education and training program. For example, through feedback during phases one and two of the program, phase three customized the scope of curricula to facilitate dedicated training and learning space to explore topics such as chronic illnesses, addictions, palliative and end-of-life care discussions, advanced care planning and medical assistance in dying.[111]

"Our ongoing collaboration with Maamwesying has ensured that the other communities will have the opportunity to benefit from natural caregiver education. This respectful partnership is deeply rooted in the value of knowledge sharing and we are confident that our ongoing collaboration will support communities' desire for natural caregiver education across the country."[112]

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[111] SE Health First Nations, Inuit and Métis Program. Caregiver education partnership final report: Maamwesying, North Shore Community Health Services. 2020.

[112] Ibid.

8.4 Life-limiting illnesses

In palliative and end-of-life care, compassionate care supports and resources are provided to people living with life-limiting illnesses—most likely complex, progressive chronic diseases ranging from cancer to organ diseases and failure. In the case of end-of-life care, death is imminent—with a life expectancy of one year or less.[113]

In Section 8.5, we invite readers to expand the scope of palliative and end-of-life care to include death in crisis (for example, sudden death) from a grief, loss and bereavement perspective.

8.4.1 Cancer diagnosis

Cancer remains the leading cause of death in Canada. An estimated two in five Canadians will be diagnosed with cancer in their lifetime and one in four will die from cancer.[114] Tumours are benign, precancerous or malignant:

- **Benign tumours** are not cancerous and rarely threaten life. They tend to grow quite slowly, do not spread to other parts of the body and are usually made up of cells quite similar to normal or healthy cells. They may cause problems if they grow very large, become uncomfortable and/or place pressure on other organs—for example, a brain tumour pressing inside the skull.
- **Precancerous (or premalignant)** is the condition involving abnormal cell growth which may develop into cancer.[115]
- **Malignant tumours** grow more quickly than benign tumours. They can spread and destroy surrounding body tissue. Malignant tumours can spread to other body parts (metastasis), growing and dividing in healthy tissues.

Cancer can be organized into five main types:

- **Carcinoma** is a cancer in the epithelial cells.[116] Carcinomas may invade the neighbouring tissues and organs and metastasize to other body parts. Examples of carcinoma are breast, lung and colon cancer.
- **Sarcoma** is a malignant tumour of the bone or soft tissue.[117] Examples of sarcoma are leiomyosarcoma, liposarcoma and osteosarcoma.

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[113] Lemchuk-Favel L. The provision of palliative end-of-life care services in First Nations and Inuit communities. FAV COM; 2016.

[114] Canadian Cancer Society. Canadian Cancer Statistics 2021. Toronto (ON); 2021. https://cancer.ca/en/research/cancer-statistics/cancer-statistics-at-a-glance

[115] https://www.cancerresearchuk.org/what-is-cancer/how-cancer-starts/types-of-cancer

[116] The lining of cells that helps protect or enclose organs.

[117] For example, fat, muscle, blood vessels and connective tissues that support and surround organs.

- **Lymphoma and myeloma** are cancers that begin in the cells of the immune system. Specifically, lymphoma is cancer of the lymphatic system which runs all through the body. Myeloma starts in the plasma cells.[118] This type of cancer affects the cell's ability to effectively produce antibodies.
- **Leukaemia** is a cancer of the white blood cells and bone marrow.[119]
- **Brain and spinal cord cancers** are cancers of the central nervous system.[120]

Compared to non-Indigenous populations in Canada,

- **First Nations adults** have higher incidences of colorectal cancer, kidney cancer, cervical cancer and liver cancer. There are lower incidences of prostate cancer, breast cancer, bladder cancer, uterine cancer, brain cancer, ovarian cancer, non-Hodgkin lymphoma, leukemia and melanoma for First Nations adults.[121]
- **Inuit adults** have higher incidences of lung cancer, liver cancer, esophageal cancer, salivary cancer and throat cancer. There are lower incidences of breast cancer, prostate cancer and endometrial cancer for Inuit adults.[122]
- **Métis adults** have higher incidences of breast cancer, lung cancer, liver cancer, throat cancer, gallbladder cancer and cervical cancer. There are lower incidences of colorectal cancer (in women), melanoma and leukemia for Métis adults.[123]

Indigenous Peoples are usually diagnosed in later stages of cancer which can reduce their life expectancy.

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[118] A type of white blood cell that produces antibodies to help fight infection.

[119] Tissue that forms blood cells.

[120] https://www.cancerresearchuk.org/what-is-cancer/how-cancer-starts/types-of-cancer

[121] Mazereeuw MV, Withrow DR, Nishri ED, Tjepkema M, Marrett LD. Cancer incidence among First Nations adults in Canada: follow-up of the 1991 census mortality cohort (1992–2009). Canadian Journal of Public Health, 2018;109(5-6):700–709.

[122] Inuit Tapiriit Kanatami. Inuit & cancer: fact sheets. Ottawa (ON); 2009

[123] Mazereeuw MV, Withrow DR, Nishri ED, Tjepkema M, Vides E, Marrett LD. Cancer incidence and survival among Métis adults in Canada: results from the Canadian census follow-up cohort (1992–2009). Canadian Medical Association Journal. 2018;190(11):E320–e6.

Incidence

Compared to the non-Indigenous population,

First Nations adults have a

Lower incidence of

- prostate cancer
- breast cancer
- bladder cancer
- uterine cancer
- brain cancer
- ovarian cancer
- non-Hodgkin lymphoma
- leukemia
- melanoma

Higher incidence of

- colorectal cancer
- kidney cancer
- cervical cancer
- liver cancer

Inuit adults have a

Lower incidence of

- breast cancer
- prostate cancer
- endometrial cancer

Higher incidence of

- lung cancer
- liver cancer
- esophageal cancer
- salivary cancer
- nasopharyngeal cancer

Métis adults have a

Lower incidence of

- colorectal cancer (in women)
- melanoma
- leukemia

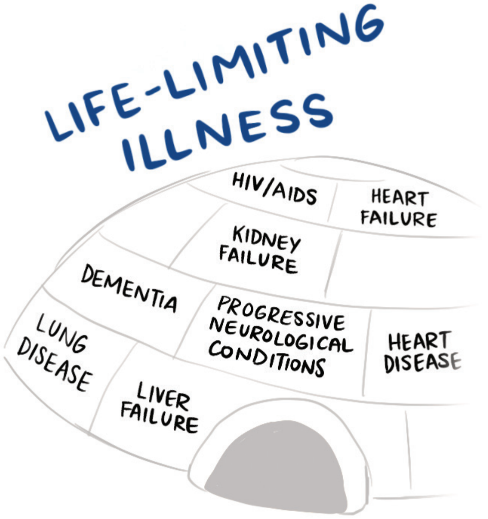
Higher incidence of

- female breast cancer
- lung cancer
- liver cancer
- larynx cancer
- gallbladder cancer
- cervical cancer

8.4.2 Non-cancer diagnosis

A palliative approach to care is also important in non-cancer diseases. Examples of life-limiting illnesses that may necessitate access to timely and culturally congruent palliative and end-of-life care are

- **Dementia.** This disease causes a deterioration of the brain. The disease progresses gradually and slowly. It gets worse over time and can result in difficulty swallowing, decreased food intake and aspiration (pneumonia).
- **Heart disease and heart failure.** This disease involves damage to the heart, whereby the heart cannot properly pump blood throughout the body. Complications from heart disease include weakness and breathing difficulties. Heart failure involves the buildup of fluid in the heart causing problems for the heart muscle's ability to properly pump.
- **HIV/AIDS.** HIV (human immunodeficiency virus) is carried from person to person through body fluids such as blood, breast milk, semen or vaginal secretions. It damages the immune system, and this damage can increase risk of illness and infection. AIDS (acquired immune deficiency syndrome) is an advanced stage of the HIV infection. The virus attacks white blood cells resulting in some individuals with AIDS developing other life-threatening illnesses such as cancer.
- **Kidney failure.** This condition involves damage to the kidneys which decreases one's ability to stay healthy. Complications with kidney failure include high blood pressure, anemia (low blood count), buildup of toxic breakdown products from the body, weak bones and nerve damage.
- **Liver failure.** This condition involves damage to the liver (cirrhosis) which puts one at higher risk of confusion, bleeding, blood clots and fluid accumulation, including to the legs and abdomen (ascites). Liver failure can also increase toxic substances in the blood.
- **Lung disease.** Lung diseases cause poor lung function. One example is chronic obstructive pulmonary disease (COPD) which causes breathing difficulties and includes emphysema and/or chronic bronchitis.
- **Progressive neurological conditions.** Many diseases affect the nervous system such as amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease and Huntington's disease. These diseases affect different areas of the nervous system and can affect muscles and movement.[124]



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[124] https://getpalliativecare.org/whatis/disease-types

8.5 Special considerations

In this section of this report, special considerations are introduced: Indigenous social determinants of health, pandemic care, medical assistance in dying and death in crisis.

These considerations recognize the specialized context, competencies and settings for advancing Indigenous approaches to palliative and end-of-life care in Canada. Each of the above special considerations are reflective of current and emerging trends and topics shaping discussions, research and applied practice in palliative and end-of-life care.

8.5.1 Indigenous social determinants of health

The most important factors influencing the health of populations are life circumstances. Often referred to as "social determinants of health," they are shaped by the distribution of money, power and resources in society and are responsible for the differences and inequities in health status within and between communities.[125, 126, 127]

The following are examples of social determinants of health:

- **Income and socio-economic status.** This determinant includes people having access to the basic needs in life (for example, food security, water quality, safety, housing/shelter) and access to high-quality health services, resources and supports (for example, access to health information and technology services; transportation to hospitals from rural, remote and northern locations; palliative and end-of-life care).[128, 129, 130, 131, 132]
- **Labour force participation.** This determinant includes people and groups accessing economic diversification and employment opportunities in communities, regions, industries and sectors. Of note, there continues to be an increase in Indigenous Peoples (in particular, younger people) leaving their home communities for economic and other opportunities (for example, formal employment). This increase has caused a significant shortage of people who can or would usually care for community members who have life-limiting illnesses.[133, 134]

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[125] Fruch V, Monture L, Prince H, Kelley ML. Coming home to die: Six Nations of the Grand River

[126] https://www.itk.ca/wp-content/uploads/2016/07/ITK_Social_Determinants_Report.pdf

[127] https://fnim.sehc.com/getmedia/960a0972-2313-4fff-b0dd-f407fc71c94d/Research_SocialDeterminantsofHealth.pdf.aspx?ext=.pdf

[128] Beatty BB, Berdahl L. Health care and Aboriginal seniors in urban Canada: helping a neglected class. The International Indigenous Policy Journal. 2011;2(1):1–16.

[129] Global Institute of Psychosocial, Palliative & End-of-Life Care. A search for solutions: a gathering on palliative care for First Nations, Inuit & Métis Peoples. GIPPEC Symposium Report; 2016.

[130] Habjan S, Prince H, Kelley ML. Caregiving for Elders in First Nations communities: social system perspective on barriers and challenges. Canadian Journal of Aging. 2012;31(2):209–222.

[131] Hordyk SR, Macdonald, ME, Brassard P. End-of-life care in Nunavik, Quebec: Inuit experiences, current realities and ways forward. Journal of Palliative Medicine. 2017;20(6):647–655.

[132] https://soahac.on.ca/wp-content/uploads/2015/01/Final-V7-SOAHAC-Palliative-Care-Report-_-July-31-16.pdf

[133] Habjan S, Prince H, Kelley ML. Caregiving for Elders in First Nations communities: social system perspective on barriers and challenges. Canadian Journal of Aging. 2012;31(2):209–222.

[134] Kelley ML. An Indigenous issue: why now? Guest Editorial. Journal of Palliative Care. 2010;26(1):5.

- **Education and literacy.** This determinant includes access to educational opportunities to support career/life development. Education and literacy barriers (including health literacy) can prevent people living with life-limiting illnesses and their families from having clear communications with health-care providers and may prevent informed decision-making regarding access to services, resources and supports.[135, 136, 137]
- **History of colonialization.** For more information about the history of colonialization, intergenerational trauma and health inequities, refer to Section 8.3.2.
- **Spirituality.** For more information about Indigenous spirituality and connections with our ancestors, refer to Section 9.3.
- **Connection to community and social support networks.** For more information about the role of community as a social determinant of health, refer to Section 9.4.
- **Culture and language.** For more information about Indigenous languages, refer to Section 9.2.3.
- **Connection to land, geography and physical environments.** Geography influences where and how Indigenous Peoples living with life-limiting illnesses and their families access timely and culturally congruent palliative and end-of-life care.

  Geography disproportionately impacts holistic care of peoples residing in rural, northern and remote communities across Canada compared to those living in urban centres. Geographic locations often prevent Indigenous Peoples living with life-limiting illnesses from having the necessary infrastructure (for example, technology, water, heating, sewage facilities, medications, diagnostic testing, medical transportation) to remain in their communities. This lack of infrastructure creates scenarios where people must move far away from their communities and their families for palliative and end-of-life care resulting in relocation, high travel costs, isolation, separation and the progression to advanced illness(es). [138, 139, 140, 141, 142, 143]

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[135] Kelley ML, Melody W, Prince H. Fort William First Nation: palliative care needs assessment. Thunder Bay (ON): Lakehead University; 2013.

[136] O'Brien AP, Bloomer MJ, McGrath P, Clark K, Martin T, Lock M, Pidcock T, van der Riet P, O'Connor M. Considering Aboriginal palliative care models: the challenges for mainstream services. Rural and remote health. 2013;13(2):2339.

[137] https://sencanada.ca/content/sen/committee/432/LCJC/Briefs/Brief_SuzanneL.Stewart_e.pdf

[138] Canadian Partnership Against Cancer. First Nations cancer control in Canada baseline report. Toronto (ON); 2014.

[139] Kelley ML. An Indigenous Issue: why now? Journal of Palliative Care. 2010, Spring;26(1):5.

[140] McGrath P. The living model: an Australian model for Aboriginal palliative care services delivery with international implications. Global Exchange. Journal of Palliative Care. 2010;26(1):59–64.

[141] McRae S, Caty S, Nelder M, Picard L. Palliative care on Manitoulin Island: views of family caregivers in remote communities. Canadian Family Physician. 2000, June;46:1301–1307.

[142] https://www.theglobeandmail.com/canada/article-how-elders-from-nunavut-end-up-in-long-term-care-thousands-of

[143] https://www.itk.ca/wp-content/uploads/2016/07/ITK_Social_Determinants_Report.pdf

Readers are invited to reflect on how palliative and end-of-life care resources need to be deliberately distributed to Indigenous Peoples living with life-limiting illnesses who reside in various geographic areas across Canada.

Legal decisions on Aboriginal title and rights are now facilitating ways for some Indigenous communities in Canada to advance self-determination through the creation of their own community-based and community-led laws, programs and services (for example, health care, infrastructure).

An overview of notable Aboriginal title and rights case law can be found on the Mandell Pinder LLP Barristers & Solicitors website; https://www.mandellpinder.com/landmark-cases.

For more information about relationships to land, people and place, refer to Section 9.2.

- **Gender and sexual orientation.** For more information about gender- and 2SLGBTQQIA+-informed palliative and end-of-life care, refer to Section 10.5.

8.5.2 Pandemic care

COVID-19 was officially declared a pandemic by the World Health Organization on March 11, 2020.[144] The COVID-19 pandemic continues to affect various aspects of our life—including our individual and collective physical, mental and spiritual well-being.

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[144] https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020

Voices from the field: An Indigenous lens on palliative and end-of-life care

In discussions with the Partnership, some Indigenous practitioners shared the following reflections on care during a pandemic:

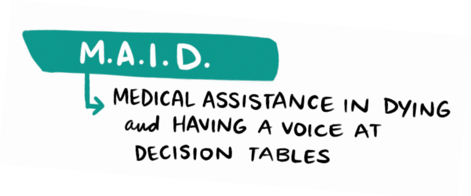
COVID has been the great magnifier of gaps in Indigenous communities, and what's happening around the recovery of our little people that were killed and murdered in residential schools, there's a lot of trauma that's happening right now in communities. Because of COVID we don't have the healthy networks that we would primarily rely on. We rely on these networks because of our concepts of kinship, but also because we don't have a lot of formalized services, so our community and family are of utmost importance.

COVID has hampered our ability to grieve and to mourn and to do the work we need to do in communities. Grief is becoming a big thing, I hear it from the health-care providers because they are the sons, daughters, nieces and nephews of the people they are providing care for.

We have tremendous amounts of grief right now. When we're looking at educational needs and resources and how to support communities, that's definitely something I would like to see happen, not only around palliative care but just in general, around loss in communities, that grief aspect.

In response to the COVID-19 pandemic, most hospitals and health-care facilities across Canada have restricted visitation, even for people during their final hours of life. These restrictions limit the capacity of families and community members to support each other in the grieving and bereavement process. Cancellations of cancer surgeries and fear of COVID-19 exposure are further delaying diagnoses and treatment of cancer and other life-limiting illnesses. These disruptions in service only add to longstanding health inequities, particularly for Indigenous Peoples, people with lower incomes and socio-economic status, 2SLGBTQQIA+ Peoples and people living in rural, remote and northern communities.

During the COVID-19 pandemic, virtual care has been used to facilitate outreach and support to people living with life-limiting illnesses, their families and communities. Furthermore, virtual engagement is also creating a safer place for dialogue and collaboration among caregivers, orders of government, health-care organizations and providers, community leaders and educators to identify gaps and co-develop strategies and programs for enhancing Indigenous approaches to palliative and end-of-life care.



8.5.3 Medical assistance in dying (MAID)

MAID occurs “when an authorized doctor or nurse practitioner provides or administers medication that intentionally brings about a person’s death, at that person’s request. This procedure is only available to eligible individuals.”[145] Ethical standards and practices associated with MAID are in the early stages of discussion in the health-care field across Canada. Therefore, further exploration is needed on this topic and its application in cross-cultural settings.

Complex planning and guidance from First Nations, Inuit and Métis Elders, Healers and Knowledge Carriers across Canada are needed as their voices and perspectives are often rare or absent from this national policy discussion.

Reflections on MAID[146]

As MAID continues to be discussed in the health-care field in Canada, consider the following questions:

- What are the attitudes and perceptions of First Nations, Inuit and Métis Peoples across the generations (from youth to Elders) regarding MAID, including expectations related to palliative and end-of-life care needs, programs and resources?
- What are the implications of possible MAID laws, policies and practices given the historical context of harm resulting from colonization directed towards First Nations, Inuit and Métis Peoples in Canada?
- What are the implications of possible MAID laws, policies and practices given the spiritual context of life-limiting illnesses, dying and death in the lives of First Nations, Inuit and Métis Peoples in Canada?

8.5.4 Death in crisis

Death in crisis brings feelings of shock, guilt, disbelief, anger and sadness to families and communities. A sudden death leaves families and communities feeling particularly vulnerable. Though it is not often discussed or associated with palliative care, readers are invited to expand their perspectives on Indigenous approaches to palliative care to include death in crisis and its connections with grief, loss and bereavement.

Death in crisis includes an unexpected/sudden death, for example, suicide, traumatic accident (motor vehicle accident, fire, drowning), overdose, perinatal loss (miscarriage and stillbirth), sudden natural causes (heart attack, fatal stroke) or murder.

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[145] https://bit.ly/3LDbfde

[146] https://sencanada.ca/content/sen/committee/432/LCJC/Briefs/Brief_SuzanneL.Stewart_e.pdf

Following a person's death in crisis, their families and communities are in a vulnerable state. During this time, it is important to have access to grief, loss and bereavement support. Caregivers, orders of government, health-care organizations and providers, community leaders and educators can each draw upon their respective competencies to offer healing and help to Indigenous families. This healing and help can be in the form of assistance in understanding their rights under the law, financial help with funeral expenses, coverage of loss of income and provision of counselling resources (for example, grief, loss and bereavement counselling).

Palliative care providers can assist families and communities experiencing death in crisis by

- proactively involving Elders, Knowledge Carriers and grief specialists as there are many complexities related to death in crisis;
- using a trauma-informed approach to grief care;
- facilitating and/or sharing thoughts and feelings with others who experienced a similar loss;
- gaining perspectives about grief, loss and death and helping to alleviate feelings of guilt; and
- supporting and navigating options and coordinating (if and where appropriate) the use of cultural protocols, activities and rituals associated with death and loss.

It is important and respectful to acknowledge that everyone grieves in their own way and in their own time.

8.6 Summary

Indigenous perspectives and considerations on palliative and end-of-life care create pathways towards truth and reconciliation. These pathways enable topics such as identity (loss, healing and reconnection), government laws and policies and the intergenerational effects of these colonial events to be recognized in relation to access to health care and related services and supports for First Nations, Inuit and Métis Peoples, their families and communities.

Through the recognition of the truth and living history of Indigenous Peoples in Canada, resiliencies and strengths can be honoured and documented. This process can aid calls for action in revising or creating new laws, policies and practices that are culturally congruent to First Nations, Inuit and Métis Peoples and that honour ways of knowing and being in areas such as health and wellness, language and culture.

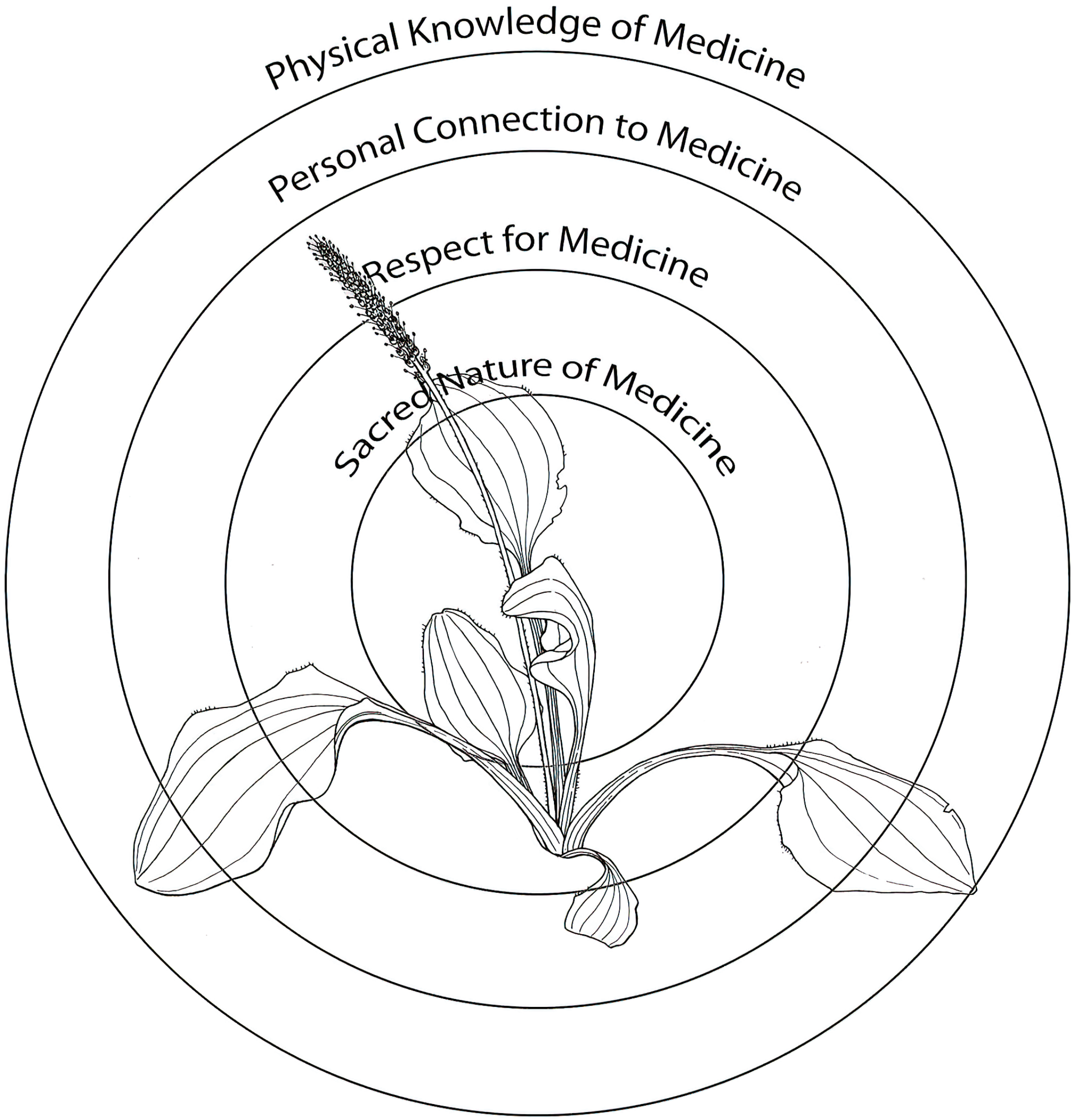
The truth and reconciliation journey is humbling as Canadians come to terms with the historical impacts of colonization and its intergenerational implications over time. Canada is endeavouring to heal as a country.

It will be important for Indigenous governments and organizations to work with and alongside orders of government to advance Indigenous approaches to palliative and end-of-life care.

As is often the case, the galvanizing of local and regional efforts and actions can create catalysts for provincial/territorial and federal levels of government to hear from citizens about Indigenous approaches to palliative and end-of-life care.

This process can commence a transformative shift in changing perspectives, attitudes and behaviours.

Figure 3. Elder Dr. Murdena Marshall's concentric circles model for Mi'kmaw Knowledge.



Credit: Collaborative work by the research team of the Canada Research Chair in Integrative Science and Mi'kmaw Elders in Unama'ki/Cape Breton.[147]

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[147] http://www.integrativescience.ca/Media

9. Culture as medicine

From the realms of the human world, the sky dwellers, the water beings, forest creatures and all other forms of life, the beautiful Mother Earth gives birth to, nurtures and sustains all life. Mother Earth provides us with our food and clean water sources. She bestows us with materials for our homes, clothes and tools. She provides all life with raw materials for our industry, ingenuity and progress. She is the basis of who we are as "real human beings" that include our languages, our cultures, our knowledge and wisdom to know how to conduct ourselves in a good way. If we listen from the place of connection to the Spirit That Lives in All Things, Mother Earth teaches what we need to know to take care of her and all her children. All are provided by our mother, the Earth.[148]

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[148] http://www.afn.ca/honoring-earth

9.1 Overview

Culture is a complex concept that refers to many aspects of living and being in the world. A holistic concept of health and wellness (the balance of the mind, body, emotions and spirit) is an integral part of having a strong cultural identity.

In many First Nations, Inuit and Métis communities, it is understood that a way to enhance individual, family and community healing and helping is through culturally congruent practices.

When culture is a core component to palliative and end-of-life care, there are opportunities for programs, policies and broader strategies to honour relationships to land, people and place; spirituality; ceremonies, ritual and cultural practices; and the roles of family and community.

Indigenous ways of knowing about healing and helping are often linked to land and place through songs, stories, ceremonies and language. As such, land and place are often fundamental dimensions of cultural identity, healing and helping (physical, mental, emotional and spiritual dimensions) for many Indigenous Peoples across Canada.

Culturally safer palliative and end-of-life care provide a welcoming space for Indigenous Peoples to connect or reconnect with their identities by being on the land and in community, speaking traditional language(s) and practicing culture.

9.2 Relationships to land, people and place

Land and community can be viewed as healers and helpers for many First Nations, Inuit and Métis Peoples in Canada. Since time immemorial, Indigenous Peoples developed their cultures, languages and ways of knowing through their understanding of and relationships with land, people and place (community). Therefore, in addition to using biomedical-based palliative and end-of-life care supports and resources, it is equally important to acknowledge and recognize how cultural ceremonies, rituals and related spiritual practices are medicine for many Indigenous Peoples.

Promising practice: Land and territorial acknowledgements

An important part of decolonization involves land and territorial acknowledgments.

Land and territorial acknowledgements do more than just recognize the land. They are a personal, reflective practice by individuals who acknowledge Indigenous Peoples' inherent right to the land while at the same time place themselves in relation to Indigenous Peoples.

Native Land provides an interactive map of Turtle Island (North America) where individuals, groups and organizations can locate and learn about the ancestral Indigenous lands in which they work and live. https://native-land.ca

9.2.1 Indigenous identity

> Identity is understood as being neither neutral nor passive....Identity has been seen as something that a person does; in other respects, identity is seen as defining what a person is. Because identities are embedded in systems of power based on race, class, and gender, identity is a highly political issue, with ramifications for how contemporary and historical collective experience is understood. Identity, in a sense, is about ways of looking at people, about how history is interpreted and negotiated, and about who has the authority to determine a group's identity or authenticity....[Indigenous] individual identity is always being negotiated in relation to collective identity, and in the face of an external, colonizing society.[149]

There is much diversity among Indigenous Peoples and communities (First Nations, Métis and Inuit) in terms of languages, lifestyles and teachings. At the same time, universal connections across Indigenous Peoples unite Indigenous identities and are sources of resiliency: relationships between people, land and place; spirituality; collectivism; balance (physical, mental, emotional and spiritual); wholeness and interconnectedness; the important role of family and community; circular (or non-linear) communication styles; and the value of experiential learning, healing and helping.

> Geography has played an important role in the development of Inuit identity. Both voluntary and involuntary migration patterns mark family and community histories. Migration trajectories affect where people choose to die, the persons who are available to provide this care, and the presence of loved ones at the time of death.[150]

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[149] Lawrence B. Gender, race, and the regulation of Native identity in Canada and the United States: an overview. Hypatia. 2003;18(2):3–31.

[150] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p.13.

STORIES

ORAL TRADITIONS

SONGS

9.2.2 Land and place-based healing and helping

> In managing a transition from a colonial to a de-colonial world, from the land to the community, and from adversity to whole health, land-based practices, and knowledges central to Indigenous resilience aim to integrate cultural processes into the everyday, while ensuring seamless continuity for those in need.[151]

Land and place-based healing and helping include a variety of activities such as

- drumming, singing, dancing and praying;
- performing rites of passage (for example, funerals);
- connecting to nature: cleansing, reconnecting to something larger than ourselves;
- listening to Elders' and Knowledge Carriers' stories and guidance; and
- involving community, for example, sharing food/meals with family and community, playing music with family and community.

Land and place-based healing and helping programs are community-driven and are developed in response to specific health priorities (for example, palliative and end-of-life care) for communities. Knowledge Carriers and Elders are engaged in land and place-based healing and helping from planning to implementation, and these programs are based on localized culturally specific worldviews, including values and healing practices.

In the *Evaluation of the health and social services system in Nunavik: The users' perspective* (2021) *report*, Inuuqatigiitsianiq (relationships) is viewed as central to the Inuit vision of health.

Inuuqatigiitsianiq generally refers to "relationships between persons sharing a place. An important aspect of health for the Inuit, the quality of relationships with family, friends, neighbours and community members (including non-Inuit) is a key dimension of the experience of health."[152]

Inuuqatigiitsianiq is further extended to Inuit connections to the traditional territory and the quality of trust between the users (for example, individuals with life-limiting illnesses) and health-care providers and helpers.[153]

Language is another dimension to delivering land and place-based healing and helping especially knowledge such as place names, cultural practices and local area history.[154]

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[151] Rady I. Land for healing: developing a First Nations land-based service delivery model. 5. Bothwell (ON): Thunderbird Partnership Foundation; 2018.

[152] https://nrbhss.ca/sites/default/files/documentations/corporatives/UserPerspective_Report_EN_digital.pdf (p. 25).

[153] https://nrbhss.ca/sites/default/files/documentations/corporatives/UserPerspective_Report_EN_digital.pdf (p. 32).

[154] Wildcat M, McDonald M, Irlbacher-Fox S, Coulthard G. Learning from the land: Indigenous land-based pedagogy and decolonization. Decolonization: Indigeneity, Education & Society. 2014;3(3):I–XV.

Snapshot: Indigenous healing and helping resources

The following is a starting point for Indigenous healing and helping resources that can inform palliative and end-of-life care for Indigenous Peoples, their families and communities:

Aboriginal healing in Canada: Studies in therapeutic meaning and practice: http://www.ahf.ca/downloads/aboriginal-healing-in-canada.pdf

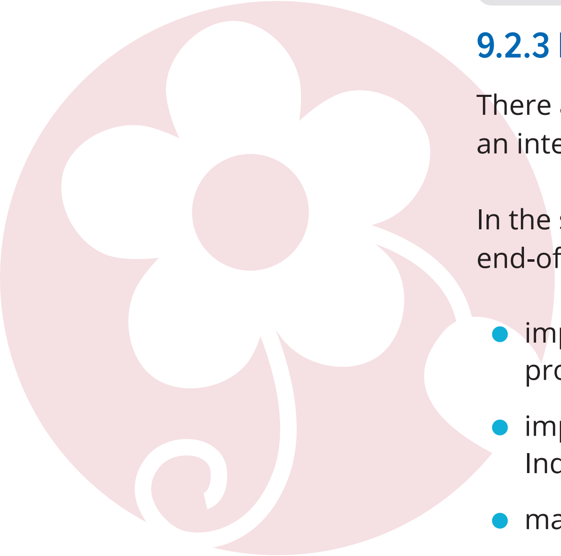
Aboriginal traditional healing: https://bit.ly/3KApUEG

First Nations Traditional Models of Wellness: https://bit.ly/3P1Kbqv

Inuit Qaujimajatuqangit: The role of Indigenous knowledge in supporting wellness in Inuit communities in Nunavut: https://www.ccnsa-nccah.ca/docs/health/FS-InuitQaujimajatuqangitWellnessNunavut-Tagalik-EN.pdf

The circle of healing: https://www.ceaa.gc.ca/050/documents/p63928/92023E.pdf

Traditional healing and wellness: https://bit.ly/3s45cqv



9.2.3 Indigenous languages

There are a vast array of Indigenous languages across Canada with over 70 Indigenous languages being spoken. For an interactive map of Indigenous languages in Canada, visit https://native-land.ca.

In the spirit of cultural revitalization, access, use and interpretation of Indigenous languages during palliative and end-of-life care can improve communications and information management for readers by

- improving health-care system navigation for families and caregivers using an Indigenous health navigation program;[155, 156]
- improving locally and culturally effective healing and helping messages through a better understanding of Indigenous health beliefs;[157] and
- making available and using Indigenous interpretation services.[158]

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[155] https://soahac.on.ca/wp-content/uploads/2015/01/Final-V7-SOAHAC-Palliative-Care-Report-_-July-31-16.pdf

[156] https://www.hospicewaterloo.ca/wp-content/uploads/2015/05/Final-Report-Aboriginal-Palliative-Care-Needs-Assessment.pdf

[157] Jacklin K, Warry W. Decolonizing First Nations Health. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012. p. 374–375.

[158] https://www.lco-cdo.org/wp-content/uploads/2019/03/Dying-alone_An-Indigenous-mans-journey-at-EOL_C-Bablitz.pdf

According to an interpreter, it must be kept in mind that expressing in Inuktitut is really not the same as expressing in English and that it can happen that one concept requiring 10 sentences to explain in English can also be accomplished in Inuktitut by using just two sentences.[159]

Interpreters played a unique role in EOL [end-of-life] care conversations among patients, families, nurses and physicians. As interpreters shared their experiences, it became apparent that the pressures they experience and challenges they face were significant. In light of this, interpreters were unanimous in stating that regular training and support was needed to fulfill their responsibilities.[160]

Interpreters also functioned as cultural brokers, at times explaining the medical culture of the doctors and nurses to patients, and at times representing the Inuit cultural perspective to doctors and nurses.[161]

The use of Indigenous languages describing palliative and end-of-life care[162] can help reduce hesitancy for people with life-limiting illnesses. Use of Indigenous languages can also minimize the use of biomedical jargon and formality while centering the continuum of care on Indigenous Peoples' individual and collective experiences and ensuring accessibility to Indigenous approaches to palliative and end-of-life care.[163, 164]

Did you know?

Through the First Peoples Cultural Council in British Columbia (BC), the First Voices website provides a wealth of information on archiving, sharing and celebrating diverse Indigenous languages in BC and across Canada.

For more information, visit https://www.firstvoices.com.

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[159] Hordyk S-R, MacDonald, M-E, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 55.

[160] Ibid. p. 60.

[161] Ibid. p. 65.

[162] For example, advance care planning decisions, illness progression, palliative care interventions, financial planning, assessment, decision-making and forms and equipment acquisition.

[163] https://www.cancercareontario.ca/en/guidelines-advice/treatment-modality/palliative-care/toolkit-aboriginal-communities

[164] Hordyk SR, Macdonald ME, Brassard P. End-of-life care in Nunavik, Quebec: Inuit experiences, current realities, and ways forward. Journal of Palliative Medicine. 2017;20(6):647–655.

9.2.4 Community engagement and partnerships

> **Nothing about us without us.**
>
> This statement signifies that local engagement and consultation with First Nations, Inuit and Métis Peoples and communities is required when developing and implementing palliative and end-of-life care programs.

NOTHING about us
WITHOUT US

Community engagement and partnerships in palliative and end-of-life care involve organizations and orders of government (for example, Indigenous governments/communities, provincial/territorial governments and the federal government). They include Indigenous approaches to palliative and end-of-life care in the form of supports and services that are multidisciplinary and expand across sectors (health, justice, skills development and employment and social services–to name a few).

> Community engagement has been recognized as a cornerstone of primary health care for at least thirty years (WHO, 1978), and continues to be promoted in current debates on social and Indigenous determinants of health as a key to addressing health inequities.[165]

Community engagement and partnerships encourage First Nations, Inuit and Métis communities and organizations to work cooperatively with health-care initiatives, policies, protocols and quality improvement to ensure a holistic continuum of health services, resources and supports that are timely, accessible and culturally congruent for Indigenous Peoples, their families and communities.

> When co-developing LEAP [Learning Essential Approaches to Palliative Care] training courses, collaboration and engagement with communities and Elders ensures that the resources will be effective and resonate in a community context and that they are developed to meet community-identified needs.
>
> It is important to have Elders and community members involved in the product in a full-circle way: right from visioning to reviewing the final product.
>
> The [LEAP] tools continue to see strong uptake in Indigenous communities because they have been developed through ongoing community engagement and are delivered in partnership with Indigenous communities across the country every year.
>
> -Jeffrey Moat (Pallium Canada Chief Executive Officer; Scottish-Canadian)

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[165] Lavoie JG, Gervais L. Access to primary health care in rural and remote Aboriginal communities: progress, challenges, and policy directions. In: Kulig JC, Williams AM, editors. Health in rural Canada. Vancouver (BC): UBC Press; 2012.

9.3 Indigenous spirituality and connections with ancestors

For many First Nations, Inuit and Métis Peoples, their families and communities, dying and death are not just about biomedical and physical processes. It is about an individual's journey to the spirit world—a social and spiritual event to be honoured and celebrated as a collective.

9.3.1 Spirit and spirituality

> A person's inner Spirit is intertwined with their family, community and the land and cannot be understood apart from them.[166]

While religion usually entails adhering to a certain belief system, spirituality is the quality of being concerned with the human spirit or soul as opposed to material or physical things. The soul is the spiritual part of a human being regarded as immortal.

For readers, gaining competencies and comfort in braiding spirituality with palliative and end-of-life care aids in

- honouring the holistic self—mind, body and spirit;
- raising awareness of spirituality of people with life-limiting illnesses;
- recognizing spiritual values as a source of strength during illness, dying and death that help many make sense and meaning out of the purpose of our lives on earth; and
- helping people living with life-limiting illnesses connect with their own powers of thinking, feeling, deciding, willing and acting.

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[166] Dell CA, Seguin M, Hopkins C, Tempier R, Mehl-Madrona L, Dell D, Mosier K. From benzos to berries: treatment offered at an Aboriginal youth solvent abuse treatment centre relays the importance of culture. Canadian Journal of Psychiatry. 2011;56(2):75–83.

9.3.2 Role of ancestors

Voices from the community: A First Nations lens on palliative and end-of-life care

I was 18 years old and my husband was 23 years old when he was diagnosed with terminal cancer. Despite having cancer, he lived six years in fairly good health. When my husband was 29 years old, tumours popped out everywhere. He told me, “Ella, please don’t let them put me in the hospital.”

He felt that the hospital was going to do everything in their power to keep him alive regardless and he simply said, “I do not want to live any longer than I need to be.”

Based on his request, my family and I kept him home during his care. He was prescribed pharmaceutical medicine because he was in a lot of pain.

My husband dealt with the pain but he was afraid. He kept seeing people and inviting them in for tea and coffee. I did not see these people as they were some of our ancestors. I believe they came to help my husband begin his journey to the spirit world.

On his last day alive, he asked me if I was ready (for him to die). I said “no, I wasn’t” but I guess I would have to be. Then, he asked if I was going to be there when he died. I said, “yes, I would be there.”

“I’m scared because I’ve never died before,” he stated. And I said, “well, I’m scared too, I’ve never seen somebody die.”

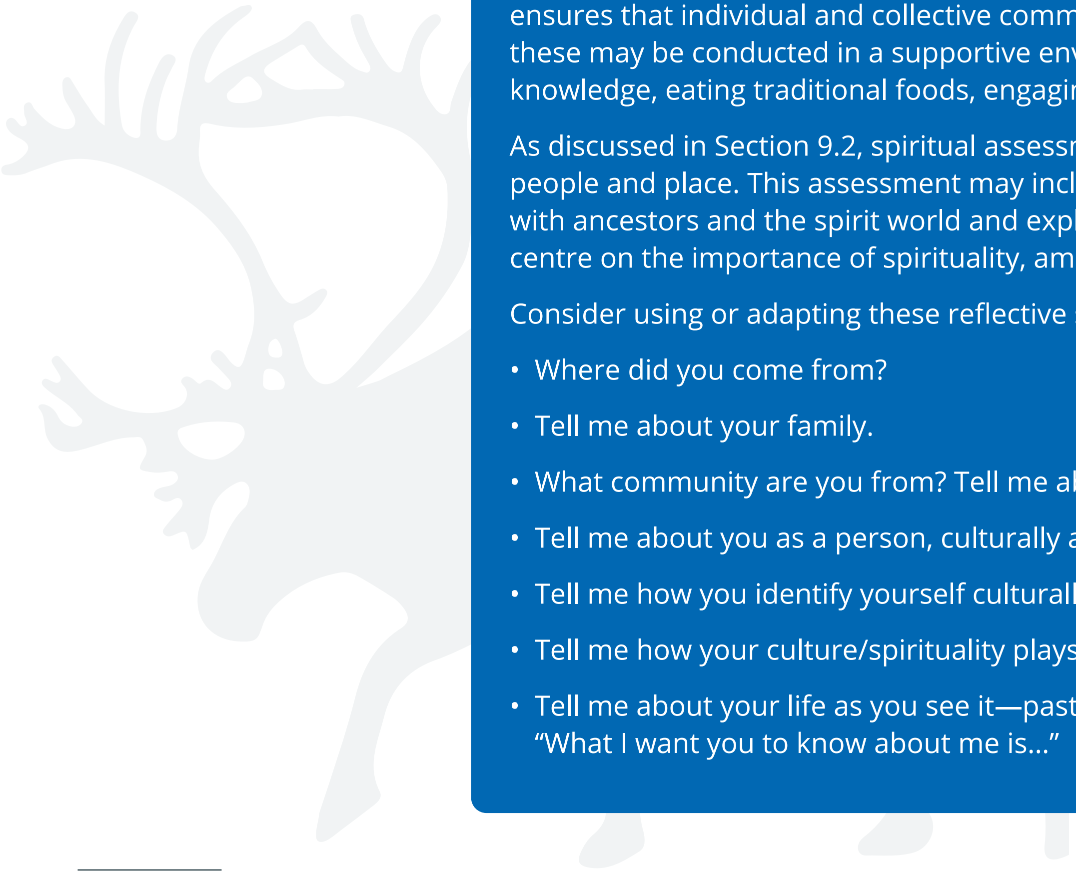
While my husband was dying, he was surrounded by his family, friends, prayers and traditional medicine. We brought in a traditional Indigenous medicine person who carries out sweats and he brought in traditional medicine. We also had a (non-Indigenous) preacher visit us – he was a good friend of the family.

> As my husband was beginning his journey (to the spirit world), it was like somebody just turned down the volume. It was also like I could almost physically see the door that my husband was preparing to go through. I could almost see it. It was like clearer and clearer space. I could almost see him go through that space. But it was like I knew I couldn't go there.
>
> The next morning, my husband went. It was very peaceful for him but very lonely for me.
>
> My husband planned everything. He planned his whole funeral including what he was going to wear in his casket. I didn't have to worry about how to comb his hair or what clothes to put on him or anything. He had it all picked out and arranged. My husband had everything laid out. He did this to make sure there was not a lot of stuff on my plate to do after he was gone – as I was raising our son.
>
> So, that was my husband. I still miss him and that was 46 years ago.
>
> In my other palliative care experiences with friends and as a helper for individuals with life-limiting illnesses, I've seen "this door and space" a few times since, and it's just over there. I know that I'm not to go over there yet, so it's like I know it's there, though. These experiences have made me more aware of the power of care.
>
> -Ella Paul (Mi'kmaw Elder)

Using a spiritual and ancestral lens, palliative and end-of-life care has the opportunity to create safer spaces to braid cultural practices and decision-making during the dying process and after death ceremonies.

For First Nations, Inuit and Métis Peoples living with life-limiting illnesses, their families and communities, culture and spirituality can protect against experiences of cultural and social isolation.

Indigenous spirituality and connecting with ancestors can establish or re-establish Indigenous identity and belonging, particularly when one is transcending from the physical life to the spirit life.



Promising practice: Spiritual assessment

Spiritual assessments can be an important part of palliative and end-of-life care. They support people living with life-limiting illnesses to make meaning of their spiritual heritage while exploring ways in which their experiences impact and influence present life issues (for example, values, attitudes, beliefs, coping strategies).

A pre-condition to these spiritual assessment conversations is establishing a relationship of mutual trust, respect, unconditional positive regard and posing questions in a fluid and flexible manner with people with life-limiting illnesses—being open to any kind of responses and inviting their own words for experiences that may lie outside of the boundaries of biomedical terms.[167, 168]

From there, spiritual assessment invites conversations in a neutral way with people with life-limiting illnesses, where they may identify areas of meaning and purpose that are spiritual or existential in nature. Assessment ensures that individual and collective community rights are respected: if religious or spiritual rituals matter, these may be conducted in a supportive environment (for example, visiting by family members and sharing knowledge, eating traditional foods, engaging in cultural practices and ceremonies).

As discussed in Section 9.2, spiritual assessments can include a review of a person's relationships to land, people and place. This assessment may include conversations on transpersonal powers such as connecting with ancestors and the spirit world and exploring beliefs about dying and death. A holistic discussion might centre on the importance of spirituality, among other elements, both individual and community-related.

Consider using or adapting these reflective spiritual questions:

- Where did you come from?
- Tell me about your family.
- What community are you from? Tell me about that.
- Tell me about you as a person, culturally and spiritually.
- Tell me how you identify yourself culturally.
- Tell me how your culture/spirituality plays into how you live your life.
- Tell me about your life as you see it—past, present or future. "What I have always wanted to tell you is…" or "What I want you to know about me is…"

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167 Hodge DR. Administering a two-stage spiritual assessment in healthcare settings: a necessary component of ethical and effective care. Journal of Nursing Management. 2015;23:27–38.

168 Nelson-Becker H, Canda ER, Nakashima M. Spirituality in professional helping interventions. In: Kaplan D, Berkman B, editors. The Oxford handbook of social work in health and aging, 2nd ed. Boston (MA): Oxford Press; 2015. p. 73–84.

It is important to acknowledge that there is much diversity among Indigenous Peoples and communities in terms of languages, lifestyles, histories, values, practices and teachings. There is also diversity in individual communities, particularly in terms of the use of Indigenous and non-Indigenous spiritual practices.

Therefore, some First Nations, Inuit and Métis Peoples with life-limiting illnesses may identify with non-Indigenous (e.g., Christian) spirituality in addition to or exclusive to traditional Indigenous beliefs, and their spiritual needs should also be met.

Each person with a life-limiting illness benefits from a spiritual assessment, and generalizations cannot be made about any Indigenous person regarding their preferred spiritual beliefs and practices.

9.3.3 Role of healing ceremonies, teachings, practices and medicine

> Traditional ceremonies and spiritual practices...are precious gifts given to Indian people by the Creator. These sacred ways have enabled us as Indian people to survive—miraculously—the onslaught of five centuries of continuous effort by non-Indians and their government to exterminate us by extinguishing all traces of our traditional ways of life. Today, these precious sacred traditions continue to afford American Indian people of all [nations] the strength and vitality we need in the struggle we face everyday; they also offer us our best hope for a stable and vibrant future. These sacred traditions are an enduring and indispensable "life raft" without which we would be quickly overwhelmed by the adversities that still threaten our survival. Because our sacred traditions are so precious to us, we cannot allow them to be desecrated and abused.[169]

Healing ceremonies, teachings and medicine are sacred spiritual practices and ways of Indigenous cultural continuity which aid in Indigenous identities, cultural resurgence and resistance to colonization and assimilation.

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[169] Jocks CR. Spirituality for sale: Sacred knowledge in the consumer age. American Indian Quarterly. 1996;20(3/4):415–431.

Further reflections on culture as medicine

Culture as medicine is often associated with the work of Eduardo Duran, particularly as it relates to healing the soul wound.[170, 171] Emphasis is placed on peoples' spiritual energy being in harmony and balance with their mental, emotional, spiritual and physical states.[172, 173]

Duran's view is that traumatic events inflict a *soul wound* on people. The soul wound is further extended to the effects of historical and intergenerational trauma experienced by Indigenous Peoples. These wounds inflicted on peoples in the past often result in unhealthy outcomes impacting the mind, body and spirit which, in turn, are often passed on from one generation to another.[174, 175]

Historical traumas are generally viewed as a collective trauma experienced over the lifespan and across generations as the result of acts of cruelty towards others (for example, legacy of the residential school experience for Indigenous Peoples in Canada, racism, genocide, colonization) and/or acts of nature (for example, natural or human-caused disasters affecting lands and peoples).

Historical and intergenerational trauma can lead to dysfunctional coping strategies (for example, substance misuse, domestic violence) which negatively affect the health and well-being of people, their families, communities and societies that experienced the given trauma(s).[176, 177]

Healing soul wounds includes coping (physical, mental, emotional and spiritual dimensions) while recognizing individual, group and community resiliencies.

Duran is supportive of helpers in health and related disciplines working with people suffering from trauma to use promising practices such as providing outreach, advocacy and healing services to the larger community of which people with life-limiting illnesses are a part of and engaging in efforts that aid in healing the land such as land-based healing and helping initiatives.[178, 179]

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[170] Duran E. Healing the soul wound: counseling with American Indians and other Native Peoples. New York (NY): Teachers College Press; 2006.

[171] Duran E, Duran B. Native American postcolonial psychology. Albany (NY): State University of New York; 1995.

[172] Duran E.

[173] Duran E, Duran, B

[174] Duran E.

[175] Duran E, Duran B.

[176] Duran E.

[177] Duran E, Duran B.

[178] Duran E.

[179] Duran E, Duran B.

In palliative and end-of-life care, opportunities exist to expand the continuum of care for First Nations, Inuit and Métis Peoples living with life-limiting illnesses, their families and communities by updating health-care policies, procedures and protocols to allow Indigenous cultural practices and ceremonies (for example, smudging,[180] engaging in pipe ceremonies,[181] engaging in sweat lodge ceremonies,[182] drumming and praying) in health-care institutions (for example, hospitals), including the culturally appropriate preparation of the body after death.[183]

To hear oral stories about the role of healing ceremonies, teachings and practices from First Nations, Inuit and Métis perspectives, visit https://livingmyculture.ca/culture.

When discussing healing ceremonies, teachings, practices and medicine, the issue of cultural appropriation often arises in relation to the use, teaching and application of Indigenous spiritual practices and rituals. As an ethical practice, experiential teachings and supervision with recognized Elders, Knowledge Carriers and/or healers is needed to continue one's safer and respectful use of Indigenous spiritual practices in one's given helping profession which includes palliative and end-of-life care.

Why cultural appropriation is disrespectful

https://www.ictinc.ca/blog/why-cultural-appropriation-is-disrespectful

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180 Smudging involves sacred herbs burned in a shell or bowl. The smoke is brushed over the participants. It is used to purify people and places. For more information, visit https://www.ictinc.ca/blog/a-definition-of-smudging.

181 https://canadianaboriginal.weebly.com/rituals-worship-and-festivals.html

182 Sweat lodge ceremonies purify the body, mind, spirit and heart and restore relationships with self, others and the Creator. The sweat lodge is a sacred space. It is a closed structure with a pit where heated rocks are placed. The sweat lodge leader pours water on the hot rocks to create steam. Participants sing, pray, talk and/or meditate as they sit. For more information, visit https://www.strongnations.com/gs/show.php?gs=4&gsd=3914.

183 Global Institute of Psychosocial, Palliative & End-of-Life Care. A search for solutions: a gathering on palliative care for First Nations, Inuit & Métis Peoples. GIPPEC Symposium Report; 2016.

9.4 The answers are in the community

Many Indigenous communities across Canada do most of the holistic caring for First Nations, Inuit and Métis Peoples. Communities know what to do.

Strengths and ways of knowing are in First Nations, Inuit and Métis communities in the form of Elders and Knowledge Carriers, Indigenous healers and helpers, community leaders, families and friends.

Relational healing and helping practices in palliative and end-of-life care facilitate healthy ways to experience grief, loss and bereavement. These practices help people and groups to develop a greater sense of connectedness to self, families, friends, community members, communities (as a whole) and Mother Earth, each of which influences how individuals and groups can understand illness, dying, death and loss.

Promising practice: Canadian Virtual Hospice—Livingmyculture.ca

Livingmyculture.ca is a repository of First Nations, Inuit and Métis stories and wisdom about living with serious illnesses, end-of-life, grief and loss and supporting others.

This website also contains multi-media resources, including more than 800 video clips in the oral storytelling tradition by people living with serious illnesses, families, Elders, Indigenous health-care providers and community leaders; four online cultural safety learning modules for health-care providers and educators; webinar recordings; online materials and print-based formats.

The primary audiences are Indigenous Peoples, health-care providers working with and alongside Indigenous Peoples and educators building the capacity of health-care providers to provide culturally safer care.

First Nations perspectives on illness, palliative and end-of-life care: https://livingmyculture.ca/culture/first-nations

Inuit perspectives on illness, palliative and end-of-life care: https://livingmyculture.ca/culture/inuit

Métis perspectives on illness, palliative and end-of-life care: https://livingmyculture.ca/culture/m%C3%A9tis

Voices from the community: Perspectives from Inuit in Nunavik on palliative and end-of-life care

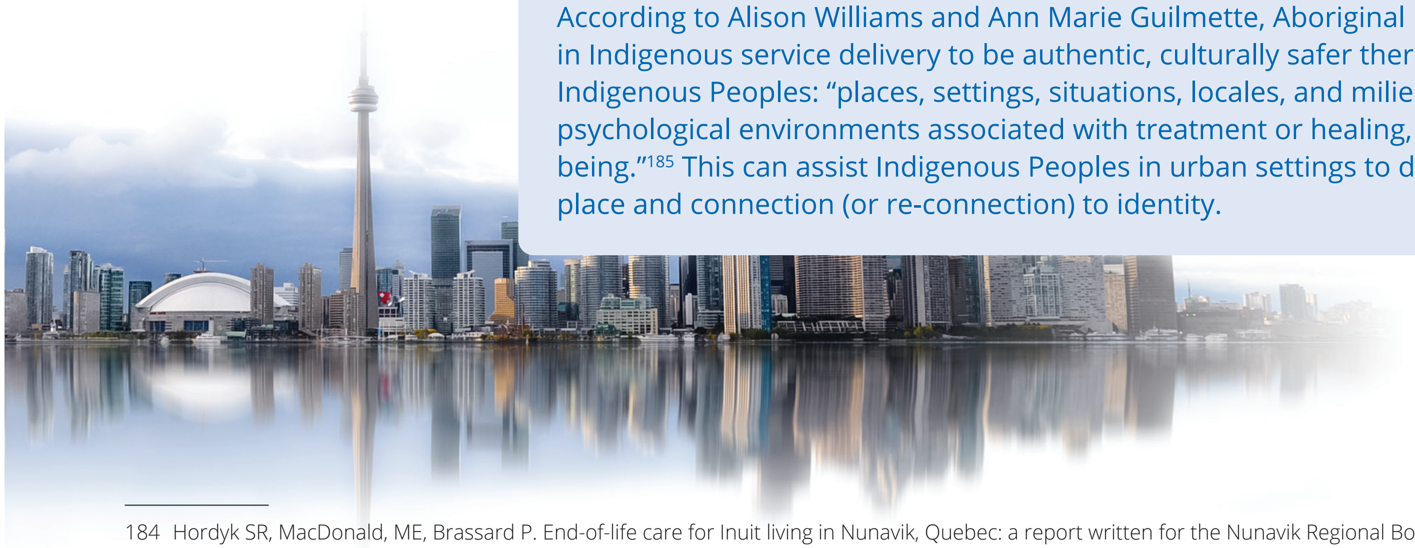
Community Elders and spiritual leaders explained that historically, once death occurred, bodies were placed under an oblong pile of rocks as the frozen tundra prevented bodies from being buried. Included were a person's key possessions such as hunting, carving, cooking and sewing tools. The rocks covering the body prevented predatory birds and mammals from preying on the deceased. In parts of Nunavik, these graves are now preserved and protected with fencing. In Nunavik communities, extended family and community members continue traditions in which immediate caregivers keep vigil during the last days of a patient's life. More recently, members of the women's auxiliary, a church-based volunteer group, assist in cleaning, cooking, keeping vigil, recruiting volunteers, if needed, and in washing bodies after death. These practices remain active.[184]

Aboriginal Friendship Centres and urban Indigenous approaches to healing and helping

Aboriginal Friendship Centres are not-for-profit organizations generally located in urban areas throughout Canada.

In the context of healing and helping, Aboriginal Friendship Centres aid in promoting, developing and delivering accessible programs and services that support First Nations, Inuit and Métis Peoples living in urban settings. Aboriginal Friendship Centres provide various services ranging from spiritual guidance, youth and cultural programs and health services to housing and employment assistance.

According to Alison Williams and Ann Marie Guilmette, Aboriginal Friendship Centres are well positioned in Indigenous service delivery to be authentic, culturally safer therapeutic landscapes (or spaces) for urban Indigenous Peoples: "places, settings, situations, locales, and milieus that encompass both the physical and psychological environments associated with treatment or healing, and the maintenance of health and well-being."[185] This can assist Indigenous Peoples in urban settings to develop (or re-develop) a strong sense of place and connection (or re-connection) to identity.



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[184] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 17.

[185] Williams, A, Guilmette, AM. A place for healing: Achieving health for Aboriginal women in an urban context. Canadian Journal of Native Studies. 2001; 21(1): p. 2.

9.4.1 Role of Elders and Knowledge Carriers

Voices from the community: A First Nations lens on palliative and end-of-life care

My friend died of cancer two years ago. The cancer attacked different parts of her body and she was in so much pain. We had a lot in common: we were both widows, both had two sons and we were both the same age.

I often went out to lunch with her and took her on drives around the community. She enjoyed the company – she talked a lot and laughed quite a bit. I remember one car ride during the fall. The leaves were red and crimson and my friend, though in pain, commented on the beauty of nature – in particular, the trees.

Unfortunately, she kept getting sicker and weaker. So, she went into the hospital. My friend was dying.

When I went to visit my friend, her hair was messy and she had a dirty old t-shirt on. I was annoyed with the nurses for not cleaning her up because my friend is a very prim and proper lady.

The next day, I bought her a bunch of night gowns and I took them to her to wear. The new night wear helped her mood and changed her outlook. I helped her change into her new clothes. My friend said that wearing the new nightgowns made her feel clean and so much better even though she was in pain.

A few days later, I got a call in the morning. My friend's son called me. He said, "will you come down (to the hospital) and smudge mom?" I said, yes and that I would be right there.

When my friend's son called me, I didn't know if she had died or if she was still alive. When I got to the hospital, my friend was still alive. I took my oldest son with me because death has really bothered him since my husband died over four decades ago. I wanted him to see the natural journey of life - how it's sad for us, but not necessarily for the person beginning their journey to the spirit world.

My friend's family were already in her hospital room. I arrived with my son...so we went into the room. They shut the door and I smudged everybody first. Her sons, and then her daughter-in-law, then her sister, her niece and my son. And then, I started to smudge my friend all around her body while I was praying.

It was really hard for me but I just kept focusing on praying. I started the smudge from her feet and all the way up her body. I then touched the feather on my friend's forehead and then on her chest. My eyes were closed during the smudge and prayers, I didn't see it but my friend's daughter and her sister said as soon as I touched her chest, my friend took her last breath. They said, "you helped her, you helped her leave." I'm really glad I did help her. I miss her and I still miss her crazy sense of humour!

As some of my friends have gone over the years, I miss them. However, they're all gone to that different space. We have to be here for them and I think that's kind of what my job is for friends and individuals with life-limiting illnesses, it's being there for them.

-Ella Paul (Mi'kmaw Elder)

Elders[186] and Knowledge Carriers[187] hold important roles in sharing traditional values and sacred teachings. They individually and collectively bring wisdom and experience to palliative and end-of-life care. Their understanding of specific First Nations, Inuit and Métis traditions and cultural expectations around dying and death enables conversations and facilitates dying and death to happen in a *good way*.

A good way

According to some Indigenous perspectives and ways of knowing, a good way can refer to the acts of doing your best; being honest, authentic, and sincere; meaning well; speaking well; acting well; following cultural protocols; and carrying out actions for the benefit of others in addition to yourself.

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[186] Elders are First Nations, Inuit or Métis individuals who make a life commitment to the health and holistic healing of their community and Peoples.

[187] Knowledge Carriers are First Nations, Inuit or Métis individuals who are recognized by their respective communities for the sharing of their culturally significant knowledge and Indigenous worldviews.

Promising practices: Elder and Knowledge Carrier engagement

For some palliative and end-of-life care initiatives in Canada, Elders' circles and/or Elders and Knowledge Advisory Committees have been formed to guide projects. Elders and Knowledge Carriers are engaged in projects from the planning stage to final product development and implementation.

When Elder and Knowledge Carrier perspectives and guidance are present from the outset of some palliative and end-of-life care initiatives, their contributions have been viewed as making a significant difference to (i) starting the project off in a good way and (ii) centering the project in Indigenous ways of knowing and practices. In this context, Elders and Knowledge Carriers are carrying (sharing and passing on) rather than keeping knowledge.

Furthermore, it is deemed advantageous, if possible, to keep the same group of Elders and/or Knowledge Carriers together during palliative and end-of-life care initiatives for continuity of perspectives, wisdom and experiences being shared.

It is recommended that honoraria be set aside when engaging Elders and/or Knowledge Carriers in palliative and end-of-life care initiatives for sharing their time, wisdom and guidance during the project journey. The Canadian Virtual Hospice's Elder and Knowledge Carriers Circle has been recognized as a promising practice that has been guiding community engagement and product development for three years. This Circle has resulted in the broader engagement of Elders by the Partnership and Pallium Canada.

The Elder and Knowledge Carriers Circle worked with Holly Prince to co-develop the *Coming full circle: Planning for your care workbook*. Link: https://livingmyculture.ca/media/3831/planning-for-your-care-large-print.pdf

Note: There is full recognition that there are hundreds of First Nations, Inuit and Métis communities across Canada. Therefore, the Partnership acknowledges terms such as Elders and Knowledge Carriers (including accompanying roles) may vary across communities and geographic regions in Canada.

INDIGENOUS HEALERS

9.4.2 Role of Indigenous healers and helpers

Indigenous healers[188] and helpers can bridge culture, land, identity and place as part of the healing medicines that aid people living with life-limiting illnesses, their families and communities. Indigenous healers and helpers can provide holistic approaches that acknowledge the interdependent relationship between mind, body, spirit and emotions from a healing and helping perspective. Complementary to Elders and Knowledge Carriers, Indigenous healers and helpers can aid in connecting or reconnecting First Nations, Inuit and Métis Peoples living with life-limiting illnesses, their families and communities to Indigenous ways of knowing, for example, end-of-life practices and ceremonies.

Navigating supports and advocating for First Nations, Inuit and Métis Peoples, particularly in rural, remote and northern communities, is critical throughout palliative and end-of-life care. The type of navigation and advocacy supports available during palliative and end-of-life care vary by jurisdiction.

Promising practice: Indigenous death doulas

In general, Indigenous death doulas (end-of-life or life spectrum doulas) are non-medical healers, helpers and companions to First Nations, Inuit and Métis Peoples living with life-limiting illnesses and their families. Doulas complement other palliative and end-of-life care services that Indigenous Peoples living with life-limiting illnesses and their families may be receiving in health-care settings. They typically provide a wide range of culturally safer holistic services, including physical, emotional, spiritual and practical support across the lifespan. This support may include facilitating and coordinating access to health-care services including traditional healing practices and spiritual and cultural supports.

For more information about Indigenous death doulas, watch the following video: https://www.facebook.com/firstnationshealthauthority/videos/282337846033277.

Note: There is full recognition that there are hundreds of First Nations, Inuit and Métis communities across Canada. Therefore, the Partnership acknowledges terms such as Indigenous healers and helpers (including accompanying roles) may vary across communities and geographic regions in Canada.

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[188] Healers (for example, medicine persons) often hold positions of high respect in First Nations, Inuit and Métis communities.

Voices from the community: An Inuit lens on palliative and end-of-life care

Historically, in some Inuit communities, certain individuals were assigned the role of the messenger (Tutsalukkaijiit). Their role was to communicate the painful news of death or loss to the families when someone had died. People assigned this task had a degree of life experience and were often respected in the community. Likewise traditional health-care workers, those who tended to birth, death, or illness in communities, were persons, usually women, who had been mentored by the previous generation. Their ability to respond to the complex physical and emotional needs of families depended on what they had learned through observing and assisting the more knowledgeable mentor. Interpreters were located at a unique juncture between historical and contemporary models of care.[189]

9.4.3 Role of community leaders

Indigenous leadership at all levels in Indigenous communities is complex, intricate and multifaceted.[190, 191] Views of leaders and leadership have been shaped by colonization and a record of dislocation and isolation, racism, violence and poverty.[192] First Nations, Inuit and Métis leaders are reminded of these events across the generations as they take on roles and responsibilities in engaging with and alongside their communities when responding to a variety of issues such as health, housing, economic diversification, education, environment, land management, children and families.[193] Furthermore, they are responsible for demonstrating leadership for the roles and responsibilities of rebuilding, reuniting, reshaping and revitalizing their respective First Nations, Inuit and Métis communities while navigating intergenerational trauma often stemming from constant reminders of colonialism which includes the effects of the residential school system experience.[194, 195]

As referenced in Section 8.3.7, strong local leaders in First Nations, Inuit and Métis communities can serve as catalysts for transformative change in making local Indigenous approaches to palliative and end-of-life care a strategic priority as part of the continuum of care for community members across the lifespan and the generations. Such leaders are passionate, respected, influential and motivating.[196]

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[189] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 60.

[190] Calliou B. The significance of building leadership and community capacity to implement self-government. In: Belanger Y, editor. Aboriginal self-government in Canada: current trends and issues. 3rd ed. Saskatoon (SK): Purich; 2008.

[191] Calliou B, Voyageur C. Aboriginal leadership development: building capacity for success. Summer 2007;4:8–10.

[192] https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Executive_Summary_English_Web.pdf. p. 50.

[193] Sandefure G, Deloria PJ. Indigenous leadership. Daedalus. 2018;147(2):124–135.

[194] https://harvest.usask.ca/bitstream/handle/10388/etd-04262005-094217/Ottmann.pdf?sequence=1&isAllowed=y

[195] Wesley-Esquimaux C, Smolewski M. Historical trauma and Aboriginal healing. Ottawa (ON): Aboriginal Healing Foundation; 2004.

[196] Kelley M., Prince H, Nadin S, Brazil K, Crow M, Hanson G, Maki L, Monture L, Mushquash CJ, O'Brien V, Smith J. Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care. Annuals of Palliative Medicine. 2018;7 (Suppl2):S52–S72.

9.4.4 Role of families and friends

Voices from the community: A Métis lens on palliative and end-of-life care

My Grandma was a kind and gentle woman. She emanated that incredibly strong and silent caring of Métis women. A caring not communicated in words, but rather through action and service of her family. With absolute fondness and heart-warming feelings, I remember her laugh, her knitting, her fried bread and her quiet nature.

When she was 73, she was admitted to the hospital for an infection. During her hospital stay, she had a serious stroke which brought her to the last hours of her life.

All of my family gathered together with her that day. There was my Mom, Dad, aunts, uncles and all the cousins. There were easily 20 of us in the room with her at all times. It was a double occupancy room, but the hospital staff kindly kept the second bed unoccupied so that we could be with her in privacy. We spent the time playing cards, talking, sharing memories, laughing and just being together as a family. Grandma was in and out of consciousness, but every so often she would open her eyes just a bit and see us all there. I'm sure she could hear us. The nurses would come in to provide her with comfort medication, but it was us who had the joy and honour of caring for her, and being with her in the last hours of her life.

We were all with her when she died.

Those last moments were a celebration of her, our family, of our past, present and our future.

-Lisa Vaughn (Métis Nation of Alberta citizen)

Throughout this report, there is recognition that palliative and end-of-life care supports and resources are not exclusive to people living with life-threatening illnesses but also extend to their families and communities. This includes the role of families and friends as caregivers when (i) there is a lack of access to palliative and end-of-life care and/or (ii) it is the preference of people with life-limiting illnesses for their family and/or friends to be actively involved in their palliative and end-of-life care rituals.[197]

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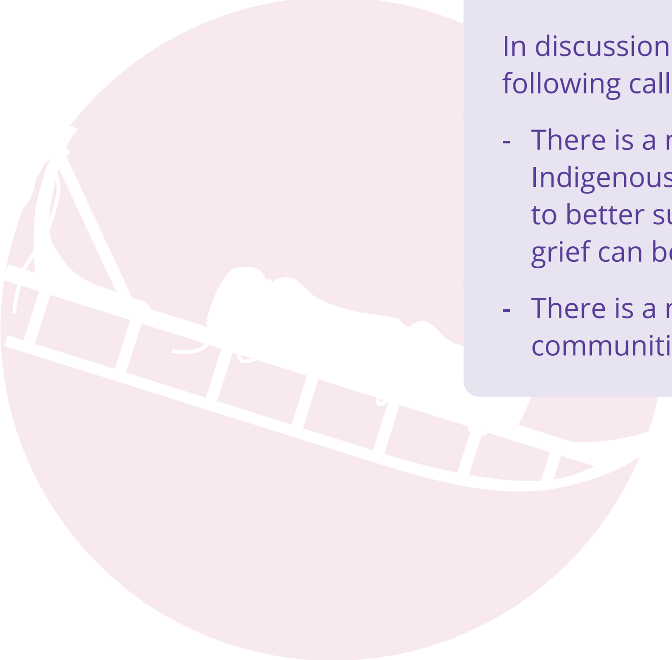
[197] Kelly L, Minty, A.. End-of-life issues for Aboriginal patients: a literature review. Canadian Family Physician. 2007;53:1459–1465.

The palliative and end-of-life care process can be stressful for families and friends.[198, 199] As a means of managing the stress surrounding illness, dying and death, Indigenous approaches to palliative and end-of-life care benefit from being guided by the roles of ancestors; community; Elders; family, friends and extended family; cultural safety; interconnectedness and relationships; diversity, self-determination and autonomy.[200]

An individual's self-concept affects identity formation, reflecting a combination of one's social identity and one's personal identity.[201, 202, 203] Families, friends and community relationships are foundational to how people define themselves. This process of connecting or reconnecting to family and friends is part of healing family structures and attachments that may have been disrupted or lost due to the effects of colonization and intergenerational trauma.[204]



Voices from the field: Calls to action in palliative and end-of-life care

In discussions with the Partnership, some Indigenous palliative and end-of-life care practitioners shared the following calls to action:

- There is a need to collaborate, cooperate and partner with others (for example, Indigenous and non-Indigenous health-care providers and professionals, service providers, orders of government and educators) to better support families who experience loss as decisions are complex, demands can be significant and grief can be intense;[205] and
- There is a need to use the principles of community resilience and community wisdom to care for families and communities who are grieving.

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[198] Gysels M, Evans N, Meñaca A, Higginson IJ, Harding R, Pool R, Project PRISMA. Diversity in defining end of life care: an obstacle or the way forward? PloS one. 2013;8(7):e68002.

[199] Keeley MP. 'Turning toward death together': the functions of messages during final conversations in close relationships. Journal of Social and Personal Relationships. 2007;24(2):225–253.

[200] https://www.fnha.ca/Documents/framework-accord-cadre.pdf

[201] The roles or group membership categories to which people belong.

[202] The traits and behaviours that people find descriptive of themselves.

[203] Tajfel H. The social identity and intergroup relations. Cambridge University Press; 1982.

[204] https://www.theglobeandmail.com/canada/article-family-raises-35000-to-bring-inuk-elder-home-from-ottawa-care-facility

[205] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 25.

Voices from the community: An Inuit lens on palliative and end-of-life care

Care providers stated that most terminally ill patients preferred to die in their homes where they are surrounded by friends, family and familiar home and community environments. Families and communities would go through great lengths to respect these wishes, often in collaboration with the local health center or regional hospitals. Families often preferred to have the patient at home for the final days of life as their own grieving process was supported when family, friends and neighbours surrounded them during the final days of a patient's life. Women tended to be the primary caregivers for family members who are dying in the home: wives, daughters and granddaughters. Men did become involved as they may have been needed to lift or move the patient and when women were unable to provide needed care.[206]

In Nunavik, the definition of family is widened, creating a broader system of relations through which EOL decisions are made and caregiving responsibilities are assumed. For example, the children of nieces and nephews were also identified as one's grandchildren and could act as key decision-makers and caregivers. Family members who had been separated by adoption as infants or youth would, at times, return and engage in providing EOL care for members of their birth family. It was not unusual for grandparents to have raised a child during formative years of that child's life. In turn, grandchildren and great-grandchildren may have been present during the decision-making and caregiving process.[207]

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[206] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 23.

[207] Ibid. p. 23.

Many Indigenous Peoples embody strength and resilience through their engagement or re-engagement in cultural and spiritual practices and an unrelenting perseverance for truth regarding the colonial history of the forced removal from traditional lands, the effects of the residential school system and cultural assimilation. Indigenous Peoples' growing strength and resilience are resulting in calls for greater access for family and friends to visit and sit with their loved ones who have life-limiting illnesses while engaging in cultural ceremonies and practices pertaining to dying and death (for example, smudging, engaging in pipe ceremonies, preparing and sharing traditional foods, engaging in creative arts[208]).

What does it mean to bear witness?

The ongoing relevance of oral traditions is clear to individuals who have had the privilege of attending a traditional gathering such as a naming ceremony or funeral. On such occasions, recordings (written, audio and/or visual) are often prohibited.

As a means of acknowledging these events, it is important to *bear witness* to these special rites of passage.

For example, as part of the traditional Coast Salish act of bearing witness, witnesses must fully understand that if in the future any questions arise as to "the work" that is carried out at a specific gathering they can be called upon to recall what they had seen and heard in an accurate and truthful manner. After all the witnesses have been called, "the work" begins. After "the work" is completed, the floor is opened to the witnesses, who have the right to speak of what they saw and heard.

9.5 Summary

Culture as medicine serves as a holistic health strategy which is often located and centred in community. As such, First Nations, Inuit and Métis cultures support resiliency in terms of the ability of people, their families and communities to flourish and adapt to situations and/or environments with minimal negative effects during and after a change, hardship or crisis. From a healing and helping perspective, resilience emphasizes a person's and/or group's ability to effectively draw on strengths and capabilities rather than focus on weaknesses or pathologies.[209, 210]

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[208] This includes, but is not limited to, writing, drawing, painting, carving, singing and dancing.

[209] Duran E. Healing the soul wound: counseling with American Indians and Other Native Peoples. New York (NY): Teachers College Press; 2006.

[210] Duran E, Duran B. Native American postcolonial psychology. Albany (NY): State University of New York; 1995.

10. Braiding Indigenous ways of knowing and biomedical approaches in palliative and end-of-life care

10.1 Overview

Based on the 2016 work of Drs. Gloria Snively and Wanosts'a7 Lorna Williams, *Knowing home: Braiding Indigenous science with Western science*, this metaphor describes how Indigenous and non-Indigenous ways of knowing can be used in a way that is mutually respectful and reciprocal. Readers are invited to apply this image to harmonizing Indigenous ways of knowing and biomedical approaches in palliative and end-of-life care.

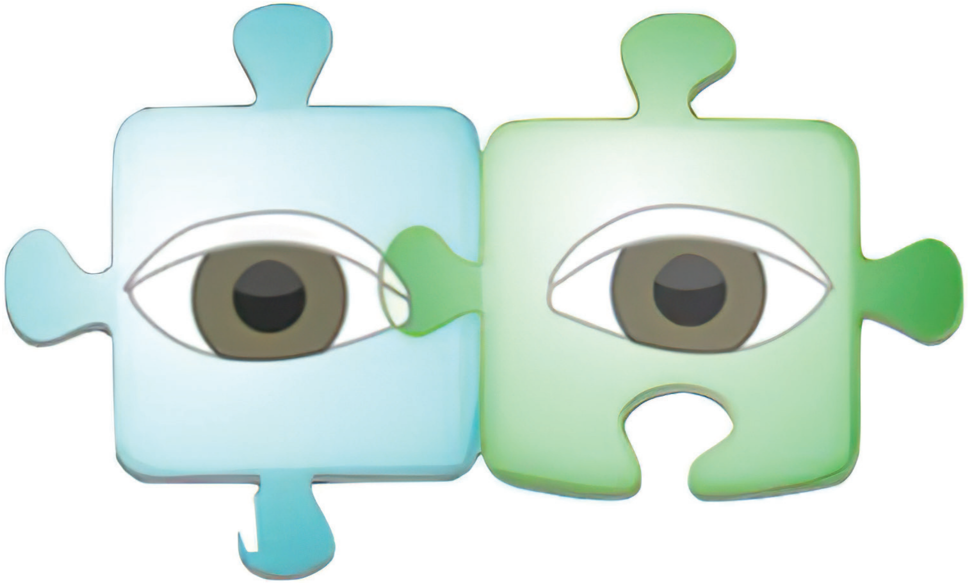

Figure 3. Etuaptmumk/two-eyed seeing. Credit: Collaborative work by the research team of the Canada Research Chair in Integrative Science and Mi'kmaw Elders in Unama'ki/Cape Breton.

In this context, braiding palliative and end-of-life care can include the use of the following: Etuaptmumk/two-eyed seeing, care across the generations, gender- and 2SLGBTQQIA+-informed care, trauma-informed care, resilience-informed care, relationships and allyship.

10.2 Etuaptmumk/two-eyed seeing[211]

Mi'kmaw Nation Elder Albert Marshall specifies that *Etuaptmumk/*two-eyed seeing is the gift of multiple perspectives treasured by many Indigenous Peoples. Etuaptmumk/two-eyed seeing supports an important shift in dialogue and reconciliation about integrative, cross-cultural and collaborative work between Indigenous and non-Indigenous peoples in Canada. As Elder Marshall further explains, Etuaptmumk/two-eyed seeing refers to learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing...and learning to use both these eyes together, for the benefit of all.[212, 213]

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[211] http://www.integrativescience.ca/Principles/TwoEyedSeeing

[212] Ibid.

[213] Rowett J. Two-eyed seeing: a research approach and a way of living. Antistasis. 2018;8(1). https://journals.lib.unb.ca/index.php/antistasis/article/view/25740

For more information about Etuaptmumk/two-eyed seeing,

- watch the following video: http://www.youtube.com/watch?v=_CY-iGduw5c

and

- visit the Integrative Science website: http://www.integrativescience.ca.

Two-Eyed Seeing is the Guiding Principle brought into the Integrative Science co-learning journey by **Mi'kmaw Elder Albert Marshall** in Fall 2004.

Etuaptmumk is the Mi'kmaw word for Two-Eyed Seeing.

In relation to palliative and end-of-life care, readers are invited to explore ways to bridge Indigenous ways of knowing and biomedical ways of knowing by using the strengths of these worldviews and approaches to aid people living with life-limiting illnesses, their families and communities.

Examples of braiding are

- improving access and accessibility to both traditional Indigenous healing and biomedical palliative and end-of-life care services close to home;[214] and
- having health-care settings (for example, hospitals, care facilities) that are responsive to cross-cultural needs by harmonizing the needs and values of people with life-limiting illnesses from a wide range of communities. The rights and cultural values of these people and their families are balanced with the hospital's commitment to provide optimal care for all people with life-limiting illnesses in its treatment areas.[215]

Promising practice: Nunavik Regional Board of Health and Social Services IQI model

Through a collaborative process, the Nunavik Regional Board of Health and Social Services and Nunavimmiut co-developed the IQI (Ilusirsusiarniq, Qanuingngisiarniq, Inuuqatigiitsianiq) model. The IQI model is based on Inuit ways of knowing which integrates data from the 2017 Qanuilirpita health survey (community-health component) to inform culturally congruent and culturally safer community health program development and implementation.[216]

Ilusirsusiarniq generally relates to the body; Qanuinngisiarniq includes feelings of being comfortable, content and without worries or pain; and Inuuqatigiitsianiq pertains to harmonious relations among people who share a place. As a collective, Ilusirsusiarniq, Qanuingngisiarniq and Inuuqatigiitsianiq are central dimensions to Inuit health at the individual, family and community levels. Based on these dimensions, the IQI model serves as a framework for informed health decision-making and culturally safer access to resources that are rooted in culture and language.[217]

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[214] Anderson M, Woticky G. The end of life is an auspicious opportunity for healing: decolonizing death and dying for urban Indigenous People. International Journal of Indigenous Health. 2018;13(2):48–60.

[215] Kaufert JM, Putsch RW, Lavallée M. End-of-life decision making among Aboriginal Canadians: interpretation, mediation, and discord in the communication of "bad news." Journal of Palliative Care. 1999;15(1):31–38.

[216] https://nrbhss.ca/sites/default/files/documentations/corporatives/UserPerspective_Report_EN_digital.pdf (p. 24).

[217] https://nrbhss.ca/sites/default/files/health_surveys/The_IQI_Model_of_Health_and_Well-Being_summary_en.pdf (p. 1).

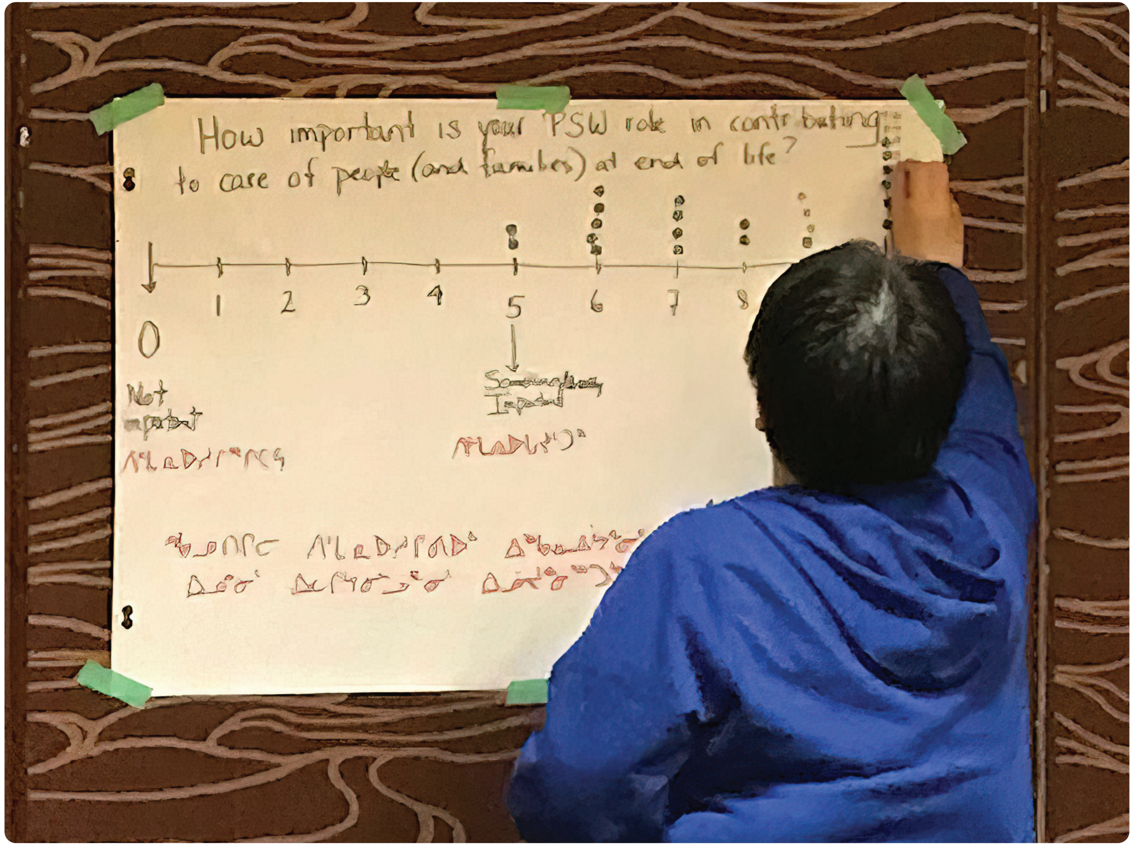
Promising practice: Pallium Canada—Learning Essential Approaches to Palliative Care (LEAP)

The goal of LEAP is to train health-care professionals on the essential skills and knowledge in providing palliative care. LEAP offers foundational, competency- and evidence-based interprofessional accredited courses that provide health-care professionals with an essential set of knowledge, attitudes and skills on the palliative care approach.

Since 2004, Pallium Canada has been working with Indigenous leaders and health professionals to integrate their learning and wisdom into Pallium's educational resources.

As part of the INTEGRATE Project in collaboration with Cancer Care Ontario, Pallium Canada worked with and alongside the Six Nations communities in southern Ontario. There was a request from the communities to focus on integrating Indigenous perspectives, wisdom and sensitization into existing LEAP courseware rather than developing a standalone LEAP course specifically for health-care professionals working in First Nations communities. This led Pallium Canada to require cultural sensitization training for all LEAP facilitators to ensure heightened sensitivity and awareness to the unique needs of Indigenous Peoples and to highlight cultural competencies in all courses, particularly when facilitating courses that include health-care professionals who provide palliative care to Indigenous Peoples.

To this end, in 2017 and 2018, Pallium Canada delivered three LEAP courses that were specifically designed "for, by and with" the following First Nations communities: Kettle & Stony Point First Nation; W̱SÁNEĆ First Nations; and Chippewas of the Thames First Nation.



Iqaluit, Nunavut January 2019 - Pallium Canada partnered with the Government of Nunavut's Department of Health to deliver six LEAP courses over a two-year period for an audience of 76 physicians, nurses, pharmacists and personal support workers. Many of the learners travelled in from across the territory, including the remote communities of Pond Inlet and Arctic Bay. Photo credit: Elisabeth Antifeau.

In January 2019, Pallium Canada partnered with the Government of Nunavut to deliver LEAP courses. Learners were physicians, nurses and Inuit personal support workers in the territory. Pallium Canada and the LEAP facilitators engaged with the Government of Nunavut to understand the local context related to care delivery, resources, language and culture. LEAP curriculum was translated into symbolic Inuktitut and translators were brought in. This approach was co-developed with and co-led by local community members. The material was also adapted for the context of the type of caregivers attending.

During the LEAP course with Inuit personal support workers, flip charts were set up around the room. As conversation unfolded, English comments were also translated into the Syllabic Inuktitut. Several participants took photos of the charts at the end of the course and commented how this information would be helpful in their palliative care work.

These courses demonstrated that LEAP courseware is adaptable to reflect unique settings, whether the course is delivered to non-Indigenous health-care providers who work with Indigenous Peoples or delivered to Indigenous health-care workers who work in Indigenous communities.

Lessons learned from the "braiding" of Indigenous and non-Indigenous ways of knowing in palliative care curriculum design and delivery include the following:

- Indigenous participants commented that "we want the best available education that everyone else is getting in Canada" with the understanding that the (LEAP) courses needed to be delivered in an Indigenous culturally congruent manner.
- Facilitation requires a very high level of adaptability, a trauma-informed approach and understanding of the intergenerational effects of colonialism, continuous and intentional self-reflection (on the part of the facilitators) in addition to having a clear sense of local Indigenous cultures, protocols and resources.
- All Pallium Canada LEAP facilitators (individuals who teach the LEAP courses) must complete Cancer Care Ontario's Indigenous relationship and cultural awareness course to become certified facilitators.

For more information about LEAP courses, visit www.pallium.ca/courses.

10.3 Decolonization in palliative and end-of-life care

Voices from the community: A First Nations lens on palliative and end-of-life care

Erica's mother during palliative care. Photo credit: Erica Williams

My mother had esophageal cancer in late 2018 and unfortunately lost her battle in January 2020.

Having such close experience in supporting a family member through palliative care has made me value the importance of decolonizing the process of death and dying in a clinical setting and begin to make practicing Indigenous ways of knowing around palliation a standard practice of care for our people.

T'oyaxsim Nism.

-Erica Williams (Gitwangak First Nation Health Director; Gitxsan Nation)

Decolonization aligns with the reconciliation goals shared by the Truth and Reconciliation Commission of Canada. Health-care settings and related palliative and end-of-life care organizations are vital sites for decolonization and empowerment for Indigenous Peoples with life-limiting illnesses, their families and communities.

What is decolonization?

Decolonization is the process of undoing colonizing practices.

In a health-care context, this means confronting and challenging colonizing practices that have influenced health care in the past and which are still present today. This often involves reflecting on the structure of health-care institutions and their role in the broader society.

In the spirit of decolonizing, access to palliative and end-of-life care for Indigenous Peoples across Canada can benefit from transformative changes by re-thinking how service delivery is carried out with and alongside Indigenous Peoples—meeting individual and community needs, ways of being and knowing.

When advancing a decolonization process, it is important to confront the power relations in health-care settings and related institutions.

Reflection questions are, Who is in control of ways of knowing? What is their role(s)? How did they gain this role(s)? What maintains their power?

In 2020, the British Columbia (BC) Minister of Health commissioned an independent review of Indigenous-specific racism and discrimination in the provincial health-care system. As the Independent Reviewer, Hon. Dr. Mary-Ellen Turpel-Lafond (Aki-Kwe; Muskeg Lake Cree Nation) outlined 24 recommendations that focused on decolonizing the health-care system in BC—which includes enhancing systemic coordination and braiding Indigenous human rights (as defined in the *United Nations Declaration on the Rights of Indigenous Peoples*) into the provincial health-care system to improve Indigenous Peoples' access to timely care.

For more information about this independent review, read *In plain sight: Addressing Indigenous-specific racism and discrimination in BC health care,* https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf.

The Truth and Reconciliation Commission of Canada reports remind us that residential schools and related colonial practices (e.g., *Indian Act* legislation and the reserve system, land appropriation, Indian hospitals, Sixties Scoop) were specifically designed to colonize the mind, the heart and the spirit. At present, colonialism is more subtle and is often perpetuated through curricula, power relations and institutional structures.

10.4 Palliative and end-of-life care across the generations

Life-limiting illnesses and death in crisis can occur at any age across the lifespan and the generations.

More often than not, discussions and initiatives pertaining to palliative and end-of-life care focus on seniors and Elders living with life-limiting illnesses. Therefore, readers are invited to frame palliative and end-of-life care from a lifespan development and generational perspective.

What does a lifespan and generational perspective mean?

When readers take a lifespan and generational perspective, they view palliative and end-of-life care based on biological, psychological and social factors and consider that all parts of the life span are interrelated.

There is further recognition that

- development is holistic and a lifelong process,
- development involves gains and losses,
- development involves changing allocation of resources,
- development shows plasticity, and
- development is influenced by historical and cultural[218] context as well as shared across the generations.

People often experience a lot of fear around illness, dying, death and loss. Limited harmonization of cultural practices and ways of knowing such as Indigenous languages and cultural knowledge in biomedical-oriented health-care services often contributes to communication and decision-making challenges, cross-cultural misunderstandings and value conflicts. These challenges and conflicts may alienate Indigenous Peoples from accessing these health-care services.[219, 220] This alienation can manifest in cultural and social isolation.[221, 222, 223] Racism, active stereotyping and other colonial health-care values also contribute to cultural isolation.[224]

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[218] For example, values, beliefs, customs and skills of a social group. These historical and cultural contexts include the role of spirituality shaping values and beliefs in human development, functioning and behaviour.

[219] McGrath PD, Patton AMS, Olgivie KF, Rayner RD, McGrath ZM, Holewa HA. The case for Aboriginal health workers in palliative care. Australian Health Review. 2007;31(3):430–439.

[220] Fruch V, Monture L, Prince H, Kelley ML. Coming home to die: Six Nations of the Grand River Territory develops community-based palliative care. International Journal of Indigenous Health. 2016;11(1):50–74.

[221] Cultural isolation for Indigenous Peoples may result from perceptions, values, beliefs, worldviews and communication styles that differ from those of the dominant society.

[222] Social isolation encompasses a sense of loneliness due to limited access to Indigenous healers and helpers in health-care settings as well as the health-care system as a whole. This isolation includes separation of Indigenous Peoples with life-threatening illnesses from family, community, Elders and Knowledge Carriers.

[223] https://www.theglobeandmail.com/canada/article-how-elders-from-nunavut-end-up-in-long-term-care-thousands-of

[224] Ibid.

Voices from the community: An Inuit lens on palliative and end-of-life care

In regards to developing culturally informed bereavement support for children and adults, research participants described different initiatives that were assisting individuals and families in the midst of grief. These practices often incorporated Inuit traditional and faith-based practices. However, existing supports could not meet the level of demand…. Participants described how the current lack of services to assist children and adults in their grief and bereavement results in complex grief reactions where feelings of sadness and anger could be overwhelming. They described how, in these instances, children would manifest their distress through acting out or withdrawal. Adolescents and adults would isolate themselves from friends, family or colleagues, or self-medicate through substance use. This unresolved grief would surface when a family member was dying of illness or natural causes. Taking care of a family member could soon become emotionally overwhelming. Participants described that avoidance of the dying might have been the only foreseeable response for some grieving family members. This resulted in increases in the transfers of patients to health facilities. Participants stated that bereavement initiatives in certain communities could be reaching more families if given funding and recognition.[225]

While relatively few children die of cancer, the needs of children are often complicated and may begin as early as birth and extend over the lifespan of the child. Families may spend extended periods away from their communities when children have life-limiting illnesses. Pediatric palliative care is different from adult palliative care. Indigenous communities can provide important support and resources for families with children with life-limiting illnesses.

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[225] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 27–28.

Reflections: Voices of Indigenous children and youth in palliative and end-of-life care

There is currently limited discussion on strategies and initiatives in advancing Indigenous approaches to palliative and end-of-life care focused on the following areas:

(1) children's needs regarding grief, loss and bereavement when family members and/or friends transition to the spirit world;

(2) children's experiences with dying and death—for example, death and dying in their own home and community; and

(3) the rights, freedoms and decisions (e.g., the rights to practice healing ceremonies, teachings and traditional medicine) of Indigenous children and youth living with life-limiting illnesses and their families.

Given public cases in Canada (circa 2014) such as J.J. and Makayla Sault,[226] there appears to be a growing need in the palliative and end-of-life care field to fully explore and document how to safely and effectively braid Indigenous identity, tradition and well-being in a manner that develops and sustains trust between health-care providers, the people with life-limiting illnesses (children and youth) and their families.

In the cases of J.J. and Makayla Sault, trust played a pivotal role in the interpersonal relationships between the health-care organizations and providers, people with life-limiting illnesses and their families. When people with life-limiting illnesses and their families have low or no trust in their health-care providers, they are more likely to question and mistrust diagnoses, prognoses, treatments and advice. Developing trust with people with life-limiting illnesses involves not only the health-care providers communicating information to people with life-limiting illnesses, but also actively listening to the people with life-limiting illnesses and their families' concerns, feelings and cultural and spiritual beliefs which may include the use of traditional medicine.

Trust is particularly important for vulnerable or marginalized populations such as children, youth and Indigenous Peoples.[227]

As discussed in Section 9.3, creating safer spaces to discuss, explore and seek spiritual support plays a significant role for many Indigenous Peoples and their families which includes hearing from Indigenous children and youth about their experiences living with life-limiting illnesses.

Children's and youths spirituality is often ignored or given limited consideration because adults may not have reflected on the impact of a child's or youth's beliefs on how they understand their experiences. Moreover, the

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[226] For a brief overview of the J.J. and Makayla Sault cases, visit https://us14.campaign-archive.com/?u=fec499aae30051a1d1e1f6301&id=a536e986c0

[227] Cohen-Fournier SM, Brass G, Kirmayer LJ. Decolonizing health care: challenges of cultural and epistemic pluralism in medical decision-making with Indigenous communities. Bioethics. 2021;35(8):767–778.

voices of Indigenous children and youth are often silenced in health-care settings.[228]

The need for and reinforcement of protective factors in community-based laws, protocols and practices (for example, family systems) are important considerations in working with Indigenous children and youth and their families.

Reflection questions to consider:

- What are the attitudes and perceptions of First Nations, Inuit and Métis children and youth regarding palliative and end-of-life care needs, services, supports and resources?
- What does informed consent look like for First Nations, Inuit and Métis children and youth regarding palliative and end-of-life care needs, services, supports and resources?
- Given the historical context of harm resulting from colonization, what are the implications of braiding Indigenous sacred and spiritual practices with biomedical interventions for Indigenous children and youth in palliative and end-of-life care policies and practices?

GENDER and 2SLGBTQQIA+

10.5 Gender- and 2SLGBTQQIA+-informed palliative and end-of-life care

In taking a gender- and 2SLGBTQQIA+-informed approach, readers commit to assessing the potential impacts of palliative and end-of-life care policies, programs, services and other initiatives on people with diverse gender identities.

People in the 2SLGBTQQIA+ community often face hostility and discrimination in health-care settings. They are also more likely to face ignorance or outright prejudice. Furthermore, fear of poor treatment in institutional health-care settings can drive many people from the 2SLGBTQQIA+ community away from accessing timely and effective palliative and end-of-life care.

The terms “men” and “women” are intended to include individuals identifying in this way, recognizing that not all people who identify as men/women were born with or have male/female anatomy. These terms may not be inclusive of all individuals that are nonbinary, agender, gender fluid or two-spirited.

Women can suffer from discrimination in the form of misogyny, stereotypes and expected gender roles. Individuals born with female anatomy can experience stigma and ostracism surrounding life-limiting illnesses such as cervical and breast cancers that can make them reluctant to seek palliative care. Also, certain cultural contexts (for example, being an Indigenous female) may further limit access to timely palliative and end-of-life care.

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[228] Cohen-Fournier SM, Brass G, Kirmayer LJ. Decolonizing health care: challenges of cultural and epistemic pluralism in medical decision-making with Indigenous communities. Bioethics. 2021;35(8):767–778.

Men can also face the negative effects of gender discrimination and societal and cultural taboos. Social norms surrounding masculinity may make some men less willing to discuss health concerns and consider certain life-saving procedures for those with male anatomy such as surgery for early-stage prostate cancer and testicular cancer due to the fear of side effects such as incontinence or impotence.

Promising practices: Gender- and 2SLGBTQQIA+-informed palliative and end-of-life care

2SLGBTQ+ Canadian Health Care Bill of Rights:
https://www.virtualhospice.ca/2SLGBTQ/media/q1yb5410/bill-of-rights.pdf

The human rights of lesbian, gay, bisexual, transgender, queer, 2-spirit and intersex persons:
https://bit.ly/37QtHRf

Inclusive care (Canadian Virtual Hospice): http://www.virtualhospice.ca/2SLGBTQ

My Choices for Safe an Inclusive Health Care:
https://www.virtualhospice.ca/2SLGBTQ/articles/my-choices-for-safe-and-inclusive-healthcare

Planning for my care: For People who identify as Two-Spirit and LGBTQ+:
https://www.virtualhospice.ca/2SLGBTQ/media/igkp01nf/2slgbtq-planning-for-my-care.pdf

Two-Spirit resources: https://egale.ca/portfolio/two-spirits-one-voice

TRAUMA INFORMED

10.6 Trauma-informed palliative and end-of-life care

Trauma is an extremely upsetting event or set of events that overwhelm one's internal resources and produce lasting psychological symptoms (for example, freezing, dissociating, hyperventilating, panicking and having intense physical sensations).[229, 230] Trauma impacts people in various ways, from heightening their concerns about personal safety to reducing their capacity for managing stressful situations.

Trauma experienced by some Indigenous Peoples may lead to feelings of distrust of the biomedical health care system and institutional settings, resulting in individuals with life-limiting illnesses and their families being less likely to access palliative and end-of-life care.

Trauma-informed palliative and end-of-life care recognizes the prevalence of trauma and how trauma affects individuals, families and communities. By helping people with life-limiting illnesses to self-soothe and regulate their

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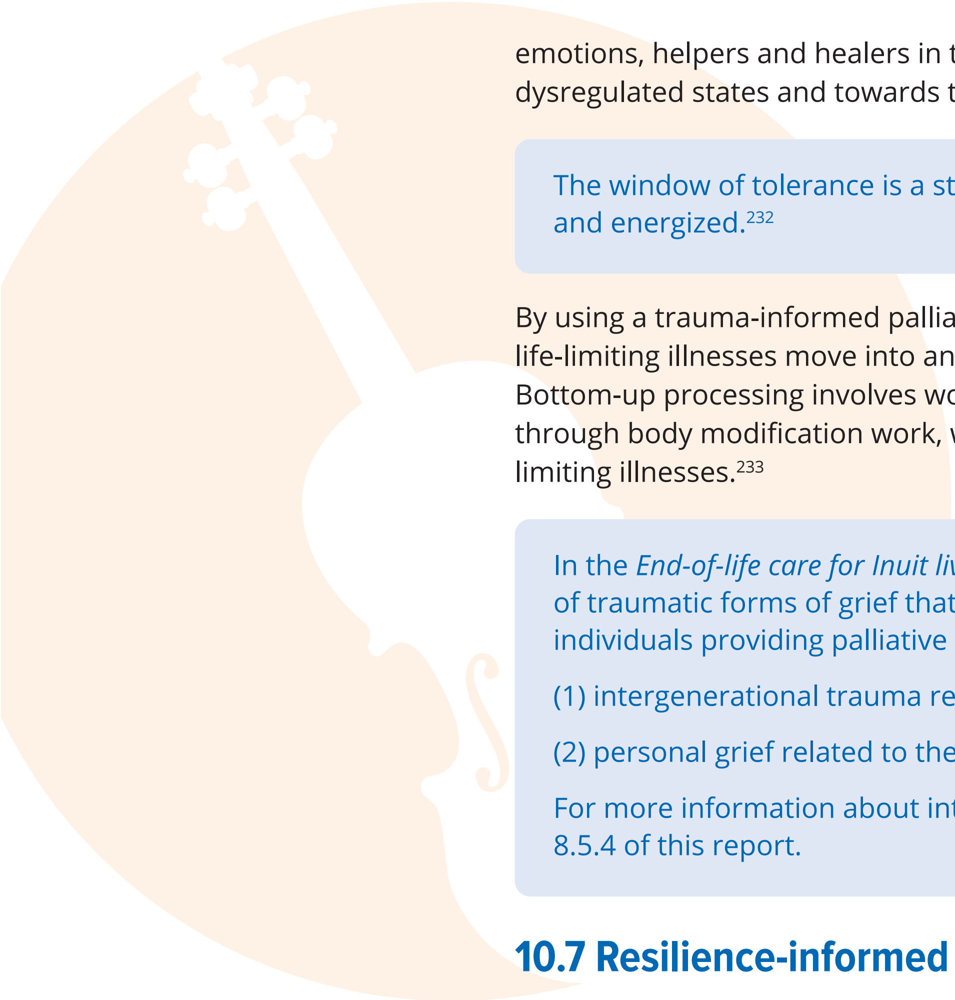
[229] Briere JN, Scott C. Principles of trauma therapy: a guide to symptoms, evaluation, and treatment, 2nd ed. SAGE; 2015.

[230] Van Der Kolk B. The body keeps the score: brain, mind, and body in the healing of trauma. Penguin Books; 2014.



emotions, helpers and healers in the palliative and end-of-life care field can help them to move away from these dysregulated states and towards their window of tolerance.[231]

> The window of tolerance is a state of being where people are able to think clearly and feel relatively calm, safer and energized.[232]

By using a trauma-informed palliative and end-of-life care approach, helpers and healers can assist people with life-limiting illnesses move into and expand their window of tolerance through bottom-up and top-down processing. Bottom-up processing involves working with the emotions and defence systems of people with life-limiting illnesses through body modification work, while top-down processing focuses on shifting thought patterns for people with life-limiting illnesses.[233]

> In the *End-of-life care for Inuit living in Nunavik, Quebec* (2016) report, research participants spoke of two types of traumatic forms of grief that can accumulate and potentially interfere with bereavement experiences of individuals providing palliative and end-of-life care:
>
> (1) intergenerational trauma related to historical experiences of loss; and
>
> (2) personal grief related to the experience(s) of death in crisis by loved ones.[234]
>
> For more information about intergenerational trauma and death in crisis, refer to Section 8.3.2 and Section 8.5.4 of this report.

10.7 Resilience-informed palliative and end-of-life care

A resilience-informed approach is guided by ethical values of respect, inclusion, truth telling, wisdom and belonging.

To reflect a resilience-informed palliative and end-of-life care approach, it would be beneficial for policies and practices to be based upon shared values, foundations and processes. These values, foundations and processes include being culturally safer, trauma- and resilience-informed and inclusive of Indigenous identity (for example,

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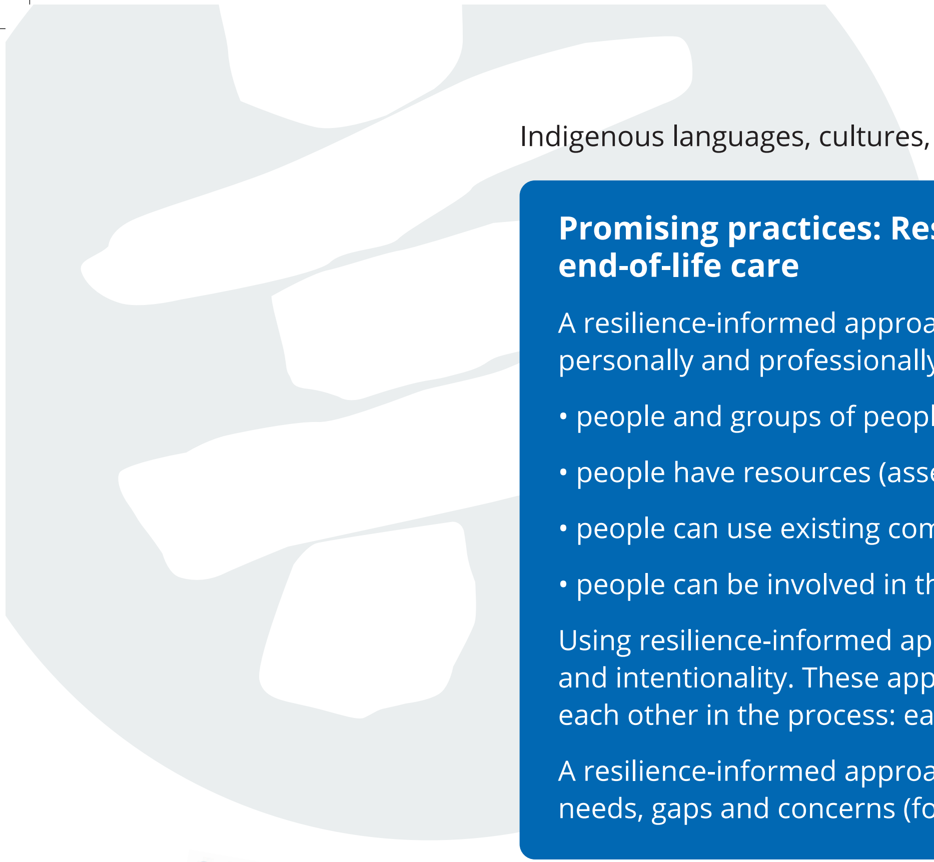
[231] NICABM. How to help a client come back into their window of tolerance with Bessel Van Der Kolk and Ruth Lanius [Video]. YouTube. https://www.youtube.com/watch?v=fmDk4sotWGs&t=9s. 2017, October 31.

[232] Ibid.

[233] ABM. Brain-based approaches to help clients after trauma (infographic). https://www.nicabm.com/brain-based-approaches-to-help-clients-after-trauma/?itl=homepageinfographics (nd).

[234] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 77.

Indigenous languages, cultures, values, beliefs, traditions and practices, worldviews and knowledge).[235]



Promising practices: Resiliency considerations in Indigenous approaches to palliative and end-of-life care

A resilience-informed approach to palliative and end-of-life care is a perspective or manner of doing things personally and professionally that is rooted in the belief of resiliency in which

- people and groups of people (includes organizations, communities) have existing competencies;
- people have resources (assets) and are capable of learning new skills and solving problems;
- people can use existing competencies to identify and address their own concerns; and
- people can be involved in the process of discovery and learning.

Using resilience-informed approaches in the palliative and end-of-life care journey should depend on capacity and intentionality. These approaches are based on the idea that people and environments interact and change each other in the process: each person has the ability to build the other's capacity.

A resilience-informed approach does not mean that you fabricate strengths, are insincere or cannot talk about needs, gaps and concerns (for example, trauma).

TRUST

RELATIONSHIPS

10.8 Relationships and allyship

In 2015, the Truth and Reconciliation Commission of Canada Chair the Honourable Mr. Justice Murray Sinclair and Commissioners Chief Wilton Littlechild and Dr. Marie Wilson wrote to the Partnership indicating that "given the important work that Canadian Partnership Against Cancer does for health care in the country, we believe that you can be an ambassador in moving reconciliation forward."[236]

Relationships and allyship dovetail with social justice in Indigenous approaches to palliative and end-of-life care. Concepts of justice play a profound role in clarifying human needs in palliative and end-of-life care. Social issues such as inequality, poverty and discrimination pose a constant challenge to policies and practices that serve the health and income needs of children, families, people from the 2SLGBTQQIA+ community, people with disabilities, the elderly and Indigenous Peoples.

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[235] https://www.fnha.ca/Documents/framework-accord-cadre.pdf

[236] Sinclair, M., Littlechild, W., & Wilson, M. Letter to the Canadian Partnership Against Cancer; 2015.

What is allyship?

Allyship is an active, consistent and challenging practice of unlearning and re-evaluating, in which a person in a position of privilege and power seeks to operate in solidarity with marginalized group(s).[237]

Part of the decolonization process in health-care settings is learning how to be an ally and to work in solidarity with one another.

For more information about allyship, visit https://theantioppressionnetwork.com/allyship.

Some examples of social justice guiding principles and associated activities are

- consciousness raising of healers and helpers regarding social, structural, systemic, eco-justice, equity issues and human rights;
- promoting education and skills development training as well as encouraging non-partisan advocacy that promotes public, organizational and legislative actions related to social justice;
- challenging inequitable forms of power that lead to injustice;
- supporting individual and collective actions to promote sustainable transformation;
- empowering ourselves even as we recognize and support the empowerment of others;
- respecting all persons and the natural environment, at all times;
- including diversity in all its aspects; and
- recognizing the variety of values, spiritual beliefs and practices that contribute to visions of a just world.[238]

There is an opportunity to advocate for social justice and social change—promoting equity and human rights for individuals and societies through action, education, consciousness-raising and advocacy.

As these social justice competencies are gaining more prominence in health-care professionals' standards of practice, relationships, allyship, diversity and inclusion bring much needed knowledge, skills and abilities in being an advocate for people with life-limiting illnesses in systems, particularly in health care.

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[237] https://theantioppressionnetwork.com/allyship

[238] https://www.edu.gov.mb.ca/k12/cur/socstud/global_issues/social.pdf

10.9 Summary

Using the Etuaptmumk/two-eyed seeing approach, palliative and end-of-life care can be proactively, respectfully and thoughtfully braided together based on the strengths from Indigenous ways of knowing and biomedical approaches. This interplay informs readers to support practices, competencies and social justice/diversity/inclusion principles that consider a lifespan and generational perspective, gender- and 2SLGBTQQIA+-informed, trauma-informed, resilience-informed approaches in the theory and practice of palliative and end-of-life care in diverse health-care settings.

11. Palliative care competencies and Indigenous promising practices

> There is a need for all health-care providers in various organizational settings across Canada to have both palliative care and cultural safety foundational training as part of their health-care practices and continuous learning (professional development).

11.1 Overview

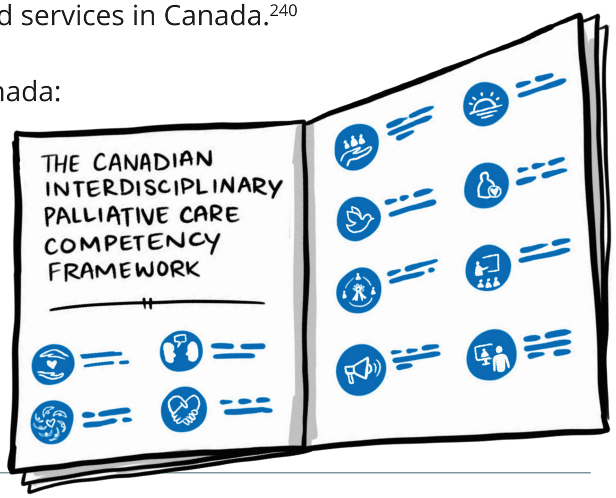
Competencies are specific and observable knowledge, skills, attitudes and behaviours associated with effective functioning in a job.

Working with partners across Canada, including the Palliative and End-of-life Care National Network and Health Canada, the Partnership developed *The Canadian Interdisciplinary Palliative Care Competency Framework* in response to the *Action Plan on Palliative Care* (2019)[239], which called for the development of a pan-Canadian, interdisciplinary palliative care competency framework that documents essential skills, knowledge and abilities for health-care workers.

The Canadian Interdisciplinary Palliative Care Competency Framework outlines a clear and common vision of the minimum standards that people (for example, caregivers, health-care providers) need to demonstrate to deliver high-quality, safe and ethical palliative and end-of-life care programs and services in Canada.[240]

There are 12 national palliative and end-of-life care competencies in Canada:

1. Principles of palliative approach to care
2. Cultural safety and humility
3. Communication
4. Optimizing comfort and quality of life



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[239] Health Canada. Action Plan on Palliative Care: Building on the Framework on Palliative Care in Canada. Ottawa, ON: Health Canada; 2019

[240] https://s22457.pcdn.co/wp-content/uploads/2021/07/palliative-care-competency-framework-EN.pdf

5. Care planning and collaborative practice
6. Last days and hours
7. Loss, grief and bereavement
8. Self-care
9. Professional and ethical practice
10. Education, evaluation, quality improvement and research
11. Advocacy
12. Virtual care

For more information about the palliative care competency framework, visit https://bit.ly/39EBwud.

Curricula and related continuous learning practices are important aspects of decolonization.

Readers are invited to consider whose knowledge and ways of knowing and being are given priority in palliative and end-of-life care.

Continual reflection is essential to decolonization which involves readers reflecting on curricula, power dynamics, structures and any actions undertaken on behalf of Indigenous Peoples with life-limiting illnesses, their families and communities during palliative and end-of-life care.

11.2 Principles of palliative approach to care

Palliative and end-of-life care are philosophies and approaches to care that support people living with life-limiting illnesses and their families to receive holistic person-centred care, support and resources across the generations.

Promising practice: The Medicine Wheel (or sacred hoops)

The Medicine Wheel is one approach to healing and helping.

Medicine Wheels have different representations, though they tend to have a circle pattern.

The foundational concepts of the Medicine Wheel are wholeness, balance, connection, harmony, growth and healing. Based on the rhythm of life, the circle shape represents the interconnectedness of all aspects of one's being, including the connection to nature.

The Medicine Wheel is divided into four parts. The powers of the four directions organize everything: the person (physical, mental, emotional and spiritual), seasons, elements of the universe and stages of life.

The Medicine Wheel teaches that the person is in the centre. Medicine Wheels are frequently believed to be the circle of awareness of the individual self: the circle of knowledge that provides the power we have over our own lives.

As a healing and helping tool, the Medicine Wheel teaches the way to balance one's life—the alignment and continuous interaction of the physical, emotional, mental and spiritual realities. This balance includes connections with family and community.

11.3 Cultural safety and humility

Cultural awareness (knowing), cultural competencies (applying), cultural safety (acting) and cultural agility (adapting) are fundamental components in understanding healing and helping with and alongside Indigenous Peoples in Canada. Cultural humility recognizes and values Indigenous ways of knowing and the role of Indigenous Elders and Knowledge Carriers.

Healers and helpers working with Indigenous Peoples with life-limiting illnesses benefit from educating themselves on colonial history and the unique local and regional histories of people with life-limiting illnesses and their communities to become culturally safer health-care providers and caregivers.[241]

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[241] Reeves A, Stewart SL. Exploring the integration of Indigenous healing and Western psychotherapy for sexual trauma survivors who use mental health services at Anishnawbe Health Toronto. Canadian Journal of Counselling and Psychotherapy. 2014;49(1):57–78.

Promising practices: Helping from an ethical and culturally safer place

It is recommended that helpers engaging in palliative and end-of-life care value diversity and multiculturalism to ensure that palliative and end-of-life care strategies are culturally congruent.

There should be no discrimination in the delivery of palliative and end-of-life care services based on human rights factors such as age, race, culture, disability, ethnicity, gender, religion, sexual orientation, marital status or socio-economic status.

Unsafe cultural practices compromise the actions of helpers and risk diminishing or disempowering the cultural identity/identities and well-being of Indigenous Peoples living with life-limiting illnesses, their families and communities.

Therefore, helpers must

- recognize the inherent worth of all people (asset-based approach; focus on strengths and potential);
- be aware of their own beliefs and how they affect others;
- recognize the reality of oppression, power and privilege;
- assess individual, situational, historical and cultural factors across the lifespan and the generations;
- develop an attitude of openness;
- become knowledgeable about various First Nations, Inuit and Métis cultures;
- involve other support/resource people from different First Nations, Inuit and Métis cultures;
- foster allyship, collaborative networks and team-based consultation;
- know how and be willing to adapt palliative and end-of-life care approaches based on the priorities of First Nations, Inuit and Métis Peoples, their families and communities; and
- develop a comfort level for ambiguity and divergent views of right and wrong when developing or enhancing palliative and end-of-life care approaches based on the priorities of First Nations, Inuit and Métis Peoples, their families and communities.

For more information on cultural safety, visit

First Nations Health Authority - Framework for cultural safety and humility: https://www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/cultural-safety-and-humility

Inuit cultural safety in the medical system: https://www.youtube.com/watch?v=4bEPqTmK-L4

Kawa Whakaruruhau: Cultural safety in nursing education in Aotearoa: https://bit.ly/3KA2xeL

San’yas anti-racism Indigenous cultural safety training program: http://www.sanyas.ca/home

Towards cultural safety for Métis: An introduction for health care providers: https://www.ccnsa-nccah.ca/docs/emerging/FS-CulturalSafetyMetis-MetisCentre-EN.pdf

Promising practice: Saint Elizabeth Health @YourSideColleague® Essential Learning

Saint Elizabeth Health @YourSideColleague® Essential Learning are accredited healthcare education courses delivered to health-care providers which are specific to the realities and needs of First Nations, Inuit and Métis communities.

These accredited courses are available free of charge through the e-platform, @YourSideColleague®, in-person and through blended methods.

Courses include

- Supporting natural caregivers course: This course assists health-care providers in providing education and supports to natural caregivers in their communities.
- Elder care course: This course focuses on the role of an Elder, cultural knowledge, historical and intergenerational trauma, Elder abuse, Medicine Wheel teaching and caring for yourself and caregivers.
- Cancer care course: This course explores First Nations cancer pathways, an introduction to cancer, types and causes of cancer, reduction in the risk of cancer; screening; early detection and diagnosis, common cancer treatments, symptom management; oncological emergencies; and psychosocial effects and needs.
- Palliative care course: This course centers on hospice palliative care; pain management; symptom management; death and dying; grief, loss and bereavement; advanced care planning; decision-making, assessment and management of pain; and planning for an expected death at home.

For more information about the Saint Elizabeth First Nations, Inuit and Métis Program – Essential Learning courses, visit https://fnim.sehc.com/se-learning/essential-learning.

Indigenous Cultural Safety Training: Advanced illness, palliative care and grief

Everyone working in healthcare has a responsibility to contribute to respectful care that honours and includes cultural traditions and beliefs. When culture and traditions are enabled, the person who is ill and their family feel heard and supported.

Living with an advanced illness is difficult for patients, their families, friends, and members of their community. Lack of cultural knowledge or failure to ask what is important to a patient and family, impacts care, makes the experience more difficult, and grief more complex.

In these modules, you will hear from Indigenous Peoples about their values, beliefs, and views about care, explore barriers to culturally safer care, and learn how to address these barriers in your role.

Thank you. Miigwetch.

MODULE 1
Understanding Indigenous culture in palliative care

MODULE 2
Indigenous peoples' journey through end-of-life care

Promising practice: Canadian Virtual Hospice—Indigenous cultural safety training

Advanced illness, palliative care and grief

This series of free online learning modules were developed by Indigenous scholars, Elders, health-care providers and informed by Indigenous Peoples living with advanced illnesses and their families.

This training includes a series of modules to promote culturally safer palliative care and grief support. The modules are available in both English and French.

As an educational tool, it is intended for a broad audience from anyone working in any health setting to health faculties and policy and planning decision-makers.

Certificates are available upon completion of each module.

For more information, visit https://culturalsafetytraining.livingmyculture.ca

11.4 Communication

Communication is essential to the delivery of palliative and end-of-life care. Specific considerations should be given to communication (for example, oral, written, virtual) as a method of establishing healthy relationships between health-care providers and people with life-limiting illnesses/family participating in informed decision-making. Effective communication includes active listening when working with and alongside people with life-limiting illnesses, their families and communities.

In the *End-of-life care for Inuit living in Nunavik, Quebec* (2016) report, physicians and nurses suggested that guidelines concerning communication with Inuit families and community members would be helpful in providing EOL care.[242] Also, research participants suggested that nurses and/or interpreters become actively engaged in communicating cultural factors in care for Inuit patients to physicians, physicians receive short written texts outlining cultural considerations and medical schools become active in providing training to physicians about Indigenous populations in Canada.[243]

Examples of effective communication are knowing

- how to discuss the need for cultural safety and cultural humility regarding spiritual beliefs and practices surrounding dying, death and loss;
- how to discuss professional and ethical practices in relation to the roles and responsibilities of caregivers and health-care providers; and
- how to engage in difficult conversations about illness, dying, death and loss.

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[242] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 40.

[243] Ibid. p. 50.

Promising practices: Culture-infused helping

Culture-infused helping centres on three core dimensions: having awareness of personal assumptions, values, and biases; understanding the worldview of people with life-limiting illnesses; and developing and sustaining culturally sensitive working alliance(s). Each of these above competencies involves knowledge, attitudes and skills.[244]

For readers who are interested in developing and implementing tools, resources and education to support the delivery of high-quality Indigenous approaches to palliative and end-of-life care,

- Be aware of and understand diverse needs/issues of people with life-limiting illnesses and related populations.
- Ask what the people with life-limiting illnesses want out of palliative and end-of-life care.
- Ask about the feelings of people with life-limiting illnesses and expectations of you as the helper which includes discussing expectations and apprehensions about the palliative and end-of-life care process and therapeutic alliance/relationship.
- Be emotionally present.
- Recognize your personal power and privilege (how your self-confidence can impact and influence people with life-limiting illnesses).
- Be courageous in your interactions with people with life-limiting illnesses; recognize that you cannot hide behind your special role as a helper.
- Be willing to confront yourself and promote self-investigation; raise questions to determine how honest you are with yourself about your motivations in carrying out specific palliative and end-of-life care approaches.
- Have a clear sense of identity personally and professionally. This understanding of self includes reflecting on your palliative and end-of-life care practice(s) and cultural identity/identities. For example, can you reflect on your self-location and how your personal culture(s) affect your palliative and end-of-life care practices? Can you examine your assumptions about health, wellness and people?
- Demonstrate authentic engagement with people with life-limiting illnesses which includes the use of non-jargon language (watch out for “assessment and diagnostic speak”), active listening and unconditional positive regard.
- Engage in continuous learning. Personal and professional development includes learning about various protocols, practices and ceremonies pertaining to palliative and end-of-life care, growing your cultural competencies, and seeking allies, supervisors, mentors and/or colleagues.

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[244] Arthur N. Counselling in cultural contexts: identities and social justice. Cham, Switzerland: Springer Nature; 2018.

11.5 Optimizing comfort and quality of life

As defined by people living with life-limiting illnesses and their families, supporting and optimizing comfort and quality of life includes comprehensively assessing and addressing their physical, emotional, psychological, social and spiritual needs. This continuous process aims to prevent, acknowledge, assess and relieve suffering in a timely and proactive manner, including symptom management that aligns with the continuum of care goals of people with life-limiting illnesses.

Promising practice: Yukon Hospital Corporation—First Nations Health Program

The First Nations Health Program provides culturally appropriate, holistic health care to First Nations Peoples, their families and communities.

Care includes access to traditional healing practices, traditional medicines and food and support services.

Liaison workers, First Nations mental health advocates and community liaison/discharge planners can advocate for, guide and support First Nations people with life-limiting illnesses and their families during their hospitalization.

For more information, visit https://bit.ly/3KAbRPJ

11.6 Care planning and collaborative practice

Care planning is a collaborative practice that includes addressing, coordinating and integrating person- and family-centred care needs. Collaborative care planning ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner. People with life-limiting illnesses and their families should be supported in care planning to the extent that they are able and request to be involved.

Promising practice: *Canadian Virtual Hospice-Coming full circle: Planning for your care workbook*

The *Coming full circle workbook* is a planning tool for clients and a resource for health-care providers to explore and communicate the values, beliefs and wishes for care at the end-of-life.

Developed by Indigenous Elders and scholars, this workbook is a gentle way of starting advance care planning that can be completed at a self-directed pace online or in a printable format. The workbook is available in both English and French.

The *Coming full circle workbook* is also accessible in a large print format.

For more information, visit https://livingmyculture.ca/media/3836/planning-for-your-care.pdf

11.7 Last days and hours

Particular attention should be paid to address care needs unique to the last days and hours of life for people with life-limiting illnesses and their families. Examples of unique care needs for some Indigenous Peoples are desired place of death, rituals and traditions regarding dying and death.

Promising practice: First Nations Health Authority and Douglas College Indigenous end-of-life guide course

In a partnership between the First Nations Health Authority and Douglas College, the Indigenous end-of-life guide course assists Indigenous Peoples (as caregivers and/or advocates) in developing end-of-life care competencies to aid them in supporting individuals with life-limiting illnesses in their last days and hours.

Co-facilitated by a course instructor and a Knowledge Carrier, the four-day Indigenous end-of-life guide course has been offered to participants in-person and in online learning formats. The co-facilitation instructional style ensures that cultural practices and protocols are thoughtfully braided across the course modules on palliative and end-of-life care.

Key course modules include learning advanced communications skills (for example, active listening and conflict resolution); engaging in advanced care planning dialogue sessions with individuals with life-limiting illnesses and their families; initiating and conducting difficult conversations about end-of-life; facilitating family meetings and community education engagement; navigating the complexities of grief, loss and bereavement; and promoting effective self-care as a caregiver and/or advocate.

For more information about the Indigenous end-of-life guide course, visit https://bit.ly/3zQ2b1U

11.8 Loss, grief and bereavement

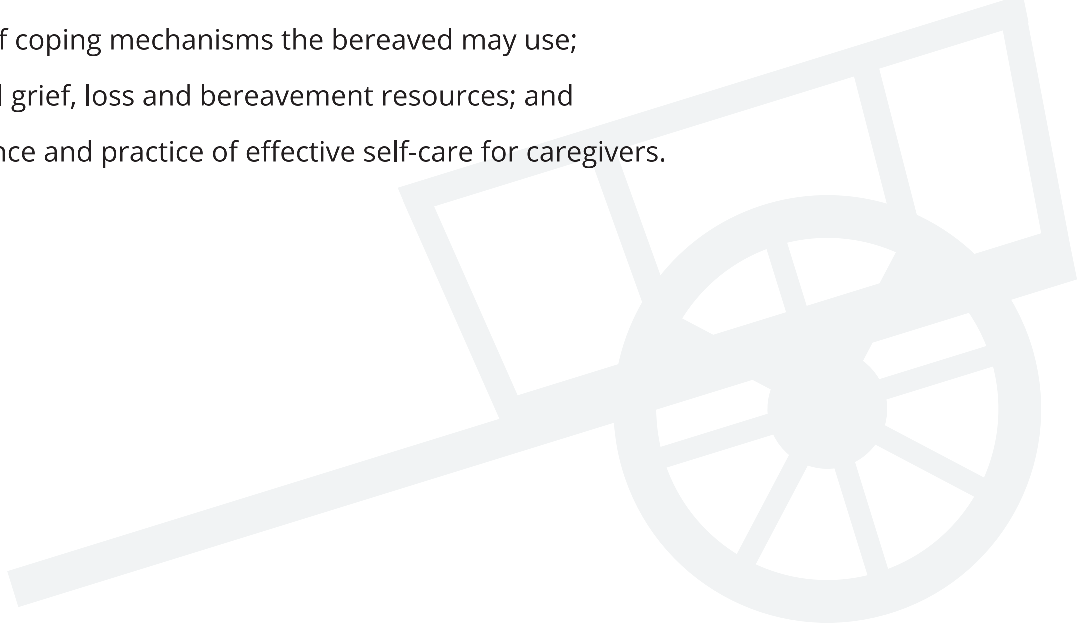
Grief is a universal experience, but there are inherently cultural variations in its expression. The realities of intergenerational and historical traumas and health inequities that face many Indigenous Peoples can lead to more complex and complicated grief for Indigenous families and communities.[245]

Bereavement is a culturally infused concept that highlights the social context influencing one's expression of grief.[246] Values, beliefs and customs of a particular culture shape the significance of a person's loss.[247]

Grief and bereavement are part of palliative and end-of-life care.

When possible, a palliative approach provides support to people with life-limiting illnesses, families and communities, throughout illness, dying and death—as they experience loss, grief and bereavement. This includes

- normalizing the grieving process as a necessary part of healing and helping;
- effectively responding to expressions of grief by families and communities;
- understanding the variety of coping mechanisms the bereaved may use;
- knowing how to access local grief, loss and bereavement resources; and
- understanding the importance and practice of effective self-care for caregivers.



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[245] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3384449

[246] Hibberd R. Meaning reconstruction in bereavement: sense and significance. Death Studies. 2013;37(7):670–692.

[247] Neimeyer RA, Prigerson HG, Davies B. Mourning and meaning. American Behavioral Scientist. 2002;46(2):235–251.

Voices from the field: Grief and bereavement supports in palliative and end-of-life care for Indigenous Peoples in Canada

In discussions with the Partnership, some Indigenous palliative and end-of-life care practitioners shared that there are substantial and persistent gaps in grief and bereavement supports. Where supports are sometimes provided by palliative and end-of-life care programs, they typically have very modest, time-limited resources for families and communities to access.

Grief support is a critical component of palliative care. In the area of healing and helping, there is insufficient knowledge of or response to the overwhelming intergenerational grief that exists for the individual experiences and collective history of Indigenous Peoples, their families and communities.

Lack of grief and bereavement support can extend the emotional pain felt by families and communities of the people with life-limiting illnesses.

There is an urgent need to deliver culturally safer and trauma-informed grief training in health faculties and health-related professional training in post-secondary institutions across Canada.

11.9 Self-care

Self-care is a responsible practice and lifespan issue, in particular for those employed in the service and care of others such as palliative and end-of-life care. Self-care is being widely discussed these days as a healthy and valuable process for ethical and effective practice.

In *Strong helpers' teachings: The value of Indigenous knowledge in the helping professions,* Dr. Cyndy Baskin states the "self is always first in the circle."[248]

Healers and helpers must take care of themselves before they can help others.

Self-care is a continuous process of self-reflection to develop an understanding of self as healer or helper, of palliative and end-of-life care and of the influence of healers' or helpers' reciprocal interaction with others (e.g., bereaved families and communities), for example,

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[248] Baskin C. Strong helpers' teachings: the value of Indigenous knowledge in the helping professions, 2nd ed. Toronto (ON): Canadian Scholars' Press; 2016.

- self-awareness and the ability to be self-reflective;
- personal and professional self-evaluation;
- recognition of the influence of healer and helper characteristics and behaviours in the palliative and end-of-life care journey;
- awareness of personal and interpersonal connections to power, privilege and oppression as well as recognition of personal biases; and
- reflection on opportunities to develop and use advocacy and social justice skills to build a more socially just, diverse society.

11.10 Professional and ethical practice

Ethics involves standards of practice as well as knowledge of relevant jurisdictional laws that apply to palliative and end-of-life care. Some examples of professional and ethical practices are

- understanding the changing landscape of regulations in palliative and end-of-life care;
- applying ethical approaches in practice, including application of ethical decision-making processes to cases;
- understanding the scope and boundaries of ethics in professional relationships, including ethical and culturally relevant strategies for establishing and maintaining in-person and technology-assisted (virtual) relationships;
- maintaining comprehensive records, which may include documenting professional activity; ensuring clarity, timeliness, legibility, appropriateness, adequacy and accuracy of records; maintaining security and preservation of records; and recognizing and addressing factors affecting confidentiality, access to information and transfer of information and records to others; and
- using technology in palliative and end-of-life care (for example, using technology for communication, program monitoring, report writing, problem solving, record-keeping, and case management in a secure and professional manner).

Traditional Native code of ethics
http://www.hulitan.ca/wp-content/uploads/2017/02/App-B-traditional-native-code-of-ethics.pdf

11.11 Education, evaluation, quality improvement and research

Drawing on current and emerging trends, palliative and end-of-life care benefits from principles and practices pertaining to lifelong learning, research, evaluation and continuous improvement.

Promising practice: Exchange of competencies

The *End-of-life care for Inuit living in Nunavik, Quebec* (2016) report recognizes existing competencies balanced with ongoing training and mutual-mentoring opportunities which have been crucial to a successful collaboration between Inuit and Qallunaat health-care providers.

Some Inuit professionals suggested that a mutual educational approach be implemented in northern communities, one in which Inuit train southerners concerning existing community health practices and initiatives, protective factors, cultural norms and successful communication strategies.

In exchange, Inuit professionals would receive training concerning medical, social and psychological models that may be adapted to their communities.

Training requests related to EOL care included a) training in dementia prevention and intervention; b) increased linguistic and communication resources; and c) exchanges with other Inuit across the circumpolar regions who are also developing EOL care services.[249]

Promising practice: The Palliative Care ECHO Project

The goal of The Palliative Care ECHO (Extension for Community Healthcare Outcome) Project is to support continuous learning in palliative care. ECHO offers programs that cultivate communities of practice and continuous professional development amongst health-care professionals who provide care to people with life-limiting illnesses, their families and communities.

Pallium Canada coordinates and connects the system of hubs across Canada, curating and supporting content development for hub partners and their spokes to meet local needs. Pallium Canada also delivers national palliative care programming and leads the overall evaluation of the Palliative Care ECHO Project’s impacts and reporting.

The Palliative Care ECHO Project covers many general areas of palliative and end-of-life care, with some First Nations, Inuit and Métis cultural components.

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[249] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health. 2016. p. 41.

Note: The ECHO Project is not a replacement for foundational training on the palliative care approach through programs such as Pallium's LEAP courses.

LEAP courses and the Palliative Care ECHO Project are complementary. They work together to equip interprofessional health-care providers and organizations from across Canada with the knowledge, skills and confidence to build capacity in providing palliative care.

For more information about this project, visit www.echopalliative.com

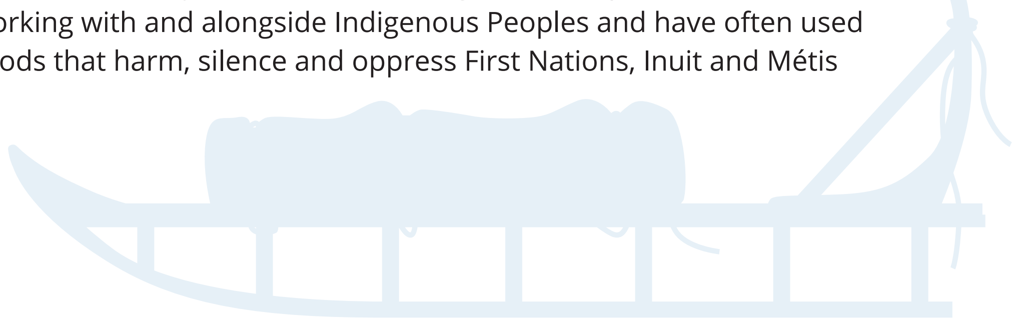
Promising practice: Pallium Canada's Indigenous cultural safety and humility learning module

This module is designed to provide all health-care providers in Newfoundland and Labrador with fundamental competencies and knowledge to provide culturally safer palliative care for First Nations, Inuit and Innu in the province, including the effects of colonialism and how health-care providers can support culturally safer care.

The module was developed in partnership with an Indigenous expert in culturally safer care, included ongoing engagement with community leaders across the province and incorporates published best practices and shared community knowledge.

The self-learning module is a free supplement for all past and future LEAP learners in the province.

Indigenous Peoples may face challenges in education, evaluation, quality improvement and research. Non-Indigenous People created and continue to perpetuate these challenges for Indigenous Peoples by imposing colonial research methods.[250, 251] It is important to note that, over the years, some non-Indigenous People have conducted research on Indigenous Peoples rather than working with and alongside Indigenous Peoples and have often used unethical and non-collaborative research methods that harm, silence and oppress First Nations, Inuit and Métis voices and truths.[252, 253, 254]



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250 Kovach M. Story as Indigenous methodology. In Indigenous methodologies: characteristics, conversations and contexts. University of Toronto Press. 2009.

251 Rix EF, Wilson S, Sheehan N, Tujague N. Indigenist and decolonizing research methodology. In: Liamputtong P, editor. Handbook of research methods in health social sciences. Singapore: Springer; 2019.

252 Brant Castellano M. Indigenous research. In: Given LM, editor. The SAGE encyclopedia of qualitative research methods. SAGE; 2008.

253 Rix EF, Wilson S, Sheehan N, Tujague N. Indigenist and decolonizing research methodology. In: Liamputtong P, editor. Handbook of research methods in health social sciences. Singapore: Springer; 2019.

254 Kovach M. Story as Indigenous methodology. In: Indigenous methodologies: characteristics, conversations and contexts. University of Toronto Press. 2009. p. 39–54.

In the *End-of-life care for Inuit living in Nunavik, Quebec* (2016) report, it appears that some Inuit communities are at a disadvantage…as their cultural and traditional expertise has largely gone unexamined and have not been given the evidence-based practice recognition stamp which is often necessary to attain funding for palliative and end-of-life care program development and capacity building.[255]

Many Indigenous scholars and communities are taking back research by using decolonizing research methodologies that honour the power of storytelling and forming diverse collaborative teams and working groups which include non-Indigenous research allies.

What are decolonizing research methodologies?

The following are promising practices that pertain to decolonizing research methodologies:

- Kirkness and Barnhardt's Four "Rs"—Principles of respect, relevance, reciprocity and responsibility https://www.afn.ca/uploads/files/education2/the4rs.pdf;
- OCAP (ownership, control, access and possession) Principles—First Nations standards in the collection, protection, utilization and sharing of data in terms of conducting research with First Nations. https://bit.ly/3y74Fb3
- Culturally congruent participatory approaches—for example, use of story maps/boards, Photovoice, infographics, focus groups and Talking Circles[256] and community interviews;
- Knowledge sharing and using knowledge with a planned and shared purpose, stating intent and obtaining informed consent; recognizing that informed consent is not a one-time event in the research relationship—it is a process for co-constructing decisions on data ownership, control, access and possession; and
- Community engagement—co-leading with community members and proactive collaborative participation by community members on project teams.

Some notable resources:

Ethical guidelines for Aboriginal research—Elders and healers roundtable: https://bit.ly/3LCCQLF

Ethics in First Nations research: http://www.afn.ca/uploads/files/rp-research_ethics_final.pdf

Framework for research engagement with First Nation, Métis, and Inuit Peoples:
https://umanitoba.ca/faculties/health_sciences/medicine/media/UofM_Framework_Report_web.pdf

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[255] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 4.

[256] For a definition of Talking Circles, refer to Section 13.

Principles of ethical Métis research:
https://achh.ca/wp-content/uploads/2018/07/Guide_Ethics_NAHOMetisCentre.pdf

Tri-council policy statement: Ethical conduct for research involving humans—Chapter 9: Research involving the First Nations, Inuit, and Métis Peoples of Canada:
http://www.pre.ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html

Promising practice: Lakehead University—Improving end-of-life care in First Nations communities

This multi-year (2010–2016) research project was based at the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University in partnership with four First Nations communities in Ontario and Manitoba. This project was funded by the Canadian Institutes of Health Research. An outcome of this research was a workbook and related resources for creating palliative and end-of-life care programs in First Nations communities.

For more information, visit https://eolfn.lakeheadu.ca

Reflections: Palliative and end-of-life care research

While great strides have been made to engage Indigenous Peoples in palliative and end-of-life care research and evaluation, much of the research and evaluation on this topic in Canada has focused on perspectives, ways of knowing and lived experiences of First Nations Peoples, their families and communities.

Métis and Inuit voices, experiences and promising practices in palliative and end-of-life care continue to be underrepresented in health research across Canada.[257, 258]

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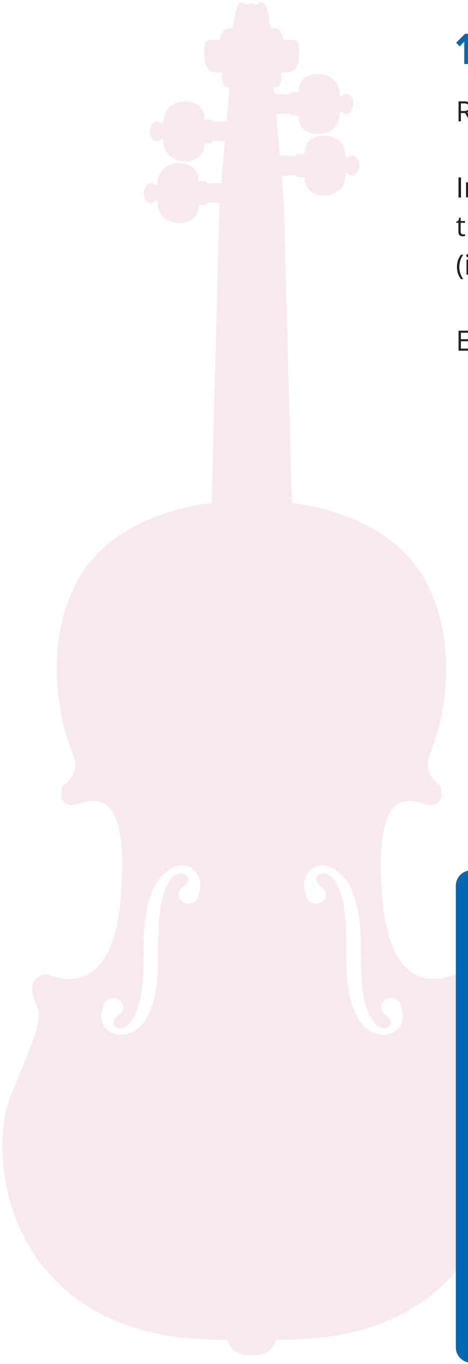
[257] Young TK. Review of research on Aboriginal populations in Canada: relevance to their health needs. BMJ (Clinical research ed.). 2003;327(7412):419–422.

[258] Furgal CM, Garvin TD, Jardine CG. Trends in the study of Aboriginal health risks in Canada. International journal of circumpolar health. 2010;69(4):322–332.

11.12 Advocacy



Relationships, allyship and social justice are important dimensions of advocacy for readers to continually reflect on.

In particular, caregivers and others can ask themselves how their values and assumptions impact and influence therapeutic approaches in the context of lived experiences of people with life-limiting illnesses at the micro (individual), meso (group and organization-wide) and macro (system-wide) levels.

Examples of advocacy are

- discussing signs and symptoms of dying;
- understanding praying and prayer support;
- describing a range of biomedical and non-biomedical interventions (e.g., Indigenous cultural practices) available to increase comfort;
- understanding the importance of and tools available for advanced care planning;
- understanding jurisdictional laws and cultural protocols for funeral practices;
- understanding jurisdictional laws that affect access to care; and
- encouraging funding and access to palliative and end-of-life care services and associated educational opportunities that contribute to policy development and address the Indigenous social determinants of health.

Promising practices: Relationships, allyship, social justice and advocacy resources

Ally bill of responsibilities: http://www.lynngehl.com/uploads/5/0/0/4/5004954/ally_bill_of_responsibilities_poster.pdf

Racism, the public health crisis we can no longer ignore: https://bit.ly/3OFyEff

Unsettling the settler within Indian Residential Schools, truth telling, and reconciliation in Canada: https://www.ubcpress.ca/asset/9215/1/9780774817776.pdf

Ways to be an ally, from two lifetimes of learning: https://thetyee.ca/Analysis/2020/06/09/Ways-To-Be-An-Ally

White privilege: Unpacking the invisible knapsack: https://www.pcc.edu/illumination/wp-content/uploads/sites/54/2018/05/white-privilege-essay-mcintosh.pdf

11.13 Virtual care

Virtual care or telehealth[259] involves the use of technology in the delivery of palliative and end-of-life care. Particularly in light of the COVID-19 pandemic and in recognition of people with life-limiting illnesses residing in rural, remote and northern locations across Canada, technologies can expand the range and type of communities that people living with life-limiting illnesses and their families can have with health-care organizations and providers.

Promising practices: Virtual care

MBTelehealth (Manitoba): https://mbtelehealth.ca/locations/first-nations

First Nations Health Authority (British Columbia): https://www.fnha.ca/what-we-do/ehealth/telehealth

11.14 Summary

To meet the current and future needs in palliative and end-of-life care for First Nations, Inuit and Métis Peoples with life-limiting illnesses, their families and communities, it is important to have a set of nationally-recognized competencies and accompanying promising practices and support tools to recruit, develop and retain a skilled group of helpers (in particular, Indigenous skilled helpers) using Indigenous approaches in palliative and end-of-life care.

The competencies outlined in this section of the report consist of knowledge, skills and abilities that are considered necessary for helper effectiveness in palliative and end-of-life care which are integral to the learning and development in this important health-care area.

Although the palliative care competency framework includes broad competencies for First Nations, Inuit and Métis Peoples, their families and communities, further engagement with First Nations, Inuit and Métis Peoples, governments, communities and organizations is needed to (1) identify gaps and opportunities in service delivery and (2) inform the development of Indigenous core competencies in palliative and end-of-life care.

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[259] Examples are synchronous and asynchronous communication, remote monitoring, messaging, phone, video visits, e-consults and related modalities. Virtual care is meant to complement rather than replace in-person palliative and end-of-life care.

12. Conclusion

As the Honourable Mr. Justice Murray Sinclair (former Chair of the Truth and Reconciliation Commission of Canada) stated, "The road we travel is equal in importance to the destination we seek. There are no shortcuts. When it comes to truth and reconciliation we are forced to go the distance."[260]

> Reconciliation is about establishing and maintaining a mutually respectful relationship between Aboriginal and non-Aboriginal peoples in this country. In order for that to happen, there has to be awareness of the past, an acknowledgement of the harm that has been inflicted, atonement for the causes and action to change behaviour.[261]

The Partnership is committed to advancing truth and reconciliation which includes achieving health equity for First Nations, Inuit and Métis Peoples.

> As a framework for reconciliation, the implementation of the *United Nations Declaration on the Rights of Indigenous Peoples* and the *Truth and Reconciliation Commission of Canada Calls to Action* with Aboriginal title and rights case law position First Nations, Inuit and Métis Peoples with opportunities to amplify their voices in advocating for and advancing Indigenous approaches to palliative and end-of-life care programs and services across Canada. This work includes (co)developing resources and supports based on a holistic set of values and principles that represent physical, mental, emotional and spiritual dimensions of self, family and community.

Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada responds to recommendations from the July 2021 virtual roundtable discussion with First Nations, Inuit and Métis Elders, Knowledge Carriers, community health professionals and researchers who have experience and knowledge of Indigenous approaches to palliative and end-of-life care.

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[260] https://nctr.ca/wp-content/uploads/2021/04/NCTR-Memorial-Register-E2.pdf

[261] Honouring the truth, reconciling for the future summary of the final report of the Truth and Reconciliation Commission of Canada, The Truth and Reconciliation Commission of Canada; 2015. p. 6.

This report highlights factors that influence First Nations, Inuit and Métis palliative and end-of-life care and promising practices in First Nations, Inuit and Métis palliative and end-of-life care.

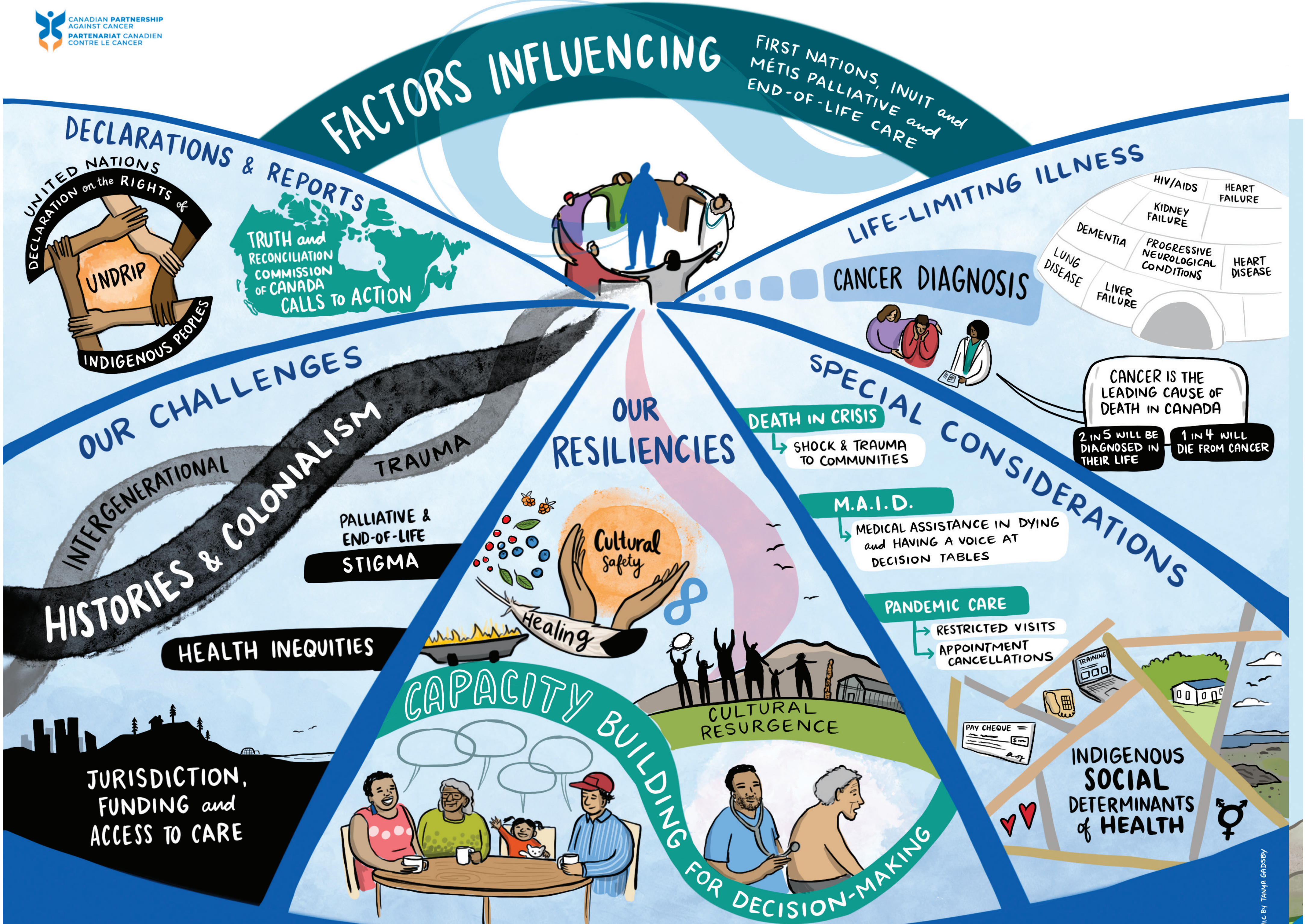
Specifically, this report summarizes (1) factors contributing to First Nations, Inuit and Métis Peoples' palliative and end-of-life care experiences; (2) identifies areas for action in palliative and end-of-life care based on priorities, gaps, challenges and needs expressed by First Nations, Inuit and Métis Peoples and communities; and (3) is strengths-based in identifying innovative and Indigenous community-based models of care and person-centred approaches to palliative and end-of-life care promising practices, resources and strategies.

Readers of this report may be at different stages of cultural awareness (knowing), cultural competencies (applying), cultural safety (acting) and cultural agility (adapting). Therefore, readers are invited to set their own pace when reading this report.

Readers are also encouraged to use this foundational background document to adapt, scale and reference strategies, programs and resources that support Indigenous approaches to palliative and end-of-life care.

In closing, we hope to build trust by upholding Indigenous cultural values and worldviews while engaging First Nations, Inuit and Métis Peoples, their families and their communities as equals to biomedical research and practice. Our purpose is to improve informed decision-making and fully recognize Indigenous approaches to palliative and end-of-life care.

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

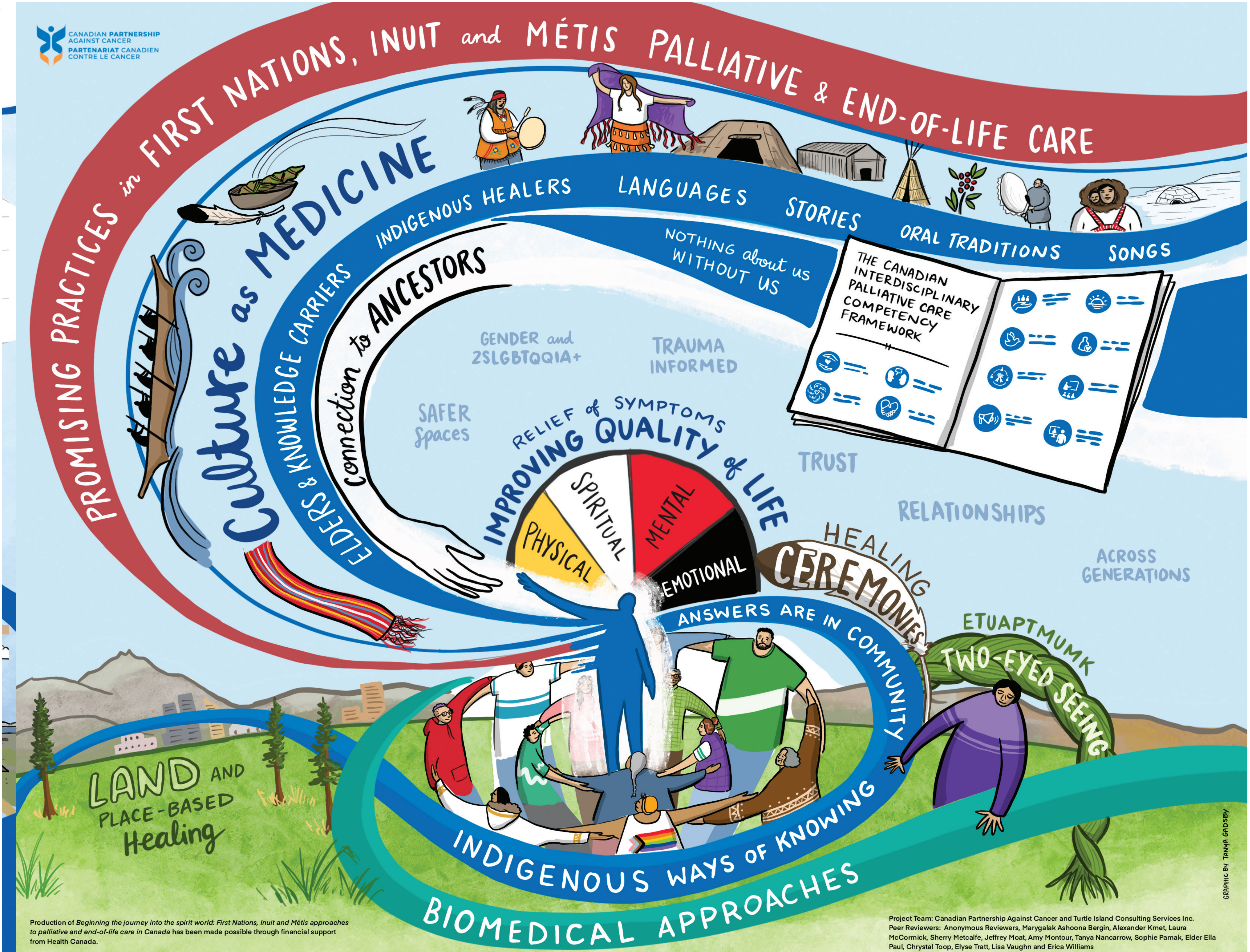


Production of *Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada* has been made possible through financial support from Health Canada.

Project Team: Canadian Partnership Against Cancer and Turtle Island Consulting Services Inc.
Peer Reviewers: Anonymous Reviewers, Marygalak Ashoona Bergin, Alexander Kmet, Laura McCormick, Sherry Metcalfe, Jeffrey Moat, Amy Montour, Tanya Nancarrow, Sophie Pamak, Elder Ella Paul, Chrystal Toop, Elyse Tratt, Lisa Vaughn and Erica Williams

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

PROMISING PRACTICES in FIRST NATIONS, INUIT and MÉTIS PALLIATIVE & END-OF-LIFE CARE



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13. Key terms

Aboriginal People. Defined in the *1982 Constitution Act of Canada*, Aboriginal refers to all Peoples of Indian (Status and Non-Status Indians), Inuit and Métis heritage. Aboriginal Peoples are Indigenous Peoples who have lived in Canada since time immemorial.

Allies. Allies seek to understand and have empathy for individuals and groups who experience discrimination and oppression through deep listening and acknowledgement of their lived experiences. Allies seek to promote and empower but not to speak for marginalized individuals and groups. Allies are committed to action to correct injustices and promote balance, through respect, cultural humility and inclusion.

Allyship. Allyship is an active, consistent and challenging practice of unlearning and re-evaluating, in which a person in a position of privilege and power seeks to operate in solidarity with marginalized groups.[262]

Bereavement. Bereavement is a time of loneliness and sadness that a person, family and/or community experiences due to a loss (for example, death of a loved one).

Biomedical. The science and study of life from a clinical medicine perspective.

Braiding. Based on the 2016 work of Drs. Gloria Snively and Wanosts'a7 Lorna Williams in the book *Knowing home: Braiding Indigenous science with Western science*, this metaphor describes how Indigenous and non-Indigenous ways of knowing can be used in a mutually respectful and reciprocal manner. A synonym for braiding is "harmonizing."

Caregivers. Family members or friends who provide assistance without pay. Caregivers play an important role in providing palliative and end-of-life care.

Colonization. The deliberate attempt by Canadian governments to destroy Indigenous institutions of family, spiritual belief systems, customs and traditional ways of life through enacted and enforced legal sanctions. Examples of colonization include the residential school system, the *Indian Act,* removal of Indigenous communities from their traditional territories and the Indian hospital system.

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[262] https://theantioppressionnetwork.com/allyship

Comfort care. Comfort care provides necessary cultural contexts that acknowledge the role of values, identities, families and communities when harmonized with palliative and end-of-life care. With a focus on kindness, compassion and quality of life, comfort care honours the spiritual beliefs, cultural protocols and practices of people living with life-limiting illnesses. In addition to care focusing on the whole person, support for the whole family and community of people living with life-limiting illnesses is included in comfort care.[263]

Competencies. Competencies are specific and observable knowledge, skills, attitudes and behaviours associated with effective functioning in a job. They can be measured against well-accepted standards, and they can be improved through education and skills development.

Cultural agility. Cultural agility means behaving in ways that put our skills in cultural awareness and safety into action—acting in ways that are curious, open-minded, flexible and appreciative of cultures that are different than our own.

Cultural awareness. When you are culturally aware, you know your own preferences and biases and acknowledge the commonalities and distinctions between cultures. Cultural awareness involves knowledge of the principles, values and cultural considerations important to Indigenous Peoples and understanding how values are uniquely expressed between and within First Nations, Inuit and Métis Peoples, families and communities.

Cultural competencies. These competencies are the attitudes, behaviours and skills that enable you (as a helper) to work ethically and effectively in cross-cultural settings; this is a journey, not a final destination.

Cultural congruence. Cultural congruence is the effective interpersonal interactions between a health-care provider and a person with a life-limiting illness, their family and/or community. Cultural congruence is a lifelong learning and developmental process in palliative and end-of-life care which is strengthened by continuous improvement in communications, cultural safety and ethics practices in care.

Cultural humility. Cultural humility is the recognition and valuing of Indigenous epistemologies (the study of knowledge) and the role of healers and Elders.

Cultural safety. Cultural safety is a way of being that is created by a trusting and respectful environment and involves the transformation of relationships—exploring and challenging power dynamics (in institutions, policies and practices). Culturally safer practices are actions in colonized spaces (for example, biomedical health-care settings) where First Nations, Inuit and Métis Peoples, their families and communities feel respected, included, welcomed and comfortable being themselves and expressing all aspects of who they are as Indigenous Peoples.

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[263] https://www.cancercareontario.ca/sites/ccocancercare/files/assets/ACCUPalliativeCare.pdf (p. 1).

Decolonization. Decolonization is the process of undoing colonizing practices. In a health-care context, this means confronting and challenging colonizing practices that have influenced health-care in the past and which are still present today. This process often involves reflecting on the structure of health-care institutions and their role in the broader society.

Elders. Elders are First Nations, Inuit or Métis individuals who make a life commitment to the health and holistic healing of their community and Peoples.

End-of-life care. End-of-life care focuses on increasing care and meeting the goals of people within their last hours, days, weeks or months of life. End-of-life care includes supporting their families through the life-limiting illness and after death. End-of-life care is part of palliative care.

Ethics. Ethics are principles (or formal sets of rules) that define behaviour as right, good and proper. Ethics is about our actions—how we act and what we do.

Family. Family refers to peoples' birth family, family through marriage and/or their family of choice. Family also includes legal guardians, friends and caregivers. In the context of palliative and end-of-life care, people living with life-limiting illnesses (for example, cancer) may identify family (or families) that they would like included in any encounters with the health-care system.

First Nations People. They are the First Peoples of Canada, both Status and Non-Status. Status (or registered) Indians are individuals who are registered according to the *Indian Act* and members of a band (aka First Nations community). Status Indians receive supports and related services (for example, housing assistance and financial assistance for post-secondary education) from Indigenous Services Canada (ISC). Non-Status Indians are individuals that are not recognized as Indians under the *Indian Act.* At present, there are over 600 First Nations communities in Canada representing more than approximately 50 Nations and language groups.

Grief. Grief is a natural response to loss in the form of strong emotions and suffering. In relation to palliative and end-of-life care, grief is associated with dying and death of loved ones. Grief has physical, socio-cultural, spiritual, emotional, physical and behavioural dimensions which can make this response complex in nature. There is anticipatory grief which provides time and space for the family and community of the person with the life-limiting illness to prepare for the eventual loss (death). There is also disenfranchised grief which refers to a grieving process that does not align with the community or broader society's attitudes and beliefs about death and loss.

Healers. Healers are people (e.g., medicine persons) who often hold positions of high respect in First Nations, Inuit and Métis communities.

Healing ceremonies. Healing ceremonies focus on traditional healing specialties that address mental, emotional, spiritual and physical aspects of health and wellness. Engagement in ceremonies and healing approaches are facilitated by traditional healers and Elders who are recognized by their Indigenous communities. These ceremonies may include the Medicine Wheel, Sweat Lodge, Ancestor Feasts and other ceremonies that provide healing, helping and cultural support.

Health-care professionals. Health-care professionals are members regulated by their health disciplines, for example, physicians, massage therapists, nurses and psychologists.

Health-care providers. These are people who provide health-related goods or services to people with life-limiting illnesses, for example, health-care professionals, students, volunteers and other individuals acting on behalf of health-care organizations.

Historical trauma. Historical trauma is the cumulative and collective trauma experienced over a lifetime and across generations as a response to acts of nature (for example, deforestation) and acts of cruelty towards others (for example, residential school experience, racism). Historical trauma leads to dysfunctional coping strategies (for example, substance misuse, domestic violence), which negatively impact the health and well-being of the individuals, families, communities and societies that experienced the trauma(s).

Indigenous Peoples. Indigenous Peoples are recognized through a process of self-identification, historical continuity, strong linkage to ancestral territories and surrounding natural resources, and distinct cultural, social, economic and political systems.[264] Indigenous Peoples have diverse histories, languages, beliefs and traditional practices.

Indigenous-informed helping. This approach to helping is based on Indigenous ways of knowing and worldviews, aimed at ensuring environments, services, practices and programs are welcoming, culturally safer and engaging for Indigenous and non-Indigenous people with life-limiting illnesses, families and communities. Biomedical and non-Indigenous ways of knowing may be integrated and used alongside Indigenous ways of knowing in Indigenous-informed helping as a way of thinking about the role of culture in compassionate caring and helping.

Indigenous-led helping. This approach includes helping and related programs, interventions, practices and services led and driven by Indigenous Peoples, communities and/or organizations exclusively aimed at addressing issues, needs and/or conditions presented by Indigenous Peoples with life-limiting illnesses, families and/or communities.

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[264] United Nations. Who are indigenous peoples? New York City (NY): United Nations; nd.

Informed consent. Informed consent is the voluntary agreement of individuals or their authorized representative who have the legal capacity to give consent and who exercise free power of choice, without undue inducement or any other form of constraint or coercion to participate in the given therapeutic relationship.

Inuit. The Inuit are Indigenous Peoples from Arctic Canada, particularly residing in Inuvialuit (Northwest Territories), Nunatsiavut (Labrador), Nunavik (Quebec), and Nunavut. These geographic areas comprise approximately 40 per cent of Canada's total land mass. In general, the Inuit population is much younger than the non-Indigenous population. The traditional language of Inuit is Inuktitut. Inuktitut dialects differ among and within regions, as different vocabulary, pronunciations and terms developed and migrated with nomadic families and clans.[265]

Knowledge Carriers. Knowledge Carriers are First Nations, Inuit or Métis individuals who are recognized by their respective communities for the sharing of their culturally significant knowledge and Indigenous worldviews.

Laws. Laws are rules of behaviour established by courts and legislation for defining the minimum standards of individual and community conduct and behaviour. Laws define the minimum standards that society will tolerate and are enforced by government. Other defining characteristics of the law are as follows: created by legislature and courts; governs citizens (local, provincial, federal); represents minimal standards; and enacts penalties in the form of fines and jail.

Life-limiting illness. Life-limiting illness means that death is expected to be a direct consequence of the specified illness. It also refers to people who are actively living with such illnesses, often for long periods of time and are not imminently dying. Therefore, life-limiting illness affects health and quality of life and can lead to death.

Life spectrum doula (death doulas or end-of-life doulas). In general, Indigenous death doulas (or life spectrum doulas) are non-medical healers, helpers and companions to First Nations, Inuit and Métis Peoples with life limiting illnesses and their families. Doulas complement other palliative and end-of-life care services that Indigenous Peoples with life-limiting illnesses and their families may be receiving in health-care settings. They typically provide a wide range of culturally safer holistic services, including physical, emotional, spiritual and practical support across the lifespan. This may include facilitating and coordinating access to health-care services including traditional healing practices and spiritual and cultural supports.

Marginalization. Marginalization is the act of putting or keeping someone or a group of people in society in a powerless or unimportant position. This act results in individuals or groups of people being disadvantaged and excluded in society.

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[265] Hordyk SR, MacDonald, ME, Brassard P. End-of-life care for Inuit living in Nunavik, Quebec: a report written for the Nunavik Regional Board of Health; 2016. p. 13.

Meaningful engagement. Meaningful engagement means a willingness and ability to provide opportunities for Indigenous Peoples or communities to actively take part in policy and decision-making processes that are balanced in terms of sharing power and influence.[266] At times, definitions of terms such as “meaningfulness” and “meaningful engagement” and the corresponding operationalization of same have been confused with parallel or similar forms of participation in policy development and decision-making such as “information sharing” and “consultation.”[267]

Medical assistance in dying (MAID). MAID occurs “when an authorized doctor or nurse practitioner provides or administers medication that intentionally brings about a person’s death, at that person’s request. This procedure is only available to eligible individuals.”[268]

Métis People. Métis People are individuals who are of historic Métis ancestry—specifically, individuals who have historical lineage rooted in the areas of land in west central North America. Métis People were important players in shaping Canada, particularly western Canada. The traditional languages spoken by Métis People include Michif and Cree.

Natural caregivers. Natural caregivers are individuals who provide care for family members (for example, Elders, individuals with life-limiting illnesses). The natural caregiver role is typically informal and unpaid though they play an important helping role in keeping community members in their home communities.

Ownership, control, access, possession (OCAP) principles. OCAP principles are First Nations standards in the collection, protection, utilization and sharing of data in terms of conducting research with First Nations.[269]

Palliative care. Palliative care is a process from diagnosis to end-of-life in relieving symptoms (pain and discomfort) and improving the quality of life for people with life-limiting illnesses (for example, cancer, dementia, heart disease, heart failure, HIV/AIDS, kidney failure, liver failure, lung disease, progressive neurological conditions). Palliative care focuses on the whole person and their families which includes physical, emotional, mental and spiritual support.

Partnerships. A partnership is the relationship between Indigenous and non-Indigenous organizations. Partnerships can be used to leverage capital as well as connections and expertise that lead to shared goals and opportunities.[270]

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[266] https://www.ictinc.ca/blog/aboriginal-engagement-vs-aboriginal-consultation-whats-the-difference

[267] OECD. Open government: the global context and the way forward. Paris; 2016

[268] https://bit.ly/3LDbfde

[269] For more information about OCAP principles, visit https://fnigc.ca/ocap-training.

[270] Blackman J. Research Indigenous partnerships: an assessment of corporate-Indigenous relations. Ottawa (ON): Indigenous Works; 2017.

Person-centred approach. This approach recognizes that the person is placed at the center of palliative and end-of-life care and treated as a person first. The focus is on the person and what they can do, not their life-limiting illness. Support focuses on achieving the person's care goals and is customized to their needs and unique circumstances.

Privilege. Privilege is a specific right that may not be given/held by other individuals and/or groups in society. According to Peggy McIntosh, it is "an invisible, weightless backpack of special provisions, maps, passports, codebooks, visa, clothes, tools, and blank checks."[271]

Resilience. Resilience is the ability of a natural and/or human system to flourish and adapt to situations or environments with minimal negative effects during and after a change, hardship or crisis. Resilience emphasizes the individual or group's ability to effectively draw on positive attributes and capabilities rather than focus on weaknesses or pathologies.

Standards of practice (standards of care). These standards are guidelines used to determine what helpers should or should not do. Standards may be defined as a benchmark of achievement which is based on a desired level of excellence. Standards of practice describe a competent level of effective and ethical care.

Strengths-based practice. Strengths-based practice respects people's rights to self-determination and empowers people through a focus on their inherent rights to be resilient in the face of adversity.

Talking circles. Talking Circles are characterized by the use of a talking artifact (for example, feather, stone) that regulates communication. Both talking and listening are important in the circle because mutual understanding facilitates more meaningful discussion. Respect for the talking artifact helps facilitators give the floor to the participants and equalizes opportunities for contributions among participants. Talking circles can be used for discussion, problem-solving and/or group decision-making. A fundamental purpose of a talking circle is to create a safer, non-judgmental place where each participant has the opportunity to contribute to the discussion of challenging and/or important issues, is open to being influenced by what happens during the process and does not enter the process hoping to persuade others or expecting a specific outcome.

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[271] https://psychology.umbc.edu/files/2016/10/White-Privilege_McIntosh-1989.pdf

Traditional teachings. In traditional teachings, the focus is on cultural teaching, healing and helping. Examples of teachings are learnings and the application of Indigenous healing approaches and practices passed on by traditional Indigenous teachers, traditional healers and/or Elders who are recognized by their Indigenous community; learnings about theory/theories and practice(s) in Indigenizing and decolonizing approaches to mental health and wellness that address disparities among Indigenous peoples in culturally relevant ways (storytelling and role modelling); approaches in Indigenous wellness, language revitalization in the context of understanding Indigenous approaches to mental health and wellness, and/or Indigenous community-based mental health program and organizational development; integration of Indigenous wellness in relation to social justice, environmental/ecological justice, and/or reconciliation among diverse Indigenous communities; and self-care for healers and helpers with Indigenous communities.

Trauma. Trauma is an extremely upsetting event or set of events that overwhelm a person's internal resources and produce lasting psychological symptoms (for example, freezing, dissociating, hyperventilating, panic and intense physical sensations).[272, 273] Trauma impacts a wide variety of people in various ways, from heightening one's concerns about personal safety to reducing their capacity for managing stressful situations. See also historical trauma.

2SLGBTQQIA+. This acronym stands for two-spirit, lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual and other sexually and gender diverse people.

Worldview. A worldview is a set of principles, values and beliefs that organize a way of knowing, being and interacting in the world. Every person and society has a worldview. Worldviews influence how we (self) locate or see ourselves in our environment.

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[272] Briere JN, Scott C. Principles of trauma therapy: a guide to symptoms, evaluation, and treatment, 2nd ed. SAGE; 2015.

[273] Van Der Kolk B. The body keeps the score: brain, mind, and body in the healing of trauma. Penguin Books; 2014.

14. Canadian Partnership Against Cancer

As the steward of the Canadian Strategy for Cancer Control (the Strategy), the Partnership works to implement the Strategy to reduce the burden of cancer on Canadians. The partner network—cancer agencies, health system leaders and experts and people affected by cancer—brings a wide variety of expertise to every aspect of our work. After 15 years of collaboration, we are accelerating work that improves the effectiveness and efficiency of the cancer control system, aligning shared priorities and mobilizing positive change across the cancer continuum. The Partnership continues to support the work of the collective cancer community in achieving our shared 30-year goals: a future in which people in Canada have equitable access to high-quality cancer care, fewer people get cancer, more people survive cancer and those living with the disease have a better quality of life. The Partnership was created by the federal government in 2006 to move the Strategy into action and receives ongoing funding from Health Canada to continue supporting partners from across Canada. Visit www.partnershipagainstcancer.ca

Since its formation in 2006, the Partnership has been working with partners from across the country to advance action on the cancer care priorities of First Nations, Inuit and Métis Peoples. The Partnership supports self-determined, Peoples-specific solutions for sustainable system change across cancer care that benefit all First Nations, Inuit and Métis Peoples, their families and communities. For more information, visit https://bit.ly/3F32wi6.

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