



INDIGENOUS HEALTH NETWORK

Hamilton Niagara Haldimand Brant
Local Health Integration Network

HNHB LHIN



Summary Report

Sharing Palliative Care Journeys: A Perspective of Indigenous Families and Communities

A report based on a Community Engagement event hosted in Niagara in November 2017

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Acknowledgements

We acknowledge the land upon which the Hamilton Niagara Haldimand Brant (HNHB) Local Health Integration Network (LHIN) is located, as the shared traditional territory of the Haudenosaunee and Anishnaabe Peoples, protected by the Dish with One Spoon Wampum Belt. This historic peace agreement between the Iroquois Confederacy, the Ojibwe and allied nations represents a commitment to share and protect the land, water, plants, and animals, with respect. We wish to honor the original Peoples of this land and express gratitude for the opportunity and privilege to work with communities across this territory.

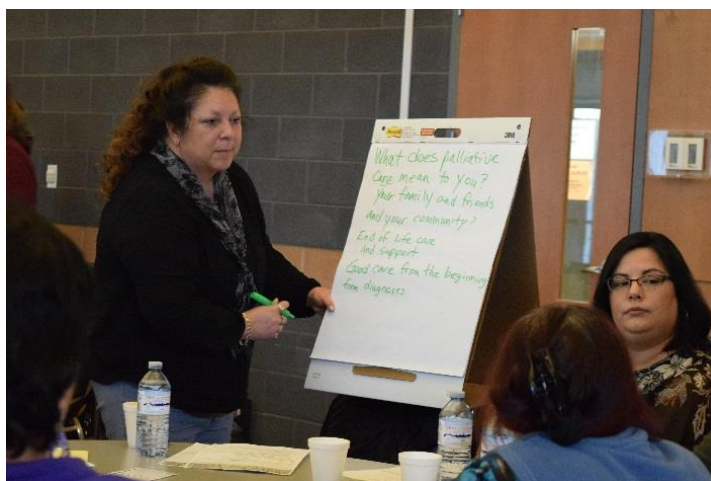
Nia:wen, Chi-Miigwech, to George Johnson for setting our minds on a good path and to all those community members who generously shared their rich experiences to bring this report to life.

This report was compiled jointly by the HNHB Indigenous Health Network (IHN) and the HNHB LHIN.

The HNHB IHN is a voluntary group of Indigenous health and social service leaders from two First Nation communities and 15 Indigenous organizations across the HNHB region.

Introduction

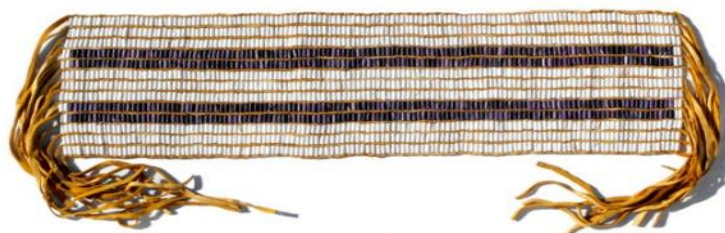
On November 29, 2017, the Hamilton Niagara Haldimand Brant (HNHB) Indigenous Health Network (IHN) hosted a community engagement gathering on: *Sharing palliative care journeys from the perspective of Indigenous families and communities*. The event was held at Ball's Falls Conservation area in Jordan and was attended by 102 individuals, approximately 30 community members and approximately 70 health care providers.



The purpose of this gathering was to focus on listening and hearing the stories of individuals, families, and communities that have experienced the palliative care journey. The engagement is an important way for community members to use their experiences to guide health care providers in improvement, where improvement is needed, and learn from family and community perspectives.

The engagement session began with a traditional opening by George Johnson who shared his wisdom, knowledge and experience. Participants engaged in talking circle conversations, facilitated by IHN members asking specific questions to consider, to arrive at a deeper understanding of the current landscape of palliative care for Indigenous Peoples in the HNHB Local Health Integration Network (LHIN). The feedback provided is a mix of Indigenous Voices and Western Voices.

Throughout the session, individuals and families shared their personal stories and experiences of palliative care to the larger group as a way of keeping the focus on the person and family. A summary of the current experiences, key themes, and opportunities for improvement have been captured in the report. The information in the report provides valuable perspectives that will help to guide and inform palliative care planning for Indigenous communities across the HNHB LHIN.



Key Themes from Talking Circle Discussions

What does Palliative Care mean to you, your family and friends, and your community?

An important comment captured during the talking circle discussions on what palliative care means was:

“Consider where the individuals is at. They may not consider themselves as dying. If they have hope that they will still live, then talk with them about living”

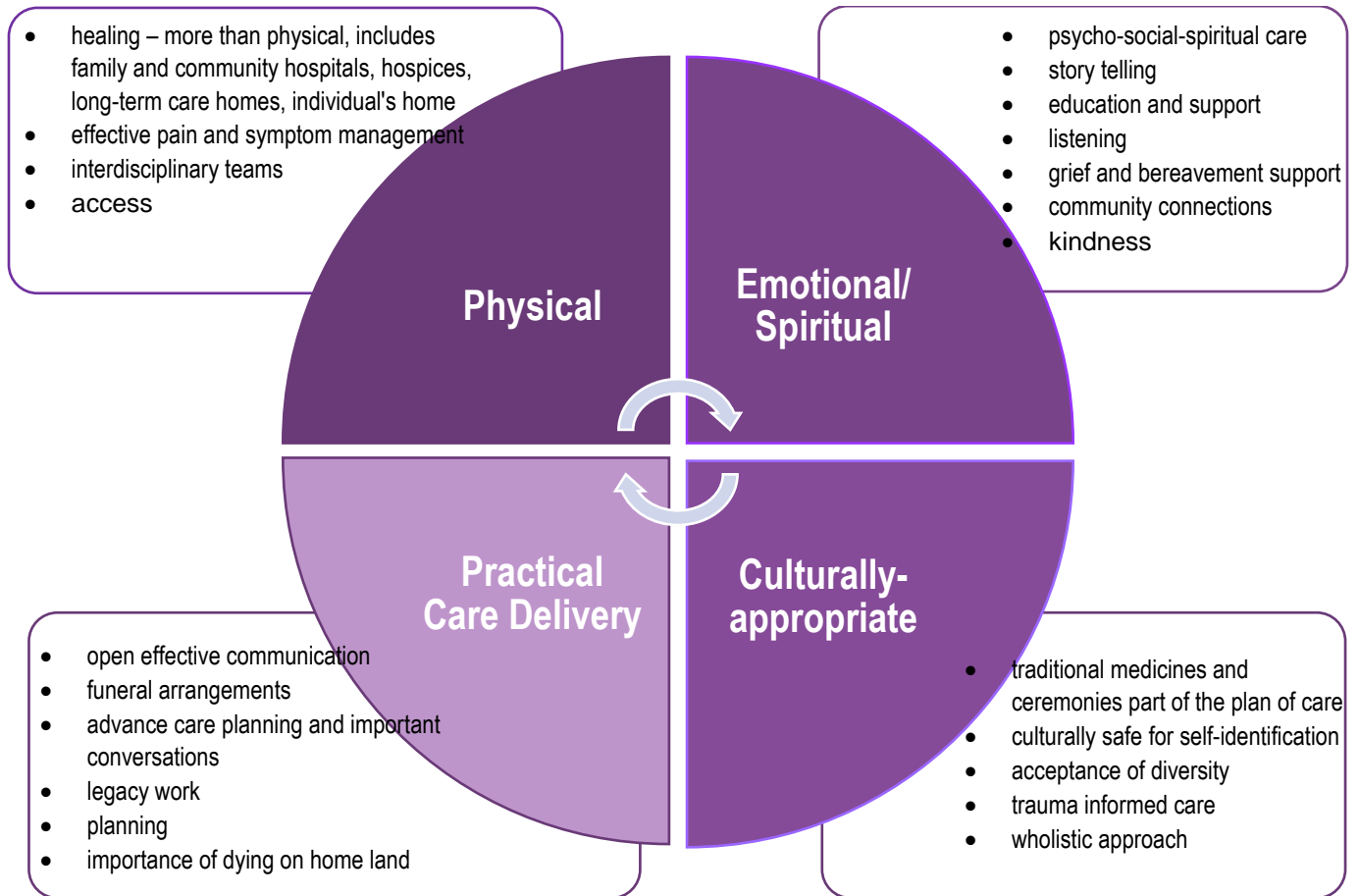
See Figure 1 for a summary of discussion circle feedback when answering the question, *What does Palliative Care mean to you, your family and friends, and your community?* Contrast this definition with Western definitions of palliative care.

Figure 1: Summary of discussion circle feedback

<p style="text-align: center;">ACTION</p> <p>Continuous care Transitions of care Open to all Wholistic care Good pain & symptom management Cost effective Accessible Early intervention Responsive care At home / close to home Culturally safe & inclusive Person-centred & guided Innovative Mindful & simple terminology Supportive Begins at diagnosis Make a plan Clear expectations After-care Bereavement support Support services for family, friends, and community Caregiver consistency 24-hour support Create a good environment</p>	<p style="text-align: center;">VISION</p> <p>Dignity Compassion Belonging Respect Mind, body, and spirit cared for Acceptance Living well while dying Culturally supported Safety Closure Acceptance Informed Aware Hope Living fully Crisis Trauma Isolating Grief Not just death and dying Fear</p>
<p style="text-align: center;">KNOWLEDGE</p> <p>Individual's wishes and choices Rituals and ceremonies Story sharing Education System advocacy Explore the afterlife Beliefs and values Remembrance / legacy of the person Philosophy of care Care vs. cure vs. comfort</p>	<p style="text-align: center;">RELATIONSHIP</p> <p>Individual Family Elders Youth Community Together Healthcare system Outreach teams Specialized teams Connection Early conversations Communication Life cycle journey Team approach Walk alongside</p>

What is involved in Palliative Care?

Talking circles highlighted the differences between the western worldview and the Indigenous worldview. The Indigenous approach to palliative care includes the community around the individual. The Indigenous community is connected - what affects one affects all. Western health policy doesn't always support or accommodate this. Components of palliative care have been grouped into four themes, however it is important to note that these themes are interdependent, harmonized, and that spiritual care drives all aspects of care.



Where does Palliative Care start and where does it end?

- Starts with a person, part of their journey, at home
- Starts with diagnosis – recognition of progressive illness
- Need for medical assessment as part of an holistic assessment, develop plan of care
- Driven by patient's wishes, values and goals
- Referral to palliative care services, palliative expertise
- Remaining at home, on their land is very important
- Grief and bereavement triggers trauma, new trauma resurfaces grief
- Traditional medicines and healing
- Complementary therapies
- Families have ceremony before death
- End with dignity for the individual
- Bereavement support for individual, family and community
- Support for staff providing care

Barriers include but are not limited to:

- Lack of respect for traditional medicines as a treatment option
- Education in schools
- Death and dying not viewed as normal
- Education about death and dying
- Involvement of agencies such as Children's Aid Society based on diagnosis and not risk

It is important to note that this is a person's journey. Palliative care is an approach to care. Palliative care has its roots in individual, family, community and culture. Indigenous communities need access to palliative care specialists to support local services.

While all participants consistently identified diagnosis as the starting point for palliative care, all groups indicated that palliative care does not have an end point.

Even after an individual dies, a palliative approach continues.

What has been your, your family and friends, and your community's experience of Palliative Care? What was good and what was not so good?

Talking circle discussions of good and not so good experiences have been captured below. Note that the not so good experiences outweigh the good experiences. When people's experiences are negative within a community it creates an expectation that care will be poor in the future. There is room to improve the experiences of palliative care for Indigenous Peoples in the HNHB LHIN.

Good Experiences

- Individuals needs are met
- Traditional ceremony and needs are provided
- Family is supportive and present for their passing
- All important people are aware of the circumstances
- Everyone remembers that the person is still a person
- Individual's wishes are followed
- Families are supported
- Person is celebrated

Not so good Experiences

- No continuity of care
- Answers are not given
- Family physician is excluded
- Trajectory of illness is not accurate
- Policies limit the number of people who can visit in a hospital room
- Uncompassionate staff
- Individuals needs are not met
- Family physician is not familiar with pain management

- Compassionate leave is available from employers
- Automatic referral processes are in place
- Everyone is comfortable with the conversation of death and dying
- Circle of care are all connected and working together
- Staff are supportive, kind, and caring
- Allow time for staff to be with the person if they have been living in a facility setting
- Quality and dignified care is provided
- Staff are self-aware and have empathy
- Nurses explain pain medication
- The person is kept calm
- The individual and family are knowledgeable of their health care team
- Palliative team provides needed services
- Pain relief
- PSW care
- Good communication, transitions, and planning
- Advance care planning is done early, even when someone is healthy
- Plans to die in home result in dying in an Emergency Department of Intensive Care Unit
- Family is in crisis, feels panicked, is not supported, is not informed of what to expect, is unprepared
- No outreach care is offered
- Dying alone
- Not being heard
- Delayed access to care and wait times for pain and symptom management
- “Why do I have to wait to be dying”
- Lack of acknowledgement or respect of cultural needs before and after death
- No culturally-based programs
- No communication about cultural needs with physician or hospital
- Animals are not present
- Individual is in too much pain to be transferred to hospice
- No diagnosis, no care
- Not admitted to hospice because of smoking
- Preferred hospice is not available
- Fear of dying, fear of the unknown, anxiety
- Quality of care for Indigenous peoples is poor



Figure 1 IHN Palliative Community Engagement Event, Balls Falls Conservation Area, November 29, 2017

What would you like your experience of Palliative Care to be? How should this look and feel for individuals, families, and communities?

Discussion table feedback regarding how palliative care should look and feel for individuals, families, and communities centred around six key themes: access, equity, quality care, connections, plans and wishes, and knowledge. See below for summary points related to these themes.

Access

- Equal access to services regardless of geography
- Transportation costs are not a barrier
- Financial supports are available for families e.g. parking fees
- Support at home is available 24/7
- No barriers to addressing individual's wishes

Equity

- Indigenous Navigator is available
- Culturally safe space is available allowing freedom for ceremonies and smudging
- Respect, acknowledgement, and encouragement of traditional medicines and ceremonies
- Individuals feel safe and are given the opportunity to self-identify as an Indigenous person
- Acceptance of diversity among cultural beliefs, values, and attitudes

Quality Care

- Good pain and symptom management
- The person's goals and wishes are driving the care planning
- Consistency
- Experts and specialists communicate in a way that is understood
- Aftercare – immediate physical care of the body that aligns with cultural ways
- PSWs and other staff are skilled and trained in palliative care

Connections

- Connection to spirit is medicine for all
- Community engagement
- Circle of care includes individual, family, physician(s), health workers, social workers, and community workers
- Circle of care works together to provide consistency and address needs
- Voluntary self-identification leads to cultural care and resources
- Funeral planning and ceremonies are arranged
- The needs of all Longhouse communities are met

Plans and Wishes

- Patient-focused and patient-driven
- Circle of care knows what to expect before it happens
- Individual's wishes are reflected in their plan
- Individual supported to die where they want to be
- Individual and family can 'do it our way'



Knowledge

- Transitions in care e.g. from hospital to home, are seamless
- Education for physicians, nurses, and specialists, cultural and palliative education
- Resources are identified and available and planned ahead
- Individual's journey is documented and available to circle of care
- Education about Truth and Reconciliation – roots of mistrust
- Supportive education on death and dying
- Openness among providers to walk into a home and say 'you teach me'
- Staff are comfortable asking if individuals self-identify as First Nations, Inuit, Metis

Summary

This day was a first step towards a deeper understanding of the needs of Indigenous Peoples in relation to a palliative approach to care. The engagement was rich in dialogue. The Indigenous Voices are blended in this feedback with Western Voices. Key messages were heard including recognition that everyone's journey is unique and may not look the same; care of the spirit is medicine for all; Indigenous Peoples deliver palliative care programs which are rooted in their families, communities and culture; and working together and being community-focused provides the best outcomes for people.



Figure 2 IHN Palliative Community Engagement Event, Balls Falls Conservation Area, November 29, 2017

When someone is diagnosed with a life-limiting progressive illness it can be a trigger of trauma, not just for the person and family, but their community as a whole. Western services supporting Indigenous people and families with palliative needs must become knowledgeable and develop understanding of Indigenous cultures and understand that it is okay to ask questions like, "how can I help you do this your way". Indigenous and non-Indigenous teams must work collaboratively to support the person and family based on their values and beliefs.

Recommendations

A key recommendation from the engagement session was that palliative care should not only be patient-centred but patient-driven. This recommendation is applicable to both Indigenous and non-Indigenous peoples. Several other recommendations that are applicable to both Indigenous and non-Indigenous peoples arose from the engagement session, including reducing barriers to access like transportation costs. Specific recommendations related to the experiences of Indigenous Peoples include:

- Creating culturally safe spaces for ceremonies and smudging as well as physical space for Indigenous Peoples' families and communities to be with them during their palliative care experience. Indigenous and non-Indigenous providers must work collectively to support the person and respect their individual values, beliefs, wishes, and goals.
- Non-Indigenous palliative care providers must continue to gain knowledge and understanding of Indigenous Peoples' cultures and what is important to them.
- The importance of traditional medicine must be acknowledged and used in harmony with Western medicine.

Next Steps

This report has been developed as a resource for Indigenous and non-Indigenous health system partners to help guide current and future palliative care planning in the HNHB LHIN. Learnings shared in this report may also be relevant and applicable to surrounding communities to provide insight on the many challenges experienced by Indigenous Peoples accessing palliative care and the opportunities to make improvements.

The HNHB IHN anticipates planning additional engagement gatherings in 2018-19 to continue facilitating opportunities for Indigenous community members to share their perspectives, spread knowledge and awareness of health care services, and harmonize relationships between mainstream and Indigenous health programs and services. Based on community feedback, future engagement topics may include; learning more about Indigenous needs in relation to death and dying, e.g. ceremonies and rituals, the role of traditional medicine in the plan of care, and creating culturally safe spaces in Western environments and with care delivery.

Contact Us

If you have questions about the content of this report or the work of the HNHB Indigenous Health Network, please contact **Kelly Cimek, Director of Planning** at kelly.cimek@hins.on.ca or 1-866-363-5446 ext. 4249.

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