Personal Support Worker Community of Practice Series

End-of-Life Care in Indigenous Contexts: Spotlight on the Six Nations Palliative Program



Hosts: Tracey Human

Presenters: Verna Fruch, Carolyn Taylor-Hill, Lori Monture, Cindy Martin & Stacey Logan

Date: May 31st, 2022

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



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Welcome and Reminders

- Please introduce yourselves in the chat!
- Your microphones are muted for background noise, but we do want dynamic sharing, so
 please raise your hand to unmute to talk. Sharing or asking questions in the chat is also
 welcome.
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session

Overview of Topics

Session#	SessionTitle	Date/ Time
Session 1	Introductory Session	Nov 16 th , 2021 from 5-6pm
Session 2	Essential Communication Skills Part 1	Nov. 30 th , 2021 from 5-6pm ET
Session 3	Essential Communication Skills Part 2	Dec. 14th, 2021 from 5-6pm ET
Session 4	Tools Practicum Part 1	Jan. 11 th , 2022 from 5-6pm
Session 5	Tools Practicum Part 2	Jan. 25 th , 2022 from 5-6pm ET
Session 6	Pain and Shortness of Breath Management	Feb. 8 th , 2022 from 5-6pm ET
Session 7	The PSWs Role in the Last Days and Hours	Mar. 8th, 2022 from 5-6pm ET
Session 8	End of Life Medications and Side Effects	Mar. 22 nd , 2022 from 5-6pm ET
Session 9	End of Life Delirium	Apr. 5 th , 2022 from 5-6pm ET
Session 10	Post-mortem Care: Cultural Considerations and what happens at the funeral Home	Apr. 19 th , 2022 from 5-6pm ET
Session 11	Culturally Relevant Care	May 3 rd , 2022 from 5-6pm ET
Session 12	Trauma Informed Care and Cultural Safety	May 17 th , 2022 from 5-6pm ET
Session 13	End of Life Care in Indigenous Contexts: Spotlight on the Six Nations Palliative Program	May 31st, 2022 from 5-6pm ET
Session 14	Understanding Tubes, Pumps, Bags and Lines	Jun. 14th, 2022 from 5-6pm ET





Introductions

Host

Tracey Human, RN, CHPCN(c), PPSMC

Director, Palliative Care, Pain & Symptom Management (PPSMC), Toronto Service 35 years of practice in palliative care specialty

Clinical Educator; Consultant; Member, Ontario Palliative Care Network Clinical Advisory Council; Content contributor palliative Practice Guidelines; Research partner

Introductions

Guest Speakers:

Verna Fruch, RN

Palliative Case Manager (Part-time)

Carolyn Taylor-Hill, RN

Palliative Case Manager, Six Nations Palliative Care Program

Lori Monture, RN

Manager, Six Nations Home and Community Care Program

Cindy Martin

Traditional Wellness Coordinator, Six Nations Health Services

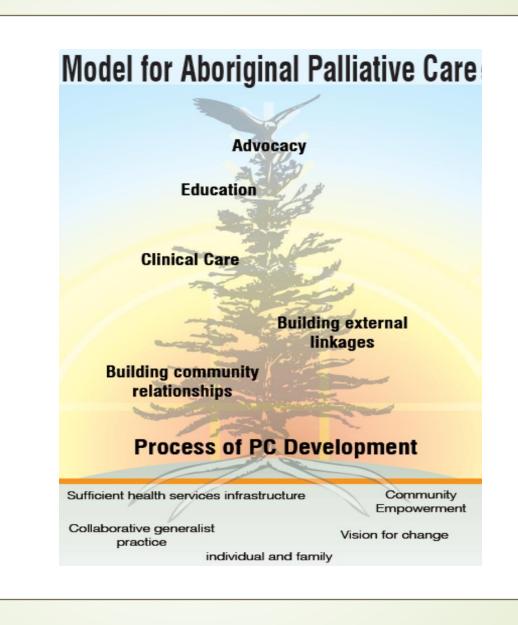
Stacey Logan, NP

Nurse Practitioner, Six Nations Palliative Care Program



SPOTLIGHT ON THE SIX NATIONS OF THE GRAND RIVER PALLIATIVE Program

May 31,2022



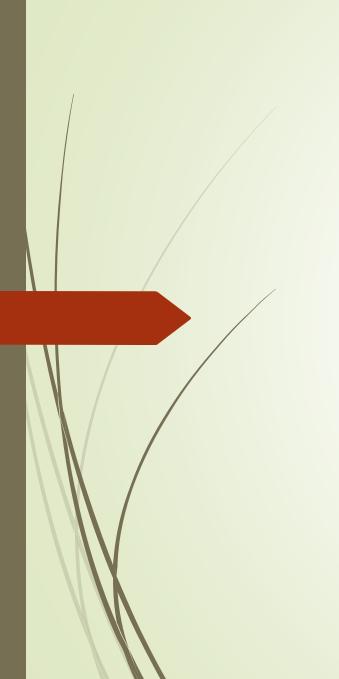
Haudenosaunee (People of the Longhouse) Philosophy

Dying is understood as part of the cycle of life and people take their place in relation to all of Creation.

Acceptance comes from a view of the natural order that accepts and celebrates that we are given life.

We exist with purpose and a duty to uphold the human responsibility to all of Creation until the time when the Creator takes back our life.





"When we are born the Creator gives us that first breath ... and when we die, he takes it back."...

Dying is a transition from our life to the Spirit and end of life care is getting ready for the journey back home.

"Our community is telling us that we need to regain our acceptance of death and dying. We have our own ways to help each other through this transition and provide supportive care as is done at birth."

"FIRST NATIONS COMMUNITIES ARE WILLING AND ABLE TO SUPPORT COMMUNITY MEMBERS AND THEIR FAMILIES TO RECEIVE A PALLIATIVE APPROACH TO CARE AND TO DIE AT HOME IF THAT IS THEIR CHOICE EOLFN 2010-2015

THE INDIGENOUS WELLNESS FRAMEWORK

"Wellness from an Indigenous perspective is a whole and healthy person expressed through a sense of balance of spirit, emotion, mind and body.

Central to wellness is belief in one's connection to language, land, beings of creation, and ancestry, supported by a caring family and environment."

(Elder Jim Dumont, 2014)

This framework was developed as part of the Honouring Our Strength: Culture as Intervention in Addictions Treatment project. (2014)

Spiritual Wellness creates Hope

Emotional Wellness creates A Sense of Belonging

Mental Wellness creates Meaning

Physical Wellness creates Purpose

..... this is Whole Person Care

First Nation Statistics

The Canadian Hospice Palliative Care Association (2013) emphasizes that palliative care is appropriate for all people and their families who are living with a life-threatening illness due to any diagnosis, including but not limited to cancer. The Palliative Approach to Care can be provided concurrently with treatment and chronic disease management.

Our community is seeing a dramatic rise in cancer and end stage chronic diseases. The top four cause of death in FN communities are diabetes, cardiac disease, respiratory disease and cancer.

Our community members do not seek medical attention until the last stages of the illness when treatment and support maybe rushed. This hesitancy may be related to historical trauma or fear of having to leave the community as there may be not sufficient services available.

Six Nations Palliative Program

- The Six Nations Palliative Care Program is situated within the Home and Community Care Program, a unit of the Health Services Department of the Six Nations Council.
- Services include: case management; physiotherapy; occupational therapy; health advocacy; nursing; adult day centre; personal support services with all 12 PSWs having palliative training, community support services; supportive housing; traditional wellness coordinator; Traditional Knowledge Carrier; family health team; and a medical centre that includes dental and public health staff, a physician, and a pharmacy. Our Elders and speakers open our gatherings with the Thanksgiving Address
- Most recent is the Palliative Shared Care Outreach Team which includes a palliative physician, a palliative advanced practice nurse and a psychosocial/spiritual/bereavement clinician
- Presently we are collaborating with the Traditional Medicine program and researching Traditional Death Doulas and with the Six Nation Paramedics to provide the palliative approach to care to community members who wish to stay at home.



Once it was time to share information about death and dying, we worked with them to produce a resource. After review of the resource, it was "approved and accepted" by the Clan Mothers, Chiefs, and Faithkeepers (as well as other Traditional Knowledge Carriers) on what could be shared.

There is an understanding that this is ancient wisdom and is very sacred; we must protect it and use it in a most respectful manner as it was intended to be.

We have embraced the Traditional Knowledge Carriers in the work that we do. They understand that it is important to teach the coming faces and are more willing to explain the ceremonies with service providers who are providing care within the community.

Initiatives Undertaken

- Palliative Shared Care Outreach Team. A key component of the functioning of a palliative shared care team is the role of the palliative physician, and specifically for this team, an Aboriginal physician.
- A Traditional Grief and Bereavement Program was developed for family members of clients who received end of life care and were to have been on their grief journey for close to a year and would be assisted with traditional practices
- A Four Strings Ceremony was facilitated by our Traditional Knowledge Carrier to support our staff members with cumulative grief, using traditional teachings to regain balance and gain coping skills and suggestions were made on lowering stress levels



Benefits

- The benefits of having the palliative care team are as follows:
- Community members now have access to round-the-clock care
- Our community members are assisted with pain and symptom management; the team can manage complex care needs
- The physician makes home/hospice visits
- Hospital emergency room visits are reduced; the risk of dying in hospital is lowered and community members are able to die peacefully in their own home or on the territory in a hospice bed.
- We have now received approval for a fulltime Palliative Case Manager and Palliative Nurse Practitioner. They will be the focal point for seamless care for the client and their families from community to hospice.

The Unit of Care-Family

- The Clan System
- In the human body, the bones are what give the body structure and the ability to function. The clan serves the same purpose in the societies of the Traditional people-Tom Porter-Bear Clan Elder of Mohawk Nation
- Our clan is our extended family and all members are important in the functioning of the family

Assisting the Unit of Care

- With grief, traditionally it is dealt with in a series of ceremonies to give time for the loved one to complete the journey on earth and it is stressed that one moves on from grief.
- Cumulative grief is of particular significance in FN communities as everyone is close knit and when several losses occur in succession the grief can build on the previous.
- See EOLFN Workbook SNGRT Four Strings Ceremony.

Traditional Remedies - The Body

- Use of the following medicines for body area:
- Mind native tobacco
- Body cedar & water, white pine use
- Traditional medicines can be utilized to wipe down and calm the dying person. This liquid is washed onto their body and helps refresh the person leaving them in a good state of mind. A cedar/white pine bath can be a comfort measure as death approaches. The family may ask for assistance from the PSW at this time.

For the Spirit

- Fast 1 or 3 days (see Medicine person) as you are alone in the bush by the fire, utilizing medicines and guided by the elements of Creation
- Personal Ceremonies (new or renewal)
- Eagle Feather Sweeping

For the Soul

- Burning native tobacco
- Sage is used for smudging as a cleansing if one is getting bothered
- When learning to speak the language it gives you pride, belonging and accomplishment
- Learning our teachings to understand yourself and role as a male or female.
- Repenting can be done anywhere, anytime to ease the soul to receive forgiveness from the Creator
- Our ancestry and Western ways clash causing an imbalance. Learning our way of life that was given to us by the Creator will help balance our lives.

For the Mind

Attending Longhouse and participating gives a sense of belonging while giving thanks for what you have and to the time of seasons.

In the Longhouse there is a male and female role. You enter separately.

When we all help one another there is a balance. We work together as a team.

When asked by a Faith Keeper to help out you are not to refuse or ask why.

You must be clean of alcohol and drugs for at least 3 days before entering the Longhouse.

Participate in the dance but if you can't, dance just walk. You will learn.

Accept all food that is given to you and drink the strawberry juice. It is disrespectful if you refuse.

When entering the Longhouse find where your clan sits and there is your place of belonging where you will feel balance.

Guiding Traditional Principles

- Have respect for yourself and others
- Balancing personal needs, wants, desires
- Establishing personal boundaries
- Maintaining a good mind
- Acknowledging your emotions, feelings
- Giving thanks to the Creator, the four Beings and related medicines

At End of Life

Before death occurs, our loved one may be restless and calling out and may be seen as in delirium and knowing our belief that "the ancestors come to get you", the family may ask a traditional speaker to come in and speak to the person who is sick.

This is what is said by the speaker:

"At this time your family has asked me to come here and speak to you, for you are gravely ill. Maybe you will come back and be healthy. Now it is the responsibility of the Creator and also his appointees, the heaven dwellers. If it happens that you become healthy, so nothing will happen to your mind this is what your family wants, so now it is the responsibility of the Creator. What he will decide on your life. Maybe his decision will be to take you back home to his land, so let your mind rest."



Repentance-A Sacred, Private Ritual

- Repenting will help ease and comfort the person by preparing for death. Repenting can be done by yourself in private or in public with the use of wampum beads. The person hangs onto them and repents all their sins and regrets. Repenting can be done in the language or in your mind with your thoughts and intentions gathered. When the time is near we want to leave this earth in peace of mind, no regrets or unfinished business.
- Sacred ceremonial objects such as Medicine bags may be seen clutched in the hand or under the pillow and are not to be removed and go with the loved one.

When Death Occurs

- The family will want time to sit with their loved one and all members will be notified, it is not to be rushed.
- The body is sacred and treated with respect and to be handled gently. The belief is that our loved ones can still hear and feel and so the Traditional speaker will describe their journey for them
- The Clan Mother will direct the preparations as per the sacred traditions. (Resource: Journey Back Home)

Resources

- Coming Home To Die- International Journal of Indigenous Health, Volume 11, Issue 1, 2016
- Journey Back Home-2018, Six Nations of the Grand River Territory, Ohsweken, ON
- ► EOLFN-Improving End of Life Care in First Nations Communities, 2010-2015, www.eolfn
- Reconnection Journey through the Tree Rings, Cindy Martin, Traditional Wellness Coordinator, cindymartin@sixnations.ca

- For further information please contact:
- Six Nations Home and Community Care Manager
- Imonture@sixnations.ca

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Wrap Up

- Please fill out our feedback survey! A link has been shared in the chat
- A recording of this session will be emailed to you within the next week
- Make sure you have the next session marked in your calendar!
 - Understanding Tubes, Pumps, Bags and Lines
 - Jun. 14th, 2022 from 5-6pm ET



Thank You See you on June 14th!



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