A Cultural Safety Perspective on Palliative Care for Indigenous Peoples

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Introduction.

I would like to acknowledge this conference and presentation is located on the traditional and unceded territory of the Mi’kmaq.

I cannot identify any conflicts of interest.

The perspectives presented are mine alone and do not reflect the views of UNB.
Demographics.

- "Aboriginal" or "Indigenous" peoples are collective names used to refer to the original peoples of North America and their descendants.

- Three groups are recognized by the Canadian constitution:
  - First Nations
  - Métis
  - Inuit

- In 2011, approximately 1.4 million individuals self-identified as FN, Métis, or Inuit (status and non-status)

- First Nations/Metis/Inuit constitute almost 5% of the population in Canada

(INAC, 2016; National Household Survey, 2011)

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Demographics (cont’d).

• Nearly half with registered status live on-reserve in Canada
  • Approximately 68% in New Brunswick

• ~6% of this population are seniors (65+ years)

• At higher risk of dying prematurely and from avoidable causes (e.g. fatal accidents, suicide)

(Park et al., 2015; Statistics Canada, 2013)
Defining Cultural Safety.

• Involves recognition that colonial history (intergenerational trauma) continues to influence the health and wellbeing of Indigenous peoples

• Surpasses mere awareness of cultural differences

• Acute insight into power imbalances and redistributing power from the provider to the patient

• The person who receives care determines whether it is culturally safe

(AFN, 2008; Brascoupe & Waters, 2009; Clarke & Holtslander, 2010; Johnston et al., 2013; University of Victoria, n.d.)
Check Assumptions.

- Indigenous peoples is a broad term to refer to a heterogeneous group of people who originate from the land-base that is now called Canada.

- Because someone self-identifies as Indigenous does not mean they are knowledgeable of/engage in any traditional practices (i.e. do not assume that all Indigenous people are ‘traditional’).

- Not all self-identifying Indigenous peoples have ‘status’ and vice versa.

- It is impossible to learn all Indigenous cultural beliefs, practices, and ceremonies associated with death and dying.

- There is no one-size-fits-all approach to culturally-safe palliative care with Indigenous peoples.

- I am not an expert because I am not an Elder.
Sociohistorical Context.

- The relationship between Indigenous peoples and settlers demonstrate a shift from partnerships to colonial domination

- Several historical and contemporary policies that continue to undermine egalitarian relationships:
  - Indian Act
  - Formation of reservations
  - The Indian residential school system in Canada
  - Indian Hospitals and TB Sanatoriums
  - 60s Scoop/foster care system
  - MMIWAG

(Benjamin, 2014; Dickason & McNab, 2009; Paul, 2006)
Navigating Challenges.

- Mindfulness of sociohistorical realities for Indigenous peoples accessing palliative care
- Survivors & descendants of the Indian residential school system
  - Provide care that is trauma-informed, i.e. will not re-traumatize the patient
  - Relationship to pain and other symptoms at EoL
  - Give as much control to the patient and family as possible
  - Do not refer to them by their room number
- Traumatic deaths & complicated grief reactions
- Reverts to speaking mother tongue
- Addressing our own biases, assumptions, judgements, and stereotypes
- Even in palliative care, racist interactions can and do happen

(Browne, 2005; Johnston et al., 2013; Ly & Crowshoe, 2015; NSDH, 2005)
Cultural Perspectives on Life & Death.

Ideal life ending is “recogniz[ing] themselves as proud Indians” (Couclough & Brown, 2014)

- Wholistic understandings of health
- Shared beliefs of a Creator/God/Entity
- Death understood as a natural life transition
- Connectedness to all of Creation (the Creator, first Mother, ancestors, spirits)
- Often linked to ceremonies and prayer, as well as involvement of Elders
- Christian faith has a strong presence in many communities
- Involvement of immediate and extended families

(CCO, n.d.; Clarke & Holtslander, 2010; Duggleby et al., 2015; Hampton et al., 2010; Kelly et al., 2009; Kelly & Minty, 2007)

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Death & Dying in Local Communities.

Wolastoquey (Maliseet) perspectives:

- “We are a spiritual being having a human experience”
- There is no word for death in the Wolastoquey language
- Mehcinet communicates that the sickness has come to an end
- Community practices after death
  - Visitation at home, sacred fire, death feasts, and more.

(M. Paul, personal communication)
Traditional Cultural Practices.

- Gatherings of families and communities
- Ceremonies
  - Pipe, sweat lodges
- Land-based medicines*
  - Cedar tea, chaga root, muskrat root
- Hand-drumming
- Prayer
- Smudging
  - Sweetgrass, sage, cedar, tobacco, bear root
- Sacred belongings
  - Eagle feathers, medicine pouches, medicines

(Hampton et al., 2010; Johnston et al., 2013; Kelly & Minty, 2007)
Relevance to Palliative Care.

Cancer Care Ontario identifies Indigenous peoples’ expectations of palliative care:

- Kind, compassionate care that is given with understanding and respect
- Care that relieves a person’s pain and symptoms for the best QoL
- Care that honours a person’s spiritual beliefs, traditions, and customs
- Care for the whole person and support for the whole family

(CCO, n.d.)
Relevance to Palliative Care.

Indigenous peoples have knowledge needs related to:

- Physical care
- Practical care related to life adjustments
- Support care
- What to do in the case of an emergency

A lack of knowledge of the above may result in feelings of helplessness, hopelessness, anxiety, panic, and frustration.

(Couclough & Brown, 2014)
Indigenous Peoples
- Mental, emotional, spiritual, physical
- Interconnectedness & relationships
- Intergenerational pain from the past and present
- Previous experiences with healthcare
- Death as life transition

Healthcare Institutions
- Emphasis on physiological health
- Biomedical interventions
- Individual autonomy & agency
- Death as end of life

How do we work in this space?

(Bartlett et al., 2007; Hatcher et al., 2009; Iwama et al., 2009; Rowan et al., 2015)
Key Messages.

- Refrain from interrupting ceremony
- Truly family and community-centred care
- Utilize translators as needed, preferably experienced non-family
- Establish authentic relationships with community healers and Elders
- Crucial questions to ask:
  - How can I provide care that is safe for you/you loved one?
  - Are there cultural practices that are important for you/your loved one?
  - May I move/touch this [sacred item]?
Help us to feel. Help us and listen to us as the First Nations people as we talk from our heart rather than from our minds. And we may talk like simple, uneducated individuals, but we’re not. We’re very articulate, deeply spiritual, intelligent people. But we don’t talk from here, we talk from our heart. Especially if there’s a loved one laying there dying. And we want them to hear that.

(Hampton et al., 2010, p. 11)
References.


- Cancer Care Ontario. (n.d.). *Palliative care in First Nations, Inuit and Metis Communities: Teachings to support grief and loss*. Retrieved from [https://www.cancercare.on.ca/](https://www.cancercare.on.ca/)


References.


References.


