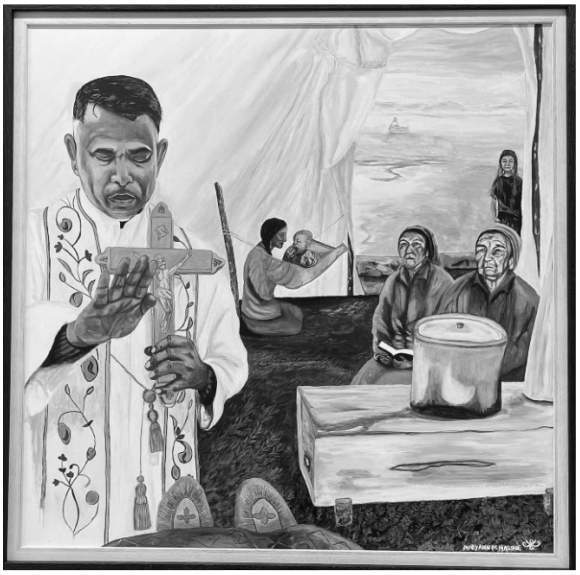
Culturally Sensitive End-of-Life Care For Indigenous Peoples Who Are Incarcerated

Barry R. Ashpole



Patshitinikutau Natukunisha Tshishennuat Uitshuau (a place for Innu Elders to spend their last days in life). For the Innu, dying in the community, either at home, in a traditional Innu tent, or "out in the country" is preferred to dying in hospital. The image is by Innu artist Mary Ann Penashue.[12]

INDIGENOUS PEOPLES ARE DISPROPORTIONATELY INCARCERATED, notably in Australia, Canada, New Zealand, and the U.S.[1,2,3] The statistics make for grim reading.

Culturally sensitive healthcare for Indigenous peoples who are incarcerated is steadily gaining traction in the literature.[4,5,6] Less attention, however, has been given specifically to palliative and end-of-life care for those diagnosed with a terminal illness; research focussed on the Indigenous peoples of Australia, Canada and New Zealand is dominant. There has been limited, if any, research on lesser known Indigenous peoples, for example, the Adivasis of India and the Sámi of Sweden. No matter from what cultural perspective palliative and end-of-life care is viewed, there remains striking similarities in the observations and conclusions drawn in many reviews of the literature from one country to the next, and from one culture to the next.

This article offers a brief overview of the current thinking.

Prison Populations: A "snapshot"

Indigenous peoples compared to non-Indigenous peoples are over-represented in prison populations. For example, in Australia (2,701 vs 208 persons per 100,000), in Canada (426 vs. 40 persons per 100,000, in New Zealand, where 50.9% of the prison population is Māori (528 per 100,000), seven times higher than the general population, and in the U.S. (763 vs 181 persons per 100,000).

The actual number of Indigenous people who are incarcerated is not fully known. In settler colonial constructs, the systems and ideologies that laid the foundation for settler societies, which displaced Indigenous populations and asserted control over their lands (principally in Australia, Canada, New Zealand and the U.S.), have impeded the official identification of every Indigenous person. This underreporting means the scope of the issue is likely greater than statistics suggest.

Such underreporting also limits the ability of *all* incarcerated people to access appropriate end-of-life care, and it makes the provision of culturally grounded care for Indigenous individuals even more challenging. Clearly, due to the high numbers of Indigenous peoples incarcerated globally, and that are also aging, a cultural lens needs to be applied to future health capacity-building strategies in prisons, particularly in the context of palliative and end-of-life care.[7]

Current Thinking: Selected Studies

For Indigenous peoples in general, healthcare systems are often viewed as inflexible, narrowly focussed, prejudiced, and traumatising, in particular for those incarcerated and nearing the end of life. In Australian prisons, as an example of a positive outlook, Indigenous Hospital Liaison Officers have proved to be a

vital cultural link between patients, families and medical staff in navigating correctional healthcare services, and also an equally important link to outside (i.e., community) resources when sought. They facilitate communication and understanding given firmly held cultural beliefs and needs.

In a study published in 2023, researchers at Melbourne's St. Vincent's Hospital identified four "overarching themes" in culturally appropriate end-of-life care for Indigenous peoples who are incarcerated: 1) the intersection of cultures (Indigenous peoples, health and palliative care); 2) the need to bridge the cultural divide (the integral role of Indigenous Hospital Liaison Officers); 3) health professionals delegating their responsibility to provide culturally appropriate care; and 4) the need to work towards a more holistic, culturally aware provision of palliative care.[8]

A more recent study at Queensland University of Technology focussed specifically on decision-making regarding healthcare towards the end of life, pointing to important implications for legal and health professionals, and policymakers. Understanding the cultural, historical, social and health factors influencing end-of-life decision-making with Indigenous peoples can support delivery of health and legal services and systems that are culturally aware, safe and responsive. This can also help reduce existing barriers to accessing palliative and end-of-life care. The authors suggest there may be value in education for Indigenous communities-at-large to support enhanced knowledge and awareness of the law and legal rights at the end-of-life.[9]

The Indigenous peoples of many countries express a common wish for what the Aboriginal peoples of Australia term "to die on Country." Country, purposely spelt with a capital "C," refers to the culturally defined homelands of Australia's Aboriginal peoples and the country's other, distinct Indigenous peoples, Torres Strait Islanders, for whom "Country" is a complex term, encompassing cultural practices, customs, law, place, language, spiritual beliefs, material sustenance, family and identity all in relation to the lands, waterways and seas to which people are connected.[10]

For the Māori of New Zealand, the role of extended families (*whānau*) is critical in the care and support as end-of-life approaches. A 2022 study at University of Waikato explored how Māori extended families interpret and enact family-based care roles as they navigate their older relative's palliative care needs, the family needs, and the formal health and support systems. Such navigation is driven by Māori worldviews, systems, and self-determination in addition to colonization-created disruptions where Māori must negotiate foreign norms, values, practices, and systems.

The authors of the University of Waikato document three culturally centred care roles carried out by *whānau* members providing palliative care: *whānau* as 1) holders and protectors of Māori knowledge; 2) weavers of *whānau* spiritual connection; and, 3) navigators in different worlds. To discuss these roles, they must be situated within the dynamics of *Te Ao Māori.* Within *Te Ao Māori*, the roles facilitate the dying *whānau* member's passing from life to death. The roles also facilitate the transition of responses to care needs as they first dawn in world of potential (*Te Kore*), become (*Te Po*) and are then enacted in the lived world of light (*Te Ao Mārama*). The roles also support *whānau* connectedness that strengthens their capacity to care.[12]

The Innu of Canada have a rich culture that contributes to the health, care, and overall well-being of Innu peoples approaching the end of life. Western medicine is often seen as beneficial in the care that it provides; however, it becomes culturally unsafe when it fails to take Innu cultural and spiritual knowledge and traditions into account; for example, the Innu's strong ties to family, friends, community, home, and the land. When care is provided without regard for the traditional needs of the Innu, then it can do harm. The findings of one study point to ways in which the healthcare system can work with the community to provide culturally safer end-of-life care to the Innu of Sheshatshiu.[11]

Canada's Healing Lodges

Correctional Service Canada established what is termed "healing lodges," specifically (but not exclusively) for Indigenous peoples who are incarcerated. They offer culturally appropriate services and programs in a way that incorporates Indigenous values, traditions and beliefs. At a healing lodge, the needs of In-

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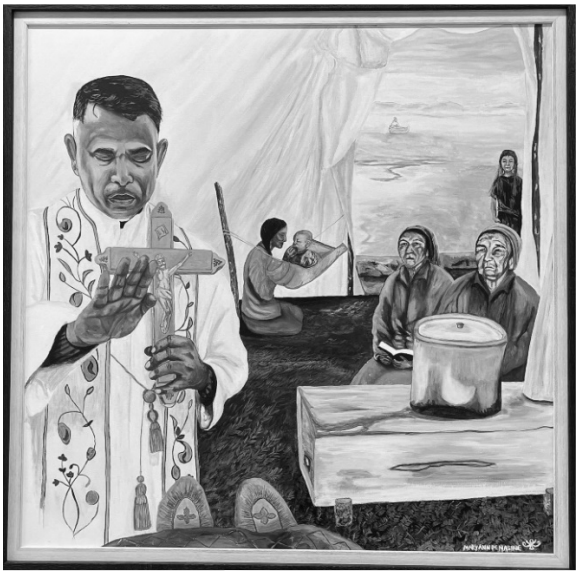

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