



# The End of Life is an Auspicious Opportunity for Healing: Decolonizing Death and Dying for Urban Indigenous People

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# **The End of Life is an Auspicious Opportunity for Healing: Decolonizing Death and Dying for Urban Indigenous People**

## **Abstract**

The majority of Indigenous peoples on Turtle Island (North America) now live in urban settlements, and likely may die in urban spaces. Based upon academic and grey literature searches in 2018 of Indigenous death, dying, grieving, and palliative care in Canada, there is a near absence of information exploring this pivotal life event in the urban context. The diversity of urban Indigenous identities, lived experiences, and degree of connection to Indigenous culture highlights the complexity of the interconnection of death, Indigeneity, and urbanity. Fortunately, signs exist of Indigenous cultural and ceremonial revitalization in urban spaces, and the end of life offers an auspicious opportunity for healing from the intergenerational trauma arising from colonization.

Despite the plurality of cultures in urban settlements on Turtle Island, colonization informs and dominates most systems, including the framing of death and dying as a medical event. However, in my experience, death is more about culture and community. Reconciliation for urban Indigenous communities involves negotiating this challenging paradox between colonial and Indigenous worldviews. Rather than developing new strategies, I posit that existing knowledge – the Medicine Wheel and the Two Row Wampum – offer a vision for restoring respect, balance, and spirit to the end-of-life journey. The Medicine Wheel and the Two Row Wampum teachings offer an Indigenous theoretical framework to consider the complex space created by the interconnection of death, Indigeneity, and urbanity and offers a strength-based approach to guide future end-of-life research, policy, and practice to improve the end-of-life experience for urban Indigenous communities.

## **Keywords**

Indigenous end-of-life care, palliative care.

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## Introduction

### Introduction

*“I’m just a human being trying to make it in a world  
that is very rapidly losing its understanding of being human”  
John Trudell – Indigenous rights activist, poet, musician*

The majority of Indigenous people on Turtle Island (North America) now live in urban settlement (Statistics Canada, 2013). It follows that they may likely die in urban spaces. Based upon academic and grey literature searches in 2018 of Indigenous death, dying, grieving, and palliative care in urban centers in Canada, there is a near absence of information exploring this pivotal life event in an urban context. There is also limited information in general related to death, dying, and grieving for Indigenous communities to inform policy, practice, and education (Kelley, 2010). This is not to suggest that Indigenous communities lack knowledge about this important life transition, but the oral nature of Indigenous knowledge is vulnerable to the disruptive effects of cultural genocide. There is a significant risk of loss of Indigenous knowledge as current Elders themselves pass into the spirit world.

To properly begin this discussion, I locate myself as an individual who strives to walk in two worlds, as many urban Indigenous people do. I was born and raised in the Greater Toronto Area and am part of Toronto’s urban Indigenous community. I am of Mohawk (Bear Clan) and English descent with family roots in Tyendinaga Mohawk Territory. Reclaiming aspects of Indigenous identity and culture that were suppressed by colonial legislation is of great importance to me. As a surgeon I have routinely witnessed medicalized death. The modern health care system frames death as a medical event and primarily considers the physical aspects of death. This approach was unsatisfying and discordant with my personal values as an Indigenous person. I vividly recall delivering the news of a terminal cancer diagnosis to a young First Nations man. After a discussion of available medical treatment options, he said it was time for him to return to his community to heal – “to get well.” He was accepting of his physical circumstances but recognized the opportunity for healing. Improving access and availability of both traditional Indigenous healing and western medical palliative care is important to afford urban Indigenous people opportunities for healing at the end of life.

I am part of Toronto’s urban Indigenous community. As such, when I walk the last stages of my life, I want the option of a different path than the health care system currently supports – one informed by Indigenous knowledge and infused with Indigenous culture. Death is not meant to be a medical event. In my experience, it is about culture and community. The Indigenous relationship with death recognizes it as integral to our understanding of life. By applying the teachings of the Medicine Wheel and the Two Row Wampum, I will offer a theoretical framework to consider the complex space created by the interconnection of death, Indigeneity, and urbanity. This space can be mediated by a dialogue about changing the shape of this relationship from hierarchal to circular – colonial to Indigenous.

## **Indigeneity in Urban Settlements**

The dramatic increase in the Indigenous population in Canada over the last decade largely results from ethnic mobility (the phenomenon by which individuals and families change their ethnic affiliation) and much of this growth has occurred in urban settlements (Peters & Andersen, 2013). The urban Indigenous community is highly diverse in their identity, lived experiences, and degree of connection to Indigenous culture (Peters & Andersen, 2013). Many urban Indigenous people are second and third generation city dwellers, thus their Indigeneity may not be primarily defined by connection to ancestral land (Peters & Andersen, 2013). Contemporary urban Indigenous people “choose from a variety of other resources to construct identities, including pan-Aboriginal cultures and activities in urban areas”(Peters & Andersen, 2013). Urban Indigenous communities are often arranged around cultural and health care organizations.

Cultural engagement has been shown to be beneficial to the health and well-being of Indigenous people (Auger, Howell, & Gomes, 2016; Gone, 2011; Gone & Looking, 2011). However, government policies aimed at cultural extermination and assimilation have resulted in a tremendous loss of Indigenous knowledge, including end-of-life practices and ceremonies. Cultural disruption poses a real risk of permanently losing much of this knowledge given the oral nature of Indigenous knowledge. Re-discovering traditional death ceremonies, increasing access to cultural supports, enhancing death education, and improving relationships with health service providers are of great importance to urban Indigenous people (Anderson, Chalklin, Downey, Lee, & Rodin, 2017). Fortunately, there are signs of Indigenous cultural and ceremonial revitalization in urban spaces and the end of life stage offers an auspicious healing opportunity.

## **Indigenous Concepts of Death and Dying**

The absence of a word for death in most Indigenous languages underscores how differently the end-of-life experience is constructed by Indigenous people. Despite being a very heterogeneous group, Indigenous people worldwide share elements of a common spirituality and worldview (Duggleby et al., 2015). The colonial worldview frames death through a linear, biomedical, and physical lens. Indigenous people view themselves as a spirit having a human experience (P. Keshane, personal communication, Jan 2017). Birth and death are inextricably linked as a transition of the spirit through this world. Thus, the end-of-life is a transition of the spirit rather than solely the end of the body. The last stages of life are an auspicious opportunity for healing of the spirit - and spirit is healed through ceremony (J. Longboat, personal communication, March 2016).

The following is an excerpt from Basil Johnston’s (Johnston, 2010) book in which he recounts the Anishinaabe story of the Gift of the Stars (Annangoog Meegiwaewinan), the origins of children to the physical world. It is transcribed here in its entirety to honor the knowledge embedded in the story and to allow for a wholistic interpretation of its message.

Johnston begins this story about a five year old, Southwind, and the teachings from his grandmother:

*"What are stars, grandmother?" he asked. "Babies," his grandmother answered. Southwind looked back up. The stars looked like sparks. But babies they must be. Had his grandmother not said so? So many babies. They filled the entire sky. A star fell. Southwind gasped. "Oh! Grandma! The baby is going to get hurt!" "Don't fret grandson. The baby won't get hurt. It will fall gently as a feather into someone's arms. Someone's going to receive a wonderful gift tonight. It will make them happy." Southwind's grandmother explained. "What kind of gift?" Some woman is going to get a baby that will make her happy," Southwind's grandmother said. Southwind looked back up into the sky. Not a word did he say. His mind was too small, too young to understand how stars and babies and gifts could be the same thing. To help Southwind understand, his grandmother told him, "One time you were a little star and you came down as a baby to your mother and to your father and to all of us. You made us all very happy. If ever a star falls near you, take it. Take it home! Look after it. It is a great gift that will make you happy." (Johnston, 2010, p. 19.)*

Southwind's grandmother explained that boys don't receive babies, but they do receive different gifts.

"In that moment Southwind wanted a star to fall nearby so that he could take it up, bring it home and look after it. But none ever fell nearby. Always they fell far away. Always they were gifts for somebody else but not for him. For five years Southwind watched stars with his grandmother. Then he stopped going with his grandmother. Looking at stars was boring. Three more years went by. His grandmother fell ill. One night Southwind went out to the knoll where his grandmother used to watch the stars. Before Southwind got to the crest of the little hill, a star fell and it fell just the other side of the hill, where there was a pond. Southwind ran up the knoll and then down the other side to the edge of the pond. But there was nothing in the pond, nothing but white flowers that he'd never before seen. There was no gift. He turned to go back home. "Take me. Take me home. I am medicine. I will make your grandmother well!" a voice said. The little voice came from the middle of the pond. But there was no one there. Again and again the voice called, "Take me! Take me home with you." At last Southwind entered the water, waded out to the middle of the pond. In front of him was the white flower that called out. "Take me! Take me home! I am medicine. I am your gift." Southwind was about to yank the flower from its stalk when it screamed, "No! All of me! All of me!" But it was not an easy thing to lift the flower from its bed. To do this Southwind had to go underwater many times to dig the long root of the flower from its muddy bed. When he finally dug the flower out, Southwind took it home. With the flower Southwind's father made a medicine. They gave it to the old sick woman. The medicine made her better. Some months later Southwind and his grandmother were standing on the knoll studying the stars. He said to her, "No'okomiss, the flower gift that I received; it was really meant for you, wasn't it?. In a way it is. But it was meant for everybody. But that's the way all human gifts are." (Johnston, 2010.p, 20).

The reader can interpret the various lessons within this story, but it is noteworthy that this is a children's story, which educates about the cycle of life. This story addresses the entering of the spirit into this physical world, by the birth of a baby. In death, the spirit is returning to the stars: departing the body as the physical body returns to the first mother, mother earth.

In 2016, a diverse group of highly engaged key informants from community, clinical, policy, government, and educational perspectives gathered to consider First Nations, Inuit, and Metis (FNIM) palliative and end-of-life care issues (Anderson et al., 2017). Numerous themes emerged from facilitated discussions and world cafes including: differing urban and remote community experiences, the need for death education, cultural barriers, challenging interactions with western medical personal, systemic racism, opportunities for healing, and the absence of spirit in the biomedical palliative care system (Anderson et al., 2017). The importance of this topic in the urban context has been affirmed by multiple sources including Indigenous Elders, the Toronto Indigenous Health Advisory Circle, and Anishnawbe Health Toronto.

## **The Medicine Wheel**

The Medicine Wheel is a circular, wholistic, relational representation of the elements of life including the physical, emotional, mental, and spiritual aspects of self in addition to life stages, seasons, sacred medicines, and the four directions (Dapice, 2006). The Medicine Wheel is widely used for health and wellbeing including as a tool for healing from the imbalance caused by colonialism (Dapice, 2006). Its use is congruent with a theoretical framework for conceptualizing death and dying as it represents the cycle of life. Furthermore, it opens the space to challenge the idea that the only death is physical and the possibility that death of all parts of self may not occur simultaneously. The explicit nature of spirit in the medicine wheel is critical at the end of life since the modern healthcare model rarely makes space for spirit. Using examples to explore this concept, I will artificially divide the discussion into the four realms of self and subsequently demonstrate the impossibility of separating them – again consistent with the Indigenous worldview of interconnectedness and relational accountability.

## **Kaswentha – The Two Row Wampum**

Based upon the Haudenosaunee principles of peace, respect, and friendship, the Two Row Wampum documents the relationship between Turtle Island's Onkwehonweh (original people) and the first European explorers. Indigenous legal scholar Robert A. Williams Jr (1990). describes the Two Row Wampum:

When the Haudenosaunee first came into contact with the European nations, treaties of peace and friendship were made. Each was symbolized by the Gus-Wen-Tah, or Two Row Wampum. There is a bed of white wampum which symbolizes the purity of the agreement. There are two rows of purple, and those two rows have the spirit of your ancestors and mine. There are three beads of wampum separating the two rows and they symbolize peace, friendship and respect.

These two rows will symbolize two paths or two vessels, travelling down the same river together. One, a birch bark canoe, will be for the Indian people, their laws, their customs and their ways. The other, a ship, will be for the white people and theirs laws, their customs, and their ways. We shall each travel the river together, side by side, but in our own boat. Neither of us will try to steer the other's vessel. (p. 327)

Thus, this belt of wampum reflects both the separation and interaction of First Nations people and the newcomers that continues to this day. This relationship applies to modern urban settlements with the same veracity as the original agreement in 1613. I propose that the modern urban Indigenous experience is rooted in the three white rows between the two purple rows – the space in between. This space in between the two rows seems congruous with post-colonial scholar Homi Bhabha's concept of a 'third space' (Bhabha, 2004) and Willie Ermine's ethical space (Ermine, 2004). This is a liminal space where two or more cultures interact. Ermine (2004) describes the ethical space as:

*“The in-between space, relative to cultures, [is] created by the recognition of the separate realities of histories, knowledge traditions, values, interests, and social, economic and political imperatives. The positioning of these two entities, divided by the void and flux of their cultural distance, and in a manner that they are poised to encounter each other, produces a significant and interesting notion that has relevance in research thought. The positioning of the two entities creates the urgent necessity for a neutral zone of dialogue.” (p. 20)*

In Haudenosaunee teachings this area is defined by peace, friendship, and respect. The urban Indigenous lived experience is often one of variable cultural connection; neither completely in the canoe or in the ship but in some third space between.

### **Conceptualizing Urban Indigenous Death and Dying: The Medicine Wheel and Two Row Wampum Exist in Urban Settlements**

The Medicine Wheel and the Two Row Wampum offer a vision for restoring respect, balance, and spirit to the end-of-life journey. These two teachings can be used to navigate the unique challenges at the intersection of death, urbanity, and Indigeneity. Together they act as an Indigenous theoretical framework for end-of-life research, policy, and practice. Despite the plurality of cultures in urban settlements on Turtle Island, colonization informs and dominates most systems. Western, colonial worldviews are transactional, hierarchal, and extractive by design. This is the antithesis of relational, collectivist, and egalitarian Indigenous worldviews. Reconciliation for urban Indigenous communities involves negotiating this challenging paradox. However, rather than developing new strategies, I posit existing knowledge – the Medicine Wheel and the Two Row Wampum – can offer an attractive way forward.

The Medicine Wheel does not frame aspects in isolation, opposition, or as separable. Intrinsic to the Medicine Wheel is a pathway for change, healing, and reconciliation. Urban Indigenous people do not have the option of living in isolation - although aspects of the colonial system continue to strive to achieve this. As a healing tool, the Medicine Wheel can help address imbalances caused by colonialism,

including in relationships by (re)connecting with Indigenous culture. This is of great importance to Indigenous people at the end of life.

The original tenets of the Two Row Wampum treaty offer a vision for weaving a relationship that is not dominated by the hegemonic culture. Approaches to this relationship that involve fitting the circular (Indigenous) into a hierarchy (western) have routinely failed Indigenous people. Trying to extract the “best” of both worlds inevitably results in the dominant culture deciding what qualifies as the “best”. While the Two Row Wampum explicitly prohibits steering each other’s vessels, it recognizes we travel the river together and provides a space for interaction. This space between the Indigenous canoe and the western ship is mediated by peace, friendship, and respect. For urban Indigenous people, existing in this liminal, ethical (third) space involves the praxis of building meaningful relationships with both the Indigenous and the non-Indigenous. Paulo Freire’s concept of praxis refers to the linking of theory, informed action, and critical reflection (Freire, 2000). Dialogue, the flow of meaning, is the principle mediator of praxis. I propose that dialogue, grounded in peace, friendship, and respect, and informed by the Medicine Wheel and Two Row Wampum teachings, can improve the end-of-life experience for urban Indigenous communities.

## **Physical**

The last stages of life frequently involve challenges to one’s physical wellbeing. The western health care system focuses on the physical realm. Nowhere is this more apparent than in the approach to pain. Despite recognizing the concept of ‘total pain,’ (Mehta, 2008; Wein, 2010) in reality, pain is viewed almost exclusively in terms of physical pain as evidenced by the near ubiquitous use of opiates as a remedy (Middleton-Green, 2008; Montes-Sandoval, 1999). An Indigenous approach would recognize the interconnectedness of the physical, emotional, spiritual, and mental aspects of pain in endeavoring to mitigate the total experience of pain (Gone, 2009). What does this look like? Through ceremonies such as drumming and smudging which can be incorporated into institutional policies, pain management can take a more Indigenous perspective if combined with traditional Indigenous healing and/or healing circles. Reducing any aspect of pain reduces total pain.

The physical structure and regulations of health care institutions are routinely hostile to Indigenous people. This is relevant in urban settlements because most of us will die in hospitals, despite our stated preferences to die at home (Kelly et al., 2009; McGrath, 2007; St Pierre-Hansen, Kelly, Linkewich, Cromarty, & Walker, 2010). Dying at home can be challenging given the high degree of mobility, precarious housing, and homelessness affecting urban Indigenous communities (King, Smith, & Gracey, 2009; Snyder & Wilson, 2015). Physical and policy limits on the number of people allowed in a room and failing to provide adequate space for family in many institutions precludes the role of the larger family, kin, and community networks that coalesce to support a dying individual. These barriers hinder the ability of a broad network of family and kin to empower the spirit for transition (Duggleby et al., 2015). Institutional policies in long term care homes, hospices, and health care facilities often prevent important ceremonies such as smudging or the pipe ceremony.

The physical layout of hospitals is intended to hide death. People enter through brightly lit, well appointed, visible front doors but the deceased are removed through unseen service doors often located at the rear of the building. The deceased are rapidly cocooned in body bags, rendered invisible, and moved to places others cannot go or see. It is as if death is shameful and to be hidden. This isn't surprising, given the illness-based, medical model's perception of death as a failure. This presents a barrier for Indigenous people who may wish to maintain a connection to their recently deceased loved one. Touching and bathing the body is an act of love and respect which can empower and release the spirit and support grieving. Superimposed upon the hidden nature of death in institutions is the invisibility many Indigenous people already experience in the health care system. For Indigenous people, death in urban hospitals is another form of systemic racism that further marginalizes Indigenous ways of knowing.

## **Mental**

There are many aspects of the mental realm which reflect the tensions between Indigenous and non-Indigenous ways of thinking. Families speak of the difficulty reconciling the health care system's drive for expediency with Indigenous consensual approaches to decision-making. An example of this is seen in the determination of substitute decision makers (SDM). The colonial approach to defining a SDM is hierarchal and legally framed by way of a presumed series of relations based on blood and lineage. Even the term lineage is inconsistent with an Indigenous way of viewing the world. Indigenous decision-making is not rooted in hierarchical authority but instead in consensus building.

I was recently told the story of an Indigenous man who was gravely injured in an accident. The healthcare team felt he was unlikely to recover and decisions regarding care were necessary. The medical team wanted an expedient decision from a SDM dictated by a non-Indigenous, hierarchal, legal protocol. The family, kin, and community gathered to take an Indigenous approach to decision-making. They sat in a circle and shared stories about this man's life, with people stepping out of the circle after each round if they felt others knew him better. This continued until only three individuals remained. None fit the legal criteria for SDM but everyone agreed they had the deepest understanding of who he was as a human being and what his care decisions would have been. Thus, a community-based, consensual approach to decision-making was employed resulting in a less expedient but more appropriate decision. This is an example of how difficult conversations may require more time, but grounding decision-making in authentic relationships and Indigenous approaches to dialogue is essential to achieve outcomes acceptable to Indigenous communities. A final sad comment is necessary here though. Although the health care professionals were accepting of this decision-making strategy, and health care colleagues I have discussed this with find the approach appealing, the actual SDM transaction had to be carried out in a colonial, hierarchal manner.

## **Emotional**

The sting of death can be lessened by family and community support or heightened if the circumstances of death are re-traumatizing. Intergenerational trauma expands unless addressed and this

is particularly true for those grieving the loss of a loved one. Colonization (e.g., the Indian Act, residential school system, Sixties Scoop, forced relocation, child welfare system) is at the root of intergenerational trauma, and has resulted in many Indigenous people experiencing repeated and ongoing traumas from a wide variety of sources, including health care professionals and institutions (Barker, Goodman, & DeBeck, 2017; Howard, 2014; Kirmayer, Gone, & Moses, 2014; Myhra, 2011; Reeves & Stewart, 2017). Therefore, death and dying may retraumatize individuals and communities resulting in expanded intergenerational trauma unless affected people are afforded opportunities to address both past and ongoing traumas (Gone, 2013). The Medicine Wheel became unbalanced through colonial practices. Restoring balance to the Medicine Wheel through decolonization offers a path to heal. Dying well, within institutions, requires more than cultural safety – it requires empathy and dignity (Chochinov, 2013; Thompson & Chochinov, 2008). A health care system that is unable to deliver on these most basic human needs has failed. Sadly, Indigenous people encounter this failure routinely.

In urban settings it is common to encounter stories of Indigenous people experiencing challenges accessing elders, traditional healers, or cultural supports as they are dying due to communication barriers with western healthcare institutions (Harrison J. personal communication, Jan 2017). Even when access to cultural support does occur, it frequently occurs late in their journey (Vautour, J. personal communication, Mar 2017). This limits the healing opportunities for individuals and families, particularly for people wishing to explore their identity and culture at the end of life. The benefits ascribed to early palliative care are not routinely afforded to Indigenous people. Improved relationships between the health care system and Indigenous organizations may enhance the opportunities for emotional support through connection to community and culture.

## **Spiritual**

Lastly, and most importantly, is the spiritual realm. In western health care there is an aversion to all things spiritual. Health care professionals and institutions continue to erect physical as well as policy barriers which impede communal and spiritual activities at the end of life. As Indigenous people, ‘we are a spirit having a human experience.’ It’s not surprising that one of the most sought out services at the end of life is receiving one’s spirit name. Creating space for spirit is both paramount and challenging at the end of life.

The last stages of life are an auspicious opportunity for healing of the spirit. Spirit is healed through ceremony. It is only very recently that Indigenous ceremonies are being permitted in some health care settings. That ceremonies (e.g., smudging, pipe ceremony) are still restricted in many institutional settings is particularly egregious given the history of legislated bans on Indigenous ceremony and culture. The *Indian Act* of 1876 outlawed Indigenous cultural and ceremonial practices in an effort to force assimilation (Joseph, 2018), the effects of which continue to be felt by many Indigenous people who are seeking to reclaim their cultural and spiritual practices. Although institutional policies regularly restrict Indigenous ceremonies, in my experience most health care workers are genuinely curious and accepting of Indigenous ceremonies. It is evident that there remains a

disconnect between policy and practice that needs to be bridged. This too speaks to the need to construct meaningful relationships.

### Discussion

The end of life offers an auspicious opportunity for healing. This isn't limited to the dying individual but extends to all of our relations. For urban Indigenous communities the network of relationships can be complex to navigate as identity and culture are not always apparent or accessible. The Medicine Wheel and the Two Row Wampum do exist in urban settlements – they may just be more difficult to find.

So how do we move forward? The current analysis and theoretical framework offer a strength-based approach for building future research and informing policy and practice. The interconnection of death, Indigeneity, and urbanity creates a new space to contemplate. Exploring this space involves building meaningful relationships and the praxis of changing the relationship's shape from hierarchal to circular – colonial to Indigenous. This praxis can be mediated by dialogue, particularly Indigenous non-hierarchal, circular, approaches to dialogue. Applying the teachings of the Medicine Wheel and the Two Row Wampum offers a framework to improve the end-of-life experience for urban Indigenous communities.

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