

Patshitinikutau Natukunisha Tshishennuat Uitshuau (A Place for Elders to Spend Their Last Days in Life): A Qualitative Study About Innu Perspectives on End-of-Life Care

Objective

The purpose of this study was to:

1. Describe the cultural and spiritual practices of the Sheshatshiu Innu related to death and dying;
2. Identify elements of current end-of-life care delivery that does/does not meet the cultural and spiritual needs of the Innu in Sheshatshiu;
3. Explore ways to achieve culturally safer care delivery for the Innu through integration of current end-of-life care delivery practices with Innu cultural and spiritual practices.

Practice Points

1. Policy development and health system leadership are often based on mainstream business/governance models, which present cultural barriers to effective Innu participation.
2. Health care providers and leaders should consider how traditional practices can be integrated into patient care for more culturally safe policies and services. Institutions should support employees to integrate traditional practices into the care they provide.
3. Collaborative efforts, in addition to systemic changes, are needed among institutions, stakeholders responsible for care of the Innu, and the community itself to ensure the provision and maintenance of resources (human, educational, structural, and financial). Increased communication is needed in areas where jurisdictional clarity is lacking for organizational responsibility in providing end-of-life care to the Innu.

Methods (J. Penashue, R. Dawe)

1. Innu and non-Innu investigators and an Innu Advisory Committee (IAC) co-led this qualitative, patient-oriented research study. Additional team members included M. P. Benuen, A. Qupee, A. Pike, M. van Soeren, C. S. Sparkes, M. Winsor, K. H. Walsh, H. Hasan, & N. Pollock.
2. Semi-structured interviews were conducted with five health care providers and six decision-makers serving the community of Sheshatshiu, Labrador. A focus group of five Innu Elders in Sheshatshiu was also conducted.
3. The non-Innu interviewers reflected upon how their own positions, perspectives, and potential biases might shape the research. The interviewers collaborated with the IAC to ensure that Innu interests, perspectives, and experiences were meaningfully integrated into the question guides, interview setting, language(s) used (where appropriate), data analysis, and interpretation.
4. Separate question guides were created for each perspective included in the study (i.e., Innu community members, decision-makers, and health care professionals). These guides included 4-8 open-ended questions that asked about Innu culture, experiences with the current health care system, and Innu needs concerning end-of-life care.
5. Innu community members provided feedback, which was incorporated into the codebook, preliminary themes (presented for discussion at a Town Hall in Sheshatshiu), and final themes throughout the thematic analysis.

Results

Table 1. Captured Themes and Corresponding Quotes

Theme	Quote
Relationships and visitation support a "peaceful death". Death is a collective experience which necessarily includes the patient's family, friends, and broader community.	<i>[W]hen she knew that [her mother] was really sick and won't have much time to live her mother would say 'don't leave me.' You take turns, like the family, take turns being there for her and the same thing with her husband you know we don't want to leave, we didn't want to leave him. We wanted to be there for support.</i> – Rose Montague, Innu Elder
Traditional locations (e.g., at home, in the community, on the land, in an Innu tent, etc.) are an important part of death and dying.	<i>Hospitals is not the best way to die. I think it's best for you to be very peaceful [...] Like my dad he was about 98 or 100 years old. He wanted to die at home. So they took him home and he died there peaceful at home. And he was alive for at least a week before he pass away and that was a good feeling for all my family visiting and cooking and all that [...] I really think all people wants to die at home.</i> – Francesca Snow, Innu Elder
Friends and community members play an important role (in addition to health care services) in providing end-of-life care.	<i>If people are going through tragedy or death or somebody is sick there's like there's always people at their house supporting, cooking, talking, and praying and there's probably 20 or 30 people there being supportive to the people that are going through it</i> – Innu Decision-maker
Health care providers and services should be flexible and communicate with patients and the community in order to prioritize and incorporate cultural practices in their end-of-life services.	<i>It was the wish of that particular Elder to pass away in a tent and that person would have had the experience of living on the land and previous to actually living in Sheshatshiu and so ... the tent was set up here at the health centre so that the providers could have that ease of access. So ... the staff there were able to, whether it be medications or assessments or just in comfort measures, were able to actually go and provide that to that individual right there on site while also maintaining what was important to that individual with regards to being in the tent.</i> – Non-Innu Decision-maker
Adequate and appropriate supports (e.g., in community) and services (e.g., translation, counselling, health care providers and support workers) were found to be lacking.	<i>Some of us probably would be suicidal and that's very important. I have families who committed suicide [...]. A lot of people lack with counselling. They never even have it and that's why it's very important for the family to have and that would satisfy me. When they are in the hospital, they have nothing.</i> – Francesca Snow, Innu Elder
The health system should develop culturally-informed policies and include members of the Innu community in leadership positions to ensure agency and input into their own services.	<i>I think wherever Innu are going to get the services they should get advice from Innu people and what they do in their own ways or Innu way and try to implement that in their policies or in the system or to get like we're not stupid, we know what we need and what we need to do it's just that sometimes it's not, I don't know what it is but I think it's all about power and control yeah and like that used to be back in a day when kids were taken away they would be at the hospital and all of a sudden they're not there because they're sent away and get adopted out and there's nothing you can do; it's the government.</i> – Innu Decision-maker
Innu health care providers and Innu patient navigators should be recruited and included in end-of-life care for the Innu.	<i>I think ideally there would be somebody like 24/7 at the hospital [...] who is simply there for that like a patient navigator type of person like you would have in St. John's. I think we need the same thing here.</i> – Non-Innu Health Care Provider

- Seven themes were decided upon by the IAC and research team. Names included in the quotes in Table 1 are attributed at the request of the Elder.



Figure 1. Painting Representing Study Findings of an Innu Elder Approaching End-of-Life in a Tent by Innu artist, Mary Ann Penashue

- This Innu painting shows the perspective of an Innu Elder and what they might want to see around them as they approach the end of this life and prepare to transition to the spirit world.
- Themes identified here include the importance of community relationships and a close connection to the land.
 - ◊ Innu Elders (seated to the right) play an important role for the dying person and their community, as they provide support, share stories, sing songs, and offer prayers.
 - ◊ The role of church and clergy has also become important for many Innu; therefore, the artist has included an Innu priest, seen here providing prayers and spiritual support.
- There are often many other community members visiting as well, and it can be a very active scene, because an Elder's transition to the spirit world is important for the entire community.
 - ◊ Therefore, we see a mother and baby seated in the background, a youth entering from outside, and another person in a boat fishing in the background. Visitation is expected and welcomed.
- In addition to their strong sense of community, the Innu are also strongly connected to the land. The scene painted here is within an Innu tent, with the traditional balsam fir or black spruce bough floor, where the hard ends of each bough are dug into the earth itself. The Elder can see the land through the entrance.
- There are often traditional medicines and traditional foods, as seen cooking on the stove. The Elder may wear traditional clothing, as seen in her moccasins near the bottom of the frame, visible below the blankets.
- Mary Ann Penashue (Innu artist living in Sheshatshiu, Labrador) painted two original versions of this scene – one to hang in Sheshatshiu with the community, and the other at Memorial University in St. John's.

Conclusions

1. The role of family, friends, and community members is an essential part of end-of-life care among the Innu of Sheshatshiu.
2. Services provided within the community are important as they serve to maintain a connection to the land and permit community members to gather and support individuals nearing end-of-life.
3. Adequate local infrastructure (e.g., a hospice or friendship centre) and supports are key to building local capacity to provide end-of-life care in the community.
4. For more information about this study, see: Dawe, R., Penashue, J., Benuen, M. P., Qupee, A., Pike, A., van Soeren, M., Sparkes, C. S., Winsor, M., Walsh, K. H., Hasan, H., & Pollock, N. (2024). Patshitinikutau natukunisha tshishennuat uitshuau (a place for Elders to spend their last days in life): A qualitative study about Innu perspectives on end-of-life care. BMC Palliative Care, 23(121). <https://doi.org/10.1186/s12904-024-01431-5>