Dying alone

An Indigenous man's journey at the end of life

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Palliative care is an approach to improving the quality of life for patients with life-threatening illnesses. It focuses on the whole person, including physical, emotional, mental, and spiritual health. There has been a recent focus on the disparity of palliative care resources in underserved areas, including First Nations reserves.[1] This prompted the Canadian Society of Palliative Care Physicians to call for all Canadians to have access to high-quality palliative care.[1] This case report highlights the inequities faced by an Indigenous patient at the end of life.

Case

A 70-year-old Indigenous man from a reserve in northern Alberta presented to an emergency department in Edmonton with a long-standing history of abdominal pain. He had a 3-month history of worsening symptoms and declining function at home. His ultrasound results revealed a Klatskin-type hilar cholangiocarcinoma with involvement of the right-sided bile ducts and hematogenous metastases to the liver. The cancer was unresectable owing to circumferential encasement of the right hepatic artery, and the family decided not to proceed with a biopsy. The patient had been living with his daughter after his wife's death 3 months earlier. Past medical history included type 2 diabetes, hypertension, and bilateral blindness from a previous work accident. His primary language was Cree, and he had 6 children who all helped to interpret.

The palliative care team was consulted for poorly controlled nociceptive epigastric pain. The team suggested titrating the morphine dose from 2.5 mg to 5 mg orally every 4 hours around the clock, with a breakthrough dose of 2.5 mg orally as needed. The Indigenous cultural helper was consulted to provide psychosocial support.

Results of the patient's initial assessment revealed a Palliative Performance Scale score of 50%, which meant he was mainly sitting or lying in bed and required considerable assistance with self-care. An *M1* goals-of-care designation was ordered, in which life-prolonging measures would be considered, but no cardiopulmonary resuscitation, intubation, or intensive care unit admission would be implemented.

A family meeting took place, and the patient and his family agreed to change his goals-of-care designation to *C1*, focusing on comfort care instead of life-prolonging measures. The attending team predicted that his life expectancy was less than 3 months, which made him appropriate for admission to a hospice. He was transferred to a hospice under the care of a family physician 15 days after hospital admission.

The patient's wish was to return home to his reserve in northern Alberta; however, there the home-care services were only available during weekday business hours, no physician was present on a regular basis, and the closest pharmacy was more than 100 km away. The family worried about a possible pain crisis without timely access to appropriate medications. After further reflection, the patient asked to die as close to home as possible, so transfer to the nearest rural hospital was arranged 15 days after admission to hospice.

Upon discharge, the patient's daughter followed up with hospice staff, communicating that they had faced challenges arranging transportation to the rural hospital. Furthermore, multiple family members could not stay overnight

Editor's key points

- Most terminally ill Indigenous patients from rural and remote communities do not have access to sufficient palliative services. They are often transferred for end-of-life care to urban tertiary care hospitals, where they are isolated from the support of loved ones and important traditional practices surrounding death. This transition to an unfamiliar environment during a particularly vulnerable time has been associated with fear of being away from home, language and cultural barriers, and loneliness.
- More action is needed by all levels of government to provide access to equitable palliative care for Indigenous populations. Issues such as inconsistent education, poor coordination of efforts, and lack of resources including federal funding support need to be addressed to create effective palliative care programs for Indigenous communities.

Points de repère du rédacteur

- La plupart des patients autochtones en phase terminale vivant dans des communautés rurales et éloignées n'ont pas accès à des services de soins palliatifs suffisants. Ils sont souvent transférés dans des établissements de soins en fin de vie dans des hôpitaux urbains de soins tertiaires, où ils sont isolés du soutien de leurs êtres chers et de leurs importants rituels traditionnels entourant la mort. Cette transition vers un milieu inconnu durant un moment de la vie d'une grande vulnérabilité a été associée à la peur d'être loin de chez soi, à des barrières culturelles et linguistiques, de même qu'à de la solitude.
- Toutes les instances gouvernementales devraient agir pour offrir aux populations autochtones un accès plus équitable à des soins palliatifs. Des problèmes comme le manque d'uniformité dans l'éducation, une coordination médiocre des efforts et l'insuffisance des ressources, y compris le soutien financier fédéral, doivent être réglés dans le but de mettre sur pied des programmes de soins palliatifs efficaces pour les collectivités autochtones.

because the patient did not have a private room. For these reasons, the patient's family could not visit as much as they had hoped.

The patient died 1 month after his transfer, and he was described as "lonely" in his discharge summary.

Discussion

Most Indigenous patients from rural and remote communities prefer to die at home[2]; however, it is an unfortunate reality that many patients living both on and off reserve do not have access to sufficient palliative services. Terminally ill patients are often transferred for end-of-life care to urban tertiary care hospitals, where they are isolated from the support of loved ones and important traditional practices surrounding death.[3] This transition to an unfamiliar environment during a particularly vulnerable time has been associated with fear of being away from home, language and cultural barriers, loneliness, and disempowerment among patients.[4]

Limited palliative care resources prevented our patient from dying at home, despite his wishes to return to friends and family. Although he had clinical improvement with symptom management, his family did not feel comfortable taking him home; they worried about recurrence of symptoms without access to palliative care, including medications. Jurisdictional issues meant that provincial palliative care services did not provide support to his communities; for example, home care, which is federally funded on reserve, was only available Monday to Friday from 9:00 AM to 5:00 PM. The patient was transferred to a treatment centre closer to home, but he was still isolated from his support network and he died lonely.

In a 2009 qualitative study exploring the experiences of bereaved Indigenous family members in the hospital setting, common themes suggest the importance of direct communication with family members, which is enhanced by frequent use of interpreters.[5] The study emphasizes compassionate caregiving, which encompasses spiritual modalities of care and a commitment from all hospital staff involved.[5] Furthermore, it explains that it is important for facilities to provide large enough rooms for extended family members to visit at any time and subsequently allow them time with the deceased.[5]

The Canadian Society of Palliative Care Physicians suggests a public health approach is required for the unique needs of vulnerable and marginalized groups.[1] Several programs in Ontario have implemented community-based palliative care programs on First Nations reserves that are uniquely adapted to community values and Indigenous culture.[6,7] These palliative care programs are individually founded on the community's traditions, assets, and relationships with regional health services. A thorough needs assessment allows programs to build on what already exists and allows leadership to stem from within the community. This model has successfully enabled several First Nations reserves to achieve capacity development in creating culturally responsive palliative care programs that supported an increase in the number of home deaths.[6]

Developing an effective palliative program in First Nations communities involves palliative care education and training for local health care providers; multidisciplinary outreach teams that include Indigenous physicians, nurses, and social workers; and traditional bereavement support programs.[6] Fruch and colleagues[6] explain that successful models were guided by the First Nations communities and included the development of partnerships with hospices, home care programs, and provincial palliative care programs. Despite these successes, the limiting factors include inconsistent education, poor coordination of efforts, and lack of resources including federal funding support. These issues remain to be addressed by all levels of government to create sustainable palliative care on First Nations reserves.

Conclusion

Family physicians providing palliative care must manage symptoms, provide support for psychosocial concerns, and help with end-of-life planning. All health care providers should be aware of the logistic challenges and inequitable access to resources for Indigenous patients from rural and remote communities. In Canada, Indigenous communities have contributed to successful programs that deliver palliative care to Indigenous peoples. We must continue to work together to provide respectful and appropriate palliative care for all patients.

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Competing interests
None declared

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