PERSONAL VIEW

Culturally safe end-of-life care for First Nations persons living on reserve

AUTHORS

Brittney Russell[1] MScOT, Graduate

David E Fred[2] BA, Co-author

Cary Brown[3] PhD, Professor *

CORRESPONDENCE

* Cary Brown cary.brown@ualberta.ca

AFFILIATIONS

[1, 2, 3] Department of Occupational Therapy, 2-64 Corbett Hall, University of Alberta, Edmonton, Canada

ABSTRACT:

End-of-life (EOL) care involves not just the final few days of a person's life but also living with a terminal illness over an extended period of time. Importantly, in addition to medical care and relief of physical suffering, it focuses on quality of life, honoring personal healthcare treatment decisions, supporting the family, and psychological, cultural and spiritual concerns for dying people and their families. The goal of this commentary is to raise rehabilitation therapists' awareness of the need for culturally safe EOL care services for First Nations persons who live on reserve and to identify strategies to help resolve this unmet need.

KEYWORDS:

Canada, end of life, First Nations, indigenous, palliative, rehabilitation therapist.

FULL ARTICLE:

Introduction

End-of-life (EOL) care involves not just the final few days of a person's life but also living with a terminal illness over an

extended period of time. Importantly, in addition to medical care and relief of physical suffering, it focuses on quality of life, honoring personal healthcare treatment decisions, supporting the family, and psychological, cultural and spiritual concerns for dying people and their families[1].The goal of this commentary is to raise rehabilitation therapists' awareness of the need for culturally safe EOL care services for First Nations persons who live on reserve and to identify strategies to help resolve this unmet need. The EOL focus of this commentary is not intended to negate that there are equally pressing health issues for First Nations' persons living in urban and non-reserve areas. Rather, we feel it is important to discuss specifics of one unmet health need at a time with sufficient depth and contextualization.

According to the National Aboriginal Health Organization[2], 'Aboriginal peoples' is a collective term for the original peoples of Canada and their descendants, which includes First Nations, Inuit and Metis. It is also a term that is used to describe the indigenous populations of Australia and New Zealand. However, this term is falling into disfavor in Canada and is considered by many groups to be unrepresentative. This article is specific to Canadian First Nations persons and we will use this term whenever possible. When citing other literature, we have used their original terminology, for example *Aboriginal peoples* in Australia and *Native American* in the USA.

Palliative care services, cultural safety and Aboriginal persons

First Nations persons in Canada are culturally diverse; however, they share a similar history of colonization, assimilation and transgenerational effects from the residential school system[3]. These historical structures and the ongoing systemic cultural insensitivity that is found in the healthcare system contribute to First Nations persons' overall poor health status. These factors are believed to significantly contribute to the disproportionately higher rates of chronic health issues, and the lower socioeconomic and political status that First Nations people living on reserve tend to have in comparison to non-First Nations Canadians[3,4]. Issues of alienation and distrust of government-aligned services are a reality that contributes to First Nations people being less likely to seek out healthcare services within the formal structures that are perceived by many to embody characteristics of a larger colonialistic, oppressive system[3,4]. Often, the situation is compounded for First Nations peoples as a result of living on reserve in rural and isolated locations with poor access to culturally appropriate mainstream health care[5-7], and, for some, limited access to traditional healers[8]. Taken together, the significant lack of resources, coupled with the distrust and reluctance to seek medical attention arising out of negative encounters with a historically culturally insensitive healthcare system, contribute to delayed treatment and an increased likelihood of more advanced disease before treatment is sought. The prevalence of terminal illnesses is increasing for both First Nations and non-First Nations Canadians[9], and EOL care services will inevitably increase with this current trend.

The concept 'cultural safety' originated in the mid-1980s in response to Maori people's experienced of racist health care in New Zealand[10]. The National Collaborating Centre for Aboriginal Health defines cultural safety as:

> a state whereby a provider embraces the skill of self-reflection as a means to advancing a therapeutic encounter with First Nations, Inuit, [and] Métis peoples ... Self-reflection in this case is under-pinned by an understanding of power differentials … a central tenet of cultural safety is that it is the patient who defines what 'safe service' means to them[11] (p. 9).

Rehabilitation healthcare professionals such as occupational therapists value and practice self-reflection as a core competency. As such, they are well positioned to address practice and assume the challenges of providing relevant and culturally safe EOL services to First Nations persons. Additionally, this self-reflective practice can facilitate working with other team members to promote both awareness of the unique risk factors to cultural safety and better access to culturally safe EOL services. Occupational therapists have developed a range of relevant resources to guide this work. These include a clear call to action from the national association, the Canadian Association of Occupational Therapists, stating that 'all people of all ages in Canada have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice[12]'. Secondly, occupational therapy professionals have significant experience in the provision of services at EOL[13]. In addition, occupational therapists in Canada have made significant progress in building awareness and capacity for providing culturally safe care within their delivery of

service[14-16]. Equally important are the growing range of guidelines and resources produced by the stakeholders with which rehabilitation therapists partner. For example, Cancer Care Ontario collaborated with First Nations organizations across the province to carry out a cancer care needs assessment. The resulting document, *Aboriginal cancer care needs assessment*[8], has a wealth of information, melding both the science and the personal stories needed to best convey the complexities of EOL care for First Nations persons. The following narrative is based on the lived experience of one of this article's authors (DEF).

> *As a First Nations person from the Okanagan Indian Band reservation, I have witnessed first-hand the gap in knowledge and services for First Nations people who are in need of medical and palliative care while living on reserve. A relative who lived on a reserve in [X] was dying of cancer. She had no driver's license and did not have a registered vehicle. Most of her appointments were in [Y] (3 towns away) and some were in Vancouver. These appointments were very stressful for her because she did not have any family nearby to support her in those cities. She had to fund her trips herself which was very hard as a single mom of two. When she could, she asked family members and cousins to help get her to her appointments; however, sometimes she couldn't get a ride. When she had to go in for palliative care, she had to move 30 km from home to [Z] because that was the closest hospice house that could assist her. Her children had to remain at home as they were attending school there while she was in the hospice. This transition was very difficult for her and her children, as they could not get a ride to and from [Z] when they wanted to visit her. Overall, my family's experience with the current healthcare system has been a stressful one. We are disappointed with how the funding for palliative care resources are utilized.*

Barriers to culturally safe palliative and end-of-life care

Canadian studies suggest that those people living in rural areas are more likely to die in cure-oriented hospital as opposed to hospice settings, which more appropriately focus on quality of life[17]. Researchers have identified several significant barriers for First Nations persons living on reserve when trying to access hospice and palliative care services. First, reserves tend to be in rural, isolated locations. This isolation is considered to be a significant contributing factor to the international problem of attracting and retaining healthcare professionals[18]. Second, there is a lack of public transportation to urban healthcare services[3,4,19]. Consequently, First Nations families and clients may be faced with only two options: leave the familiarity of their community and move into urban areas in order to receive EOL care or receive no specialized EOL care at all.

For many, the choice of moving to urban areas for EOL care is unacceptable. The historic effects of colonization, such as intergenerational traumatic experiences and past prejudicial treatment within Western institutions and government bodies, add layers that may intensify feelings of isolation and disrespect when treated with a non-culturally sensitive approach in urban institutions[3,4,15,20]. Stereotypes and misconceptions about First Nations clients may lead to discriminatory clinical judgement and may result in clients avoiding the use of urban EOL services[20,21]. Research shows that isolation from family support is a particularly significant barrier for First Nations persons[3], and, to date, little has been done to creatively address ways to reduce this barrier. through provision of services within the community and better linkages through telecommunication and electronic mediums to family supports if care must be provided outside of the community.

Other, pragmatic, obstacles to EOL services include a lack of awareness of the rehabilitation equipment (such as lifts, braces, and mobility devices such as wheelchairs) available and a lack of funding for this equipment[15,22]. Funding can be a problem for First Nations people living on reserves because of the different federal funding sources required to pay for necessary EOL equipment[15,22], and this can delay access to needed EOL services and equipment and create inconsistent access to healthcare services in general.

Strategies for culturally safe end-of-life care services

There are three key strategies rehabilitation therapists can employ to sensitize themselves to culturally safe practice and to contribute to meaningful end-of-life care.

1. Educating healthcare providers

Therapists should access cultural safety awareness training. For example, occupational therapists can join the Occupational Therapy Aboriginal Health Network, sponsored by the Canadian Association of Occupation Therapists, and use seminal works on cultural safety from an occupational therapy perspective to engage in discussion and self-reflection[14]. Other healthcare professional organizations also have useful documents for this self-exploration process. For example, the College of Family Physicians of Canada provides information and self-reflection questions to guide healthcare providers in working towards culturally safe practice[23]. Therapists can seek out traditional healers and indigenous elders in their communities who can help build awareness to ensure that the holistic focus on balancing spiritual, physical, emotional and mental health valued by many First Nations clients and reflected in medicine wheel teachings[8,24] is maintained. The article 'Completing the circle'[25], which reports the narratives of Aboriginal elders in Saskatchewan in response to the question 'What would you like non-Aboriginal healthcare providers to know when providing end-of-life care for Aboriginal families?', can serve an important foundational role for all healthcare providers as they learn. The companion website, *Completing the circle: end of life care with, by and for Aboriginal families*, offers important learning resources[26]. Encouragingly, many universities and large health districts have developed networks of stakeholders to help connect non-indigenous service providers to the growing, but dispersed, volume of resources. For example, the University of Alberta hosts an Aboriginal/indigenous portal on their website that includes resources for community engagement and identifying partners for special initiatives[27].

2. Delivering services using telehealth and social media

According to Isaacson et al.,[22] healthcare providers and Native American members in South Dakota, USA have looked at telehealth service as an affordable alternative for some forms of EOL care on their reserves; this type of care could be an option for First Nations members who live on Canadian reserves. This modality allows healthcare providers to interact and communicate with patients through a computer interface in their home or in community centres. Many therapy services focused on quality of life and family education could potentially be delivered through telehealth and social media platforms like Skype, Zoom, and eConsulting. Additionally, using telehealth links, service providers, such as occupational therapists, can provide education and support to healthcare assistants who are members of the patient's own community and support network. Telehealth can serve to support cultural safety by facilitating important traditions and ceremonies. For example, for many First Nations members, death is a familial process that involves spiritual ceremonies and transferring of one's energy to the dying family member[25]. Supporting an environment that electronically links distant family members with patients can help strip alienating, institutionalized characteristics away and facilitate traditional practices to take place that incorporate family members and familiar practices. Therapists can work with patients and families to use technology to promote cultural safety and meaningful EOL activities for their clients[4,25].

3. Sharing information about resources and building community awareness

Stakeholders need to know more about which resources are required to support EOL care at home and why they are necessary. Evidence supporting best practice in health literacy and educational strategies for First Nations persons is still scarce[28]; however, some models exist from work carried out in other countries. For example, the issue of a lack of awareness of palliative services on reserves was addressed in an Australian study which found that after healthcare providers educated members of a rural Aboriginal community about available palliative services, the members were more likely to seek out those resources in the future[29]. A range of health education strategies include written and electronic resources, oral stories and working with translators. Involving family members[30] and First Nations elders as educators and awareness developers in communities is integral when planning EOL interventions. Therapists can work closely with key stakeholders to ensure these resources are relevant, informative and culturally respectful. When EOL care involves a child, Jordan's principle can become very important. A deeper discussion of this is outside the scope of this article but all therapists working with children should be aware of this and can access more information on the Indigenous and Northern Affairs Canada website[31].

Conclusions

Culturally safe service delivery involves the acknowledgement of systemic, socially produced power differentials among different groups within Canada and requires healthcare providers, including rehabilitation therapists, to engage in ongoing self-reflection and communication to effect genuine change. A critical need for culturally safe palliative and EOL care exists for First Nations persons who live on reserve and service providers must assume a stronger role in facilitating the knowledge, skills and resources needed to make this needed change a reality.

Acknowledgements

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