Promising Practice

Indigenous End-of-Life Doula Course: Bringing the Culture Home

Gina Gaspard, Carrie Gadsby, Jennifer Mallmes

ARTICLE INFO

Keywords:

Death
Dying
End of life
Palliative care
First Nations, Indigenous
Video
Advocacy
Education
Cultural practices
Health care

<https://doi.org/10.32799/ijih.v16i2.33230>

ABSTRACT

Many Indigenous people who live on their traditional territory die in hospital when their preference is to enter the spirit world from their home. Indigenous people in Canada describe experiencing many barriers that prevent them from making this final choice in life. The First Nations Health Authority in British Columbia (BC), Canada, in collaboration with Douglas College, offered end-of-life doula training classes to Indigenous people in BC in 2019. The goal was to build on the strengths of community members already supporting people and their families during their final journey into the spirit world. There were 86 participants (72% identified as Indigenous) from the five health regions in BC, representing 47 Indigenous communities. Participants were overwhelmingly satisfied with the five-day course and planned to take their new learnings back to their community. It was noted, however, that this course would benefit from adaptations, including a greater emphasis on traditional Indigenous practices, facilitation tips, and strategies to support people through loss and bereavement. Furthermore, the term “end-of-life doula” is sometimes associated with a for-profit business, which is counterintuitive to traditional Indigenous practices, highlighting the necessity for a name change. Further evaluation over the next year is necessary to confirm that the course makes a positive difference in the final journey for Indigenous people.

AUTHOR INFO

Gina Gaspard, RN, MN, GNC (c), Clinical Nurse Specialist Healthy Living, Chronic Disease, and End of Life, First Nations Health Authority, Vancouver, British Columbia, Canada

Carrie Gadsby, BA Communications and Psychology, Senior Communications Officer, Marketing & Measurement, First Nations Health Authority

Jennifer Mallmes, BGS Sociology and Gerontology; Lead Instructor, End-Of-Life Doula Certification Program, Douglas College, New Westminster, British Columbia, Canada. Email: mallmesj@douglascollege.ca

Acknowledgements

The authors wish to acknowledge all the participants who have returned to Indigenous communities in BC and continued their important work to support people with life-limiting illnesses, and to assist with preparation for their journey into the spirit world.

Introduction

Wanting to Die at Home When Death Is Expected

Many Indigenous people in Canada state that they would prefer to die at home or in their community, and yet they often die in hospital away from family and community, or even in an ambulance on the way to the hospital (Castleden et al., 2010; Verde et al., 2010). Although this experience may also be true for other Indigenous people globally, the promising practice highlighted in this paper focuses on Indigenous people living in Canada, and specifically in British Columbia (BC). Indigenous people experience deficits both in health determinants and in the significant gap in health equity for palliative care services in or near their home (First Nations Health Authority [FNHA], 2016). This places them in a position of double vulnerability (Reimer-Kirkham et al., 2016). There are a number of gaps and barriers that can prevent Indigenous people from receiving high-quality palliative care (FNHA, 2016). In many cultures, it is the traditional protocols and roles which support the grieving journey and healing that are important. Healing practices that only consider Western medicine, without space for traditional options, are not culturally sensitive nor culturally safe care (Verde et al., 2010).

There are several key reasons for some Indigenous people's preference to remain at home, on their land, and among family, healers, and traditional medicines at the end of life. Traditionally, Indigenous families want to care for one another. Each Nation has protocols or systems of care to ensure the community supports someone at home to die. By remaining at home, the person can be offered traditional medicines and healing practices specific to the Nation and culture. These may include smudging, cedar brushing, drumming, and large gatherings. Furthermore, Elders state that the practices of culturally significant death protocols ought to be observed and preserved for future generations when expected deaths occur in the community (FNHA, 2016). By honouring these preferences, individuals and families use a palliative approach.

For most Indigenous people in Canada, the traditional preference is to view death as a journey into another realm—rather than as a final event—with a focus on preparing the person for a safe journey into the spirit world (Anderson & Woticky, 2018). Cultural protocols and traditional treatments that help with this preparation for the spirit journey may not be accommodated in hospitals or other institutional settings (Castleden et al., 2010; FNHA, 2016). Hospitals do not always support the use of traditional pain medications or treatments, and they commonly follow a medicalized approach to dying (Jensen, 2019). Traditional systems and protocols for this final journey into the spirit world are often not observed or facilitated. As a result, the hospital is a less than ideal default location for wholistic, culturally safe, end-of-life

care. The challenge to providing culturally sensitive and culturally safe palliative care in institutions is also influenced by Canada's history of colonial practices.

Historical Influences

The Indian Act of 1876 established the federal government as the guardian of Indigenous Peoples with authority to control most aspects of their everyday lives, including status, land, resources, wills, education, and more, with assimilation to Western ways as the goal (Milloy, 2008). The Indian Act is a Canadian Act of Parliament that is widely viewed as a colonizing piece of legislation and is still enforced today, with amendments. The Act is wide-ranging in scope and covers governance, land use, health care, and education. The Act is unilateral in nature, as it is imposed on Indigenous Peoples of Canada. Further colonial policies have included forced relocation, residential schools, and the Sixties Scoop. "Sixties Scoop" is a term used to describe the forced removal, from the 1950s to the 1980s, of over 20,000 Indigenous children in Canada from their families, language, and culture to become wards of the court and to be raised mostly by non-Indigenous foster parents (Crey & Fournier, 1998). These colonial policies contributed to intergenerational trauma, deficits in the determinants of health, and a resultant mistrust of, and discomfort with, the government system (Anderson & Woticky, 2018; Castleden et al., 2010; Turpel-Lafond, 2020).

Historically, throughout the past two centuries of Canadian history, the hospital has been an institution that has had a profoundly negative impact on many Indigenous individuals and families (Geddes, 2017; Lux, 2016). Common practices included non-consensual experiments, forced malnutrition, abuse, and racism (Geddes, 2017; Lux, 2016). Mitchell and Maracle (2005) contend that trauma has significantly contributed to the disparities in health status for Indigenous Peoples. Hospitals for Indigenous-only patients were created to segregate them from non-Indigenous patients. The federally funded Indigenous-only hospitals were provided with fewer resources, services, and supports compared to non-Indigenous hospitals (Lux, 2016). Megan Jensen (2019) writes, "For Indigenous communities across Canada, colonization has resulted in the wiping out or suppression of cultural end of life care practices." We suggest that colonization is a contributing factor in the loss of culture at the end of life.

Colonization Still Exists

Accessibility of palliative care services cannot be fully realized while colonial practices are still in use in Canada today, and as purposeful assimilation approaches remain part of the health care system. Racism, the inability to bring cultural practices into institutional health care settings, and health care providers' lack of understanding about historical trauma are examples of colonial practices that can be seen in health care today. Colonial policies (e.g., the Indian Act) continue to drive inequity and health outcomes. As a result, some Indigenous people may not trust the health care system based on past negative experiences, racism, and continued trauma today (Turpel-Lafond, 2020). Reciprocal trust and respect are important elements of accessible palliative care services, particularly for the health and well-being of Indigenous people (FNHA,

2016). There is an intuitive aspect to respect in Indigenous culture and practices, because it involves knowing how to be with oneself and with others (FNHA, 2019).

The different worldviews of Western and Indigenous cultures can challenge effective communication, and can cause and perpetuate trauma if health care providers erroneously assume everyone holds similar perspectives. Indigenous people often experience and view the world as interconnected and wholistic (Anderson & Woticky, 2018; Ross 2014). This view places the individual as a smaller part of a collective whole, which does not align with the individualistic, biomedical, and physical perspective underlying Western medicine (Anderson & Woticky, 2018). Furthermore, Indigenous people may not completely understand where they are on their “Western” health journey because they define health in terms of a balance between mental, emotional, spiritual, and physical wellness (FNHA, 2019). If information, in the context of Western medicine, is not accessible or clearly understood by the person and/or family, clarifying questions may not be asked. A lack of awareness of available options and resources is further compounded by the fear of getting into “trouble” or being accused of doing something wrong by being disrespectful. For many Indigenous people, this discomfort with asking questions could be the result of growing up during a time when Indigenous people were taught to blindly obey “white authority”; subsequently, this fear was passed down to other generations (Sellars, 2013). Lucy Barney, an Indigenous advanced practice nurse, further explains:

As a First Nations person, I have many relatives who use the health care system, and they do not have the education or knowledge of the outside world. They do not know their body scientifically and wouldn't know to ask the right questions. I hope the health care provider would ask the right questions of them. (Personal communication, October 17, 2019)

Even as a trained, practising health care provider herself, she expresses and demonstrates that she believes her relatives are uninformed about options available and the best way forward regarding medical care and choices. As an Indigenous person, she understands how people are not comfortable asking questions but will rather wait for health care providers to ask. If the health care provider does not take the time and fails to ask questions, important information may not be exchanged.

Closer to Home

Indigenous communities in BC employ nurses who provide services for all ages and health issues. Most Indigenous communities in BC are small and support approximately three expected deaths each year, with less than one expected death each year occurring in community (FNHA, 2017). As a result, there is no clinical opportunity for nurse specialization in palliative care. Instead, nurses rely on their palliative nurse colleagues from other institutions to provide mentorship and professional support when a situation presents. Currently, access to training, education, and palliative care specialists for nurses in Indigenous communities is not standardized across the province, which can impede knowledge, confidence, and the ability to provide palliative care support to clients and families in their homes.

Furthermore, it can be difficult to attract health care providers to practise in rural and remote communities (Auditor General of BC, 2018), leaving these communities no choice but to contract nurses and physicians to provide in-and-out service. This impedes the opportunity to build a trust-based relationship between Indigenous clients and care providers, and to offer consistent, seamless care. Nursing shortages are not uncommon in the general health care system, but in Indigenous communities they can translate into very limited access or no nurse at all. Without access to a nurse, when families caring for someone at the end of life have concerns or questions, they have no alternative but to call the hospital or ambulance service. This call usually translates to the person in need having to leave the community. Clearly, more community supports are needed.

The end-of-life doula is a relatively new role that aims to empower, educate, and encourage people and their families to be involved in making decisions. This support is based on the palliative approach to care which is specific to a person's needs, beliefs, and desires (described on the website of the End of Life Doula Association, 2017 <https://endoflifedoulaassociation.org/>). We describe a promising practice for improving access to palliative care by offering education to community members who choose to become end-of-life doulas.

Materials and Methods

The FNHA believes in building on the strengths and confidence of community members already supporting people and their families as they prepare for, and during, their final journey to the spirit world. Building capacity in community could widen access to culturally acceptable end-of-life care by re-establishing cultural traditions and protocols, providing culturally relevant support to families, and complementing and building trust with elements of the system, such as palliative care teams, paramedics, police, and funeral providers. FNHA heard of this promising practice and reached out to Douglas College to learn more about the college's end-of-life doula program and determine if it might be adapted to meet the learning needs of Indigenous people.

The end-of-life doula course was created in 2016 by Douglas College in New Westminster, BC, and is open to anyone who would like to learn how to facilitate a palliative approach. No formal health care background is required. The doula's person-centred approach aligns with the beliefs and values around good end-of-life care. Students who complete this course develop an understanding of how to better support people and their families by empowering, educating, and advocating for the best possible end-of-life care (Douglas College, n.d.).

FNHA collaborated with Douglas College to offer five separate end-of-life doula courses across the province. The course was developed for Indigenous participants living in BC communities who did not have a formal health care background. Some adaptations were made to provide a cultural focus that reflected the practices of the territory where the course was held.

Figure 1*Locations for BC Indigenous End-of-Life Doula Sessions, Spring 2019*

The invitation for the course went out to regional nursing teams, community engagement coordinators, health directors, and nurses working in Indigenous communities, asking them to encourage interested community members to apply. No previous health care training was required—only the desire to support people and families at the end of life. For successful applicants, the costs of transportation, accommodation, meals, tuition, and books were covered by FNHA.

The classes were located around British Columbia (Nanaimo, New Westminster, Prince George, Kelowna, and Kamloops) to promote accessibility for people living in all regions (Figure 1). Each training session was opened by an Elder to welcome participants to the territory and to start the program in a thoughtful, grounded way. Some Elders were able to offer cedar brushing and smudging, which are traditional healing practices in some cultures. The program ended after five days with closing words from the Elder and the presentation of a college certificate of attendance (Figure 2).

The content of the program included a description of palliative support, the importance of end-of-life care, and the voluntary role of an Indigenous end-of-life doula. At this time, there is no funding for a paid doula role. One focus was on enhancing communication skills, including active listening plus initiating and conducting difficult conversations about the end of life. The complexity of grief was discussed, including a variety of coping mechanisms, useful resources, and the importance of effective self-care. Conversations about advance care planning were highlighted, including information on the range of medical and non-medical interventions available to ensure comfort, as well as tools for planning and making wishes known to others. The course provided opportunities to discuss issues, ask questions, and find a community of practice for participants' personal support. Cultural practices and protocols unique to the territory on which the course was held were interwoven into content. Each participant was asked to

complete a course evaluation on the final day (see Appendix) and to expect an online follow-up survey in six months, which would go to them as well as the community health director. The participants were aware that all evaluation opportunities were strictly voluntary and would be used to improve future courses for this pilot project. All evaluation forms were anonymous. Two FNHA advanced practice nurses individually reviewed all the evaluations and identified patterns. There was a consensus on the common themes and ideas which were revealed.

Figure 2

Indigenous End-of-Life Doula Student Cheryl Bailey (left) Holding Her Certificate Of Attendance With Instructor Jennifer Mallmes

Ethical Statement

All participants in the end-of-life doula course were aware that they were part of a pilot project. They were also aware that their voluntary feedback would be used and shared to evaluate and improve the course. The project was conducted in accordance with FNHA's values and seven directives (FNHA, 2019) and the Canadian Nurses Association Code of Ethics (Canadian Nurses Association, 2017). FNHA and Douglas College took direction from participants from Indigenous communities in BC throughout the project to ensure a community-driven approach. We sought permission, using consent forms, to share pictures and contact information. Participating in the course, responding to evaluation surveys, and sharing photographs and contact information, plus using the information when returning to live in their community, were all voluntary, with no negative repercussions should the participants change their mind.

Relationship

FNHA collaborated with Douglas College and with an Indigenous instructor, Jennifer Mallmes, who offers monthly community-of-practice calls to participants after successful completion of the course. Each session benefited from the support of an Elder from the territory to open and close the course, and to provide traditional healing such as smudging and/or cedar

brushing. Each session had an FNHA employee in attendance to further support the session in a coordinating role.

Course Evaluation / Results

There were 86 participants (72% identified as Indigenous) from the five health regions of BC, representing 47 Indigenous communities from as far north as Mowachaht/Muchalaht, as far west as Seabird Island, and as far east as Ktunaxa First Nation. Initial results have been overwhelmingly positive. Each class had a wait-list, and requests have been received provincially, nationally, and internationally to attend future sessions.

The participants completed a post-session evaluation (Appendix). FNHA advanced practice nurses reviewed and categorized the evaluations according to common ideas. This led to the following emerging themes: (a) I can help, (b) Plan for care in the future, and (c) A new perspective.

I Can Help

Participants were quick to recognize that they had a role in sharing with their community the information, resources, and required legal forms to support expected home deaths. When asked if the course would help them support others at the end of life (EOL), almost all participants responded affirmatively.

For many, the paperwork and legal requirements were unfamiliar or new information. Many responses on the post-session evaluations acknowledged the forms were important to share when they returned to their community. Examples of participant evaluation responses with the theme of “Eager to return home to help with legal paperwork” include:

- “I cannot wait to help others in their EOL process and provide information to my community about important paperwork.”
- “Have tools to bring home to show and provide resources to prepare for end of life.”
- “Sharing knowledge about paperwork and website with anyone.”
- “Did not know of all the paperwork involved in EOL, how important it is to have all ‘ducks in a row’ for EOL.”

Plan for Care in the Future

The second theme was the importance of advance care planning (ACP) conversations. Participants acknowledged the fear of death. In some communities, there was a fear of talking about death because it was thought to bring death upon someone. Information and discussion provided during the classes dissolved these fears and inspired participants to have more discussions when they returned home. Almost all participants identified the importance of completing their own advance care plan first, before initiating conversations with others in the community. Having early conversations about health care wishes was identified as an important step to plan for a good death. Examples of participant evaluation responses about ACP include:

- “Talking about death/End of Life is a necessary conversation. I need to do my own Advance Care Plan.”
- “Yes it will help lots. I look forward to starting with my family.”
- “Start planning for the future, writing out my wishes, completing my Advance Care Plans.”
- “Get my paperwork in order and help Elders get their paperwork in order.”
- “Be the role model to start the ACP with myself.”
- “I am going to do my ACP.”
- “I will be working on my plan and talking to my family of my plan.”
- “I plan to do my ‘Advance Care Planning’ for myself and family.”

A New Perspective

The third theme was a shift away from thinking that all deaths are negative and traumatic. Some participants acknowledged that their community’s view on death could be “healthier.” Undeniably, some deaths are unexpected and traumatic. However, in the situation of an anticipated death, good planning with ACP conversations can contribute to a good death, including comfort, dignity, and respect. This possibility brought a sense of hope. Examples of participant evaluation responses that demonstrate a shift in perspective about death and dying include:

- “New appreciation for the beauty of death (circle of life) and respecting one’s wishes. The importance of planning ahead and having these conversations with family/clients.”
- “Start talking [to] people about death.”
- “Deal with someone dying in a different way and knowledge learned. I have learned it is ok to talk about death.”
- “I will see the way to assisting people as less complex. To be able to start the conversation now.”
- “Community members will be informed now in the new way.”
- “Approach EOL with more confidence.”
- “Not be afraid to talk about health.”
- “Talk about End of Life more!”
- “I am a support within my community and have gained more tools to help me support community.”
- “Lots to put in my toolbox and think of things in a different way.”
- “I can help our people live their last days comfortable.”
- “Yes the resources are out there and our people don’t need to die alone or be alone with a dying loved one.”
- “The people will have preparation and have a clearer understanding of what is needed before they die. The people will be more open about the EOL with each other.”

In September 2019, six months after the course was offered, two confidential online surveys were sent to 40 health directors and 80 course participants. Six participants did not have email addresses. We were interested in whether uptake of the course suggestions had occurred. The response rate to the survey was very low, with four (10%) completed surveys from health directors and 16 (20%) completed surveys from participants. Due to the low response rate and the potential for identifying the responder, all six-month follow-up surveys were analyzed together. Of those who responded, there were comments that indicated the course supported work that was done naturally in communities and built on existing strengths, promoted teamwork, and uncovered a need for continued education. Examples of participant and health director six-month evaluation responses include:

- “Being an end of life doula is just sitting there and offering comfort to everyone and it is in our nature to do that already.”
- “Good to know that there is a name for what our nation has been doing for many centuries.”
- “Myself and the personal care workers have sat with our members who choose to live out the end of their lives here at home surrounded by their loved ones.”
- “The nurse and I have been working together to advocate the importance of advance care planning. We have also started building a relationship with the Hospice Society.”
- “I met with one of the local doctors and gave him a brief description of what I was providing for his client and he was quite pleased.”
- “This was a wonderful experience and a good knowledge base. In the future I wish that we can continue to work together to make death a peaceful, and supportive experience.”
- “I did love the training and do believe all communities need this education.”
- “I will recommend more people take the end of life doula.”
- “Continue to provide this training for this end of life, so we have enough to have a team approach, so we can support citizens and the team.”
- “I wish to have other staff members trained.”

Limitations

During the first sessions, some participants were not necessarily the most appropriate students for this course. In some cases, accepted participants could not attend, and instead of cancelling and freeing a space for someone on the wait-list, another community member unexpectedly arrived who had limited interest in supporting people through their final journey. Health care professionals, such as social workers and nurses, also attended and, predictably, found the course was limited in meeting their clinical learning needs.

Results to evaluate the end-of-life doula role in Indigenous communities are preliminary and limited. We know the participants enjoyed the course, gained new knowledge and skills, and

planned to share these with their community. We do not yet know if the individual living with a life-limiting illness has experienced better care or has more options when choosing where to enter the spirit world.

Discussion

The early evaluative results for this strategy are hopeful. Most participants found the course relevant, informative, validating, and inspiring. They left the course with more tools to continue to support people on their spirit journey and their families who are left behind. There is a wait-list and a continuous request for more sessions. The concept of a team approach is essential so every person feels supported in this work, and no person experiences caregiver fatigue.

It is important that the new end-of-life doulas receive diverse opportunities for support to continue their work. As more community members take the course, more end-of-life doulas will be available to support one another. FNHA offered to pay a one-year membership fee to participate in an end-of-life doula community of practice, which includes relevant education each month and ongoing support from their instructor. Approximately one-third of the participants accepted this support; however, in the past six months, very few have participated in the monthly calls. Instead, end-of-life doulas connected directly with the instructor and colleagues. Other methods are needed to support caregivers in their self-care.

Having people in the community, including health care providers, understand the role of an end-of-life doula will also support the success of their work. In collaboration with the FNHA communications department and Indigenous Elders who do this work, a ten-minute end-of-life-doula video was developed to inform communities about the role of the doula and the importance of planning ahead and seeking support for the expectation of a good death. The video is available on the FNHA website.

The goal of the course was to build on the strengths and confidence of community members already supporting people and their families as they prepare for, and during, their final journey to the spirit world. By building capacity in individuals, we believe there is potential to re-establish cultural traditions and protocols around death, provide culturally relevant support to families, plus complement and build trust with elements of the system, such as palliative care teams, paramedics, police, and funeral providers.

Based on feedback from participants, both during the course (informally) and via evaluation forms and surveys after the course (formally), the planning committee has collectively decided to make adaptations to the next set of courses. This curriculum change necessitated a name change from “end-of-life doula” to “Indigenous end-of-life guide.” The term “end-of-life doula” is sometimes associated with a for-profit business, which is counterintuitive to traditional Indigenous practices during end of life, so the name shift will reflect these values. To the authors’ knowledge, this role has not been formally established elsewhere in Canada.

As we plan to continue providing and improving the course, the length will be reduced from five days to four. The curriculum will shift to better meet the learning needs of Indigenous

participants and not cover the business aspect of being a paid doula. Other components of the new curriculum for Indigenous end-of-life guides are (a) an expansion on the roles of the palliative care team, (b) communication in relation to culture and complex and historical grief, (c) more on providing comfort in the final days, (d) information on ACP that includes traditional Indigenous practices, and (e) additions to the resources that are available in Indigenous communities. The new curriculum provides additional time to discuss boundaries and self-care due to the uniqueness of living in small communities. The students are also encouraged to brainstorm how they could bring their new skills back to their communities.

In efforts to enhance traditional teaching, the instructor will co-facilitate with an Elder from the territory who is respected and recognized as a Knowledge Keeper. The Knowledge Keeper will be paid to provide spiritual guidance, explain cultural practices, and encourage strategies for self-care. Participant acceptance criteria will prioritize non-health care professionals who identify as being Indigenous. These are people who are seen as natural caregivers and an integral, permanent part of the community. Given their long-term relationships, they are perfectly positioned to bring sensitive information back to the community and work with the health director and health care team members (who are often less permanent members of the community and non-Indigenous).

End-of-Life Doulas: Guiding the Journey Video

A video was created featuring Elders, the instructor, and participants to offer Indigenous community members the opportunity to enhance what they were already doing naturally plus build on their knowledge and skills which complement their worldview. The video is available on the FNHA website (<https://www.fnha.ca/about/news-and-events/news/end-of-life-doulas-guiding-the-journey-to-the-spirit-world>).

Future Work / Direction

Continued long-term evaluation is needed to determine if cultural traditions and protocols around death have been re-established, culturally relevant support to families has been offered, and trust in the health care system has increased. Short-term evaluation has been completed; however, long-term evaluation is required because Indigenous communities in rural BC have fewer expected deaths each year on which to base the evaluation.

The target group for the course was people living in rural Indigenous communities in BC where there are limited resources and supports. As the strategy evolves, invitations need to extend to those living away from home and off reserve to better support the many urban-dwelling Indigenous people who also lack access to culturally safe, appropriate palliative care.

As word of the course has spread, there have been growing requests to continue offering the end-of-life guide course. Ideally, a minimum of two people from every Indigenous community in BC would have the knowledge and skills to work as a team with nurses and other health care providers to meet the needs of people with life-limiting illnesses.

Conclusion

Comfort, dignity, and respect are hallmarks of quality end-of-life care, meeting emotional, mental, spiritual, and physical needs. For people facing the end of their life, continuity of care and advocacy for their health care treatment decisions can be supported and honoured by an end-of-life guide. This role is also meant to complement the work of nursing and medical communities, with Indigenous guides able to support community-specific traditional practices and protocols. For the people and their families who wish to remain at home, the end-of-life education a guide provides is one promising strategy to improve access to culturally safe palliative services, to facilitate a good journey into the spirit world, and to support the grief and healing of those left behind.

References

- Anderson, M., & Woticky, G. (2018). The end of life is an auspicious opportunity for healing: Decolonizing death and dying for Indigenous urban people. *International Journal of Indigenous Health*, 13(2), 48–60. <https://doi.org/10.32799/ijih.v13i2.32062>
- Auditor General of British Columbia. (2018). *An independent audit of the recruitment and retention of rural and remote nurses in Northern BC*. https://www.bcauditor.com/sites/default/files/publications/reports/Report_Rural_Nursing_FINAL.pdf
- Canadian Nurses Association. (2017). *Code of ethics for registered nurses*. <https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/code-of-ethics-2017-edition-secure-interactive>
- Castleden, H., Crooks, V. A., Hanlon, N., & Schuurman, N. (2010). Providers' perceptions of Aboriginal palliative care in British Columbia's rural interior. *Health and Social Care in the Community*, 18(5), 483–491. <https://doi.org/10.1111/j.1365-2524.2010.00922.x>
- Crey, E., & Fournier, S. (1998). *Stolen from our embrace. The abduction of First Nations children and the restoration of Aboriginal communities*. Douglas & McIntyre.
- Douglas College. (n.d.). End of life doula (Brev1100). <https://www.douglascollege.ca/programs-courses/continuing-education/health/courses/brev1100>
- First Nations Health Authority. (2016). *Synthesis report: Feedback from BC Elders Gathering on end-of-life/palliative care issues*. Unpublished document.
- First Nations Health Authority. (2017). Online nursing survey. Unpublished document.
- First Nations Health Authority. (2019). *First Nations perspective on health and wellness*. <http://www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/first-nations-perspective-on-wellness>
- Geddes, G. (2017). *Medicine unbundled: A journey through the minefields of Aboriginal health care*. Heritage House.
- Jensen, M. (2019). A dignified death. *Briarpatch Magazine*. <https://briarpatchmagazine.com/articles/view/a-dignified-death>

- Lux, M. K. (2016). *Separate beds: A history of Indian Hospitals in Canada, 1920s–1980s*. University of Toronto Press. <https://doi.org/10.3138/9781442663114>
- Milloy, J. (2008). Indian Act colonialism: A century of dishonour. 1869–1969. National Centre for First Nations Governance. http://fngovernance.org/ncfng_research/milloy.pdf
- Mitchell, T., & Maracle, D. (2005). Healing the generations: Post traumatic stress and the health status of Aboriginal populations in Canada. *Journal of Aboriginal Health*. 14–23.
- National Consensus Project for Quality Palliative Care (A Consortium of the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Last Acts Partnership, and National Hospice and Palliative Care Organization). (2004). National Consensus Project for Quality Palliative Care: Clinical practice guidelines for quality palliative care, executive summary. *Journal of Palliative Medicine*, 7(5), 611–627. <https://doi.org/10.1089/jpm.2004.7.611>
- Reimer-Kirkham, S., Stajduhar, K., Pauly, B., Giesbrecht, M., Mollison, A., McNeil, R., & Wallace, B. (2016). Death is a social justice issue: Perspectives on equity-informed palliative care. *Advances in Nursing Science*, 39(4), 293–307. <https://doi.org/10.1097/ANS.0000000000000146>
- Ross, R. (2014). *Indigenous healing: Exploring traditional paths*. Penguin Books Canada.
- Sellars, B. (2013). *They called me Number One: Secrets and survival at an Indian Residential School*. Talonbooks.
- Turpel-Lafond, M. E. (2020). In plain sight: Addressing Indigenous-specific racism and discrimination in B.C. health care. <https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Summary-Report.pdf>
- Verde, M., Shervill, L., Foreman, J., & Ward, A. (2010). Addressing barriers to palliative care services in northwest BC First Nations communities. Northern Health and BC Cancer Agency. <http://www.bccancer.bc.ca/research-programs-site/Documents/FinalReportAddressingBarrierstoPalliativeCareamong.pdf>

Appendix

Evaluation of end of life doula course—Participant evaluation

1. How was the length of the program for your learning needs? Please provide comments

Too Short Just Right Too Long

Comments

2. The presenter provided the content in a way I understood.

Strongly Disagree Disagree Agree Strongly Agree

Comments

3. What I learned in this class will help me as I provide support to others at the end of life.

Strongly Disagree Disagree Agree Strongly Agree

Comments

4. A variety of teaching learning strategies were used.

Strongly Disagree Disagree Agree Strongly Agree

Comments

5. What questions do you have that weren't answered during the program?

6. Is there anything else you would like to have learned?

7. What will you do differently when you return home?

8. Were you given an opportunity to share your cultural teachings around end of life support?

9. What stands out for you from your learning experience? What was most significant?

10. In your opinion, what are ways this training will improve end of life care in your community?

11. Any other comments or suggestions?