



## CHAPTER 16

# Traversing Landscapes of Dying and Grief: A Palliative Care Ethic for Nursing at the End of Life

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*“Death is not the opposite of life, but a part of it.”*

(Murakami, 2006, p. 237)

**IMAGINE, FOR A MOMENT, THAT YOU ARE DYING.** You are reaching the end of your own life, and you are experiencing the best death that you could have wished for. As you imagine this, ask yourself the following questions: Where are you and who is with you? What are you thinking and feeling? Are you awake or asleep? Are you comfortable? What do you hope for?

Conjuring images of our own death might seem morbid, but exercises like this can encourage thoughtful reflections on what we value, for ourselves and those we care for, at the end of life. In this

chapter, we consider different places where death and dying occur in Canada, showing how each are imbued with important ethical considerations. We reflect on the nature of suffering in end-of-life care, and challenge readers to critically examine the ubiquitous assumption that the alleviation of suffering is invariably a moral good. We then introduce the notion of a palliative ethic, which provides guidance for nurses and other health care providers (HCPs) through end-of-life care by upholding two fundamental values: dignity and justice. Nurses in advanced practice leadership roles are in key positions to support such values. We offer analysis of two case studies, one about medical assistance in dying, and the other about equity in care. We finish the chapter by centring the perspectives of LGBTQ2 people who—like so many other marginalized groups—are often left out of end-of-life scholarship and practice. The questions above are useful to keep in mind while moving through this chapter, as we consider the heterogeneous landscapes of death and dying in Canadian health care, and the ways in which important nursing values are enacted (or undermined) across this terrain.

## Places for End-Of-Life Care

Although acute care hospitals and long-term care residences are common places of dying in Canada, they are often ill-equipped to support a quality end-of-life experience. In a Canadian ethnography of an acute medicine unit in a large urban hospital, Chan et al. (2018) described a culture of busyness where the needs of dying people were de-prioritized. In this context, it was not the knowledge or skill of individual nurses that shaped end-of-life care, but rather “a systematic, taken-for-granted lack of importance granted to dying patients on the acute medical ward” (p. 462). Similar issues play out in long-term care. Wiersma and colleagues (2019) described how long-term care is characterized by a focus on time, tasks, and care of physical bodies, where “residents’ emotional and psychosocial needs can be ignored as the staff work is reduced to a series of tasks to be ticked off at the end of the shift” (p. 271).

When asked, many Canadians would prefer to die at home. But achieving a home death requires significant resources—particularly

unpaid family caregiving and skilled nursing support—which are often unavailable. As noted in interviews of bereaved people in Toronto (Mohammed et al., 2018), family caregivers in the home are often “thrust into a situation of needing to assume responsibility for crucial tasks” (p. 1234). They take on these responsibilities not because they want to, but because they are compelled to fill gaps created by the unavailability of professional palliative home care services.

Dedicated palliative care settings are another important location for end-of-life care. Here, nurses and other health care providers have expert knowledge about end-of-life issues, and are well-equipped to organize care around giving people their best chance at achieving the kind of death that they find meaningful, a “good death”—whatever that means for them. However, specialized palliative care settings are not a panacea for issues faced in dying, death, and grief. In contrast to the places described above, nursing care has a slower pace, and the fact that families are not overwhelmed with formal caregiving responsibilities means that distinct kinds of ethical questions rise to the surface. For example, should nurses turn and position an immobile patient who is close to death, whose bone pain makes it impossible to tolerate more than one specific position, and whose skin is breaking down? How should nurses approach the symptom management of a patient whose shortness of breath could be relieved by morphine, but whose family adamantly refuses it because of the symbolic associations they draw between opioids and death? Although some might find it tempting to locate an answer to such questions in a clinical, logical approach, this can obscure the human values at stake in these scenarios.

## **Suffering in End-Of-Life Care**

Persons approaching end of life experience many types of suffering (Krikorian et al., 2012). The phenomenology of this suffering is often related to the inability to do meaningful things, a loss of dignity, and a change in one’s sense of personhood, particularly in relation to how others view them (Svenaeus, 2020). The goal of palliative care is to prevent and relieve such suffering (World Health Organization, 2020). But the irony of such a goal is that it may also

set up the expectation that one should not suffer at the end of life, an expectation that may be difficult to achieve in light of the multiple concurrent losses that persons experience as they approach death (Henry, 2017). While great progress has been made within palliative care in the suffering related to physical symptoms, the existential suffering that occurs as a result of these losses can be more difficult to treat.

Evidence-based treatment options for such existential suffering are few. “Dignity Therapy” (Dignity in Care, n.d.), in which people conduct a life review, has shown promising benefits for patients and their families (Martínez et al., 2017). Recently, there has been interest in the use of psychedelics for the treatment of existential and psychological suffering at the end of life. There is preliminary evidence to suggest that psychedelic-assisted therapy may induce mystical-like experiences that can improve mood and anxiety with lasting benefits (Rosenbaum et al., 2019). Palliative sedation is an established treatment for refractory symptoms: sedatives are used in proportions that alleviate a patient’s symptoms, even to the point of unconsciousness. However, there is ethical debate about whether palliative sedation should be used to treat existential suffering, or whether it should be reserved for physical symptoms such as breathlessness or restlessness (Rodrigues et al., 2018). This type of existential suffering often leads to medical assistance in dying (MAID) as a treatment option. As reported in the *Second Annual Report on Medical Assistance in Dying in Canada* (Health Canada, 2020), the two most prevalent sufferings that led to a request for assisted death were the loss of ability to engage in meaningful activities (84.9%) and a loss of ability to perform activities of daily living (81.7%). Even for physical suffering, some people will place a higher moral value on being comfortable than being awake, while others will prefer to forego symptom relief so they can engage in important cognitive or spiritual work and meaning-making before death (Wright et al., 2020).

In considering these options for treating suffering, it is important for nurses to understand how world views (for example, values, beliefs, explanatory narratives) frame individuals’ perspectives of suffering. Suffering is always socially mediated, and can be framed on a continuum, from something that should be abolished, to some-

thing that has an inherent role in human growth and transformation (Aaltola, 2018; Beaman & Steele, 2018). In a spiritually and culturally diverse society, there will be various interpretations of the role and value of suffering in a good life and a good death.

The meaning that individuals assign to their death, and their beliefs about what comes after, are essential to consider as part of ethical end-of-life care. The *Code of Ethics for Registered Nurses* (Canadian Nurses Association [CNA], 2017) recognizes how important such beliefs are to human dignity: “In health-care decision-making, in treatment and in care, nurses work with persons receiving care to take into account their values, customs and spiritual beliefs, as well as their social and economic circumstances without judgment or bias” (p. 12). Ultimately, these beliefs provide patients and families an integrating framework for life and for death. Individuals use them to make sense of their being in the world and to guide their choices toward a moral good. In that sense, they can be a stabilizing force as persons receiving palliative care face the impending death of their physical bodies.

Cassell and Rich (2010) argue that a person is “an embodied, purposeful, thinking, feeling, emotional, reflective, relational human individual existing through time in a narrative sense” (p. 436). Suffering, according to these authors, occurs when there is disruption to the coherence or cohesiveness of that narrative whole. In a recent text that chronicled stories from the field of palliative care nursing, White (2022) highlighted the long-lasting ramifications of disrespecting deeply held desires in end-of-life care, including the desire to abstain from interventions meant to promote comfort. The author described a disruption to the narrative coherence of a bereaved spouse whose husband did not wish to receive medication before he died, when a nurse was unable to accept this choice.

In caring for her husband at the end of his life, she wanted to honor his wish not to receive medication through his transition between life and death. He had been a scholar of Advaita Vedanta and Eastern philosophies and he wanted a clear mind at the end of life. When her husband, in his dying hours, was appearing uncomfortable, the nurse encouraged [her] toward a decision to medicate. In the end,

she acquiesced at the constant insistence of the nurse who said that the amount of medication was very small, and her husband received medication. This decision stays with her to this day; it is one she still questions. (White, p. 29)

In reflecting on the choices available at the end of life, Farrow (2018) encourages us to pay attention to the “human vocation to immortality” in connecting the well-being of the body and soul. For those who, based on their faith commitments, embrace this vocation, a good death could include such commitments. This is just one of the many reasons why interdisciplinary approaches are critical for high-quality end-of-life care. Only an interdisciplinary approach, including contributions from experts in spiritual care, can provide the perspectives that are required for an ethical approach to human diversity. Advanced practice nurses are in key roles to promote such interdisciplinary collaboration.

## **A Palliative Care Ethic**

Using a palliative approach as an overall ethic of care orients health care practitioners in articulating a philosophy of practice that centres certain values as fundamental in the care of dying people, their families, and their communities. Of course, seeking to articulate a unifying framework for ethical end-of-life care, based on core values, is a risky endeavour. In their now classic critique of the ideology of a “good death” for palliative care, Hart and colleagues (1998) highlighted the inherent normativity of this concept, which risks labelling certain modes of dying, and by extension the people who die in those ways, as morally inferior:

And so we have “good deaths” and “bad deaths,” and “good” and “bad” patients; these stereotypes recur within hospitals and hospice care. Sociological, psychological and nursing research has already demonstrated, through recurring themes in the literature, that “bad” patients are those who fail to conform, who deviate from normative behaviours and choices, and who fail to legitimate the roles of their caregivers. (p. 72)

Our challenge is thus to articulate an ethics for end-of-life care nursing that is both specific enough to focus on meaningful values, and also resists marginalizing the diverse interests and perspectives of those it purports to support. Although all of the values articulated in the 2017 CNA *Code of Ethics* are relevant to the ethics of end-of-life care, we suggest that two are particularly salient for the care of people facing death, dying, and grief: honouring dignity and promoting justice.

Next, we present and analyze two cases that, in different ways, surface ethical questions around how nurses can honour dignity and promote justice in their end-of life care practice.<sup>1</sup> In the first case, we discuss medical assistance in dying (MAID). This topic is important in Canada, as the legislative landscape for end-of-life care continues to change, and nurses are challenged to care for patients in ways that may be unfamiliar to them. In the second case, we consider questions of equity in palliative care nursing. Taken together, the cases demonstrate an approach to analyzing the ethics of end-of-life care nursing, in diverse contexts, through reference to two fundamental questions: What is at stake for this person/family/community, at this time and in this place? And how do we best honour dignity and promote justice in this situation?

## **Expanding Options: Medical Assistance in Dying (MAID)**

Canadians who meet the eligibility criteria defined in Bill C-7 (Parliament of Canada, 2021) have the option of ending their lives through MAID. MAID is the administration of medications to cause death either through oral self-administration, or through intravenous administration by a physician or nurse practitioner. Increasing numbers of persons are choosing this end-of-life option, particularly in BC and Ontario (Government of Canada, 2020). As of March 2021, MAID is not restricted to those who are at the end of life. Rather, persons whose death is not reasonably foreseeable are also eligible for MAID providing they meet certain criteria, as outlined in Bill C-7.<sup>2</sup> As such, increasing numbers of nurses who work in diverse practice areas will be involved in caring for people requesting MAID. Nurses will need to become familiar with end-of-life

practices as they seek to provide care for all those choosing MAID, including those who do not have a terminal diagnosis.

MAID generated significant moral debate in Canada. Public consultation in preparation for Bill C-7, the revision that allowed MAID for those persons whose death is not reasonably foreseeable, provided some indication of this debate (Government of Canada, 2020). Of the eight central themes generated from the 254,000 comments by Canadians, one was about ongoing opposition to MAID and one was about concerns related to expanding eligibility requirements. Preliminary evidence from nurses in Canada reflected the same range of moral response; nurses described a process of morally grappling with this new treatment option (Beuthin et al., 2018; Pesut, Thorne, Storch, et al., 2020; Wright et al., 2021). For some nurses, participation in MAID has been one of the most rewarding aspects of their career. These nurses characterized MAID as a beautiful death, and their involvement as life- and career-changing. In part, this is a result of the long legacy of nurses who bore witness to suffering with few options available to relieve it. However, for other nurses, the introduction of MAID into their working environments has been so morally difficult that they have chosen to change jobs or retire from nursing. When nurses are reluctant to be involved in MAID, the reasons are multi-faceted. For some, it may be related to a belief that it is morally wrong to hasten death. For others the reluctance may be related to the emotional labour and impact of participating in MAID; previous personal and professional experiences of suffering and end-of-life care; or feelings of incompetence related to MAID policies and procedures (Brown et al., 2021). Although a percentage of nurses have clear beliefs about whether they support or are opposed to MAID, there are many who describe themselves as being in a state of moral indecision; they are not sure what they believe about MAID, but they are open to learning and making a decision over time as they experience the MAID process (Pesut, Thorne, Storch, et al., 2020).

What unites nurses across these moral differences is agreement that the implementation of MAID has been emotionally impactful for all involved. Nurses have described their initial experiences with MAID with a sense of shock attended by a wide range of emotional responses (Pesut, Thorne, Storch, et al., 2020). Although the initial

shock typically wanes, the sense of gravity and profundity of the act does not.

The MAID legislation, as well as professional and health-region standards, permits nurses to take a stand of conscientious objection to MAID. In the case of conscientious objection, nurses are required to make a declaration to a supervisor well in advance of their potential involvement in a MAID case, and supervisors are required to make accommodations. However, all nurses are still required to perform relevant responsibilities derived from the 2017 CNA *Code of Ethics*, such as non-abandonment, and there are limits on what nurses can conscientiously object to. For example, in many health regions nurses are only allowed to step back from participation in the actual administration of the medications, while being required to provide other aspects of care for persons and family.

Evidence from the experiences of nurses in the Canadian context indicates that being a conscientious objector can have negative consequences. Nurses may feel stigmatized or unsupported in their workplaces (Lamb et al., 2019; Pesut, Thorne, Schiller, et al., 2020) or worry about putting excessive burdens of care on their colleagues (Pesut, Thorne, & Greig, 2020). For example, in busy workplaces, nurses are aware that the forms of patient care they object to must be done by someone else, and working with patients and families considering or receiving MAID can be difficult, emotional work. These concerns are particularly relevant for those nurses for whom MAID has become a regular part of their employment responsibilities. For example, community care nurses who work with clients living with palliative needs in the home may find themselves developing long-term relationships with clients, and then handing over their care to another provider at the very time when those clients need them the most. In these situations, nurses experienced very real moral tensions when they believed they had no good options (Pesut, Thorne, Storch, et al., 2020).

It is important to note that conscientious objection is not the only reason that nurses choose not to be involved in MAID. One of the most morally relevant reasons is that some nurses find themselves having psychological sequelae after participating in a number of medically assisted deaths. These nurses are not conscientious objectors; they agree with the right to an assisted death,

but they are no longer able to participate because of the emotional impact that involvement has had on their lives (Pesut, Thorne, Storch, et al., 2020). Nurses described this experience as ruminating excessively over medically assisted deaths to the point where it started to impact other aspects of their lives. Allowances for conscientious objection do not consider these other morally difficult situations, and so it is critical that nursing leaders recognize and provide options for nurses who find themselves in these situations.

We now turn to Ethics in Practice 16-1 to illustrate the conflicts an NP may feel when they are facing a MAID situation.

### **ETHICS IN PRACTICE 16-1**

#### *“Suffering Unbearably”: Engaging With MAID Through a Relational Lens*

Mona, a 45-year-old woman living on a disability pension, has struggled with severe rheumatoid arthritis and chronic pain for decades. She is becoming increasingly dependent upon others for her care and states that she is suffering unbearably. She has lived independently to this point but must soon seek a different living arrangement as she is no longer able to cope on her own. There are limited housing options available in her rural community, but she is unwilling to relocate from the community where she was born and where she raised her children. Her two children live at a distance but keep in regular contact with their mother by phone. Mona decides that she no longer wants to live this way, contacts the MAID coordination service, and requests assessment for MAID.

Mona’s children strongly object to this decision. They immediately fly out to convince Mona to withdraw her request. They have a number of concerns: they believe that their mother has many years of life left, and they are worried that she has become depressed because her symptoms have not been treated adequately. They are willing to relocate her to their own homes and ensure that she gets good treatment for her arthritis and pain. They worry that she is making a decision that is not in keeping with her long-held values.

Mark is the nurse practitioner assigned to do Mona’s assessment. Mark is the provider for a group of patients in the community living with advanced chronic illness and requiring palliative care. Mark decided to become involved in MAID in his rural community because there were no other assessors and providers willing to do the work. This involvement has come at a cost; some members of his rural community have disagreed with his decision and no longer seek his professional care. Mark feels

conflicted about providing MAID to Mona, whose death is not reasonably foreseeable, and he is not sure how to approach her assessment.

### **REFLECTIVE QUESTIONS**

1. *What equity issues are involved in this situation?*
2. *How might Mark decide whether this is a fully informed and authentic choice for Mona?*
3. *How should the opinions and needs of Mona's children be addressed?*
4. *How should Mark be involved given that he is conflicted about MAID when death is not reasonably foreseeable?*
5. *What is Mark's duty of care in Mona's situation?*

## **Assessing the Ethics of the Situation: Relationships, Goals, Beliefs, and Values**

Persons often choose MAID because they want choice over their lives and wish to maintain a sense of dignity. Many describe the moment of choosing to have a MAID assessment as the line in the sand where the situation in which they find themselves makes death preferable to life as they endure ongoing suffering. Mona, it seems, has reached that point. The situation that she finds herself in because of pain and loss of independence means that she now wants to consider at least having the option of an assisted death. This is an important point. Requesting a MAID assessment does not always mean that the individual is choosing to have a medically assisted death; rather, it becomes an option if their situation becomes unbearable. Nurses have described the change that they see in some persons once they have the option of MAID; they become more relaxed, hopeful, and, in some cases, their symptoms diminish (Pesut, Thorne, Schiller, Greig, Roussel, et al., 2020). Having choices is therapeutic for many patients.

Mona's relationships are also an important consideration. Her family is worried that Mona has been put in an untenable situation because of inadequate care, and that her choice is out of alignment with her long-held values. An important equity question in this

Ethics in Practice case is whether Mona has access to the care and living situations that would alleviate her suffering. Nurses are expected to “work with persons receiving care to explore the range of health-care choices available to them, recognizing that some have limited choices because of social, economic, geographic or other factors that lead to inequities” (CNA, 2017, p. 10). People living in rural areas of Canada often lack the same access to health care options and living arrangements that are available to persons living in urban areas (Wilson et al., 2020).

Furthermore, we need to learn whether this decision is in keeping with Mona’s long-held values. NPs who perform MAID assessments suggest that one of the most important indicators that they look for is whether this is a decision in keeping with who this person has been over time (Pesut, Wright, et al., 2021). Nurses should pay attention to what family members and significant others have to say on this topic. Those nurses who have been involved with MAID over time suggest that working with the family unit to gain a deeper understanding is one of their most important interventions.

Finally, we come to Mark and his situation. With the change in law, it is now important for Mark to consider his own beliefs and values about MAID. Mark has a number of difficult considerations: can he come to terms with providing MAID to a person whose death is not reasonably foreseeable? If not, does he risk moral injury by agreeing to be involved? Early evidence from research with Canadian nurses has indicated that this is not an uncommon moral question (Pesut et al., 2021). How does Mark weigh the value of being involved in MAID assessment and provision against his other responsibilities to care for persons in his rural community? Will more persons decline his care when they hear of his involvement? Rural NPs have indicated that this is one of the most concerning aspects of providing MAID-related care in their communities (Pesut, Thorne, Storch, et al., 2020). Ultimately, Mark needs to balance his own beliefs and values, his relationships with those in his community, and his professional obligations as a health care provider.

## Reflecting on and Reviewing Potential Actions

What are some nursing actions that can be taken in this complex situation? First, Mark can take time to hear Mona's story of suffering to gain a deeper understanding of the situation, thus fulfilling the 2017 CNA *Code of Ethics* requirement to “work with persons receiving care to take into account their values, customs and spiritual beliefs as well as their social and economic circumstances without judgement or bias” (p. 12). NPs responsible for MAID assessment need to include the illness trajectory of the patient, the circumstances surrounding their decision to apply for the assessment and what prompted it, and, importantly, how they thought about MAID prior to this decision (Pesut, Wright, et al., 2021). For example, if Mona was opposed to MAID, what factors influenced her to change her decision? Mark also needs to explore the degree to which the circumstances that have led to this suffering have been or can be addressed. Has Mona's health care provider addressed her issues of pain? Does she know her options in terms of remaining independent? Is she aware of the possible living arrangements in her community?

Once Mark has gained a deeper understanding of the situation, he can request Mona's permission to have a family conference. In doing so, he will be fulfilling the 2017 CNA *Code of Ethics* responsibilities to “respect the privacy of persons receiving care” (p. 12) while also seeking to “assist families in gaining an understanding of the person's decisions” (p. 12). NPs who conduct these family conferences suggest that families are much better prepared to support decisions when they have the chance to hear the story of their family member's suffering in detail (Pesut, Thorne, et al., 2020). Family, particularly those who live at a distance, may not be aware of the day-to-day suffering experienced by those living with illness. A request for MAID assessment can also imply that family caregiving has been insufficient (Pesut, Wright, et al., 2021). If left unaddressed, such interpretations risk negative consequences as the family experiences grief after the person dies.

Mark can also spend some time reflecting on his own moral responses to the situation. The 2017 CNA *Code of Ethics* envisions a “moral community in which ethical values and challenges can be

openly discussed and supported” (p. 13). Nurses engaged in MAID-related care indicate that discussing their choices about their involvement in MAID with their family and colleagues is essential (Pesut, Thorne, Storch, et al., 2020). There is a cost, particularly for Mark, in being involved in MAID, and it is important that the significant people in his personal life are supportive of him in this choice. Likewise, colleagues can help him understand their own moral reasoning related to their involvement and the subsequent impacts on their lives and practice. In this moral reflection, Mark can explore whether he should perform the assessment about MAID but not the provision. This is an intermediate option if Mark wants to be available to support his patient, but cannot reconcile with providing assisted death himself.

### Selecting an Ethical Action: Maximizing the Good

Mark decides that in this situation he needs to complete Mona’s assessment. As he hears her story of suffering, he feels deeply empathetic to her situation and agrees that she has met the criteria under the law, but cannot imagine himself providing MAID for her. Many good outcomes are derived from the family conference: Mona’s children become proactive in advocating for more aggressive symptom management after they better understand what she has endured. Two assessors find Mona eligible for MAID, but she decides not to proceed with the provision at this time; she is content to have the option available should she wish to proceed. Mark notifies the MAID coordination service that in future he will only provide assessments and provisions to those clients who are already part of his primary care practice. The coordination service agrees to seek out other health care personnel who can fill the gap.

Nurses in diverse roles in Canada have provided leadership in regard to MAID. Canadian NPs act as assessors for and providers of MAID, and registered nurses, particularly advanced practice nurses, often lead interdisciplinary teams. The moral climate of the workplace is established by providing clear guidance for high quality patient and family care, establishing processes that allow nurses to choose whether to participate in MAID in accordance with their conscience, and providing resources (for example, team support,

debriefing) to support nurses' wellness as they participate in this emotionally challenging care. Health systems need to be structured so that nurses are not forced to leave their employment or to retire should they choose not to participate in MAID, whether their reasons be related to conscientious objection, psychological sequelae, or other moral concerns.

## Equity

Ethics in Practice 16-2, our second case study, shows how raising questions around equity, such as differential access to care based on place of residence, is an essential aspect to analyzing the ethics of end-of-life care. Nurse-scholar Kelli Stajduhar (2020) examines the ways in which people who belong to marginalized groups—those made vulnerable by housing instability, mental illness, substance use, street involvement, or racialization and colonization—are excluded from palliative care and its practitioners' focus on quality of life and alleviation of suffering. She notes that “[a]s a concept, hospice and palliative care seems to be unanimously supported, but that is what it remains for some people: an idea that only becomes reality for the few who are privileged enough to have access to it” (p. 89). She further urges us to see how vulnerability to suffering is socially mediated; a product of one's “location within the hierarchical social order within society, which encompasses not only political and economic inequalities but also a wider range of cultural determinants (e.g., the medicalization / pathologization of ‘at-risk’ populations, cultural views on the ‘worthiness’ of particular groups, etc.)” (p. 90). In a similar way, the 2017 CNA *Code of Ethics* expects that nurses will recognize that “vulnerable groups in society are systematically disadvantaged (which leads to diminished health and well-being)” (p. 19). Nurses, according to the 2017 CNA *Code of Ethics*, advocate for the quality of life of such people, and act to overcome the barriers to health care that they face.

**ETHICS IN PRACTICE 16-2***“I’m a Writer”: Approaching Equity Through a Focus on Personhood*

Anna is a community outreach nurse for a clinic specializing in the care of people in vulnerable housing in a major Canadian city. A typical day involves visiting her patients wherever they are, whether on the street or in shelters, to provide whatever nursing care is needed. This morning Anna is going to see Bill at his home—a single room-occupancy dwelling in the core of the city. As she approaches the building on her bicycle, she is struck by the juxtaposition of abject poverty and gentrification on the same city block. Luxury condominiums rise to the sky, and artisanal boutiques and coffee shops dot the street at eye level, alongside several smaller dilapidated buildings that serve as rooming houses. Her purpose for today’s visit is ostensibly to dress a wound created by a diabetic foot ulcer, and to review some new prescriptions, but ultimately, she is there to check on how Bill is doing.

Over the last two years, Bill would regularly “disappear” every several months, avoiding all contact at the clinic and not answering his phone. About three months ago, Bill suddenly lost a lot of weight and became extremely weak. Because of an absolute refusal to go to hospital, Bill does not have a formal diagnosis, although Anna suspects he is in the advanced stages of a terminal cancer. Today, when Anna arrives, Bill does not come to the door, but he calls for her to enter. He has left the door unlocked and is slouched in a recliner by the singular window at the far end of the room. A cigarette hangs from his mouth and his eyes are half-open. Next to him is what looks like a new book—a 2017 version of *The Cambridge Companion to Canadian Literature*. Anna smiles to herself, remembering long conversations she’s had with Bill about the time he spent studying creative writing at university forty or so years ago. As Anna approaches, she asks Bill how he is feeling. “Like crap,” he replies.

As Anna dresses the wound on Bill’s foot, they talk about how things are going. Bill is getting progressively weaker. He eats almost nothing and spends all day and all night in his chair. Anna suspects that he can no longer walk to the bathroom, as she can smell urine. She offers to help Bill to the shower, which he refuses, though he allows her to help him to change his pants. As he stands, his knees buckle, and he becomes severely short of breath. He sits back down and curses. Anna has already talked to Bill about residential hospice, which he adamantly refuses. They will not let him smoke in his room, and regardless, he will not under any circumstances enter a health care facility.

He has told Anna of spending many years being turned away from emergency rooms, and being subjected to the judgmental gazes of nurses and doctors who believe that his life is nothing but the product of his own bad choices. He has told Anna that if he is going to die, he will do so here: in this chair, gazing out this window, where no one can touch him. She’s asked him whether she can continue to check in on him

until that happens, to which his answer was, “Yes. You’re nice. You’re not like them.” As Anna packs up her supplies, she verifies that Bill has enough pills and enough cigarettes to last until his cousin’s visit in two days, when she will refill both. She also asks about the book on Bill’s table, which leads to a short conversation about his time at university. “I’m impressed you keep up with the current literature!” she says. Bill musters a sly smile. “Of course,” he answers. “After all, I’m a writer.”

### REFLECTIVE QUESTIONS

1. *Where do you think Bill should receive end-of-life care—is it safe for Anna to respect his decision to stay right where he is?*
2. *What is Anna’s role in this scenario?*
3. *What broader ethical considerations does this case raise about how we live, die, and care for one another in today’s world?*

## Assessing the Ethics of the Situation; Relationships, Goals, Beliefs, and Values

In this situation, it is apparent that Anna and Bill have established a trusting relationship. He invites her into his home, despite his deep mistrust of health care providers. This mistrust makes sense given the long-standing discrimination and stigma he has faced when engaging with the health care system. The 2017 CNA *Code of Ethics* articulates trusting relationships as foundational to ethical nursing practice: “Nurses build trustworthy relationships with persons receiving care as the foundation of meaningful communication, recognizing that building these relationships involves a *conscious* effort. Such relationships are critical to understanding peoples’ needs and concerns” (p. 8, emphasis in original). Here we see that Bill’s openness to Anna is not merely a chance alignment of personalities, but the result of a conscious effort on Anna’s part to engage with Bill on his own terms. She shows genuine curiosity about his life and admiration for his many strengths, beyond his current challenges. She takes a broad assessment of Bill’s situation, recognizing that the nursing task of foot care, while important, is only one small piece of a wider constellation of health needs and

concerns. Likewise, she affirms Bill's identity not simply as a person who is vulnerable and marginalized, but also brilliant and creative.

The 2017 CNA *Code of Ethics* reminds us that "Nurses support each other in providing person-centred care" (p. 15). Anna's commitment to holding this broader view, refusing to limit understanding to narrow stereotypes and deficit-based discourses, is an example of person-centred care. However, as this passage from the 2017 CNA *Code of Ethics* makes clear, such care is not only realized from within the individual nurse-patient relationship, but requires the support of others. This raises other questions about the relationships at play in Anna's work environment. Does she have nursing colleagues on whom she can depend, to help her think through the challenges she faces in caring for Bill and to support her in meeting his goals? Do the leaders and organizational structures of her institution facilitate or hinder the broad approach that she takes to her nursing practice? For example, does Anna have the time, space, and resources required to attend to her patients' needs in a fulsome way? How can advanced practice nurse leaders be involved in resource allocation? What are the implications for future policy work?

### **Reviewing Potential Actions in Light of a Patient's Values and Sense of Dignity**

Bill's living situation, and the choices he makes as his health worsens, are likely to provoke moral uncertainty in nurses responsible for his care. According to the 2017 CNA *Code of Ethics*, "Nurses support persons receiving care in maintaining their dignity and integrity" (p. 12). But what does dignity mean in this context? The challenges Bill faces in completing basic activities of daily living, such as toileting, are an important threat to dignity. But the prospect of having to leave his home to enter an institutional setting where he has felt disrespected and dehumanized is also a threat to his dignity. One of the ways that nurses honour dignity, according to the 2017 CNA *Code of Ethics*, is by encouraging people at the end of life to be clear about what they want. Nurses "listen to a person's stories to gain greater clarity about their goals and wishes" (p. 13). By checking her own assumptions about which types of settings are

most appropriate for Bill to experience a dignified end to his own life, and by listening to Bill's stories and accepting without judgment what he values and why, Anna can come to a deeper understanding of what ethical end-of-life care might look like for Bill, and how to support this from within whatever context he chooses for himself.

### Selecting an Ethical Action: Maximizing the Good

Through multiple conversations with Bill, Anna comes to see his desire to die at home as his way of exerting agency at the end of his life, which has been marked by multiple losses and hardships over which he had little control. She recognizes that being the only person that Bill trusts poses risks to them both; shouldering full responsibility for Bill's safety and well-being could become unsustainable for her over time, and if Anna is unavailable to care for Bill, he will be left with no one.

Anna arranges for an NP from a local hospice, with expertise in trauma-informed care and harm reduction, to accompany her on one of her visits with Bill. During this visit, the three of them review Bill's symptoms and adjust his medications to alleviate his shortness of breath. The NP assures Bill that if at any point he decides he would like to transfer to the hospice, she has confirmed that volunteers and paid staff are available to take him outside—even after he can no longer walk—to smoke. In the meantime, the NP will remain available to Anna to adjust Bill's treatment plan as needed to keep him comfortable and support his decision to remain at home.

Anna also connects with Bill's cousin, Charlene, with his permission. She coordinates the time of her next visit to happen while Charlene is present with Bill. She learns that Charlene and Bill share a strong bond and are an important source of support to one another. The three of them talk about Bill's health, and their shared commitment to help Bill die comfortably. Over the next several weeks, Anna focuses her visits not only on how Bill is doing, but also on Charlene and her feelings in anticipation of Bill's death. Anna asks to hear stories of their relationship and of the adventures that Charlene and Bill have had together. Anna also connects Charlene with the same local hospice, which offers resources to support her in grief, both in advance of and after Bill's death.

In discussions with nursing colleagues, Anna reflects on the many injustices that Bill has faced, in relation to his experiences of health care as well as housing. She reflects on the growing invisibility of people like Bill and Charlene, given the widening gap between those with and without money in this neighbourhood. Anna connects with her provincial nursing association and finds a group focused on palliative care and social justice. There, she meets colleagues with similar values, experiences, and observations, and together they strategize about how to advocate effectively at a systems and policy level for people like Bill who face structural disadvantage in end-of-life care.

## **Sexual and Gender Diversity**

As highlighted in the previous Ethics in Practice case, nurses encounter many intersecting axes of social vulnerability in their end-of-life care practice. One such axis, which has received relatively little attention in Canadian research about end-of-life care, is sexual and gender diversity. In this final section, we focus specifically on some of the unique considerations for enacting a palliative nursing ethic with members of LGBTQ2 communities.

In our own practice, we have noticed that frequently, disclosure of LGBTQ2 identity in palliative care happens organically, when nurses create a trusting context in which the person feels at liberty to speak about their identity and their relationships. Although the creation of this relational context is admirable, a nurse in such a situation might ask themselves a critical question: Why did I not already know this about this person? In a focus group of LGBTQ2 seniors about their hopes and fears approaching the end of life, Wilson and colleagues (2018) note that systematically asking people about their sexual orientation and gender identity is not routine practice in Canadian health care. This has consequences for the visibility of LGBTQ2 people in care, contributing to their erasure. As one participant in this study commented: “There are LGBT people in every [care setting] ... most of them are in the closet or back in the closet again” (p. 28). As LGBTQ2 people age and approach the end of life, many worry about having to keep their sexual and/or gender identity secret. In other words, they worry about being forced back

into the closet. In the focus group study just referred to (Wilson et al., 2018), one participant spoke of knowing someone who received good care at the end of his life, but “at the cost of him saying ‘don’t tell anyone I’m gay’” (p. 28). This fear is particularly painful, given that LGBTQ2 seniors will often have only come out of the closet later in their lives. For many, it was not safe to do so earlier.

Importantly, outright homophobia or transphobia by care providers is not the only cause of retreating into the closet. Aging LGBTQ2 people may assume that nursing care will be unsafe, until it proves itself otherwise. This fear comes from having lived through decades of oppression, stigma, and a shifting legal context that has only recently begun to affirm their dignity as fully human. LGBTQ2 people are therefore pushed back into the closet, not just by overt instances of hostile discrimination, but also when they are lacking an explicit confirmation that the settings and providers tasked with their end-of-life care will affirm and celebrate their LGBTQ2 personhood.

Ethical end-of-life nursing requires awareness of, and a commitment to address, the reasons that LGBTQ2 communities may rightfully mistrust our end-of-life care systems. One important consideration is that in Canada, much palliative care is delivered within faith-based institutions. Although the nursing care delivered in such institutions may or may not have any actual connection with religion, many LGBTQ2 people will be triggered by the mere thought of having any kind of religious organization provide their health care. This grievance comes from the legacies of oppression—historical and contemporary—by some religious institutions against LGBTQ2 identity. As articulated by one participant in the Wilson et al. (2018) study:

“Let’s put that on the table right now ... I’m very frustrated and angry about faith-based approaches to anything regarding our health. If you choose that and wish that, cool. I’m sure there’s many places you can access, but to even consider it or think about being what I would call trapped or prisoned in a faith-based institution makes me nearly apoplectic.” (p. 27)

While some people in the LGBTQ2 community, such as the person quoted above, experience faith-based institutions as a symbol of their own oppression, for others organized religion is a valued source of spiritual meaning. Cheri DiNovo (2021), a United Church of Canada minister and former politician (who passed into law more pro-LGBTQ2 legislation than anyone in Canadian history), writes the following about her own experience of being both a queer woman and a person of faith: “[When] I find myself in another city looking to worship in a local church, I look for similar markers: pro same-sex marriage, anti-war. I’ve never been disappointed in finding such a church anywhere in the world. The Christian Right (which is neither) gets the press, but there has always been an alternative” (p. 47). The important lesson here is to respect and acknowledge how and why some LGBTQ2 people will fear for their dignity within faith-based health care delivery, while also resisting a master-narrative that erroneously conflates all organized religion with anti-LGBTQ2 bigotry. As DiNovo writes about her own identity, “At my queerest I’m a person of faith. At my most faithful I’m most queer. There’s no separation. Never was” (p. 196).

Beyond dimensions of faith, the culture of institutions providing end-of-life care in Canada are characteristically heteronormative and cis-normative. This means that even in the absence of homophobic or transphobic attitudes, which are always unacceptable, care providers who are not themselves members or strong allies of LGBTQ2 communities will often lack the cultural competence to fully engage with the intricacies, struggles, and triumphs of what it means to have lived an LGBTQ2 life in this world. These gaps have important implications for the ethos of palliative care nurses, whose practice revolves around family-centred care, legacy building, storytelling, and grief work. In order for LGBTQ2 people to benefit from relational practice, they require more than just not to be discriminated against. Nurses and other providers need to be genuinely committed to understanding and honouring them—their individual and collective histories, grief, and resilience. As one participant in the Wilson et al. study (2018) stated: “[I]t’s not an easy thought to think in later life [about] finding a new doctor who understands what you’ve been through” (p. 27).

## Conclusion

There is no standard nursing script for ethical engagement with people as they approach their death, weigh their options, and make their choices. A typical nursing day involves having to move in and out of peoples' stories, adjusting to the rhythms and dynamics of each one to create moments of relational connection that are attuned to whatever specifics are in play. Such movement can mean encountering different situations that initially appear similar, but on closer examination reveal themselves to be radically unique. By committing to a form of narrative proximity (Malone, 2003), nurses contribute to safe spaces for people to work through what matters most to them, and to craft an end-of-life experience that meets their needs and aligns with their values. To do this, nurses must really hear the concerns that people articulate, and accept whatever interpretations they develop.

The nurses in each of the two Ethics in Practice scenarios presented in this chapter are, in different ways, role models for enacting a relational ethic of end-of-life care, where dignity and justice are honoured and promoted in everyday practice. Of course, the successes portrayed in scenarios such as these depend not only on the competence of individual nurses, but on the structures and systems that facilitate—or interfere with—ethical nursing practice. Advanced practice nurse leaders are key in advocating for policy change to ensure that the appropriate structures and systems are available. At the institutional level, clinical and political leadership is essential in creating nursing practice environments where nurses can provide ethical nursing care. Leaders who support nurses in focusing on the “big picture” of what people face as they die, and practice environments that reflect an ethos where the concerns of dying people truly matter, are two examples of structures that influence nurses' moral agency in end-of-life care.

In this chapter, we have invited reflection on the myriad ethical complexities that characterize experiences of dying and death. Such complexity is inevitable regardless of the actual options chosen for end-of-life care or the places in which they are enacted. Through their commitment to honour and engage this complexity, rather

than rushing to simplify or solve it, nurses offer crucial support to people approaching, and grieving, end-of-life situations.

### **QUESTIONS FOR REFLECTION**

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1. *In this chapter, we have suggested dignity and justice as two core values that underpin an ethical philosophy of practice for end-of-life care nursing. What other values would you consider core to this philosophy?*
2. *How can we best enact a palliative care ethic, when the person receiving care does not share the same values around suffering and its alleviation as we do?*
3. *The two cases in this chapter are about MAID and equity in care. In what ways do these two topics intersect? In other words, what implications do you see for MAID policy and practice, when approached from a social justice lens?*

## Endnotes

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- 1 Our analysis of each case follows a series of questions for ethical reflection, taken from the Oberle and Raffin model as adapted by the *Code of Ethics for Registered Nurses* (CNA, 2017).
- 2 The bill requires that patients have a “grievous and irremediable medical condition” that is not related to mental health. To use the terms of this chapter, people seeking MAiD eligibility have to show a physician that an incurable physical condition is causing existential suffering and a loss of personhood.

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