5.3.2 Providing Medical Assistance in Dying (MAiD)

Angel Petropanagos, Ph.D.

Educational Objectives:
- Discuss the legal and regulatory requirements for medical assistance in dying (MAiD)
- Discuss the ethical disagreements surrounding the provision of MAiD
- Identify and evaluate the personal, professional, institutional, and social values that are relevant to the provision of MAiD

Case:
Evelyn R. is a 59-year-old woman who was first diagnosed with breast cancer eight years ago. At that time, she had a mastectomy, chemotherapy and radiation. Six months ago, Evelyn began experiencing extreme nausea, loss of appetite, shortness of breath, progressive pleuritic chest pain and muscle weakness. She went back to see her oncologist, Dr. S. Tests revealed that her breast cancer had returned and metastasized to her lungs, chest wall, several long bones, and her liver. Once again, Evelyn began chemotherapy. She was also given palliative care aimed at pain management. After completing five cycles of chemotherapy Dr. S. told Evelyn that her cancer was unresponsive to treatment. Her condition had deteriorated and she was experiencing severe chest pains, difficulty breathing even at rest, fatigue, jaundice accompanied by progressive weight loss. Evelyn, her partner Sara, and Dr. S. discussed stopping treatment aimed at cure or control of her cancer and considered additional palliative care options. However, during this discussion on strategies to palliate her symptoms, Evelyn asked Dr. S. whether she would qualify to access medical assistance in dying (MAiD). She told Dr. S. that she did not want to endure further pain or suffering. She told Sara that she was not afraid to die and desperately wanted to control the timing and circumstances of her death. Sara did not want Evelyn to continue to suffer. Eleven days ago, Evelyn submitted a written request for MAiD. Dr. S. determined that Evelyn met the criteria for accessing MAiD based on the fact that she is a competent adult who is suffering from a grievous and irremediable medical condition. A second physician, Dr. A. agreed with Dr. S. after he evaluated Evelyn. Yesterday, Dr. S., with the assistance of her health care team, administered a lethal injection (a combination of midazolam, propofol, and rocuronium) and Evelyn died quickly and peacefully with her partner Sara by her side.

Although Sara did not want Evelyn to suffer, she was devastated by her death. The hospital offered Sara access to bereavement support services.

Dr. S. felt some anxiety leading up to the administration of the lethal injection, but she also wanted to help end Evelyn’s unbearable suffering. Following MAiD, Dr. S. experienced a sense of shock by the suddenness of Evelyn’s death and worried about what might happen if her colleagues learned about her participation in MAiD. She worried about what they might think of her and about whether she would end up having to complete all of the MAiD requests at her hospital. Like Dr. S., the other healthcare providers directly involved in Evelyn’s care, including a nurse, a pharmacist, and a social worker, had mixed feelings about their participation in Evelyn’s case. This was the first time that Dr. S. had provided MAiD. It was also the first case of MAiD at the hospital at which Dr. S. works. A debriefing meeting has been scheduled with the hospital ethicist and the healthcare team directly involved in Evelyn’s case.

Questions:
1. What does Canadian law say about MAiD?
2. What are the primary ethical considerations that support the provision of MAiD?
3. What are the primary ethical considerations that challenge the provision of MAiD?
Discussion

Legal Considerations

1. What does Canadian law say about MAiD?

On February 6, 2015 the Supreme Court of Canada ruled on the case of Carter v. Canada (Attorney General). The Court found that the prohibition on voluntary euthanasia (when a physician directly administers a substance that causes death) per s.14 of the Criminal Code and assisted suicide (when a physician gives or prescribes a drug that is self-administered by the patient to cause death) as per s.241(b) of the Criminal Code violates section 7 of the Canadian Charter of Rights and Freedoms, whereby “everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” In other words, the Court decided that assisted dying should be legally permissible for consenting adults who have “a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.”

On June 6, 2016 the prohibitions on voluntary euthanasia and assisted suicide were lifted. On June 17, 2016 Federal Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) came into effect. This Act creates exemptions in the Criminal Code which permit medical practitioners (physicians) and nurse practitioners to provide MAiD, without being legally culpable. It states that this service can only be provided to a patient meets all of the eligibility criteria below.

A person may receive medical assistance in dying if and only if they:

- are eligible for publicly funded health services in Canada;
- are at least 18 years of age and capable of making health care decisions;
- have a grievous and irremediable medical condition;
- have made a voluntary request for medical assistance in dying; and
- give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

In addition, the Act lays out protective measures and safeguards to protect against coercion or impulse. It requires that:

- requests for medical assistance in dying are in writing and witnessed by two independent witnesses;
- individuals seeking medical assistance in dying obtain a second opinion from an independent physician or nurse practitioner; and
- there are at least 10 clear days between the date that the request is signed by or on behalf of the person and the day on which the medical assistance in dying is provided or — if they and the other medical practitioner or nurse practitioner referred are both of the opinion that the person’s death, or the loss of their capacity to provide informed consent, is imminent — any shorter period that the first medical practitioner or nurse practitioner considers appropriate in the circumstances.

The federal Act serves as a legal framework for the implementation and regulation of MAiD under the criminal law. (See the Environmental Scan for a summary of and links to provincial and territorial guidelines.)
Evelyn’s case, illustrates a scenario in which the use and provision of MAiD occurred in accordance with Bill C-14. As a competent adult who was suffering from a “grievous and irremediable medical condition” and who voluntarily requested and consented to MAiD, Evelyn met the eligibility criteria. As a result of her stage 4 breast cancer, Evelyn was experiencing intolerable suffering and her death was reasonably foreseeable. The attending physician, Dr. S., and the hospital at which she works also met the protective measures and safeguards for MAiD set out in federal legislation.

Ethical Considerations

2. What are the ethical considerations that support the provision of MAiD?

Even in cases that meet the legal requirements for MAiD, the practice of assisted dying raises important ethical considerations for patients, families, health care providers, and society more generally. Ethical considerations within the MAiD context are grounded in different perspectives on the nature of suffering and death, autonomy, dignity, the nature of the physician-patient relationship, and the goal(s) of medicine. Several of these ethical considerations are mentioned in the Carter Case and Bill C-14.

a) suffering and death

The experience of suffering is a profoundly personal experience, that can include both physical and psychological aspects. It is complex, context dependent, and relational in nature. In Evelyn’s case, she was experiencing both physical and psychological pain and suffering. A recent empirical study on assisted dying found that physical pain is typically not the primary motivation for requesting MAiD (Emanuel et al 2016).

Patients might experience additional suffering, harm, or stress as a result of the perceived or actual burdens they may impose upon family and friends. Furthermore, delays surrounding access to MAiD, social stigma surrounding MAiD, and other factors have the potential to compound some patients’ suffering at end of life. Family, friends, and those treating a patient who is suffering can also experience a degree of suffering alongside the patient in witnessing their suffering. In Evelyn’s case, Sara may have suffered alongside her and it is important that healthcare providers offered her bereavement support services to address the suffering of family members.

Patients who request MAiD can perceive their suffering as harm that prohibits them from living well and the ability to choose a ‘good death’ can support their well-being. A systematic review of the international literature on assisted dying found that the right to choose a good death for competent patients, is at the heart of the arguments in favour of MAiD (Hendry et al. 2012). A good death is one which respects competent patient autonomy and choice and can serve to protect patient dignity. According to Evelyn, she wanted to control the timing and circumstances of her death and no longer wanted to suffer from her illness. Providing assistance to alleviate the intolerable physical and psychological suffering of patients can be viewed as promoting their well-being and autonomy (Young 2007; Sumner 2011).

Personal life experiences and social contexts can shape individuals’ perceptions of suffering and dying. Evelyn’s own experiences of cancer shaped, in part, how she viewed suffering and death. A recent systematic literature review examined patients’ views and attitudes on assisted dying and found that patients often adopted a broad conception of suffering which included factors that may not be amenable to palliative care, such as dependency, burden, and loss of self (Hendry and colleagues 2012). Another study found that patients who request assisted dying describe several elements as constitutive of their unbearable
suffering, including: fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness, and being tires of living. They also found that the burden of suffering is influenced by patients’ personality characteristics and biographical aspects (Dees et al 2011). Thus, each patient may understand and experience their suffering differently.

b) autonomy
Most generally, autonomy, the right to self-determination, encompasses the idea that an individual should have the freedom to choose what happens to their own body and control their life. This principle of autonomy often plays a central role within Western medicine and society more generally.

Edmund Pellegrino (1994) describes an autonomous person as one whose thoughts, words and actions are in accordance with the norms that she chooses as her own without constraint or coercion by others. Yet, autonomy should not be understood as full, meaning that people have unrestricted independence or unrestricted isolation. Instead, autonomous individuals should be understood as persons living within a number of social relations. Relational conceptions of autonomy hold that persons are socially embedded and their identities are formed within contexts of social relationships and various intersecting social identities, such as gender, race, class, and ability (Mackenzie and Stoljar 2000). Accordingly, healthcare providers should understand that considerations of personal and social values and norms can shape patient decision-making and the provision of these services. Physicians should be especially cognizant of the ways in which the interactions between patients, family members, and healthcare professionals can promote or hinder patient autonomy.

Evelyn’s desperation to control the timing and circumstances of her death suggest the important role that self-determination and choice played in her request for MAiD. It is also important to consider the ways in which Evelyn’s relationship with Sara and her healthcare providers may have worked to support her in this exercise of her autonomy.

c) dignity
The concept of dignity, understood as personal dignity, can include a person’s value, worthiness, self-esteem, or pride. Dignity is often connected to perception about one’s quality of life and given concerns about the implications for persons with disability or illness, the meaning of dignity is hotly debated. Concerns about the preservation of dignity, particularly at the end of life, includes pain management and care for physical, psychological, social, spiritual, and existential aspects of patient experience (Chochinov 2002). Some may believe that a patient’s dignity is threatened if they experience impairments in cognitive functioning or if they lose their ability to perform tasks of daily living. Patients may be concerned about the loss of their independence or parts of their identity. They may be concerned about burdening others with their care. Concerns related to the loss of dignity is frequently mentioned as a reason for assisted dying requests (Emmanuel et al 2016).

In Evelyn’s case, her ability to avoid future suffering and to control the timing and circumstances of her death can be viewed as supporting a dignified death.
3. What are the ethical considerations that challenge the provision of medical assistance in dying?

a) suffering and death
Some may question whether MAiD is an appropriate response to patient’s suffering and believe that a request for MAiD is an opportunity to discuss other options for reducing or alleviating a patient’s suffering. Indeed, the law requires that patients have been “informed of means that are available to relieve their suffering, including palliative care.” It is important to understand that patients do not have to choose palliative care or other means offered them. Others may worry that patients’ perceptions of suffering are inappropriately influenced by pain or that patients do not fully understand their healthcare options. Although such concerns may warrant giving patients additional information, they do not warrant actions that would serve to undermine the authenticity or degree of patient suffering.

Similarly, perceptions of the meaning of death can influence a physician’s comfort levels with discussing or providing MAiD (see: Sumner 2011, pp 8-15). Those who view death as the greatest harm may choose not to participate in MAiD. Perceptions of life and death can be influenced by philosophical, moral, or faith-based commitments.

In Evelyn’s case, Dr. S. may have felt anxiety before and after the provision of MAiD because of personal views (or uncertainties) surrounding the meanings of suffering and death.

b) autonomy
Although one might support a patient’s right to choose what happens to her body, physicians may nevertheless be concerned about whether patients can competently choose MAiD at the end of life. At present, patients who request MAiD must have capacity. Yet, some worry about the degree to which pain and suffering can unduly influence a patient’s capacity to consent to treatment (Kolva et al 2014). Capacity assessment tools can be helpful in the context of MAiD. Further, some worry whether patients who request MAiD fully understand their healthcare options. The law requires that patients who request MAiD are informed of their other treatment options, including palliative care.

Further, some may worry that MAiD can put vulnerable populations at risk of decreased autonomy or harm. This includes concerns about the efficacy of safeguards, a growing social acceptance (or desensitization) towards assisted dying, and the social implications for persons with disabilities who want to live. Some worry that persons with diminished capacity, including the very old, children, and people with severe mental or physical illness or disability could feel pressured into requesting medical assistance in dying. Some of these concerns are addressed in Bill C-14. A recent report by the Canadian Association for Assisted Living identifies several criteria and approaches to assessing vulnerability that could serve as safeguards for protecting vulnerable populations.

Finally, some may argue that physician autonomy is also important in considerations of MAiD. The notion of patient autonomy, while exceedingly important, is not a stand-alone consideration guiding the fulfillment of physicians’ duties to patients. Moreover, autonomous decisions by patients do not necessarily compel actions on the part of others, each of whom are also autonomous moral agents. As moral agents, physicians have a right to exercise their autonomy in the provision of services, but are also bound by their professional responsibilities to patients. Although providers are not legally or professionally obligated to
provide MAiD, those who object to the practice must ensure that the patient is able to access another provider or agency. (See Case 2 on Conscientious Objections to MAiD.)

c) dignity
Dignity, understood as basic human dignity, is individuals’ inherent and inalienable right of self-respect, self-worth, physical and moral integrity, and empowerment (Pullman, 2001). In providing MAiD, a healthcare professional may believe that they have violated an individual’s basic human dignity by ending their life. Providers who oppose MAiD on these grounds must refer patients to another provider or agency. A similar conception of basic human dignity is often invoked by disability rights activists’ who oppose MAiD. Furthermore, the ability to “suffer with” another person may provide opportunities for preserving and enhancing the dignity of patients, caregivers, and healthcare providers (Pullman 2002). Given the subjectivity of the notion of dignity, there are legitimate concerns about who gets to define what “dying with dignity” means and about the broader social implications of the practice.

In Evelyn’s case, some members of her healthcare team may have worried that the provision of MAiD was in tension with Evelyn’s basic human dignity. Those who had such concerns could have exercised their option to refuse to participate.

In summary, support for and concerns about MAiD fall within a complex web of ethical considerations. Healthcare professionals can also emphasize different ethical considerations at different points in time or with respect to different cases. There are a number of ethical principles that will shape or influence the decision of healthcare professionals to participate in MAiD.

4. How might MAiD change the physician-patient relationship, the goals of medicine, and influence healthcare team dynamics?
Various healthcare professionals, institutions, legislators, and the public might view the scope and aims of medicine quite differently. These differences can manifest in disagreements about not only whether MAiD ought to be offered, but also the manner in which it is offered. What are the competing perspectives and values of MAiD on the nature of physician-patient relationship, the appropriate goals of medicine, and team dynamics?

a) physician-patient relationship
Several different models have been proposed to characterize the nature of the relationship between physicians and their patients, including the paternalistic model, the informative model, the interpretive model, and the deliberative model (see Emmanuel and Emmanuel 1992). Each model proposes a different power relationship and corresponding role for physicians and patients, particularly with respect to healthcare decision-making. Some physicians may worry that MAiD will shift the power away from physicians and undermine their clinical judgment. Others may worry that a relationship that is paternalistic will make it difficult for patients to access MAiD.

The way that physicians understand and construct their relationships with patients can also influence how they understand other relationships embedded in the MAiD context. For example, in Evelyn’s case, if Dr. S. assumes that she is the only person responsible for the Evelyn’s care, she may fail to recognize the important role that the nurse and social worker have played in caring for Evelyn and supporting her decision-making. In the case above, the debriefing with the ethicist can serve as an important tool for clarifying healthcare provider’s roles in the context of MAiD and emphasizing the importance of team work.

Furthermore, existing institutional structures can promote or hinder the ethical provision of
medical assistance in dying. For example, clear reporting structures, prebriefing and debriefing for medical assistance in dying can support evidence based decision making for physicians.

b) goals of medicine
The physician-patient relationship is embedded within the broader context of medicine. Most generally, medicine is committed to promoting the health of patients. Many conceptualize the goals of Western medicine as grounded in the Hippocratic Oath, whereby the good of the patient is held as the appropriate end of medicine (Hulkower 2010). A deep commitment to saving or prolonging life stands in opposition to MAiD. As such, some physicians believe that MAiD is beyond the scope of acceptable practices or do not think that it ought to be classified as medical treatment (Beaudreau and Somerville 2013). Others assert that MAiD is legally and ethically defined as a medical treatment. Adopting this requires that the goals of medicine are seen as the promotion of patients’ wishes and values relating to their own life, well-being and medical needs. This is what has been described as “patient-centred” care (Kaba and Sooriakumaran 2007). Some people also advocate for adopting values that are internal to medicine and medical professionalism, instead of emphasizing the values espoused by the Hippocratic Oath (Jotterand 2005). This controversy surrounding the goals of medicine ground some disagreements about whether and, if so, when, a physician should participate in MAiD. Even if physicians were to accept the provision of quality of care for patients as a primary goal of medicine, they would disagree about how this goal is expressed in practice. In the case study above, Evelyn’s case represents the first time that MAiD was provided at the hospital where Dr. S. works. It is important that institutional structures and policies are in place to support patients, families, and healthcare providers involved with MAiD.

c) team dynamics
Personal, professional, and institutional disagreements about the goals of medicine and the appropriate role of the physician serve to compound the potential for ethical tensions and moral distress amongst healthcare providers who participate in MAiD. There may also be uncertainty about the professional roles that healthcare providers play within the context of MAiD. Although physicians and nurse practitioners are the only ones legally permitted to provide MAiD, the provision of this service involves many members of the healthcare team, including nurses, personal support workers, pharmacists, and social workers. As outlined in Bill C-14, various healthcare professionals can provide support to the physician providing MAiD, that plays a role in ensuring the health and well-being of a particular patient will be affected when a patient is helped to die. Building and promoting positive team dynamics can help to address moral discomfort or confusion around medical assistance in dying and also ensure that patients who wish to access this service feel supported.

Some evidence suggests that physicians who participate in assisted dying experience some adverse emotional and psychological effects (Stevens 2006). For example, many physicians experience feelings of shock, isolation, and are concerned about the ethical toll of providing MAiD. In the case of Evelyn, Dr. S. may fear what her colleagues think of her and worry about earning a reputation as “Dr. Death” if she continues to assist her patients in dying. However, patient privacy regulations preclude the sharing of patient information to outside of the circle of care. Unless Dr. S. publically announced her willingness to provide MAiD, or discuss her participation in the practice, or another colleague breached patient privacy, others would not know about her participation. Further, Dr. S.’s anxiety surrounding the provision of MAiD could be explained, in part concerns about whether she will end up accepting an unfair proportion of the ethical burden for this service. However, practically
speaking, if a physician felt that they were accepting an unfair proportion of the burden for this, they usually have the option of referring the patient to another physician. Note, this may not be the case in rural or remote areas of Canada.

Other staff involved in Evelyn’s case may have similar anxiety and concerns related to their current or future participation in MAiD. Those who feel positively about helping a patient end her suffering, may be wary of acknowledging or sharing this feeling because of the potential social implications. It is important that healthcare providers have access to psycho-social supports, such as team huddles. Employee assistance programs, chaplaincy, and other forms of support for staff and employees may also be accessed.

5. What are your personal values and how do you feel about MAiD? What are you prepared/ willing to do or not do?

In summary, even when a MAiD case meets the legal criteria, ethical tensions or disagreements can arise between providers, patients, and families, and also individuals themselves, may have conflicting feelings about the practice. At times, doing what is legally permissible might not feel right for some individuals. It is important to note that one’s involvement in medical assistance in dying may take an emotional toll on some individuals even if, in theory, they believe in the value of this service. As a healthcare provider, there are a number of national, provincial/ territorial and institutional tools and resources available to assist with the ethical and emotional concerns that might arise. Personal reflection, critical thinking, the building and strengthening of professional relationships can help to identify and address some of these ethical challenges. Consideration of ethical principles can help physicians to engage in meaningful discourse on MAiD. For example, principles of respect for persons; equity; respect for physician values; consent and capacity; clarity; dignity; protection of patients; accountability; solidarity; and mutual respect can help physicians to navigate some of the ethical challenges surrounding the provision of MAiD. Ongoing and open discussion about the meaning(s) of life, human suffering, what constitutes a “good” or “bad” death, the meaning of patient-centered care (especially at end of life), as well as the appropriate roles of healthcare providers and the goals of medicine are important.

Several resources, such as the Canadian Medical Association’s online training module and a value clarification guide (Frolic et al 2016) can assist healthcare providers with identifying and evaluating their own personal feelings and thoughts surrounding MAiD. In addition, documents produced by the Canadian Medical Association, the College of Family Physicians of Canada, the Royal College of Physicians and Surgeons of Canada and the Joint Centre for Bioethics at the University of Toronto, outline ethical principles and frames that can help with MAiD decision-making surrounding.

In conclusion, it is important for physicians to reflect on their own personal values and beliefs related to assisted dying. What are your own beliefs and values concerning suffering, death, patient autonomy, dignity, and the goals of medicine? What factors may influence your personal values and beliefs? What do you think about MAiD? What are you prepared to do in your practice, and why? What are you not willing to do, and why not? Consider how your values and beliefs may change overtime.
References
5. Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982,


