

Medical Aid in Dying: An Overview of Care and Considerations for Patients With Cancer

Thalia DeWolf, RN, BSN, PHN, CHPN, and Naomi Cazeau, MSN, ANP-BC, AOCNP®



BACKGROUND: Medical aid in dying (MAID) is increasingly becoming a legal option for patients with terminal illness who desire greater control over how they end their life. The majority of patients who pursue this option are those with terminal cancer.

OBJECTIVES: This article provides foundational knowledge on MAID, including key considerations for nurses practicing in states where MAID is legalized.

METHODS: Available research and data on MAID are summarized, as well as clinical recommendations for patient education, counseling, and supportive care. A case study is included to illustrate relevant concepts.

FINDINGS: MAID is becoming an accepted practice for patients with terminal cancer through increasing legislation across the United States. Nursing knowledge of critical considerations for patients with terminal cancer who choose to pursue MAID is integral to the provision of optimal clinical oncology care at the end of life.

KEYWORDS

medical aid in dying; MAID; hospice; palliative care; end-of-life care

DIGITAL OBJECT IDENTIFIER

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RECOGNIZING AND RESPONDING TO PATIENTS' GOALS OF CARE, even in their final moments, is vital to maintaining patients' sense of autonomy, dignity, and control (Cohen et al., 2015). In jurisdictions where it is legal, medical aid in dying (MAID) offers patients the opportunity for greater control over their dying experience. Increasingly, patients with terminal cancer are opting to end their lives at the time and place of their choosing with MAID. As of 2020, 11 jurisdictions in the United States have legalized MAID (Mroz et al., 2021) (see Figure 1). More than 70% of patients who receive MAID in the United States are patients with cancer, and a report indicated that 56% of oncologists surveyed in the United States have received requests for MAID (Emanuel et al., 2016; Kozlov et al., 2022). Formal education on this practice is limited, which challenges the ability of nurses to feel confident educating and supporting patients who request MAID as an option (Lehto et al., 2016). This article provides an overview of MAID, including its potential role in end-of-life care and nursing considerations. A case study illustrates the process of MAID for a patient with terminal cancer.

MAID

MAID is a term used to describe the process when a physician provides medication or a prescription to patients at their explicit request, with the understanding that the patient intends to self-administer the medications to end their life (Emanuel et al., 2016; Roy, 2022). In 1997, Oregon was the first state in the United States to legalize and implement MAID, following a Supreme Court decision that upheld states' rights to decide on legalization (Riley, 2017). Several states have since followed, in part, because of a growing older adult population and increased societal appreciation for autonomy, secularization, and patient empowerment (Li, 2021).

MAID should be carefully distinguished from euthanasia, which is illegal in the United States and involves the direct administration by a physician of life-ending medication to a patient who is terminally ill (Roy, 2022). MAID is also different from suicidality, which is a medical emergency that warrants immediate nursing assessment. According to the American Association of Suicidology (2017), MAID differs from suicide medically, legally, and conceptually by its intention, the absence of physical self-violence, and the fact that the decision is not influenced by mental illness or self-destruction. Of note, research has shown that individuals who received prescriptions for MAID had lower desires to die and lower levels of hopelessness (Ganzini et al., 2008). An observational study by Al Rabadi et al. (2019) of 3,368 MAID

prescriptions written in Oregon between 1998 and 2017 and in Washington between 2009 and 2017 showed that 24% of patients who received prescriptions did not ultimately die by lethal ingestion. Inappropriately labeling patients who inquire about MAID as suicidal can adversely affect their trust in providers (Li, 2021). In addition, doing so may have negative implications for a patient's eligibility to receive MAID in states where it is a legal option (Gerson et al., 2020; Lehto et al., 2016).

The impetus for requesting MAID largely includes fears about loss of autonomy, dignity, and/or quality of life because of terminal illness (Al Rabadi et al., 2019; Buchbinder, 2018). Although patients' symptom burden rarely drives MAID requests, hospice care remains critical to palliate symptoms at the end of life and may help patients to make decisions about if and when to plan their death (Lehto et al., 2016). Most patients who request MAID actively pursue palliative care, enroll in hospice, and subsequently have good symptomatic relief. In Oregon and Washington, two of the first U.S. states to legalize and implement MAID, survey findings showed that more than 80% of patients were enrolled in hospice at the time of their MAID procedure (Emanuel et al., 2016).

Similar to that of any patient with a terminal illness, hospice and palliative care are key components of care for patients with cancer seeking MAID. Palliative and hospice care are sometimes thought to be one and the same; however, there are key differences to understand about each approach. Palliative care is specialized medical care that is focused on enhancing patients' symptom management and quality of life (National Institute on Aging, 2021). Hospice care is focused on providing comfort and optimal quality of life for patients who are terminally ill with a prognosis of six months or fewer. Hospice care is typically provided in the home or facility where the patient lives (National Institute on Aging, 2021).

“More than 70% of patients who receive MAID in the United States are patients with cancer.”

Eligibility Criteria

Eligibility criteria for MAID vary by state. However, most states use the criteria established by the state of Oregon, which requires the following (Blanke et al., 2017):

- Being aged 18 years or older
- Having a residence in the state where MAID is legal
- Having a prognosis of six months or fewer
- Two oral requests for MAID separated by a waiting period, the length of which varies by state
- A written request from the patient signed in the presence of two witnesses
- A prescribing physician and a consulting physician who confirm the diagnosis, terminal prognosis, and the patient's capacity to make and communicate healthcare decisions

Psychological evaluations are advised for patients when either physician determines that the patient's judgment may be compromised by a mental health disorder. The prescribing physician must review feasible alternatives, including comfort care, hospice care, and pain control, with the patient. Lastly, patients must be permitted to change their mind (Lehto et al., 2016; Stokes, 2017).

Pharmacology

There are a variety of MAID prescription regimens. In the United States, the most commonly used regimen consists of a combination of benzodiazepines, barbiturates, morphine sulfate, antidepressants, and cardiotoxins (American Clinicians Academy on Medical Aid in Dying [ACAMAID], 2021a; Engelhart et al., 2022). In 2020, ACAMAID collected data that indicated that the use of sedatives alone reliably induced unconsciousness but did not reliably suppress cardiac function within a reasonable time frame of a few hours (Shavelson & Parrott, 2020). By 2022, ACAMAID innovated what is now the predominate combination of medications used for MAID, which include diazepam, digitalis, morphine, amitriptyline, and phenobarbital. This combination includes three sedatives that saturate three distinct receptors to quickly suppress consciousness and breathing, as well as two cardiotoxins with later onset that cause bradyarrhythmia and

FIGURE 1.
U.S. JURISDICTIONS WITH LEGALIZED MEDICAL AID IN DYING AS OF 2020

- California
- Colorado
- Hawaii
- Maine
- Montana
- New Jersey
- New Mexico
- Oregon
- Vermont
- Washington
- Washington, DC

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tachyarrhythmia, and, ultimately, lead to death in less than five hours (ACAMAID, 2021b).

MAID medications are compounded into powder form by independent compounding pharmacies. Patients or caregivers are advised to carefully mix the medications with clear-filtered apple juice, followed by small amounts of frozen juice, such as a popsicle or sorbet, to offset their bitter taste and the possible burning sensation that may occur before the sedatives take effect (ACAMAID, 2021a).

The gastrointestinal tract is the only administrative route allowed for MAID medications in the United States. Therefore, patients who request MAID must be able to either swallow medication or push a syringe of the medications into their gastrointestinal tract via a gastric or rectal tube. This allows the medications to be absorbed in the bloodstream where they can affect the heart and lungs. Peristalsis and absorptive function must be maintained. Nausea and vomiting must be controlled, particularly in the week before MAID medications are ingested. Many typical antiemetic drugs, such as prochlorperazine, are sedating or anticholinergic, which may exacerbate gastroparesis, particularly in older patients or patients who are cachexic. Glucocorticoids (e.g., low-dose dexamethasone) are preferred in the weeks before MAID medications are ingested because they can also improve other symptoms, such as pain, loss of appetite, and fatigue. Controlling constipation and avoiding diarrhea, which may reverse the osmotic gradient in the bowel and slow absorption, ensure optimal drug absorption. Patients are encouraged to eat at least a minimal amount to maintain their intestinal villi, which are fed by passing nutrients. Good hydration, without overloading, is also helpful to maintain euolemia so that medications can enter systemic circulation (DeWolf, 2021).

The rate of complications with MAID—historically and variously defined as awakening after drug ingestion, difficulty ingesting medications, regurgitation, prolonged death, or seizures (Al Rabadi et al., 2019; Emanuel et al., 2016)—has become extremely low with the continued development of best practices. For example, public health data collected from 1998 to 2021 from the state of Oregon indicate that the rate of patient awakening post-ingestion has significantly reduced based on changes in the commonly used MAID regimens (Oregon Health Authority, 2022). Having an experienced clinician present at the time of death can ameliorate any side effects and provide reassurance to family and caregivers who may be alarmed by some of the natural symptoms of dying that present (Mroz et al., 2021).

Nursing Considerations

The MAID process legally begins with a conversation between patients and their providers (i.e., primary oncologist), which can then be received and charted as their first verbal request, if appropriate. These conversations are mostly patient-directed and take place in the context of larger goals-of-care discussions

(Brassfield & Buchbinder, 2021; Li, 2021). Some patients may feel uncomfortable expressing their views or desires regarding MAID for fear of either judgment or abandonment by their providers (Brassfield & Buchbinder, 2021; Lehto et al., 2016). The Hospice and Palliative Nurses Association, Oncology Nursing Society, and American Nurses Association all “uphold nurses’ responsibility to provide supportive care, relieve pain and symptoms, and support patients’ rights to dignity, self-determination in decision making, and care regardless of choices at the end of life” (Lehto et al., 2016, p. 185). Therefore, avoiding unwarranted judgmental statements or actions toward patients who express a desire for MAID is essential (Stokes, 2017). In addition, to avoid inadvertently disenfranchising patients, nurses can help patients to clarify their end-of-life wishes and if needed, refer them promptly to physicians who can help them navigate the process.

Most nurses support MAID as an option for patients with terminal illness (Davidson et al., 2022). However, it is estimated that 84% of nurses lack either personal or professional experience caring for a patient or loved one who is pursuing MAID. This lack of knowledge and experience limits the ability of nurses to adequately respond to patient requests. Study results have also demonstrated fear among nurses of disciplinary action for discussing MAID with their patients (Davidson et al., 2022). In addition to adhering to local legislation, nurses need to have a keen awareness of the guidance within their local nurse practice acts and their healthcare institution’s policies that govern the nursing role in MAID (Lehto et al., 2016). Although nurses cannot administer life-ending medication, they can provide support for their patients through education, appropriate referrals, and continued provision of supportive care to manage symptoms (Roy, 2022).

The Hospice and Palliative Nurses Association (2017) provides the following guidance for nurses about how to respond to patient inquiries regarding MAID:

- Clarify request.
- Assess the patient, with the aim of understanding the background of the request.
- Determine whether the patient has the following:
 - Decision-making capacity
 - Unmanaged pain
 - Other uncomfortable symptoms
 - Psychosocial distress
 - Existential and/or spiritual suffering
- Evaluate the patient for any unmanaged symptoms and refer as necessary to appropriate consultations (e.g., advanced practice RN, physician, palliative and hospice care experts).
- Collaborate with the patient to determine short- and long-term plans, which may include new symptom management plans and/or consultations with a chaplain or social worker.
- Consult and collaborate with the interprofessional team to ensure attention to all aspects of the patient’s quality of life.

- Provide additional information, as requested by the patient, regarding palliative care options (e.g., palliative sedation, withholding or withdrawing life-sustaining treatments, MAID where legalized).
- Provide ongoing palliative care and support to the patient and family.

The nurse's role throughout the MAID process is shaped by institutional policy. Self-awareness of individual feelings and views regarding MAID is important for nurses. Nurses have the right to conscientiously object to being involved with the MAID process. According to the American Nurses Association (2019), "Nurses who work in jurisdictions where medical aid in dying is legal have an obligation to inform their employers that they would predictively exercise a conscience-based objection so that appropriate assignments could be made" (p. 2). If the nurse-patient relationship needs to be terminated based on a conscientious objection, it must be made clear to the patient that the conscience-based refusal is not based on personal prejudice or bias (Stokes, 2017). The patient must also be immediately reassigned to another provider who is willing to continue care in the context of MAID.

Patients often rely on nurses for information that can help them to make informed decisions about the timing of their death. As such, continued discussion about the disease trajectory, likely end-stage scenarios, and subsequent palliative measures, in collaboration with the treating physician, are usually welcome. Nurses can identify and communicate to patients any signs or symptoms that indicate they are entering the active dying phase, such as delirium, loss of appetite, lethargy, or incontinence (Hui et al., 2015). This may indicate a decisional moment for the patient and require the nurse to support their informed consent. Patients and caregivers may also appreciate reassurance that the nurse will continue monitoring, communicating about, and managing symptom burden throughout the remaining time of the patient's life.

Providing counseling and support to patients who are ineligible for or lose their eligibility for MAID is equally important. Establishing eligibility for MAID is often powerfully therapeutic for patients, and being deemed ineligible can lead to existential distress and complicated grief (Buchbinder, 2018; Li, 2021). Nurses, along with palliative care specialists, can mitigate distress

FIGURE 2. CASE STUDY

K.M., a 72-year-old woman, presented to her primary care physician with unexplained weight loss, nausea, and vomiting. She was diagnosed with locally advanced unresectable pancreatic ductal adenocarcinoma. Scans revealed a large tumor with lymph node involvement and metastasis to her liver. K.M. understood that given the severity of her stage IV disease, her prognosis was poor (less than 6 months without treatment and not much longer with treatment). Her oncologist determined that various chemotherapy regimens could improve her quality of life and potentially extended her prognosis, but not reliably to more than 1 year.

K.M. wanted to understand all options for her care. In addition to second opinions, she sought further palliative care consultation to understand what symptoms she might experience, and ultimately, what her end of life might look like. She understood what hospice care entailed and wanted to know more about MAID, which was legalized in her state. She brought it up with her oncologist, who appeared startled and stated, "We don't do that at this organization." Undaunted, K.M. researched a doctor mentioned in the news (Dr. S), who had opened a practice to provide end-of-life care to patients considering MAID as an option. K.M. met with Dr. S shortly thereafter. During their meeting, she reiterated that she had interest in MAID but was not sure she would ever use it if all went well with treatment. Dr. S clarified for K.M. that although she would never be obligated to take the MAID medications, she could not pursue this option if she did not finish the steps to become eligible.

After K.M. confirmed her interest in pursuing MAID, Dr. S proceeded to document her first verbal request. During the waiting period, K.M. continued

to explore other treatment options, and Dr. S gathered medical records that verified her prognosis of less than 6 months, as well as her mental capacity to make her own medical decisions. A consulting doctor was identified, and the other necessary forms, including a signed and witnessed written request, were completed. The prescriptions were written and filled at a local compounding pharmacy. K.M., emboldened by the fact that her end of life could be on her terms, went on to pursue treatment with a chemotherapy regimen suggested by her oncologist. She developed symptoms that were managed by the palliative team supporting her care.

During this time of her care, K.M. shared her decision about MAID with a close friend and expressed, "The whole time I've been getting chemo[therapy], I knew that I had the aid-in-dying card in my back pocket, so that if I needed an exit, I could have one. . . . It's helped me feel strangely safe."

K.M. lived an additional 2 years, punctuated by weekly rounds of chemotherapy. When her tumors stopped responding to treatment and new metastasis appeared, she stopped chemotherapy and entered hospice care. She was carefully followed by Dr. S, who promised to notify her when her option for MAID would expire. A month later, when she was no longer able to eat and her cognition began to decline, she chose to self-administer the prescribed MAID medications. With Dr. S and her family at her bedside, K.M. became unconscious within 8 minutes and died 75 minutes later.

MAID—medical aid in dying

Note. Based on information from Compassion and Choices, n.d.

by helping patients to develop detailed contingency plans that include relevant details about their preferences for palliative care alternatives if MAID is no longer an option (Gerson et al., 2020; Li et al., 2017).

Emotional distress may occur among providers following MAID deaths, similar to that of any loss of a patient who dies (Gerson et al., 2020; Li et al., 2017). Self-care and psychosocial support are critical. Clinical teams participating in MAID may consider debriefing sessions before and/or after MAID deaths (Li et al., 2017). See Figure 2 for a case study illustrating the MAID experience for a patient with terminal cancer.

Implications for Practice

Healthcare institutions and individual providers have the right to deny the provision of MAID even when it is legal in their state. In such cases, providers have a duty to facilitate immediate transfer of the patient's care to willing providers at the patient's request (Li, 2021). This process may create many barriers to access and delays in achieving this goal of care for patients at a tenuous time point in their disease trajectory. Li et al. (2017) shared their model of care, which includes a team of dedicated clinical volunteers within their institution's supportive care department, to whom providers can refer for needed assessments and clinical interventions for patients requesting MAID within the organization. Although this process may help streamline access to MAID, it may also require significant investments in professional and financial resources. Non-MAID providers may also research MAID providers in their area with whom they can develop relationships and to whom they can refer patients when needed (Engelhart et al., 2022).

The provision of MAID in states where it is legal is a complex interprofessional process that may include nursing, social work, pastoral care, case management, medicine, and hospice and palliative care specialists (Roy, 2022). Therapists and counseling professionals can also alleviate some of the related psychological burden for patients and caregivers during the MAID process (Blanke et al., 2017; Emanuel et al., 2016).

Once MAID eligibility has been established, patients and families are often initially relieved. After barriers have been overcome, requirements have been met, and the prescriptions are held at the pharmacy, difficult questions may arise regarding if and when to take the medications, and palliative needs become more complex.

MAID deaths, although planned, are no less associated with grief and loss. The desire for autonomy and independence at the end of life may drive patients to pursue MAID, but the process can foster a unique form of dependency because the individual choreographs a complex dying process with the support of loved ones (e.g., completing paperwork, filling prescriptions, planning last day). This shared experience may take a toll on the family and caregivers involved in the process, not only through the loss

IMPLICATIONS FOR PRACTICE

- Understand the potential implications for the care of patients with terminal cancer with the growing acceptance and legalization of medical aid in dying (MAID).
- Provide optimal care at the end of life for patients with terminal cancer by obtaining foundational knowledge about MAID.
- Review current MAID legislation and related nursing implications.

itself, but also by their potential role in it (Buchbinder, 2018). Family conflicts over acceptance can be particularly distressing for patients and their clinicians. Although families generally have their own processes to work through these differences, hospice providers, counselors, and social workers can provide critical emotional support to family and caregivers during this challenging time (Emanuel et al., 2016). Nurses are commonly at the bedside with patients, supporting them with skill and grace in making these complicated decisions, and are often with patients when they die.

Socioeconomic-based patterns of privilege are associated with MAID (Buchbinder, 2018). Typical patients are White men aged 60–85 years who are medically insured and college educated (Mroz et al., 2021; Roy, 2022). Many costs associated with MAID may be covered by insurance, but critical components of care, such as the cost of medications from compounding pharmacies, are not covered and may run as high as \$700. Compounding pharmacies that are willing and able to facilitate prescriptions are also limited (Gerson et al., 2020). This may add

FIGURE 3. RESOURCES ON MEDICAL AID IN DYING

WEBSITES

AMERICAN CLINICIANS ACADEMY ON MEDICAL AID IN DYING

- www.acamaid.org

DEATH WITH DIGNITY

- <https://deathwithdignity.org>

END OF LIFE CHOICES OREGON

- <https://eolcoregon.org>

HOSPICE AND PALLIATIVE NURSES ASSOCIATION

- <https://advancingexpertcare.org>

POSITION STATEMENTS

AMERICAN NURSES ASSOCIATION

- <https://bit.ly/3W0zsQo>

HOSPICE AND PALLIATIVE NURSES ASSOCIATION

- <https://advancingexpertcare.org/position-statements>

to existing end-of-life care disparities for Medicaid recipients, who may have limited coverage for hospice care (Wachterman & Sommers, 2021). For these patients, physicians may be reticent to initiate discussions about MAID. Therefore, the patient's level of medical literacy may be a barrier to treatment. In addition, access to providers may be challenging in rural locations (Roy, 2022). Nurses can play key roles in local and national advocacy to help bridge access gaps in legal jurisdictions and address end-of-life care disparities.

The emergence of MAID creates opportunities for nursing research that explores where this option will ultimately fit in the greater context of end-of-life care. This includes a better understanding of the nursing and advanced practice roles, the patient's symptom burden at the time of request, socioeconomic and demographic disparities, and the use of hospice care among patients who employ this strategy, as well as family and caregiver satisfaction and psychological sequelae. Knowledge about MAID will advance as more states adopt this practice. Figure 3 provides a list of additional resources.

Conclusion

MAID is becoming an option for more patients approaching the end of life. Nurses caring for patients with terminal illness in states where MAID is legal can help patients and their families to navigate the MAID process. With the increased use of MAID among patients with terminal cancer, oncology nurses can serve as frontline providers by fielding questions from patients about MAID and providing education. Having a strong foundational knowledge of MAID, in addition to an awareness of related laws and practice policies, will allow oncology nurses to provide optimal care to their patients who seek this option at the end of life.

Thalia DeWolf, RN, BSN, PHN, CHPN, is a director of nursing education at the American Clinicians Academy on Medical Aid in Dying in Berkeley, CA; and **Naomi Cazeau, MSN, ANP-BC, AOCNP®**, is a nurse practitioner at Memorial Sloan Kettering Cancer Center in New York, NY. Cazeau can be reached at ncazeau@gmail.com, with copy to CJONEditor@ons.org. (Submitted May 2022. Accepted August 25, 2022.)

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