

Hospice Nurse Ethics and Institutional Policies Toward Medical Aid in Dying

How can nurses fulfill their duty to patient and family?

ABSTRACT: A significant number of hospices in U.S. jurisdictions where medical aid in dying is legal have implemented policies that require nurses to leave the room when a patient ingests aid-in-dying medication. Two questions with ethical implications arise from these policies: (1) Is it ethically supportable for a hospice to require that staff leave the room while a patient ingests aid-in-dying medication? and (2) Does this requirement compromise the nurse's professional commitment to the patient and family?

This article reviews the origins of this common policy, as well as nursing codes of ethics and professional organization policy statements as they relate to nursing commitments to patients. It finds that an institutional policy requiring nurses to leave the room while a patient ingests aid-in-dying medication risks violating professional nursing standards, reinforces stigma regarding medical aid in dying, and potentially abandons patients and loved ones at a critical time in their passage toward a desired and legal death. The authors describe a case that depicts these three potential risks, concluding that even if such policies are not legally prohibited by state aid-in-dying statutes, hospices should eliminate them or at least be transparent about the practice and its rationale before accepting patients who request medical aid in dying.

Keywords: aid in dying, ethics, hospice policy, medical aid in dying, nurse responsibilities, nursing ethics, professional ethics

A patient and family engaged a hospice agency that advertised as supporting patients who were considering aid in dying, a legal option in their state. On the day of the planned ingestion of aid-in-dying medication at the patient's home, a hospice nurse was present along with family members and close friends. Pursuant to her hospice's policy that staff must leave the room while patients ingest aid-in-dying medication, the nurse stepped out of the room while the patient consumed the medication. The family had not previously been aware of this policy. The nurse returned to the room when the family urgently requested her presence because the patient was choking on the medication slurry. While this violated the hospice's policy, the nurse felt morally and professionally responsible to respond to the acute needs of the patient and family. The hospice terminated her employment for violating its policy.

This article reviews the ethics of this common hospice policy and examines whether leave-the-room rules are justifiable. Is it ethically supportable for a hospice to require that staff leave the room

while a patient ingests aid-in-dying medication? Does this requirement violate the nurse's professional commitment to not abandon the patient and family?

RELEVANT BACKGROUND AND FACTS

Eleven U.S. jurisdictions, encompassing about 25% of the U.S. population, allow medical assistance in dying.^{1,2} Hospices in these states have struggled to define their role. Physicians and nurses cannot administer aid-in-dying medication directly; the patient must self-administer. But the scope of hospice engagement and policies for employee practice vary widely. For example, in a 2014 review of hospice policies in Washington State, the language used for "medically assisted death" varied; many hospices tended to see this as a "physician-directed" process rather than as a "hospice-assisted" one.³ This review also highlighted the diversity of hospice policies regarding staff presence during self-administration, with only six of 33 institutions explicitly allowing staff to be present at the time of ingestion or after ingestion but before death and 78% (26 of 33) restricting staff from being present at the time



Illustration by Janet Hamlin.

of patient self-administration or between ingestion and death.³ Such policies have been evolving over time, though we continue to find a significant number of hospices that prohibit staff presence at the time of ingestion. Hospice policies regarding the specifics of attendance by staff at the time of ingestion are hard to clarify in many instances, despite the recent transparency requirements of California's Senate Bill 380.⁴ But the practice of restricting staff from being present during and after ingestion is still widely reported.⁵⁻⁹

Evolving nurse perspectives. As with institutions and providers, nurse perspectives on medical assistance in dying have evolved over time, with U.S. nurses growing increasingly more supportive. In 2020, Davidson and colleagues surveyed over 2,040 members of the American Nurses Association (ANA), one-quarter of whom practiced in states allowing medical assistance in dying.¹⁰ While half did not personally support the practice, 86% stated they would care for a patient who was contemplating medical assistance in dying, and 67% said they would care for a patient during the final act.

Yet, notwithstanding this widespread support, recent nursing literature continues to reflect differing interpretations of the roles of hospice nurses in educating and caring for patients in the face of their

increasingly frequent requests for medical assistance in dying.^{8, 10, 11}

Legal and funding realities. From a legal perspective, as noted, 11 U.S. jurisdictions allow physicians (or advanced practice nurses or physician assistants in New Mexico) to prescribe lethal doses of medication, at the patient's request, to competent terminally ill patients for the purpose of ending their life.^{1, 12} These are California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, Washington, and Washington, DC. Ten of these jurisdictions have statutes providing that aid in dying is not to be construed as suicide, assisted suicide, or euthanasia under the law.¹ (Montana allows aid in dying through a state supreme court decision only.)

But institutions remain concerned about the federal Assisted Suicide Funding Restriction Act (ASFRA), which President Clinton signed into law in April 1997.¹³ This legislation was enacted in direct response to the first statute legalizing physician assistance in dying in Oregon. ASFRA provides that no federal funding "may be used . . . for the purpose of causing, or for the purpose of assisting in causing, the death of any individual, such as by assisted suicide."¹³

ASFRA matters because federal funding is the predominant source of payment for hospice. Moreover, hospices are paid primarily under Medicare Part A, which also specifically prohibits the use of such funds for assisted suicide.¹⁴ All state aid-in-dying statutes specifically define medical assistance in dying as not being "assisted suicide."² But this cannot change the meaning or impact of a federal statute that was intended to target medical assistance in dying when it was widely conceived as "physician-assisted suicide." Violation of ASFRA or Medicare laws can result in suspension of payments and other penalties.¹⁴

The fear of violating ASFRA is salient to hospices. As recently as 2022, the Centers for Medicare and Medicaid Services (CMS) noted the "potential role hospices could play in medical aid in dying (MAID) where such practices have been legalized in certain states."¹⁵ In the regulations setting fiscal year 2023 hospice payments, the CMS wrote that "we wish to remind hospices that the [ASFRA] prohibits the use of Federal funds to provide or pay for any health care item or service or health benefit coverage for the purpose of causing, or assisting to cause, the death of any individual including mercy killing, euthanasia, or assisted suicide."¹⁵

On the other hand, the CMS also recently announced that it would be updating the provider reimbursement manual's cost-reporting instructions

to include costs prohibited by ASFRA as an example of a nonreimbursable cost.¹⁵ This implies that hospices may participate in medical assistance in dying, so long as they do not specifically bill for those costs.

Still, uncertainty about the scope and impact of ASFRA has chilled participation not only by hospices but also by other types of providers. For example, one California veterans home prohibited medical assistance in dying on its premises, claiming that such a prohibition was “required” by ASFRA.¹⁶ Nevertheless, to date there is no evidence of hospice penalties for staff such as nurses being present during a patient’s ingestion of aid-in-dying medication.

HOSPICE PERSPECTIVES ON LEAVE-THE-ROOM POLICIES

Hospices that have a policy requiring nurses to leave the room during ingestion of aid-in-dying medication base this policy on several concerns. First, they fear losing Medicare payments because ASFRA forbids federal funding for aid in dying.¹³ Although there is no direct policy advice from national professional hospice organizations, hos-

ping patients. They argue that patients and families can understand and accept their policy as based on their interpretation of federal or state law when this is explained to them.

HOSPICE PERSPECTIVES ON ALLOWING NURSE PRESENCE AT INGESTION

Hospices that allow nurses to be present at ingestion and death explain their choice by arguing that hospice services require attendance to all patient and family needs and strict adherence to professional nursing standards. First, nonabandonment is a core ethical duty.^{17, 18} It is also a dominant theme in most hospice policies, along with continuity of care, relief of pain and suffering, and compassionate care.³ Second, there have been no known instances of hospice programs having federal funds withheld because staff were present to support patients who chose aid in dying. This track record is based on nearly 25 years of experience in some states. Third, there is nothing in any of the state aid-in-dying laws that prohibits a hospice nurse or other staff from being in the room during the ingestion of medication.

When a nurse’s obligation to stay with the patient conflicts with organizational policy, the nurse’s commitment remains to the patient.

pices are closely regulated by Medicare fiscal intermediaries, which withhold funds when hospices deviate from regulations. This has led many hospices to partially support medical assistance in dying by adopting policies of “engaged neutrality” or policies designed to avoid questioning by Medicare fiscal intermediaries.³

Second, some hospices interpret the “self-administration” mandate in state aid-in-dying statutes to require staff to completely refrain from being in the presence of ingestion.^{3, 8} They fear that staff will be put in a “compromised position” by witnessing an ingestion. Or they may fear that staff will feel a potential duty to report illegal activities if a family member (rather than the patient) administers the medication or pressures the patient into self-ingesting.

Third, hospices assert they are still affirming patient autonomy and nonabandonment, even if nurses aren’t present during ingestion for aid-in-

Finally, hospices allowing employees to be present at ingestion and subsequent death acknowledge that while complications are not common, they do occur, both during and following ingestion. Accumulated data show that at least one in 20 patients experiences choking, vomiting, or other complications during ingestion.¹⁹ In other countries, including the Netherlands and Canada, professional staff are permitted to be present²⁰ and clinicians can administer end-of-life medication parenterally if needed. In other words, clinician-administered aid in dying is available as a backup to patient-administered aid in dying. In those countries, almost all patients choose to have professional support during what can be considered a complex medical “procedure.”

NURSING POSITION STATEMENTS ON AID IN DYING

All professional health care associations have produced statements emphasizing their fiduciary

relationship to patients, respect for patients, and commitment to avoid abandonment of patients. The following are the relevant codes and position statements from nursing associations.

ANA position statement on medical aid in dying. In 2019, the ANA directly addressed the role of nurses in aid in dying in its “ANA Position Statement: The Nurse’s Role When a Patient Requests Medical Aid in Dying.”²¹ The statement advises nurses to “never ‘abandon or refuse to provide comfort and safety measures to the patient’ who has chosen medical aid in dying.” The ANA recognizes that “nurses understand that aid in dying legislation consistently requires that the patient—never a health care professional—obtains, prepares, and self-administers the aid-in-dying medication. It is a strict legal and ethical prohibition that a nurse may not administer the medication that causes the patient’s death.”²¹ The ANA, however, also states that a patient may request a nurse be present when she or he ingests the aid-in-dying medication, as this is “consistent with the *Code of Ethics for Nurses* [and] includes sensitivity to the patient’s vulnerability, demonstration of care and compassion, and promotion of comfort to sustain trust.”²¹

The ANA position statement further advises that when deciding “whether to be present, the nurse should consider personal values and organizational policy, as well as the professional relationship that exists with the patient and family. If present . . . , the nurse promotes patient dignity as well as provides for symptom relief, comfort, and emotional support to the patient and family. . . . The nurse’s decision to be present should not be negatively evaluated.”²¹ The Oncology Nursing Society (ONS) has affirmed the ANA’s statement as their position as well.²²

ANA’s Code of Ethics. In addition to its position statement on aid in dying, the ANA has relevant guidance in its *Code of Ethics for Nurses with Interpretive Statements*, which states that the “nurse’s primary commitment is to the recipients . . . whether individuals, families, groups, communities, or populations” (Provision 2.1).¹⁷ The code further provides that nurses must “follow a code of ethical conduct that includes moral principles such as . . . respect for the dignity, worth, and self-determination of patients” (Provision 4.2).¹⁷ Nurses are “obliged to provide for patient safety, to avoid patient abandonment, and to withdraw only when assured that nursing care is available to the patient.” (Provision 5.4).¹⁷

Hospice and Palliative Nurses Association position statement on medical aid in dying.

Unlike the ANA, the Hospice and Palliative Nurses Association (HPNA) doesn’t address bedside attendance in its position statement, but the statement does emphasize that “all patients [must] have access to quality hospice and palliative care.”¹⁸ The HPNA asserts that “hospice and palliative nurses must not abandon patients who request [physician-assisted death/physician-assisted suicide] and adhere to nursing code of ethics and policies and procedures concerning non-abandonment.”¹⁸ The statement is currently under review per the HPNA.

STATE NURSING PRACTICE ACTS

In addition to private professional society statements like those from the ANA, ONS, and HPNA, every U.S. state has a nursing practice act (NPA) that specifies professional duties and expectations for nurses licensed in that state. These NPAs typically require that nurses not abandon their patients.²³ For example, the Virginia Board of Nursing states that patient abandonment can constitute a violation of other duties and qualify as “unprofessional conduct” or as “practicing in a manner contrary to the standards of ethics.”²⁴ The Minnesota Board of Nursing states that it will review a nurse’s conduct in instances where they accept responsibility for an assignment but either do not fulfill that responsibility or transfer it to another qualified person.²⁵ Furthermore, nursing boards regularly discipline nurses for even temporarily abandoning patients, such as to make a phone call from their car.²⁶

ARGUMENTS SUPPORTING LEAVE-THE-ROOM HOSPICE POLICIES

The following arguments support hospice policies prohibiting nurses from being present during ingestion of medication in the aid-in-dying process.

- **Institutional loyalty.** Nurses are hired by an institution and commit to honoring that institution’s policies as part of their employment. Institutions have varying risk-based policies and professional commitments that include contractual constraints. Nurses acknowledge these in accepting employment.
- **Federal prohibition.** Hospice organizations could face legal and financial risks based on interpretations of ASFRA as restricting involvement or the appearance of involvement in actively hastening death. If hospices lose certification, their services will be unavailable to dying persons beyond those seeking aid in dying. But no evidence supports such a risk-averse interpretation.

- **Legal permissibility.** All aid-in-dying statutes permit institutions to decline to participate in medical assistance in dying while acting “within the course and scope of any employment.”^{2,4} If this is interpreted to mean that parties such as hospitals can decline to participate, then by extension so can hospices. Some argue that if hospices can completely prohibit participation, they can partially prohibit participation.
- **Patient and family understanding.** With careful planning, written instruction, and emotional preparation, a patient and family made aware of an employer’s leave-the-room requirement are less likely to perceive the nurse’s action as abandonment.
- **Stigma for staff objecting to participation.** A policy allowing the presence of nurses during ingestion of aid-in-dying medication may pressure those who wish to support patients but limit the scope of their participation.¹⁰

ARGUMENTS OPPOSING LEAVE-THE-ROOM HOSPICE POLICIES

Balanced against arguments supporting leave-the-room policies are arguments supporting nurse presence (if the patient and family wishes) during all aspects of the aid-in-dying process.

- **Respect for the patient.** Respecting a patient’s autonomous wishes requires both honoring a patient’s valid and legal choice and fulfilling a commitment to comfort, minimize suffering, and provide support and expertise during the exercise of that choice.¹⁷ It also includes avoiding “doing harm.” Leaving the room during ingestion of aid-in-dying medication can potentially cause both physical and emotional harm to the patient and the family. Leaving a patient alone at any point in the dying process is contrary to the philosophy of the hospice and its staff to respect the patient and family before, during, and after the patient’s death.
- **Patient safety.** Nurses have a professional commitment to providing palliative and comfort care expertise.^{18,27} If the nurse leaves the room and the bedside during ingestion of aid-in-dying medication, the patient may not swallow the medication safely or quickly enough to avoid vomiting or choking. The nurse’s presence may be even more important if medication is being ingested through a nasogastric or rectal tube. Nurses are expected to carefully monitor the patient’s ingestion of self-administered medication and to document all activities involved in the care of patient and fam-

ily during the process of a medically assisted death. (Some clinicians suggested to the nurse colleague in our opening case scenario that she should have considered omitting documentation to avoid institutional constraints, as they had.) In an example from Washington State, a hospice nurse who had developed a close professional relationship with her patient decided to attend “as a friend, not as a nurse,” to avoid her hospice’s restrictions.³

- **Affirmation of legitimacy.** In the 11 U.S. jurisdictions where medical assistance in dying is legal and not defined as euthanasia or suicide,² leaving the room during ingestion may be perceived as stigmatizing this solemn and, for many, sacred activity as morally or legally questionable. It can convey a message to the patient and family that aid in dying is not viewed as ethically acceptable by the hospice provider.
- **Ethical nonabandonment.** Meeting a patient’s needs is the nurse’s primary responsibility. When a nurse’s obligation to stay with the patient conflicts with organizational policy, the nurse’s commitment remains to the patient. As the ANA position statement states, the nurse should never “abandon or refuse to provide comfort and safety measures to the patient” who has chosen medical aid in dying.²¹
- **Legal nonabandonment.** None of the aid-in-dying statutes restricts hospice nurses from being present during self-administration of aid-in-dying medication.² Nor is there any prohibition in NPAs or boards of nursing regulations. The scope of restrictions is a matter for state regulation and NPAs are not discretionary. It is illegal for an institution to force a professional to violate their own profession’s practice act by requiring that a nurse abandon their patient. In some cases, a state NPA prohibits this directly and explicitly.²³ Other NPAs prohibit “unprofessional practice,” which a substantial body of jurisprudence clarifies as including nonabandonment.^{24,25,28} Therefore, it is illegal to require the nurse to abandon patients.

CONCLUSIONS AND RECOMMENDATIONS

Hospice leave-the-room policies underscore the ethical tension between the nursing profession’s legal and ethical duties to patients and the right of health care entities to define and enforce their values. While there have been no known instances of hospice programs having federal funds withheld because they supported patients who chose aid in dying, institutional “leave-the-room” policies are

often shaped and motivated by regulatory and legal concerns.

As we have reviewed above, there are arguments for both sides of this ethical dilemma, but arguments in favor of a nurse presence are weightier. While state aid-in-dying laws may permit hospice organizations to require nurses to leave the room while a patient ingests aid-in-dying medication, such policies violate the hospice nurse's professional commitments to provide the best care to the patient and family.

We conclude that an institutional policy requiring nurses to leave the room during the ingestion of aid-in-dying medication is ethically unsupportable because it risks violating professional nursing standards, reinforces stigma concerning medical assistance in dying, and potentially abandons patients and loved ones at a critical time in their passage toward a desired and legal death.

If institutions wish not to support patients considering aid in dying, processes exist for non-participation. In all U.S. aid-in-dying jurisdictions, hospice programs have the legal choice to opt out of participating in aid in dying and may decline to accept patients who indicate an intention to take that path. However, if an institution makes a commitment to support patients who choose aid in dying, that commitment should align with best practices in supporting the patient and family. Partial participation where leaving the room is mandated by policy is less than a full commitment.

Few hospices make their aid-in-dying policies apparent to patients when they are considering or are admitted to that hospice. The American Clinicians Academy on Medical Aid in Dying has received numerous reports of patients discharged from hospices when they decided to move ahead with aid in dying without being given advance notice that this was the hospice's policy. In addition, many hospices that say they "support" aid in dying also tell patients the nurse must leave the room during ingestion of the medications. In response to such occurrences, California's SB 380, enacted in 2022 to amend the California End of Life Option Act, requires hospices to "post on the entity's public internet website the entity's current policy governing medical aid in dying."⁴

We recommend that hospice agencies review those policies that require nurses to leave the room at the time of ingestion. The patient and/or family may, of course, request privacy. We suggest that a more patient- and family-centered policy should allow hospice staff to be present

before, during, and after the death of a patient utilizing aid-in-dying medication. Furthermore, all hospice agencies must be transparent about policies for aid-in-dying practices and procedures, including restrictions on staff participation at the time of ingestion, so that patients and families considering hospice providers can make an informed choice.

While our opening case scenario and discussion focus on nursing roles and responsibilities, many of these policies also apply to other hospice staff. These include physicians, social workers, chaplains, and others engaged in the process of supporting patients pursuing medically assisted dying. ▼

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