

Oncology Nursing Society

125 Enterprise Drive • Pittsburgh, PA 15275-1214 Toll Free: 866-257-4ONS • Phone: 412-859-6100 • Fax: 412-859-6165 help.ons.org • www.ons.org

The Nurse's Role When a Patient Requests Medical Aid in Dying

This position statement was endorsed by the ONS Board in September 2019 and was republished with permission from the American Nurses Association (ANA).

Effective Date: 2019 Written by: ANA Center for Ethics and Human Rights

Adopted by: ANA Board of Directors

Purpose

The purpose of this position statement is to provide guidance on ethical decision-making in response to a patient's request for medical aid in dying. This statement offers assistance with understanding nurses' ethical obligations in the context of this end-of-life option, which is legal in an increasing number of U.S. jurisdictions. This position statement recognizes that there are a plurality of views on the issue, that there is a paucity of available research on medical aid in dying. The goal of this position statement is not to frame a stance for or against medical aid in dying but rather to frame the nurse's compassionate response within the scope of practice, based on the Code of Ethics for Nurses with Interpretive Statement is intended to reflect only the opinion of ANA as an organization regarding what it believes is an ideal and ethical response based on the Code of Ethics for Nurses with Interpretive Statements. Nothing in this statement is intended to advocate for the limitation of nurses' rights and protections under applicable laws and regulations or the violation of any laws or regulations that may conflict with or appear to conflict with this statement.

Statement of ANA Position

The delivery of high-quality, compassionate, holistic and patient-centered care, including end-of-life care, is central to nursing practice. Hallmarks of end-of-life care include respect for patient self-determination, nonjudgmental support for patients' end-of-life preferences and values, and prevention and alleviation of suffering. In states where medical aid in dying is legal, patient self-determination extends to include a terminally ill patient's autonomous, voluntary choice and informed request to self-administer medication to hasten death. Medical aid in dying is not synonymous with euthanasia. There is a key distinction between the two terms. Laws that allow medical aid in dying permit an adult patient with a terminal illness and the capacity for medical decision-making to self-administer oral or enteral medication when certain criteria are met. Euthanasia, which is not legal in the United States, occurs when someone other than the patient administers medication in any form with the intention of hastening the patient's death. Euthanasia is inconsistent with the core commitments of the nursing profession and profoundly violates public trust. The term medical aid in dying will be used in this document.

This position statement clarifies the scope of the nursing role in the care of patients who request medical aid in dying, with a particular focus on the Code of Ethics for Nurses with Interpretive Statements' elucidation of nurses' ethical obligations and responsibilities regarding this end-of-life option (ANA, 2015a). Nurses are ethically prohibited from administering medical aid in dying medication.

Yet they must be comfortable supporting patients with end-of-life conversations, assessing the context of a medical aid in dying request (e.g., concern about treatable depression or coercion), advocating optimized palliative and hospice care services, and knowing about aid in dying laws and how those affect practice. Nurses should reflect on personal values related to medical aid in dying and be aware of how those values inform one's ability to provide objective information in response to a patient's request. ANA recognizes that medical aid in dying is a controversial topic that encompasses a plurality of views. Arguments for medical aid in dying are based on respect for patients' self-determination, a desire to prevent unnecessary suffering, assurance that patients have access to the full range of care options at the end of life, and consideration that medical aid in dying is a last act of autonomy. Arguments against medical aid in dying include the sacredness of life, the potential conflict with professional core values, and fears of a "slippery slope," where the increased acceptability of medical aid in dying may impact perceptions of a "life worth living" (Olsen, Chan, & Lehto, 2017; Sulmasy et al., 2018).

Recommendations

"It is the shared responsibility of professional nursing organizations to speak for nurses collectively in shaping health care and to promulgate change for the improvement of health and health care" (ANA, 2015a, p. 36).

Therefore, the American Nurses Association supports recommendations that nurses:

- Remain objective when discussing end-of-life options with patients who are exploring medical aid in dying.
- Have an ethical duty to be knowledgeable about this evolving issue.
- Be aware of their personal values regarding medical aid in dying and how these values might affect the patient-nurse relationship.
- Have the right to conscientiously object to being involved in the aid in dying process.
- Never "abandon or refuse to provide comfort and safety measures to the patient" who has chosen medical aid in dying (Ersek, 2004, p. 55). 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.
- Protect the confidentiality of the patient who chooses medical aid in dying.
- Remain objective and protect the confidentiality of health care professionals who are present during the aid in dying process, as well as the confidentiality of those who choose not to be present.
- Be involved in end-of-life policy discussions and development (Ersek, 2004) on local, state, and national levels, including advocating for palliative and hospice care services.
- Furthermore, research is needed to better understand the phenomenon.

History/Previous Position Statements

The position statement titled Euthanasia, Assisted Suicide and Aid in Dying (2013) was a revised, combined position statement that originated from The Center for Ethics and Human Rights Task Force on the Nurse's Role in End-of-Life Decisions, Center for Ethics and Human Rights. Previously, there were two separate position statements: Assisted Suicide (12/08/94) and Active Euthanasia (12/08/94). The position statement on active euthanasia was then retired. This position statement supersedes those two previous statements.

Other Nursing Organization Positions

The International Council of Nurses (ICN) position statement Nurses' Role in Providing Care to Dying Patients and Their Families (2012) focuses on the right to die with dignity as a basic human right. The ICN also recognizes the impact of cultural values on end-of-life discussions and the role of nurses in these discussions. The ICN highlights the role of the patient in making informed choices and having the right to be free from pain. The Hospice & Palliative Nurses Association (2017) recognizes that nurses employed in states where aid in dying is legal may experience significant moral and ethical conflict.

Background and Supporting Material

Natural Continuum of Life

Nurses recognize that death is part of the natural continuum of life and respect that end-of-life decision making is multifactorial and deeply personal. Nursing: Scope and Standards of Practice (ANA, 2015b) informs the discussion on aid in dying, noting that "nursing occurs whenever there is a need for nursing knowledge, wisdom, caring, leadership, practice, or education. The term 'whenever' encompasses anytime, anywhere, with anyone" (p. 16). Nurses provide expert care throughout life's continuum, managing the biopsychosocial and spiritual needs of patients and families both independently and in collaboration with interprofessional health care teams. The Code of Ethics for Nurses Interpretive Statement 5.3 underscores that in patient care at every stage of life, including at the end of life, "nurses assist others to clarify values in reaching informed decisions, always avoiding coercion, manipulation, and unintended influence. When nurses care for those whose health condition, attributes, lifestyles, or situations are stigmatized, or encounter a conflict with their own personal beliefs, nurses must render compassionate, respectful and competent care" (ANA, 2015a, p. 20). Interpretive Statement 1.2 of the Code supports this as well, stating that "nurses establish relationships of trust and provide nursing services according to need, setting aside any bias or prejudice.... Such considerations must promote health and wellness, address problems, and respect patients' or clients' decisions" (ANA, 2015a, p. 1).

Participation

The Code is clear in Interpretive Statement 1.4 that nurses "should provide interventions to relieve pain and other symptoms in the dying patient consistent with palliative care practice standards and may not act with the sole intent to end life" (ANA, 2015, p. 3). A nurse's ethical response to a patient's inquiry about medical aid in dying is not based on the intention to end life. Rather, it is a response to the patient's quality-of-life self-assessment, whether based on loss of independence, inability to enjoy meaningful activities, loss of dignity, or unmanaged pain and suffering. 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. A nurse is not actively participating in medical aid in dying when supporting dialogue, assessing the context for the request for medical aid in dying, as well as decisional capacity and patient understanding; providing factual information in a neutral manner or responding to a patient request to be present. These nursing actions are aligned with the ethical commitment to support patients in clarifying their goals of care and making fully informed decisions (Scanlon & Rushton, 1996).

Suffering

ANA's Social Policy Statement (2010) includes alleviation of suffering as part of the core definition of nursing, a nursing action fundamental to patient and family- centered care. Requests for medical aid in dying often originate from fear of unmanaged physical pain, suffering, and loss of control (Hamric, Schwarz, Cohen, & Mahon, 2018; Sulmasy et al., 2018). States with long-standing statutes that allow medical aid in dying provide perspectives about the main reasons patients request this option. In Oregon, the most frequent reasons, which have remained stable since 1997, include loss of autonomy (89.5 percent), decreasing ability to participate in activities that made life enjoyable (89.5 percent), and loss of dignity (65.4 percent) (State of Oregon Health Authority, 2016). Fear of intractable pain and suffering associated with dying are very real concerns for people at the end of life. Some health care professionals might argue that palliative and hospice care are designed to address the symptoms, pain, and suffering, thus medical aid in dying is not necessary. Indeed, since legalizing medical aid in dying in Oregon, there has been significant growth in the use of palliative and hospice care resources (Oregon Health Authority Death with Dignity Annual Reports, 1998–2017). A central feature to ethical nursing practice in the care of patients requesting medical aid in dying is ensuring exploration of all alternatives, including high-guality palliative care and aggressive management of pain and suffering. Further research is needed to better understand the medical aid in dying process and the variables impacting patient decisions.

Conscience-Based Refusals

Interpretive Statement 1.2 of the Code notes that "respect for patient decisions does not require that the nurse agree with or support all patient choices" (p. 1), thus the nurse is not required to compromise his or her integrity in the provision of such care. Such situations may result in the nurse experiencing moral distress. "When a particular decision or action is morally objectionable to the nurse, whether intrinsically so or because it may jeopardize a specific patient, family, community, or population, or when it may jeopardize nursing practice, the nurse is justified in refusing to participate on moral grounds. Conscience-based refusals to participate exclude personal preference, prejudice, bias, convenience, or arbitrariness" (ANA, 2015a, p. 21). A well-established ethical commitment when declining to provide care on moral grounds is the primacy of patient care. "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" (ANA, 2015a, p. 21).

Presence

A patient may request that a nurse be present when the patient ingests the aid in dying medication. Presence that is consistent with the Code of Ethics for Nurses includes sensitivity to the patient's vulnerability, demonstration of care and compassion, and promotion of comfort to sustain trust in an established nurse-patient relationship (Numminen, Repo, & Leino-Kilpi, 2017). When making the decision on 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 during medical aid in dying, the nurse promotes patient dignity as well as provides for symptom relief, comfort, and emotional support to the patient and family. The nurse must maintain patient confidentiality and privacy in the aid in dying process. The nurse's decision to be present should not be negatively evaluated (Ersek, 2004; Johnson & Weiler, 1990; Orentlicher et al., 2016).

Regional and Organizational Alignment

Nursing: Scope and Standards of Practice (ANA, 2015b) underscores the importance of knowing state statutes and organizational policies that guide aid in dying practice. "To function effectively, nurses must be knowledgeable about the Code of Ethics for Nurses with Interpretive Statements; standards of practice for the profession; relevant federal, state, and local laws and regulations; and the employing organization's policies and procedures" (ANA, 2015b, p. 12). This is crucial in the context of medical aid in dying, whether a nurse works in a jurisdiction where this option is legal or not.

Summary

Patients expect nurses to be able to discuss all end-of-life options (Monteverde, 2017; Vogelstein, 2019). An understanding of the ethical issues surrounding medical aid in dying is essential to support patients to make informed end-of-life decisions. Nurses should be aware of ethical arguments that support and challenge medical aid in dying. It is especially important that nurses are clear about the ethical foundations of their own views on medical aid in dying. Knowledge of one's own stance helps clarify the boundary between nonjudgment and respect for patients' decisions, and imposition of personal values. Clarity about personal and professional values related to end-of-life options and care can also help nurses recognize the conditions to which they may wish to conscientiously object. The nurse understands the distinction between medical aid in dying and euthanasia, and refrains from acting with the sole intent to end life.

References

American Nurses Association. (ANA). (2010). Nursing's social policy statement: The essence of the profession (3rd ed.). Silver Spring, MD: Author.

American Nurses Association. (2013). Euthanasia, assisted suicide, and aid in dying [Position statement]. Silver Spring, MD: ANA.

American Nurses Association (2015a). Code of ethics for nurses with interpretive statements. Silver Spring, MD: <u>http://nursingworld.org/code-of-ethics</u>

American Nurses Association. (2015b). Nursing: Scope and standards of practice (3rd ed). Silver Spring, MD: Author

Ersek, M. (2004). The continuing challenge of assisted death. Journal of Hospice and Palliative Nursing, 6(1), 46-59.

Hamric, A. B., Schwarz, J. K., Cohen, L. & Mahon, M. (2018). Assisted suicide/aid in dying: What is the nurse's role? American Journal of Nursing, 118(5), 50-59.

Hospice & Palliative Nurses Association. (2017). HPNA position statement: Physician assisted death/physician assisted suicide. Retrieved from https://advancingexpertcare.org/position-statements/

International Council of Nurses. (2012). Nurses' role in providing care to dying patients and their families. Retrieved from <u>https://www.icn.ch/nursing-policy/position-statements</u>

Johnson, R. A., & Weiler, K. (1990). Aid-in-dying: Issues and implications for nursing. Journal of Professional Nursing, 6(5), 258-264.

Monteverde, S. (2017). Nursing and assisted dying: Understanding the sounds of silence. Nursing Ethics, 24(1), 3-8. doi: 10.1177/0969733016684967

Numminen, O., Repo, H., & Leino-Kilpi, H. (2017). Moral courage in nursing: A concept analysis. Nursing Ethics, 24(8): 878-891.

Olsen, D. P., Chan, R. & Lehto, R. (2017). Ethical nursing care when the terminally ill patient seeks death. American Journal of Nursing, 117(7), 50-55.

Oregon Health Authority. (n.d.). Death with dignity annual reports. Retrieved from https://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/arind https://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/arind https://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/arind

Orentlicher, D., Pope, T. M., & Rich, B. A. (2016). Clinical criteria for physician aid in dying. Journal of Palliative Medicine, 19(3), 259-262.

Russell, J.A., Epstein, L.G., Bonnie, R.J., Conwit, R. Graf, W.D., Kirschen, M., ...Williams, M.A. (2018). Lawful physician-hastened death: AAN position statement. Neurology, 90, 420-422. doi: 10.1212/WNL.0000000000000012

Scanlon, C. & Rushton, C.H. (1996). Assisted suicide: Clinical realities and ethical challenges. American Journal of Critical Care, 5(6) 397-403.

Sulmasy, D. P., Finlay, I., Fitzgerald, F., Foley, K., Payne, R. & Siegler, M. (2018). Physician-assisted suicide: Why neutrality by organized medicine is neither neutral nor appropriate. Journal of General Internal Medicine, 33(8), 1394-1399.

Vogelstein, E. (2019). Evaluating the American Nurses Association's arguments against nurse participation in assisted suicide. Nursing Ethics, 26(1):124-133. doi: 10.1177/0969733017694619. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/28532236