Guidelines for the Role of the Registered Nurse and Advanced Practice Registered Nurse When Hastened Death is Requested

Position Statement

People living with advanced illnesses who want to hasten death or avoid prolongation of dying have various options available to them. The Patient Self-Determination Act[1] allows patients to refuse or stop life-sustaining therapies (e.g., ventilator support, cardiac support devices, feeding tubes, nutrition and hydration, etc.),[2] and in states where physician-assisted death/physician-assisted suicide (PAD/PAS) is legal, this as an option as well. It is therefore necessary that palliative and hospice registered nurses (RNs) and advanced practice registered nurses (APRNs) understand the issues related to PAD/PAS. The issues germane to clinical practice include: professional statements, state statutes, organizational policies, patient-centered care, and resource utilization.

The Hospice and Palliative Nurses Association (HPNA) position statement on PAD/PAS states that HPNA does not recognize PAD/PAS as part of palliative care but does emphasize that all patients are entitled to expert and compassionate palliative care.[3] Given that PAD/PAS is legally sanctioned in many states, with legislation in additional states anticipated, guidelines to assist palliative and hospice nurses on how to respond when hastened death is requested are necessary.

Background

The essence of nursing is care for patients across the life cycle. Palliative and hospice nurses focus on the promotion of quality of life to enable patients to live as fully as possible, on their terms, from diagnosis to death. Because the trajectory of dying has changed and people are living longer with progressive debilitating diseases, palliative and hospice nurses care for patients in a variety of settings including acute care, critical care, clinic, home care, long-term care, and hospice care settings.

Caring for patients with progressive debilitating diseases can be challenging especially in the presence of advanced technology when life can be prolonged for extended periods of time and the dying process protracted. In addition, with

overall advances in disease-directed treatment and preventative healthcare, sanitation and nutrition, many people are living longer lives.

Through quality palliative nursing care, most patients experience a peaceful death. However, a person with serious illness may find it difficult to accept a quality of life they deem unacceptable. They may experience existential distress, fear of loss of control, and fear of burdening their family, among other things. This may lead to the desire to hasten their death, often in the form of a request for PAD/PAS to enable a death that comes at a time of their choosing.

Many such patients still require and expect expert palliative and hospice care. It is essential that palliative and hospice nurses are prepared to deliver care to all patients, including those who have requested a hastened death.

To effectively and compassionately respond to the palliative care needs of patients who may hasten death, it is important for RNs and APRNs to proactively consider the issues related to such a request. This includes the *Code of Ethics for Nurses with Interpretive Statements* and the nurse's personal core values. By understanding these aspects of caring for a patient who requests a hastened death, nurses can create a patient-centered plan of care.

Individual palliative and hospice nurse responsibilities:

- Recognize personal and professional values of nursing[4-8] and palliative nursing.[9-11]
- Understand important terms such as dignity, autonomy, and fidelity as defined below.
- Understand that a palliative and hospice nurse can respect a patient's decisions while not agreeing or supporting those choices personally.[5]
- Continue the provision of quality palliative and hospice care.
- Maintain a nonjudgmental attitude and assure fidelity.[5]
- Understand that palliative and hospice nurses may defer involvement with a patient requesting PAD/PAS due to a conscientious objection, but they must follow organizational policy to ensure that care is transferred to another provider.
- Ensure respect for colleagues who may have different opinions pertaining to PAD/PAS and respond in a supportive, nonjudgmental manner.
- Acknowledge that the Patient Self-Determination Act[1] allows patients to refuse or stop life-sustaining therapies (e.g. mechanical ventilation, cardiac support devices, feeding tubes).[2]

Nursing process for patients requesting a hastened death:

- Understand the professional, legal, and ethical issues related to PAD/PAS.
- Reflect on and consider personal moral and ethical values related to PAD/PAS.

- Ensure expert pain and symptom management to eliminate physical distress and refractory symptoms as a factor in a request for hastened death.[6]
- Provide expert palliative care even if, and as, a request for PAD/PAS is being evaluated.
- Determine an understanding of the basis and decision-making behind the request.
- Communicate effectively and compassionately.
- Utilize appropriate resources and specialists to assure optimal palliative care and promote quality of life in all the domains (e.g. physical, psychological, social, spiritual).
- As appropriate, assure that patients understand choices for withholding/withdrawing life-sustaining treatments, voluntary cessation of eating and drinking, and palliative sedation.[4]
- Respond to patient requests for PAD/PAS within legal and professional parameters.
- Support and respect colleague responses to PAD/PAS.

Responding to Requests for Hastening Death[12]

- Clarify the patient's request.
- Assess the patient and attempt to understand the background regarding the request.
- Determine whether the patient:
  - has decision-making capacity;
  - has unmanaged pain;
  - has other uncomfortable symptoms;
  - is experiencing psychosocial distress; and/or
  - is experiencing existential and/or spiritual suffering.
- Evaluate if the patient's symptoms have been fully managed with appropriate interventions and refer as necessary to attend to them. This may require consultation with an APRN, physician, and other palliative and hospice care experts.
- Collaborate with the patient to determine a short-term plan (e.g. new symptom management plan).
- Collaborate with the patient to determine a long-term plan (e.g. consultation with additional resources that may include a chaplain, social worker for family support, bereavement support).
- Consult and collaborate with the healthcare team to assure attention to all dimensions of quality of life. Consult with palliative, hospice, and other specialists.
- Provide additional information, as requested by the patient, regarding options about palliative sedation, withholding/withdrawing life-sustaining therapies, and/or hastening death. Nurses must provide information about those options and/or ensure that another provider can provide the information.[5]
  - Information regarding withholding/withdrawing life-sustaining

    - therapies (e.g. hemodialysis, peritoneal dialysis, mechanical ventilation, cardiac support devices, nutrition and hydration). Refer to HPNA's position statement *Withholding/Withdrawing of Life-Sustaining Therapies*.
    - Information regarding voluntary cessation of eating and drinking.
    - Information regarding palliative sedation for intractable symptoms. Refer to HPNA's position statement *Palliative Sedation*.
    - Information, if desired, regarding the process for being evaluated for PAD/PAS where legalized. Refer to HPNA's position statement *Physician-Assisted Death/Physician-Assisted Suicide.*
- Provide ongoing palliative care and support to the patient and family.

Definition of Terms

Autonomy: A multidimensional ethical concept. It is the right of a capable person to decide their own course of action based on personal values and goals of life. Self-determination is a legal right.[13,14]

Dignity or respect for person: A fundamental ethical principle. Dignity is the quality and state of being honored or valued. Respecting the body, values, beliefs, goals, privacy, actions, and priorities of an autonomous adult preserves their dignity. This is a broader concept than autonomy.[13-15]

Fidelity: The ethical imperative to keep promises. For healthcare providers, fidelity includes the promise not to abandon the patient.[13]

Forgoing life-sustaining treatment: To do without a medical intervention that would be expected to extend the patient's life. Forgoing includes withholding (not initiating) and withdrawing (stopping).[16]

Life-sustaining therapies: "Any medical intervention, technology, procedure, or medication that forestalls the moment of death, whether or not the treatment affects the underlying life-threatening diseases or biological processes. Examples include mechanical ventilation, dialysis, CPR, antibiotics, transfusions, nutrition, and hydration."[16]

Palliative sedation: "When terminally ill, conscious patients experience intolerable symptoms that cannot be relieved by expert palliative care, palliative sedation involves administering sedatives and nonopioid medications to relieve suffering in doses that may induce unconsciousness, but not death."[17(pp583)]

Physician-assisted death (PAD)/Physician-assisted suicide (PAS): The practice of a physician providing a terminally ill patient, who has decision-making capacity, the means to take their own life through the provision of a prescription for a lethal dose of medication.[18]

Refractory symptom: A symptom that cannot be adequately controlled in a tolerable time frame or at a tolerable level despite aggressive use of usual

therapies and seems unlikely to be adequately controlled by further invasive or noninvasive therapies without excessive or intolerable acute or chronic side effects/complications.[19]

References

1. Patient Self-Determination Act of 1990, HR 4449, 101st Cong, 2nd Sess (1990).
2. McCormick AJ. Self-determination, the right to die, and culture: a literature review. *Soc Work*. 2011;56(2):119-128.
3. Hospice and Palliative Nurses Association. *Physician-Assisted Death/Physician-Assisted Suicide*. Pittsburgh, PA. 2013; http://advancingexpertcare.org/wp-content/uploads/2017/07/Physician-Assisted-Death-Physician-Assisted-Suicide.pdf. Accessed July 13, 2017.
4. American Nurses Association. *Nursing Scope and Standards of Practice*. 3rd ed. Silver Spring, MD: American Nurses Association; 2015.
5. American Nurses Association. *Code of Ethics for Nurses with Interpretive Statements*. Silver Spring, MD: American Nurses Association; 2015.
6. American Nurses Association. *Euthanasia, Assisted Suicide, and Aid in Dying*. Silver Spring, MD: American Nurses Association. 2013; http://www.nursingworld.org/euthanasiaanddying. Updated April 24, 2013. Accessed July 13, 2017.
7. American Nurses Association. *Nursing Care and Do Not Resuscitate (DNR) and Allow Natural Death (AND) Decisions.* Silver Spring, MD: American Nurses Association. 2012; www.nursingworld.org/dnrposition. Updated March 12, 2012. Accessed July 13, 2017.
8. American Nurses Association. *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life.* Silver Spring, MD: American Nurses Association. 2010; www.nursingworld.org/MainMenuCategories/Policy-Advocacy/Positions-and-Resolutions/ANAPositionStatements/Archives/etpain14426.pdf. Updated June 14, 2010. Accessed July 13, 2017.
9. American Nurses Association, Hospice and Palliative Nurses Association. *Palliative Nursing: Scope and Standards of Practice.* Silver Spring, MD: American Nurses Association; 2014.
10. Dahlin C, ed. *Competencies for the Hospice and Palliative Advanced Practice Nurse*. 2nd edition. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2014.
11. Sutermaster DJ, Dahlin C. *Competencies for the Hospice and Palliative Registered Nurse*. 3rd edition. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2015.
12. Orentlicher D, Pope TM, Rich BA. Clinical criteria for physician aid in dying. *J Palliat Med*. 2016;19(3):259-262. doi:10.1089/jpm.2015.0092.
13. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 7th ed. New York: Oxford University Press; 2012.
14. Dalinis PM. Informed consent and decisional capacity. *Journal of Hospice and Palliative Nursing*. 2005;7(1):52-57.

15. Elsayem A, Curry LE, Boohene J, et al. Use of palliative sedation for intractable symptoms in the palliative care unit of a comprehensive cancer center. *Support Care Cancer*. 2009;17(1):53-59. doi:10.1007/s00520-008-0459-4.
16. Policy on Forgoing Life-Sustaining or Death-Prolonging Therapy. Cleveland Clinic Web site. https://www.clevelandclinic.org/bioethics/policies/policyonlifesustaining/ccfcode.html. Accessed March 20, 2018.
17. McPhee SJ, Winker MA, Rabow MW, Pantilat SZ, Markowitz AJ. *Care at the Close of Life: Evidence and Experience*. New York, NY: The McGraw Hill Companies; 2011.
18. Medical Definition of Physician-Assisted Suicide. Medicine Net Web site. https://www.medicinenet.com/script/main/art.asp?articlekey=32841. Accessed March 20, 2018.
19. Arnstein PR, Robinson EM. Is palliative sedation right for your patient? *Nursing*. 2011;41(8):50-54. doi:10.1097/01.NURSE.0000399637.52835.d8.

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This position statement reflects the bioethics standards or best available clinical evidence at the time of writing or revisions. This position statement is based on evidence that reflects patients with advanced illnesses and may not be applicable in all palliative circumstances.

To obtain copies of HPNA Position Statements, contact the national office at
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