2019 Membership Assembly
Consideration of ANA's Revised Position Statement: The Nurse's Role When a Patient Requests Medical Aid in Dying

Submitted by: ANA Ethics and Human Rights Advisory Board

During the 2018 Membership Assembly, attendees participated in a Dialogue Forum to consider revising ANA's position statement, *Euthanasia, Assisted Suicide and Aid in Dying (2013)*. The purpose of this report is to present for consideration the revised position statement, *The Nurse's Role When a Patient Requests Medical Aid in Dying* (Appendix A).

2018 Membership Assembly agreed that the following be incorporated into a revised position statement by the ANA Ethics and Human Rights Advisory Board:

- Nurses must respect patients' right to request aid in dying.
- Nurses must be knowledgeable of the law regarding aid in dying in the state or territory in which they practice.
- While nurses are ethically permitted to participate in aid in dying, in states or territories where it is legal, they retain the right to conscientiously object.
- Nurses must be able to provide information on aid in dying and provide emotional support to patients and families who face this decision at the end of life.

Background

There is tremendous controversy over the practice of medical aid in dying. Medical aid in dying is an end-of-life option in which mentally competent, terminally ill adults receive a prescription from their physician for medication that the patients can, if they choose, self-administer to bring about a peaceful death.

The current ANA position statement *Euthanasia, Assisted Suicide and Aid in* Dying (AID) posits that nurses are prohibited from any participation in aid in dying, even in states where it is legal. This topic is nationally relevant as stated in the position statement, "Historically, nurses have played a key role in caring for patients at end-of-life across healthcare settings. Nurses provide expert care throughout life's continuum and at end-of-life in managing the bio-psychosocial and spiritual needs of patients and families both independently and in collaboration with other members of the interprofessional healthcare team". The current ANA position statement was developed when aid in dying was illegal in most states in the US. Aid in dying is now legal in nine jurisdictions, impacting almost 1 million registered nurses. The current ANA position statement does not support nurses' practicing in these states and therefore a recommendation was made by the Professional Policy Committee to revise this position.

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The Ethics Advisory Board began the revision process in July 2018. This included an in-depth review of literature and research on medical aid in dying. Initial discussions focused on each of the recommendations approved at the 2018 Membership Assembly and the alignment with the *Code of Ethics for Nurses with Interpretive Statements*. After several iterations, the proposed draft was submitted for a 60-day public comment period beginning on February 8, 2019 through April 8, 2019. Public comment announcements were disseminated through multiple ANA member emails, social media channels, ANA Constituent and State Nurses Associations, and ANA Organizational Affiliates. As a result, over 2,700 comments were received.

Notable organizations and members that provided comments include the National Association of Catholic Nurses-Canada, Georgetown University Kennedy Institute of Ethics, ANA-New York, ANA- California, ANA-Vermont, American Public Health Association, ANA-Michigan, American Dental Association, American Medical Association, Guam Nurses Association, American Academy of Nursing, American Association of Critical-Care Nurses, Virginia Nurses Association, Kansas Nurses Association, among many others.

While the initial comments were supportive, constructive and evidence informed, subsequent comments towards the public comment deadline were negative and unsupportive of this position. As expected, we received numerous letters of concern and opposition from members of Catholic health associations, "pro-life" organizations, and an online petition against the position. The comments in **opposition** were for some of the following reasons:

- Nurses should not be forced to end a person's life.
- There is an implication that nurses should promote more widespread aid in dying because it is expensive. There is no right to kill oneself, and no reason to promote societal resources for this.
- ANA clearly wants nurses to support aid in dying to make it accessible and affordable in all states- as part of social justice. This is a misunderstanding of the word.
- AID puts enormous pressure on patients to commit suicide.
- In the Netherlands, those considered killable are the terminally ill, chronically ill, people with disabilities, and the elderly with non-threatening illnesses.
- There is no moral difference between euthanasia and AID and nurse involvement should be absolutely prohibited in both.
- Life is a precious gift and suicide should not be advocated for.
- Pain medication is allowed in nursing care, but certainly not an overdose.
- I believe only God should have this right to bring life to a close, not any certain individual.

However, the majority of the comments that were received were positive, supportive, and sought constructive clarification. The comments in **support** were for some of the following reasons:

- Appreciate the clarification in terminology. I wonder if the statement should also just mention that some literature has also used "PAID" (physician aid in dying) and "MAID" (medical aid in dying).

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- With the End of Life Option Act into effect in California since 2015, more and more nurses will be faced with patients asking about information regarding this issue. In light of this new legislation, we want to congratulate ANA in their efforts to re-visit the current Code of Ethics guidelines regarding nurses' position and involvement in Aid in Dying in order to be better prepared and professionally supported by our profession's organization.
- I think this amazingly good! I think this is a helpful addition to practice. Excellent clarification in aid in dying and euthanasia.
- I am a supporter of a patient's right to die with dignity. If a patient that makes it known they want assistance with dying, I don't tell them how to take their own life but refer them to the internet on which states have a right to die legally.
- Great use of references not only from one specialty, but also from intensive care journals, international council, and medical journals that support the position of nurses in the aid in dying process.
- Nurses must be educated on AID so that they can be able to answer the questions the patient may ask.
- I agree with The International Council of Nurses (ICN) position and their statement in Nurses' Role in Providing Care to Dying Patients and their Families (2012). I believe this is a strong argument which is valid and relevant in this statement.
- The language is clear and I appreciate the approach that was taken with both the wording and the role of nurses during this transition for patient during AID.
- I find this to be a remarkably well-written & clear document offering needed guidance in a manner that balances the needs of patients with the individual integrity of nurses. I admire the simultaneous comprehensiveness & succinctness of the text & would have no concern embracing the position statements & recommendations. The quality of the Code of Ethics clearly provides a strong foundation to navigate this & similarly challenging ethical situations.

Summary

Reflecting on comments received during the public comment period, the Ethics Advisory Board revised several sections of the draft position. The section on social justice was removed due to significant negative comments related to its meaning and value. Several comments suggested that the language "aid in dying" be more clinically directed and in alignment with global language. Therefore, the term "medical aid in dying" is now used. In addition, several comments were made regarding the word "nonjudgmental people" and this was changed to "objective people". The recommendations section was moved to the beginning of the position statement for a stronger impact. Lastly, a host of minor word edits, grammar and syntax changes were made.

The Ethics Advisory Board approved moving this position statement forward to the Professional Policy Committee on April 23, 2019.

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Suggested Recommendation

The Committee on Ethics and Human Rights recommends approval of the revised ANA position statement, *The Nurse's Role When a Patient Requests Medical Aid in Dying* (see Appendix A).

Appendix A: Revised Position Statement: The Nurse's Role When a Patient Requests Medical Aid in Dying

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American Nurses Association. (2013). Euthanasia, assisted suicide, and aid in dying [Position Statement]. Retrieved from https://www.nursingworld.org/~4af287/globalassets/docs/ana/ethics/euthanasia-assisted-suicideaid-in-dying_ps042513.pdf

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APPENDIX A

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

DRAFT ANA Position Statement (copyedited)

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 Statements*.

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

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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:

1. Remain objective when discussing end-of-life options with patients who are exploring medical aid in dying.
2. Have an ethical duty to be knowledgeable about this evolving issue.
3. Be aware of their personal values regarding medical aid in dying and how these values might affect the patient-nurse relationship.
4. Have the right to conscientiously object to being involved in the aid-in-dying process.
5. 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.
6. Protect the confidentiality of the patient who chooses medical aid in dying.
7. 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.
8. 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.
9. 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

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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 discussion 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

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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-quality 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

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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

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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.

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