

AMA CODE SAYS

AMA Code of Medical Ethics' Opinions Related to End-of-Life Care

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Abstract

Caring for patients at the end of life (EOL) can be emotionally and ethically challenging for patients, families, and physicians and other health professionals. In accordance with the principle of respect for patient autonomy, patients should feel comfortable expressing their preferences for the EOL care they would like to receive, setting goals for treatment, and choosing surrogate decision makers as appropriate. Physicians are responsible for assisting patients in creating plans for EOL care, encouraging discussion of this subject with sensitivity to patients' situations, and respecting patients' preferences for EOL care. In many cases, compassion and clear communication are important in providing optimal EOL care, as discussed in Chapter 5 of the *Code of Medical Ethics*, "Opinions on Caring for Patients at the End of Life."

Advance Care Planning

Opinion 5.1, "Advance Care Planning," encourages physicians and patients to plan "in advance for decisions about care in the event of a life-threatening illness or injury."¹ [Advance care planning](#) is an effective way to engender discussions among patients, health professionals, surrogate decision makers, family members, and other close contacts about end-of-life (EOL) care. These discussions can support patients in determining their values and preferences regarding the goals of care and the types of services they want to receive as they approach death. Physicians can also take this opportunity "to address patients' concerns and expectations and clarify misunderstandings individuals may have about specific medical conditions or interventions."¹ However, such discussions should not begin only after a potentially fatal illness or injury has befallen a patient. Physicians should "regularly encourage all patients, regardless of age or health status" to consider these issues, "periodically review" with them their "goals, preferences, and chosen decision maker," and include notes from these conversations in medical records.¹ Physicians should make an effort to discuss advance care planning with patients across the age spectrum, encouraging them to think proactively about issues in EOL care, as any patient can find himself or herself afflicted with a potentially fatal condition. For example, medical literature indicates that young adults, who may become caregivers for aging family members, and adolescent oncology patients in particular need to be engaged in advance care planning.²⁻⁴ However,

whenever physicians approach the topic of EOL care, they “should be sensitive to each patient’s individual situations and preferences,” considering the various factors that might affect patients’ decision making, such as “culture, faith traditions, and life experience.”¹

Opinion 5.2, “Advance Directives,”⁵ discusses the importance of documenting advance care planning discussions. **Advance directives**, “whether oral or written, advisory or a formal statutory document,” allow patients to “express their values, goals for care, and treatment preferences to guide future decisions about health care” and to select their surrogate decision makers.⁵ These directives can be changed by patients or created with the help of surrogates. When patients maintain decision-making capacity, their opinions expressed at the time of care supersede any preferences listed in their advance directive, and, as patients continue to make treatment decisions, advance directives and other medical records should be updated accordingly.⁵ When patients lose **decision-making capacity**, physicians and surrogate decision makers, if available, can use advance directives “to make good-faith efforts” to understand patients’ treatment preferences, uphold their values, and—if there is enough information available—make decisions similar to those the patients might have made on their own.⁵ If a surrogate’s wishes contravene an advance directive or if a surrogate is unavailable, physicians should consult “an ethics committee or other appropriate resource” to help resolve the issue.⁵ When an advance directive is not readily available in an emergent situation, “physicians should provide medically appropriate interventions when urgently needed to meet the patient’s immediate clinical needs.”⁵ Once a patient’s preferences can be ascertained, ongoing interventions that violate those preferences can be withdrawn at that time.⁵

Refusal or Removal of Life-Saving Care

Opinion 5.3, “Withholding or Withdrawing Life-Sustaining Treatment,”⁶ discusses cases in which patients (or their surrogates) may refuse or ask to stop life-sustaining treatment. These decisions can be made “even when that decision is expected to lead to [the patient’s] death and regardless of whether or not the individual is terminally ill.”⁶ Such decisions can be applicable to situations of withholding certain life-sustaining treatment altogether or starting and then withdrawing such treatment if certain outcomes (predetermined by the patient or surrogate) are not achieved.

A do-not-attempt-resuscitation (DNAR) order, as detailed in Opinion 5.4, “Orders Not to Attempt Resuscitation (DNAR),”⁷ specifies that no resuscitative measures can be used on patients if they enter cardiopulmonary arrest “in any care setting.” Such orders “can be appropriate for any patient medically at risk of cardiopulmonary arrest, regardless of the patient’s age or whether or not the patient is terminally ill.”⁷ **DNAR orders**, like advance directives, should be included in a patient’s medical record to facilitate use by health professionals.⁷ If there is no DNAR order in the health record, “resuscitation should be attempted if it is medically appropriate.”⁷ If a DNAR order is found after resuscitative

measures have already begun, “the attending physician should order that resuscitative efforts be stopped.”⁷

When discussing the creation of DNAR orders, physicians should clearly explain to patients the resuscitative procedures that might be used, their probability of clinical benefit, and the possible quality of life that may result after such measures are taken. Physicians should also clarify that DNAR orders do not apply to other medical interventions, such as “antibiotics, dialysis, or appropriate symptom management” that, if appropriate, would be “provided or withheld in accordance with the patient’s wishes.”⁷ If a DNAR order is appropriate to the situation of a patient with no DNAR order on record and the patient loses decision-making capacity or cannot express his or her preferences, physicians should “candidly and compassionately” work with surrogates, if available, and “consult with an ethics committee or other appropriate institutional resource” to decide on the best course of action.⁷ Physicians should ensure that the patient or surrogate understands that, beyond the interventions declined, “all other medically appropriate care will be provided, including aggressive palliative care [and] appropriate symptom management if that is what the patient wishes.”⁶

Other Issues in EOL Care

According to Opinion 5.6, “Sedation to Unconsciousness in End-of-Life Care,” when “aggressive, symptom-specific palliation” does not relieve severe pain and distress, the physician can “offer sedation to unconsciousness as an intervention of last resort.”⁸ “Sedation to unconsciousness” refers to the palliative practice of controlling a patient’s symptoms through the continuous administration of a sedative to keep a patient unconscious until death, differentiating it from other forms of palliative sedation that do not result in unconsciousness.⁹ However, these measures “must never be used to intentionally cause a patient’s death,” should be limited to “patients in the final stages of terminal illness,” and should be used after “consult[ation] with a multi-disciplinary team (if available), including an expert in ... palliative care” to ensure that such care is “the most appropriate course of treatment.”⁸ Sedation to unconsciousness can only be used to “address refractory clinical symptoms, not ... existential suffering arising from ... death anxiety, isolation, or loss of control,” which “should be addressed through appropriate social, psychological or spiritual support.”⁸ The patient or surrogate should be educated on the plan of care and give informed consent, and the patient should be closely monitored after sedation.⁷

Opinions 5.7, “Physician-Assisted Suicide,” and 5.8, “Euthanasia,” acknowledge that patients in severe distress may unfortunately “come to decide that death is preferable to life.”^{10,11} However, according to the *Code*, both physician-assisted suicide and euthanasia are “fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”^{10,11}

Summary

The *Code* recognizes the paramount importance of respect for patient autonomy in making decisions about EOL care. Physicians play a crucial role in helping patients and their families to plan in advance for possible life-threatening situations by assisting patients and surrogates with potentially difficult choices and respecting and upholding patient values with compassion and sensitivity. Despite the challenging nature of EOL care, physicians can work together with patients, families, surrogates, and members of the health care team to provide quality care to patients at the end of life.

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