

CHAPTER 5: OPINIONS ON CARING FOR PATIENTS AT THE END OF LIFE

The Opinions in this chapter are offered as ethics guidance for physicians and are not intended to establish standards of clinical practice or rules of law.

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5.1 Advance Care Planning

The process of advance care planning is widely recognized as a way to support patient self-determination, facilitate decision making, and promote better care at the end of life. Although often thought of primarily for terminally ill patients or those with chronic medical conditions, advance care planning is valuable for everyone, regardless of age or current health status. Planning in advance for decisions about care in the event of a life-threatening illness or injury gives individuals the opportunity to reflect on and express the values they want to have govern their care, to articulate the factors that are important to them for quality of life, and to make clear any preferences they have with respect to specific interventions. Importantly, these discussions also give individuals the opportunity to identify who they would want to make decisions for them should they not have decision-making capacity.

Proactively discussing with patients what they would or would not want if recovery from illness or injury is improbable also gives physicians opportunity to address patients' concerns and expectations and clarify misunderstandings individuals may have about specific medical conditions or interventions. Encouraging patients to share their views with their families or other intimates and record them in advance directives, and to name a surrogate decision maker, helps to ensure that patients' own values, goals, and preferences will inform care decisions even when they cannot speak for themselves.

Physicians must recognize, however that patients and families approach decision making in many different ways, informed by culture, faith traditions, and life experience, and should be sensitive to each patient's individual situations and preferences when broaching discussion of planning for care at the end of life.

Physicians should routinely engage their patients in advance care planning in keeping with the following guidelines:

- (a) Regularly encourage all patients, regardless of age or health status, to:
 - (i) think about their values and perspectives on quality of life and articulate what goals they would have for care if they faced a life-threatening illness or injury, including any preferences they may have about specific medical interventions (such as pain management, medically administered nutrition and hydration, mechanical ventilation, use of antibiotics, dialysis, or cardiopulmonary resuscitation);
 - (ii) identify someone they would want to have make decisions on their behalf if they did not have decision-making capacity;

- (iii) make their views known to their designated surrogate and to (other) family members or intimates.
- (b) Be prepared to answer questions about advance care planning, to help patients formulate their views, and to help them articulate their preferences for care (including their wishes regarding time-limited trials of interventions and surrogate decision maker). Physicians should also be prepared to refer patients to additional resources for further information and guidance if appropriate.
- (c) Explain how advance directives, as written articulations of patients' preferences, are used as tools to help guide treatment decisions in collaboration with patients themselves when they have decision-making capacity, or with surrogates when they do not, and explain the surrogate's responsibilities in decision making. Involve the patient's surrogate in this conversation whenever possible.
- (d) Incorporate notes from the advance care planning discussion into the medical record. Patient values, preferences for treatment, and designation of surrogate decision maker should be included in the notes to be used as guidance when the patient is unable to express his or her own decisions. If the patient has an advance directive document or written designation of proxy, include a copy (or note the existence of the directive) in the medical record and encourage the patient to give a copy to his or her surrogate and others to help ensure it will be available when needed.
- (e) Periodically review with the patient his or her goals, preferences, and chosen decision maker, which often change over time or with changes in health status. Update the patient's medical records accordingly when preferences have changed to ensure that these continue to reflect the individual's current wishes. If applicable, assist the patient with updating his or her advance directive or designation of proxy forms. Involve the patient's surrogate in these reviews whenever possible.

AMA Principles of Medical Ethics: I,IV

5.2 Advance Directives

Respect for autonomy and fidelity to the patient are widely acknowledged as core values in the professional ethics of medicine. For patients who lack decision-making capacity, these values are fulfilled through third-party decision making and the use of advance directives. Advance directives also support continuity of care for patients when they transition across care settings, physicians, or health care teams.

Advance directives, whether oral or written, advisory or a formal statutory document, are tools that give patients of all ages and health status the opportunity to express their values, goals for care, and treatment preferences to guide future decisions about health care. Advance directives also allow patients to identify whom they want to make decisions on their behalf when they cannot do so themselves. They enable physicians and surrogates to make good-faith efforts to respect the patient's goals and implement the patient's preferences when the patient does not have decision-making capacity.

An advance directive never takes precedence over the contemporaneous wishes of a patient who has decision-making capacity.

In emergency situations when a patient is not able to participate in treatment decisions and there is no surrogate or advance directive available to guide decisions, physicians should provide medically appropriate interventions when urgently needed to meet the patient's immediate clinical needs. Interventions may be withdrawn at a later time in keeping with the patient's preferences when they become known and in accordance with ethics guidance for withdrawing treatment.

Before initiating or continuing treatment, including, but not limited to, life-sustaining interventions, the physician should:

- (a) Assess the patient's decision-making capacity in the current clinical circumstances.
- (b) Ascertain whether the patient has an advance directive and if so, whether it accurately reflects his/her current values and preferences. Determine whether the patient's current clinical circumstances meet relevant thresholds set out in the directive.
- (c) Ascertain whether the patient has named a health care proxy (e.g., orally or through a formal legal document). If the patient has not, ask who the patient would want to have make decisions should he or she become unable to do so.
- (d) Document the conversation, including the patient's goals for care, and specific preferences regarding interventions and surrogate decision maker, in the medical record; incorporate any written directives (as available) into the medical record to ensure they are accessible to the health care team.
- (e) When treatment decisions must be made by the patient's surrogate, help the surrogate understand how to carry out the patient's wishes in keeping with the advance directive (when available), including whether the directive applies in the patient's current clinical circumstances and what medically appropriate interventions are available to achieve the patient's goals for care. When conflicts arise between the advance directive and the wishes of the patient's surrogate, the attending physician should seek assistance from an ethics committee or other appropriate institutional resource.
- (f) When a patient who lacks decision-making capacity has no advance directive and there is no surrogate available and willing to make treatment decisions on the patient's behalf, or no surrogate can be identified, the attending physician should seek assistance from an ethics committee or other appropriate resource in ascertaining the patient's best interest.
- (g) Document physician orders to implement treatment decisions in the medical record, including both orders for specific, ongoing interventions (e.g., palliative interventions) and orders to forgo specific interventions (e.g., orders not to attempt resuscitation, not to intubate, not to provide antibiotics or dialysis).

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5.3 Withholding or Withdrawing Life-Sustaining Treatment

Decisions to withhold or withdraw life-sustaining interventions can be ethically and emotionally challenging to all involved. However, a patient who has decision-making capacity appropriate to the decision at hand has the right to decline any medical intervention or ask that an intervention be stopped, even when that decision is expected to lead to his or her death and regardless of whether or not the individual is terminally ill. When a patient lacks appropriate capacity, the patient's surrogate may decline an intervention or ask that an intervention be stopped in keeping with ethics guidance for surrogate decision making.

While there may be an emotional difference between not initiating an intervention at all and discontinuing it later in the course of care, there is no ethical difference between withholding and withdrawing treatment. When an intervention no longer helps to achieve the patient's goals for care or desired quality of life, it is ethically appropriate for physicians to withdraw it.

Physicians should elicit patient goals of care and preferences regarding life-sustaining interventions early in the course of care, including the patient's surrogate in that discussion whenever possible. When facing decisions about withholding or withdrawing life-sustaining treatment the physician should:

- (a) Review with the patient the individual's advance directive, if there is one. Otherwise, elicit the patient's values, goals for care, and treatment preferences. Include the patient's surrogate in the conversation if possible, even when the patient retains decision-making capacity.
- (b) Document the patient's preferences and identify the patient's surrogate in the medical record and ensure that the record includes the patient's written advance directive or durable power of attorney for health care (DPAHC), where applicable.
- (c) Support the decision-making process by providing all relevant medical information to the patient and/or surrogate.
- (d) Discuss with the patient and/or surrogate the option of initiating an intervention with the intention of evaluating its clinical effectiveness after a given amount of time to determine if it has led to improvement. Confirm that if the intervention has not achieved agreed-on goals, it may be withdrawn.
- (e) Reassure the patient and/or surrogate that all other medically appropriate care will be provided, including aggressive palliative care, appropriate symptom management if that is what the patient wishes.
- (f) Explain that the surrogate should make decisions to withhold or withdraw life-sustaining interventions when the patient lacks decision-making capacity and there is a surrogate available and willing to make decisions on the patient's behalf, in keeping with ethics guidance for substituted judgment or best interests as appropriate.
- (g) Seek consultation through an ethics committee or other appropriate resource in keeping with ethics guidance when:
 - (i) the patient or surrogate and the health care team cannot reach agreement about a decision to withhold or withdraw life-sustaining treatment;
 - (ii) there is no surrogate available and willing to make decisions on behalf of a patient who does not have decision-making capacity or no surrogate can be identified;
 - (iii) in the physician's best professional judgment a decision by the patient's surrogate clearly violates the patient's previously expressed values, goals for care, or treatment preferences, or is not in the patient's medical interest.
- (h) Ensure that relevant standards for good clinical practice and palliative care are followed when implementing any decision to withdraw a life-sustaining intervention.

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5.4 Orders Not to Attempt Resuscitation (DNAR)

The ethical obligation to respect patient autonomy and self-determination requires that the physician respect decisions to refuse care, even when such decisions will result in the patient's death. Whether a

patient declines or accepts medically appropriate resuscitative interventions, physicians should not permit their personal value judgments to obstruct implementation of the patient's decision.

Orders not to attempt resuscitation (DNAR orders) direct the health care team to withhold resuscitative measures in accord with a patient's wishes. DNAR 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. DNAR orders apply in any care setting, in or out of hospital, within the constraints of applicable law.

In the event a patient suffers a cardiopulmonary arrest when there is no DNAR order in the medical record, resuscitation should be attempted if it is medically appropriate. If it is found after the code is initiated that the patient would not have wanted resuscitation, the attending physician should order that resuscitative efforts be stopped.

Physicians should address the potential need for resuscitation early in the patient's course of care, while the patient has decision-making capacity, and should encourage the patient to include his or her chosen surrogate in the conversation. Before entering a DNAR order in the medical record, the physician should:

- (a) Candidly describe the procedures involved in resuscitation, the likelihood of medical benefit in the patient's clinical circumstances, and the likelihood of achieving the patient's desired goals for care or quality of life to address any misconceptions the patient may have about probable outcomes of resuscitation.
- (b) Ascertain the patient's wishes with respect to resuscitation—directly from the patient when the individual has decision-making capacity, or from the surrogate when the patient lacks capacity. If the patient has an advance directive, the physician should review the directive with the patient and confirm that the preferences set out in the directive about resuscitation are current and valid. The DNAR order should be tailored to reflect the particular patient's preferences and clinical circumstances.
- (c) Reinforce with the patient, loved ones, and the health care team that DNAR orders apply only to resuscitative interventions as they relate to the patient's goals for care. Other medically appropriate interventions, such as antibiotics, dialysis, or appropriate symptom management will be provided or withheld in accordance with the patient's wishes.
- (d) Revisit and revise decisions about resuscitation—with appropriate documentation in the medical record—as the patient's clinical circumstances change. Confirm whether the patient wants the DNAR order to remain in effect when obtaining consent for surgical or other interventions that carry a known risk for cardiopulmonary arrest and adhere to those wishes.
- (e) Document in the medical record the patient's clinical status, prognosis, current decision-making capacity, and preferences with respect to resuscitation, as well as the physician's medical judgment about the appropriateness of resuscitation.

When the patient cannot express preferences regarding resuscitation or does not have decision-making capacity and has not previously indicated his or her preferences, the physician has an ethical responsibility to:

- (f) Candidly and compassionately discuss these issues with the patient's authorized surrogate and document the surrogate's decision in the medical record.
- (g) Revisit with the surrogate decisions about resuscitation as the patient's clinical circumstances change, revising the decision as needed and updating the medical record accordingly.

- (h) Seek consultation with an ethics committee or other appropriate institutional resource if disagreement about a DNAR order that cannot be resolved at the bedside.

When the patient's preferences cannot be determined and the individual has no surrogate, the physician should consult with an ethics committee or other appropriate institutional resource before entering an order not to attempt resuscitation.

AMA Principles of Medical Ethics: I,IV,VIII

5.5 Medically Ineffective Interventions

At times patients (or their surrogates) request interventions that the physician judges not to be medically appropriate. Such requests are particularly challenging when the patient is terminally ill or suffers from an acute condition with an uncertain prognosis and therapeutic options range from aggressive, potentially burdensome life-extending intervention to comfort measures only. Requests for interventions that are not medically appropriate challenge the physician to balance obligations to respect patient autonomy and not to abandon the patient with obligations to be compassionate, yet candid, and to preserve the integrity of medical judgment.

Physicians should only recommend and provide interventions that are medically appropriate—i.e., scientifically grounded—and that reflect the physician's considered medical judgment about the risks and likely benefits of available options in light of the patient's goals for care. Physicians are not required to offer or to provide interventions that, in their best medical judgment, cannot reasonably be expected to yield the intended clinical benefit or achieve agreed-on goals for care. Respecting patient autonomy does not mean that patients should receive specific interventions simply because they (or their surrogates) request them.

Many health care institutions have promoted policies regarding so-called “futile” care. However, physicians must remember that it is not possible to offer a single, universal definition of futility.” The meaning of the term “futile” depends on the values and goals of a particular patient in specific clinical circumstances.

As clinicians, when a patient (or surrogate on behalf of a patient who lacks decision-making capacity) request care that the physician or other members of the health care team judge not to be medically appropriate, physicians should:

- (a) Discuss with the patient the individual's goals for care, including desired quality of life, and seek to clarify misunderstandings. Include the patient's surrogate in the conversation if possible, even when the patient retains decision-making capacity.
- (b) Reassure the patient (and/or surrogate) that medically appropriate interventions, including appropriate symptom management, will be provided unless the patient declines particular interventions (or the surrogate does so on behalf of a patient who lacks capacity).
- (c) Negotiate a mutually agreed-on plan of care consistent with the patient's goals and with sound clinical judgment.
- (d) Seek assistance from an ethics committee or other appropriate institutional resource if the patient (or surrogate) continues to request care that the physician judges not to be medically appropriate, respecting the patient's right to appeal when review does not support the request.

- (e) Seek to transfer care to another physician or another institution willing to provide the desired care in the rare event that disagreement cannot be resolved through available mechanisms, in keeping with ethics guidance. If transfer is not possible, the physician is under no ethical obligation to offer the intervention.

As leaders within their institutions, physicians should encourage the development of institutional policy that:

- (f) Acknowledges the need to make context sensitive judgments about care for individual patients.
- (g) Supports physicians in exercising their best professional judgment.
- (h) Takes into account community and institutional standards for care.
- (i) Uses scientifically sound measures of function or outcome.
- (j) Ensures consistency and due process in the event of disagreement over whether an intervention should be provided.

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5.6 Sedation to Unconsciousness in End-of-Life Care

The duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients. When a terminally ill patient experiences severe pain or other distressing clinical symptoms that do not respond to aggressive, symptom-specific palliation it can be appropriate to offer sedation to unconsciousness as an intervention of last resort.

Sedation to unconsciousness must never be used to intentionally cause a patient's death.

When considering whether to offer palliative sedation to unconsciousness, physicians should:

- (a) Restrict palliative sedation to unconsciousness to patients in the final stages of terminal illness.
- (b) Consult with a multi-disciplinary team (if available), including an expert in the field of palliative care, to ensure that symptom-specific treatments have been sufficiently employed and that palliative sedation to unconsciousness is now the most appropriate course of treatment.
- (c) Document the rationale for all symptom management interventions in the medical record.
- (d) Obtain the informed consent of the patient (or authorized surrogate when the patient lacks decision-making capacity).
- (e) Discuss with the patient (or surrogate) the plan of care relative to:
 - (i) degree and length of sedation;
 - (ii) specific expectations for continuing, withdrawing, or withholding future life-sustaining treatments.
- (f) Monitor care once palliative sedation to unconsciousness is initiated.

Physicians may offer palliative sedation to unconsciousness to address refractory clinical symptoms, not to respond to existential suffering arising from such issues as death anxiety, isolation, or loss of control. Existential suffering should be addressed through appropriate social, psychological or spiritual support.

AMA Principles of Medical Ethics: I,VII

5.7 Physician-Assisted Suicide

Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good.

Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Physicians:

- (a) Should not abandon a patient once it is determined that cure is impossible.
- (b) Must respect patient autonomy.
- (c) Must provide good communication and emotional support.
- (d) Must provide appropriate comfort care and adequate pain control.

AMA Principles of Medical Ethics: I,IV

5.8 Euthanasia

Euthanasia is the administration of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering.

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life.

However, permitting physicians to engage in euthanasia would ultimately cause more harm than good.

Euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks. Euthanasia could readily be extended to incompetent patients and other vulnerable populations.

The involvement of physicians in euthanasia heightens the significance of its ethical prohibition. The physician who performs euthanasia assumes unique responsibility for the act of ending the patient's life.

Instead of engaging in euthanasia, physicians must aggressively respond to the needs of patients at the end of life. Physicians:

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