CENTER FOR PRACTICAL BIOETHICS

GUIDANCE AT THE CROSSROADS OF DECISION

Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatment

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Executive Summary

Considerations Regarding Withholding/ Withdrawing Life-Sustaining Treatment was published in 1992 and revised in 1995, 1997, 2004 and 2015. The basic principles established in the original document endure; however, decisions to withhold or withdraw life-sustaining treatment involve serious ethical issues in the context of the current healthcare delivery environment. Periodic review of the guidelines ensures that ethics committees and their organizations will have fresh and relevant guidance as they review cases, develop educational programs, and help formulate policies within their organizations.

The following issues received additional emphases in the revised document:

- decision making for people who are unbefriended and incapacitated;
- how physicians may respond to requests for treatments they consider ethically inappropriate;
- the increasing acceptance of, and capacity to provide, palliative care; and
- shifting from "futile" care to "non-beneficial" care.

Decisions to forgo life-sustaining treatment pose significant difficulties for providers, patients, and families. Medical boards, legal associations, and many other thought leaders support patient choice, but providers and families are often reluctant to act on decisions that reflect these choices because of personal values, professional standards, and/or perceived legal risks.

There is increasing data that providing palliative care to those who are seriously ill and dying improves quality and outcomes and actually prolongs life.

The revised guidelines provide support and resources to healthcare providers, patients, and families to help them determine whether withholding/withdrawing life-sustaining treatment is the most appropriate treatment they can offer to their patients and loved ones.

The Kansas City Area Ethics Committee Consortium is among the oldest ongoing groups of its kind in the United States. The Consortium is composed of representatives from more than three dozen hospital ethics committees, meeting every other month to discuss complex cases, share educational opportunities, and develop policy guidelines. More than a dozen guideline documents have been created and widely disseminated on issues ranging from withholding and withdrawing life support to ethical issues in managed care, to difficult patient-provider relationships.

Copies of Considerations Regarding Withholding/Withdrawing Life Sustaining Treatment can be obtained by calling the Center for Practical Bioethics at 816 221-1100 or email the Center at bioethic@practicalbioethics.org.

Considerations Regarding Withholding / Withdrawing Life-Sustaining Treatment

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Prologue

Members of the Ethics Committee Consortium believe that these considerations for forgoing life-sustaining treatments will benefit ethics committees as they review cases, develop educational programs, and assist in the development of policies within their institutions. These suggestions are intended to assist hospital ethics committees, palliative care consultation services, family caregivers, healthcare providers, and others. It is important to note also that Consortium members do not believe that this guideline is all-inclusive. It is not the goal of the Consortium to develop a model policy or a community standard.

I. Purpose/Rationale/Goals

A. Provide practical guidance to consortium members, ethics committees, palliative care consultation services, risk managers, and others about ethical issues related to withholding/withdrawing life-sustaining treatment.

B. Protect patients from unwanted treatment and treatments that are potentially harmful.

C. Provide support to healthcare providers who believe withholding/withdrawing life-sustaining treatment is the most appropriate treatment option.

D. Establish a coherent philosophical/ethical foundation to help ethics committees become more effective when providing case consultation involving withholding/ withdrawing life-sustaining treatment.

E. Empower institutions to facilitate appropriate discussion of withholding/ withdrawing life-sustaining treatment.

F. Promote the integration of palliative care.

G. Establish decision making procedures based on systematic, rational, ethically defensible considerations.

II. Problem/Needs to be Addressed

A. Increased technological capacity to sustain life has created the need for critical examination of circumstances in which such treatment may be inappropriate.

B. Providers must respect the critical role that patients and families play in healthcare decision making.

C. The decision to forgo life-sustaining treatment poses significant psychological difficulties for providers, patients, and families.

D. Although medical boards, legal associations, and many other thought leaders support patient choice, the legal system continues to be drawn into withholding/withdrawing treatment decisions. Many providers and families are reluctant to make decisions that reflect the patient's choice because of perceived legal risks.

E. Inequalities in the availability of healthcare raise concerns about the inappropriate use of scarce resources.

F. Due to the aging population and more assertive patients, providers are confronted with an increasing number of cases involving forgoing life-sustaining treatment.

G. Various studies indicate that even when an ongoing provider-patient relationship exists, providers are hesitant to discuss end-of-life issues with patients and their families and often do not know the patient's values and goals.

H. Within and between institutions, there are diverse practices regarding withholding/withdrawing life-sustaining treatment. Regulatory agencies will increasingly require providers to develop policies and procedures regarding these decisions.

I. Court decisions in some states have given healthcare providers cause for concern about the potential for legal problems should they withdraw artificially administered nutrition and hydration from a patient without capacity.

J. Healthcare providers are being asked to provide treatments which they believe to be ethically inappropriate and without benefit to persons who lack decision-making capacity.

K. Palliative care is not yet universally available to all patients.

III. Definitions

A. **Best interest decisions** — the method used by surrogate decision makers to determine what is best for a patient whose preferences are not known; a decision based on what reasonable persons would choose under similar circumstances.

B. **Decisional capacity** — the ability of a patient to make a specific decision; that is, the ability to understand relevant information, to reflect on it, and to communicate (verbally or nonverbally) decisions or preferences to providers.

C. **Family** — a relative or intimate friend.

D. **Life-sustaining treatment** — interventions that are judged likely to be effective in prolonging bodily functions.

E. **Non-beneficial care** — a treatment determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient's well-being or of achieving agreed-on goals of care.

F. **Palliative care** — a range of treatments intended to provide relief of pain and/or suffering, control symptoms, reduce anxiety, and provide comprehensive support to patients. Such care is sometimes referred to as "comfort" care — care that serves to relieve or alleviate pain and suffering without attempting to cure. It has been proven that those who receive palliative care live longer.

G. **Persistent vegetative state** — a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.

H. **Substituted judgment** — the method used by surrogate decision makers who know the patient well enough to determine what he or she would decide; a decision by a surrogate based on the expressed preferences of the patient.

I. **Surrogate** — an agent or agents who act on behalf of a person who lacks

capacity to participate in a particular decision. An appropriate surrogate may be 1) identified by the patient (e.g., in a healthcare treatment directive, living will, or durable power of attorney); 2) appointed by a court (e.g., a guardian); or 3) the adult who is most involved with the patient and most knowledgeable about the patient's personal values and preferences.

J. **Terminal Illness** — an illness, which because of its nature, can be expected to cause the patient to die, usually within six months; an irreversible and unrelenting condition for which there is no known cure.

IV. Identification of Principles/Values

All persons, regardless of their diagnosis or condition (including their medical, ethnic, social, religious, and financial condition) have intrinsic value and personal dignity and deserve compassion.

A. *The principle of respect for autonomy*
Patients have the right to be self-ordering and to make treatment decisions that will affect the course of their lives. This is often called the patient's right of self-determination or autonomy. Important aspects of autonomy include the concept of informed consent; the presumption that patients have the capacity to make decisions and the right to delegate decision making authority; the patient's right to be adequately informed; and, the right to authorize or refuse any medical treatment.

B. *The principle of beneficence/nonmaleficence*
The obligation to promote the good of the patient is basic to the relationship of healthcare professionals and patients. The obligation to promote the patient's good involves identifying the possible benefits and burdens from the patient's perspective. One of the oldest and most established principles of healthcare ethics counsels providers to avoid or minimize any harm to patients. Providers are obligated to carefully weigh the burdens and risks associated with any proposed treatment. When treatment becomes unacceptably burdensome to the patient, no longer provides reasonable benefits to the patient, or is inconsistent with the patient's known wishes or goals of treatment, it should be discontinued.

C. *The principle of justice*
Decisions about life-sustaining treatment should be based on clinical judgment and the patient's known goals and wishes, not on considerations of race, ethnicity, or socioeconomic status. Simply stated, like cases should be treated similarly.

V. Assumptions Regarding Decisions to Withhold/Withdraw Life-Sustaining Treatment

A. A patient's decision to forgo life-sustaining treatment does not constitute a decision to commit suicide. Death occurs as a result of the patient's underlying condition.

B. A healthcare provider's decision to respect the patient's or surrogate's wishes to withdraw or withhold life-sustaining treatment does not constitute killing, assisted suicide or euthanasia.

C. Healthcare providers have an obligation to provide treatment and care that will allow a peaceful and dignified death with minimal suffering.

D. The assumption that patients and families want to prolong life in every circumstance provides inadequate guidance to healthcare providers.

E. Healthcare providers and/or institutions that object to a decision to forgo treatment should inform the patient or surrogate of their position and assist in the orderly transfer of care to another provider or institution. Institutions that have policies that limit patients' choices should make those policies known to patients on or before the time of admission.

F. All life-sustaining treatment, including, for example, artificial nutrition and hydration, may be withheld or withdrawn. If doubt exists regarding possible benefits or burdens of a treatment, time-limited trials of treatment may be helpful and should be undertaken with the clear understanding that ineffective treatments can be stopped.

G. Treatment that is unwanted and/or deemed "non-beneficial" may cause additional harm and suffering to patients.

H. When a decision to forgo a particular life-sustaining treatment is made, both healthcare providers and the institution, have a continuing obligation to provide palliative care.

I. Providers usually have the obligation to respect patients' (or patients' surrogates') requests to be provided with, and continue to receive, life-prolonging treatment. However, providers are not obligated to provide treatments that are clearly non-beneficial; nor are they obligated to provide treatment if in their judgment it is ethically inappropriate. If conflict occurs, providers are obligated to engage in conflict resolution. If the conflict cannot be resolved, they are obligated to assist in the orderly transfer of the patient to another physician.

J. Therapy that has been initiated as part of an experimental protocol or because of complications of medical treatment should be irrelevant in a withholding or withdrawing treatment decision.

VI. General Guidelines for Decision Making

A. Model of Shared Decision Making

These guidelines presume that the ideal model for making treatment decisions is one in which the responsibility is shared by providers and patients or surrogates although, when known, the goals and values of the patient are given special consideration and are always at the center of decision making. Members of the healthcare team and the patient or surrogate should have an opportunity to participate actively in all such decisions. When there are conflicting judgments regarding the appropriateness of a decision, mechanisms such as ethics committee consultations or palliative care consults should be available to address and help resolve such conflict.

B. Sound Ethical Decision Making Criteria

Clinical decision making is a complex process. No simple formulas or rules will suffice; however, there are parameters about which there is general consensus. Used with knowledge and experience, these parameters provide guidance about how to make an ethical treatment decision.

1. Persons with decisional capacity may choose to forgo any medical or surgical intervention. (Affirmed by the US Supreme Court in 1990 – Cruzan case)

2. Surrogate decision making for persons without decisional capacity:
   a. Substituted judgment decisions: If the providers and surrogate determine that forgoing life-sustaining treatment is clearly in accord with the patient's values and previously expressed

preferences, that plan of care should be pursued.

b. Best interest decisions: When the wishes and values of the patient are not clearly known or discernible, the providers and surrogate cannot determine that forgoing life- sustaining treatment is in accord with the patient's values and preferences. In such cases, decisions should be based on the patient's best interest. Best interest can be defined as the choice that reasonable persons would make for themselves if they were in the patient's condition. In applying this standard:

- To patients who are terminally ill, the major considerations are to avoid the burden of prolonging dying and to determine whether the patient has the potential to achieve some satisfaction from prolonged life.
- To patients who have a severe and irreversible illness, the decision should be made by balancing the benefits and burdens in each case.

In all cases involving the best interest standard, an ethics consultation may be helpful.

3. No simple formula will capture the complexities involved in determining who among the patient's friends and relatives is or are the appropriate surrogates if no one has been designated by the patient. The responsibility is, therefore, on the physician, with the assistance of the care team and / or ethics committee, to identify a surrogate who is well acquainted with the patient and willing to assume this role.
4. In situations where no surrogate can be found who is well acquainted with the patient and willing to assume this role, an ethics committee may be helpful to the provider. The provider in consultation with others (e.g., nursing home staff, ethics committee members) should be comfortable making decisions about withholding or withdrawing treatment without involving the court. Seeking a court-appointed guardian should be considered a matter of last resort. In such cases, the decision making process and justification for the decision should be well documented. Consultation with the ethics committee may be helpful.

C. Role of the Healthcare Provider

Providers have a responsibility to advocate for the well-being of their patients. This responsibility will ensure that decisions to forgo life-sustaining treatment are patient-focused and complemented by palliative care and that concerns about cost and malpractice do not become the grounds for decision making. The provider's responsibility includes ensuring that

- a comprehensive and accurate evaluation of the patient's condition has taken place;
- the entire range of treatment options consistent with standards of practice has been carefully considered;
- time-limited therapies have been conducted as appropriate;
- palliative care has been included in the treatment plan;
- the appropriate surrogate has been determined; and
- the patient or surrogate is informed and involved in the process.

D. Non-beneficial Treatment

Non-beneficial treatment is any therapeutic act or course of action determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient's well-being or helping to achieve the agreed on goals of care. Providing non-beneficial

treatment may increase the patient's pain and suffering and shorten life.

1. If the care providers directly involved in the care of the patient agree that a treatment is non-beneficial, there is no ethical obligation to provide the treatment.
2. A patient or the patient's surrogate should be fully informed when a treatment that could be used, such as CPR, is considered non-beneficial.
3. If a patient, the patient's surrogate, or physician requests a non-beneficial treatment, all options should be explored for resolving the conflict, including an ethics committee consultation. If the conflict cannot be resolved, the provider may withdraw from the case and transfer care to another physician. Although the provider has no ethical obligation to provide non-beneficial treatment, he or she is morally obligated not to abandon the patient.
4. Involving the court in conflicts related to medical decision making should always be a last resort.

E. Role of the Patient or Surrogate Decision Maker

1. **Patients with decisional capacity:** The decision by a patient with decisional capacity to forgo a potentially life-sustaining intervention is attested by the patient's informed consent. Adults with decisional capacity, even when not terminally ill, have the right to refuse to authorize any medical or surgical intervention.

1. **Patients who have made their wishes known:** If a patient who lacks decisional capacity has previously executed an advance directive or otherwise made known his or her preference that a life-sustaining treatment be withheld or withdrawn, such directions should be respected. Where a patient has appointed a surrogate to make such decisions (i.e., a "durable power of attorney" or "healthcare surrogate"), decisions made by the surrogate should be honored.

   Surrogate decisions can always be challenged on the basis that the surrogate is not acting consistently with the expressed preferences and values of the patient. As surrogates are obligated to act in accord with the patient's expressed wishes, the surrogate who is not following the patient's expressed wishes must be able to provide the basis for the decision. An ethics committee consultation may be appropriate in these circumstances.

2. **Patients with prior decisional capacity who have not executed an advance directive or appointed a surrogate:** Where possible, providers of such patients should work with the patient's family and appropriate others to identify an appropriate surrogate decision maker: one who knows the patient's values and preferences. If the patient has been declared legally incompetent, the surrogate would usually, but not always, be the court-appointed guardian.

3. **Patients who lack decisional capacity, are unbefriended, or who never developed decisional capacity:** When decisions to forgo life-sustaining treatment involve a person who has never developed decisional capacity, such as infants, young children, or persons with severe mental impairment, or unbefriended persons, it is not possible to base such decisions on the individual's preferences and values. Surrogate decision making in these circumstances will be based on the best interest standard. Ethics committee

consultation may be helpful and/or required in such cases.

F. Role of the Institution and the Ethics Committee

1. The primary duty of the healthcare institution is the care of patients, including supporting those patients and families who face decisions about withholding and withdrawing treatment. The institution can fulfill its responsibilities to these persons through a wide range of mechanisms, including case management conferences, mental health or pastoral counseling, palliative care consultation, and review by the institutional ethics committee.

2. The primary responsibilities of the ethics committee are advocacy, case consultation, and policy review and development.

   a. The primary role of the ethics committee is to assure that the patient's goals and values are heard and respected.
   b. The ethics committee provides a forum in which questions and/or disagreements regarding decisions to forgo life-sustaining treatment can be discussed and recommendations made.
   c. Committee consultation and review may occur in response to a request from a patient, the patient's family or surrogate, or from any provider directly involved in the patient's care.
   d. Ethics committee consultation is strongly recommended for cases in which an appropriate surrogate has not been found for a patient lacking decisional capacity and in cases in which there is persistent disagreement among those responsible for making the decision.
   e. Legal resolution should be an option of last resort.

VII. Changing the Decision

All parties in decisions to forgo life-sustaining treatment should be aware that such decisions can be changed at any time if desired by the patient or if a reassessment or change in the condition of the patient warrants such a change.

VIII. Documentation

A. Discussions and decisions regarding the withholding or withdrawing of life-sustaining medical treatment should be documented in the medical record. Documentation should include the basis of the decisions and a record of the process by which the decisions were made.

B. When an ethics committee consultation regarding withholding or withdrawing treatment has occurred, that fact should be noted in the medical record in addition to the ethics committee's own documentation of the consultation.

This document was completed in 1992 with revisions in 1995, 1997, 2004 and 2015.

For additional copies, contact

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