MBC CONSORTIUM DOCUMENT

Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatment

by the Kansas City Area Ethics Committee Consortium of Midwest Bioethics Center

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MIDWEST BIOETHICS CENTER

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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 specifically to assist ethics committees; this is not a document intended for the general public. It is important to note also that Consortium members do not believe that this list is comprehensive. It is not the goal of the Consortium to in any way develop a model policy or a community standard.

NOTE: In 1997, members of the Consortium decided to review this document for two reasons:

1. *There was a proliferation of articles about "medical futility;" and*
2. *Consortium members were concerned about decision making for persons who had either lost capacity without providing information about or insights into their personal treatment preferences, and persons who had never developed the capacity to make such decisions.*

I. Purpose/Rationale/Goals

A. Provide practical guidance to consortium members, their ethics committees, and their institutions about the ethical issues.

B. Provide support to health care providers who believe withholding/withdrawing life sustaining treatment is the most appropriate treatment option.

C. Establish a coherent philosophical/ethical foundation to help committees become more effective when providing case consultation.

D. Empower institutions to facilitate appropriate discussion of withholding/withdrawing life-sustaining treatment on a regular basis.

E. Attempt to establish decision-making procedures based on systematic, rational considerations.

II. Problem/Needs to be Addressed

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

B. Providers must come to respect the critical role that patients and families play in health care decision making.

C. The traditional assumption that providers have an obligation to prolong life in every circumstance provides inadequate guidance

D. The decision to forgo life-sustaining treatment poses significant psychological difficulties for providers.

E. The legal system has become inappropriately drawn into withholding/withdrawing treatment decisions because many providers and families are reluctant to make such decisions because of perceived legal risks.

F. Inequalities in health care availability have led to concerns about the inappropriate use of scarce resources.

G. Due to the aging population providers will be confronted with an increasing number of cases involving forgoing life- sustaining treatment.

H. The traditional relationship between physician and patient was governed by the notion that the physician should make the decision and may have provided the physician with knowledge about the patient's goals and values; this relationship often does not exist in contemporary health care delivery context.

I. 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.

J. Current case law in Missouri has raised questions in the minds of health care providers about potential legal problems if food and hydration are withdrawn or withheld from a person without capacity, without "the clear and convincing" evidence standard in Missouri.

K. Health care providers are being asked to provide to persons without capacity treatments which they believe are inappropriate and without benefit.

III. Definitions

A. Decisional capacity—a term used to reflect the ability of a patient to make a specific decision, i.e., the ability to understand relevant information, to reflect on it, and to communicate (verbally or nonverbally) decisions or preferences to providers.

B. Life-sustaining treatment—interventions that are judged likely to be effective in prolonging the life of a patient or which are being utilized to sustain the life of a patient.

C. Comfort 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 often referred to as "palliative" care — care that serves to relieve or alleviate without attempting to cure.

D. Terminal Illness—an illness, which because of its nature, can be expected to cause the patient to die. Usually thought of as an irreversible and unrelenting condition for which there is no known cure.

E. Surrogate—an agent who acts on behalf of a person who lacks capacity to participate in a particular decision. An appropriate surrogate may be: 1) delegated by the patient (e.g., in a health care treatment directive, living will, and/or durable power of attorney); 2) designated 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. No simple formula will capture the complexities involved in determining who among the patient's friends and relatives is the appropriate surrogate if none has been designated by the patient. The responsibility is, therefore, on the physician to identify a surrogate.

In situations where no surrogate can be found, an ethics committee or provider who is well acquainted with the patient may assume that role. Seeking a court appointed guardian should be considered as a matter of last resort.

F. Futile—a treatment determined on the basis of current medical knowledge and experience by the patient's attending physician to hold no reasonable promise for contributing to the patient's well being. Palliative care is never futile.

G. Family—a relative or intimate friend.

IV. Identification of Principles/Values

Health care has traditionally been based on the

assumption that human life is precious and that it should be preserved whenever possible. However praiseworthy, this important principle does not provide a full understanding of the many ethical principles that should be considered when withholding/withdrawing treatment.

A. The principle of autonomy

Patients have the right to make decisions about the course of their life for themselves. 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; the presumption that patients have a 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 "do no harm" (nonmaleficence)

One of the oldest and most established principles of health care 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 no longer provides reasonable benefits or becomes unacceptably burdensome, it should be stopped.

C. The principle of beneficence

The obligation to promote the good of the patient is basic to the relationship of health care professionals and patients. Extending life usually, but does not always, promote the good of the patient. The patient's life, for example, may be full of pain or suffering, and the patient may prefer to forgo the treatment even though it means an earlier death. The obligation to promote the patient's good involves identifying the possible benefits and burdens from the patient's perspective. If continuing to provide a treatment offers inadequate benefits to the patient, it should be stopped.

D. The principle of justice

Considerations of procedural justice require that decisions about withholding and withdrawing treatment should involve shared decision making by patients/surrogates and providers. The magnitude of decisions to withhold or withdraw life-sustaining treatment requires considerations of justice as fairness, i.e., that such decisions should incorporate the ideals of due process.

E. The principle of equity (distributive justice)

There are serious problems regarding the just distribution of health care resources in the United States. The lack of guidance and support for withholding and withdrawing inappropriate life-sustaining treatments may contribute to the unjust distribution of these resources.

The magnitude of decisions to withhold or withdraw life-sustaining treatment requires considerations of justice as fairness, i.e., that such decisions should incorporate the ideals of due process.

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

(These are assumptions that have been agreed to by the people working on this document. They are not to be construed as anything more.)

A. A patient's decision to forgo life-sustaining treatment does not constitute a decision to commit suicide. A decision to withhold or withdraw such treatment from a patient does not involve "killing," "causing a person to die," or "active euthanasia."

B. Health care providers have an obligation to try to provide treatment and care that will result in a peaceful and dignified death with minimal suffering. Requests by patients for interventions intended to terminate their life should not be honored.

C. Health care providers and/or institutions who have an objection 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.

D. Any life-sustaining treatment may be withheld or withdrawn. If doubt exists regarding possible benefits or burdens of a treatment, time-limited trials of treatment should usually be undertaken.

E. Treatments involving life prolonging artificial nutrition and/or hydration may be withheld or withdrawn under appropriate circumstances.

F. When a decision to forgo a particular life-sustaining treatment is made, both health care providers and the institution have a continuing obligation to provide a comprehensive range of comfort care and supportive treatment including the consideration of alternative methods of care such as hospice programs.

G. Providers usually have the obligation to respect the requests of patients (surrogates) to be provided or to continue to receive a life-prolonging treatment. However, providers are not obligated to provide treatments that are clearly futile; nor are they obligated to provide treatment if in their judgment it is ethically inappropriate.

H. That a therapy has been initiated as part of an experimental protocol should be irrelevant in a withholding or withdrawing of treatment decision.

VI. General Guidelines for Decision Making

A. Model to Shared Decision Making

These guidelines presume that the ideal model for making such decisions is one in which the responsibility is shared by providers and patients or surrogates. It is assumed that all members of the health care team and the patient or surrogate must have the opportunity to participate actively in all such decisions. This model also presumes that such decisions will not be implemented unless there is consensus among those responsible regarding the appropriateness of the decision. When there are conflicting judgments regarding the appropriateness of such a decision, mechanisms must be available to address and, hopefully, 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 agreement. Coupled with medical 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.

2. Surrogate decision making for persons without decisional capacity:

   a. Substituted judgment decisions: If the providers and surrogate agree 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: If the providers and surrogate cannot agree that forgoing a life-sustaining treatment is in accord with the patient's values and preferences, then decisions should be based on what is in that patient's best interest by

reference to more objective societally determined standards. Another way of expressing best interest criteria is to choose so as to promote the patient's interests as they would be conceived by reasonable persons when in the patient's condition. In applying this standard:

- To patients who are terminally ill the major considerations are usually avoiding the burden of prolonging dying and whether the patient has the potential benefit of achieving 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.
- To the patient with an irreversible loss of consciousness consideration of the benefits and burdens to caretakers and family are appropriate.

C. Role of the Health Care Provider(s)

Providers have the responsibility for loyalty to the welfare of the patient, ensuring that decisions to forgo life-sustaining treatment are patient focused and that concerns about cost and malpractice do not become the providers' primary grounds for decision making. The providers' responsibility includes ensuring that comprehensive and accurate evaluation of the patient's condition has taken place; that the entire range of treatment options has been carefully considered; that appropriate therapeutic trials have been considered and conducted where appropriate; and, that the patient or surrogate is informed and involved in the process.

D. Futile Treatment

Futile treatment is a treatment determined on the basis of current medical knowledge and experience by the patient's attending physician to hold no reasonable promise for contributing to the patient's well being. Palliative care is never futile.

1. If there is no surrogate for an incapacitated patient, and care providers directly involved in the care of the patient agree that a treatment is futile, there is no ethical obligation to provide the treatment.
2. A patient/surrogate should be informed both when and why a treatment that could be used, such as CPR, is considered to be futile.
3. Should a patient/surrogate request a futile treatment, the provider and patient/surrogate should explore all options for resolving the conflict. However, the provider has no ethical obligation to provide futile treatment.

If the conflict cannot be resolved, the health care provider may withdraw from the case and transfer care to another physician who will honor the patient/surrogate's wishes.

E. Role of the Patient or Surrogate Decision Maker

1. Patient with decisional capacity: A decision to forgo a potentially life-sustaining intervention in the case of a patient with decisional capacity requires the informed consent of the patient. Adults with decisional capacity, even when not terminally ill, have the right to refuse to authorize any medical intervention.
2. Patient who has executed an advance directive: If, when a patient without decisional capacity has previously

executed an advance directive 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 ("durable power of attorney" or "health care surrogate"), decisions made by the patient's agent should be honored.

3. Patient with prior decisional capacity who has 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. If the patient has been declared legally incompetent, the surrogate would usually be the court appointed guardian.

4. Patient who has 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 severely mentally impaired persons, it is not possible to base such decisions on the individual's preferences and values. Decision making will usually be based on the "best interest" standard.

F. Role of the Institution and the Ethics Committee

1. A health care institution can discharge its responsibilities for supporting persons making these difficult decisions through access to a wide range of mechanisms to address conflict including consultation, case management conferences, mental health or pastoral counseling, ethics consultation and/or review by the institutional ethics committee.

   a. A primary role of the ethics committee is that of providing a forum in which questions and/or disagreements regarding decisions to forgo a life-sustaining treatment can be discussed and resolved.

   b. Committee consultation and review may be undertaken in response to a formal request by a patient, family/surrogate, or any provider directly involved in the care of the patient.

   c. Such consultation should be strongly considered in cases in which an appropriate surrogate cannot be identified for a patient without decisional capacity and in cases in which there is persistent disagreement among those responsible for making the decision. In such cases, the ethics committee may play the role of surrogate decision maker.

2. Legal resolution should only be an option of last resort.

VII. Changing the Decision

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

VIII. Documentation

All discussions regarding and decisions to withhold or withdraw life-sustaining medical treatment should be documented in the medical record. Documentation should include both orders necessary to implement such decisions and appropriate documentation of the justification for and the process by which the decision was made.

(This document was completed in 1995 and revised in 1997.)

Kansas City Area Ethics Committee Consortium

Organized in 1996, the Kansas City Area Ethics Committee Consortium is now the oldest in the United States. Approximately three dozen health care providing institutions participate in the consortium, which meets bimonthly. Members include physicians, attorneys, philosophers, nurses, administrators, board members, patient representatives, social workers, and clergy.

In addition to sharing educational opportunities, policies, case experiences, and staying apprised of current health care legislation, Consortium members undertake projects on current issues in health care ethics, researching, discussing, reaching conclusions, and writing papers that document their work. Midwest Bioethics Center acts as a repository for the Consortium documents.

Additional information and a list of Consortium documents may be obtained from Midwest Bioethics Center, 1021-1025 Jefferson Street, Kansas City, MO 64105.