

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 Confirm that if the intervention has not achieved agreed-on goals, it may be withdrawn.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.

AMA Principles of Medical Ethics: I,III,IV,V

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report D-A-91 Decisions to forgo life-sustaining treatment for incompetent patients

CEJA Report B-A-91 Decisions near the end of the life

Opinion of the Judicial Council, Dec 94 Terminal illness – patients' preferences

CEJA 3-A-16 Modernized Code of Medical Ethics

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- (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. [New guidance incorporated consistent with 5.1.]*
- (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. [New guidance incorporated consistent with 5.1.]*
- (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. [New content addresses gap in current guidance.]*
- (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.*
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- (g) Seek consultation through an ethics committee or other appropriate resource in keeping with ethics guidance when:
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 - (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. [New content incorporated consistent with 5.6.]*

AMA Principles of Medical Ethics: I,III,IV,V

INTRODUCTION

Report 33 of the Council analyzes the right of competent patients to refuse life-sustaining treatment, including artificial nutrition and hydration. However, many patients who are critically ill and dependent on life supports are also incompetent to make decisions about their medical treatment. The number of persons who lack decision making capacity who are dependent on life-sustaining treatment has increased with the advance of the medical technology of life support and the use of medications (such as highly toxic cancer drugs) that impair decision making capacities.¹ It is estimated that there are between three and six million elderly persons who are incompetent due to different forms of dementia.¹ At the other end of the life spectrum are those minors who lack decision making capacity due to their immaturity. Seriously ill newborns are a group for which there has been considerable controversy about decisions to forgo life support. It has been estimated that 6% of all live-born infants are admitted to a neonatal intensive care unit, where the average stay is 8-18 days.² Furthermore, there are patients who, due to mental retardation, brain damage, or mental illness, have diminished capacity to make decisions. Therefore, this report will examine the ethical guidelines regarding withdrawing/withholding life-sustaining treatment from incompetent patients.

DECISION MAKING CAPACITY AND COMPETENCE

The concept of decision making capacity is also referred to as "competence." Competence in other contexts has been defined as a determination of a person's general soundness of mind. However, in this context the term signifies the capacity to perform the specific task of deciding to receive or forgo life-sustaining treatment.^{1,2} In other words, competence here is to be understood as a "task-relative" condition.¹ An evaluation of a patient's competence or decision making capacity should not necessarily be a legal determination.² A determination of a patient's competence or decision making capacity should be based on an evaluation of the patient's decision making process rather than on the content of the decision.^{1,2} While a decision to refuse life sustaining treatment may prompt an evaluation of competence, the refusal should not be the basis by which the patient is deemed incompetent. A judgement of decision making capacity should not be based on the patient's age or diagnosis. For example, there are fairly mature children and mildly retarded persons who may be competent to make medical decisions. Factors that must be considered when evaluating decisionmaking capacity are the patient's capacity to understand, reason and communicate.

It should be noted that there are patients who do not have decision making capacity but still possess a limited ability to comprehend, reason or express preferences. Such patients should participate in the decision making process and should have influence on the decision. For example, incompetent patients who have some capacity for understanding should be informed about their situation and the decisions that will have to be made. Preferences about treatment should be elicited from patients who can express preferences. Efforts should be made to accommodate these preferences except when doing so would conflict with the patient's previous preferences or values or would be detrimental to the patient's well-being.^{1,2}

The competence of some patients may fluctuate. In other words, some patients who are judged to be incompetent may regain competence at a different time or in a different situation.^{1,2} Furthermore, for some patients the barriers to decision making capacity may be removable, at least temporarily. Every effort should be made to identify the causes for incompetence and the

situations in which a person may regain competence.² Patients should be given the opportunity to make treatment decisions when they are competent unless competence is too brief for the patient to make a reasoned decision.²

GUIDELINES FOR MAKING DECISIONS FOR INCOMPETENT PATIENTS

There are two principal aims that must guide treatment decisions; (1) respecting and promoting patient autonomy, and (2) fostering the well-being of the patient.^{1,3} Respect for a patient's autonomous decision to forgo life-sustaining treatment is likely to best promote the patient's well-being because treatment decisions often involve personal values and preferences along with objective medical considerations. Judgments about which treatments are too burdensome and when one's life is not worth preserving vary tremendously depending upon individual values and preferences. Further, by respecting patients' decisions, medicine maintains the fundamental bioethical principle of patient autonomy.¹

Autonomous decision making, however, requires that the person have the capacity to make decisions (i.e., the ability to understand, communicate and reason). Some incompetent patients may be so incapacitated that they cannot decide or communicate a decision. Further, when patients are able to express a decision, but are incapable of either understanding or reasoning, their choices cannot be relied upon to promote their well-being.

On the other hand, the right to forgo burdensome treatment persists for persons even though they may be incompetent to make decisions about life support.^{1,4-6} To balance this right against the need to protect incompetent persons from potentially harmful choices, three standards have been established in the bioethical and legal literature to guide decisions about life sustaining treatment for incompetent patients. These standards are referred to as; (1) the advance directive, (2) substituted judgment, and (3) best interests.

ADVANCE DIRECTIVES

An advance directive is a document that enables competent persons to exercise their right to direct medical treatments in the event that they lose their decision making capacity. There are two categories of advance directives: (1) a living will, which indicates the types of treatment that an individual wishes to receive or forgo under specified circumstances, and (2) a durable power of attorney for health care, which designates a proxy to make treatment decisions. There are a number of different advance directive forms currently available and many more are being developed. Some forms may combine a proxy designation with specific instructions for the proxy.

The obligation to respect a competent patient's right to self-determination includes the obligation to follow the instructions of an advance directive. An advance directive directly reflects the patient's values and preferences with regard to life-sustaining treatment.¹

The designation of a proxy is an effective way to ensure appropriate interpretation of the patient's preferences in specific circumstances which the patient may not have foreseen at the time the directive was issued. On the other hand, the specificity of a living will may better ensure that in a circumstance that was anticipated, decisions will reflect the patient's preferences. To have the benefits of a durable power of attorney and a living will, patients may document a proxy designation and, while competent, discuss with their proxies their preferences and values that should be considered when making treatment decisions. Individuals may also want to document specific instructions to be used by their proxies.

To aid future decisions about life-sustaining treatment, physicians should routinely discuss with patients treatment preferences while patients are competent to make decisions about their health care.⁷ Physicians should explain the types of situations that would require life-sustaining treatment and the kinds of decisions that might have to be made. Physicians should inform their patients of the opportunity to issue an advance directive and discuss the benefits and drawbacks of the different types of forms. Physicians should also encourage patients to discuss their preferences and values with friends and family, in particular those who may have to act as their surrogate decision makers.

Forty-one states currently have living will statutes and 22 have statutes recognizing the durable power of attorney for health care specifically for decisions about life-sustaining treatment.⁸ Though the vast majority of people support the use of advance directives, only about 5-10% of adults have them.⁹ However, the Supreme Court decision in *Cruzan v. Director, Missouri Department of Health*¹⁰ has been generating an enormous increase in public interest in advance directives. The number of requests for sample living wills and similar documents from the Society for the Right to Die increased 500 percent after the Supreme Court's decision last June.⁹ In addition, the passage of the Patient Self-Determination Act in October 1990 will likely increase the number of people who issue advance directives. When the act takes effect in December 1991, any health care facility that receives funds from Medicaid or Medicare will be required to provide written information to all patients about advance directives and their rights under their state laws, and to document whether or not a patient has an advance directive.¹¹

SUBSTITUTED JUDGMENT

When a patient does not have an advance directive that specifies which treatments are to be received or foregone under the particular circumstances facing the patient, another individual or individuals will have to make a decision for the patient about life-sustaining treatment. The surrogate decision maker(s) might be designated by the patient in an advance directive, but often will not be. Whenever possible, the surrogate should base treatment decisions on what the patient would likely decide if he or she were capable of making the decision.^{1,3,4,12} This standard, or guiding principle, is called substituted judgment. The surrogate decisionmaker should look to the patient's previously expressed preferences and values to determine what the patient would have decided. Substituted judgment is valuable as a guiding principle because it gives weight to the subjective nature of decisions about life-sustaining treatment.^{1,12}

BEST INTERESTS

General. If there is no reasonable basis upon which to interpret what a previously competent patient would have decided, or if the patient never possessed decisionmaking capacity, the surrogate decisionmaker should base treatment decisions on which outcome would most likely promote the patient's well-being.^{1,3,4,12} This guiding principle is referred to as the "best interests" standard. Determining what choice would be in the patient's best interests entails weighing the harms and benefits of various options.¹ In particular, factors that should be considered when weighing harms and benefits of treatment include the expected duration of life with and without treatment, pain and suffering associated with the treatment, and the amount of incapacitation and ability to interact with others if life is sustained.

When using the best interests standard, the subjective perspective of the surrogate decision maker will unavoidably enter into judgments about the quality of life that would exist for the patient

with life-sustaining treatment.¹ "Quality of life" here is defined as the worth to the individual whose life is in question, and not as a measure of social worth.¹ Surrogate decision makers should try to minimize the influence of their own personal values on the decision. One way to help ensure that a decision is not inappropriately influenced by the surrogate's own values is to determine whether the decision is one that most reasonable persons would choose for themselves in similar circumstances. Decisions based on the personal interests of surrogates are not in the best interests of the patient, except when such interests are also clearly in the interests of the patient or when the patient would want the surrogates to take their interests into account.

Permanently Unconscious Patients and Seriously Ill Newborns. There are two specific cases when the determination of the best interests of the patient becomes particularly complex: permanently unconscious patients and seriously ill newborns.

When a permanently unconscious patient does not have an advance directive and previous preferences or values are either not clear or not ascertainable, or when the patient was never competent, there must be a determination of the patient's best interests. However, since a patient in a persistent vegetative state does not experience any pleasure, pain or suffering it seems that the patient would have little interest in living or dying. Some commentators argue that in this case, the interest in preserving life should prevail and life-sustaining treatment should be continued. Specifically, they argue that life should always be continued in these circumstances because of the chance that, while the patient is kept alive, there might be medical advances which would restore the patient's consciousness.

However, as Justice Brennan argued in his dissent in *Cruzan v. Director, Missouri Department of Health*, in the situation of a permanently unconscious patient, prolonging life may not necessarily be in the interests of the patient.¹⁰ An existence that is severely degraded and causes constant suffering of loved ones who must stand by to watch the patient linger on the edge of life may not be worth prolonging from the patient's perspective. In addition, there may be a patient interest in the kind of memories left behind. The longer a permanently unconscious person is kept alive the more likely the memory of the person will be of her or him in a persistent vegetative state than as the person was before his or her illness or injury.¹³

In response to the argument that the chance of medical breakthroughs restoring the patient to consciousness requires life to be sustained, rarely does such an advance of technology occur so rapidly without prior indication of developments in the scientific literature. Furthermore, this hope generally will be a consideration of the surrogate decision maker, but may not necessarily outweigh the harms to continued treatment.

There is, in fact, evidence that many, if not most, people would not want their lives prolonged in a persistent vegetative state. One poll found that 85% of those surveyed would not want their lives maintained with artificial nutrition and hydration if they became permanently unconscious.¹³ Though this evidence of public opinion does not justify withdrawing life-sustaining treatment for every permanently unconscious patient, it does mean that a surrogate's decision to withdraw life support is reasonable.

Since there is no objective way to ascertain what would be in the best interests of a permanently unconscious patient, any previous preferences of the patient should weigh heavily on the surrogate's decision, even if the patient was never competent or if the preferences were not very clear. When there are no previously expressed preferences that could be used to guide the decision maker, there will be little direction other than the decision maker's impressions about what would be best for the patient.

When the best interest standard must be used for a permanently unconscious person the surrogate's decision should not be challenged as long as the decision is based on true concern for what would be best for the patient. Due to the complexity of decisions for permanently unconscious patients, an ethics committee should be available, whenever possible, to help the surrogate and protect the patient's interests.

Unlike the permanently unconscious patient, a newborn does not have previous interests, but does have clear present and future interests. Present interests include achieving pleasure, avoiding pain and discomfort, and being alive.¹ Specifically, the pain caused by a therapy should be weighed against the pain resulting from forgoing the therapy. Future interests include, having at least some amount of agency, or ability to act at will; being able to develop personal relationships; and having future happiness and pleasure outweigh future pain and suffering.

The area of neonatology, however, involves many uncertainties, particularly with regard to the prognoses with and without aggressive treatments.² In addition to the problems of uncertainty, weighing present interests against future interests makes decision making for surrogates extremely difficult. For example, in some circumstances there may be a good chance that heart surgery would extend a newborn's life, but the surgery would have to be performed without anesthesia due to the immense stress that anesthesia can create on the infant's system.

It is important, therefore, that parents, who will generally be the decision makers for the infant, be provided full information about the nature of treatments, the therapeutic options and the expected prognosis with and without therapy. In particular, physicians should discuss the risks and uncertainties involved and answer any questions the parents may have. When possible, parents should be given time to adjust to the shock of the situation and absorb the medical information presented to them before making decisions about life-sustaining treatment. In addition, counseling services and an opportunity to talk with couples who have had to make similar decisions should be available to the parents. As with permanently unconscious patients, ethics committees should be available, when possible, to facilitate sound decision making for decisions about life-sustaining treatment for newborns.^{2,3}

WHO SHOULD DECIDE

It is clear that the surrogate decision maker carries a great responsibility for interpreting either what the patient would have decided or, absent such information, which option would most likely promote the patient's well-being. Therefore, determining who is to act as the surrogate decision maker is critical to this analysis.

The family of the patient should be responsible for decisions that so profoundly affect the patient's well-being. "Family" is generally understood to be the person's closest biological or legally recognized relations. In this analysis, family includes whoever is closely associated with the patient. For example, unmarried living partners and close friends should be considered family in addition to spouses, siblings, parents and others who are traditionally considered family members. This concept of "family" is especially important to recognize at this time when alternatives to marriage and the nuclear family unit are fairly common in this society.^{1,2} In the case when there is no person who is closely associated with the patient, but there are persons who both care about and have some relevant knowledge of the patient, these relations should participate in the decision making process, and in some situations may be appropriate surrogates.

The family should be relied upon to make treatment decisions because family members are generally best suited to determine what the patient who lacks decision making capacity would have chosen. Family members are most likely to have had conversations with the patient specifically about the withdrawal of life-prolonging treatment. In addition, because an individual's values are developed primarily in the context of the family, family members have the most intimate understanding of the patient's perspective. Parents understand their children's values because they helped form them,¹⁴ children understand their parents' values because they were taught them, and spouses and living partners understand each other's values because their values evolve together. Family members best know the patient's philosophical, religious and moral views; the patient's values about life and the way it should be lived; and the patient's attitudes toward sickness, suffering, medical procedures and death.

Moreover, family members are generally the most concerned with the patient's welfare. "It is they who provide for the patient's comfort [and] care...and they who treat the patient as a person rather than a symbol of a cause."¹⁵

Finally, participation in a family "as an intimate association is one important way in which individuals find or construct meaning in their lives."¹ Since intimate relationships require a large amount of privacy and autonomy to develop and thrive, those who are outside the family, such as the state or health care institutions, should be wary to intrude upon family decisions particularly when the decisions are within a reasonable range of choices.

Commentators who question a family's decision to forgo treatment observe that, in the absence of clear instructions from the patient, we should err on the side of life. Thus concern is understandable. On the other hand, most people share this sentiment about their loved ones. In fact, one recent study which surveyed spouses predictions of the patient's preferences regarding cardiopulmonary resuscitation (CPR) and mechanical ventilation found that spouses tended to overestimate patients' preferences for these life-sustaining treatments.¹⁶

Decisions which profoundly affect a loved one who is incompetent to make medical decisions are generally painful for a family due to the emotional distress that naturally results from the situation. It is essential for health care providers to be sensitive to the range of emotional and psychological responses of the family. Emotionality should not be interpreted as irrationality and used to justify overriding the family's decision making authority. If a physician feels that the decision making capacity of the family as a surrogate decision maker is significantly diminished by emotional distress, efforts should be made to help the family regain its capacity. In particular, counseling services should be made available to help families cope with having a loved one near the end of life or severely debilitated.

Some commentators maintain that the courts are generally the best forum for making decisions about life-sustaining treatment for incompetent patients. While certain aspects of judicial decision making are attractive - there are numerous procedural safeguards and efforts are made to help ensure the impartiality of the decision maker - the slow and cumbersome nature of the judicial process makes routine judicial review for decisions regarding life support impossible.¹ In addition, the public, adversarial and tremendously time-consuming and costly nature of the judicial process would create significant hardship for the patients and families involved. Furthermore, routine judicial review would remove the decision making process from families, thereby devaluing the family's role in decisionmaking.¹

The principal decision maker should not act in isolation, but should receive support and information from a number of persons. Health care providers, in particular, should offer relevant

medical information and explanations as well as medical opinions based on their professional expertise.¹⁷ The physician's responsibilities also include explaining to the family that decisions should be based on substituted judgment when possible, and otherwise on the best interests principle. Effective communication between physicians and family is essential for appropriate decision making.

Especially in critical care situations, stress, fear, intimidation, and unfamiliarity with the setting can overwhelm even sophisticated patients and families. Health professionals are responsible not merely for attempting to communicate, but for ensuring that effective communication takes place.¹⁷

Effective communication will go far in preventing major disputes among family members and health care providers. However, some disputes will occur. There are three situations that may require either institutional or judicial review and/ or intervention in the decision making process. These situations are when (1) there is a dispute among family members and there is no decision maker designated in an advance directive, (2) a health care provider believes that the family's decision clearly deviates from any choice that could be reasonably judged to be in accordance with the patient's wishes or, when there is no evidence of previous wishes or values, best interests,¹⁸ and (3) there is no available family willing to be the surrogate decision maker.

In the first two cases efforts should be made to communicate and mediate differences before resorting to more formal procedures. A serious disservice is done to the family and the patient when the decision making process is unnecessarily brought into a forum that is cumbersome and adversarial.^{1,2,4} Many health care institutions have ethics committees which may aid in resolving conflicts before resorting to the courts. The benefit of ethics committees is that they can help ensure that decision making is based on ethical principles. In addition, institutional ethics committees are more informal than the courts and can maintain the privacy of the family decision making process to a greater extent than judicial review.¹

Ethics committees that are used for resolving conflicts and facilitating sound decisionmaking should be structured so that a diversity of perspectives are represented. In addition to physicians, nurses and other health care providers, attorneys, social workers and patient advocates should be included on these committees. Committees generally should refrain from making treatment decisions. Instead, they should facilitate sound decision making by families and when necessary refer cases to the courts.¹ By facilitating sound decision making, ethics committees should ensure that the ethical guidelines described by the Council for decision making for incompetent patients are followed. Ethics committees can also provide support and counseling for family members, patients and physicians.

When there are disputes among those who are closely associated with the patient, there are certain factors the ethics committee should consider when mediating a resolution. Family members may disagree when they do not understand the medical circumstances, each other's reasons for their views, or that the decision must be made, when possible, according to what the patient would have decided. Therefore, ethics committees should try to facilitate communication and understanding of these factors.

Family members may also not be able to reach a consensus on treatment decisions because they are unsure about how to determine what the patient would have decided. Ethics committees should explain that evidence of the patient's previous preferences and values should guide a decision about what the patient would have likely decided. Committees should also suggest that, if the treatment decision is made by a person or persons who have the best understanding of the

patient's previous preferences and values, the decision will most likely reflect what the patient would have decided. As a guide, the committee should suggest that persons who have had fairly recent involved discussions with the patient about life, death, illness, religion, and/ or life-sustaining treatment or persons who in their experience with the patient have come to know the values and preferences of the patient intimately may be most likely to make a decision that the patient would have made.

In some cases there will be no evidence about how the patient would have decided if competent. In these cases, the committee should explain that the decision should be made on which outcome would best promote the well-being of the patient (i.e., best interests). The committee should suggest that, if the family cannot reach a consensus, the decision of a person or persons who have the closest relationship with the patient is most likely to promote the patient's well-being. The committee should suggest factors that may guide the determination of who is closest to the patient. These factors include the amount of personal contact with the patient, amount of *recent* personal contact, and strength of dedication to the patient. In addition, the committee should warn against decision making based on a conflict of interests.

When necessary, the committee members may indicate who they think should make the decision in situations where the decision should be based on substituted judgement or when it should be based on best interests. When disputes among those closely associated with the patient are intractable, the committee should refer the dispute to the courts.

When a health care provider challenges the decision of the family, an ethics committee should first verify that the challenge is based on a belief that the decision is clearly not what the patient would have decided; or when the best interest standard must be used, the committee should verify that the family's decision is clearly not a decision that could reasonably be judged to promote the patient's well-being. If this is the case, the ethics committee should try to ensure that the health care provider and the family understand each other's reasoning. In particular, efforts should be made to ensure that the family understands the medical information. If the conflict is intractable the dispute should be referred to the courts.

In the situation where there is no willing family to be a surrogate decision maker, a surrogate who is not close to the patient will have to be appointed. Some institutions and states are experimenting with various alternatives for providing a surrogate for these patients.¹⁹ In particular, there are three mechanisms for appointing a surrogate decision maker that have adequate safeguards. Treatment decisions may be made by a court appointed guardian; an institution may create a surrogates committee to appoint a decision maker; the state may permit ombudsmen in state programs to either make treatment decisions, appoint a surrogate or oversee the decision making of a committee appointed surrogate or court appointed guardian.¹⁹ In these cases, although many persons should have input in the decision making process, there should be only one person acting as the surrogate decision maker. The surrogate or guardian should conduct an investigation to uncover the patient's previous values and preferences. Also, whenever possible, appointed surrogates and guardians should consult with ethics committees that facilitate decision making.

It should be emphasized that referring the case to the courts is a last resort for decision making about life-sustaining treatment. It is strongly encouraged that when judicial review is necessary, in non-emergency situations, the courts generally should determine who is to make treatment decisions, including appointing a guardian, rather than making treatment decisions.

RECOMMENDATIONS

The Council on Ethical and Judicial Affairs recommends the following:

Advance directives, (living wills and durable powers of attorney for health care) are the best insurance for individuals that their interests will be promoted in the event that they become incompetent. Generally, it is most effective if the individual designates a proxy decisionmaker and discusses with the proxy his or her values regarding decisions about life support.

Without an advance directive that designates a proxy, the patient's family should become the surrogate decision maker. Family includes persons with whom the patient is closely associated. In the case when there is no person closely associated with the patient, but there are persons who both care about the patient and have some relevant knowledge of the patient, such relations should be involved in the decision making process, and may be appropriate surrogates.

It is the responsibility of physicians to provide all relevant medical information and to explain to surrogate decision makers that decisions should be based on substituted judgment (what the patient would have decided) when there is evidence of patients' preferences and values. If there is not adequate evidence of preferences and values the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being).

Institutional ethics committees should be established for the purpose of facilitating sound decision making. These ethics committees should be structured so that a diversity of perspectives, including representation by those from outside medicine.

The surrogate's decision should almost always be accepted by the physician. However, there are four situations that may require either institutional or judicial review and/ or intervention in the decision making process. These situations are when (1) there is no available family willing to be the patient's surrogate decision maker; (2) there is a dispute among family members and there is no decision maker designated in an advance directive, (3) a health care provider believes that the family's decision is clearly not what the patient would have decided if competent, and (4) a health care provider believes that the decision is not a decision that could reasonably be judged to be in the patient's best interests. Decisions based on a conflict of interest generally would not be in the patient's best interest. In these four cases, the guidelines outlined in the report should be followed. In particular, when there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decision making is recommended before resorting to the courts.

Judicial review for decisions about life-sustaining treatment should be a last resort. It is strongly encouraged that when judicial review is necessary, in non-emergency situations, the courts should determine who is to make treatment decisions, including appointing a guardian, rather than making treatment decisions.

When a permanently unconscious patient was never competent or had not left any evidence of previous preferences or values, since there is no objective way to ascertain what would be in the best interests of the patient, the surrogate's decision should not be challenged as long as the decision is based on the decision maker's true concern for what would be best for the patient.

In the case of seriously ill or handicapped newborns, present and future interests of the infant must be considered. Due to the complexities involved in deciding about life support for seriously ill newborns, physicians should specifically discuss with parents the risks and uncertainties

involved. When possible, parents should be given time to adjust to the shock of the situation and absorb the medical information presented to them before making decisions about life sustaining treatment. In addition, counseling services and an opportunity to talk with couples who have had to make similar decisions should be available to the parents.

Due to the complexity of decisions for permanently unconscious patients and newborns, an ethics committee should be available, whenever possible, to facilitate the surrogate's decision making. Hospitals and other health care facilities should establish protocols regarding assessment of decision making capacity, informing patients about advance directives, identifying surrogate decision makers, the use of advance directives, substituted judgment and best interests in decision making, and the procedures for challenging the decision of a surrogate. These protocols should be in accordance with the Council's preceding guidelines.

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CEJA Report B – A-91 Decisions Near the End of Life

INTRODUCTION

There is a long-standing tradition in medicine that physicians must do everything medically possible to keep a patient alive. In recent years, the issue of allowing and even helping patients to die has been opened up to vigorous debate. At present do-not-resuscitate orders are commonplace.^{1,2} Courts have upheld the right of patients to refuse life-sustaining treatment in over 130 cases, and the U.S. Supreme Court recently indicated that a right to refuse life-sustaining treatment can be found in the U.S. Constitution.³ There is a surprising amount of support even for the proposition that physicians should be allowed to deliberately end a patient's life upon the patient's request. In one poll conducted in 1988 in New York City, 58% of the physicians responded that physicians should be lawfully able to end the life of terminally ill patients at the patients' request.¹⁴

Since the turn of the century, there has been a dramatic shift in the places where people die. Sixty years ago, the vast majority of deaths occurred at home. Now most people die in hospitals or long-term care facilities. Approximately 75% of all deaths in 1987 occurred in hospitals and long-term care institutions,⁵ up from 50% in 1949, 61% in 1958 and 70% in 1977.⁶ This move of the locale of death from the privacy of the home to medical institutions has increased public awareness and concern about medical decisions that lead to patients' deaths. "Since deaths which occur in institutions are more subject to scrutiny and official review, decisions for death made there are more likely to enter public consciousness."⁷

A related phenomenon, the advance of life-saving medical technologies, also has contributed to the increased attention to medical decisions that lead to the deaths of patients. These advances have resulted in a lengthening of the average life span, which has had the effect of increasing the proportion of deaths caused by chronic conditions. One study in 1968 found that half of all deaths are caused by an illness diagnosed at least 29 months earlier. Another study found that a chronic condition was the cause of 75% of all deaths in 1986.⁸ In addition, with the development of sophisticated life support technologies, medicine now has the capacity to intervene and forestall death for almost any case. The Office of Technology Assessment Task Force estimated in 1988 that 3775 to 6575 persons were dependent on mechanical ventilation and 1,404,500 persons were receiving artificial nutritional support.⁹ Bioethicist Alexander Capron has argued:

There is no such thing as a "natural" death. Somewhere along the way for just about every patient, death is forestalled by human choice and human action, or death is allowed to occur because of human choice. Life-support techniques make death a matter of human choice and hence a matter that provokes ethical concern.⁷

As a result, the public has become increasingly concerned about the prospect of protracted deaths marked by incapacitation, intolerable pain and indignity, and invasion by machines and tubes. In a public opinion poll 68% of respondents believed that "people dying of an incurable painful disease should be allowed to end their lives before the disease runs its course."^{1,10} A number of comparable surveys indicate similar public sentiment.¹

The Council has previously issued opinions on withdrawing and withholding life-prolonging treatment from patients who are terminally ill or permanently unconscious (2.20 and 2.21 in *Current Opinions*) and reports concerning do-not-resuscitate orders,^{11,12} euthanasia,¹³ and withdrawal of life-prolonging treatment from permanently unconscious patients.¹⁴

At the 1990 Annual Meeting of the AMA's House of Delegates, Resolution 267, "Suicide-Assisting Devices," was referred for decision. This report will examine the Council's existing positions and will expand the analysis to include physician-assisted suicide and withdrawing/withholding life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious.

DEFINITIONS

The four categories of medical actions that can lead to the death of a patient are: withholding/withdrawing life-sustaining treatment, the provision of palliative treatment that may foreseeably hasten death, euthanasia, and assisted suicide.

Life-sustaining treatment is any medical treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment includes, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics and artificial nutrition and hydration. At one time, the term "passive euthanasia" was commonly used to describe withholding or withdrawing life sustaining treatment. However, most experts now refrain from using the term "passive euthanasia."

The provision of a palliative treatment that may foreseeably hasten death is also described as "double effect euthanasia". The Intent of the treatment is to relieve pain and suffering, not to end the patient's life, but the patient's death is a foreseeable side effect of the treatment. For example, a physician may gradually increase the morphine dosage for a patient to relieve severe cancer pain, realizing that large enough doses of morphine may depress respiration and cause death.

Since the term "euthanasia" has various meanings, it is important to specify the definition the Council intends in this report. In this country, euthanasia is commonly defined as the act of bringing about the death of a hopelessly ill and suffering person in a relatively quick and painless way for reasons of mercy. In this report, the term "euthanasia" will signify the medical administration of a lethal agent to a patient for the purpose of relieving the patient's intolerable and incurable suffering.

The terms "voluntary" and "nonvoluntary" will be used to modify euthanasia. Voluntary euthanasia is euthanasia which is provided to a competent person upon his or her informed request. Non-voluntary euthanasia is the provision of euthanasia to an incompetent person according to a surrogate's decision. Involuntary euthanasia, in theory, would be euthanasia performed against a person's will. However, the term "involuntary euthanasia" will not be used since it is difficult to imagine a merciful assistance to death ever occurring against a competent person's will.

Euthanasia and assisted suicide differ in the degree of physician participation. Euthanasia entails a physician performing the immediate life-ending action (e.g., administering a lethal injection). 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 is intending to commit suicide).

Discussions about life-ending acts by physicians often refer to the patient's "competence" or "decision making capacity." The two terms are often used interchangeably. However, "competence" can refer to a *legal* determination of a person's soundness of mind. "Decision making capacity" is a more specific term that is not determined in the courts and signifies the ability to make a particular decision. The term "competence" for the purposes of this ethical analysis is intended to mean "decision making capacity."

The evaluation of a person's decision making capacity is an assessment of the person's capabilities for understanding, communicating and reasoning. Patients should not be determined to lack decision making

capacity based on the view that what they decide is unreasonable.¹⁵ For example, a considered refusal of a blood transfusion by a Jehovah's Witness should generally be respected even though it may be viewed as an unreasonable choice by most people. People are entitled to make decisions that others think are foolish as long as their choices pose no significant harm to others.

ETHICAL FRAMEWORK

Determining the ethical responsibilities of physicians when patients wish to die requires a close examination of the physician's role in society. Physicians are healers of disease and injury, preservers of life and relievers of suffering. Ethical judgments become complicated, however, when these duties conflict. The four instances discussed in this report in which physicians might act to hasten death or refrain from prolonging life involve conflicts between the duty to relieve suffering and the duty to preserve life.

The considerations that must be weighed in each case are 1) the principle of patient autonomy and the corresponding obligation of physicians to respect patients' choices, 2) whether what is offered by the physician is sound medical treatment, and 3) the potential consequences of a policy that permits physicians to act in a way that would lead to a patient's death.

PATIENT AUTONOMY

The principle of patient autonomy requires that patients who possess decision making capacity have the opportunity to choose among medically sound treatments and to refuse any unwanted treatment offered by their physicians. Absent countervailing obligations, physicians must respect patients' decisions. This ethical principle has been consistently upheld in the courts and is the basis of the doctrine of informed consent.¹⁶ Justice Cardozo pronounced in 1914, "[e]very human being of adult years and sound mind has a right to determine what shall be done with his [*sic*] own body."¹⁷

Treatment decisions often involve personal value judgments and preferences in addition to objective medical considerations. We demonstrate respect for human dignity when we acknowledge "the freedom [of individuals] to make choices in accordance with their own values."¹⁸

SOUND MEDICAL TREATMENT

The physician's obligation to respect a patient's decision does not require a physician to provide a treatment that is not medically sound. Indeed, a physician is ethically prohibited from offering or providing medically unsound treatments. Sound medical treatment is defined as the use of medical knowledge or means to cure a medical disorder, relieve distressing symptoms, and/or prevent the occurrence of either.

This criterion of soundness arises from the well-established medical ethical principles of beneficence and nonmaleficence. The principle of nonmaleficence requires that physicians not use their medical knowledge nor skills to harm patients, while the principle of beneficence requires that medical knowledge and skills be used to benefit patients.

The criterion of soundness is particularly relevant to the discussion of physician participation in treatments, or non-treatments, that can lead to deaths of patients. Generally, a treatment that is likely to cause the death of a patient is considered unsound, and a failure to save a patient's life is negligent. However, the situations which will be examined in this report are extremely complicated because they involve the unique circumstance where the patient does not consider his or her death to be an undesirable outcome.

PRACTICAL CONSIDERATIONS

Policies governing the care of patients who wish to die must also be evaluated in terms of their practical consequences. The ethical acceptability of a policy depends upon the benefits and costs that result from the policy. In addition to the impact on individual cases {e.g., patients will die according to their decision to have life supports withdrawn), there are likely to be serious societal consequences from policies regarding physicians' responsibilities to dying patients. For example, while the withdrawal of artificial nutrition and hydration facilitates the relief of suffering, some commentators believe that it undermines society's commitment to feed those who cannot feed themselves.

WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT

The principle of patient autonomy requires that physicians respect a competent patient's decision to forgo any medical treatment. This principle is not altered when the likely result of withholding or withdrawing a treatment is hastening the patient's death.⁶ The right of competent patients to forgo life-sustaining treatment has been upheld in the courts and is generally accepted by medical ethicists.¹⁹ The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research stated in 1983:

[t]he voluntary choice of a competent and informed patient should determine whether or not life sustaining therapy will be under taken, just as such choices provide the basis for other decisions about medical treatment. Health care institutions and professionals should *try* to enhance patients' abilities to make decisions on their own behalf and to promote understanding of the available treatment options.⁶

In part, the reasoning behind the right of competent patients to forgo life-sustaining treatment is that decisions which so profoundly affect a patient's well-being cannot be made independent of a patient's subjective preferences and values.²⁰ Many types of life-sustaining treatments are burdensome and invasive, so that the choice for the patient is not simply a choice between life and death.⁹ When a patient is dying of cancer, for example, a decision may have to be made whether to use a regimen of chemotherapy that might prolong life for several additional months but also would be painful, nauseating and debilitating. Similarly, when a patient is dying, there may be a choice between returning home to a natural death or remaining in the hospital, attached to machinery, where the patient's life might be prolonged a few more days or weeks. In both cases, individuals might weigh differently the value of additional life versus the burden of additional treatment.

The physician must ensure that the patient has the capacity to make medical decisions before carrying out the patient's decision to forgo (or receive) life-sustaining treatment. In particular, physicians need to be aware of the possibility that the patient's decision making capacity can be diminished by a misunderstanding of the medical prognosis and options or by a treatable state of depression.

The withdrawing or withholding of life-sustaining treatment is not contrary to the physician's obligation to provide only medically sound treatments. The physician is obligated only to offer treatment. Withdrawing or withholding are not treatments but the forgoing of treatments. Physicians are not entitled to impose treatment on patients who do not want them.

Some commentators argue that, if a physician has a strong moral objection to withdrawing or withholding life sustaining treatment, the physician may transfer the patient to another physician who is willing to comply with the patient's wishes. It is true that a physician does not have to provide a treatment, such as an abortion, that is contrary to his or her moral values. However, if a physician objects to withholding or withdrawing the treatment and forces unwanted treatment on a patient, the patient's

autonomy will be inappropriately violated even if it will take only a short time for the patient to be transferred to another physician.

Withdrawing or withholding some life-sustaining treatments may seem less acceptable than others. For example, some have objected to the right to refuse artificial nutrition and hydration, while accepting the right to refuse mechanical ventilation because food and water are considered basic patient care. The distinction between extraordinary and ordinary medical treatments has been proposed as a standard to determine whether a life sustaining treatment can be refused by a patient. The Council, along with most experts, believes that the difference between extraordinary and ordinary treatment is not a valid ethical distinction.⁶ If "ordinary" care is defined as treatment that provides a basic requirement of life regardless of the underlying condition, ventilators which provide oxygen to patients would also be "ordinary" care.

Moreover, the standard of extraordinary versus ordinary treatment implies that ordinary, unlike extraordinary life sustaining treatment is not burdensome to the patient. To the contrary, artificial nutrition and/or hydration immobilize the patient to a large degree, can be extremely uncomfortable (restraints are sometimes used to prevent patients from removing nasogastric tubes), and can entail serious risks (for example, surgical risks from insertion of a gastrostomy tube and the risk of aspiration pneumonia with a nasogastric tube).

The right to refuse artificial nutrition and hydration has also been contested by some because the provision of food and water has a symbolic significance as an expression of care and compassion. These commentators argue that withdrawing or withholding food and water is a form of abandonment and will cause the patient to die of starvation and/ or dehydration. However, it is far from evident that providing nutrients through an IV line to a patient for whom it is unwanted is comparable to the typical human ways of feeding those who are hungry.²¹ In addition, discomforting symptoms can be palliated so that a death that occurs after forgoing artificial nutrition and/ or hydration is not marked by substantial suffering.²² Such care requires constant attention to the patient and the patient's needs. Therefore, respecting a patient's decision to forgo artificial nutrition and hydration will not constitute an abandonment of the patient, symbolic or otherwise, when comfort care is maintained.

There is also no ethical distinction between withdrawing and withholding life-sustaining treatment. Withdrawing life support may seem ethically more difficult than withholding life support because the physician performs an action which hastens death. When life-sustaining treatment is withheld, on the other hand, death occurs because of an omission rather than an action. This action/omission distinction has been used to differentiate between killing and allowing to die. However, as most bioethicists now recognize, the action/omission distinction lacks ethical significance.⁶ First, the distinction is often meaningless. For example, if a physician fails to provide a tube feeding at the scheduled time, would it be a withholding or a withdrawing of treatment? Second, ethical relevance does not lie with the action/omission distinction, but on other factors such as the motivation and professional obligations of the physician. For example, refusing to start a ventilator despite the patient's need and request because the patient's heir has promised the physician a share of the inheritance is clearly ethically worse than stopping the ventilator for a patient who has decided to forgo it. Third, prohibiting the withdrawal of life support would inappropriately affect a patient's decision to initiate such treatment. If treatment cannot be stopped once it is initiated, patients and physicians may decide not to begin treatment.⁶

The practical benefit of respecting patients' choices is that decisions will maximize patient interest and well-being. Patients are in the best position to determine what is in their interests. In addition, if patients did not have control over decisions about life-sustaining treatment the principle of patient self-determination over health care would be eroded.

There are negative consequences of a policy to withhold or withdraw life support upon a patient's request.

First, deaths may occur as a result of uninformed decisions or from pain and suffering that could be relieved with measures that would not cause the patient's death. And second, there may exist pressures, whether subtle or overt, from family, physicians or society to forgo life-sustaining treatment, rendering the patient's choice less than free. These pressures could revolve around beliefs that such patients' lives no longer possess social worth and are an unjustifiable drain of limited health resources.

It is the responsibility of physicians to provide sufficient information to ensure patient understanding. It is also essential that all efforts be made to maximize the comfort and dignity of patients who are dependent on life-sustaining treatment and that patients be assured that these efforts will be made. With such assurances, patients will be less likely to forgo life support because of suffering or anticipated suffering that could be palliated.

The risks associated with potential pressures on patients to forgo life-sustaining treatments are an important concern. The Council believes that the medical profession must be vigilant against such tendencies, but that the greater policy risks are of undermining patient autonomy.

In summary, according to the principle of respect for patient autonomy, patients who possess an adequate decision making capacity have the right to forgo any life-sustaining treatment. Physicians must respect the decisions of patients, and they must ensure that patients both are well informed about their prognoses and treatment options and understand that comfort and dignity will be a top priority whether or not they decide to forgo life support.

PROVIDING PALLIATIVE TREATMENT WHICH MIGHT HASTEN DEATH

The Council stated in its 1988 report on "Euthanasia" that "the administration of a drug necessary to ease the pain of a patient who is terminally ill and suffering excruciating pain may be appropriate medical treatment even though the effect of the drug may shorten life."¹³ The Council maintains this position and further emphasizes that a patient possessing a decision making capacity must be the one who decides whether the relief of pain and suffering is worth the danger of hastening death. The principle of respect for patient autonomy and self-determination requires that patients decide about such treatment.

The ethical distinction between this situation and euthanasia lies in the difference between administering a medically sound pain relief treatment which will likely shorten the patient's life and providing a treatment to cause death as the means by which relief of suffering is achieved. The distinction is subtle because in both cases the action that causes death is performed with the purpose of relieving suffering, but the distinction is ethically significant. Most medical treatments entail some undesirable side effects. In general it should be the decision of the patient with the help of his or her physician to decide to either risk the side effects or forgo the treatment. A patient competent to make this decision has the right to weigh the risk of hastening death against the potential for relief of pain and suffering.

The concrete benefit of allowing physicians to provide palliative treatments is the relief of unrelenting and intolerable suffering. For many patients, relief may be worth even a great risk of death. An important concern is that patients who are not fully informed about their prognosis and options may make decisions that unnecessarily shorten their lives. In addition, severe pain might diminish the patient's capacity to decide whether to choose a treatment that risks death. Caution when determining decision-making capacity in this situation, therefore, must be exercised, and patients should be fully informed.

EUTHANASIA

Euthanasia is the medical administration of a lethal agent to a patient in order to relieve intolerable and untreatable suffering of the patient. The issue of whether or not a physician may use the skills or

knowledge of medicine to cause an "easy" death in a patient who requests such assistance has been debated since the time of Hippocrates. Recently, euthanasia has been gaining support from the public and some in the medical profession. In the Netherlands, for example, since 1984 euthanasia by physicians is not prosecuted when a case falls within certain established criteria.²³ These criteria include that (1) euthanasia is explicitly and repeatedly requested by the patient and there is no doubt that the patient wants to die; (2) the mental and physical suffering is severe with no prospect for relief; (3) the patient's decision is well informed, free and enduring; (4) all options for alternate care have been exhausted or refused by the patient and (5) the physician consults another physician.²⁴ Though currently there are no official statistics on the frequency of euthanasia in the Netherlands, it has been estimated to range from 2,000 to 10,000 persons per year.²³

In the United States there has been growing public support for legalized euthanasia. The Hemlock Society, an organization dedicated to legalizing voluntary euthanasia and physician-assisted suicide, has doubled its membership in the past five years to approximately 33,000.²⁵ Currently, an initiative in Washington state that would legalize euthanasia has gained 35,000 signatures over the 150,001 needed to put the initiative on the ballot this November.²⁶ This apparent increase in support for euthanasia poses a difficult question for the medical profession. What is the physician's role in treating patients who are suffering intolerably and are not dependent on life-sustaining treatment?

Though the principle of patient autonomy requires that patients who possess decision-making capacity be given the opportunity to choose among offered medical treatments and to forgo any treatment, it does not give patients the right to demand euthanasia. At issue is whether it is ever ethical for physicians to offer euthanasia in certain circumstances. On the other hand, there is an autonomy interest in directing one's death. But this interest does not override considerations of professional responsibility.

In the United States there is currently little data regarding the number of euthanasia or assisted suicide requests, the concerns behind the requests, the types and degree of intolerable and unrelievable suffering, or the number of requests that have been granted by health care providers. Before euthanasia can ever be considered a legitimate medical treatment in the United States, the needs behind the demand for physician-provided euthanasia must be examined more thoroughly and addressed more effectively. A thorough examination would require a more open discussion of euthanasia and the needs of patients who are requesting it. The existence of patients who find their situations so unbearable that they request help from their physicians to die must be acknowledged, and the concerns of these patients must be a primary focus of medicine. Instead of condoning physician-provided euthanasia, medicine must first respond by striving to identify and address the concerns and needs of dying patients.

There is evidence to suggest that most requests for euthanasia or assisted suicide would be eliminated if patients were guaranteed that their pain and suffering will be eased and their dignity and self-sufficiency promoted.²⁷ The success of the hospice movement illustrates the extent to which aggressive pain control and close attention to patient comfort and dignity can ease the transition to death.²⁸ Health care professionals have an ethical duty to provide optimal palliative care to dying patients. At the present, many physicians are not informed about the appropriate doses, the frequency of doses and alternate modalities of pain control for patients with severe chronic pain.²⁸ In particular, addiction should not be a concern when providing analgesia to these patients. Physicians should inform the patient and the family that concentrated efforts will be a priority in the care of the patient, since fear of pain is "one of the most pervasive causes of anxiety among patients, families and the public."¹

There may be cases, however, where a patient's pain and suffering is not reduced to a tolerable level and the patient requests a physician to help him or her die.^{1,28} If a physician cannot ease the pain and suffering of a patient, by means short of death, using medical expertise to aid an "easy" death may seem to be the humane and appropriate treatment for the patient.

There are, however, serious risks associated with condoning physician-performed euthanasia. The prohibition against medically killing patients is a strong and lasting tradition in medical ethics. This tradition is based upon a commitment that medicine is a profession dedicated to healing, and that its tools should not be used to kill patients. Weakening this prohibition against euthanasia, even in the most compelling situations, has troubling implications.^{29,30} Though the magnitude of such risks are impossible to predict accurately, the medical profession and society as a whole must not consider these risks lightly.

The prohibition of killing is an attempt to promote a solid basis for trust in the role of caring for patients and protecting them from harm. This prohibition is both instrumentally and symbolically important, and its removal would weaken a set of practices and restraints that we cannot easily replace.¹⁶

If euthanasia by physicians were to be condoned, the fact that physicians could offer death as a medical treatment might undermine public trust in medicine's dedication to preserving the life and health of patients.³¹ Some patients may fear the prospect of "involuntary" or nonvoluntary euthanasia if their lives are no longer deemed valuable as judged by physicians, their family, or society.³¹ Other patients who trust their doctors' judgments may not feel free to resist their physicians' suggestion that euthanasia may be appropriate for them.^{31,32,33}

Another risk is that physicians and other health care providers may be more reluctant to invest their energy and time serving patients whom they believe would benefit more from a quick and easy death. Caring for dying patients is taxing on physicians who in the process must face issues of their own mortality, and who often perceive such care as a reminder of their failure to cure these patients.^{6,18} In addition, the increasing pressure to reduce health costs may serve as another motivation to favor euthanasia over longer term palliative care.

Finally, allowing euthanasia to be a medical treatment for a limited group of patients who may truly benefit from it will present difficult line drawing problems for medicine and society. In specific cases it may be hard to distinguish which cases fit the criteria established for euthanasia. For example, if the existence of unbearable pain and suffering were one of the criteria for legitimate euthanasia, the definition of unbearable pain and suffering could be subject to different interpretations. Determining whether a patient will benefit from euthanasia requires an intimate understanding of the patient's concerns, values, and pressures that may be prompting the euthanasia request. In the Netherlands, where euthanasia seems to be fairly successful, physicians who provide euthanasia generally have a life-long relationship with the patient which enables the physician to have access to this vital information.³⁴ In the U.S., however, physicians rarely have the depth of knowledge about their patients that would be necessary for an appropriate evaluation of the patient's request for euthanasia.

More broadly, the line drawing necessary for the establishment of criteria for acceptable euthanasia is also problematic. If competent patients can receive euthanasia, can family members request euthanasia for an incompetent patient? Would it be acceptable for physicians to perform euthanasia on any competent individuals who come to them requesting it? Furthermore, since it will be physicians and the state who would decide which patients are eligible for euthanasia, value judgments about patients' lives will be made by another person or entity other than the patients.

Since it is unclear at this time where these lines should be drawn, the proposition of allowing euthanasia is particularly troublesome. A potential exists for a gradual distortion of the role of medicine into something which starkly contrasts with the current vision of a profession dedicated to healing and comforting. Before society can comfortably make exceptions to the prohibition against physicians deliberately intervening to cause the deaths of patients, more resources must be devoted to the study of the present situation of patients who request aid in dying.

PHYSICIAN-ASSISTED SUICIDE

Physician-assisted suicide has only recently become the focus of public attention. In particular, in June 1990, the Dr. Kevorkian case provoked strong responses on all sides of the issue. Dr. Kevorkian is a physician who assisted the death of a person with the use of a "suicide machine," which he invented. This case was an extreme example of assisted suicide and has been criticized by many for the irresponsible way in which it was carried out by the physician.²⁵ More recently, an article was published in the *New England Journal of Medicine* by a physician who described his role in providing the medication for a patient to commit suicide.³⁵ The care and compassion evidenced by the physician and the clearly reasoned decision-making process of the patient marked this account as truly compelling. Besides these two very public cases of physician-assisted suicide, there is reason to believe that it has been occurring for some time.¹

Some physicians, believing it to be the last act on a continuum of care provided for the hopelessly ill patient, do assist patients who request it, either by prescribing sleeping pills with knowledge of their intended use or by discussing the required doses and methods of administration with the patient.¹

There is an ethically relevant distinction between euthanasia and assisted suicide which makes assisted suicide a more attractive option. Physician-assisted suicide affords a patient a more autonomous way of ending his or her life than does euthanasia. As a result, if patients were to perform the life-ending act themselves, they would have the added protection of being able to change their minds and stop their suicides up until the last moment.

However, the ethical concerns about physician-assisted suicide are similar to those of euthanasia since both are essentially interventions intended to cause death. Physician-assisted suicide, like euthanasia, is contrary to the traditional prohibition against using the tools of medicine to cause a patient's death. Physician-assisted suicide also has most of the same societal risks as euthanasia, including the potential for coercive financial and societal pressures on patients to choose suicide. Further, determining the criteria for assisting a patient's suicide and determining whether a particular patient meets the criteria are as problematic as deciding who may receive euthanasia.

While in highly sympathetic cases physician-assisted suicide may seem appropriate, due to the likelihood of grave harm, the medical profession cannot condone physician-assisted suicide at this time. The medical profession instead must strive to identify the concerns behind patient's requests for assisted suicide, and make concerted efforts at finding ways to address these concerns short of assisting suicide, including providing more aggressive comfort care.

RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends the following: The principle of patient autonomy requires that physicians must respect the decision to forgo life-sustaining treatment of a patient who possesses decision making capacity. Life-sustaining treatment is any medical treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment includes, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics and artificial nutrition and hydration.

There is no ethical distinction between withdrawing and withholding life-sustaining treatment. Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This includes providing effective palliative treatment even though it may foreseeably hasten death. More research must be pursued examining the degree to which palliative care reduces the requests for euthanasia or assisted suicide.

Physicians must not perform euthanasia or participate in assisted suicide. A more careful examination of the issue is necessary. Support, comfort, respect for patient autonomy, good communication, and adequate pain control may decrease dramatically the public demand for euthanasia and assisted suicide. In certain carefully defined circumstances, it would be humane to recognize that death is certain and suffering is great. However, the societal risks of involving physicians in medical interventions to cause patients' deaths is too great in this culture to condone euthanasia or physician- assisted suicide at this time.

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TERMINAL ILLNESS – PATIENTS’ PREFERENCES. A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision. The preference of the individual should prevail when determining whether extraordinary life-prolonging measures should be undertaken in the event of terminal illness. Unless it is clearly established that the patient is irreversibly, terminally ill, a physician should not be deterred from appropriately aggressive treatment of a patient.