WITHHOLDING AND WITHDRAWING
LIFE-SUSTAINING THERAPY

THIS OFFICIAL STATEMENT OF THE AMERICAN THORACIC SOCIETY was adopted by the ATS Board of Directors, March 1, 1991.

Preface

American Thoracic Society (ATS) members who practice pulmonary and critical care medicine commonly care for patients receiving mechanical ventilation and other life-sustaining therapy. They not only participate in decisions to withhold and withdraw such therapy but are also professionally and personally involved in the medical, ethical, and legal issues arising from those decisions. Recognizing the importance of these issues to its membership, the ATS Board of Directors approved formation of an ad hoc Bioethics Task Force to develop an official ATS statement related to withholding and withdrawing life-sustaining therapy.

The purpose of this statement is to define acceptable standards of medical practice and make recommendations related to withholding and withdrawing life-sustaining therapy in the same manner that previous ATS statements have done for other clinical and ethical issues. This statement has three specific objectives: (1) to enhance the understanding of physicians and other health care providers of the issues involved in withholding and withdrawing life support; (2) to promote medically and ethically sound decision making in clinical practice related to withholding and withdrawing life support; and (3) to assist in the development of institutional and public policies related to these issues.

This statement was specifically written to apply to the medical care of adults with or without decision-making capacity. In addition, it may also be useful in caring for children who have variable degrees of ethical and legal autonomy. On the other hand, because of the unique ethical, medical, and legal issues involved in their care, the Task Force decided to exclude neonates from its consideration.

Section 1. Respect for Patient Autonomy is the Primary Basis for Withholding and Withdrawing Life-Sustaining Therapy

In an adult patient, who has decision-making capacity and is appropriately informed, has the right to forgo all forms of medical therapy including life-sustaining therapy. The right to refuse treatment applies equally to withholding therapy that might be offered, such as cardiopulmonary resuscitation (CPR), and to withdrawing therapy that is already underway, such as mechanical ventilation or artificially provided hydration and nutrition. This right is based on the ethical principle of autonomy, or self-determination.

Physicians and other health care providers have a responsibility to respect patient autonomy by withholding or withdrawing any life-sustaining therapy as requested by an informed and capable patient. In this regard, there is no ethical difference between withholding and withdrawing. Helping a patient forgo lifesupport under these circumstances is regarded as distinct from participating in assisted suicide or active euthanasia, neither of which is supported by this statement. However, if carrying out such a request would violate the personal moral code of a physician or other health care provider, that individual generally has the right not to participate in the process. If this occurs, others should be made available to carry out the patient's request.

The patient's physician and other health care providers also have a responsibility for carrying out the patient's request in a humane and compassionate manner. To this end, the patient's pain and other suffering, including dyspnea, should be relieved by administration of sedatives and/or analgesics. The dosage of medication should be determined by titrating the agent carefully according to signs and symptoms of distress. It is ethically permissible to provide sufficient medication to relieve a patient's pain and suffering arising from withholding or withdrawing life-sustaining therapy, even if the patient's death may be unintentionally hastened in the process.

Discussion

Respect for patient autonomy is one of the fundamental ethical principles underlying the current practice of medicine (1, 2). Both the ethical principle of autonomy and the legal principle of informed consent (1) support the right of appropriately informed adult patients with decision-making capacity to refuse any or all medical therapy including life-sustaining treatment. Although this right is not absolute, in the recent past it has ordinarily outweighed countervailing state's interest in this regard (3). Beginning with the landmark 1976 New Jersey Supreme Court decision in the Karen Ann Quinlan case (4), a strong ethical (2, 5, 6) and legal (7, 8) consensus has developed in its support. Furthermore, the U.S. Supreme Court 1990 decision in the Nancy Cruzan case in effect recognized a constitutional right of capable adults, even those not terminally ill or facing imminent death, to refuse any medical therapy including life-sustaining therapy and artificially provided hydration and nutrition (9, 10). A professional duty to respect patient autonomy in decisions to withhold or withdraw life-sustaining therapy is also supported by the ethical codes of national organizations of other physicians (11-13) and by consensus statements of health care professionals (14-17).

The validity of the decision-making process related to a patient's request for forgo life-sustaining therapy depends to a great degree on the assessment and guidance provided by his or her physician. Physician responsibilities related to this process include:

(1) Assessing whether a patient has adequate decision-making capacity in relation to the decision at hand; this assessment should utilize appropriate consultation if indicated by the clinical situation or if disagreement with the initial assessment arises among health care providers or from the patient or his or her family members. Critical elements of decision-making capacity include: (a) the ability to understand the medical information presented; (b) the ability to reason and consider this information in relation to his or her own personal values and goals; and (c) the ability to communicate meaningfully.

(2) Informing the capable patient regarding his or her diagnosis, prognosis, the risks, benefits, and consequences of the full range of available medical interventions including the option of no therapy. Particular care should be taken to present this information in terms understandable to the patient. If medically indicated or requested by the patient, consultation should be used to confirm the medical diagnosis and prognosis and to provide further information on the therapeutic options available. The physician should take the initiative to establish with the patient an...
overall treatment plan with mutually agreed upon goals that are derived from the patient’s values and life goals and that defines the role, if any, of life-sustaining interventions. (3) Providing a professional recommendation regarding the medical choices available, including the use of life-sustaining therapy, based on knowledge of both the medical situation and the values and goals of the patient. The purpose of this recommendation is to improve the patient’s decision-making process by clarifying how the choices available would relate to the patient’s values and goals. Recommendations should be respectful of the patient’s autonomy and not coercive or manipulative so that the patient can make his or her decision as voluntarily as possible (1, 2).

The type of communication described above between physician and capable patient is an integral part of good medical practice; it should preferably be carried out while the patient is well or relatively stable, if possible, rather than when a life-threatening situation is imminent or has developed. If the patient has decided to forgo life-sustaining therapy under some or all circumstances, he or she should be encouraged to express his or her preferences as specifically as possible in an advance treatment directive, i.e., a “living will” (2, 5, 18). The patient should also be encouraged to share and discuss the advance directive with his or her physician to promote proper interpretation of the document and to facilitate its implementation. The physician should assist the patient so that the directive actually includes statements of the patient’s preferences applied to specific medical situations and does not solely rely on ambiguous phrases such as when there is “no reasonable expectation of my recovery” (18). These specific situations should include not only those that might occur to any patient, such as what therapy, if any, is desired if he or she becomes permanently unconscious, but even more importantly, those that might likely be encountered by that particular patient, such as use of mechanical ventilation or cardiac resuscitation in a patient with advanced chronic obstructive pulmonary disease or advanced lung cancer. In addition, the patient should discuss his or her preferences and share this advance treatment directive with a trusted family member, friend, or other person who, if willing, should be designated by the patient as his or her surrogate decision maker (see below, Section 2); this designation should be made as legally possible and use of a durable power of attorney for health care decisions (1, 2, 5) as permitted and defined by the applicable jurisdiction.

After a decision has been made to withhold or withdraw life-sustaining therapy, the physician also has a responsibility to offer to relieve the pain and suffering that might arise from implementing that decision. The patient or the patient’s surrogate decision maker should be informed of, and agree with, such palliative therapy, which may unintentionally contribute to the patient’s death. Withholding and withdrawing life-sustaining therapy, with or without palliative sedation or analgesia, are generally, but not universally (19), considered to be ethically and legally distinct from assisted suicide and active euthanasia (2, 5, 20). The latter is the administration of a lethal agent for the purpose of causing death. Physician involvement in assisted suicide and active euthanasia, even if requested by the patient, is not endorsed by the ATS.

Section 2. When a Patient Lacks Decision-making Capacity, a Surrogate Decision Maker Should Be Identified to Help Make Decisions on the Patient’s Behalf Regarding Life-sustaining Therapy. An adult patient who no longer has decision-making capacity should continue to have the right to refuse all forms of medical therapy; however, this right must be exercised on the patient’s behalf by an appropriate surrogate decision maker. Under these circumstances, the surrogate decision maker and the patient’s physician should jointly deliberate decisions regarding withholding or withdrawing life-sustaining therapy with the physician providing help and advice to the surrogate in making the decisions. The surrogate decision maker may be a court-appointed representative, an individual previously designated by a capable patient in an oral or written advance directive or a specific family member as stipulated by state law. If no such person exists, the physician should help to identify one or more close family members or close friends of the patient to be the surrogate decision maker primarily on the basis of both their knowledge of the patient’s preferences, values, and goals and their commitment to supporting the patient’s rights and best interests. Whenever possible, out of respect for the patient’s autonomy, the surrogate decision maker should make the same decisions about the patient’s care as the patient would have made if capable of doing so, based on the patient’s prior oral or written statements concerning use of life-sustaining therapy. If the patient made no known prior oral or written statements or if they are not applicable to a particular decision, then the surrogate should use his or her best judgment of what the patient would have preferred under the circumstances based on his or her understanding of the patient’s values and goals in life. If circumstances arise in which the surrogate decision maker cannot make a decision based on the patient’s prior statements or of the patient’s values and goals, he or she should collaborate with the patient’s physician and other health care providers to make decisions for the patient based on what is determined to be in the patient’s best interests. This process should be as reasonable and objective as possible by weighing the benefits of the therapy against its burdens on the patient. If the benefits of the therapy exceed the burdens, the therapy should be administered; if the burdens exceed the benefits, the therapy should be forgone. This same basis of decision making on the patient’s behalf i.e., weighing benefits versus burdens, should also be used when no advance treatment directive by the patient is available and when no surrogate decision maker who has known the patient can be found. In this latter circumstance, when no one who has known the patient can be located, the patient’s health care institution should have a mechanism for identifying an appropriate person or persons to serve as surrogate decision maker for the patient.

Discussion Although there is a general ethical and legal presumption that all adult patients have decision-making capacity while participating in their medical care (1), this should be applied with particular caution to a critically ill patient receiving life-sustaining therapy. As a general rule, loss of some or all decision-making capacity can be expected to occur frequently in such a patient because of the deleterious effects of medical interventions on the patient’s cognitive function and ability to communicate. Some of these factors include confusion, amnesia, and other alterations in consciousness, such as sedation or delirium, caused by anxiety, pain, sleep deprivation, and medications as well as by the critical illness itself. Although tracheal intubation may compound these factors in causing difficulty in communication, tracheal intubation by itself should not imply lack of decision-making capacity. Because it may be difficult to assess decision-making capacity accurately in such a patient, serial examinations by one or more health care providers are important to note how consistently he or she is able to meet the criteria for decision-making capacity listed previously. Observations by close family members and friends are often helpful in judging not only the patient’s cognitive functioning and ability to communicate but also whether currently expressed opinions, if any, are in accord with the patient’s long-standing preferences, values, and goals.

A seriously ill patient receiving life-sustaining therapy commonly becomes dependent both on that therapy and on his or her health care providers; because of the potential adverse effects of such dependency on the patient’s expression of his or her autonomy, it is important for the health care team to be consistently mindful to promote, respect, and affirm the patient’s autonomy. First, this can be done by enhancing the patient’s decision-making capacity as much as medical circumstances allow through efforts to reverse cognitive dysfunction and to improve the patient’s ability to communicate. Second, health care providers should encourage the patient’s family and friends to visit and support the patient and should collaborate with them and with the patient’s prior health care providers, if any, to obtain knowledge of the patient and of his or her values and goals. This is especially important if the patient is in an intensive
care unit whose physician and nursing staff may not have known the patient previously. Even if the patient lacks decision-making capacity, the patient’s autonomy and prior preferences can still be respected by fostering identification of and collaboration with an appropriate surrogate decision maker for the patient. The basis for identifying the surrogate decision maker may be primarily legal or ethical depending on the applicable jurisdiction. A legal basis for such a designation would hold if the patient has previously arranged for another person to have a legally valid durable power of attorney for health care decisions on his or her behalf, has a prior court-appointed representative, or is located in a state that specifies by statute or case law a legal basis and hierarchy for family members to serve as surrogate decision maker (8).

The ethical basis for identification of an appropriate surrogate is primary when none of the preceding legal bases apply. Under these circumstances, the patient’s physician and other health care providers have the responsibility to foremost obtain the patient’s capacity, the patient’s autonomy and prior preferences to serve their patient’s best interest, to help identify the person or persons who are best able to affirm the patient’s autonomy by using their knowledge of the patient’s previously expressed preferences or values and goals to make decisions about the patient’s medical treatment on the patient’s behalf (1, 2, 5). This process is usually not difficult if the patient’s family members and friends agree that one or two persons should be the surrogate because they were closest to the patient or if the patient, when capable, formally designated a close family member or friend as surrogate. However, this process may become difficult in other circumstances; examples include when there is continuing disagreement among family members over who should be the surrogate or what the patient would have preferred, when the person who would be surrogate is not disinterested, i.e., being potentially influenced by personal gain from a certain decision, or when there are conflicts regarding decisions among family members who were estranged from the patient for years and patient’s closest friend or friends with whom he or she confided preferences regarding life-sustaining therapy. Finally, another difficult situation may arise in which the legally specified surrogate does not know the patient’s preferences or values and goals or is not willing to participate in the decision-making process whereas another relative or close friend of the patient is appropriately able and willing to serve as surrogate. In such difficult cases, health care providers should be knowledgeable of the applicable legal directives and limits and of their ethical responsibility to the patient and they should try to build a consensus among party so as to permit the patient’s preferences or values and goals to determine the decisions made on his or her behalf. If this consensus cannot be achieved by those involved, consultation with the health care institution’s ethics committee may be useful in helping to reach one. As a last resort, if conflict over who should be the surrogate remains a critical unresolved issue, the patient’s health care providers should request that their health care institution seek judicial review regarding the appropriate designation of a surrogate decision maker for the patient.

At times even after a good faith search, no one who has known the patient can be found to serve as surrogate decision maker. In these circumstances, health care institutions should have an explicit mechanism for identifying a surrogate to help determine and serve the patient’s best interests. Although not recommended in general because of potential problems in objectivity (5), if no one else is available, the patient’s physician may act as the patient’s surrogate as long as substantive life-sustaining health care decisions, especially those related to withholding or withdrawing life-sustaining therapy, are subject to institutional review prior to implementation.

Although presumptively valid and binding, a directive from a surrogate decision maker may not be compelled as the same directive stated by a capable informed patient because of the potential for ambiguity and uncertainty inherent in the surrogate’s directive (1, 2). Such ambiguity and uncertainty may arise from two sources: the first is from interpreting a patient’s prior statements or in understanding a patient’s values and goals and the second is from applying those preferences or values to a situation not previously experienced or even considered by the patient. For example, an advance directive with a written statement that the patient would want food and water withheld if she or he is in a persistently unconscious state can be interpreted with minimal ambiguity with only the duration of unconsciousness not clearly defined. In contrast, commonly used “living wills” often contain ambiguous terms, such as forgoing “heroic measures” when there is no reasonable expectation for recovery (18), whose meanings can be interpreted quite differently by health care givers or surrogates. This reemphasizes the essential need for inclusion of specific statements of the patient’s preferences in advance directives along with discussion of their proper interpretation prior to the patient’s possible loss of decision-making capacity.

For these reasons, it is important that the health care team continue to participate actively in making health care decisions on the patient’s behalf in conjunction with the patient’s surrogate. This includes a responsibility to evaluate the surrogate’s directives and bases and to disagree and refuse, if necessary, to carry out the directive if it clearly does not seem to be either in accord with representations of the patient’s long-held values and goals or consistent with any reasonable conception of the patient’s best interests. For example, a surrogate should not be allowed to override a known and clearly expressed preference to forgo life support by a previously capable and informed patient, such as not wanting cardiac resuscitation under any circumstances. On the other hand, if the patient had only made a general statement, such as “I want everything done,” when asked about his or her preferences concerning the role of life-sustaining therapy prior to losing decision-making capacity, serious questions should arise in the minds of the patient’s health care providers and surrogate regarding the significance of the patient’s statement, which is essentially meaningless by itself because of its vagueness. In the absence of more specific statements of that patient’s preferences, the surrogate and health care providers should try to make decisions based on the patient’s values and goals if known or, if not known, on what is determined to be in the patient’s best interests as noted previously. If disagreements over these issues arise between health care providers and the surrogate decision maker, further exploration of their respective points of view may help, first, in identifying mutually agreeable goals of therapy and, second, in reaching consensus of how various life-sustaining interventions relate to the patient’s goals. Persistent disagreements may be addressed by consultation with the institution’s ethics committee or, as a last resort, by judicial review of the dispute.

Section 3. A Life-sustaining Medical Intervention Can Be Limited without the Consent of Patient or Surrogate When the Intervention Is Judged to Be Futile

Based on the ethical principles of beneficence and nonmaleficence that underlie the practice of medicine and define its goals, the purpose of a life-sustaining intervention should be to restore or maintain a patient’s well-being; and it should not have as its sole goal the unqualified prolongation of a patient’s biological life. On this basis, a life-sustaining intervention may be withheld or withdrawn from a patient without the consent of the patient or surrogate if the intervention is judged to be futile. A life-sustaining intervention is futile if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for that patient. Here, meaningful survival specifically refers to a quality and duration of survival that would have value to that patient as an individual. Survival in a state with permanent loss of consciousness, i.e., completely lacking cognitive and sentient capacity, may be generally regarded as having no value for such a patient. A physician has no ethical obligation to provide a life-sustaining intervention that is judged futile as defined previously, even if the intervention is requested by the patient or surrogate decision maker. To force physicians to provide medical interventions that are clearly futile would undermine the ethical integrity of the medical profession. If a physician decides to withhold such an intervention, he or she has a responsibility to inform the patient’s or surrogatedecision maker of that decision and to explain the decision’s rationale. He or she should also offer reas-
...survance that the patient will continue to receive all other care that is medically indicated within the context of an overall treatment plan agreed upon for the patient. If the patient or surrogate decision maker disagrees with the decision to limit the intervention, he or she should have opportunity to transfer responsibility for the patient’s care to another physician who is willing to provide the disputed intervention in the same or another institution. If no such physician can be found, or if transfer between institutions is not medically or otherwise possible, the intervention may be withheld or withdrawn in accordance with institutional policies and applicable laws.

Furthermore, a health care institution has the right to limit a life-sustaining intervention without consent of a patient or surrogate by restricting admission to, or continued care in, a special care unit, such as an intensive care unit, based on the ethical principle of just allocation of scarce resources and the principle of medical triage. On these bases, an institution can have an explicit policy for a special care unit that establishes criteria for admission and discharge. These criteria should be as medically objective as possible and include diagnosis, severity of illness, the type and certainty of prognosis, and a weighing of the extent of benefits reasonably expected for a given patient versus the burdens to that patient as well as to what degree the unit’s limited resources would be restricted by providing that patient’s care. On the other hand, admission to or continued care in such a special care unit should not be precluded solely on the basis of nonmedical factors, such as advanced age or perceived usefulness to society or because a patient or surrogate has decided to forgo CPR. In the latter case, he or she might benefit significantly from other forms of medical therapy, excluding CPR, available in such a unit.

Discussion

The principles of beneficence (being of benefit to the patient) and nonmaleficence (doing no harm to the patient) have formed the ethical foundation of the practice of medicine from the Hippocratic era (21) to the current era (2, 5). These two principles have also been the ethical bases for decisions by physicians not to treat patients who request nonbeneficial, useless, or futile interventions or those that would be solely harmful (22). The principle of autonomy that gives an informed and capable patient the right to refuse medical therapy does not give him or her the right to demand nonbeneficial, futile, or solely harmful medical interventions. Although there is substantial ethical support (2, 5, 11, 17, 23) and support from case law (24, 25) for a physician’s right to refuse to provide a futile intervention, the ethical opinions are not unanimous (13, 26) with significant disagreement existing over the following two issues: the first relates to the proper definition of futility, especially if life-sustaining interventions are judged futile based on quality of life judgments, and the second is whether patients or surrogates should be informed of a decision to limit a life-sustaining intervention on the basis of futility (23, 27–31).

This statement defines a futile life-sustaining intervention generally in terms of a combination of two major criteria: lack of medical efficacy, as judged by the patient’s physician, and lack of a meaningful survival, as judged by the personal values of the patient. Two types of futile interventions are exceptions to this because they meet only one of these two criteria. The first occurs when the intervention is judged to be physiologically futile, i.e., highly unlikely to produce its intended physiological result which is survival per se. In this case the criterion of lack of medical efficacy alone defines futility. The second exception occurs in patients with permanent unconsciousness for which life-sustaining interventions are regarded as futile because such survival is generally held to have no value for the patient; in these cases, lack of a meaningful survival is defined without reference to the patient’s personal values unless the patient, when capable, had explicitly specified in an advance directive that such an existence would have value to him or her. In the latter circumstance, health care providers may provide life-sustaining interventions out of respect for the patient’s prior expression of autonomy.

To judge that a life-sustaining intervention would lack medical efficacy requires the ability to predict the outcome of that intervention with a high degree of confidence. Although a growing body of scientific information is available to guide physicians in predicting the outcome of some life-threatening conditions (32–34), medical prognosis remains an inexact science when applied to an individual patient; consultation with other health care practitioners is often helpful to reduce the likelihood of error in decisions based on prognosis. When the efficacy of an intervention is still uncertain, a time-limited trial of the intervention that is agreed to by all involved may increase the certainty of the prognosis.

The following examples illustrate how this statement’s definition of futility may be applied to life-sustaining interventions. First, as noted above, a potentially life-sustaining intervention can be futile in the narrow sense of being physiologically futile. For example, cardiac resuscitation would be futile in this sense when it is highly likely to consist only of a succession of failed defibrillation attempts. Such high likelihood of failure of cardiac resuscitation occurs commonly in intensive care units when a patient, because his or her condition is irreversible and untreated despite receiving aggressive medical intervention, deteriorates to the point where death by cardiac arrest is imminent.

Second, a life-sustaining intervention can be futile in the sense that although it results in survival, that survival lacks value for the patient, i.e., the value of the survival is judged from the patient’s, not the physician’s, perspective. Because most capable patients state their preferences regarding life-sustaining therapy, as a general rule, in the context of their life goals and values, it may seem contradictory how such a patient might receive an intervention resulting in a quality of life that lacked value to that patient. In rare cases, a capable patient may have clearly made known his values and goals in life but may not have expressed, or may no longer be able to express, his preference to forgo a life-sustaining intervention. For example, such a patient may have agreed to begin a certain intervention as a therapeutic trial to achieve a certain result and, if he or she lost decision-making capacity before it became clear that the intervention was highly unlikely to achieve that result, such an intervention would be futile at that point in relation to his or her previously stated life goals and values. Such an intervention would generally be withheld or withdrawn from the patient with a surrogate’s consent on the basis of respecting the patient’s preferences or values and goals. However, in rare cases in which the surrogate is unwilling to agree, the intervention could also be ethically withheld or withdrawn on the basis of futility.

The third example of a futile life-sustaining intervention occurs when a patient is permanently unconscious with no cognitive or sentient capacity and had not prepared an advance directive explicitly requesting life-sustaining interventions if in such a condition (2, 23). In principle, it would be ethically permissible to withhold or withdraw all life-sustaining interventions from a permanently unconscious patient on the basis of futility and without the need for consent of the surrogate decision maker; however, such a withdrawal might not be legally permissible. In cases of disagreement over limiting interventions under these circumstances, the family should be allowed to transfer the patient’s care to another physician or institution; if this is not possible, then the patient’s health care providers with their institution’s support should consider requesting judicial review to resolve the disagreement.

Another ethical basis for limiting a life-sustaining intervention without the patient’s or surrogate’s consent, in addition to futility, is based on the ethical principle of just allocation of scarce resources and the principle of triage (2, 5). A health care institution’s intensive care unit that has limited resources can have an explicit institutional policy for prioritizing admissions and discharges based on medically objective criteria as noted above. Decisions restricting access to such a unit should be consistent with the principle of proportionality according to which the extent of benefits that are reasonably expected for the patient from care in the unit are compared against the burdens that are expected both on the patient and on the unit’s limited resources (2, 5). On this basis, patients not only can be denied admission to...
such a unit but also can be transferred out of the unit because they have deteriorated to a point where they no longer have a reasonable likelihood of receiving benefit from continued care in the unit (2, 5). To restrict access to limited institutional resources is the right of a health care institution and not that of an individual physician because of the institutional nature of this issue and the need for appropriate review and approval of the criteria setting process and policy.

The decision to withhold or withdraw life-sustaining therapy on the basis of futility and its reasoning should be discussed with the patient or surrogate prior to its implementation for a number of reasons. The first reason is to give the patient or surrogate, if he or she disagrees with the physician’s decision, the opportunity to transfer responsibility for the patient’s care to another physician or to another institution. A second reason is in recognition of the current state of affairs in acute care hospitals in which CPR has become a presumption in the minds of patients, families, and the general public and, as such, is a medical intervention expected to be received. A third reason is to avoid any suggestion of covert decision making by health care providers regarding limitation of life-sustaining therapy, especially CPR. A final reason is that such discussion is consistent with this document’s emphasis on the importance of open discussion between health care providers and patient or surrogate for the purpose of establishing a treatment plan with explicit goals that are both medically appropriate and meaningful for the patient. As a corollary to the above list of reasons, physicians should not use the availability of withholding a life-sustaining intervention on the basis of futility as an excuse to avoid possibly difficult discussions concerning limitation of life-support with the patient or surrogate decision maker.

If a patient or surrogate disagrees with the decision to limit a life-sustaining intervention on the basis of futility or admission or discharge criteria of a special care unit as noted above, he or she should have the right to transfer care to another physician or to another institution that would be willing to provide the disputed intervention. Consultation with the institution’s ethics committee or similar resource is also recommended to facilitate discussion among disagreeing parties and to review the decision-making process and the decision. An institution’s policies with regard to withholding or withdrawing life-sustaining therapy, especially without the consent of a patient or surrogate, may be constrained by applicable legal limits. Physicians and their health care institutions should know and respect the laws applicable to their clinical decision making; however, if it is the strong consensus of health care providers of that institution that an existing law is ethically or medically inappropriate as applied to care of a specific patient, they should try to modify the law through appropriate means including requesting judicial review of the case.

Section 4. Health Care Institutions Have a Responsibility to Promote Ethically Sound Decision Making Regarding Life-sustaining Therapy

Because of their societal missions as health care providers and their potential to infringe on the autonomy of their patients, hospitals, and long-term-care facilities have a responsibility to promote ethically sound approaches to issues relating to withholding and withdrawing of life-sustaining therapy. This responsibility should include both an educational program and a related set of written policies. The former should be directed to meeting the educational needs of patients, their families, and the institution’s medical, nursing, and legal staff as well as other employees. As part of this program, the institution should ensure that personnel with expertise in clinical ethics are available to provide ethics consultations, to assist in policy development and to serve as a general educational resource. The institution should also ensure that its legal counsel has accurate and current knowledge of the legal limits related to withholding and withdrawing of life-sustaining therapy within the specific jurisdiction applicable to that institution and is readily available for consultation with health care providers regarding these issues. Finally, because these ethical issues are intrinsic to the practice of medicine in general, physicians and other health care givers, particularly those experienced in providing life-sustaining therapy, have a responsibility to become knowledgeable in the ethical and legal dimensions of these issues and to provide leadership and active support to these institutional educational and policy-making efforts.

The institution’s written policies should define not only the circumstances in which it is acceptable to withhold and withdraw life-sustaining therapy in that institution but also the circumstances in which there may be limits to a patient’s or surrogate’s directives either to forgo or to request life-sustaining interventions. Policies should explicitly note the elements required for the decision-making process in these circumstances and should define the procedures for documentation and for implementation of the decision. The rights and responsibilities of a patient and his or her surrogate and of physicians and other health care providers should also be described. Institutional policies should be consonant with the principles and positions stated above except when doing so would conflict with applicable legal limits or the explicitly stated mission and moral code of that institution. These policies should be made available automatically to all patients or surrogate decision makers at, or preferably prior to, a patient’s admission to that institution.

Discussion

Because of the reasons previously noted, health care institutions should be regarded as moral agents whose activities, like those of health care professionals in general, should be based on the ethical principles of beneficence, nonmaleficence, and respect for patient autonomy (35). Although decisions regarding withholding and withdrawing life-sustaining therapy are commonly made by the persons involved without disagreement as to the correctness of the decision, in view of the pluralistic nature of current society regarding values and goals in life, some conflicts regarding these decisions or their implementation can be expected to arise. Health care institutions should have available a formal mechanism to help resolve such conflicts when they occur. This may be a multidisciplinary institutional ethics committee (2, 5, 6), or another institutional resource that can be requested by an individual involved in the conflict, i.e., patient, family member or surrogate, nurse, physician, or other employee of the institution. An institutional ethics committee or other means of ethics consultation may serve as a conflict resolution mechanism by facilitating the communication of values, emotions, and other opinions among the disagreeing persons and by reviewing the applicable legal and institutional context and the ethical implications of the relevant issues. The institutional ethics consultation may also be helpful by judging the appropriateness of the alternative decisions under consideration and by documenting its consultation and its judgments in the patient’s medical record. Health care institutions should also ensure the availability of counseling or other appropriate resources to provide emotional support to patients, families, and staff involved in these decisions; this may be especially needed during withdrawal of life-sustaining therapy.

How institutional policies and practices concerning withholding and withdrawing life-sustaining therapy relate to different views of risk reduction from liability is worth noting because of the important role of the institution’s legal counsel in policy development and in implementation. What some institutional attorneys conventionally perceive as “risk management” may only promote legal conflict liability when applied to issues regarding forgoing life-sustaining therapy. An alternative view, supported by this statement, is that effective risk management for an institution occurs when the patient’s needs and best interests are that institution’s first consideration. Because of this, it is essential that the institution’s policies on forgoing life-sustaining therapy be developed and implemented on sound medical, ethical, and legal bases and that the institution’s legal counsel, in addition to being well informed and current on these issues, be involved in policy development related to these issues (36).

In addition to the moral obligations arising from their societal mission, health care institutions also have responsibilities to support patient autonomy and ethically valid decision making that are recommended or required by external sources. These include those related to specific recommendations in
this regard by the Joint Commission on Accreditation of Healthcare Organizations (37), those arising from state regulations related to patients’ rights and those resulting from state and federal laws. For example, recently enacted federal legislation, the Patient Self-Determination Act, will require several types of health care institutions, including hospitals and long-term care facilities that receive Medicaid and Medicare funds, to develop policies related to the use of advance directives for withholding and withdrawing life-sustaining therapy and to provide patients with information concerning advance directives and these policies (38).

Note: This document should not be interpreted as providing legal advice regarding these issues; for the purpose of obtaining such legal advice, because legal limits related to these issues continue to evolve and because states and other jurisdictions may differ substantially from each other, readers are strongly advised to confer with an attorney who has expertise and current knowledge of this subject in their local jurisdiction.

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