The End-of-life Sequence
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"The timing of death—once a matter of fate—is now a matter of human choice."‡

The end-of-life issues of the 1960s and 1970s gave birth to the specialty of bioethics and have been the most active area in the field until recent questions of health care reform captured the spotlight.¹ By moving the discussion from patients' rights to refuse treatment to patients' rights to demand treatment, this analysis advances chronologically and conceptually.

Patients' Rights to Refuse Life-Sustaining Treatment

In 1968, withdrawal of life support from a living person was outside the realm of ethical behavior for physicians. For example, the Harvard Committee to Examine the Definition of Brain Death said, "It should be emphasized that we recommend the patient be declared dead before any effort is made to take him off a respirator... [because] otherwise, the physicians would be turning off the respirator on a person who is, in the present strict, technical application of law, still alive."³

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Two cases, 14 yr apart, helped establish the right of patients to refuse care considered necessary for life. In 1976, the courts upheld the legality of disconnecting the ventilator from Karen Ann Quinlan, who was thought to be in a permanent vegetative state and dependent on a ventilator.§ After the ventilator was disconnected, Quinlan lived for nearly a decade sustained by nasogastric feedings. Nonetheless, this event began to define the right of patients to refuse care considered necessary for life.³

Basing the decision in part on the general constitutional right to privacy, the court determined that a surrogate had the right to decline medical treatment for an incompetent patient if the surrogate surmised that the patient would have preferred limited care. This substituted judgment is grounded in the surrogate's presumed intimate understanding of the patient. Quinlan's father was thus able to discontinue his daughter's mechanical ventilation. The problems with using the substituted judgment standard center on the degree and sufficiency of the knowledge required by the surrogate. A family member, the customary surrogate, may not be adequately intimate with the incompetent patient, or the patient may have preferred a different surrogate decision maker.⁵ This standard puts significant burdens on decision makers who may have legitimate doubts about the correctness of their decisions.⁵

The 1990 Cruzan case concerned a young woman involved in an automobile accident that left her incapable of expressing a preference, much like Quinlan. But several years earlier, Nancy Cruzan had expressed to a friend in a somewhat serious conversation a desire not to live in a state of diminished capacity. Basing treatment on statements of a once competent patient's previously expressed preferences for end-of-life care is called the subjective standard. The difficulty lies in knowing what authority to give these informal statements. Although comments such as these may be meaningful, they are difficult to put in perspective and may have been made without sufficient forethought. In light of these concerns, the State of Missouri enacted legislation requiring "clear and convincing" evidence of a
patient's wishes before terminating life-sustaining treatments. The Supreme Court of Missouri held that Cruzan's informal statements did not meet this evidentiary standard and mandated continuation of treatment. The case was appealed to the United States Supreme Court, whose decision was most influential in affirming the use of the subjective standard to guide care. The decision did, however, uphold the rights of states to determine evidentiary standards, and thereby allowed Missouri to continue to require "clear and convincing" evidence of the patient's wishes.

The Cruzan case further solidified the right of a competent patient to refuse medical treatment. Unlike the Quinlan case, this right to refuse treatment was more solidly grounded in the liberty interest of the Fourteenth Amendment, which states, "No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty or property..." Further, the Supreme Court's Cruzan ruling significantly extended the Quinlan decision by including artificial nutrition and hydration (tube feedings) as medical care that may be refused or discontinued by the competent patient or surrogate. In 1996, competent patients had a virtually unlimited right to refuse any, even life-saving, medical treatment.

For the incompetent patient, three hierarchical levels of judgment direct the decision-making process for end-of-life care. For patients who were once competent, the subjective standard is preferred. This is based on direct knowledge of a patient's previously expressed wishes. When these are not known, the substituted judgment standard must be used, based on a general knowledge of the patient's attitudes and beliefs. In the most difficult cases, surrogates are asked to make decisions for patients who have never been competent, such as young children or adults with mental disabilities. In these cases, substituted judgment is impossible, and surrogates must rely on their assessments of the patient's best interests.

Refusal of Cardiopulmonary Resuscitation

Cardiopulmonary resuscitation is the only medical therapy that requires a physician's order for it to be withheld. Since the incorporation of cardiopulmonary resuscitation into practice in the 1960s, medicine in general has made the assumption that a patient would always prefer to be resuscitated. Cardiopulmonary resuscitation became part of every dying patient's care.

Recognizing this potential problem, the American Medical Association in 1974 endorsed a policy that said in part, "the purpose of cardiopulmonary resuscitation is the prevention of sudden unexpected death. Cardiopulmonary resuscitation is not indicated in cases of terminal irreversible illness where death is not unexpected."

Two years later, the approach to do-not-resuscitate (DNR) policies from Boston's Beth Israel Hospital and Massachusetts General Hospital were published in the New England Journal of Medicine. These policies acknowledged the need to protect patients' rights to limit the use of modern technology during terminal illness.

The acceptance and use of DNR orders progressed from the wards, to intensive care units, and finally to the operating room. The right of a patient to reject unwanted therapy in the operating room is well accepted and endorsed by the professional bodies of anesthesiologists and surgeons. Before proceeding to the operating room, preoperative DNR orders should be reconsidered in light of the patient's overall goals.

The anesthesiologist should clarify with the patient the relative merits of retaining, suspending, or modifying the DNR order for the operating room. Arguments for retaining DNR status are based on the individual's right to determine care. Arguments for suspending DNR status in the operating room center on the nature of anesthesia. It is difficult to draw a line between routine anesthesia care and resuscitation. Anesthesia promotes instabilities to which the anesthesiologist routinely responds and the demarcation of a point at which "resuscitation" begins is unreasonable. Faced with limited treatment options, an anesthesiologist may give a "light" anesthetic that, although designed to decrease the necessity for resuscitation, may also not give the patient the full benefit of anesthesia. Further, patients should know that the outcomes from witnessed arrests are much better than from those that are unwitnessed, especially when the cause of the arrest is iatrogenic.

As such, the chance of quality survival after an arrest
in the operating room is higher than after an arrest elsewhere.

Resuscitation should be discussed and defined in light of the surgical procedures, the anesthetic options, and patients' goals. Anesthesiologists should elucidate patients' concerns. Understanding patients' specific fears, such as long-term suffering in the intensive care unit or being an emotional or economic burden to their family helps patients, anesthesiologists, and other caregivers articulate concerns and plan appropriate resuscitation measures. Patients' expectations from discussions with other caregivers should also be reviewed. Anesthesiologists are then prepared to clarify and document the desired resuscitation status in the operating room by using one of two broad, overlapping approaches, the procedure-based approach or the goal-based approach.

The procedure-based approach centers on defining which interventions will be performed in light of a patient's goals for the procedure, anesthesia, and end-of-life care. In other words, a patient may choose not to receive chest compressions and pharmacologic therapy because he or she does not want to undergo a lengthy and painful death in the intensive care unit. Relevant procedures that may need to be defined and are often included on checklists include tracheal intubation or other airway management, postoperative ventilation, chest compressions, defibrillation, vasoactive drugs, invasive monitoring, blood product transfusion, supplemental oxygen, and intravenous access. These checklists are also useful for spurring discussions and defining desires. Use of a checklist for defining and documenting care in the operating room grew out of the procedure-based approach of ward DNR orders. The clarity and precision a checklist offers is well suited to the ward, wherein multiple providers, many of whom have never met the patient, are responsible for making resuscitating interventions.

The goal-based approach centers on defining the patient's preferences in terms of outcome without cataloging which interventions will be performed. One practical way of implementing such a system involves the patient choosing between two statements: one requesting that "full resuscitative measures be employed" and the other stating that "clinical events believed to be temporary and reversible will be treated." Another approach is that patients and their caregivers can construct statements to guide caregivers. Requests are defined on three axes: discomfort involved, likelihood of successful resuscitation, and likelihood of having a defined quality of life after resuscitation. Example statements may include "I am willing to undergo a great deal of discomfort to be resuscitated if you think it is likely that I will retain my usual function" or "I am willing to undergo only the most minimal discomfort and only for a high likelihood of successful resuscitation." The goal-based approach arose from the idea that because patients think in terms of outcomes, it may be more natural and effective to communicate about goals rather than procedures. Goal-based and procedure-based approaches require the anesthesiologist to make predictions about the outcome of resuscitation. But because the goal-based approach allows the prediction to be made at the time of resuscitation, it is likely to be more accurate. In the previous example, instead of agreeing to not provide chest compressions and pharmacologic therapy, the caregivers can agree to provide such interventions if the likelihood of success, as defined by the patient, is acceptable, and to not intervene or to stop interventions if the likelihood of success is not acceptable. Goal-based agreements are more practical in the operating room than on the ward because they can be established with specific providers for a finite period of time.

In practice, defining and documenting a patient's preferences for resuscitation in the operating room can involve both approaches. An anesthesiologist may use a procedure-based approach to facilitate discussion and determine a patient's general preferences while still incorporating a mechanism to include a more aggressive intervention if the likelihood of a successful resuscitation is good. For example, the patient and anesthesiologist may agree to attempt resuscitation should there appear to be an acute reversible process such as ventricular fibrillation from insertion of a central venous catheter, but not attempt resuscitation if the cause seems less reversible.

Either approach negotiated with the patient may include a time-limited trial of intubation and ventilation if it is impossible to extubate the patient's trachea at the end of the case. Although many clinicians are more comfortable withholding life-sustaining treatments than

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† Truog RD: Do not resuscitate orders in the operating room: where have we been, where are we going? Seminars in Anesthesia 1993;12:178–86.

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withdrawing them, a large body of ethical and legal opinion agrees that these actions are conceptually equivalent. Caregiver discomfort about withdrawing treatments often are based on personal beliefs and values. Physicians may believe that beginning a treatment binds them to a responsibility for continuing that treatment. Withdrawing such treatment may make these clinicians believe they are breaching expectations or that they have personally failed in their duties to the patient. Clarification of personal and professional goals and expectations at the outset may help avoid these ethically troubling situations. Legally, a physician should be no more concerned about stopping an ineffective treatment than about not starting one. Withholding a therapy may require a higher degree of certainty about its probable failure or lack of desirability than withdrawing a therapy requires after demonstration that it has not achieved its goals. The ethical considerations involved in a decision to withdraw mechanical ventilation should be the same as those involved in a decision to withhold it.

Patients and anesthesiologists should be aware of the need for a negotiated and universal agreement. Discussions should include other pertinent caregivers such as surgeons, intensivists, and primary care providers; preferably all members of the team should at least be willing to abide by the agreement. This provides greater patient satisfaction and a higher likelihood of conformity with the agreement. Achieving concurrence among the parties may be facilitated by an ethics consultant. If conflicts are irreconcilable, the "anesthesiologist should withdraw in a nonjudgmental fashion, providing an alternative for care in a timely fashion." If the proposed interventions "conflict with generally accepted standards of care, ethical practice or institutional policies, then the anesthesiologist should voice such concerns and present the situation to the appropriate institutional body." If time does not permit pursuing such alternatives, then the anesthesiologist is directed to provide care "with reasonable adherence to the patient's directives."

A DNR order in an emergency situation without time to clarify a patient's wishes is inherently different. The traditional bias of providing treatment in the absence of a clear decision not to treat should hold for the anesthesiologist in the emergency situation. A simple and all-too-real example may be the patient who arrives in the emergency room in respiratory distress. Medical judgment dictates rapid tracheal intubation, but a relative might insist that the patient does not wish to be intubated if he will "be stuck on a ventilator." The relative may even claim to have a "form" at home, 1 h away. Although no reason exists to disbelieve the relative, the consequences of the relative misinterpreting the patient's preferences are irreversible. In this scenario, the best option is to intubate the trachea and provide support. After the patient's condition is stabilized, the patient's preferences can be clarified and implemented. The ability to give the patient a trial of therapy such as mechanical ventilation is one of the better ways to fulfill this patient's end-of-life desire to be the recipient of resuscitating efforts without the possibility of being "stuck on the ventilator." If the time-limited trial is unsuccessful or if tracheal intubation is inconsistent with the patient's preferences, then mechanical ventilation can be withdrawn consistent with the patient's goals.

Redirecting Care at the End of Life

Do not-resuscitate orders address only one aspect of end-of-life care. In the 1990s, some institutions are moving beyond DNR policies to address these issues more globally. The Joint Commission on Accreditation of Healthcare Organizations now requires hospitals to have comprehensive guidelines for redirecting end-of-life care, away from therapies that prolong the dying process and toward therapies that promote comfort. These policies should emphasize what will be done to promote comfort, not what will not be done to prolong life. "There is nothing more we can do" is not an appropriate comment to a dying patient.

Advance Directives

The Cruzan decision held that states may require "clear and convincing" evidence that an incompetent patient would prefer to have care limited. Unfortunately, by the time a patient would benefit from limiting care, the patient is at best in a highly emotional state and at worst unable to communicate. Advance directives can help a person discuss with loved ones and physicians end-of-life issues before the emotional upheaval associated with that time. Advance directives are
instructions a competent patient completes to guide care if he or she should become incompetent.

There are two types of advance directives: living wills and health care proxies (also known as durable powers of attorney for health care decisions). Living wills allow patients to state what kind of interventions they would want in different clinical situations. For example, living wills may declare whether patients would want resuscitation or dialysis if they were in a permanent vegetative state. Health care proxies, on the other hand, permit patients to designate surrogate decision makers to make decisions for them should they become unable to make such decisions for themselves.

Living wills have been criticized for not being able to reflect all of the subtle differences that inevitably characterize real clinical situations. Although they can provide a general idea about the wishes of the patient, living wills can be difficult to apply in specific clinical settings. For this reason, some prefer the greater flexibility provided by the health care proxy, wherein the surrogate decision maker can consider all of the specific details when making clinical decisions. Further, this allows assignment of surrogacy when the preferred surrogate is not a family member. Surrogacy is not effective, however, for patients who do not make their preferences clearly known to the surrogate before losing their decision-making capacity. Given the strengths and weaknesses of each approach, some believe that a combination of the two (a designated proxy with some written form of preferences) may be the best option.

### Patients’ Rights to Demand Treatments

Although the 1970s and 1980s were characterized by controversy over the rights of patients to refuse treatments, the 1990s may well be remembered for debates over the limits of patients’ rights to demand treatment.

#### The Futility Debate: The Demand for Life-sustaining Therapies

The futility debate focuses on whether a therapy should be used when a specified goal is unlikely to be achieved but the therapy is demanded by the patient or surrogates. The debate centers primarily on two clinical situations. The first involves the permanently unconscious patient who is not imminently terminal but has minimal likelihood of recovering. The second involves the presumptively terminal patient who demands certain therapies, particularly cardiopulmonary resuscitation. The 1976, the Karen Ann Quinlan case centered on a family’s desire to withdraw therapy from a permanently unconscious patient while the hospital wanted to continue therapy. In 1991, the opposite situation occurred. Oliver Wanglie wished to continue care for his wife, Helga Wanglie, an 86-year-old woman who had been in a vegetative state for more than 1 yr. A patient in a vegetative state has no detectable signs of awareness of self or environment (table 1). By definition, persistent vegetative state is a vegetative state present one month after acute traumatic or nontraumatic brain injury or lasting for at least one month in patients with degenerative or metabolic disorders or development malformations. The term permanent vegetative state indicates the diagnosis with a “high degree of clinical certainty” that the patient’s condition is irreversible. Although improvement of consciousness after 12 months is extremely unlikely, it has occurred. Mr. Wanglie, although acknowledging the limited hope of recovery, strongly believed that his wife valued any life and would want care continued. Her physicians wished to discontinue care, citing evidence that patients in a permanently unconscious state rarely, if ever, recover significant function. The court upheld the husband’s right to surrogacy and to have care continued.

A presumptively terminally ill patient may request a therapy the clinician does not believe will be successful. Some hospitals have incorporated policies that permit physicians to unilaterally withhold treatment with a low likelihood of success. Others recognize the inherent

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<th>Table 1. Criteria for Diagnosis of Vegetative State as Reported by the Multi-Society Task Force on PVS</th>
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<tr>
<td>No evidence of awareness of self or environment and an inability to interact with others</td>
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<td>No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli</td>
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<td>No evidence of language comprehension or expression</td>
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<td>Intermittent wakefulness manifested by the presence of sleep-wake cycles</td>
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<td>Sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical or nursing care</td>
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<tr>
<td>Bowel and bladder incontinence</td>
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<td>Variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes</td>
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problems in determining qualitative and quantitative thresholds for futility judgments. For example, how low does the probability of success have to be for a therapy to be considered futile? How great a benefit must a patient receive from a therapy for that therapy not to be considered futile? How certain must we be of our predictions? How do the patient’s values play into these determinations? Because these questions are difficult to answer, a growing trend is to step away from defining a specific policy to limit futile care and instead focus on individual benefits and burdens in the particular situations.53

Palliation and Comfort Care

Many studies have clearly shown that terminally ill patients are inadequately treated for their pain.52,53 To cite just one example, in a survey of 1,400 physicians and nurses, 81% of respondents said that the most common form of narcotic abuse in these patients was undertreatment of their pain.54 This is alarming, given the evidence that optimal use of pain and comfort management can ameliorate pain without intolerable side effects in 70–95% of terminally ill patients.55 That survey also revealed that 40% of the respondents believed that clinicians give inadequate pain medication to terminally ill patients most often from fear of hastening death.54 This indicates that many clinicians are unaware of the current ethical and legal consensus regarding palliative care at the end of life. This consensus is built around the principle of the double effect (which is discussed in the first of this series of articles).56 The thrust of the principle is to focus on the intention of the caregiver in seeking to provide comfort to terminally ill patients, even if the clinician realizes that a side effect of the medications could be respiratory depression and earlier death. In the classic example, physicians may titrate increasing doses of morphine to a dying patient, using as much as necessary to attain adequate pain relief, without fear of violating current ethical or legal norms. On the other hand, if the clinician uses a dose of morphine far in excess of that required to make the patient comfortable, or if the patient chooses an agent without pain-relieving properties (such as potassium chloride or pancuronium), then the clinician can no longer plausibly claim that the intention of the action was focused solely on relief of the patient’s pain and suffering. This is the basis for the currently accepted distinction between an intensive approach to palliative care (ethically accepted and even mandatory) and euthanasia or physician-assisted suicide (currently illegal, but see sections that follow for recent developments).

The principle of double effect continues to be an area of lively debate in bioethics, in part because of the ambiguous intentions of caregivers in treating patients at the end of life. For example, even when a physician has no desire to hasten the patient’s death, the death of the patient may nevertheless be seen as a good or desirable outcome. Despite these ambiguities, however, the principle remains an ethical and legal touchstone around treatment of the terminally ill.57,58 Not only is it well enunciated in the law, but all of the major religions have doctrines that support this approach (the principle of double effect was initially developed in the Catholic tradition). Clinicians should therefore never withhold needed pain medications from terminally ill patients for fear of hastening their death through respiratory depression or other complications.

Demands for Physician-assisted Death

‘I’d rather live a little less and go out on my own terms.’

Many consider a good death a necessary conclusion to a good life. The terminology of physician-assisted death can be confusing. Voluntary euthanasia is the act of intervening ‘to cause the patient’s death at the patient’s explicit request and with full informed consent.’59 Nonvoluntary euthanasia and involuntary euthanasia are the same acts with the consent of the incompetent patient’s surrogate or without the competent person’s consent, respectively. Physician-assisted suicide entails the physician making available to the patient an intervention (usually pharmacologic) for the patient to use to commit suicide. Physician-assisted suicide differs from physician-administered euthanasia in that the former requires the patient to make the final act of taking the drug or poison. Some believe that this is an important safeguard against abuse. Others disagree, however, and believe that the acts are ethically indistinguishable because they require substantial involvement of the physician. In addition, the courts have implied that laws permitting physician-assisted suicide but not euthanasia could be discriminatory against terminally ill patients who are too ill to administer the drugs to themselves. For purposes of this discussion, unless oth-


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erwise specified, voluntary euthanasia and physician-assisted suicide will be considered together and the term physician-assisted death (PAD) is used to denote both. Arguments surrounding PAD center on interpretations of the principles of respect for autonomy and beneficence and the possible ramifications of legalization (table 2).

The Northern Territory of Australia and the Netherlands permit PAD. In that part of Australia, the passing of the Northern Territory Rights of the Terminally Ill Act in 1995 made it legal for a terminally ill person to request assistance from a medically qualified person to voluntarily terminate his or her life in a humane manner. This act took effect in 1996, and it is too early to learn from it or to see if it will survive legal challenges.

The Dutch have been openly practicing PAD for two decades. In 1993, the Dutch parliament granted physicians immunity from prosecution if the patient repeatedly requests euthanasia freely, has suffered that cannot be relieved, and the physician reports the true cause of death to the coroner. The Dutch discern no ethical difference between euthanasia and physician-assisted suicide, and so a large proportion of PAD consists of euthanasia. Two nationwide investigations have been conducted into the Dutch practice of PAD. The first, in 1990, is commonly called the Remmelink study, and it found that of the 130,000 deaths in the study period, 2,700 resulted from PAD. Most (99%) patients who received PAD were expected to die within 1 month, and physicians rejected more than two thirds of patient requests for PAD. In addition to those 2,700 cases of PAD, however, the Remmelink study found that an additional 1,000 patients had their lives ended by a physician without the explicit request of the patient, thereby not fulfilling an essential requirement of the policy.

Primary reasons given by patients requesting PAD were loss of dignity, pain, discomfort, fear of pain and discomfort, dependency, and “tiredness of life.” Pain was the sole reason for a patient to request euthanasia in only 5% of cases. When more than one reason was given, loss of dignity (57%) was most frequently given followed by pain (46%). These findings were discouraging to those who believed that better pain control at the end of life would significantly decrease requests for PAD. Although this might have been one reason for advocating better pain control for the terminally ill, other equally important motivations should be sufficient.

A follow-up study was conducted in 1995. The results were similar. Explicit requests for PAD increased by 9% (from 8,900 to 9,700) and the percentage of granted requests decreased slightly. Deaths from PAD increased as a percentage of total deaths, perhaps due to the aging Dutch population having a higher incidence of terminal cancer. Nearly all the patients who received PAD appeared to have had a short life expectancy. The incidence of PAD in patients not explicitly requesting assistance declined from 0.8% to 0.7% of all deaths.

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Table 2: Arguments Surrounding PAD

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<td>Autonomy</td>
<td>Since the definition of a good death is personal, people should be allowed to control the circumstances.</td>
<td>Requests for PAD are not a true expression of autonomy because: Inadequate patient and physician education about pain and comfort control leads to a choice that is not informed. The patient may be depressed or feel like a burden on the family and thus the choice may not be made freely.</td>
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<tr>
<td>Beneficence</td>
<td>If the burdens of being alive outweigh the benefits, physicians are obligated to permit PAD.</td>
<td>Medicine can do a better job of pain and comfort control, thus decreasing the loss of dignity.</td>
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<tr>
<td>Legalization</td>
<td>Physicians can truly be a doctor from cradle to grave. Patients will feel supported by physicians during this important time. Legal safeguards will prevent abuses.</td>
<td>Permitting PAD will gravely harm the image of physician as healer. There will be concern about the caregivers’ impetus for offering euthanasia (e.g., race/gender/socioeconomic status). Permitting PAD will discourage physicians from actively seeking solutions to the problems of those near the end-of-life. Permitting PAD will devalue the sanctity of life, thus further nudging society down the slippery slope toward nonvoluntary euthanasia.</td>
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PAD = physician-assisted death.
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One interpretation of these two studies is that the consistency exhibited during the 5-yr period indicates that the Dutch are not sliding down a slippery slope to increased misuse. Another view, however, is that insufficient time has passed between studies to determine if this slide is occurring. Either way, significant concerns remain about the patients who did not explicitly request PAD. It is, of course, difficult to determine if these patients had previously requested PAD. Nonetheless, the fact that this tenet requiring a competent patient to request PAD could be disregarded so easily warrants continued observation.

Although there are certainly situations where PAD is justified, the possibility of an individual act of PAD does not necessarily imply that PAD on the whole is a good social policy for the United States.** And although some physicians support certain forms of PAD,48-51 many medical groups do not support any kind of PAD.52 Community-generated referendums on physician-assisted suicide have been initiated.53 Recently, the Ninth Circuit Court of Appeals and the Second Circuit Court of Appeals ruled that prohibitions of assisted suicide in Washington state and New York, respectively, were unconstitutional, based in part on the due process clause in the Fourteenth Amendment.54-56 These rulings have been appealed to the Supreme Court and will be considered in 1997.57

Anesthesiologists, with expertise in pain management and pharmacology, have been identified by some as the natural choice for performing PAD, if and when it becomes legalized.60 Most ethicists disagree, however, and emphasize that the primary care physician, with intimate knowledge of the patient, prognosis, and disease process, should be the physician to provide PAD. Perhaps the anesthesiologist’s role should be to provide consultation, as well as high-quality pain and comfort management, to ensure that euthanasia is never chosen as a recourse to treatable pain.62

Brain Death and Organ Procurement

Until recently, death was defined by cardiopulmonary failure, evidenced by loss of pulse and respiration. In the late 1950s, however, the development of mechanical ventilation made possible the resuscitation of patients with beating hearts but irreversible brain injury. These patients aroused little interest until the 1960s and the advent of organ transplantation, and with it the need for transplantable organs. In 1968, an ad hoc committee at Harvard Medical School coupled these two issues by proposing “a new criterion for death.”55

The American Academy of Neurology’s algorithm for determining brain death starts with ensuring the presence of diagnostic criteria such as a known proximate cause, evidence of a compatible central nervous system catastrophe, absence of a confounding metabolic or toxic disturbance, and normothermia.56 Clinical signs of unresponsiveness and absent brain-stem reflexes are sought, such as a lack of pupillary, corneal, and pharyngotralce reflexes, as well as a lack of spontaneous motor activity. Finally, testing for brain-stem function concludes with performance of the apnea test.

The apnea test cannot be performed in the presence of hypotension or hypoxemia because these conditions could be responsible for false-positive findings. Ventilation is discontinued and continuous intratracheal oxygen is delivered. The patient is monitored for respiratory movements. A positive apnea test (supporting the diagnosis of brain death) occurs if respiratory movements are absent and arterial pressure of carbon dioxide is greater than 60 mmHg or increases 20 mmHg over baseline. This usually requires 8-10 min of apnea. An apnea test is negative if respiratory movements occur. Certain seemingly contradictory events may occur during the apnea test that are consistent with the diagnosis of brain death. These include spinal reflexes such as spontaneous limb movement, respiratory-like movements such as shoulder movement, and back arching and hemodynamic responses such as sweating, blushing, and vital sign changes. Dramatic examples of these have been described in the literature as the Lazarus sign.57,58 Because these movements originate from spinal neurons below the level of the brain stem, they do not rule out the diagnosis of brain death.

After a clinical examination consistent with the diagnosis of brain death, the examination should be repeated 6 h later before the diagnosis is confirmed. The use of other confirmatory tests, such as electroencephalogram, angiography, and transcranial Doppler ultrasonography, is controversial. There is significant intra- and interobserver variation in diagnosing brain death by electroencephalogram, and brain wave activity may persist for several days after clinical brain death.59,60 Trans-

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cranial Doppler and angiography depend on blood flow, and the presence or absence of blood flow does not necessarily correlate with the presence or absence of function.61

A promising technique is the use of technetium 99m hexamethylpropyleneamineoxime, which, after injection, is taken up by the brain cells and can image brain activity.62 Experience with this technique is limited. In general, confirmatory testing is not necessary unless some aspect of the clinical examination is ambiguous or cannot be performed.

At a more conceptual level, however, much of the controversy over ancillary testing is rooted in confusion over the concept of brain death itself. Simply put, the definition of brain death is not entirely compatible with the tests that we use to make the diagnosis. For example, the definition of brain death adopted in the Uniform Determination of Death Act requires “complete absence of all function of the entire brain.” By this definition, we should never declare brain death on any patient who does not have diabetes insipidus because persistence of the regulated secretion of antidiuretic hormone is clearly a brain function. Nevertheless, evidence of diabetes insipidus is never mentioned as a requirement for the diagnosis of brain death, and 22–100% of brain-dead patients in different series have been found to retain free-water homeostasis through the neurologically mediated secretion of arginine vasopressin.63–65 Patients diagnosed as brain dead often have evidence of other function as well. Thus some people have argued that the Uniform Determination of Death Act should be reinterpreted to require only the complete loss of all “significant” brain function. Nevertheless, there has never been a satisfactory account that provides a reasoned analysis of the functions that should be considered significant and that should be considered trivial. One of the authors (R.D.T.) has developed these issues in more detail elsewhere.65

Even without these confusing conceptual issues, the diagnosis of brain death is unsettling. The cadaver of the loved one looks no different to the family than the bodies of the living patients in the intensive care unit: the ventilator is cycling, the skin is warm, and the pulse is felt. These patients are theoretically capable of reproduction, which biologists sometimes cite as the *sine qua non* of life. Phrases such as “withdrawing life sup-

port” are not only incorrect but are also misleading and potentially harmful to family members struggling with the diagnosis. Life support cannot be withdrawn from a dead person, and such linguistic imprecision can confuse an already shaken family as to the meaning of the diagnosis. At this point, the only purpose of support is to maintain homeostasis for possible organ procurement. If donation has not been chosen by the family, then support should not be continued beyond an appropriate time for the family to bid farewell. Notably, some patients who are Orthodox Jews and fundamentalist Christians do not believe that the current definitions of death are appropriate.66 Families of these groups tend to define death in the more traditional terms of a cardio-pulmonary death. Although individual convictions and religious beliefs should be supported, maintenance of prolonged intensive care is expensive and states differ in the degree to which they require clinical diagnosis to defer to religious conviction.67

Discussion of organ donation should routinely follow the clinical diagnosis of brain death. A responsibility exists to the donor, who may have wished to donate organs, to the family, who may receive solace from the opportunity to salvage some good from an otherwise tragic situation, and to those in need of a transplantable organ.68 Federal law requires clinicians working in institutions that receive federal funds to seek permission for organ procurement (the “required request” law), and the Joint Commission on Accreditation of Healthcare Organizations requires “a mechanism for notifying the family . . . of the option to donate or decline to donate any organs or tissues.”69

Increasingly, the anesthesiologist will be directly or indirectly involved in discussions concerning end-of-life issues. It behooves us to be well informed and more fully participatory in the ensuing debate as knowledgeable physicians within the medical community and as citizens with bioethical expertise within our greater society.

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