12. Differentiate between active and passive euthanasia.
13. Explain how a communitarian approach might hold a solution to a scarcity of organs for donation.
14. Discuss the religious and nonreligious arguments against the adoption of active euthanasia as a practice of modern health care.
15. Discuss the current position taken by the health care community in regard to the practice of both active and passive euthanasia.
16. Discuss the nature of the Hospice Movement in the United States and how this may impact the debate regarding euthanasia.
17. Discuss the general position taken by the Supreme Court in regard to a "right to die."

KEY TERMS

active euthanasia
advanced directives
best-interest standard
biographical life
biological life
clear and convincing evidence standard
cognitive sapient state
DNR (do not resuscitate) orders
hospice movement
involuntary euthanasia
ordinary and extraordinary care
palliative care
parens patriae
passive euthanasia
Patient Self-Determination Act of 1990 (PSDA)
personhood
substituted-judgment standard
voluntary euthanasia

I cannot but have reverence for all that is called life. I cannot but have compassion for all that is called life. This is the beginning and foundation of morality. . . . It is good to maintain and cherish life; it is evil to destroy and check life.

Albert Schweitzer

Possibly . . . no contemporary superstition is so stupid and pernicious as the indiscriminate adoration of the word life, used without any definite meaning but effectively hiding the fact that life includes the most loathsome forms of disease and degradation. Sanity and wisdom consist not in the pursuit of life but in the pursuit of the good life.

Morris Cohen

BIOLOGICAL AND BIOGRAPHICAL LIFE

Of all the problems that can be considered life and death ethics, none causes more moral anguish than the end of life issues of withholding/withdrawing life-support, **euthanasia**, and assisted suicide. The attitudes and values expressed in the quote by Dr. Schweitzer are a positive affirmation of life, and it is often sentiments such as these that bring individuals to the practice of health care. Today, however, the practitioner is faced with the frustrating problem of available technology that allows for life extension but cannot restore the patient to a life free of pain and misery—or even, in some cases, to an awareness of the environment. This frustration often leads to a new attitude toward life, one that finds expression in statements like the preceding one by Morris Cohen. The practitioner's duty to respect life and preserve it where possible may at times come into direct conflict with the duty to alleviate pain and suffering. The Hippocratic Oath binds physicians to take upon themselves the duty to adopt practices that shall benefit the patients and protect them from hurt or wrong. What is to be done when the care we offer appears to have no value to the patient? What is to be done when the quality of life restored has a negative value, when life itself appears to be an added injury?

It has been suggested that what is needed is a restatement of what is meant by the word *life*. In the common use of the term, we often mean two very different things. In one sense we use the word living to differentiate the things of our world into two basic categories: one of bugs, bushes, deer, and humans, which are considered living things, and the other of air, water, and minerals, which are nonliving things. With the question, "Is there life on Mars?" we are thinking of life in a biological sense. While **biological life** is not uniquely human, we also separate the life of humans into a different category from the life we share with trees—the human life that is captured in weddings, memories, relationships, and so on, can be termed **biographical life**. It is biographical life that truly separates us from other life forms and makes us uniquely human.

Anyone involved in the practice of critical care medicine can readily bring to mind patients who, due to injury, arrive in the intensive care unit (ICU) in a coma and are placed on life-support systems. If the brain damage is extensive and the care is of high quality, some of these patients can survive in a persistent vegetative state (PVS) for months or even years. With current technology, we can often sustain life in a biological sense, but we cannot restore individuals to an awareness of themselves or others. In many cases, an individual may survive for years without gaining consciousness. The gravestone of Nancy Cruzan, who was removed from life support following an automobile accident, as shown in Figure 9-1, indicates the level of ambiguity that is often felt in regard to the individual value of biological life.[1]

The decision to preserve biological life at any cost leads to immense personal and social tragedies that consume individuals, human energies, and scarce resources—for no seeming good. The question, then, is what is to be done when all individual personality is permanently lost and all we can sustain is biological life?

FIGURE 9-1 Gravestone of Nancy Cruzan

BRAIN DEATH

One essential differentiation among patient types is between those who have suffered brain death and those who are in a persistent vegetative state (PVS). With the modern technology of respiratory and cardiac support, in certain cases of severe brain trauma we can keep the remainder of the body's cells alive for days and months with no brain activity being present. This has raised major problems in terms of the classic definition of death based on the loss of cardiac and respiratory function. As a result of these technological changes, a majority of jurisdictions within our nation have accepted the concept of brain death. Figure 9-2 lists the criteria for brain death given by the Harvard Medical School Ad Hoc Committee.[2]

Brain death cases are often very problematic to families, as the patient appears to have natural warmth and color, the EKG may be in sinus rhythm, and the chest rises and falls with each cycle of the ventilator. Families view these as signs of life and need time to be brought to an understanding of the true condition. During this period of counseling, the practitioners will often broach the question of consent to arrange for the harvest of valuable organs for transplantation.

At these times, a natural shift occurs; nothing more can be done for the brain-dead patient, who is deceased. The support of the family in this time of personal loss becomes the major concern of the health care practitioner. In a real sense the family becomes the patients with whom the health care practitioners are involved. Great care and sensitivity must be taken as equipment is removed. Often the devices are turned down slowly so that cardiac failure takes place to simulate death. The removal of the equipment, however, is not an act of "allowing to die," as, in fact, a corpse (as defined by brain death) cannot be thought to die. Out of respect to the families or out of fear of legal issues, practitioners may delay the removal of life-sustaining equipment, but no consent is required for unhooking a ventilator from a dead body.

Unreceptivity and unresponsiveness
No movements or breathing
No reflexes
Flat E.E.G. of confirmatory value

FIGURE 9-2 Harvard Medical School Brain Death Test

IN THE NEWS

The Jahi McMath Case

This 2013 California case involves a 13-year-old female patient (Jahi McMath) who, following a rather minor surgery aimed at relieving symptoms of sleep apnea, suffered massive blood loss, cardiac arrest, and loss of blood flow to her brain. After resuscitative efforts and ventilator maintenance, three days later, tests revealed a total absence of brain activity and her doctors pronounced her "brain dead," which constitutes a legal measure of death in all states.

While on the ventilator, the teenager's chest rose and fell in a normal pattern, giving the appearance that she was sleeping. Her parents vigorously disagreed with the diagnosis of brain death and asked for a second opinion. A second physician repeated the test and confirmed the criteria for the diagnosis had been met.

Continues

The Jahi McMath Case (cont.)

Under normal conditions, the next step would be to pronounce her dead, request permission to recover organs for donation and disconnect the ventilator, after which her breathing would cease and her heart would fail. However, her parents refused to believe the results of the tests and requested and were granted an extension of the ventilator and feeding tube support. The hospital argued against the extension and continuance of the ventilator, feeling that it was unethical and "grotesque" to require the hospital and its staff to provide medical care to a dead person. After a series of court hearings before a Superior Court judge, it was agreed that the mother could remove her daughter from the hospital as long as the hospital's doctors would not be required to perform a tracheostomy and insert a feeding tube in preparation for the transfer and that the mother assumed full responsibility.

The family assumed custody and moved the girl to an undisclosed location where a tracheotomy and feeding tube were inserted. She was then transferred to a long-term care facility in New Jersey.[3]

1. New Jersey and Japan have laws that would have allowed the young woman to be classified as being "alive" if that is what the parents believed. Do we need a "conscience based" default position about the definition of death to accommodate religious beliefs in cases like this?
2. Often hospitals will continue cardiac and ventilator support on patients declared brain dead to allow for the harvesting of organs. Given there is no law against continuing to ventilate a dead person, should the hospital have continued in this case, especially if the family would personally assume the costs?
3. There are some who believe that the shift to a brain death definition was done to facilitate organ harvesting rather than waiting for respiration and cardiac failure, which might harm the desired organs. Do you consider this appropriate?
4. As health care providers do you feel we have the right to refuse to provide inappropriate care on a dead person based on the principle of professional autonomy?

As a postscript: In 2015 the family celebrated the fifteenth birthday of their daughter at her bedside in the New Jersey facility, and posted pictures of the event on her Facebook page. There are many in the Right to Life movement who believe she is still alive and in a persistent vegetative state. Recently, a court in California permitted the mother to present evidence that her daughter "has standing" to bring a lawsuit. Because a dead person has no legal standing to sue, if the court agreed, it would open the door for the presentation of evidence that her current condition does not meet the clinical criteria of brain death.[4]

PERSISTENT VEGETATIVE STATES

In April 1975, a 21-year-old female, while with friends, ingested an undetermined amount of alcohol and tranquilizers. She was brought to the hospital in a coma, having suffered two periods of apnea (not breathing) lasting for at least 15 minutes. This resulted in brain damage with the diagnosis of persistent vegetative state (PVS), in which she had no recognizable cognitive function. PVS is characterized by a permanent eyes-open state of unconsciousness. The patient is not comatose; she is awake but unaware. The eyes are often vacant, and often the patient assumes a severely contracted body position. Clinically, PVS suggests the irreversible loss of all neocortical function. Generally, brain stem functions remain, and patients can breathe on their own. They do not, however, match the criteria of brain death, inasmuch as they have elicitable reflexes, spontaneous respirations, and reactions to external stimuli. Recovery from PVS is rather remote. Using the guidelines of waiting 3 months in cases of PVS following cardiac arrest, 6 months for patients under 40 with head injuries, and 12 months for patients under 25 with head injuries, the chance of any sort of recovery is less than one in a thousand.

The 21-year-old patient remained in this state for a period of 7 months, being sustained by a ventilator and feeding tubes. At this time, the physicians in the case indicated to the family that it was their opinion that there was no hope she would ever regain consciousness and that she would die if ventilator support was removed. After hearing this grim prognosis, the family requested the ventilator be removed. It was their religious conviction that this was in keeping with God's will, and they felt their daughter would not have wanted to live this way. However, in that the patient did not match the criteria for brain death, the physicians refused to remove the ventilator and the family took the matter to court.

The press exposure from this early case made Karen Ann Quinlan a name recognized by everyone and brought increased awareness of the need for a procedure whereby extraordinary care could be withdrawn from patients.[5] In the lower court decision, the family was refused permission to have the ventilator removed. However, on appeal, the New Jersey Supreme Court overturned the lower court decision and appointed Karen's father as her guardian for purposes of discontinuing the ventilator. The court ruled that when an individual has no chance of recovering a **cognitive sapient state**, the argument for the protection of life weakens and the individual's right to privacy would allow for discontinuance of burdensome life support, as determined by a guardian. Karen's nurses, understanding that the court might grant the family permission to remove the ventilator, began to wean the patient from the device, so that when it was finally removed, she continued to breathe. Karen remained in a persistent vegetative state for an additional ten years. In June 1985, she contracted acute pneumonia and died. Antibiotics that might have been used to continue her existence were not used.

The case of Karen Ann brings up many ethical problems in regard not only to removal of ventilators from patients with no chance of recovering but also what constitutes **ordinary and extraordinary care**.

ORDINARY AND EXTRAORDINARY CARE

It is generally held that one can ethically forgo extraordinary means of continuing life but is obliged to continue ordinary means of care. At the end of the twentieth century, the Catechism of the Catholic Church (#2278) upheld this tradition:

> Discontinuing medical procedures that are burdensome, dangerous, extraordinary or disproportionate to the expected outcome can be legitimate; it is the refusal of "over-zealous" treatment. Here one does not will to cause death; one's inability to impede it is merely accepted.[6]

Although not binding as a statement of practice, the catechism is important given that the source could be expected to be on the conservative side of the sanctity of life issue.

Questions as to what constitutes ordinary and extraordinary care have two basic problems. First, if the criteria are based on current technology, rapid advances make what seems extraordinary today quite ordinary tomorrow. The second problem is the lack of patient reference. What might be extraordinary care for a 92-year-old with terminal cancer might be considered ordinary for a 30-year-old postappendectomy patient. A good example of lack of patient reference was the nasogastric feeding and IV fluids given to Karen Ann Quinlan. Under normal conditions, these are considered ordinary; however, their continuance forced Quinlan to continue a life without personal value for another decade following the removal of the ventilator. In that the procedures offered no reasonable hope of benefit, perhaps they also were extraordinary care.

Figure 9-3 gives a formulation provided by Father Gerald Kelly, S. J., for ordinary and extraordinary care that allows for consideration of costs, pain, inconvenience, and potential benefit. Under this definition, the problems of technological change and patient reference are satisfied. Any form of care can be extraordinary if it offers no hope of benefit. Under this definition, IV fluids and nasogastric feedings would qualify as extraordinary care in patients with irreversible PVS as they offer no potential benefit.[7] With this line of reasoning, the focus is placed on the usefulness and burdensomeness of care rather than on any characteristic of the treatment itself. There are other scholars, however, who would argue that food and water are not in a real sense medical care at all but rather "the sort of care that all human beings owe each other" as a function of our common humanity.[8] The removal of food and water seems more causally related to the death of the patient than just standing aside and allowing her to die.

Ordinary means are all medicines, treatments, and operations that offer a reasonable hope of benefit and that can be obtained without excessive expense, pain, or other inconvenience.

Extraordinary means are all medicines, treatments, and operations that cannot be obtained or used without excessive expense, pain, or other inconvenience or that, if used, would not offer a reasonable hope of benefit.

FIGURE 9-3 Ordinary vs. Extraordinary Means

Source: Gerald Kelly, *Medico-moral Problems*

PERSONHOOD

One rather controversial line of reasoning that seems appropriate for cases involving patients in a PVS with no hope for recovery is the examination of the requirements of **personhood**. While we generally agree that human beings have certain rights and privileges, and that these rights are not extended to rocks, trees, or animals, what is the essential difference? What types of beings can be thought of as bearers of rights? What types of beings can be thought of as persons?

Philosophers such as Joseph Fletcher[9] and Joel Feinberg[10] have attempted to define characteristics that a being must possess in order to be considered a bearer of rights. Among the suggested criteria are:

1. One who could be said to have interests; a person for whom something can be said to be good for his or her own sake.
2. One who has cognitive awareness; a being of memories, expectations, and beliefs.
3. One who is capable of relationships. Interpersonal relationships seem to be at the very essence of what we idealize in truly being a person.
4. One who has a sense of futurity. How truly human is someone who cannot realize there is a time yet to come as well as a present? The words, "What do you want to become," make sense only in relation to a person.

If these criteria were accepted as being necessary for one to be considered a bearer of rights (a person), then patients in PVS do not meet the criteria. Whereas Karen Ann Quinlan, prior to her accident, may have had the right to vote, right to freedom of speech, and many other rights, it becomes incomprehensible to consider her as a possessor of these rights once she irreversibly lost neocortical function. These patients cannot be thought of as beings for whom rights make sense—either the right to life or the right to die. Since patients who have become irreversibly comatose cannot be thought of as having interests, nothing we do to them can run counter to their interests. In this sense, what we do or don't do is rather dependent on the interests of others—society, family, health care practitioners—who can be considered bearers of rights. The patients themselves can be left out of the equation. Some have suggested that personhood should replace brain death as the legitimate criterion for death. But what if PVS is not as we suppose?

IN THE NEWS

Trapped between Life and Death

Traditionally PVS has been described as an eyes-open state of unconsciousness. The patient is not comatose; they are awake but unaware. They can smile, grasp your hand, grunt, cry, but are unable to see or understand speech. These are random, reflexive movements, as their minds are firmly shut off from events around them. They appear to have lost their memories, emotions, and intentions, the qualities that we recognize as making each of us a person.

This traditional description of PVS is now being questioned at least in some cases. Scientists using brain scanners find that some patients may only be trapped inside their bodies, and are still able to think, be aware, and feel to varying extents. Using positron emission tomography (PET) one can highlight different metabolic processes in the brain, such as oxygen and sugar use. Another device known as functional magnetic resonance imaging (FMRI) can reveal active centers in the brain by detecting the tiny surges in blood that takes place as the mind whirls.

Using a series of normal test subjects, the scientists asked them to imagine playing tennis, and then to imagine walking through the rooms in their home. These imagined activities resulted in consistent but two very different brain scan patterns, as different as "yes" and "no."

When they matched the playing of tennis to the answer "yes" and walking about your home to "no" they found that some patients were able to answer correctly five of six questions about their earlier lives, such as where they went on vacations prior to their injury, and the names of close relatives. This occurred in some who had been in a vegetative state for five years.

Researchers believe that as many as 20–40 percent of patients thought to be vegetative are, when examined closely, partially aware.[11]

1. Does this introduce a new category of patients? Are these PVS patients misdiagnosed?
2. If the patient remained in the closed off state for the rest of their lives, aware, but unable to communicate outside of brain scans, do you feel this makes it easier or harder for the family? How would provided health care be different?
3. If a PVS patient with a DNR order was tested and found to be minimally aware, should the DNR order be removed?
4. Does minimal personal awareness move someone into the personhood category?

These findings, if true, make the personhood argument a rather slippery slope that could allow some monstrous wrong to be perpetrated against a helpless minority in the future. The historical precedence of one group denying others the classification of personhood and then using this argument to justify slavery or sterilization rings frighteningly true and appalling. What can militate against such a philosophy is that the criterion being used for personhood is currently very basic. As long as the definitions remain at the level of self-awareness, no

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potential group of targeted and persecuted minorities could be excluded. Denying personhood to those with PVS (without awareness) does not say anything about them or suggest what it is that we might do to or for them; it just excludes them from the community of those who can be thought to bear rights.

It is clear that the reasoning involved in questions of personhood are of vital importance to the study of biomedical ethics. Most of the focus of ethical thought is the person, the being who bears personal rights and responsibilities. In the past, judgments in this regard have excluded such groups as women, blacks, and American Indians. The abortion debate is the most obvious situation in which we are searching for the definition of a human being.

ADVANCED DIRECTIVES

In 1983, at 25 years of age, Nancy Cruzan lost control of her car and was thrown into a ditch. Although she was resuscitated at the scene of the accident, she never regained consciousness. Like Karen Ann Quinlan, Nancy was diagnosed as being in PVS, and physicians estimated that she could live for another 30 years being supported by feeding tubes. In describing her condition, her father stated that "since the accident, she has never had what we felt was a thought-produced response to anything. We feel the most humane and kind thing we can do is to help her escape this limbo between life and death."[12] Given the prognosis, the family requested that the feeding tube be removed and Nancy be allowed to die. When the Missouri Rehabilitation Center refused the request, the family took the case to the lower courts, which ruled in their favor. This affirmation was overturned by the state supreme court on the basis that the state's greater duty to preserve life outweighed any right that the parents might have to refuse treatment for their daughter.

In December 1989, the Cruzan case became the first of the right-to-die cases to be heard by the Supreme Court of the United States. In its decision, the Court upheld the Missouri Supreme Court position that not even the family should make choices for an incompetent patient in the absence of "clear and convincing evidence" of the patients' wishes. In a five-four decision, the Court ruled that states do have these rights for the following reasons:[13]

- The state has a right to assert an unqualified interest in the preservation of human life.
- A choice between life and death is an extremely personal matter and requires clear and convincing evidence of choice.
- Abuse can occur when incompetent patients don't have loved ones available to serve as surrogate decision makers.

To accommodate the **clear and convincing evidence standard** required by the court, three friends of Nancy came forward claiming to have had conversations with her prior to the accident in which she expressed the conviction that she would never want to live the life of a vegetable. As a result, the State of Missouri no longer opposed her parents in this action, and the feeding tube was removed. Nancy Cruzan died shortly after the removal.

The call for clear and convincing evidence in regard to these cases increased the interest in **advanced directives.** The 1990 **Patient Self-Determination Act (PSDA)**, is a federal law regarding advanced directives. Medical facilities that receive Medicaid or Medicare funding must have procedures for handling advanced directives and to tell patients upon admission about their rights under state law. The purpose of the PSDA is to make people aware of their rights. The Joint Commission, which evaluates and accredits 20,500 health care organizations, has developed standards for the documentation of patients' wishes regarding advanced directives, which apply to the vast majority of health care institutions.[14] Figure 9-4 is an example of a Living Will Statement.

There is, however, no uniformity in laws on living wills and surrogate decision makers. In some states, the advanced directives go into effect only if a patient is terminally ill and death is imminent. In others, the physician is given civil and criminal immunity from prosecution when he fails to honor the living will, when in his judgment continued treatment may be of benefit to the patient and if it is a good-faith action based on medically valid reasons. Under some state laws, advance directive instructions to refuse treatment may not be honored while a woman is pregnant.[15]

Due to the inconsistencies and limitations found in these statutes, many authorities recommend the use of durable power of attorney over a living will. This allows you to name someone as proxy, with the authority to make medical decisions on your behalf should you become incompetent and unable to make the decisions yourself. This form of legal arrangement seems to offer the greatest flexibility in making your wishes known after you have lost competency, as the proxy individual is in the position to react to changes in your situation.

According to a study by the American Medical Association, only a small proportion of our citizens have any form of advanced directive in place. Young people and the poor are the least likely to request and implement these forms. As is true with many social issues, the poor and poorly informed suffer the consequences of having the least protection.

Although the Supreme Court held to a narrow focus in the Nancy Cruzan case, several critical aspects were reinforced by the decision. First, the Court upheld the concept that competent individuals could refuse life-sustaining treatment. Second, it made no legal distinction between tube feeding and other life-sustaining measures. Nutrition and hydration may be withheld when either of the two following conditions is met:[16]

1. **The treatment is futile.** In cases where all efforts to provide nutrition would be ineffective and cause pain (e.g., patients whose cardiac status is such that any IV fluids would overload the heart).
2. **No possibility of benefit.** While it is most often reasonable practice to provide nutrition and hydration, in those cases where the family and caregivers agree that the practice offers no benefit, such as a PVS case, there should be no barrier to discontinuance.

I, ____________________, am of sound mind, and I voluntarily make this declaration.

I direct that life-sustaining procedures should be withheld or withdrawn if I have an illness, disease, or injury, or experience extreme mental deterioration, such that there is no reasonable expectation of recovering or regaining a meaningful life.

These life-sustaining procedures that may be withheld or withdrawn include, but are not limited to:

Cardiac resuscitation, ventilatory support, antibiotics, artificial feeding and hydration.

I further direct that treatment be limited to palliative measures only, even if they shorten my life.

Specific instructions:

A. Specific instructions regarding care I do want:

B. Specific instructions regarding care I do not want:

My family, the medical facility, any physicians, nurses, and other medical personnel involved in my care shall have no civil or criminal liability for following my wishes as expressed in this declaration.

I sign this document after careful consideration.

I understand its meaning and I accept its consequences.

Date: ____________ Signed: ________________

Address: ________________

____

This declaration was signed in our presence. The declarant appears to be of sound mind and to be making this declaration voluntarily without duress, fraud, or undue influence.

Signed by witness: ________________

Signed by witness: ________________

FIGURE 9-4 Living Will Statement

Decision-making processes in questions where life support is withheld or withdrawn are some of the more difficult issues in health care ethics. Even when ethicists and legal scholars have argued through the issues for decades and have come to at least an outline of what is appropriate in these difficult cases, we will often discover elements that make us question conventional judgment. Consider the case study "A Question of Motivation."

CASE STUDY

A Question of Motivation

In 1990, a 26-year-old woman collapsed at home and suffered brain damage as a result of oxygen deprivation. The medical malpractice case that ensued resulted in a monetary judgment and trust fund adequate to pay for her lifetime care. Some medical and legal specialists have argued that she does not meet all the criteria of a persistent vegetative state. Nevertheless, since her initial collapse, due to her limited state of consciousness, she has been dependent on medically assisted nutrition and hydration administered by gastric tube. This level of support is necessary for her survival, as she is unable to feed herself.

Although some have argued in this case that the woman's apparent eye contact, gestures, and movements indicate that rehabilitation is possible, other specialists state that these are mere reflexes. What is clear is that she did not provide written documentation of her desires prior to the event and that she is not able to speak for herself. She is not ventilator dependent, not brain dead, not in a comatose state, not terminally ill, and not in imminent danger of death given that she has had no problem assimilating the nutrition.

Unfortunately, there is disagreement in the family as to what needs to be done, and a long and exhaustive legal battle has ensued. Her husband has affirmed that he remembers his wife stating that she would not wish to be kept alive in such a condition. Her parents and siblings, on the other hand, have taken comfort in the limited responses she can give and feel that with appropriate rehabilitation, she can make some level of recovery.

The woman's parents and siblings have volunteered to take responsibility for her care, but the husband has refused this, stating that he wishes to remain true to the desires of his wife and allow her to die. The culmination of the court case came when the judiciary agreed that the feeding tube providing nutrition and hydration could be removed and the appeal to the state Supreme Court was refused. The tube providing nutrition and hydration was removed, which would have resulted in her death; however, in an extraordinary intervention by the governor and state legislature, the tube has been reinserted.

1. What do you think is most appropriate in this case?
2. Would it affect your judgment if you knew:
    a. The husband will gain financially when his wife dies.
    b. The husband is living with another woman and they have children.
    c. One of the nurses on staff has sworn under oath that when giving the husband an update, he said "When is that bitch going to die?"
3. To what extent do you think the motivation of participants should be taken into account in these cases?
4. In cases where there is a clear conflict of interest, should there be a mechanism to shift the decision-making burden to other individuals?

PROXY DECISION-MAKING STANDARDS

The courts have not made their decisions on the basis of personhood criteria but rather have created standards for the allowance of decisions by proxy. Complicating these issues are two groups of cases—one involving competent individuals who become incompetent without expressing their wishes, and a second group, the mentally retarded, who may never have met the criterion of competence.

If a patient, due to mental retardation or some other factor, was never in a position to formulate a decision regarding acceptance or refusal of care, often the physician, hospital, or a family member may seek resolution of the problem from the courts prior to implementing a decision. Under the doctrine of ***parens patriae***, the state accepts these cases on the basis of a legitimate duty, abiding in the principles of beneficence and nonmaleficence. This duty requires the protection of citizens under legal disability from harms they cannot themselves avoid. In cases in which individuals were incompetent to decide for themselves, the courts have generally used the best-interest standard.

The **best-interest standard** most often takes into account such tangible factors as harms and benefits, physical and fiscal risks. In health care, the courts might rely on such truisms as "Health is better than illness," and "Life is preferable to death." In cases in which children have been denied life-preserving care by their parents, the state has often overturned the parental decisions based on the best-interest standard.

Unlike the best-interest standard, the **substituted-judgment standard** maintains that the decision about treatment or nontreatment must remain that of the patient, based on the principle of autonomy. The fact that a previously competent patient becomes incompetent to make a decision for himself does not take from him the right to self-determination. A substitute is selected who is required to act in proxy for the patient—that is, to make the decision that the incompetent patient (such as Karen Ann Quinlan) would have made if the patient had remained competent.

INFORMED NONCONSENT

In the cases of Karen Ann Quinlan and Nancy Cruzan, the patients were considered incompetent to make their own decisions and needed others to determine whether treatment should be continued or withdrawn. What is to be done in cases involving competent patients who understand the nature of their conditions and the consequences of refusing care and choose informed nonconsent?

Elizabeth Bouvia was a 28-year-old quadriplegic suffering from severe cerebral palsy. During her hospitalizations, she asked that her pain be controlled and that she be allowed to starve herself to death. Physicians and hospital authorities refused her request, and she was force-fed through a nasogastric tube to maintain body weight. She requested that the feeding be stopped, and the hospital refused even though her competency was not questioned. Bouvia went to court several times during the next several years, making media headlines and becoming a symbol of the right-to-die movement. The lower courts affirmed the hospital's decisions, but these decisions were finally overturned by the appeals court. The court in its ruling determined that the fact that Bouvia was young and therefore had a potential for a long life was essentially irrelevant. The decision stated that the time allotted for continued life was not the issue, only the perceived quality of that life, and that "if a right exists, it matters not what motivates its exercise." Although the Bouvia case did not affirm a basic right to die, it did become a landmark decision regarding the right to informed nonconsent.[17]

Cases such as this seem to indicate a growing consensus in regard to the allowance of personal autonomy and informed nonconsent. Several critical elements were reinforced by the court decisions:

1. The acuity of the patient is irrelevant to the allowance of treatment refusal. The patient's right to refuse care is not dependent on having a terminal illness.
2. The patient's own perceived view of her quality of life and the treatment requirements necessary to preserve it are of paramount importance. The fact that Elizabeth Bouvia could potentially live for another four decades and be a productive citizen could not overcome her autonomous choice to refuse care.
3. There is no meaningful legal distinction between mechanical life support and nasogastric feeding; both are invasive.
4. Distinctions between withholding and withdrawing care are legally irrelevant.

DO NOT RESUSCITATE (DNR) ORDERS

CASE STUDY

Do Not Resuscitate Orders

Mildred is an 85-year-old with terminal cancer admitted to the hospital for chemotherapy. Because of her poor prognosis, she is approached about a DNR order. In response, she requests a full code be provided. Your intern suggests that you take the middle ground and sign a "slow code," where the response is purposely inadequate, most often used to provide comfort to family, and not intended to resuscitate the patient.

1. Should you request a "slow code"? While perhaps compassionate, they are always deceitful.
2. Can a DNR order be written even though she has refused that option?

Cardiopulmonary resuscitation (CPR) and advanced cardiac life support (ACLS) are interventions that could theoretically be offered to all patients within the hospital. By the 1970s, it became obvious that it was not in the best interest of certain patient groups to be resuscitated, and hospitals began to initiate policies governing **DNR (do not resuscitate) orders**. Because of uncertainty as to appropriate criteria for selecting these patients, the late 1970s and 1980s were a period of confusion in which health care support staff were left to find their way through an ambiguous maze of verbal orders as well as DNR orders. Figure 9-5 differentiates between these various types of DNR orders. DNR policies are now required of all hospitals by the Joint Commission. Figure 9-6 provides general guidelines that one might expect for the establishment of DNR policies in a health care facility.

Code: A call for cardiopulmonary resuscitation efforts. In the hospital setting, a code would usually contain all the elements of advanced cardiac life support, which includes oxygenation, ventilation, cardiac massage, electroshock as necessary, and emergency drugs. These are sometimes announced as "code blue" or some other designation to signal the emergency team of the need to respond.

No code: DNR (do not resuscitate). A written order placed in the medical chart to avoid the use of cardiopulmonary resuscitation efforts. In previous times, the charts were often labeled with devices such as "red tags" or "purple dots" to designate DNR status.

Slow codes: This is a practice whereby the health care team slows the process of emergency resuscitation so as to appear to be providing the care but in actual fact is only providing an illusion. The intent of the practice is more for family comfort than patient benefit.

Chemical code: Similar in intent to the slow code. In this practice, the team provides the drugs needed for resuscitation but does not provide the other services. There is a real question as to whether slow codes, chemical codes, and other forms of resuscitation that contain only partial efforts are appropriate for anything other than theatrics.

FIGURE 9-5 Language of DNR

1. DNR orders should be documented in the written medical record.
2. DNR orders should specify the exact nature of the treatments to be withheld.
3. Patients, when they are able, should participate in DNR decisions. Their involvement and wishes should be documented in the medical record.
4. Decisions to withhold CPR should be discussed with the health care team.
5. DNR status should be reviewed on a regular basis.

FIGURE 9-6 DNR Guidelines

Even given the wide use and acceptance of DNR orders, the selection of patients still raises some concern. In our age of cost containment and stretched resources, do DNR patients belong in intensive care units? Studies show that these patients in ICU are sicker, have longer stays, have poorer prognosis, consume more resources (both human and fiscal), and have a higher mortality rate than do non-DNR patients.

In their *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*, the Hastings Center authors concluded that the intent of DNR orders did not preclude either the use of any other treatment modalities or admission and treatment in an intensive care unit. When treatment (either curative or palliative) cannot be obtained in other units outside intensive care, the patient's rights to autonomy, beneficence, and nonmaleficence, coupled with the requirements of fidelity, make the ICU use a reasonable choice.[18]

The initiation of DNR orders is best performed after an understanding by physicians, patients, family, and staff has been reached. This is an area in which value preference will make a great deal of difference.

BABY DOE

Unlike the informed nonconsent of autonomous adults or the substituted-judgment cases involving those who are irreversibly incompetent to make decisions are those situations involving withholding or withdrawing care from infants. No decisions are more filled with anguish for all involved, parents and health care providers alike. In the spring of 1982, an infant known as Baby Doe was born with an esophageal-tracheal fistula and trisomy 21, a form of mental retardation known commonly as Down syndrome. The esophageal-tracheal fistula needed immediate surgery if the infant was to be fed. The decision of whether to do the surgery would not have been questioned for a normal infant. The physicians split in their recommendations as to whether to provide the surgery in this case, the parents with court concurrence elected to refuse the surgery on behalf of their child, and the infant died. The parents based their decision on their view that it would not be in their son's best interest to survive, since he would always be severely retarded.[19]

In March 1983, in response to this case and others like it, the U.S. Department of Health and Human Services issued an Interim Final Rule, which directed that all health care facilities dealing with infants less than one year of age and who received federal funding prominently display an antidiscrimination notice protecting these infants. The notice provided a "handicapped infant hot-line" for those who might witness cases where infants were receiving less than "customary medical care."[20] Anyone in the nursery could then call and complain about care, and the federal government would send representatives to investigate the allegations. The fear of "Baby Doe squads" descending on the health care facility and involving themselves in what had previously been a rather private parent-physician arena of decision making had a serious chilling effect on deliberations having to do with infant care. The force of the notices was to place a potential conflict between the law and the moral obligations of the health care providers. Legal duties in and of themselves do not establish moral duties and vice versa.

As with most other important issues, responsible forces lined up on both sides. Opposing the regulations were groups such as the American Academy of Pediatrics and the American Medical Association. In support were groups such as the American Association of Retarded Citizens, who felt that the decision to provide care should be neutral in respect to handicap. In other words, if a "normal infant" would have received the surgery, then infants with handicaps should also. Of the almost 4 million infants born each year, approximately 10 percent are born prematurely or with major birth defects. Modern surgery and neonatal care has been rather miraculous; however, many of these infants still face life severely handicapped.

In 1985, the Department of Health and Human Services provided a final draft of the Baby Doe regulations regarding the treatment of handicapped children. If there is available treatment for the condition, it must be provided. The regulations consider the withholding of medical care for these handicapped infants to be reglect. The regulations provided three exceptions:

1. When the infant is chronically and irreversibly comatose.
2. When treatment would only prolong dying.
3. When the treatment would be futile, or inhumane.[21]

With this ruling, the federal government was out of the Baby Doe business, and parents and physicians once again could wrestle with these problems somewhat out of the public eye.

Regardless of who the primary decision makers are, the ethical problems remain. Whereas parents have a right to privacy and to be left alone in their decisions in regard to their children, this is not an absolute right and does not extend to child abuse. What is the child's best interest in these cases?

If the infant's mental and physical handicaps are overwhelming, it would be inhumane to provide life-extending care and to salvage the infant to a life whose only awareness is that of pain and suffering. On the other hand, to refuse care to a child on the whimsy of being dissatisfied with a particular model is equally distasteful. The right choice for these babies is easy to determine at the extremes, but it becomes a true problem when deciding for the infants—in which it is not clear—as to what constitutes their best interest. Perhaps these are cases that are best served by basing the judgments on the quality-of-life issue or personhood.

Translated into the language of personhood, an infant who has no present or future potential for self-awareness or relationships can be said to have no interests at all. It then becomes incomprehensible to provide life-extending care based on the child's best interests, as it makes no difference to the child whether the equipment is maintained for five minutes or five years.

LEGAL CASE STUDY

A Question of Futility: Baby K, 832 F. Supp. 1022 (E.D. Va. 1993)

In this case, the infant girl was born with the congenital malformation anencephaly that left only her brain-stem functioning. The limited function allowed for a continuation of breathing but the infant was permanently unconscious; she could not see or interact with her environment. At birth the physicians and institutional ethics committee had advised the mother that the ventilator had been put in place awaiting a firm diagnosis. But given the child's prognosis its continued use was futile, and it should be removed. The mother disagreed, and several other hospitals were contacted to see if the baby could be transferred. All refused, and finally the child was transferred to a nursing home.

On several occasions the child was readmitted to the hospital through the emergency room and given ventilator support. The hospital attempted to resist these admissions, but the court held they must provide the services. The court determined that to refuse care to the infant would be in violation of the Emergency Medical Treatment and Active Labor Act (EMTALA), the Americans with Disabilities ACT (ADA), and parental decision-making rights as guaranteed by the Fourteenth Amendment to the Constitution.[22]

1. How would you resolve this dilemma?
2. How would you define futility? How does the child fit in your definition?
3. Review the EMTALA statute and explain why the courts used it to cover this case.

ORGAN DONATION

The field of organ transplantation had its inception in the early 1950s. From the very beginning, its development has been accompanied by difficult ethical questions in regard to when it is permissible to remove organs, who should receive them, and how it is to be financed.

Advances in technique and the development of powerful immunosuppressive drugs have made it possible to transplant hearts, lungs, kidneys, livers, bone marrow, skin, corneas, and pancreases from cadavers. If the past is any predictor of the future, the variety of organs suitable for transplant will increase. In all areas of transplant technology, the survival and success rates are progressively improving, with areas such as cornea transplants having a success rate in restoration of sight nearing 100 percent. Unfortunately, for the length of time that the technology has been available, there has been a huge and frustrating shortage of supply. Figure 9-7 illustrates the growing organ need vs. supply problem.

According to the U.S. Department of Health and Human Services, Organ Procurement and Transplantation Network, in mid-2015 there were 122,435 people needing a life-saving organ, with 79,000 on the "active waiting list." By October of that year, 18,048 transplants had been performed and 8,757 total donors. Every ten minutes someone is added to the national transplant waiting list, and on average, 22 people die each day while waiting.[23]

This ongoing shortage has created in some cases perhaps the most challenging and basic of health care policy decisions. "Who is to live, and who is to die?"[24]

The transplantation of organs from one human to another has become somewhat commonplace. Most public opinion polls show high public support for organ donations, although not all cultural groups have shown the same level of acceptance. Some traditional cultures have strong reservations based on issues such as the need for body integrity at burial.[25]

Most donors have been young adults who were in excellent health until an unexpected and unpredictable event, such as an accident, murder, suicide, or intracranial bleed, brought on brain death. The acceptance of brain death criteria has been critical to the successful practice of organ donation. However, the need for a rapid determination of brain death creates a

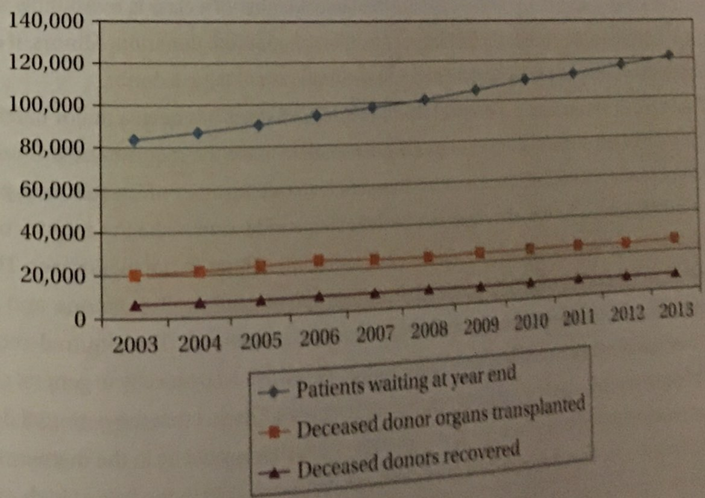

FIGURE 9-7 Organ Shortage

Source: U.S. Department of Health & Human Services, *Organ Procurement and Transplantation Network* situation in which families are forced to deal with the horrors of sudden loss and the potential donation of a loved one's organs virtually in the same instant. To bring order to the process of organ procurement, Section 1138, Title XI of the Omnibus Budget Reconciliation Act of 1986 required hospitals to establish organ procurement protocols or face the loss of Medicare and Medicaid funding.

The Uniform Anatomical Gift Act (2006 Summary) enacted in all 50 states attempts to assist in the process of increasing the availability of donor organs. Organ donation is a purely voluntary decision that must be clearly conveyed before an individual's organs are available for transplant.

The current mechanism for donating organs is a document of gift that an individual executes before death. The 2006 Act further simplifies the document of gift and accommodates the forms commonly found on the backs of drivers' licenses in the United States. It also strengthens the power of an individual not to donate his or her parts by permitting the individual to sign a refusal that also bars others from making a gift of the individual's parts after the individual's death. Importantly, the summary strengthens prior language barring others from attempting to override an individual's decision to make or refuse to make an anatomical gift.

If the individual does not prepare a document of gift, organs may still be donated by those close to the individual. Another achievement of the 2006 summary is that it allows certain individuals to make an anatomical gift for another individual during that individual's lifetime. Health care agents under a health care power of attorney and, under certain circumstances, parents or a guardian have this power. The donor must be incapacitated and the permission giver has to be the individual in charge of making health care decisions during the donor's life. Second, the 2006 summary adds several new classes of persons to the list of those who may make an anatomical gift for another individual after that individual's death. The adoption of clear rules and procedures, combined with the definition of "reasonably available," provide clarity to the decision-making process. If more than one member of a class is reasonably available, the donation is made only if a majority of members support the donation. Minors, if eligible under other law to apply for a driver's license, are empowered to be a donor.

The need to obtain family consent in a time of grief and stress has been a major barrier to organ procurement. Health care providers are often loath to make the request and put further stress on a family at a time of loss. Some have argued for a public policy of "required request," which would remove the decision from the health care provider and make the inquiry of the available family part of the procedures for discontinuing life support in hopeless cases. This is somewhat problematic in that it presumes that a single policy matches all situations, and it infringes on the professional autonomy and judgment of the practitioner. The required-request policies are justified by proponents as serving the greater good gained by society in general as the result of an increased supply of cadaver organs for transplants. The fact that the potential donor is often young and the family does not know what his or her views would be in the matter makes the question in a moment of stress and grief even more troubling. Even in the face of high public support for organ donations, the refusal by families in this moment of crisis is often 50 percent.

Volunteerism and public education have not provided adequate supplies of organs for donation, and the gap seems to be widening. This increasing problem has stimulated a need for the reexamination of options. Table 9-1 provides a review of potential options.[26]

Volunteerism and public education have not provided adequate supplies of organs for donations and there have been many options explored to increase the availability of the

TABLE 9-1

Options for Increasing the Supply of Salvageable Organs

OPTION	DESCRIPTION
Mandated choice	The mandated choice option would require all competent adults to decide and record whether they wish to become organ donors at their death. This might be accomplished during driver's license applications or on tax returns.
Presumed consent	Presumed consent would allow the routine salvage of organs unless the donor opts out. This shifts the responsibility of organ donation from the donor families to donors, who would be given ample opportunity during their lifetime to object or consent. In the face of no information regarding a decision, the presumption would be for consent.
Financial incentives	Although controversial and currently illegal, a commercial market in organs has been suggested. One suggestion for a nonfinancial incentive is the offering of preferred status, in which those who sign donor cards are placed ahead of others who have not signed cards, should the need arise.
Xenografting	Although there are still technical and ethical issues to work through, the ability to use animal organs as permanent replacements for failing human organs offers a solution to the acute shortage of available organs.
Altering the current meaning of death	The use of brain death as a replacement of a cardiopulmonary standard is a relatively recent concept, which has allowed the advancement of clinical transplantation. Some have argued for a modification of the brain death standard (total cessation of cortical and brain stem function) to a definition based on the loss of cortical function only. This would allow the harvesting of organs from individuals in a persistent vegetative state and from anencephalic infants.
Use of condemned prisoners	Organ donation from executed prisoners has generally been deemed to be unethical unless the individual made the decision to donate prior to conviction.

Source: Arthur L. Caplan and Daniel H. Coelho, ed., *The Ethics of Organ Transplants* resource. Some have advocated the adoption of "presumed consent" in those cases in which neither the person nor the surrogates have rejected such use of the body. This seems a reasonable proposal given that the majority of citizens appear to favor organ transplantation, even though few complete the necessary paperwork to be a donor. Yet is this a true choice? This can be likened to the Book of the Month Club that sends you the book if you don't send back the notice rejecting the selection. Does the receiving of the book indicate consent, or is it merely that humans often do not take the trouble to reject the offer? Would a presumed consent be true consent or merely an exploitation of the all-too-human trait of failure to follow through?

IN THE NEWS

A Thriving Global Market for Human Body Parts

Killing Children for Parts: A member of the Knights Templar drug cartel was arrested in Morelia, Mexico and charged with kidnapping and killing children for their organs. One group of children kidnapped while on a school beach outing was found in a refrigerated container. The number of children murdered by this organization for body parts is still unknown.

Nepal's Organ Trail: Kavre, a small district in Nepal, is ground zero for the black market organ trade in that country. Preying on the poor and uneducated, a well-organized and well-funded group of organ traffickers have offered payments for what they call a "piece of meat" often with the promise that it would "grow back." It is estimated that more than 300 people of the district have been victims of kidney traffickers in the last five years. It is likely the number is significantly higher as social stigma and threats of violence keep many victims silent. This small district has been the primary source for Nepal's desperate kidney patients awaiting transplants for several decades.[27]

Others have argued that when volunteerism fails to provide adequate scarce resources, the free market may be a better way to secure the needed organs. If organs were bought and sold on the open market, the supply would increase. For some, the very thought of selling tissue or organs is morally repellant. The National Transport Act of 1984 (amended in 1990) forbids the sale of organs in interstate commerce. Yet if we believe that the individual is the sole owner of his organs, then it would seem that he would have as much of a right to sell his property as he would in donating it.

Would the placement of organs on the open market raise the price and thus disenfranchise the poor? Would the poor be exploited and coerced into selling their organs or the organs of their deceased loved ones in times of severe need? Would fiscal coercion overcome any true form of personal autonomy and consent on the part of the poor in an open market situation?

Would the placement of organs on the open market create an international trade in which organs were transferred from developing nations to rich ones? Would it be ethical to purchase organs from developing nations? In regard to matched organs such as kidneys, is the forbidding of the selling of a single kidney on moral grounds by an individual who needs the money to keep his family from starving a strange form of paternalism and self-righteousness? Which is the greater harm: the starving family or the individual with a single kidney?

Some have advocated harvesting the organs of prisoners. For prisoners who have been given the death penalty, could a nation keep such individuals alive for harvesting until a buyer needed a particular body part? Would this create too great an incentive for juries to give the death penalty? How might this affect human rights in nations that do not have strong traditions in this area? If a free market approach to selling of organs were established, it would at the very least necessitate the crafting of law that ensured that the sale was truly voluntary.

CASE STUDY

"Go Ahead and Cut Him!" Right Answer, Wrong Reason

A newly appointed transplant surgeon is called concerning a young man with fatal head trauma. The next of kin is an older brother who is in the waiting room. Before the surgeon can get beyond the first sentence about the possibility of organ donation, the brother stops him abruptly: "Go ahead and cut him. Take the organs. I hated him! Where do I sign?"

Altruistic counseling is designed to make an individual aware of the needs of others. In this case, the brother is filled with hatred, and there is little appreciation for the altruism of the act he is agreeing to. Should that matter now that the legal ramifications of the issue have been covered with a signed consent from the next of kin?

1. Does motivation matter in this case?
2. Is the consent valid? Does the surgeon need to seek another relative for consent?
3. How much should the concept of the greater good enter into the surgeon's decision?

There are others who argue that organs are not personal property at all but should be considered a national resource. Most authorities believe that the current system of considering organs as personal gifts, which can be freely given or withheld, is wasteful in regard to this scarce resource. What if we as a society viewed organ ownership in a communal sense, in which organ donation was considered a special social duty that was expected of any of us who die in circumstances that would allow the harvesting of our organs? In order to satisfy certain personal and cultural aversions to such a policy, one could set up a "conscientious objector" status much like those set up for pacifists who have a moral aversion to participation in war. Under normal circumstances, the retrieval of organs would be a routine expectation unless the newly dead had signed up for an exemption from policy. Such a communitarian stance would seem to have great utility in that it would increase the number of available organs and would be a great symbol of commitment to the lives of others within the community. Even the allowance of the conscientious objector status would speak to the respect that the community had for individual differences and would protect the system from authoritarian abuse.

LEGAL AND SOCIAL STANDING OF EUTHANASIA

> *I cannot emphasize strongly enough that people should only help each other to die if there is a bonding of love or friendship, and mutual respect. If the association is anything less, stand aside.*
>
> Derek Humphry, cofounder, Hemlock Society

> *Derek:*
>
> *There. You got what you wanted. Ever since I was diagnosed as having cancer, you have done everything conceivable to precipitate my death. I was not alone in recognizing what you were doing. What you did—desertion and abandonment and subsequent harassment of a dying woman—is so unspeakable there are no words to describe the horror of it.*
>
> Last words of Ann Humphry, cofounder, Hemlock Society

Between these two rather remarkable quotes by the cofounders of the Hemlock Society lies the great unspoken debate over assisted suicide and self-deliverance. Within the first quote is the concern and respect for the autonomy of others, which appears to drive the right to die movement. Within the second is the great fear. What is our societal motive as we move to embrace a right to die? Are we doing so out of love and compassion—or because we have ceased to value the lives of those who are old, weak, sick, and vulnerable? Do individuals seek euthanasia because they want to control this part of their lives, or do they do so because as a society, we have made the dying more frightening than death itself?

In June 1990, Janet Adkins ended her life in a secluded county park with the assistance of the now infamous, Dr. Jack Kevorkian. By the end of June 1998, Kevorkian had participated in over 130 similar events using his suicide machines (Thanatron, Mercitron). Among the deaths he assisted with are individuals with emphysema, Alzheimer's, rheumatoid arthritis, multiple sclerosis, as well as those declared terminally ill by their physicians. Adkins, the first, is also perhaps the most troubling. At the time of her death, Adkins's memory loss from Alzheimer's disease was still at the stage of forgetting to take her purse or missing a tennis lesson. The last evening of her life was spent among friends in cogent conversation regarding the music of Bach. Prior to her death, she had arranged with a therapist to assist her family through the bereavement period. These are not the activities of someone who normally is thought of as the classic candidate for assisted suicide. While common wisdom teaches, "It is better too early than too late," it would seem that her death was a bit premature.

For a period of time, Kevorkian, his death machine, and his attendant legal problems, brought euthanasia and physician-aid-in dying (PAD) to center stage. As of 2016 Oregon and four other states now allow PAD. Although popular among segments of the public, there is no clear consensus for legalizing euthanasia.[28]

The ethical and legal issues of withholding or withdrawing life support have been reasonably worked out in cases such as those of Karen Ann Quinlan and Nancy Cruzan, and there appears to be some consensus for allowing health care providers to participate under these circumstances in **passive euthanasia**. The allowance of a deadly process to proceed without intervention is generally acceptable in the United States when the treatment is futile, and no possibility of patient benefit exists. Every day, in a hundred hospital settings, do-not-resuscitate (DNR) orders are written in charts, respirators are disconnected, IV lines are removed, and proposed surgeries are canceled. All states today have legislation covering advanced directives, and many specifically provide that a patient or proxy can authorize the withholding or withdrawal of life-support systems.

IN THE NEWS

Health Care: The Return of "Death Panels"

New Medicare rules were authorized in January 2010 that included reimbursement for physician counseling sessions with their elderly patients to discuss end-of-life decisions. The conversations would encourage the elderly to think ahead, and put their wishes in a living will or other document; it is argued that these new rules gives patients more control over what happens to them should they become incapacitated by illness.

In passing the Affordable Care Act, promises were made that the reforms would bend the health care cost curve downward. The incentivized end-of-life counseling sessions are occurring in an environment where Medicare is spending 50-plus billion a year on just the last two months of elderly patient's lives—and with the baby boom generation swelling the ranks of the elderly, that figure is sure to rise. To accomplish cost containment, some feel that end-of-life care costs must be cut, and that the counseling sessions are an administration effort to have the patients choose the least expensive end-of-life options, those that bring about their death sooner than later.[29]

1. Do you feel the counseling sessions are designed to provide the patient with more autonomous control over their end-of-life care, or is it merely a cost-cutting device designed to lower end-of-life care?
2. Is it possible that it will do both?

Although still somewhat controversial, the issue today does not revolve around passive euthanasia, that is, standing aside and allowing the terminal patient to die. Figure 9-8 is the anonymously written "Time to Go," which elegantly states the socially agreed upon case for passive euthanasia.

However, our system currently holds that there is an important distinction between actively participating in death of patients and letting them die, even though the outcome seems the same. Figure 9-9 is the American Medical Association position regarding active euthanasia.[30]

The AMA does not, however, have the same admonition against allowing a person to die. In the one case, you are initiating the process that brings about the death; in the other, you are just allowing a deadly process, which you did not initiate, to continue. The one case is viewed as morally wrong and the other as morally permissible. Some question this reasoning, asking whether the removal of the ventilator, IV lines, and feeding tubes from a patient who cannot breathe or eat for himself any less a complicity in the resulting death than if you provided a bolus of morphine to hasten the process? If there is no difference, is the bolus the more humane act?[31]

The term euthanasia comes from the Greek for *good death* and in English has taken the meaning of easy death or the *painless inducement of quick death*. The concept of easy death is further divided into two categories: passive euthanasia, which involves doing nothing to preserve life, and **active euthanasia**, which requires actions that speed the process of dying. Euthanasia is further divided, depending on whether the process is initiated by patient request, and is therefore voluntary or involuntarily implemented without patient permission.

Involuntary euthanasia, which ignores the individual's autonomous rights and could potentially bring about the death of an unwilling victim, is not easily distinguished from

Time To Go

Pardon me, doctor, but may I die?
I know your oath requires you try
As long as there's a spark of life
To keep it there with tube and knife;

To do cut-downs and heart massages,
Tracheotomies and gavages.
But here I am, well past four-score.
I've lived my lifetime (and a little more)

I've raised my children, buried my wife.
My friends are gone, so spare the knife.
This is the way it seems to me
I deserve a little dignity . . .

Of slipping gently off to sleep
And no one has the right to keep
Me from my God: when the call's this clear
No mortal man should keep me here.

Your motive's noble, but now I pray
You'll read my eyes, what my lips can't say
Listen to my heart! You'll hear it cry;
"Pardon me, Doctor, but may I die?"

FIGURE 9-8 Time To Go
Source: Anonymous

American Medical Association Code of Medical Ethics
Opinion 2.21, Euthanasia

Euthanasia is the administration of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering.

It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in euthanasia would ultimately cause more harm than good. Euthanasia is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

The involvement of physicians in euthanasia heightens the significance of its ethical prohibition. The physician who performs euthanasia assumes unique responsibility for the act of ending the patient's life. Euthanasia could also readily be extended to incompetent patients and other vulnerable populations.

Instead of engaging in euthanasia, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication. (I, IV)

Issued June 1994 based on the report "Decisions Near the End of Life," adopted June 1991 (JAMA. 1992; 267: 2229-2233); Updated June 1996.

FIGURE 9-9 American Medical Association Code of Medical Ethics, Opinion 2.21, Euthanasia
Source: American Medical Association

murder. There is very little disagreement in our society that involuntary euthanasia is morally indefensible. The focus of the current controversy that rages through our health care system is whether there is a moral difference between active and passive **voluntary euthanasia**. Several states have put statutes before the citizens in regard to legalizing voluntary active euthanasia.

It is perhaps important to differentiate between killing (involuntary euthanasia) and suicide, although neither provides the focus of this chapter, which is centered on the question of allowing voluntary active euthanasia. Tom Beauchamp offers a precise definition of suicide that separates it from the process of passive or active voluntary euthanasia. A person has committed suicide when:

1. That person brings about his or her own death;
2. Others do not coerce him or her to do the action; and
3. Death is caused by conditions arranged by the person for the purpose of bringing about his or her death.[32]

Although the frequency of occurrence is unknown, it is not a rare event for physicians to prescribe sleeping and pain medications for hopelessly ill patients who request them, knowing full well that their intended use is suicide. Some physicians see this as the last act in a continuum of care. As noted above, suicide differs from euthanasia in that the health care provider does not participate in the act of bringing about death. Any physician who becomes involved in the suicide of a patient must first be assured that the patient is indeed in a hopeless situation and not just suffering from treatable depression, common in individuals with terminal illnesses.

Prior to his conviction, the real problem with Dr. Kevorkian and his death machine (the Mercitron) was determining whether his patients committed suicide, whether he was practicing voluntary euthanasia, or perhaps murdering these unfortunates. When he built the machines, advertised in newspapers, videotaped the events, purchased the lethal dosages, arranged for undisturbed sites, put in IV lines, and finally arranged for postmortem press conferences, had he stepped beyond being a mere observer when the patients push the button to release the drugs?[33]

Some find the acts of Dr. Kevorkian similar to the political terrorist who bombs buildings and buses to bring about political change. These criminal acts have at times brought about positive political change. Kevorkian may be the harbinger of change and usher in a new specialty known as obiatry, practitioners of which would legally perform euthanasia in our society. Perhaps in the future there will be obiatry clinics in every major city. However, just as some terrorist acts usher in positive developments, others do nothing more than murder innocents and leave no permanent positive effects for their efforts. Perhaps Kevorkian was nothing more than a serial killer with a gimmick. History has yet to determine whether Kevorkian was in the

forefront of change or just a wild, uncontrolled eccentric who captured headlines and eventually faded from the attention of the media.

The World Status of Euthanasia and Assisted Suicide

This section will introduce laws for voluntary euthanasia in countries that have sanctioned physician-assisted suicide.[34]

Netherlands

In 2002, the Netherlands became the first modern industrialized nation to fully sanction physician-assisted suicide. For physicians to assist with voluntary euthanasia, the following must be in place:

- The patient must request the assistance freely and frequently after careful consideration.
- The physician may act on the request only if the patient is terminally ill, with no hope of improvement and in severe pain.
- The physician must consult with another physician and file a report with the coroner.

In 2010 over 3,000 outpatients received medically prescribed lethal cocktails. A similar practice occurs in hospitals with patients who have a life expectancy of two weeks or less. Under these conditions they may be provided palliative sedation, where they are put into a medically induced coma, and nutrition and hydration removed.

Almost immediately following the Dutch government's decision to fully legalize physician-assisted euthanasia, the issue was inflamed by a court finding that a doctor was guilty of malpractice for helping an 86-year-old former senator die because he was tired of living. Although the court found him guilty, the doctor was neither sentenced nor fined for the offense. Many in the Netherlands feel that the protective guidelines developed during the review period are too strict. The debate now seems to be moving toward whether elderly people should be prescribed a suicide pill when they feel the time is right.

German-speaking Nations

Nazi eugenic policies are still fresh in the minds of most German-speaking countries, so the term euthanasia is generally avoided when considering physician-assisted dying. Instead, policy makers use the terms active-assisted suicide and assisted suicide. As in the United States, Germany does not allow active-assisted suicide—where the physician prescribes and administers the lethal dose. But the law does allow assisted suicide, so long as the drug is taken without any help, such as someone holding the cup and placing it at the patient's lips. Switzerland also allows physician-assisted suicide but has much less restrictive laws as it allows the process as long as there are no "self-seeking motives."

IN THE NEWS

Switzerland's Suicide Tourists

"Going to Switzerland" has become a euphemism for assisted suicide. As many as 200 individuals a year travel to the country for the sole purpose of ending their lives. The only safeguard is that it cannot be carried out for "self gain."

Swiss right-to-die organizations, such as Dignitas, charge a membership fee of more than $5,000. Studies have shown that 21 percent of their customers since 2008 did not have a terminal or progressive illness. Many customers were able to travel to Switzerland, see a physician, and die—all in a single day.[35]

Belgium

In 2002 following the Netherlands, Belgium became the second Western nation to legalize physician-assisted suicide. Belgium's policies are less stringent than those found in the Netherlands as physicians may assist patients in dying if a patient freely expresses a wish to die on the basis of intractable and unbearable pain. If an inpatient expresses a desire for euthanasia, prior to becoming comatose, or in a vegetative state, physicians may comply with the request. The method of deliverance is unstated in the policy with the exception that the physician must remain at the patient's bedside until the final breath. This is unlike policies in the United States where the physician only provides the prescription for the drugs. A high percentage of those seeking physician-assisted death in Belgium are elderly Dutch-speaking patients who come for the less restrictive rules.

The policies in Belgium for physician-assisted death have been extended to include children who with the expressed permission of their parents may receive a lethal injection. The child must be terminally ill, beyond medical assistance, and be conscious of their decision.

The United States

Doctors are allowed to prescribe lethal doses of drugs to terminally ill patients to "aid in dying" in five U.S. states. However active euthanasia is illegal.

In November 1995, Oregon voters approved a ballot initiative (Measure 16) that would allow a terminally ill patient to obtain a physician's prescription for a fatal drug for the expressed purpose of ending his or her life, becoming the first state to legally allow assistance-in-dying.[36]

Like the law in the Netherlands, the Oregon Death with Dignity Act attempts to provide protections to ensure that abuses do not occur. Figure 9-10 provides the safeguards and guidelines found in the Oregon Act.[37]

This legislative action was challenged in court with plaintiffs claiming Measure 16 violated the Equal Protection and Due Process clauses of the Fourteenth Amendment to the Constitution.[38]

To request a prescription for lethal medications, the DWDA requires that a patient must be:

- An adult (18 years of age or older),
- A resident of Oregon,
- Capable (defined as able to make and communicate health care decisions), and
- Diagnosed with a terminal illness that will lead to death within six months.

Patients meeting these requirements are eligible to request a prescription for lethal medication from a licensed Oregon physician. To receive a prescription for lethal medication, the following steps must be fulfilled:

- The patient must make two oral requests to his or her physician, separated by at least 15 days.
- The patient must provide a written request to his or her physician, signed in the presence of two witnesses.
- The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
- The prescribing physician and a consulting physician must determine whether the patient is capable.
- If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological examination.
- The prescribing physician must inform the patient of feasible alternatives to DWDA, including comfort care, hospice care, and pain control.
- The prescribing physician must request, but may not require, the patient to notify his or her next-of-kin of the prescription request.

FIGURE 9-10 Safeguards and Guidelines in the Oregon Act
Source: Oregon Public Health Division, *Death with Dignity Act Requirements*

In 1997, the Supreme Court ruled that the Constitution does not guarantee Americans a right to physician-assisted suicide and returned the issue to the state legislatures for continued debate. In its decision, the Court placed emphasis on the American tradition of condemning suicide and valuing human life. In its ruling, the Court made it clear that the states have a legitimate interest in banning physician-assisted suicide, but it also left it open to them to legalize the practice.[39] Figure 9-11 provides a listing of the seminal events of the right-to-die movement.

1976—Karen Ann Quinlan case: New Jersey Supreme Court ruled that the state has no right to order respiratory support to be continued. U.S. Supreme Court refused to intervene, setting no legal precedent.

1990—Nancy Beth Cruzan case: U.S. Supreme Court rules that an individual has a "right to die" grounded in the Fourteenth Amendment's guarantee of personal liberty. In its ruling, the Court called for a clear and convincing evidence standard, which spurred the interest in and development of living wills and durable power of attorney documents to provide evidence of the patient's previously expressed wish to die.

1990—Michigan pathologist Jack Kevorkian, known as Dr. Death, assists Janet Adkins in ending her life. This will be the first of over 50 similar events using his suicide machine. His activities sparked a nationwide debate regarding assisted suicide. Following many efforts to charge him with murder and other crimes, he was convicted and incarcerated.

1995—Oregon voters approved a ballot initiative (Measure 16) that would allow a terminally ill patient to obtain a physician's prescription for a fatal drug for the expressed purpose of ending his life.

1997—The U.S. Supreme Court rules that the Constitution does not guarantee Americans a right to commit suicide with the help of a physician. The issue has been left to state legislatures to decide.

FIGURE 9-11 Milestones in the Right-to-Die Movement

The result of the Supreme Court's decision was to leave to the individual states the chore of working out their legislation. It is interesting to note that the Court resisted the path it took in the 1973 landmark abortion case, when it usurped state action by finding a fundamental constitutional right to end a pregnancy. With the matter returned to the states, advocates on both sides of the issue are predicting more controversy and debate.

More than a decade after Oregon legalized physician-assisted suicide, Washington State approved similar legislation to the Oregon model. This was followed in 2014 by Vermont. Court decisions have rendered the practice legal in Montana and New Mexico.

Some opponents to the legalization of active euthanasia oppose the practice on the basis of the principle of beneficence and the fear of beginning a slippery slope. Under this scenario the practice would first be limited only to voluntary patients. In that those lacking capacity must be provided the same rights as the competent, the practice could then be extended to include the noncompetent patient if the surrogate agreed. Finally, the process could be extended to include others based on a perceived need of society such as rationing.

CASE STUDY

Extending the Right to Die: A Slippery Slope

One of the fears of opponents regarding a "right to die" is that in the future the courts will extend the "right" to other vulnerable populations. Under the Oregon legislation, the patient is prescribed a lethal medication but in the end must take it himself. This then is a form of physician-assisted suicide. Could it be argued that the incapacitated patient who could not take the medication without assistance has an equal right? Would this then expand the right not only to physician-assisted suicide but to physician active euthanasia?

In the *Vacco* v. *Quill* case, it was argued that if a right to die could be found under the Fourteenth Amendment to the Constitution, then a law that allowed a patient who wanted to be disconnected from artificial life support to do so, but barred others who wanted to take lethal drugs to similarly hasten their death, would violate the amendment's equal protection guarantee because it treated the two groups differently.

1. Are the two groups—patients refusing care and an individual wishing a lethal prescription—the same?
2. The U.S. Supreme Court did not find a right to die under the Constitution. Do you think this was the right decision?

MERCY KILLING

A health care practitioner who deliberately hastens the death of a patient under the guise of **"mercy killing"** has entered into a practice prohibited under homicide laws. Common and criminal law regard life as sacred and inalienable and look at any premeditated killing as homicide. "Consent and humanitarian motive" is never a defense under the law for murder. "He nonetheless acts with malice if he is able to comprehend that society prohibits his act regardless of his personal beliefs."[40]

Unfortunately periodically there are cases involving allied health and nursing personnel and mercy killing. Most of these cases come to the attention of authorities as clusters of patient deaths are detected in quality-assurance and risk-management studies. The impact on the communities, the patients' families, and the nursing profession has been profound and negative. The intensity of the negative public reaction is perhaps a measure of how comfortable the average citizen is with the allied health practitioner or nurse as a patient advocate. When that trust is betrayed, there is a natural sense of outrage, "as the good (nurse, therapist, clinician) couldn't possibly act this way."

Mercy killing as an accepted practice is not something that can be entered into lightly, inasmuch as the act of putting someone to death—regardless of motive—involves the closure of all future options. It rules out any possibility of unanticipated discovery of wrong diagnosis, new treatments, spontaneous remission, or improvement as a result of continued treatment. There seems some right reasoning in the caution for prudence, "When in doubt—don't!"

CASE STUDY

Katrina: Hard Choices

As the hurricane approached, the hospital staff settled in preparing to wait out the storm. About 1,500 people sheltered in the hospital Sunday night, many were nonmedical, simply seeking a place of refuge. When the storm passed, there was a sigh of relief that the worst was over. However, early Tuesday morning the levies surrounding the city collapsed under the storm surge.

New Orleans is below sea level. Suddenly water was pouring out of the manholes in the streets and the water level rose about a foot an hour. It seemed relentless; by that evening the hospital was flooded with ten feet of water. Power failed, backup generators failed, telephones were out, ventilators stopped, and there was limited food. Staff could hear gunfire outside as looters sacked the corner drugstore. Many people came to the door seeking higher ground, but they had to be turned away, and the doors were boarded over. At this point there were approximately 2,000 people—employees, patients and relatives—essentially trapped in the hospital.

By the fourth day there was hope of rescue, but conditions were desperate. The sewer lines backed up, contaminating the water system, the air temperature rose to over 110 degrees, the odor was horrendous, and breathing was difficult. Potable water was in short supply, all of the staff and patients suffered, but it was on the seventh floor where the situation was most dire. This was a separate long-term facility. These were critically ill patients who, under the best of circumstances, might not survive an arduous evacuation. Given the critical nature of the patients, it was decided not to attempt evacuation of patients with a DNR order. If these patients could not be evacuated, what was to be done? They could not abandon the patients, leaving them to suffer and die. It was at this time that discussions occurred among the staff that it would be more humane to end the lives of those who could not be moved rather than allow them to continue to suffer.

When the crisis was over, there were over 30 dead patients, the largest number of casualties in any of the city's hospitals. In the end, a highly respected physician and two nurses were charged with administering lethal doses of painkillers to four patients.[41]

1. Because this was essentially battlefield conditions, is there a different standard for ethical decision making?
2. The State Attorney General is quoted as saying, "This is not euthanasia. This is plain and simple murder." Do you agree?
3. Is this a case where "mercy killing" is morally justified, even though illegal? Defend your answer.

As a postscript: Although reputations were destroyed, when the case reached the grand jury in 2007, they refused to indict the medical personnel on a single count.

ARGUMENTS FOR AND AGAINST EUTHANASIA

The arguments for the practice of euthanasia can be expressed in both utilitarian and duty-oriented terms. In the first case, it can be argued as a concern and compassion for those who are painfully and/or terminally ill. This view is strongly put forward by the noted ethicist and theologian Joseph Fletcher, who feels that

> it is harder morally to justify letting someone die a slow and ugly death, dehumanized, than it is to justify helping him to escape from such misery. This is a case at least in any code of ethics which is humanistic or personalistic, i.e., in any code of ethics which has a value system that puts humanness and personal integrity above biological life and function.[42]

The duty-oriented arguments are centered on an extension of personal autonomy—the rights accorded us in Western societies to live our life according to our own vision, unrestricted by the views of others. If we can live our lives according to a personal inner vision, then should this aspect of human dignity based on free choice also be extended to the termination of our lives?

For those who oppose active euthanasia on religious grounds, the basic concern seems to be the view that our lives are not ours but gifts from God. In this view, humans hold their lives as a trust. If this is true, then we are bound to hold not only the lives of others inviolate but also our own, since to take our life is to destroy what belongs to God. In Exodus 34:7 and Daniel 13:53, scriptures taken from the Old Testament, the doctrine of the sanctity of life principle is upheld, except in rare instances of self-defense. Judeo-Christian precepts generally condemn active euthanasia in any form, but allow some forms of passive euthanasia. The difference is that of omission and commission: While the Judeo-Christian philosophy might tolerate the allowance of death, acts that permit death, it draws the line in regard to acts that cause death.

Nonreligious arguments against active euthanasia usually follow a slippery slope or wedge line of reasoning. In some ways the arguments recall the parable of the camel who pleaded with his owner to be allowed to put his nose into the tent to keep it warm against the cold desert night. Once the nose was allowed, other adjustments were requested, and the owner found himself sleeping with his camel. Is there something so persuasive about putting others to death that, if allowed, would become gross and commonplace? The Nazi "final solution," which brought about the death of millions of Jews, gypsies, and other eastern Europeans, could be traced to compulsory euthanasia legislation that, at the time of its enactment, included only mental cases, monstrosities, and incurables who were a burden of the state.

Perhaps Sigmund Freud was right as he wrote:

> What no human soul desires there is no need to prohibit; it is automatically excluded. The very emphasis of the commandment "Thou shalt not kill" makes it certain that we spring from an endless ancestry of murderers, with whom the lust for killing was in the blood, as possibly it is to this day with ourselves.[43]

Clearly, there is a wide chasm between the grossness of the actions of certain totalitarian states and the perceived need for voluntary euthanasia in the context of an American medical-moral-legal framework. The chasm is so wide that the use of the Nazi, Soviet, and Cambodian experiences is perhaps not suitable at all.

Yet, how does one decide that euthanasia is appropriate for another? Does our subjective view taken from a position of health, in regard to the quality of another's life, or how a family is suffering, justify the ending of a patient's life without his consent? Does the authority to kill an innocent individual provide the wedge that breaks down the barriers needed to protect the severely handicapped, unwanted newborns, the frail elderly, the "useless" members of our society? Once euthanasia is allowed and accepted, where is the rational ground on which to stand and declare, "This far and no more!" Perhaps the rational ground is clear and convincing evidence of the will of the individual patient, and where that is not provided or possible, there can be no allowance for outside interference with life.

It would seem that perhaps the debate involving active euthanasia in the United States is premature. Prior to deciding whether individuals have a right to self-determination regarding this issue, it would be wise to consider why the concept is so popular. Modern death often involves overwhelming fiscal costs, pain, isolation among strangers, and the invasion of one's body by technology. Perhaps even more terrifying is the chance that one will not be allowed to die at all but continue in an elongated state of unconsciousness. Is it any wonder that a now-rather-than-later mentality has infected the population?

THE HOSPICE ALTERNATIVE

It is unlikely that the increased public acceptance of active euthanasia is based on any perceived need for an extension of personal autonomy to a "right to die." It is more likely that the genesis for the support is the fear of a lingering and painful death, surrounded by impersonal technicians, in a cold and unfamiliar environment.

If this is true, then the **hospice movement** may make some arguments moot in regard to active euthanasia. The word *hospice* has been used since medieval times to indicate a place of rest for the weary traveler. In the modern use of the term, the journey is different, but the concepts of rest and comfort are retained. The best-known hospice is St. Christopher's, in Great Britain, founded by Dr. Cicely Saunders in 1967. There are none of the usual trappings of a modern hospital. The rooms are cheerful, flowers are abundant, and the patients receive personalized care designed to virtually eliminate pain and suffering. Great effort is devoted to keeping the patient clean, caring for the skin, preventing bed sores, controlling nausea and vomiting, and treating neuropsychiatric symptoms. For the patient who is terminally ill, the balance between minimizing pain and suffering and the potential for hastening death is clearly struck in favor of relief of pain and suffering. Families are encouraged to stay all day and take their meals with the patients. Dying persons, when possible, are encouraged to take home visits whenever their stamina allows for them. The physicians and staff do not make rounds in white coats, ordering this and that, but rather there is a lot of touching, hand holding, and listening. The emphasis is on honest communication with both the patients and their family. The dying patient is freed from as much pain as possible and encouraged to face the situation of death with dignity. For dying patients, the need for **palliative care** to relieve pain and suffering may rival the intensity of curative efforts found in the acute hospital setting.

Hospice programs are set up to provide palliative care, abatement of pain, and an environment that encourages dignity, but they do not cure or treat intensively. Since its inception, the hospice has ceased to be a place and has become a concept. Individual hospices now come in a variety of forms: community volunteer programs, home services, free-standing units, in-hospital palliative care units, in-hospital hospice teams, or combinations of each. In these cases, it is important for all health care providers to set a tone of caring and support. It is not the technology found in the hospital setting that dehumanizes; it is the human component or lack thereof. The basic philosophy of hospice is that dying is a natural part of life. The hospice concept has been very effective in dealing with the terminally ill. These are specialized units designed to reduce suffering and provide humane care for the dying. The hospice movement, while developed in England, has blossomed in the United States.

CONCLUSION

In a less complicated era, the traditional definition of death was based on cardiopulmonary function. One died when heart and lung function ceased. This is clearly inadequate today, as patients in the midst of open heart surgery often meet this criterion.

Medical science can now save biological life so effectively that we have been forced away from using a heart-respiration definition of death to certification of a total loss of brain function (brain death). We have also, as a product of technological and therapeutic advancements, been able to fend off brain death only to expose the patient to a life in a persistent vegetative state in which the life of memories, relationships, and biographical events may be irretrievably lost.

In this chapter, we have examined several classes of patients where decisions of withholding and withdrawing of care have been reasoned. In many instances, we have reached a cultural, legal, and ethical consensus, as to how they are to be handled. The handicapped infant, the mentally retarded, the persistent vegetative state patients, and those who choose informed nonconsent, each require a different basis for our decisions. In some cases, the framework of what is to be done has been postponed, and has become instead, who is to decide?

Some instances of nontreatment seem to have gained acceptance and are rather noncontroversial. The 98-year-old with severe dementia and no relatives who contracts pneumonia might be allowed to die quietly. The real questions in regard to health provider duty do not lie in the extremes, such as an infant born with no brain inside its skull, but in the middle ground where there will be a potential for personhood and meaningful life. In the extreme cases in which no potential exists, or in which the best interests of the individual seem best served by withholding or withdrawing treatment, a form of passive euthanasia has been allowed. Euthanasia, which literally means a gentle or easy death, has been divided into two major groupings, passive and active. This chapter has generally been involved in the issues of passive euthanasia, the process of doing nothing to prolong life or fend off death, and physician assisted death. Active euthanasia, as defined by the active participation of ending life, is currently forbidden by most codes of ethical conduct in the United States.

KEY CONCEPTS

- The difference between biological and biographical life forms the basis of much of the discussion in situations in which withholding and withdrawing life support becomes necessary.
- The acceptance of the concept of brain death has allowed the rapid clinical development of organ transplantation.
- Many clinicians and scholars have begun to argue in favor of a neocortical definition of death.
- Best interest and substituted judgment are two legal standards used to assist in proxy decision making for those incapable of deciding for themselves.
- Following the Nancy Cruzan decision, the courts moved to a "clear and convincing evidence" standard for withdrawing and withholding care. The call for clearance and convincing evidence of choice has stimulated renewed interest in advanced directives.
- The courts have consistently held that competent adults have the right to informed nonconsent to care.
- The current voluntary process of securing organs for transplant has so far proved unable to meet societal demands for these tissues.

- Several modifications to the current process of securing organs for transplant are currently under consideration. The withholding or withdrawing of life support in certain types of cases and allowing a deadly process to proceed without intervention is the basis of passive euthanasia. Passive euthanasia is a generally accepted practice in cases of futility and where no possibility of patient benefit exists.
- Active euthanasia, in which the health care provider takes actions that speed the process of dying, does not have ethical or legal support in the United States.
- Involuntary euthanasia, in which the patient has not indicated a desire to be assisted in death, is not easily differentiated from murder.
- The current U.S. Supreme Court position on a right to die is that it is not a right that can be construed from the U.S. Constitution. The position of the Court is that this matter should be determined through individual state legislation.
- The law in regard to mercy killing is unequivocal: personal motivation is not a defense in murder. The public has been particularly outraged when this practice involves those entrusted with health care.
- The hospice movement may offer relief for the terminally ill patient and lessen the need for legislating physician-assisted suicide or euthanasia.

REVIEW EXERCISES

A. The case involves a young, ventilator-dependent quadriplegic patient who, after being shunted about to various facilities, sought to have his ventilator unhooked. The court recognized him as a competent adult and allowed the withdrawal of his life support.

In this case, neither the court, the health care providers, the right-to-life movement, nor the churches came forward to argue that the ventilator should be continued. After he had gained permission to withdraw from life support, the patient decided against the action and remained on the ventilator.

The question that this case brings forward is whether the young man's demand to have the "right to die" was real or just another way of saying, "Do you care about me?" A secondary question that is equally problematic is whether the acceptance of his request was based on a respect for his personal autonomy, or was it just an answer to the, "Do you care about me?" question with a "No!"

Respond to the idea that our current acceptance of "a right to die," especially for those who are unconscious and need a proxy decision maker, is a rather slippery slope that may in the future be used not to protect individual autonomy or privacy but rather as a facade to rid us of individuals whose lives we do not value.

B. Differentiate between the various lines of reasoning and arguments needed to decide the following types of cases in regard to withdrawing or withholding care:

1. Persistent vegetative state cases
2. Profoundly retarded patient cases
3. Baby Doe cases
4. Informed nonconsent cases

Which of these case types is best served by proxy judgments, and if so, what form: best interest or substituted judgment?

C. The philosopher Joseph Fletcher issued a paper listing the characteristics of a person. The following are taken from his positive criteria:[44]

1. Minimal IQ: Mere biological life, before minimal intelligence is achieved or after it is irreversibly lost, is without person status.
2. Self-awareness: The development of self-awareness in babies is what we watch and take such joy in. In psychotherapy, the lack of self-awareness would represent grave pathology.
3. Self-control: An individual not only not controllable by others (without restraint), but also not in his own control.
4. A sense of time: Memories, a feeling of now, and expectations for the future.
5. The capability to relate to others: Interpersonal relationships seem essential to being a person in any meaningful sense.
6. Concern for others: Extra-ego orientation is a vital characteristic of a "real person."
7. Curiosity: A person is a learner; total indifference is inhuman.
8. Communication: Utter alienation or disconnection from others is not a characteristic of humanity.
9. Neocortical function: Personal reality is dependent upon cerebral function; it forms the basis between life in a biographical and biological sense.
10. Idiosyncrasy: Humans are distinct; to be a person is to have identity, to be recognizable or callable by name.

Rank-order the list from most important to least important in your view of what makes up a person. Check those that you would consider to be essential in regard to personhood. If you feel that a particular characteristic is essential, you must be willing to deny those who do not possess it the rights and privileges of person status.

In regard to the personhood criteria that you have selected, state how this would affect your decisions in the following cases.

Nancy Cruzan

Elizabeth Bouvia

Baby Doe

Baby K

In regard to KoKo the Gorilla, who uses sign language to communicate with humans and appears to have a kitten that she cares about and misses when it is gone, what is her level of personhood?

If an angel or alien appeared out of the sky and had all the elements that you said were essential to being a person, would the alien have all the rights and privileges of a person?

D. Assuming that Baby Doe would have grown up to know himself, know those around him, walk, talk and play, and perhaps even go to school, was the decision not to provide the surgery ethical? Regardless of how you answer, justify your decision using ethical criteria. Also note that legal decisions are ethics neutral, and vice versa: Something truly can be legally correct, medically correct, socially correct, and morally reprehensible. Ask Dr. Mengele (Nazi war criminal who performed ghoulish experiments in the death camps), for he surely felt that relative to his society, what he was doing was socially, medically, and legally correct.

E. Mr. Martinez was a 75-year-old chronic obstructive pulmonary disease patient. He was in the hospital because of an upper respiratory tract infection. He and his wife had requested that CPR not be performed should he require it. A DNR order was written in the charts. In his room on the third floor, he was being maintained with antibiotics, fluids, and oxygen and seemed to be doing better. However, Mr. Martinez's oxygen was inadvertently turned up, and this caused him to go into respiratory failure. When found by the therapist, he was in terrible distress and lay gasping in his bed.

Should Mr. Martinez be transferred to intensive care, where his respiratory failure can be treated by a ventilator and his oxygen level can be monitored? Whatever your answer, provide an ethical rationale.

NOTES

1. Nancy Cruzan gravestone, Centerville Cemetery, Centerville, MO.
2. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Death, "A Definition of Irreversible Coma," *Journal of the American Medical Association*, November 13, 1981.
3. *Winkfield* v. *Children's Hospital Oakland, et al.* Document 18. January 6, 2014.