SECTION IV

BIOMEDICAL ETHICAL ISSUES

Section IV analyzes consent and issues at the end of life, the biomedical ethical issues commonly confronted by health services managers and their organizations. Myriad other biomedical ethical issues affect some managers, including genetic engineering, screening, and counseling; reproductive technologies; psychosurgery and behavior control; the right to healthcare; personhood, fetal rights, and abortion; implants and transplants; and mental illness and involuntary commitment.

The thorny issue of consent is addressed in Chapter 9. Consent affects managers in all types of health services organizations. The law defines acceptable relationships between provider and patient; for managers this is but a starting point, one that builds on their moral agency and the organization's expected philosophy.

Chapter 10 addresses ethical issues arising at the end of life, often called the *ethics of dying and death*. Changes since the 1970s, many caused by technology, raise new questions. The chapter addresses the definition of death, application of life-sustaining treatment (using the example of infants with impairments), withholding or withdrawing treatment, futile care guidelines, and the ethics of terminal illness. Health services organizations are affected by some or all of the ethical issues that arise at the end of life. As with consent, these have major implications for managers.

Chapter 11 explores the relationships among physician-assisted suicide (PAS), autonomy, and the organization. PAS is an ethical issue with deep historical roots in medicine, even though it is prohibited by the Hippocratic tradition. European views and actions regarding PAS are explored and contrasted with developments in the United States.

CHAPTER 9

CONSENT

Consent is an ethical imperative of great importance to managers and clinicians. It is clear that patients want to be more involved in medical decision making. The issues that consent raises suggest both a problem and a goal for health services providers.

The concept of consent in medical care evolved to protect patients from nonconsensual touching. Although the ethical and legal dimensions overlap, the legal requirements of consent are the minimum expected. The ethics of consent are grounded in the principle of respect for persons, specifically the element of autonomy, which reflects a view of the equality and dignity of human beings. In addition, the ethics of consent reflect the special relationship of trust and confidence between physician and patient and between organization and patient. This fiduciary relationship is supported by the principles of beneficence and nonmaleficence. The manager's virtues of trustworthiness, honesty, integrity, and candor also support the ethics of consent.

According to the law, failure to obtain consent can support a legal action for battery, an intentional tort. Beyond this, an action for negligence can be brought if the physician breaches the duty to communicate information necessary for the patient to give informed consent.

Paternalism stems from beneficence and is the ethical value that competes with patient autonomy in implementing consent. Paternalism arises naturally from the relationship between physician and patient because psychologically, technically, and emotionally, the physician is in a position of superior knowledge and is expected to help choose the best course of action for the patient. This reflects the ethics of care discussed in Chapter 1. The paternalism inherent in the physician–patient relationship was first described in the Hippocratic oath. Beneficence, nonmaleficence, and paternalism continue to be important and are implicit elements of the practice of medicine. The revisions of the Principles of Medical Ethics adopted by the American Medical Association (AMA) in 1980 moved organized medicine from paternalism toward autonomy and patient rights, themes that continued in the 2001 revision. The AMA's Council on Ethical and Judicial Affairs amplified these themes in its Fundamental Elements of the Patient–Physician Relationship statement. This document and the 2001 Principles of Medical Ethics are reproduced in Appendix B.

Specialized codes that guide biomedical research (e.g., the Declaration of Helsinki) also recognize the importance of consent. The emphasis on patients' rights or sovereignty in documents such as these are ideals toward which managers and organizations should strive.

LEGAL ASPECTS

Legally, consent must be voluntary, competent, and informed. The law presumes that persons unable to give consent in an emergency want to receive treatment. The presumption of wanting treatment can be rebutted if a competent patient declines it or if the person requiring treatment has an advance directive, such as a nonhospital do-not-resuscitate order. In addition, if that

person's attorney-in-fact (e.g., someone who holds a durable power of attorney) is present, consent must be obtained. If minors or persons considered mentally incompetent are patients and those who speak for them refuse to give consent, and withholding treatment is not in the patient's best interests, the organization is usually successful in persuading a court to order treatment.

Even in nonemergencies, general consent for treatment is implied by the patient's presence in the outpatient department, for example, which shows the patient's apparent desire to be treated. Noninvasive elective treatment of a routine nature requires only general consent. Special consent is necessary, however, for invasive, surgical, or special procedures, or when the patient is part of an experiment. Consent for the invasive procedures common in intensive care units is problematic, for example, especially because they are often performed as emergencies and patients may not be able, or their surrogates may not be available, to give informed consent.[1] Oral consent is legally binding, but staff changes, faulty memories, and prudence dictate that consent is written. The George Washington University Medical Center's general and special consent forms are shown in Figures 7 and 8, respectively.

To be *voluntary*, consent must be given free of duress. Duress can be subtle and its presence depends on the facts. Threats or force are clearly duress. Persons with diminished autonomy cannot make voluntary choices; military personnel or prisoners are examples. Historically, the military and prisoners were important sources for research involving human subjects. Negative publicity and public indignation have virtually eliminated experimentation in such settings.

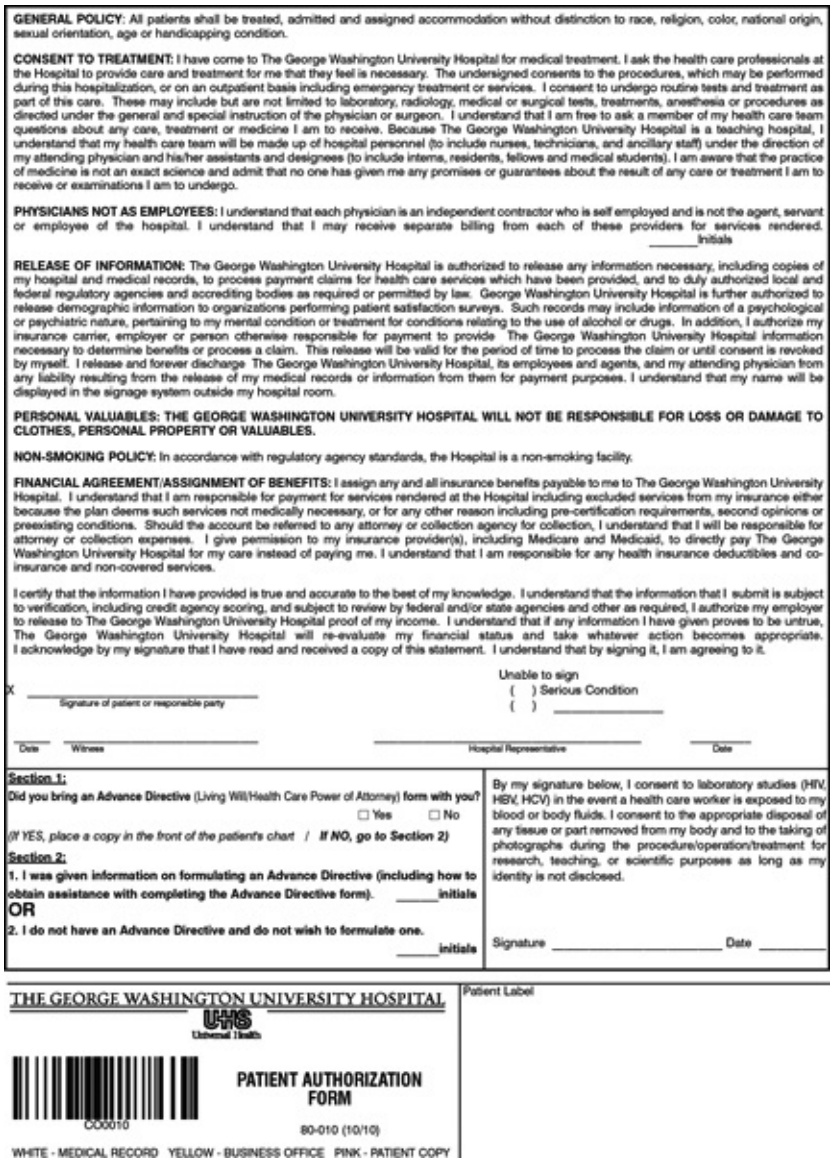
Competent consent means that the person has the capacity to understand the nature and consequences of the treatment or nontreatment. The law presumes minor children to be incompetent. In addition, persons whose mental illness or cognitive disability have resulted in a legal determination of incompetence may not decide about medical treatment or experimentation; others must make such decisions for them. Judging mental competence is complex when patients are terminally ill, depressed, or suicidal; expert opinion is required.

Consent must be *informed*. The law requires full disclosure of the nature of the patient's condition and treatment proposed, available alternatives, and consequences and difficulties that may likely result from treatment or nontreatment. The courts are about evenly split between those holding that patients should receive as much information as a reasonable physician would provide under the same or similar circumstances, and those using a standard based on what a reasonable patient would want to know. A legal criterion used by a few courts—and one oriented to patient sovereignty—is what that specific patient would want to know.

Historically, cases involving Jehovah's Witnesses, a religion that prohibits even homologous (self-donation) transfusions of whole blood or components, have been problematic for hospitals. Potential legal liability for transfusing or not transfusing the patient has resulted in numerous court cases. In early cases, courts often overrode the patient's wishes and ordered transfusion when patients, especially mothers, had significant family responsibilities. These cases showed that judges considered more than liberty rights (autonomy) when important societal interests such as caring for children were present. Developments in bloodless medicine and surgery in the 1960s and 1970s were spurred in the mid-1980s by problems with the blood supply, such as transmission of hepatitis and the human

immunodeficiency virus. These developments have caused a rethinking of the use of blood and blood products; transfusion is avoided, if possible. New evidence suggests that transfusion requirements are often overestimated and that there are several modalities to treat Jehovah's Witnesses with acute blood loss, for example.[2]

The right of competent persons to refuse treatment is well established in the law:



GENERAL POLICY: All patients shall be treated, admitted and assigned accommodation without distinction to race, religion, color, national origin, sexual orientation, age or handicapping condition.

CONSENT TO TREATMENT: I have come to The George Washington University Hospital for medical treatment. I ask the health care professionals at the Hospital to provide care and treatment for me that they feel is necessary. The undersigned consents to the procedures, which may be performed during this hospitalization, or on an outpatient basis including emergency treatment or services. I consent to undergo routine tests and treatment as part of this care. These may include but are not limited to laboratory, radiology, medical or surgical tests, treatments, anesthesia or procedures as directed under the general and special instruction of the physician or surgeon. I understand that I am free to ask a member of my health care team questions about any care, treatment or medicine I am to receive. Because The George Washington University Hospital is a teaching hospital, I understand that my health care team will be made up of hospital personnel (to include nurses, technicians, and ancillary staff) under the direction of my attending physician and his/her assistants and designees (to include interns, residents, fellows and medical students). I am aware that the practice of medicine is not an exact science and admit that no one has given me any promises or guarantees about the result of any care or treatment I am to receive or examinations I am to undergo.

PHYSICIANS NOT AS EMPLOYEES: I understand that each physician is an independent contractor who is self employed and is not the agent, servant or employee of the hospital. I understand that I may receive separate billing from each of these providers for services rendered. _____Initials

RELEASE OF INFORMATION: The George Washington University Hospital is authorized to release any information necessary, including copies of my hospital and medical records, to process payment claims for health care services which have been provided, and to duly authorized local and federal regulatory agencies and accrediting bodies as required or permitted by law. George Washington University Hospital is further authorized to release demographic information to organizations performing patient satisfaction surveys. Such records may include information of a psychological or psychiatric nature, pertaining to my mental condition or treatment for conditions relating to the use of alcohol or drugs. In addition, I authorize my insurance carrier, employer or person otherwise responsible for payment to provide The George Washington University Hospital information necessary to determine benefits or process a claim. This release will be valid for the period of time to process the claim or until consent is revoked by myself. I release and forever discharge The George Washington University Hospital, its employees and agents, and my attending physician from any liability resulting from the release of my medical records or information from them for payment purposes. I understand that my name will be displayed in the signage system outside my hospital room.

PERSONAL VALUABLES: THE GEORGE WASHINGTON UNIVERSITY HOSPITAL WILL NOT BE RESPONSIBLE FOR LOSS OR DAMAGE TO CLOTHES, PERSONAL PROPERTY OR VALUABLES.

NON-SMOKING POLICY: In accordance with regulatory agency standards, the Hospital is a non-smoking facility.

FINANCIAL AGREEMENT/ASSIGNMENT OF BENEFITS: I assign any and all insurance benefits payable to me to The George Washington University Hospital. I understand that I am responsible for payment for services rendered at the Hospital including excluded services from my insurance either because the plan deems such services not medically necessary, or for any other reason including pre-certification requirements, second opinions or preexisting conditions. Should the account be referred to any attorney or collection agency for collection, I understand that I will be responsible for attorney or collection expenses. I give permission to my insurance provider(s), including Medicare and Medicaid, to directly pay The George Washington University Hospital for my care instead of paying me. I understand that I am responsible for any health insurance deductibles and co-insurance and non-covered services.

I certify that the information I have provided is true and accurate to the best of my knowledge. I understand that the information that I submit is subject to verification, including credit agency scoring, and subject to review by federal and/or state agencies and other as required, I authorize my employer to release to The George Washington University Hospital proof of my income. I understand that if any information I have given proves to be untrue, The George Washington University Hospital will re-evaluate my financial status and take whatever action becomes appropriate. I acknowledge by my signature that I have read and received a copy of this statement. I understand that by signing it, I am agreeing to it.

X _____ Signature of patient or responsible party

Unable to sign
( ) Serious Condition
( ) _____

_____ Date _____ Witness

_____ Hospital Representative

_____ Date

Section 1:
Did you bring an Advance Directive (Living Will/Health Care Power of Attorney) **form with you?**
☐ Yes ☐ No
*(If YES, place a copy in the front of the patient's chart / **If NO, go to Section 2)***

Section 2:
1. I was given information on formulating an Advance Directive (including how to obtain assistance with completing the Advance Directive form). _____**initials**
OR
2. I do not have an Advance Directive and do not wish to formulate one.
_____**initials**

By my signature below, I consent to laboratory studies (HIV, HBV, HCV) in the event a health care worker is exposed to my blood or body fluids. I consent to the appropriate disposal of any tissue or part removed from my body and to the taking of photographs during the procedure/operation/treatment for research, teaching, or scientific purposes as long as my identity is not disclosed.

Signature _____ Date _____

THE GEORGE WASHINGTON UNIVERSITY HOSPITAL
UHS Universal Health

CO0010

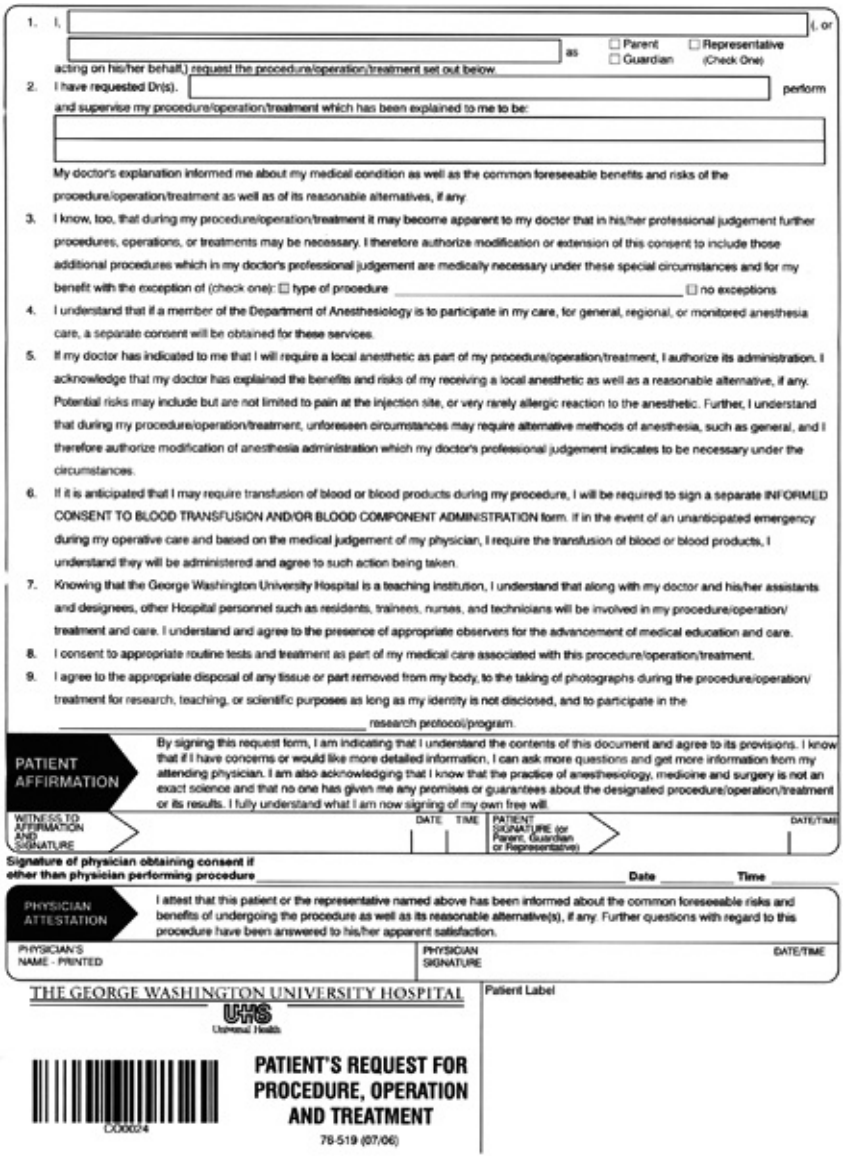
PATIENT AUTHORIZATION FORM

80-010 (10/10)

WHITE - MEDICAL RECORD YELLOW - BUSINESS OFFICE PINK - PATIENT COPY

Patient Label

Figure 7. A general consent form. (From The George Washington University Medical Center. Copyright © 2011. Reprinted by permission.)



1. I, _____ (, or _____ as ☐ Parent ☐ Guardian ☐ Representative (Check One) acting on his/her behalf,) request the procedure/operation/treatment set out below.
2. I have requested Dr(s). _____ perform and supervise my procedure/operation/treatment which has been explained to me to be:

_____

My doctor's explanation informed me about my medical condition as well as the common foreseeable benefits and risks of the procedure/operation/treatment as well as of its reasonable alternatives, if any.

3. I know, too, that during my procedure/operation/treatment it may become apparent to my doctor that in his/her professional judgement further procedures, operations, or treatments may be necessary. I therefore authorize modification or extension of this consent to include those additional procedures which in my doctor's professional judgement are medically necessary under these special circumstances and for my benefit with the exception of (check one): ☐ type of procedure _____ ☐ no exceptions
4. I understand that if a member of the Department of Anesthesiology is to participate in my care, for general, regional, or monitored anesthesia care, a separate consent will be obtained for these services.
5. If my doctor has indicated to me that I will require a local anesthetic as part of my procedure/operation/treatment, I authorize its administration. I acknowledge that my doctor has explained the benefits and risks of my receiving a local anesthetic as well as a reasonable alternative, if any. Potential risks may include but are not limited to pain at the injection site, or very rarely allergic reaction to the anesthetic. Further, I understand that during my procedure/operation/treatment, unforeseen circumstances may require alternative methods of anesthesia, such as general, and I therefore authorize modification of anesthesia administration which my doctor's professional judgement indicates to be necessary under the circumstances.
6. If it is anticipated that I may require transfusion of blood or blood products during my procedure, I will be required to sign a separate INFORMED CONSENT TO BLOOD TRANSFUSION AND/OR BLOOD COMPONENT ADMINISTRATION form. If in the event of an unanticipated emergency during my operative care and based on the medical judgement of my physician, I require the transfusion of blood or blood products, I understand they will be administered and agree to such action being taken.
7. Knowing that the George Washington University Hospital is a teaching institution, I understand that along with my doctor and his/her assistants and designees, other Hospital personnel such as residents, trainees, nurses, and technicians will be involved in my procedure/operation/treatment and care. I understand and agree to the presence of appropriate observers for the advancement of medical education and care.
8. I consent to appropriate routine tests and treatment as part of my medical care associated with this procedure/operation/treatment.
9. I agree to the appropriate disposal of any tissue or part removed from my body, to the taking of photographs during the procedure/operation/treatment for research, teaching, or scientific purposes as long as my identity is not disclosed, and to participate in the _____ research protocol/program.

PATIENT AFFIRMATION

By signing this request form, I am indicating that I understand the contents of this document and agree to its provisions. I know that if I have concerns or would like more detailed information, I can ask more questions and get more information from my attending physician. I am also acknowledging that I know that the practice of anesthesiology, medicine and surgery is not an exact science and that no one has given me any promises or guarantees about the designated procedure/operation/treatment or its results. I fully understand what I am now signing of my own free will.

WITNESS TO AFFIRMATION AND SIGNATURE | DATE | TIME | PATIENT SIGNATURE (or Parent, Guardian or Representative) | DATE/TIME

Signature of physician obtaining consent if other than physician performing procedure _____ **Date** _____ **Time** _____

PHYSICIAN ATTESTATION

I attest that this patient or the representative named above has been informed about the common foreseeable risks and benefits of undergoing the procedure as well as its reasonable alternative(s), if any. Further questions with regard to this procedure have been answered to his/her apparent satisfaction.

PHYSICIAN'S NAME - PRINTED | PHYSICIAN SIGNATURE | DATE/TIME

THE GEORGE WASHINGTON UNIVERSITY HOSPITAL

UHS Universal Health

Patient Label

LD0024

PATIENT'S REQUEST FOR PROCEDURE, OPERATION AND TREATMENT

76-519 (07/06)

Figure 8. A special consent form. (From The George Washington University Medical Center. Copyright © 2011. Reprinted by permission.)

> On the basis of either the common law liberty right to be free from unwanted treatment or by statute, competent adults, incompetent adults who have clearly expressed their wishes, and even older minors with adult-like decision-making capacity can legally refuse unwanted blood transfusions. As for minor children generally, although parents may not deprive their children of necessary care, if the parents have a choice between two or more effective treatment options, the state has no *parens patriae* interest in mandating treatment entailing the use of blood simply because it is the popular or standard approach. If the child's health problem can be effectively managed without the use of homologous blood, the parents should be free to choose that treatment option without governmental interference.[3]

An ethic that emphasizes autonomy and respect for persons can significantly affect the patient–caregiver relationship. Fully expressed, patients alone choose the level of involvement they want. In the early 1980s, the President's Commission stated that patient sovereignty with complete participation in the process is a desirable, if not a readily achievable, goal.[4] The principle of respect for persons cannot be realized, nor participation achieved, absent truthfulness and the organization's consistent efforts. Autonomy means patients may not agree with caregivers' recommendations and assessments. Sometimes, clinicians and organizations

find this concept threatening.

Some patients choose not to participate in decision making. Explicitly or implicitly, they want to remain ignorant of their medical problems and exclude themselves from decision processes. They prefer paternalism and choose to delegate decision making to caregivers to do what they think is best. This relationship between patient and caregivers is neither the one envisioned as ideal by the President's Commission nor that demanded by contemporary patient rights advocates. Autonomy is also violated if the patient is forced to participate, however. Caregivers and managers should consider a decision not to participate to be acceptable and work to make it a reality. Delegating to others the authority to make decisions may be the ultimate expression of autonomy.

More Serious than She Knows[5]

Lilah is 6-months pregnant with her first child. Her husband, a member of the U.S. Army, is currently deployed to a combat zone. During his absence, Lilah has moved back to her hometown, where she has the emotional support of her tight-knit family and access to basic medical care at a small-town community hospital. Lilah's mother is excited at the prospect of being her daughter's birthing coach. In anticipation of her due date, Lilah has signed releases authorizing the hospital and her obstetrician to share her medical information with her mother.

At her 6-month office visit, Lilah's blood pressure was slightly elevated. This prompted her obstetrician, Dr. Campos, to refer her to the hospital for outpatient testing to rule out preeclampsia, which is a potentially deadly complication of pregnancy. She was released after three hours with a clean bill of health and given instructions to avoid strenuous activity and to watch her diet. When Lilah and her mother returned to Dr. Campos's office three days later for a regularly scheduled ultrasound, the nurse noted that her blood pressure was even higher than before. Lilah told the nurse that she had followed the hospital's discharge instructions and suggested that the rise in blood pressure was caused by anxiety over her husband's safety, since his unit had suffered several casualties recently.

The ultrasound revealed that the baby's growth was unexpectedly retarded. Suspecting that Lilah and her child needed resources beyond the scope of the local hospital, Dr. Campos, immediately referred her to a perinatologist in a large city three hours away. "It's probably nothing serious, but it's better to err on the side of caution," he assured Lilah. "You and your mother can make a vacation of it. You could stay overnight and shop for the baby after the appointment."

As the nurse and Lilah completed paperwork in another room, Dr. Campos turned to Lilah's mother and said, "I don't want to cause Lilah additional stress, but this could be far more serious than she knows."

The law and medical ethics include the concept of therapeutic privilege, which permits physicians to withhold information from patients when the physician believes it serves the patient's best interests. States recognize therapeutic privilege in several ways; a general rule is difficult to formulate. Some reference the danger that full disclosure may cause to the patient's physical or mental health; others focus on patient best interests. Such paternalism is supported by the principles of beneficence and non-maleficence and the virtue of caring. The therapeutic privilege exception is pragmatic and avails physicians of a range of actions. It is desirable that physicians possess the latitude to make such judgments, especially if the alternative is probable harm to the patient. If so, beneficence and non-maleficence take precedence. Lilah's case is an expression of therapeutic privilege. Dr. Campos is concerned that apprizing Lilah as to the potential risks of her pregnancy may cause further stress and aggravate her condition. Telling Lilah's mother may assuage Dr. Campos's reluctance to communicate vital information to Lilah. Also, it makes her mother more alert to changes that may require emergency attention.

ETHICAL ASPECTS

The premise for a discussion of the ethics of consent is that the ethical standard is significantly higher than the legal standard. This expectation arises from exercising the principles of respect for persons (autonomy) and nonmaleficence—which are based on Kantian deontology (see Chapter 1), natural law, and rule utilitarianism—and is supported by virtue ethics as expressed by virtuous managers acting as moral agents.

The nuances inherent in duress and inducement are important in determining whether consent is *voluntary*. In these cases, ethical considerations and duties extend well beyond the standard in the law. Can patients suffering from a fatal disease make medical decisions voluntarily? Are patients' decisions free of duress if they fear losing their physicians' friendship and loyalty because they prefer an option the physician opposes? Clinical staff talk about "bad" patients, usually defined as uncooperative patients. Such patients are not intentionally harmed or mistreated, but they may not receive the same attention as "good" or pliable patients. Patients sense this attitude and it affects their volition. Patients are also heavily influenced by family and friends and may make decisions because of them. Similarly, family members may ask clinicians to act in ways that may be unwanted by a patient who is considered incompetent or that, under the principles of beneficence or nonmaleficence, do not serve the patient's interests.

Such considerations suggest that consent may never be entirely voluntary. Some have argued that patients' personal freedom to accept or reject medical treatment has been so reduced that it is only a right to veto unwanted procedures.[6] This argument is bolstered by the increasingly complex relationships in medical care and its delivery, all of which preclude simple answers and easy determinations as to the voluntariness of consent. Managerial and clinical staff must understand the difficulties of consent and make all efforts to further patient autonomy and control of medical decision making.

In determining the voluntariness of consent, some groups present special problems. As noted, in the past healthy persons with diminished autonomy, notably military service members and prisoners, participated in experimentation that was nontherapeutic—meaning that it had no direct benefit for them. The consent of persons in such groups is seen as non-voluntary, and their use as healthy subjects is rare. Voluntariness may also be reduced because inducements are so significant that prudence is cast aside. Money or other incentives may be offered to those who participate in high-risk experimentation; for example, some persons may be persuaded by payments that, for them, are significant. Students who participate in experiments are unique in this regard and may fit into several categories. Often, they are economically disadvantaged. In addition, some faculty encourage students to participate in experiments by exempting them from other, seemingly more onerous requirements, such as research papers or examinations. Occasionally, there is implicit, or even explicit, coercion by faculty who control the students' academic (and sometimes economic) destiny, and who unethically use this position to "encourage" consent and participation in research.

Usually, the ethical aspects of whether one is *competent* to consent are easier than the ethics of whether consent was voluntary. Competence is assumed in adults. Typically, clinical staff can determine if a patient's mental status is questionable and then seek consultation. Absent evidence of questionable mental status, the organization's policies should include an explicit assumption that patients are autonomous for the purposes of decision making. It is

incumbent on managers to assist in this process through staff education and the support provided by appropriate systems and procedures.

The third element of consent is that it must be *informed*. Some commentary suggests that being "informed" is the only criterion for consent. Because of the complexity of informed consent, whether the patient was *adequately informed* receives the most attention. Some states have statutes designed to ensure that patients obtain sufficient information to make informed medical decisions. A Virginia law regarding consent, for example, resulted from reports that physicians performed radical mastectomies (even though removal of the malignancy would have sufficed) and that women were not given enough information to make an informed decision.[7]

Wait a Little Longer, We'll Do It Then

The emergency department at County Hospital has a typical caseload: some true emergencies and urgent medical conditions, but many sniffles and other non-emergencies. The hospital contracts with an emergency medicine group, but administrative activities, including systems, procedures, and personnel, are the hospital's responsibility. The process for obtaining consent is typical: Unconscious patients are treated as their conditions necessitate. Competent patients who are able to communicate sign a consent form authorizing treatment. Parents and other family members are involved as needed and as available.

Early one afternoon, a conscious, middle-aged man who had been in a car accident was brought in. He was diagnosed with internal injuries that required immediate exploratory surgery. He was asked to sign the consent form but refused because, as a Christian Scientist, receiving medical treatment violated his religious beliefs. He asked for a Christian Science practitioner.

The physician-director of the emergency department was paged, and, after reviewing the chart, she felt certain she could obtain his consent for surgery. She discussed the situation with the patient, who clearly understood that without surgery he was likely to die. He continued to refuse and repeatedly asked for a Christian Science practitioner. The physician-director left the treatment area very agitated; her mouth and chin shook in anger. She said, "This man is throwing his life away, all in the name of some religion that denies scientific medicine to its followers. I can't believe he's doing it!" She turned to the nurse and whispered, "Let me know when he's unconscious and we'll save his life, despite his silly ideas."

Such deception rides roughshod over the patient's clearly expressed wishes. The patient is competent and informed; his refusal is voluntary. In addition to violating the principle of respect for persons (autonomy), the physician is ignoring the AMA's Principles of Medical Ethics and the AMA's Council on Ethical and Judicial Affairs's Fundamental Elements of the Patient–Physician Relationship. Such methods are unconscionable.

The organizational philosophy should prospectively consider the issues in this case. The discussion of Baby Boy Doe in Chapter 1 suggested that the organization might have intervened by petitioning a court to order life-saving surgery. Such intervention gives less weight to the principle of respect for persons (autonomy) and more to beneficence (and its corollary, utility) and paternalism. Increasing focus by courts on liberty rights such as autonomy make it unlikely that the Christian Scientist will be forced to undergo surgery, even if he has a family dependent on him. The principle of nonmaleficence supports action by the hospital. However, forcing treatment is paternalistic and greatly diminishes autonomy. The competing ethical principles in such cases pose true ethical dilemmas for organizations and managers.

ROLE OF THE ORGANIZATION

What is the organization's role in consent? Patients should give informed, voluntary, and competent consent before treatment—a simple ethical concept. As is often true, difficulties arise in operationalizing the concept; it is in instances such as these that the criteria for consent

may be more often violated than met. Since the 1970s, organizations have focused greater attention on consent, an emphasis that likely reflects fear of legal problems more than a desire to do what is ethically right. Before the 1970s, organizations were less concerned about consent because they adopted and amplified the historic, paternalistic view of the patient, a view consistent with the Hippocratic concept of the physician–patient relationship.

At minimum, policies and procedures consistent with the organizational philosophy must be established for obtaining consent, and their application must be systematically monitored. If, as it should, the philosophy emphasizes patients' rights, actions and efforts to perfect those rights will be encouraged while actions and efforts that contravene them will be restricted. There are specific means that allow patients to assert their rights, but these means are costly and can result in adversarial relationships. One is to provide an advocate for each patient. Another establishes an ombudsman office to review problems and prevent them in the future.

Often, the circumstances of consent are complicated because many parties are involved.

When Is Consent Consent?

Henry Franklin was an emergency admission to University Hospital. He was diagnosed with mild cardiac failure by an attending physician. Because he was 78 years old and had complicating medical conditions, a dispute arose as to the proper course of treatment. The consulting cardiologist recommended that Franklin be treated medically and given the best quality of life possible. The cardiologist estimated that Franklin had 6 months to live.

The cardiac surgeons who also consulted on the case saw things differently. They recommended replacing the aortic and mitral valves and estimated that this procedure would provide at least 2 years of useful life. When the options were described to Franklin, he was told the probability of surviving the surgery was 50%. He decided he would work with the cardiologist.

After hearing his decision, the surgeons intervened directly with Franklin's family, with whom they had had previous conversations. The family agreed with the surgeons and pressured Franklin to consent, which he did. Franklin's body could not withstand the rigors of surgery; he died in the operating room.

Even if informed and competent, Franklin's final decision was made under duress. The coercive circumstances greatly reduced his autonomy. In such situations, family and physicians press for what they assert are the patient's best interests. However, sometimes both groups are driven by motives that conflict with the patient's self-expressed decision. Family may have various psychological and financial motives; physicians may act out of technological daring or hubris.

The challenge managers face is ensuring patient autonomy. Patients may choose a course of action that is not their first choice or even in their best interests (as the patient views them) because they defer to the wishes of others. They may fear abandonment or caregivers' anger if they choose a course of action other than what caregivers suggest or what they think caregivers want. An added complexity is that patients are often uncertain about what to do; they vacillate between wanting and not wanting aggressive treatment. Preserving patient autonomy in these circumstances is difficult, perhaps impossible, but must be attempted nonetheless.

The surgeons were important in the Franklin case. They may have allowed bravado to cloud their judgment, especially given the probability of success. Franklin's family was also important. Health services organizations interfere at their peril in situations that reflect family dynamics, even though their duty clearly lies with the patient. Involvement of the institutional ethics committee could provide an important buffer for the patient.

What is the role of the organization in determining that patients have consented in a way

that meets ethical criteria? Obvious coercion will likely be noticed by staff. A patient advocate program may minimize duress. Complicating efforts to ensure consent is that the private attending physician has an independent ethical duty to inform patients about the procedure's nature, consequences, risks, and alternatives. The attending physician determines that the patient is competent to give consent and does so voluntarily. Some health services organizations see their ethical duty as independently determining or verifying that the criteria of consent have been met. Others ask only that patients sign an authorization verifying that their physician has informed them about the procedure and that the hospital may participate in rendering the care to which the patient has previously consented.

Unless it is certain that patients have been informed about the treatment in a way that meets organizational criteria, the ethically preferred course is that staff be involved, at least to the extent of verifying that the patient is informed and competent. The manager must fulfill the organization's positive ethical duty to monitor consent, which includes processes and procedures to assist and guide staff, as necessary. Physician and non-physician staff will also benefit from education about the ethical (and legal) dimensions of consent.

The case of Henry Franklin is distinguishable from that of the Christian Scientist. Franklin had more time to consider his decision, which was likely influenced by his age. The other patient was middle-aged, with the potential for decades of life remaining. Beyond these apparent differences, both cases raise questions about patient autonomy and its relationship to the principles of beneficence and nonmaleficence. The weight given these principles in the organizational philosophy and the personal ethic of the actors determines the outcome.

Managers of nursing facilities face ethical issues regarding consent similar to those of their counterparts in acute care hospitals. Decision making in nursing facilities is more likely to be complicated by factors such as competence or abandonment of patients. Thus, the process requires special attention.

I Intend to Be Independent

Oliver Harris is 82 years old and has been a resident at Five Oaks Nursing Home for 7 years. When he first sought admission, Harris had been evaluated and found to be only marginally in need of the care provided at Five Oaks. Because he was a private-pay patient, management decided to admit him. For 5 years his health was such that he needed minimal nursing care. In the sixth year, he began to show evidence of dementia. Medical evaluation found that he had experienced several small strokes. Harris likes to visit with other residents as he walks around the facility. His declining physical condition has resulted in several falls, which caused cuts and bruises but no broken bones.

Harris's case was discussed at a staff conference. It was the consensus to physically restrain him so that he could not ambulate independently. Under federal guidelines, this was possible only with an order from Harris's physician. Staff doubted the physician would agree, but they believed that if Harris continued to walk unassisted, it was only a matter of time before he fell and sustained a fracture. Staff also believed that even if his physician ordered restraints, Harris would fight them. When the issue was discussed with Harris, he was adamant that he not be restrained. His daughter, however, agreed that physical restraint was wise.

Staff and management face a dilemma: How can they meet their duty of nonmaleficence to Harris while maximizing his autonomy under the principle of respect for persons? Harris is competent to decide about restraints. It is clear to staff (and to Harris) that his well-being is at risk. Major injury will likely cause deterioration of his general health. Staff does not seem very creative in finding a way to allow him to ambulate safely. Such options should be explored first. Alternatively, various possibilities should be tested for short periods. If Harris

cannot be persuaded to accept restraints, he should be allowed to ambulate freely in the facility. But is Harris's choice to walk untethered different from a younger person who chooses to skydive, bungee jump, or extreme ski?

MEDICAL EDUCATION

The case of Richard Weidner in Chapter 7 involved problems of consent in the context of medical education. Weidner was admitted to the hospital for a cardiac catheterization following recurrent chest pain. His cardiologist allowed him to think that she would perform the procedure, but a cardiology resident actually did the catheterization. The misrepresentation violated Weidner's right to autonomy and informed decision making and angered him greatly. There is significant tension between medical education's legitimate needs and the rights of patients to be treated with dignity and respect. The two are not incompatible, however.

Medical education is a major source of problems in consent, especially as to patient knowledge about who will provide treatment. The conclusions of a New York State Assembly task force were based on interviews with chiefs of surgery, attending surgeons, residents, and anesthesiologists at 34 hospitals in the state. It reported:

- Private surgical patients in teaching hospitals are usually not operated on by the attending surgeon they retained, but rather by residents. Between 50% and 85% of the surgery in teaching hospitals is done by residents.
- Although most residents operated only under the close supervision of attending surgeons, some residents performed surgery without supervision, and some attending surgeons left the room while the operation was still in progress or before the incision was closed.
- Most patients are unaware of the degree to which residents participate in their surgery, and consent forms that name the attending surgeon and "such assistants as he shall select" do not give patients meaningful notice that a resident may do the actual cutting or suturing.[8]

The authors of the report stressed that there was no evidence that allowing residents to be active participants in surgery caused harm to patients. However, other researchers were less certain, suggesting that harm to patients from care rendered by physicians in training may be much more common than is generally known.[9] Whether harm occurs is a utilitarian measure. Kantians do not consider outcomes, but rather determine only whether actions meet the criterion of respect for persons. Misleading patients or lying to them violates this principle.

The report addressed the disclosure necessary for informed consent and sufficient supervision to ensure patient safety. It also recommended that physicians be required to obtain the patient's consent for each person who participates in the surgery and that vague phrases (e.g. "such assistants as the surgeon may select") be deleted from consent forms. The recommendations encouraged adequate supervision by limiting the number of patients a surgeon could treat and the number of operating rooms surgeons could reserve at one time.[10]

The AMA and the American College of Surgeons (ACS) have addressed the question of medical education and consent. They agree that if a resident—rather than the surgeon retained

by the patient—actually performs the surgery, the patient must be made aware of that fact and consent to the substitution. The *Report of the Council on Ethical and Judicial Affairs of the AMA* states

> A surgeon who allows a substitute to operate on his or her patient without the patient's knowledge and consent is deceitful. The patient is entitled to choose his or her own physician and should be permitted to acquiesce in or refuse to accept the substitution.
>
> Under the normal and customary arrangement with patients, and with reference to the usual form of consent to operation, the operating surgeon is obligated to perform the operation but may be assisted by residents or other surgeons. With the consent of the patient, it is not unethical for the operating surgeon to delegate the performance of certain aspects of the operation to the assistant provided this is done under the surgeon's participatory supervision, i.e., the surgeon must scrub. If a resident or other physician is to perform the operation under nonparticipatory supervision, it is necessary to make a full disclosure of this fact to the patient, and this should be evidenced by an appropriate statement contained in the consent. Under these circumstances, the resident or other physician becomes the operating surgeon.[11]

The ACS devotes the second part of its Statements on Principles to "Relation of the Surgeon to the Patient"; in the section titled "The Operation—Responsibility of the Surgeon," it states

> The surgeon is personally responsible for the patient's welfare throughout the operation. . . . The surgeon may delegate part of the operation to associates or residents under his or her personal direction, because
>
> > modern surgery is often a team effort. If a resident is to perform the operation and is to provide the continuing care of the patient under the general supervision of the attending surgeon, the patient should have prior knowledge. However, the surgeon's personal responsibility must not be delegated or evaded. It is proper to delegate the performance of part of a given operation to assistants, provided the surgeon is an active participant throughout the key components of the operation. The overriding goal is the assurance of patient safety. . . .
> >
> > *It is unethical to mislead a patient as to the identity of the surgeon who performs the operation*. This principle applies to the surgeon who performs the operation when the patient believes that another physician is operating ("ghost surgery") and to the surgeon who delegates a procedure to another surgeon without the knowledge or consent of the patient.[12]

These statements are unambiguous. The patient must be informed about a resident's participation in the operation. The evidence suggests, however, that these principles are often violated. Learning by doing is most apparent in surgical training. There is no ethical difference, however, between a surgical resident wielding a scalpel and a medical resident ordering a treatment or medication under the general supervision of an attending physician if patients have not given consent for them to participate in their care.

Patient consent in medical education settings generally receives inadequate attention. Examples range from conducting pelvic examinations on anesthetized women without their consent (37% of medical schools taught pelvic exams in this manner) to performing procedures (for educational purposes) on dead bodies without family members' consent. Almost half of accredited emergency medicine programs permitted physicians in training to perform procedures on dead bodies; three quarters admitted that they almost never obtained consent from family members.[13] Such breaches are all the more unacceptable because there is no therapeutic benefit derived by the "patient."

Similar ethical breaches occur in nonsurgical settings. Examinations and participation by physicians in training pose less risk to patients than those by surgeons in training. Nonetheless, the same ethical principles are violated if patients do not consent to participate in medical education.

Role and Status Uncertain

An internationally known medical center has a large number of physicians on staff. Consultants are ranked highest, are board-certified, and have achieved preeminence in the organization. Below them are fellows and residents, both of whom see patients with general supervision from the consultant to whom they have been assigned. Fellows and residents hold state licenses and have been evaluated through a credentialing process. Fellows work more independently than do residents. Residents may be at various points in their post–medical school training. Residents report to fellows or to the consultant, depending on the clinical service and the wishes of the consultant.

The three categories of physicians wear the same type of name badges. The badges do not identify their category or position in the organization's hierarchy. Typically, a resident or fellow sees the patient first. Only rarely do they identify themselves to patients other than to state something such as "Hello, I'm Dr. . . . " Sophisticated patients and returning patients understand that a fellow or resident usually performs the preliminary examination or has the first interaction with the patient. The consultant follows after, conferring with the fellow and/or resident.

One patient was bold enough to ask the consultant, whom she had seen on a previous visit, about the roles of the other two physicians who had already examined her. She wondered aloud why she had not been told that they were physicians in training and, as she stated, "were not fully qualified to be her doctors."

There is evidence that the problem described above is widespread. One study[14] found that

> Residents introduced themselves as a doctor 82% of the time, but identified themselves as a resident only 7% of the time. While attending physicians introduced themselves as a "doctor" 64% of the time, only 6% identified themselves as the supervising physician. Patients felt it was very important to know their physicians' level of training, but most did not.

In addition to the ethical and legal expectations incident to informed consent, the information about training status is important to patients. Patients in emergency departments prefer not to be seen by trainees; those informed about physicians' credentials were less willing to be seen by more junior trainees.[15]

Failure to obtain patient (or family) consent for purposes of medical education occurs despite the work of accreditors such as the Joint Commission on Accreditation of Healthcare Organizations and the Liaison Committee on Medical Education, both of whom emphasize proper consent. This issue raises questions about the adequacy of consent for treatment and emphasizes the need for increased attention by the organization and its managers.

Medical education and patient consent are compatible, but medical educators may fear that obtaining explicit consent will diminish educational opportunities and therefore the quality of the educational program. Patients and families are likely to cooperate if asked to help with teaching needs.[16] In addition, patients will likely cooperate if they know that physicians in training will play a role in their care.[17] Patients who do not consent to residents' participation in their care should have their decision respected, or they should be encouraged to seek care elsewhere. Ignoring their autonomy shows that an ethical commitment to patient rights is lacking, that the organization and staff violate their moral obligations to patients, and that managers violate the virtues of honesty and trustworthiness.

CONCLUSION

This chapter addressed the ethical issues of consent. Health services organizations and their managers should consider legal requirements a minimum. Ethical principles should be the basis for a strong relationship with the patient. This independent relationship stems from autonomy and the respect owed the patient.

Operationalizing the desire of and need for patients to be fully involved in consent requires

managerial attention to the consent process—itself not an easy task. More involvement means overcoming a history of medical paternalism and educating patients as well as encouraging and assisting them to become involved.

A significant ethical problem is that of providing information about treatment to patients in health services organizations in which clinical education occurs. Managers face many barriers in convincing attending staff and trainees that fully informing patients will not lead to less "clinical material" for teaching. Evidence suggests that few patients will refuse to participate after they have been informed; there is reason to believe that patients will overwhelmingly agree to having medical and surgical residents participate in their treatment. Regardless, the needs of medical education must be secondary to the right of patients to consent.

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CHAPTER 10

DYING AND DEATH

Dying and death are intrinsic to human existence. As with abortion, the ethical questions involved often prompt emotional responses from the public and many health professionals. Ethical issues in dying and death arise in ways such as treating neonates with severe disabilities who are unlikely to survive, and caring for children or adults who are terminally ill and unable to be autonomous.

Technology is at the heart of the matter. Since the 1970s, renal dialysis, mechanical ventilation, cardiac medications, and intensive care units (ICUs) have made it possible to postpone the end of life. Similar developments allow neonates who would have died in the 1980s to survive. A great deal has been written about the questions such technology raises, but there are few widely accepted courses of action. Sometimes an ethical dilemma occurs when a person asks the health services organization to assist in achieving pain-free death.

Adding complexity to these ethical issues is that many are poorly developed in the law. Deliberately shortening a patient's life raises important ethical and legal questions. Juries are reluctant to convict perpetrators, even when violent means have been used to end the painful life of someone terminally ill.

Chapter 9 noted that in the early 1980s, the President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended a physician–patient relationship that maximizes patient sovereignty, with the patient fully participating in the decision process. Often, by the time crucial medical decisions must be made, the patient can no longer participate effectively, however, and may not be competent. If available, advance medical directives are helpful, but families and caregivers may disregard them. A medical ethic dedicated to preserving life and staving off death controls, and it is typical that the technological imperative results in expending all efforts, many times with marginal results. The economic, emotional, and psychological costs are obvious.

Managers may feel uneasy discussing dying and death. They may think that decision making at the end of life is clinical, a situation in which they play no role. Certainly, physicians are the lead actors in these dramas, but the effect of such issues on the organization requires that managers are knowledgeable about them and participate in developing and implementing policies and procedures. Managers must also be involved in the work of relevant committees.

In the mid-1980s, a distinction was drawn between treatments that were life prolonging and those that were life sustaining. Since then, however, the two concepts have merged and are simply called *life-sustaining treatments*. Life-sustaining treatment is "any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration."[1]

DEATH DEFINED

Historically, death was defined as the stoppage of blood circulation and the cessation of circulation-dependent animal and vital functions, such as respiration and pulsation. New technology proved this definition inadequate. Table 3 summarizes definitions of death. Definitions based in law and theology provide limited guidance for contemporary clinicians.

In 1968, a Harvard Medical School committee defined *irreversible coma*, which solved some problems but created others. The Harvard criteria were accompanied by a report stating that only a physician can determine the patient's condition, and that when the condition is found to be hopeless certain steps are recommended:

> Death is declared and *then* the respirator is turned off. The decision to do this and the responsibility for it are to be taken by the physician-in-charge, in consultation with one or more physicians who have been directly involved in the case. It is unsound and undesirable to force the family to make the decision.[2]

This quote is noteworthy because of changes in society's attitudes and perceptions that have occurred since 1968, including emphasis on patient autonomy and natural death statutes, family involvement in decision making, and establishment of institutional ethics committees (IECs). These changes have reduced the physician's primacy in decision making.

Table 3. Definitions of death

Concept of death (Philosophical or theological judgment of the essentially significant change at death)	Locus of death (Place to look to determine whether a person has died)	Criteria of death (Measurements physicians or other officials use to determine whether a person is dead—to be determined by scientific empirical study)
1. Irreversible loss of flow of vital fluids (i.e., the blood and breath)	Heart and lungs	Visual observation of respiration, perhaps with the use of a mirror
		Feeling of the pulse, possibly supported by electrocardiogram
2. Irreversible loss of the soul from the body	Pineal body (?) (according to Descartes)	Observation of breath (?)
	Respiratory tract (?)	
3. Irreversible loss of the capacity for bodily integration	Brain	Unreceptivity and unresponsivity
		No movements or breathing
		No reflexes (except spinal reflexes)
		Flat electroencephalogram (to be used as confirmatory evidence)
		All tests to be repeated 24 hours later (excluded conditions: hypothermia and central nervous system depression by drug)
4. Irreversible loss of consciousness or the capacity for social interaction	Probably the neocortex	Electroencephalogram

Adapted from Veatch, R.M.S. (1976). *Death, dying, and the biological revolution: Our lost quest for responsibility* (p. 53). New Haven: Yale University Press. Copyright © Yale University Press. Used with permission. This table has been modified using material from the 1989 second edition.

Note: Death is defined as a complete change in the status of a living entity characterized by the irreversible loss of those characteristics that are essentially significant to it. The possible concepts, loci, and criteria of death are much more complex than the ones provided here. These concepts are simplified models used to define death. It is obvious that those who believe that death means the irreversible loss of the capacity for bodily integration (3), or the irreversible loss of consciousness (4), have no reservations about pronouncing death when the heart and lungs have ceased to function. This is because they are willing to use loss of heart and lung activity as shortcut criteria for death, believing that once the heart and lungs have stopped, the brain or neocortex will necessarily stop, as well.

Note: In the table, *(?)* signifies uncertainty.

Near the time that the Harvard criteria were developed, a Virginia court issued one of the first rulings accepting brain death.[3] The case raised issues of consent, appropriate criteria and process for determining death, conflicts of interest, beneficence, nonmaleficence, and organizational philosophy and managerial ethics. The physicians involved tried to use a brain death standard but failed to meet the Harvard criteria because there was no electroencephalogram to verify brain activity and the respirator was turned off *before* the patient was pronounced dead. Despite the lapses, the court made legal history by accepting a determination that the patient was dead using a brain death criterion.

The National Conference on Uniform State Laws developed the Uniform Determination of Death Act (UDDA) in 1980 in cooperation with the American Medical Association (AMA) and American Bar Association (ABA). The AMA and ABA officially approved the UDDA in 1980 and 1981, respectively.[4] It provides alternative definitions of death. One uses the

traditional definition—that is, irreversible cessation of pulsation (circulatory and respiratory functions); the other uses whole brain death. By 2008, a version of the UDDA had been enacted in 50 states and the District of Columbia.[5] The uniform act states:

> An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.[6]

The UDDA has been endorsed by the National Kidney Foundation, the North American Transplant Coordinators Association, and the American Nephrology Nurses' Association.[7]

Brain death, as shown in the preceding UDDA definition, or some variation, as stated below, is now a commonly used alternative criterion for death:

> The three cardinal findings in brain death are coma or unresponsiveness, absence of brainstem reflexes, and apnea. The clinical examination of the brainstem includes testing of brainstem reflexes, determination of the patient's ability to breathe spontaneously, and evaluation of motor responses to pain.[8]

Definitions vary slightly, but the concept of whole brain death—defined as irreversible cessation of all functions of the brain, including the cortex and the brainstem—has been endorsed by the AMA, the ABA, and the American Academy of Neurology. Efforts continue to make the clinical determination of brain death more precise and standardized.[9] Use of the whole brain death concept is law in 46 states.[10, 11]

As scientific developments permit increasingly sophisticated assessments of a patient's condition, especially prognosis, brain death criteria may be superseded by those that incorporate psychosocial factors. Prominent among the criteria proposed is the capacity or potential capacity for social interaction. This definition raises ethical issues and jeopardizes persons with no capacity for typical social interaction (e.g., persons with significant cognitive disabilities). A definition that includes a lack of the potential for typical social interaction was applied when infants with mental retardation, such as Baby Boy Doe, were allowed to die. Federal regulations since the 1980s specifically prohibit applying quality of life criteria to infants with disabilities who have life-threatening medical conditions, but there is evidence that quality of life criteria are commonly, if implicitly, used in decision making for other types of patients.

ADVANCE MEDICAL DIRECTIVES

When the federal Patient Self-Determination Act (PSDA) of 1989 took effect December 1, 1991, efforts to achieve patient participation in and control of their healthcare decisions gained a significant impetus. PSDA requires that hospitals, nursing facilities, hospice, home health agencies, and managed care organizations that participate in Medicare and Medicaid give all patients written information about their rights under state law to accept or refuse medical or surgical treatment and to formulate advance medical directives (AMDs). Adult patients must also be given the provider's written policies about implementing these rights. Medical records must document whether a patient has executed an AMD. Providers must also educate their staffs and communities about AMDs. Despite PSDA and the fact that all 50 states have laws authorizing some type of AMD (e.g., living wills, healthcare agents, medical powers of

attorney),[12] problems continue in operationalizing patient involvement in decision making about AMDs; relatively few patients execute them. It is estimated that only 20% of Americans have AMDs.[13] As few as 5% of individuals older than age 65 may have AMDs.[14] A Maryland study found that about one-third of respondents had AMDs; those over 65 were more likely than younger adults to have an advance directive.[15]

The Joint Commission on Accreditation of Healthcare Organizations requires accredited hospitals to address the wishes of patients relating to end-of-life decisions. Adults must be given written information about their right to accept or refuse medical or surgical treatment, including forgoing or withdrawing life-sustaining treatment or withholding resuscitative services.[16] The decisions that patients should consider in their AMDs include specific types of life-sustaining treatment that they want used, withheld, or withdrawn. Examples include cardiopulmonary resuscitation (CPR), elective intubation, mechanical ventilation, surgery, dialysis, blood transfusions, artificial hydration and nutrition (AHN), diagnostic tests, antibiotics, and other medications and treatments, as well as future admission to the ICU. Patients tend to choose more restrictions on treatment as diseases progress.[17]

Living Wills

The living will was developed long before passage of the PSDA so that persons unable to participate in decision making could guide caregivers. The words *living* and *will* seem contradictory. Wills are the legal mechanism by which a deceased person's wishes as to disposition of real and personal property are known. Living wills allow persons unable to communicate with caregivers to express their wishes about the extent of treatment they want. Living wills allow persons to specify what is done for and to them and to control the technological imperative, regardless of its potential benefit. Absent state legislation or case law, living wills have no legal status; patients must rely on the willingness of caregivers to follow the directives in them. Generic living wills are useful in states without specific legal requirements.

State Statutes

Interest in living wills and public reaction to cases in which seemingly excessive treatment was provided led to rapid enactment of state laws recognizing the patient's right to control treatment processes. These laws are variously known as living wills laws, advance medical directives, natural death acts, or death with dignity laws. In early 1983, 14 states had such laws; by 1985, there were 35 states and the District of Columbia.[18] In 2009, all states and the District of Columbia had a medical directive law.[19] The Virginia Advance Medical Directive form is shown in Figure 9.

Generally, these statutes recognize a patient's right to direct physicians to withhold or withdraw life-sustaining treatment. When statutory requirements are met, the directives are legally binding on caregivers. The laws tend to be drafted narrowly and apply when a physician has determined that the patient who signed the declaration is terminally ill and has no prospect of recovery. Some statutes require that the directives must be reaffirmed when

patients know they are terminally ill. Some include penalties against caregivers and the organization if directives are ignored. In addition to statutes, state court decisions affect how the laws are interpreted and their effect on use of life-sustaining treatment.

VIRGINIA ADVANCE MEDICAL DIRECTIVE

I, _____, intentionally and voluntarily make known my wishes in the event that I am incapable of making an informed decision, as follows:

I understand that my advance directive may include the selection of an agent in addition to setting forth my choices regarding health care. The term ***"health care"*** means: the furnishing of services to any individual for the purpose of preventing, alleviating, curing or healing human illness, injury or physical disability, including but not limited to medications; surgery; blood transfusions; chemotherapy; radiation therapy; admission to a hospital, nursing home, assisted living facility or other health care facility; psychiatric or other mental health treatment; and life-prolonging procedures and palliative care.

The phrase ***"incapable of making an informed decision"*** means: unable to understand the nature, extent and probable consequences of a proposed health care decision; unable to make a rational evaluation of the risks and benefits of a proposed health care decision as compared with the risks and benefits of alternatives to that decision; or unable to communicate such understanding in any way.

This advance directive shall not terminate in the event of my disability.

(YOU MAY INCLUDE IN THIS ADVANCE DIRECTIVE ANY OR ALL OF SECTIONS I THROUGH V BELOW.)

SECTION I: APPOINTMENT OF AGENT

(CROSS THROUGH SECTION I AND SECTION II BELOW IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE HEALTH CARE DECISIONS FOR YOU.)

I hereby appoint the following as my primary agent to make health care decisions on my behalf as authorized in this document:

Name of Primary Agent | Telephone | Fax if any

Address | E-mail if any

If the above-named primary agent is not reasonably available or is unable or unwilling to act as my agent, then I appoint the following as successor agent:

Name of Successor Agent | Telephone | Fax if any

Address | E-mail if any

I hereby grant to my agent named above full power and authority to make health care decisions on my behalf as described below whenever I have been determined to be incapable of making an informed decision. My agent's authority is effective as long as I am incapable of making an informed decision.

In exercising the power to make health care decisions on my behalf, my agent shall follow my desires and preferences as stated in this document or as otherwise known to my agent. My agent shall be guided by my medical diagnosis and prognosis and any information provided by my physicians as to the intrusiveness, pain, risks and side effects associated with treatment or nontreatment. My agent shall not make any decision regarding my health care which he or she knows, or upon reasonable inquiry ought to know, is contrary to my religious beliefs or my basic values, whether expressed orally or in writing. If my agent cannot determine what health care choice I would have made on my own behalf, then my agent shall make a choice for me based upon what he or she believes to be in my best interests.

My agent shall not be liable for the costs of health care that he or she authorizes, based solely on that authorization.

SECTION II: POWERS OF MY AGENT

(CROSS THROUGH ANY POWERS IN THIS SECTION II THAT YOU DO NOT WANT TO GIVE YOUR AGENT AND ADD ANY POWERS OR INSTRUCTIONS THAT YOU DO WANT TO GIVE YOUR AGENT.)

The powers of my agent shall include the following:

A. To consent to or refuse or withdraw consent to any type of health care, treatment, surgical procedure, diagnostic procedure, medication and the use of mechanical or other procedures that affect any bodily function, including, but not limited to, artificial respiration, artificially administered nutrition and hydration, and cardiopulmonary resuscitation. This authorization specifically includes the power to consent to the administration of dosages of pain-relieving medication in excess of recommended dosages in an amount sufficient to relieve pain, even if such medication carries the risk of addiction or of inadvertently hastening my death.

My agent's authority under this Subsection A shall be limited by any specific instructions I give in Section IV below regarding my health care if I have a terminal condition.

B. To request, receive and review any oral or written information regarding my physical or mental health, including but not limited to medical and hospital records, and to consent to the disclosure of this information.

C. To employ and discharge my health care providers.

D. To authorize my admission to or discharge (including transfer to another facility) from any hospital, hospice, nursing home, assisted living facility or other medical care facility. If I have authorized admission to a health care facility for treatment of mental illness, that authority is stated in Subsections E and/or F below.

E. To authorize my admission to a health care facility for the treatment of mental illness for no more than 10 calendar days provided that I do not protest the admission and provided that a physician on the staff of or designated by the proposed admitting facility examines me and states in writing that I have a mental illness, that I am incapable of making an informed decision about my admission, and that I need treatment in the facility; and to authorize my discharge (including transfer to another facility) from the facility.

F. To authorize my admission to a health care facility for the treatment of mental illness for no more than 10 calendar days, **even if I protest**, if a physician on the staff of or designated by the proposed admitting facility examines me and states in writing that I have a mental illness, that I am incapable of making an informed decision about my admission, and that I need treatment in the facility; and to authorize my discharge (including transfer to another facility) from the facility.

(If you give your agent the powers described in this Subsection F, your physician must complete the following attestation.)

Physician attestation: I am the physician or licensed clinical psychologist of the declarant of this advance directive. I hereby attest that I believe the declarant to be presently capable of making an informed decision and that the declarant understands the consequences of this provision of this advance directive.

Physician Signature _____ Date _____

Physician Name Printed _____

G. To authorize the following specific types of health care identified in this advance directive **even if I protest.**
(Specifically cross-reference any applicable sections of this advance directive.)

_____

_____

(If you give your agent the powers described in this Subsection G, your physician must complete the following attestation.)

Physician attestation: I am the physician or licensed clinical psychologist of the declarant of this advance directive. I hereby attest that I believe the declarant to be presently capable of making an informed decision and that the declarant understands the consequences of this provision of this advance directive.

Physician Signature _____ Date _____

Physician Name Printed _____

H. To continue to serve as my agent even if I protest the agent's authority after I have been determined to be incapable of making an informed decision.

I. To authorize my participation in any health care study approved by an institutional review board or research review committee according to applicable federal or state law if the study offers the prospect of direct therapeutic benefit to me.

J. To authorize my participation in any health care study approved by an institutional review board or research review committee pursuant to applicable federal or state law that aims to increase scientific understanding of any condition that I may have or otherwise to promote human well-being, even though the study offers no prospect of direct benefit to me.

K. To make decisions regarding visitation during any time that I am admitted to any health care facility, consistent with the following directions:

L. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

(Add below any additional powers you give your agent, limits you impose on your agent or other information to guide your agent.)

I further instruct my agent as follows:

SECTION III: HEALTH CARE INSTRUCTIONS

(CROSS THROUGH SUBSECTIONS A AND/OR B BELOW IF YOU DO NOT WANT TO GIVE ADDITIONAL SPECIFIC INSTRUCTIONS ABOUT YOUR HEALTH CARE.)

A. I specifically direct that I receive the following health care if it is medically appropriate under the circumstances as determined by my attending physician:

B. I specifically direct that the following health care not be provided to me under the following circumstances:
(You also may specify that certain health care not be provided under any circumstances.)

SECTION IV: INSTRUCTIONS ABOUT END-OF-LIFE CARE ("LIVING WILL")

(CROSS THROUGH THIS SECTION IV IF YOU DO NOT WANT TO GIVE SPECIFIC INSTRUCTIONS ABOUT YOUR HEALTH CARE IF YOU HAVE A TERMINAL CONDITION.)

If at any time my attending physician should determine that I have a terminal condition where the application of **life-prolonging procedures** – including artificial respiration, cardiopulmonary resuscitation, artificially administered nutrition and artificially administered hydration – would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

In the absence of my ability to give directions regarding the use of such life-prolonging procedures, it is my intention that this advance directive shall be honored by my family and physician as the final expression of my legal right to refuse health care and my acceptance of the consequences of such refusal.

(Cross through Subsections A and/or B below if you do not want to give additional instructions about care at the end of your life.)

A. OTHER DIRECTIONS ABOUT LIFE-PROLONGING PROCEDURES

*(If you wish to provide your own directions about **life-prolonging procedures**, or if you wish to add to the directions you have given above, you may do so in this Subsection A. If you wish to give specific instructions regarding certain life-prolonging procedures, such as artificial respiration, cardiopulmonary resuscitation, artificially administered nutrition and artificially administered hydration, this is where*

you should write them. If you give specific instructions in this Subsection A, cross through any of the language above in this SECTION IV if your specific instructions that follow are different.)

I direct that:

B. DIRECTIONS ABOUT CARE OTHER THAN LIFE-PROLONGING PROCEDURES

(You may give here any other instructions about your health care if you have a terminal condition aside from your instructions about life-prolonging procedures, which are addressed in Subsection A above.)

I direct that:

SECTION V: APPOINTMENT OF AN AGENT TO MAKE AN ANATOMICAL GIFT OR ORGAN, TISSUE OR EYE DONATION

(CROSS THROUGH THIS SECTION V IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE AN ANATOMICAL GIFT OR ANY ORGAN, TISSUE OR EYE DONATION FOR YOU.)

Upon my death, I direct that an anatomical gift of all of my body or certain organ, tissue or eye donations may be made pursuant to Article 2 (§ 32.1-291.1 et seq.) of Chapter 8 of Title 32.1 of the Code of Virginia and in accordance with my directions below, if any. I hereby appoint as my agent to make any such anatomical gift or organ, tissue or eye donation following my death *(choose one)*:

❍ the same agent (and alternate) named in SECTION I above; **OR**

❍

Name of Agent | Telephone | Fax if any

Address | E-mail if any

I further direct that:

(Declarant's directions, if any, concerning anatomical gift or organ, tissue or eye donation.)

(You must sign below in the presence of two witnesses.)

AFFIRMATION AND RIGHT TO REVOKE: By signing below, I state that I am emotionally and mentally capable of making this advance directive and that I understand the purpose and effect of this document. I understand that I may revoke all or any part of this document at any time (i) with a signed, dated writing; (ii) by physical cancellation or destruction of this advance directive by myself or by directing someone else to destroy it in my presence; or (iii) by my oral expression of intent to revoke.

Signature of Declarant | Date

The declarant signed the foregoing advance directive in my presence.

(Witness) | (Witness)

—page 4 of 4—

This form is provided by the Virginia Hospital & Healthcare Association as a service to its members and the public. (May 2010, www.vhha.com)

Figure 9. An example of an advance medical directive. (Retrieved April 4, 2011, from www.vsb.org//sections/hl/VA-2010-Basic.pdf)

These laws solve some of the issues of control (autonomy), patient role, and, to an extent, organizational and provider efforts to comply with the patient's wishes. Even when there is an AMD, caregivers may not comply. Fragmentation of care among several providers and organizations further complicates patients' use of AMDs and poses a special challenge to managers in the organization to which the patient has been transferred. For example, an AMD in a nursing facility medical record may not accompany the patient to the hospital, especially in an emergency. A study of older patients hospitalized for acute illnesses found that in 75% of cases the medical record did not indicate that physicians had consulted the patient's living will or designated proxy before making treatment decisions, including whether to resuscitate. The problem was attributed to several factors: nursing facilities failed to transfer the information, patients were not asked or did not volunteer the information, and the hospital staff failed to ask or to ensure that such documents were part of the record. Once documented in the hospital medical record, AMDs influenced treatment decisions in 86% of cases involving patients who were judged incompetent.[20]

There are other problems with AMDs, including determining mental status and whether the patient comprehends the effect of what is being done and establishing the presence of a terminal illness. Of course, ethical issues arise for organizations when the patient has not met statutory requirements or there is no statute or AMD.

The challenge for the organization is to provide processes that promote the completion of AMDs. Completion rates for AMDs can be markedly improved by altering the time when information is distributed to patients entering hospitals for planned admissions. Patients were far more likely to complete an AMD at a hospital that distributed information several days before admission rather than only on the day of admission. The most common reason given for not completing an AMD was that it was not seen or was not read, a problem more common in hospitals that did not provide information in advance.[21] Other data suggested that providing reminders, education, and feedback to attending physicians and a new documentation form used by physicians for AMDs can greatly increase the percentage of patients with AMDs. The study also found that 87% of physician-attested directives agreed with the treatment preferences of patients interviewed. Other results showed that physicians' attitudes and interest in AMDs improved.[22] Research suggested, too, that changes in the care of dying patients may not have kept pace with national recommendations, in part because many physicians and nurses disagreed with and may have been unaware of some key guidelines, such as the permissibility of withdrawing treatment.[23]

Surrogate Decision Making

Surrogate decision making occurs when someone other than the patient makes decisions about healthcare. A form of surrogate decision making called *substituted judgment* occurs when someone makes decisions for a patient who is unable to do so, and the surrogate's decisions are based on what the surrogate believes the patient would want were the patient able to make a decision. Surrogates are needed to make decisions when patients are too young or otherwise legally incompetent or have a physical or mental infirmity and no AMD. Historically, surrogates have been appointed by courts upon a petition that a person was incompetent to make healthcare decisions. To avoid the cost and delay of court proceedings, some states enacted laws that established a priority list of relatives who could make decisions for someone with no AMD. In 2009, 43 states and the District of Columbia had statutes specifically authorizing surrogate decision making.[24]

Powers of attorney are another type of surrogate decision making. Powers of attorney are prepared before the fact and are a delegation of decision-making authority by a competent person, who is called the *principal*. Powers of attorney may be *general* (broad powers to act for the principal) or *limited* (authority to act for the principal for a specific purpose). Powers of attorney are *durable* when the grant of authority extends beyond the principal's incapacitation. Capacity (competence) is an important issue in healthcare decision making. Healthcare agents are persons who have been granted durable powers of attorney to make healthcare decisions for the principal. States may use different names for these limited, durable powers of attorney. By the end of 2001, all 50 states had statutes recognizing appointment of healthcare agents.[25] Figure 9, the Virginia Advance Medical Directive form, includes

appointment of a healthcare agent. State advance directive laws vary.

Do-Not-Resuscitate Orders

The do-not-resuscitate (DNR) order is a type of AMD that is used at the point of service delivery. As noted, many patients have neither living wills nor AMDs complying with state requirements. This emphasizes the organization's need to have policies and processes about resuscitating patients who are terminally ill and patients for whom life continuation decisions must be made (e.g., a patient in persistent vegetative state [PVS]*). Health services organizations usually have DNR policies affirming the legal right of a patient (or surrogate, as appropriate) to direct caregivers. The DNR policy should identify the chemical and mechanical technologies included and the specific instances in which they will be applied. Patients who are DNR may require surgery and anesthesia management for palliative care, for relief of pain or distress, or to improve the patient's quality of life. DNR orders present unique ethical problems that should be addressed prospectively by the organization.[26]

In the 1990s, state laws began to recognize nonhospital DNR orders that allow persons to refuse resuscitation when medical emergencies occur. By 2003, more than half the states had such laws;[27] in 2011, the number was 47.[28] These are known as emergency medical services do-not-resuscitate (EMS DNR) orders. EMS DNR orders make the patient's wishes legally binding in the home or a similar setting and supersede state laws that require EMS technicians to undertake CPR.

A study of three Houston teaching hospitals without DNR policies reported inconsistent application of DNR orders.[29] The study found that some patients with DNR orders underwent chemotherapy and surgery and were admitted to the ICU unit while others received inadequate hydration and nutrition. Staff are often confused about what types of care DNR patients should receive, perhaps because they disagree with such decisions. The study found that in 10% of cases, no decision had been reached about keeping the patient alive. This finding indicates that efforts to decide about resuscitation before a crisis commonly fail. In most no-decision cases, the subject of DNR had not been broached with the patient or family. Other studies of DNR orders report similar findings.[30] A key aspect of DNR is whether patient wishes about CPR are clear to physicians. One study found that in nearly one of three cases, the patient's preference not to be given CPR was at odds with the doctor's perception of what the patient wanted.[31]

Summary

It has been suggested that the widespread use of AMDs, such as natural death act declarations, may encourage systematic rationing of healthcare to older adults. If a right to die becomes a duty to die, the living will and its progeny, the natural death act declaration, will become a Frankenstein monster. Indeed, the suggestion by former Governor Richard Lamm of Colorado, as well as by officials at the U.S. Department of Health, Education, and Welfare (now called the Department of Health and Human Services [DHHS]), that older people should be required to have living wills raised a storm of protest. Regardless of true motives, such suggestions are often seen as motivated by economics.

It has been suggested that treatment may end because physicians assume it is not in a

patient's interest or because physicians believe the patient would not want it.[32] Others, however, assert that physicians are caught up in the same ethos of "death as failure" as patients and family; these commentators are focusing on what has been called the riddle—physicians' determination to diagnose and cure the disease. When there is no longer a riddle —when death is inevitable—physicians' interest may decline or be lost entirely, and having lost the major battle, they may try to maintain some authority by controlling the dying process of their patients.[33] If correct, these views neither consider patients as independent decision makers nor as involved participants, and thus physicians may be acting other than in the patients' best interests, as determined by the patient. Both suggest significant ethical problems in meeting the wishes of terminally ill patients.

It would seem that surrogate decision makers will accurately reflect patient's wishes about life-sustaining treatments. That appears not to be true, however. Even those who know patients well are not highly accurate in predicting their life-sustaining treatment preferences. Chronically ill patients are more satisfied with their primary care physicians and the care they deliver when AMDs are discussed.[34] Neither AMDs nor discussion of directives significantly improved the accuracy of substituted judgment, however.[35] Family members were more accurate in making substituted judgments than were physicians, but even they still fell short of complying with patients' wishes. The presence of AMDs assisted hospital-based physicians but not primary care physicians in their actions as surrogate decision makers.[36] Significant work remains if health services organizations are to provide health services consistent with AMDs and patients' wishes regarding end-of-life care. Furthermore, end-of-life care needs improvement both in meeting patients' wishes to die at home (rather than in an institution) and in the quality of palliative care.[37] The role of palliative care is discussed in Chapter 13.

The organization must be alert to the ethical issues of AMDs, which are present regardless of a natural death act statute or a living will. Health services organizations and their managers must consider these issues prospectively and develop policies that respect patients' wishes, consistent with the organizational philosophy.

Improving care of the dying in health services organizations should include the following: reaffirming patients' rights to palliative care, providing adequate pain and symptom management, improving policies and procedures to ensure that AMDs are available as needed, ensuring a well-functioning IEC, improving access by all concerned to the IEC, enhancing community outreach education, ensuring timely referrals to hospice and family support services, and encouraging medical education in dying and ethics.[38]

EUTHANASIA

Euthanasia comes from the Greek *eu* (good) and *thanatos* (death). In the context of the Hippocratic tradition, which prohibits physicians from administering a deadly drug, euthanasia describes care that makes an inevitable death pain-free.

In contemporary parlance, however, euthanasia describes situations in which active steps cause death. Such word use blurs important distinctions. Providing comfort care and pain control without purposefully hastening death allows persons to die with dignity and free of pain. This discussion uses the contemporary definition of euthanasia as active steps to cause

death—that is, mercy killing. Actively ending life is illegal in all states.[39]

Morphia Somnolence

Henrietta Morrow was diagnosed with inoperable cancer 18 months ago. Chemotherapy was ineffective. The lymph system had spread the disease throughout her body, and Morrow was in severe pain. Initially, she received care through a home hospice program. As the disease worsened, she became an inpatient at the hospice. She was expected to live less than 3 months.

Morrow received nutrition, hydration, and comfort care. The morphine used for pain control was increased as the disease progressed and her pain worsened. A staff member asked the medical director about the depressant effect that morphine would have on Morrow's respiration. She worried about depressing respiration so much that death would result. Her concern was expressed in both legal and ethical contexts. The medical director assured her that there were no legal problems and described the ethical considerations, including ordinary versus extraordinary care, active and passive euthanasia, voluntary versus involuntary euthanasia, and the rule of double effect.

Ordinary versus Extraordinary Care

Hastening or bringing about death by increasing the morphine beyond that needed to control pain would be euthanasia, an unethical and illegal act. For Morrow, comfort care and pain relief will have the benefit of providing a comfortable and pain-free dying process—defined as ordinary care. Because the hope of benefit for recovery from the cancer is virtually nil, further chemotherapy is defined as extraordinary care. Natural hydration and nutrition are always ordinary care. Artificial hydration and nutrition (AHN) is ordinary care, too, if there is hope of benefit from administering it. AHN becomes extraordinary when a patient's condition is such that there is no hope of benefit. Some assert that AHN is never extraordinary, however. The principle of nonmaleficence provides a distinction:

> Ordinary means are all medicines, treatments, and operations which offer reasonable hope of benefit and which can be obtained and used without excessive expense, pain, or other inconvenience. Extraordinary means are all medicines, treatments, and operations which cannot be obtained or used without excessive expense, pain, or inconvenience, or which, if used, would not offer a reasonable hope of benefit.[40]

Simply put, continuing a course of treatment (including AHN) that offers no hope of benefit only prolongs the dying process and inflicts unnecessary suffering and discomfort on the patient.

Ordinary and *extraordinary* are not defined as usual and unusual, respectively. This definition could be confusing because there is variation even among similar hospitals as to which treatments are usual or unusual. The usual emergency treatment in a shock trauma unit is different from that provided in a community hospital emergency room. Instead, the criterion is hope of benefit as compared with excessiveness of expense, pain, or other inconvenience. Absent hope of benefit, any medicine, treatment, or operation is extraordinary. If there is hope of benefit, use of the same medicines, treatments, and operations is ordinary care if they can be obtained and used without excessive expense, pain, or inconvenience.

Some ethics literature uses benefits to, and burdens on, the patient—the proportionality of treatment. It is suggested that proportionate and disproportionate are more clear and descriptive than ordinary and extraordinary. The criteria used to measure proportionate and disproportionate care are like those used for ordinary and extraordinary but are stated somewhat differently. The type of treatment and its complexity or risk, cost, and appropriateness are studied and compared with results to be expected, taking into account the

state of sick persons and their physical and moral resources.[41] Using this calculus, it is ethical to provide the treatment if the potential benefit justifies the burden. Like ordinary and extraordinary, proportionate and disproportionate are primarily qualitative measures of the ethical appropriateness of treatment. Crudely summarized, ordinary/ extraordinary and proportionate/disproportionate mean "Does the benefit justify the burden?"

Types of Euthanasia

Euthanasia has four permutations: voluntary active, voluntary passive, involuntary active, and involuntary passive. *Voluntary* means that the person has freely consented. *Involuntary* means that the person either has not freely consented, or cannot freely consent, but is presumed to want to die. *Active* means that positive steps are taken to bring about death, an action that should be called killing. *Passive* means that nothing is done to hasten death; it is only the natural course of the disease that causes death. All types of euthanasia include providing comfort care and pain control.

Active or Passive Euthanasia The case of Henrietta Morrow raises questions about the concept of euthanasia: Does increased morphine for pain control constitute euthanasia that is active or passive or voluntary or involuntary? Active euthanasia occurs when someone's death is purposely hastened. Intentionally giving Morrow more morphine than needed to control pain is active euthanasia, an act that is both unethical and illegal. Passive euthanasia occurs when the patient is allowed to die and no extraordinary means are used to sustain life, or when extraordinary means for sustaining life are withdrawn and the patient dies as the result of the natural course of the disease. Withholding or withdrawing life-sustaining treatment does not preclude providing comfort care and pain control. AHN are extraordinary (disproportionate) care, however, if they offer no reasonable hope of benefit.

Voluntary or Involuntary Euthanasia Voluntary and involuntary euthanasia refer to patient decisions about treatment. It is unknown whether Morrow is aware that increasing the amount of morphine may shorten her life, and if she agrees to hazard a shortened life. It is reasonable to assume that she prefers to live pain-free despite morphine's side effects. Organizations emphasizing patient autonomy will involve competent patients in decisions regarding all treatment, including pain control, to the fullest extent possible.

Rule of Double Effect Morrow's situation suggests application of the moral rule of double effect (RDE). Like ordinary and extraordinary care, double effect is a subset of nonmaleficence.

Classic formulations of the RDE identify four conditions or elements that must be satisfied for an act with double effect to be justified. Each is a necessary condition, and together they form sufficient conditions of morally permissible action.

1. *The nature of the act*—The act must be good, or at least morally neutral (independent of its consequences).
2. *The agent's intention*—The agent intends only the good effect. The bad effect can be foreseen, tolerated, and permitted, but it must not be intended.
3. *The distinction between means and effects*—The bad effect must not be a means to the good effect. If the good effect were the direct causal result of the bad effect, the agent would intend the bad effect in pursuit of the good effect.
4. *Proportionality between the good effect and the bad effect*—The good effect must outweigh the bad effect.

> That is, the bad effect is permissible only if a proportionate reason is present that compensates for permitting the foreseen bad effect.[42]

The rule of double effect allows ethical use of morphine, even in increasing quantities, to ease Morrow's pain.

PATIENT DECISION-MAKING PROCESS

Competent Persons

Persons who are competent have an ethical and a legal right to decide what treatments they will accept. This precept applies equally to withholding and withdrawing treatment. Consent is discussed in Chapter 9. Anecdotal evidence suggests that staff find it easier to withhold than withdraw treatment. Reluctance to discontinue treatment may be driven by fear of legal liability as well as by uncertainty as to the ethically correct choice.

The Henninger Case The case of 85-year-old G. Ross Henninger was decided by the New York State Supreme Court. Henninger was confused, depressed, and irritable when he was hospitalized for treatment of fever and infection. His medical problems were compounded by a stroke, arthritis, heart disease, and hardening of the arteries. The court stated it would not "go against [Henninger's] wishes and order this 85-year-old person to be operated on, or be force fed, or to be restrained for the rest of his natural life."[43] The decision followed a hearing in which attorneys for Henninger and the nursing facility where he lived petitioned the court to determine the legality of the facility allowing him to starve to death, which was his wish. Henninger died the day following the decision.

The case of Henrietta Morrow suggests the similarity of decisions about dying and death in various types of health services organizations. Nursing facilities, hospice, and home health agencies must prospectively address the ethical issues that end-of-life decisions raise. This focus entails a review from organizational philosophy down to operational policies. The philosophy and policies regarding matters such as life-continuation decisions and AHN must be communicated to patients and potential patients and their families.

Somebody Changed the Rules!

In 1996, Ruth Mittlemann was admitted to the Hebrew Home, a nursing facility. Mittlemann suffered from amyotrophic lateral sclerosis, or Lou Gehrig's disease. Her condition deteriorated gradually. By late 1999, it was clear that she would soon be unable to swallow and thus could not take food and water by mouth. Before entering the facility, Mittlemann had executed a living will expressly stating that she did not want to receive artificial hydration or nutrition; she wished to be kept comfortable and treated for pain when she could no longer swallow. At the time Mittlemann entered the Hebrew Home, her living will posed no problem because the facility had no organizational policy on this issue.

In early 1998, the Hebrew Home's board of trustees began work on a policy regarding artificial nutrition and hydration. It was the most rancorous issue the board ever considered. Several members resigned because of the intense debate, which sometimes degenerated into personal attacks. The result was a policy adopted in late 1998 stating that the sanctity of life had to be respected and that only if death were imminent could patients or their surrogates direct that such basic human care as food and water be stopped.

Mittlemann learned of this new policy only when she was informed that it would be necessary to place a nasogastric tube so that she could be hydrated and fed. She protested vehemently and reaffirmed her living will. She did not want to move to another nursing facility in the area; she liked where she was. She only objected to being forced to receive treatment that she did not want.

On its face, this change is fundamentally unfair to Mittlemann. She is caught in a situation not of her making and beyond her control. The organization also faces a dilemma: acceding to Mittlemann's wishes causes the organization to violate its new values statement about the sanctity of life.

The principle of respect for persons—specifically, fidelity (promise keeping)—governs the Mittlemann case. The organization is obliged to apprize patients of policies that affect them. Because the Hebrew Home had no written policy on AHN when Mittlemann was admitted, the trust she placed in the organization when she chose it is being violated. Moving her elsewhere does not eliminate the home's duty. As distasteful as it may be to the organization and its board, Mittlemann's wishes must be an exception to the policy.

Formerly Competent Patients

In theory, patients retain the right to determine what care they receive and when it will be discontinued. However, treatment decisions, even for competent inpatients, often become psychologically and physically overwhelming. The processes and the persons who apply them dominate; the patient loses control. Patients (or their advocates) may be forced to bring legal action to reassert their autonomy.

Instructions from a Formerly Competent Patient

Constance Emerson had lived a full life. She had been active in the community. She worked as a volunteer at Homer House, a noted settlement house, where she developed educational programs for children of working mothers. Emerson is 92 and lives in a nursing facility. In 1995, she fell and sustained a cerebral hemorrhage. Her mental faculties remain impaired even after extensive therapy.

After her injury, Emerson's husband cared for her until his own health deteriorated and it became impossible for him to continue. Emerson has long had diabetes. She requires a special diet and insulin. She eats only soft foods or liquids and is bedridden, blind, and deaf. Emerson experiences occasional respiratory infections that respond well to treatment. Her heart is strong. Except for mild arthritis, she has no pain. She sometimes recognizes her husband when he visits, but her speech is often unintelligible.

Three years before her injury, Emerson gave a talk on the miseries of prolonging life for older adults who are dying. Having experienced the agony of deterioration in her relatives, she made an eloquent plea for a "dignified and simple way to choose death." She showed the manuscript to her husband and mentioned publishing it, but since then she had not done so. Her husband now fears speaking to her about what she had written or how she feels about her life because she might infer that he wants her to die. The Emersons' son visits her weekly and feels they should not disturb the care she is receiving.[44]

This case illustrates the ethical problems of caring for older people who are infirm and no longer mentally competent. The care provided to Emerson maintains her life; her brain injury is irreversible. The evidence as to Emerson's views about people in a situation like hers is several years old. Her mental state precludes knowing her current wishes. Even if Emerson could direct her care or had an AMD, she could not force the organization to help her end her life.

Applying the criteria of ordinary and extraordinary care to Constance Emerson, who needs a special diet, insulin, and occasional antibiotics, leads to the conclusion that nothing being done is extraordinary. All care offers reasonable hope of benefit without excessive expense, pain, or inconvenience. Reasonable hope of benefit is not based on an expectation that she will regain her former cognitive and physical condition, but that she will have the life of a 92-year-

old woman who has sustained a brain injury. She is not terminally ill; discontinuing treatment is unethical.

It is instructive to apply the last definition of death in Table 3 (see above) to Emerson. Is she "alive" if a social interaction criterion is applied? The case notes that she sometimes recognizes her husband when he visits. Whether she has the capacity for social interaction could be determined. If she is not capable of social interaction, this definition of death would allow the organization to withhold antibiotics or insulin, thus rapidly hastening her death. Given the facts in this case, however, the only ethical action is to continue hydration, nutrition, and medication.

Noncompetent Adult Patients

The Quinlan Case Karen Ann Quinlan was 21 years old in mid-1975 when she became comatose after overdosing on alcohol and tranquilizers. On appeal, the New Jersey Supreme Court permitted Karen's father to be appointed her guardian.[45] The court authorized Quinlan to discontinue all extraordinary measures to sustain life if the family and physicians agreed that there was no reasonable possibility that Karen would emerge from her vegetative state and if there was consultation with the hospital ethics committee. This ruling was among the earliest recognitions of an ethics committee and stimulated New Jersey hospitals to establish more of them. It is clear from the opinion that the court intended to reference a prognosis committee, whose role is very different from that of contemporary ethics committees.

After her father ordered the respirator disconnected, Karen was successfully weaned and able to breathe unaided. She was discharged to a nursing facility, where she remained until her death in mid-1985. When she died, she weighed 66 pounds and her body was locked in a fetal position.

In addition to New Jersey, courts in Massachusetts and New York have been especially active in cases like Quinlan. The cases have been brought by families seeking to regain control from the organization or by managers wanting protection from legal claims. Not all like cases follow Quinlan, however. Some patients continue to receive treatment absent hope of benefit. In others, painful treatment of little benefit was withheld. With court guidance, health services organizations are attempting to solve the problem of when to withdraw life-sustaining treatment. The courts are a necessary final arbiter in settling legal questions that arise, especially when there is dissonance in the ethics of those involved (including the organization). Court decisions aid persons and organizations in developing and refining their ethic. They should be a last resort, however.

The Cruzan Case A landmark legal case on withdrawing life-sustaining treatment was handed down by the U.S. Supreme Court in 1990. Nancy Cruzan was a young adult who sustained severe injuries in a 1983 automobile accident. She was subsequently diagnosed as being in PVS. A permanent gastrostomy tube provided hydration and nutrition. When it became apparent that Cruzan had virtually no chance of regaining her cognitive faculties, her parents asked the Missouri state hospital caring for her to end AHN. The staff refused to do so without court approval. A state trial court found that someone in Cruzan's condition had a fundamental right under state and federal constitutions to refuse treatment or direct the withdrawal of

"death-prolonging procedures."

The Missouri Supreme Court reversed the trial court's decision and ruled that the state constitution included no right to privacy that would support an unrestricted right to refuse treatment. The court found that Missouri's living will statute embodied a policy strongly favoring preservation of life, and that Cruzan's statements to her housemate that she would not want to continue her life unless she could live "halfway normally" were unreliable in determining her intent.[46] The court concluded that her parents could not withdraw medical treatment because no one can make that choice on behalf of an incompetent person absent the formalities required by the state's living will statute or clear and convincing evidence of the patient's wishes.

In mid-1990, the U.S. Supreme Court affirmed the Missouri decision.[47] It held that the U.S. Constitution does not forbid Missouri to require that an incompetent person's wishes about withdrawing life-sustaining treatment be proved by clear and convincing evidence. The Court distinguished the rights of competent persons, who it assumed have a constitutionally protected right to refuse life-sustaining hydration and nutrition, from those of incompetent persons. It noted that the state had established procedural safeguards to ensure that a surrogate's action conforms as closely as possible to wishes expressed while the person was competent. The Court granted broad latitude to the states to protect and preserve human life, and recognized their right to require a standard of clear and convincing evidence as to a person's intentions regarding life-continuation decisions. It noted that the state is entitled to guard against potential abuses by surrogates who may not act to protect the patient's interests. In addition, states may decline to judge the quality of a person's life and simply assert an unqualified interest in preserving human life, to be weighed against the constitutionally protected interests of the individual. The Cruzan case makes it clear that the U.S. Supreme Court is unwilling to extend to incompetent persons (through surrogates) the same constitutional right of self-determination available to competent persons.

In November 1990, Cruzan's parents were granted a second hearing in state court, which Missouri did not oppose. New evidence convinced the judge that Nancy Cruzan would not have wanted to live in PVS. In late 1990, he ordered the feeding tube removed. Anti-euthanasia groups unsuccessfully sought to intervene, but the state did not appeal the decision. Cruzan died of dehydration 2 weeks later, 8 years after her accident.[48]

The Cruzan decision granted the states broad latitude to legislate in such situations. State law guides health services organizations. In addition, they shoulder a special burden: advising patients about their legal rights regarding AMDs, as directed by federal law. The organization must go beyond informing and assisting patients to actually ensuring that the guidance is part of the medical record and is applied in the process of care. Health services organizations meet that challenge as part of their commitment to the principles of beneficence, nonmaleficence, and respect for persons.

Cases such as Henninger and Cruzan have not settled the issue of withdrawing life-sustaining treatment for those in PVS. The case of Terri Schiavo in Florida[49] and similar situations are fueling a debate about whether health services organizations and their clinical staff are ethically and legally obliged to provide AHN to patients in PVS. When patients must

be sedated or restrained to endure tube feedings or intravenous lines, the burdens are significant and it must be asked whether care in this context is required.[50] Another way to state the issue is whether life-sustaining hydration and nutrition for this type of patient is extraordinary (disproportionate) care, although under usual circumstances nutrition and hydration are ordinary (proportionate) care.

Some may question whether feeding and hydrating patients who are terminally ill or in PVS should ever be considered extraordinary (disproportionate) care. The AMA addressed this issue in the mid-1980s when it stated that it was not unethical for physicians to discontinue "life-prolonging" medical treatment for patients with terminal illness or irreversible coma when the physician determined that the burdens of treatment outweighed its benefits. Treatment was defined to include medication and artificially or technologically supplied respiration, nutrition, or hydration.[51] There were protests from those who feared that the new policy might cause physicians to discontinue nutrition and hydration when they considered it in the patient's best interests, even though patients believed their interests were furthered by continuing these treatments but could not communicate this decision. The AMA maintains this position but with greater emphasis on patient autonomy and surrogate decision making, where necessary, rather than on a physician determination of benefits and burdens.[52]

The goals of AHN are often unclear. When initiated, the hope is that AHN will sustain the patient until improvement or recovery occurs. Subsequently, however, the situation is often allowed to drift so that AHN continues without an identified end point. Here, the greater reluctance of clinicians (and family) to withdraw treatment than withhold it has been identified. Furthermore, AHN for dying patients may prolong life but simultaneously worsen suffering. Of the many potential complications of AHN, the largest risk is fluid overload. It is recommended that a defined therapeutic goal for AHN is firmly stated and agreed on before intervention; family members should be part of the decision process and the evaluation of the results of AHN.[53]

A common question regarding patients denied hydration and nutrition has been whether it is inhumane because of the pain they are believed to experience. The issue may not be entirely settled, but the weight of evidence is that prolonged dehydration and starvation produce no pain and that ice chips or swabs will relieve the limited discomfort from a dry mouth. Problems with excessive secretions, edema, or incontinence can be alleviated.[54] As Sullivan[55] stated,

> In the setting of dehydration and starvation, death can occur from a multitude of causes. Arrhythmia, infection, and circulatory system collapse due to volume depletion are common terminal events. The clinical course of each should be rapid and, ideally, not associated with perceived discomfort by the patient.

Sullivan's conclusion is supported by nurses' assessments that patients who refused food and water had "good deaths," generally within 2 weeks, with little pain or suffering, thus refuting the popular assumption that such a death is painful and gruesome.[56] Some organizations insist on continuing hydration even though nutrition is stopped, an action that seems pointless and only prolongs the dying process.

Objections to this ethic are heard less often now than in the mid-1990s. Most people are likely to find themselves greatly discomforted if food and water are not provided. Regardless

of debate at the theoretical level, an ethic must be applied at the bedside. What is the ethically correct action for a particular patient? This may begin the debate anew.

Infants

The Baby Doe cases added an important dimension to what began with the Quinlan case in the mid-1970s. The name Baby Doe derives from court proceedings in several states in the early 1980s. All cases involved parents who decided to forgo life-sustaining treatment of their newborn infants with treatable genetic anomalies. Publicity surrounding the subsequent deaths of two such infants prompted the DHHS to issue regulations in April 1982 prohibiting hospitals that receive federal funds from withholding life-sustaining treatment from infants with disabilities. Authority for this action was claimed under Section 504 of the Rehabilitation Act of 1973 (PL 93-112), which prohibits discrimination on the basis of disability. The regulations were challenged by health services organizations on procedural grounds, and a court injunction suspending implementation was issued. Another attempt to promulgate a modified version of the regulations followed in 1983. Like the first regulations, they mandated telephone hotlines to report alleged cases of withholding life-sustaining treatment from newborns with serious illnesses. Signs with information about the need to treat such newborns had to be posted. For providers, the hotlines were the most hated and controversial requirement. Opponents claimed the regulations turned providers into spies. An important modification in the 1983 revision was that impossible or futile acts or therapies that merely prolong the dying of an infant born terminally ill are not required. Opponents of the regulations successfully obtained judicial relief preventing implementation.

In June 1985, the U.S. Supreme Court agreed to hear a U.S. Justice Department appeal of a lower court decision that invalidated the Baby Doe regulations. This was surprising because the actions of Congress and the DHHS had eliminated the need for the first regulations. In June 1986, the high court agreed with the lower court in an opinion that struck down the Baby Doe rules. It agreed that Section 504 of the Rehabilitation Act of 1973 did not empower the DHHS to force hospitals to treat infants with severe disabilities over parental objections. The Court's decision displeased some disability advocacy groups, who claimed that there are major enforcement problems with the Child Abuse Prevention and Treatment Act Amendments of 1984 (PL 98-457), both procedurally and because of a basic antidisability bias held by some physicians and child protective services agencies. They contended that these biases will result in do-not-treat decisions in large numbers of cases.

Child Abuse Amendments

The original controversy surrounding the Baby Doe cases prompted Congress to address the question of newborns with serious disabilities in the Child Abuse Amendments of 1984. Subsequent regulations established treatment and reporting guidelines for care of newborns with significant disabilities. Withholding medically indicated treatment from infants with disabilities is illegal except when

> In the treating physician's (or physicians') reasonable medical judgment any of the following circumstances apply:
> (i) the infant is chronically and irreversibly comatose; or
> (ii) the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the

infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or

(iii) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.[57]

The definition of *medically indicated treatment* includes appropriate care, such as nutrition, hydration, and medication.[58] The regulations do not allow decisions based on subjective opinions about the future quality of life of a person with mental retardation or another disability.[59]

Under the law, affected health services organizations must designate persons who will report suspected problems to state child protective services agencies. The agencies coordinate and consult with those persons and, after notification of suspected medical neglect, may initiate legal action.

CONCLUSION

Ethical issues arising from end-of-life decisions are among the most common that health services organizations and their clinical and managerial staffs encounter. Technology is central to the ethical and legal problems surrounding dying. New technology may solve some problems, but if history is prologue, technology will likely create as many ethical dilemmas as it solves. For treatments such as tube feedings, which extend life using low technology, the issue is more basic. Food and water are fundamental to human existence. It is likely, however, that both will be seen as extraordinary treatment when their continued provision offers no reasonable hope of benefit.

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**Permanent* is used instead of *persistent* after a vegetative state has continued longer than one year.

CHAPTER 11

PATIENT AUTONOMY AND THE PARADIGM OF PHYSICIAN-ASSISTED SUICIDE

Physician-assisted suicide (PAS) became a prominent ethical and legal issue in the United States in 1990, thrust into the public's consciousness by the machinations of Jack Kevorkian, MD, a Michigan pathologist. Though seldom discussed, it is widely understood that the preeminent role of the physician is to "comfort always," a role especially important when hope of benefit from further treatment has faded. This ethic has never included assisting in suicide. Sometimes, eliminating pain necessitated large amounts of morphine, but an unintended death in pursuit of comfort care raised few ethical (or legal) concerns. Doubtless, physicians and other caregivers (e.g., nurses) have sometimes heeded the pleas of pain-wracked patients to help them die, or solely from humanitarian instincts they have occasionally performed involuntary active euthanasia on a medically hopeless patient who could no longer communicate. The Hippocratic tradition prohibits physicians from giving a deadly drug and considers it unethical for physicians to deliberately cause death, whether requested by the patient or for the noble purpose of pain relief. Patient wishes are given no weight. The Hippocratic ethic is reflected in the illegality of homicide and the laws in almost all states that prohibit assisting in suicide.

PAS is one of three types of aid in dying or physician-assisted death. The three are sometimes incorrectly treated as synonymous. Strictly defined, PAS fits none of the types of euthanasia described in Chapter 10. It has characteristics of voluntary (patient desired), active (specific steps) euthanasia, but it differs in a critical aspect. PAS occurs when a physician provides the means and medical advice that enable someone to commit suicide. In some manifestations, the physician's assistance is such as to provide assurance that the suicide will be successful. In all manifestations of PAS, however, patients perform the act that directly causes their deaths. Broadly defined, it is a good death because it is intended to be pain-free. It is not, however, euthanasia, as defined previously. Physical disability prevents some from engaging in an act that would cause death. They are candidates for voluntary active euthanasia should it become legal. The mental competence of those wishing to be assisted in suicide or to be euthanized is always an issue.

LEGAL ASPECTS OF PAS IN THE UNITED STATES

Legalizing PAS was considered in ballot initiatives in Washington State (1991) and California (1992). Both initiatives were rejected. In 1994, Oregon voters narrowly (52% to 48%) approved an initiative to enact the Death with Dignity Act, which legalized PAS. Court challenges delayed implementation. The legislature asked voters to repeal the law, but this request was soundly defeated (60% to 40%). PAS became available for terminally ill

Oregonians in late 1997.

In 2011, PAS was legal in Oregon, Washington State, and Montana. In 2009, the Montana Supreme Court held that PAS did not violate state law or contravene supreme court precedent, and therefore was not unlawful.[1] PAS legislation has been considered in more than a dozen other states.[2] PAS is illegal by specific statute or common law precedent in almost all states. In 2011, statutes in 36 states prohibited assisted suicide; in 7 states, the common law achieved the same purpose. Four states and the District of Columbia had neither statutory nor common law prohibitions against assisted suicide.[3] This legal context is resoundingly inconsistent with the polls that show that a large majority of Americans favor physician help in ending lives of the terminally ill (see the section below titled "Issues for Health Services Managers").

In March 1996, the California-based federal 9th Circuit Court of Appeals ruled in *Washington v. Glucksberg* that the Washington State law making physician-assisted suicide a felony was a denial of due process of law under the 14th Amendment to the U.S. Constitution. Its reasoning relied heavily on the Supreme Court's abortion cases, which the circuit court found to have compelling similarities.[4] A month later, the New York–based federal 2nd Circuit Court of Appeals ruled in *Vacco v. Quill* that terminally ill people have the same right to hasten death by taking drugs as they do by refusing artificial life support, thus striking down a New York law. Its ruling was based on the equal protection clause of the 14th Amendment.[5]

In 1997, the U.S. Supreme Court agreed to hear appeals of these two cases. A unanimous U.S. Supreme Court ruled in *Washington v. Glucksberg*[6] and *Vacco v. Quill*[7] that states may ban assisted suicide without violating either the due process or equal protection clauses of the 14th Amendment to the U.S. Constitution, respectively. The Court did not decide whether states could pass laws permitting assisted suicide. In a companion case, the Court declined to review a lower court ruling in *Lee v. Harcleroad*,[8] holding that a group of terminally ill persons and their physicians had no standing to challenge the constitutionality of Oregon's PAS law because it posed no personal danger to them.[9] Thus, the issue of physician assistance in suicide remains firmly within the purview of the states.

The Case of "Dr. Death"

In 1990, 54-year-old Janet Adkins, who suffered from early-stage Alzheimer's disease, feared losing her memory and the ability to engage in normal activities. She sought the help of Dr. Jack Kevorkian, a retired pathologist, to assist her in committing suicide before her mental abilities became so impaired that she could no longer make a rational decision.[10] Kevorkian had gained national prominence earlier that year at a press conference in which he showed a device he had designed that enabled persons who wanted to die to self-administer toxic chemicals, after initial assistance from a physician. Kevorkian's help to Adkins was criticized as procedurally flawed, and Adkins's competence was questioned because of her diagnosis.[11] The case starkly focused the public's attention on the issue of active, voluntary euthanasia and the right to assisted suicide.

In early assisted suicides, Kevorkian played an active role by starting a saline IV. The patient then initiated the flow of potassium chloride and barbiturates that caused death. Kevorkian's role changed as he continued to assist in suicides. After his medical license was

revoked, Kevorkian, or "Dr. Death" as his critics called him, could no longer legally obtain the chemicals used previously. He began using carbon monoxide, which was breathed through a mask placed on the face of the patient, who then initiated the flow of gas. Kevorkian began videotaping conversations with "patients" held before assisting their suicide, in which they answered questions that documented their state of mind as well as their desire to die. By the end of 1996, Kevorkian had assisted in more than 40 suicides. All of his assisted suicides occurred in Michigan, which initially had no law banning it. Hastily passed legislation outlawing assisted suicide did not stop him and he continued the practice.

The numerous criminal proceedings against Kevorkian for assisting in suicide were unsuccessful for various reasons: the Michigan Court of Appeals ruled that the ban on assisted suicides was passed illegally; judges dismissed charges against Kevorkian, ruling that assisted suicide is a constitutional right; and juries acquitted him.[12] Kevorkian was finally convicted of second-degree murder in 1998, a conviction substantially based on a videotape that he made. It showed him administering a lethal injection to a person with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease). Kevorkian called it a mercy killing (euthanasia); prosecutors and a jury disagreed. He was sentenced to a term of 10–25 years in prison. Kevorkian was paroled in 2007, after serving 8 years. He promised to continue working to legalize assisted suicide.[13] By his own count, Kevorkian assisted in at least 130 suicides.[14] Of 69 persons known to have died with Kevorkian's assistance or intervention, only 25% had been diagnosed as terminally ill.[15] The majority were suffering from early stages of degenerative disease, a fact that raises significant ethical issues.

Kevorkian has been criticized on professional and ethical grounds, including assertions that he did not know his "patients," was unqualified to diagnose or understand illnesses because he is a pathologist, had a conflict of interest because of his desire to publicize himself and his suicide machine, assisted persons who did not have terminal illness, and was not qualified to judge the mental competence of the persons he assisted. Kevorkian had hoped to establish an obitorium, a clinic where terminally ill persons wanting to commit suicide could be assisted to do so.

One of Kevorkian's stated goals was to test the limits of patient autonomy. His primary defense was that the law criminalizing assisted suicide is an unconstitutional interference in the right to privacy. This defense used reasoning like that in *Roe v. Wade*, the U.S. Supreme Court decision that found a constitutional right to privacy protected a woman's decision to abort her pregnancy in the first trimester, free from state interference. Assisted suicide presents an even stronger case for individual autonomy as expressed in the right to privacy because no other life (i.e., a fetus) is involved. Experts disagree on the constitutionality of assisted suicide, however.[16, 17] In mid-1995, the U.S. Supreme Court declined to review Kevorkian's appeals from his criminal conviction.[18]

The Oregon Experience

Several states have introduced bills to legalize PAS. At this writing, however, only Oregon and Washington have enacted PAS. Their statutes have many similarities. The Oregon statute has a longer history and is the focus of this discussion.

Oregon law permits physicians to prescribe but not administer medications to end life. To request a prescription for lethal medications, a person must be 18 years of age or older, a resident of Oregon, capable (able to make and communicate healthcare decisions), and diagnosed with a terminal disease that will lead to death within 6 months. Having met that threshold, a series of steps must be followed to receive the prescription:

- Patients must make two oral requests to their physician, separated by at least 15 days.
- Patients must provide a written request to their physician, signed in the presence of two witnesses.
- A prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
- If either physician believes the person'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 assisted suicide, including comfort care, hospice care, and pain control.
- The prescribing physician must request, but may not require, the patient to notify their next of kin of the prescription request.[19]

The law was amended in 1999 to require that pharmacists must be informed of the ultimate use of a prescription involved in PAS.[20] The physician may attend the patient when medication is taken, but is not required to do so.[21] Physicians must report their participation to the state health division; those who act in good faith within the law are protected from both professional discipline and legal liability.[22]

Results The first suicide under the Oregon law was reported in March 1998.[23] The Blue Cross and Blue Shield plans of Oregon began covering PAS in early 1998.[24] In late 1998, the Oregon Health Plan (which covers Medicaid patients) added PAS to end-of-life comfort care services, alongside such measures as pain medication and hospice care.[25] By the end of 2010, a total of 525 Oregonians had been assisted in suicide since the law passed.[26]

Patient Characteristics Oregonians who choose PAS continue to be concerned about loss of autonomy, loss of dignity, and a decreasing ability to engage in activities that make life enjoyable. In 2010, most participants were over 65 years of age (70.8%), white (100%), well educated (42.2% had at least a baccalaureate degree), and had cancer (78.5%). Overwhelmingly, they had some form of insurance (96.7%); 92.6% were enrolled in hospice. Approximately one-third (36.7%) had no insurance other than Medicare or Medicaid.[27] These data should allay fears that the law will be used primarily by Oregonians who are poor, uneducated, mentally ill, or socially isolated. As in the Netherlands, however, older adults may begin to believe that they are at special risk because of an express or implied utilitarian calculus that they have less social and economic value than younger persons do. Chapter 14 addresses this aspect of PAS in the context of equity and allocation decisions.

Physician Characteristics In 2010, 55 physicians wrote 96 prescriptions for lethal doses

of medication; the number of prescriptions written by individual providers ranged from 1 to 11. One physician was referred to the Oregon Medical Board for failing to wait the required 48 hours between the time of the patient's written request and provision of the prescription.[28]

Summary In previous annual reports, Oregon's Department of Human Services noted that availability of PAS may have led to improved end-of-life care using other modalities. For example, most major hospitals have established effective pain management programs to give patients an alternative to assisted suicide.[29] Also, a request for PAS offers an opportunity for physicians to explore patients' fears and wishes about end-of-life care and the options available. Reportedly, physicians have sought to learn more about pain medications for the terminally ill, improve their recognition of psychiatric disorders, and refer patients more frequently to hospice care.[30] Few complications of the suicide process are being reported in Oregon—a result inconsistent with data from the Netherlands discussed below. No complications were reported in 2009. The time from ingestion to death ranged from 2 minutes to 4 1/2 days.[31] One wonders if lingering for days after ingesting a "fatal" dose of medication can be anything other than a complication.

One possible conclusion of the Oregon data is that physicians are using the law prudently and cautiously. Another explanation is that there are too few data for a true picture to emerge. The findings may also suggest a high level of tentativeness on the parts of both physicians and those who might seek assistance in suicide—tentativeness likely to diminish over time and as PAS becomes more common and socially acceptable. Given the evolution of PAS in the Netherlands, this latter explanation warrants attention.

PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA IN THE NETHERLANDS

International comparisons are instructive. Assisted suicide has been available in parts of Switzerland since 1942; increasingly, that country is a destination for "suicide tourists."[32] In 2002, Belgium legalized voluntary euthanasia and assisted suicide with a law similar to that of the Netherlands (the Dutch law is discussed below).[33] In mid-2003, a year after passage of the original law, Belgian lawmakers proposed expanding euthanasia to children younger than 18 years of age.[34] PAS and euthanasia are being debated elsewhere in Europe, notably in Spain and France. A 2002 survey in France showed that 88% favor or would tolerate euthanasia.[35] Assisted suicide is illegal in Britain; however, prosecutors there have indicated that they will be less likely to charge someone who was wholly motivated by compassion and reported a suicide to the police than someone who was paid to assist in a suicide or was acting as a medical or healthcare professional. The distinction is stated as "compassionate support versus malicious encouragement."[36] Such prosecutorial discretion adds ambiguity and may cause inconsistent applications of the law. Regardless, it signals a move toward greater tolerance of assisting in suicide.

The vanguard of assisted dying, however, is the Netherlands, where euthanasia and PAS have been practiced since the 1980s—despite their illegality at the time—and where 92% of the population supports the practice.[37] Before they were made legal in 1993, a 1990

government study found that 2% of deaths were the result of euthanasia and PAS.[38] It was found that in 1,000 other cases, a patient's life was ended without an explicit recent request to die.[39] The data also showed that in 1990, death was hastened for 16,850 patients, of whom 8,750 died by withholding or withdrawing treatment and 8,100 died by administering pain-killing drugs. Consent was obtained from only 3,100 of the 8,100 patients in the second group. Thus, the majority of patients from whom treatment had been withdrawn or withheld or who had died from administration of painkilling drugs (5,000) had not consented.[40] Data from a 1995 Dutch government study showed 3,600 deaths from assisted suicide and euthanasia, of which 900–1,000 were officially acknowledged to have been involuntary. Another 2,000 patients were given large doses of painkilling drugs with the primary aim of ending their lives, but these cases were not classified as euthanasia.[41] These data show that even after voluntary euthanasia and PAS became legal, involuntary euthanasia continued—a practice that may have stimulated passage of another revision of the law in 2001.

The revision of the 1993 law that first legalized voluntary active euthanasia and PAS went into effect in 2002.[42] It expanded the categories of persons who may use euthanasia and PAS. Physicians who provide these "services" are required to use due care in terminating a life (euthanasia) or assisting in suicide. By performing the procedure in a medically appropriate manner, the crimes of euthanasia and assisted suicide are legally defined as medical treatments.

The statute specifically allows euthanasia for incompetent patients. Persons 16 years and older can make an advance written statement containing a request to terminate their lives, which a physician may carry out. The written statement need not be made in conjunction with a specific medical condition and it could have been written years before, based on views that may have changed. The physician can administer euthanasia based on the prior written statement.[43]

In addition, the law allows other categories of persons to request and receive euthanasia or assisted suicide: teenagers (with varying degrees of parents' or guardians' approval, depending on age), and persons for whom the doctor "holds the conviction that the patient's suffering is lasting and unbearable."[44]

The 2002 Dutch law requires physicians to meet specific criteria to be immune from criminal prosecution. The following must be considered:

- *Voluntary*—The physician must be convinced that the patient has made a voluntary, persistent, and carefully considered request to die.
- *Suffering*—The physician must be convinced that the patient's suffering is unbearable and that there is no prospect of improvement of the patient's situation. (There is no requirement that the suffering must be physical or that the patient must be terminally ill.)[45]
- *Informed*—The physician has informed the patient about his or her medical situation and medical prospects.
- *Alternatives*—The physician, together with the patient, must be convinced that there is no reasonable alternative.
- *Consultation*—The physician has consulted at least one other physician with an independent

viewpoint who has seen the patient and given a written opinion on the due-care criteria [*sic*].
- *Due care and attention*—The physician must have assisted the patient to die with due medical care and attention.[46]

These criteria are similar to the 1993 law. The review of assisted deaths in the 2002 law, however, is very different.

All oversight of euthanasia and assisted suicide is done by a regional review committee for termination of life on request and for assisted suicide. The committees comprise a legal specialist, a physician, and an expert in philosophical issues, specifically with expertise as to the requisites for meaningful life. Significantly, the 2002 law shifts the burden of proof. No longer must the physician justify the need to terminate life. It is the prosecutor who must show that terminating a life failed to meet the requirement of due care. Prosecutors will only learn about termination of a life if the regional committee sends information to them. The law does not prohibit physicians from administering euthanasia to a nonresident.[47] It is hoped that the law will bring into the open euthanasia that historically has been hidden. New concerns about "hidden euthanasia" surfaced only a year after the 2002 law went into effect. Terminal sedation, for example, occurs when physicians give to patients in severe pain quantities of morphine large enough to also hasten death. Because euthanasia is defined as the active termination of life on request, such overdoses are not reportable—it is not clear that the death was intended. The death is considered a natural death.[48]

Some argue that, in effect, the Netherlands will "be issuing retrospective licenses for consensual killing."[49] Legally sanctioning active euthanasia for various groups of "patients" (with varying degrees of consent from parents or guardians for certain of them) is a significant change and moves euthanasia from the exceptional to an accepted way of dealing with medical conditions beyond serious or terminal illness. Palliative care is one casualty of the Netherlands's history of PAS, and hospice care use there lags behind other countries.[50]

The technical aspects of PAS appear to be simple. Data from the Netherlands suggest, however, that problems occur even when a physician is present. Problems include medications not working as expected, technical difficulties, or unexpected side effects. In 16% of cases in which patients tried to kill themselves using doctor-prescribed drugs, the medication did not work as expected. Furthermore, 7% of the time technical problems or unexpected side effects occurred. Physicians witnessing the attempted suicide felt compelled to intervene and ensure death in 18% of cases. Even when a doctor directly performed euthanasia, the researchers found that there were complications 3% of the time. In another 6% of attempts, patients took longer to die than expected or went into a drug-induced coma that was supposed to be fatal but from which they later awoke.[51] Thus, it appears that assisted suicide and euthanasia do not necessarily result in the easy and peaceful death that they promise, and that they can in fact add to the patient's misery and suffering. Rather than showing that they are absent, the lack of reported complications in Oregon data suggests inadequate reporting and follow-up.

The 1993 law may have only recognized existing practice—de facto became de jure. That a western European democracy was willing to acknowledge this development, however, raises

important ethical questions. Seemingly begun as a way to enhance individual self-determination, the Dutch experience shows that active euthanasia is not limited to persons who request it. The continuing and troubling scenario of large numbers of persons being involuntarily, actively euthanized highlights the slippery slope, defined as one exception leading to other, more easily accepted exceptions.

That there is no requirement for suffering to be physical or that the patient must be terminally ill suggests a significant new dimension for active euthanasia and assisted suicide—persons tired of living and choosing to end their lives. Persons who are in various states of aging, have a disability, or have health problems now face the prospect that they will have to justify their continued existence. Given that Dutch physicians historically have been willing to actively euthanize persons without their consent, the persons at risk fear that their lives will be ended against their will.[52] This fear has caused many of those most vulnerable—individuals with disabilities and older adults—to carry cards specifying their desire to continue to stay alive.[53]

Dutch health services organizations participate in euthanasia-assisted suicide (EAS) and physician-assisted suicide. The 2002 euthanasia act and national guidelines are the most commonly cited sources of institutional policy statements and practice guidelines. About one-quarter of Dutch healthcare institutions do not have policy statements on EAS. Physicians reported that written guidelines for EAS supported them in their decision making after a patient's request for EAS.[54] Only a minority of patients in a cross section of healthcare settings requested EAS at the end of life; of these requests, more than half were not granted.[55]

SUICIDE AND THE ORGANIZATION: THE CASE OF ELIZABETH BOUVIA

In late 1983, a dramatic case began in California that highlights several of the concepts described in this chapter. Elizabeth Bouvia, a 26-year old with cerebral palsy, entered the county-owned Riverside General Hospital and asked that the staff aid her in fasting until she died. Unable to move, she required assistance in all physical activities. She wanted the hospital to provide hygienic care and the drugs necessary to give her a painless death by starvation. A court injunction prevented the hospital from discharging her. To ensure adequate nutrition, hospital staff inserted a nasogastric tube, allegedly against her wishes. She asserted that she had reached a competent and rational decision, one her lawyer argued was protected by the constitutional right to privacy and self-determination. Her mental competence was confirmed by several psychiatrists.

California has criminal penalties against aiding and abetting a suicide. After a hearing on whether the hospital could be forced to assist Bouvia in her suicide, the court ruled that "despite her right to commit suicide, which is not illegal in California, she could not ask society in the person of the hospital staff to help her because she was not a terminal patient."[56] The court distinguished Bouvia from individuals with terminal illnesses. In January 1984, the California Supreme Court refused to hear her appeal.[57]

The decision permitted the hospital to force-feed Bouvia. She was discharged from

Riverside General on April 7, 1984, and was hospitalized in Tijuana, Mexico.[58] It was reported that she had reconsidered her demand to die and would return to the United States for medical treatment. Her lawyer maintained that she still wished to die, despite the fact that she had been accepted for care somewhere in California on the condition that she not stop eating.[59]

After a year in the new institution and a subsequent stay of several months at an acute care hospital, where a morphine pump was installed for pain control, Bouvia was admitted to Los Angeles County–High Desert Hospital in late 1985. As at Riverside General Hospital, and against her wishes, the staff inserted a permanent feeding tube. Court action by Bouvia initially resulted in the court's refusal to order discontinuation of the forced feeding. On appeal, however, the case was remanded, with instructions to consider her request further. As a result, tube feeding was discontinued and Bouvia was discharged. Her attorney stated, "She's promised to continue to eat her liquid diet. I know she would welcome death . . . but she has renounced [suicide]."[60] In May 1986, Bouvia was hospitalized at Los Angeles County University of Southern California Medical Center, where she was treated for chronic pain.[61] In June 1986, the California Supreme Court affirmed a lower court decision allowing her to die by refusing force-feeding (at the time she was accepting a liquid diet). The hospital had argued that removing the tube would officially endorse suicide.[62] Elizabeth Bouvia was reported alive in 2005.[63] Since then, she has shunned publicity.

Ethical Issues and Legal Considerations

In addition to highlighting the problems of situations that do not involve terminal illness, the Bouvia case delineates the clash between organizational philosophy (here with both ethical and legal justification) and patient autonomy. Bouvia's problem was not that the health services organization where she was treated refused to discharge her; instead, it was difficult to find a facility that would admit her. Those that agreed to admit her insisted on doing everything they could to maintain or improve her physical condition—thus the force-feeding. Several state courts have specifically addressed this issue. A number of states have statutes that permit withholding or withdrawing tube feeding, but several prohibit such actions under certain circumstances.[64]

The Bouvia case suggests the limit of what patients can legally (and ethically) ask of health services organizations. As shown by Bouvia, the law determines what the organization and its managers can do, and the obligation to obey the law is a minimum performance. The ethics reflected in the organization's philosophy determine the extent to which it uses a higher standard. The law is different in other states (e.g., New York, New Jersey), and this difference reinforces the organization's need to be aware of state law and, more important, to address such issues prospectively.

If assistance in suicide gains wider social acceptability and becomes legal in more states, health services organizations will have to address the ethical issues it raises. Nursing facilities, hospice, and acute care hospitals have patients with degenerative neurological diseases and those who are terminally ill or in a persistent vegetative state (PVS). Traditional conscience clause protections will likely be available to providers who find assistance in suicide morally repugnant. Further, various federal laws protect those who refuse to provide

medical services that they find morally unacceptable.[65] This reinforces the need for health services organizations to address issues such as end-of-life care in their values statements. A longterm, clearly enunciated position lends credence to the organization's position. The values statements of most organizations will likely take patients' rights and reasonable expectations into account.

Perhaps the most important reason for traditional health services organizations to decline to provide assistance in suicide is that the members of the public may find it inconsistent that providers they trust to help them regain and maintain their health also assist in suicide. The public may distrust providers because their role at any one time may be unclear. This suggests that establishing specialized facilities—such as the obitoria suggested by Kevorkian—and even commercialization of assistance in suicide, are possible.

ISSUES FOR HEALTH SERVICES MANAGERS

Public opinion polls in the United States consistently show a high and increasing level of support for legalizing and regulating PAS. Polls taken before and after the conviction of Jack Kevorkian showed an increase in public support of PAS from 70% to 75%.[66] In 2007, 53% of Americans surveyed thought Kevorkian should not have been jailed; more than two-thirds believed that there are circumstances when a patient should be allowed to die.[67]

As noted, there are ethical distinctions between providing comfort care and pain control to allow a pain-free, dignified death and hastening death through active intervention. Kevorkian's uses of PAS did not occur in health services organizations, nor could an organization have legally assisted him. Even under Oregon law, the assistance provided is only that of a physician who writes a prescription. Kevorkian's "patients" were ambulatory. They were not in skilled nursing facilities or hospitals, for example, when questions of assistance in dying arose. He assisted them to die by various means and in settings that included a motel room and a minivan.

Nonetheless, the opinion poll cited above should strongly encourage health services organizations to prospectively address assisted suicide. In this effort, managers are a vital resource. As moral agents and the organization's conscience, health services managers play a crucial role in identifying, reinforcing, modifying, and monitoring the organization's values. To be effective in these activities, the manager must have a well-defined personal ethic that is consistent with the organization's values, and a clear understanding of its application in strategic and tactical management decision making. The importance of the manager's role in setting the ethical tone for the organization and leading by example cannot be overstated.

Economics of Physician-Assisted Suicide

Developments in Oregon suggest that third-party payers and managed care organizations will offer assistance in suicide as a covered benefit soon after it becomes legal. They may even urge enactment of such laws. Covering PAS, however, raises significant issues of duality of interests. The savings of early death may produce economic benefits for insurers, regardless of any reduction in discomfort and lessened suffering for the insured.

Traditionally, physicians who advocated for their patients and were not pressured to

control costs or prioritize services tended to counterbalance system efforts to limit services. Traditional relationships in the private sector are changing, however. This change will make more prominent the questions of aid in dying as arrangements that economically bind physicians and organizations, especially hospitals, become increasingly common. Physician networks and alliances are the logical extension, and the private sector is establishing them.

Psychological or economic oneness between physician and organization raise significant ethical issues, including the risk that a focus on the interests of patients will diminish. Economic incentives in traditional private, fee-for-service medicine reward too much care, and the physician's and organization's interests in voluntary or involuntary passive euthanasia are limited to questions of the futility, or hope of benefit, from continued treatment. Newer forms of payment and organizational arrangements will change the incentives for health services organizations, even as they become less able to meet the costs of services. Since the early 1980s, hospitals have had a form of capitation. The incentive of diagnosis-related groups (DRGs)—the payment scheme for Medicare and Medicaid—is to limit services. Cost shifting is increasingly difficult for health services organizations. Thus, they must either reduce costs through greater productivity (achieving the same results with fewer resources) or change the content of care.

Fixed-sum payment schemes such as capitation or DRGs have the incentive to minimize the number and range of services, especially those that are more costly. Such incentives cause an inherent conflict of interest between providing services that might be in the patient's best interests and holding to a fixed monetary limit. The implications are the same for private insurers and government. Although government is likely to use euphemisms such as "quality of life" and insurers are likely to focus more overtly on costs, the issue is the same for both: How can costs be controlled? Certain services (especially costly ones) are likely to be withheld, and services will be withdrawn from persons who are deemed to have a poor quality of life or prognosis (e.g., cases of futile care). Here, the fact that earlier death is the ultimate cost reduction may provide an attractive economic alternative. Awareness that this duality of interests is present enables the manager to monitor utilization data to minimize potential harm to patients. Systems in the United States in which capitation or global budgets are used may not take positive steps to end life, but rather may simply deny certain types of care because they are uneconomic or have little effect on improving the quality of life. In such cases, Oregon's priority list of services for Medicaid beneficiaries, discussed in Chapter 13, is instructive.

Summary

Often, hospitals and nursing facilities have patients who are in PVS, bedridden with a terminal illness, or too ill to transfer. What are their rights compared with those of the organization? The importance of an organizational philosophy with specific attention to aid in dying is clear; legally and ethically, the organization cannot be forced to compromise its values.

International comparisons may help predict evolution of the issues of assisted suicide and euthanasia in the United States. The Dutch experience clearly shows that 30 years of debate led to a slippery slope. The rules governing assistance in suicide and euthanasia became less demanding and ever broader in their application. PAS—illegally performed in Michigan, and legally performed in Oregon—did not involve health services organizations. It seems a small

step to involve them, however. As noted, health services organizations in the Netherlands are involved in euthanasia and PAS. This concern was raised in Belgium as its euthanasia law was debated.[68] Given the seemingly inevitable erosion of safeguards protecting those whom caregivers may consider to have an inadequate quality of life, health services organizations will be pressured to participate.

ISSUES FOR PHYSICIANS

A primary issue for many physicians is that their profession is being turned on its head. Traditionally, physicians have been guardians of life. Now they may be asked to assist in causing death. If physicians may legally euthanize their patients, the trust so important to the patient–physician relationship will end. Older adults, individuals with disabilities, and others with lives of perceived "diminished quality" will correctly fear that instead of helping them live, their doctors may hasten their deaths. To prove the assertion that physicians and nurses, like anyone, can become inured to what is essentially murder, one only need read media reports describing killing patients as common practice.[69] The extraordinary the case of Dr. Harold Shipman is chilling. Shipman was a general practice physician in Manchester who became England's most prolific serial killer. Early in his career, Shipman received psychiatric and drug treatment after the death of his first victim. Subsequently, he killed at least 215 of his patients during a 24-year medical career. Possible reasons for his actions include easing the burden on the National Health Service (England's government-run health system) and wanting to play God. Of great concern is that Shipman could elude detection for so long by issuing death certificates attributing his patients' deaths to natural causes.[70]

Proposals in the United States that physicians provide aid in dying have been roundly condemned by organized medicine. This condemnation, however, may overstate physicians' opposition; they may be more willing to provide aid in dying than the Hippocratic tradition allows. A national survey taken in the late 1990s, when physician assistance in suicide was illegal everywhere in the United States, found that 6% of physicians responding who regularly cared for the dying had either given at least one lethal injection or written a prescription so patients could kill themselves. The survey also found that a third of doctors would write prescriptions for deadly doses and a quarter would give lethal injections if these activities were legal.[71] Similarly, in 1995, 12% of responding physicians in Washington State reported receiving one or more explicit requests from patients for PAS; 4% had received one or more requests for euthanasia.[72] State surveys from the mid-1990s found that a majority of physicians in Michigan (Dr. Jack Kevorkian's home state) and in Oregon favored legalization of assisted suicide, although a sizable minority (31%) in Oregon objected to legalization and participation on moral grounds.[73] A 2007 survey of physicians in Washington State found that 50% supported PAS legislation similar to that in Oregon, while 42% opposed it.[74] Physicians in Vermont who cared for terminally ill patients were far less likely to support legislation for PAS, perhaps because they are more experienced with palliative care.[75]

Data from a survey of Oregon physicians not opposed to PAS help explain their concerns about assisting in suicide. Half feared that the attempt would fail and cause harm, half were not

confident that their prognosis of 6 months to live was accurate, half were unsure which drug to prescribe, one-third feared someone other than the patient would take the drug, one-third were not confident they could recognize depression, and some did not want to become known as "suicide doctors."[76]

The willingness of physicians to perform euthanasia and PAS is reinforced by findings from the early 1990s that only 11% of Dutch physicians said they would not participate in euthanasia or assisted suicide.[77] Given legal developments in the Netherlands and apparent widespread public support, however, medical practice and public opinion will become inured to PAS and euthanasia and fewer and fewer physicians will be unwilling to provide aid in dying.

The question of aid in dying raises significant moral questions and necessitates a thorough reexamination of the physician–patient relationship. To this point, physicians cannot be required to perform a procedure that they morally oppose. Our society's tradition of the overriding importance of personal conscience in such matters must govern. Perhaps thanatology, the study of death and dying, will be recognized as a new medical specialty.

CONCLUSION

As framed, the debate on decisions at the end of life focuses on negative rights. Freedom from unwanted health services is a negative ethical and legal right grounded in the right to freedom from unwanted interference. Simply stated, this is autonomy. Continued attention to the implications of technology for patient autonomy and the principle of nonmaleficence are necessary if the organization is to fulfill its mission in the context of its philosophy.

It is noteworthy that none of the legislation that allows physician assistance in suicide establishes a patient's positive right to assistance in dying. A physician willing to assist the patient must be found; as yet, physicians cannot be compelled to provide assistance in suicide. It is almost certain that if assistance in suicide and active euthanasia become more accepted, the number of physicians willing to perform such acts will increase. The dehumanization of provider and patient will become ever more common, and the hardening of the human beings involved will make such actions commonplace, even lauded.

Demedicalizing assistance in suicide reduces ethical problems for physicians, but it raises ethical issues for society in general. German law, for example, effectively makes it illegal for physicians to assist in suicides. Neither suicide nor assisting in the suicide of persons who are capable of exercising control over their actions and have freely made a responsible choice to commit suicide are illegal, however, so unique views about suicide and assistance in suicide have developed in Germany. One expression of these views is the development of societies organized to assist members to commit suicide.[78]

The incentives resulting from cost constraints and the increasingly interlocking economic and psychological interests of physicians and organizations, whether or not under healthcare reform, ensures a reassessment of aid in dying. Numerous questions must be answered. Must physicians meet the demands of their patients for aid in dying through active means? Is it reasonable (or wise) to ask those committed to preserving and extending life to become thanatologists? Do patients who cannot physically participate in assisted suicide have a legal

(or moral) right to voluntary active euthanasia? For health services managers, does the organization have a role to aid in dying, regardless of how the current controversy is resolved? It is possible that like abortion, suicide will be defined by courts or legislatures as a privacy issue. If so, health services organizations and their managers will be forced to address assisted suicide solely from the perspective of its ethical implications. At minimum, health services managers are ethically obliged to ensure that in their organization, a right to die does not become a duty.

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