

PART I

Curriculum for Ethics Committees

Part I is an eight-chapter curriculum designed to introduce the fundamentals of bioethics, explain the key concepts, and provide a basic analytic framework for addressing and resolving ethical dilemmas. Each chapter highlights a set of ethical issues that commonly arise in the clinical setting and generate requests for ethics committee attention. It is beyond the scope of this handbook to provide a comprehensive treatment of these topics, and our discussion of the basic ethical principles and concepts draws on the work of expert theorists and practitioners who have contributed to the vast scholarly and clinical literature.

We encourage you to consult the selected but by no means exhaustive references listed at the end of each chapter. Classic texts, such as Beauchamp and Childress's *Principles of Biomedical Ethics*, anthologies, such as Arras, Steinbock, and London's *Ethical Issues in Modern Medicine*, newsletters, such as *Medical Ethics Advisor*, as well as journals, such as the *Hastings Center Report*, the *Journal of Law, Medicine & Ethics*, *The American Journal of Bioethics*, and the *Journal of Clinical Ethics*, should be part of any ethics committee's library. The American Society for Bioethics and Humanities' forthcoming publication *Improving Competence in Ethics Consultation: A Learner's Guide* will be a valuable resource for individuals and organizations providing clinical ethics consultation and education. Finally, Websites, such as www.asbh.org (American Society for Bioethics and Humanities) and www.ethicsweb.ca/resources/bioethics/institutes.html (a comprehensive list of resources with links to ethics institutes and organizations), are an important source of current information about what is happening in bioethics. These references are essential, providing ready access to the relevant research and in-depth analysis applicable to the cases and issues that committees consider.

1

Ethical Foundations of Clinical Practice

The role of ethics in clinical medicine

Ethics committees in the health care setting

Fundamental ethical principles

Respecting patient autonomy

Beneficence

Nonmaleficence

Justice

The role of culture, race, and ethnicity in health care

Conflicting obligations and ethical dilemmas

III As a member of your hospital's ethics committee, you have been called by Dr. Thomas, a second-year surgical resident who was paged for the following consult: Ms. Lawrence is a 23-year-old woman who was returning home from her bridal shower when her car skidded on the ice and hit an oncoming truck. Although her multiple injuries are serious, with immediate surgery and replacement of lost blood, her chances of full recovery are excellent.

Ms. Lawrence is in considerable pain, but she appears coherent and her answers to Dr. Thomas's questions reflect understanding of her condition, the treatment options, and their consequences. Because of her beliefs as a Jehovah's Witness, however, she will not accept blood or blood products and will not consider surgery unless she is promised that it will be done without transfusions.

Dr. Thomas knows that surgical and hemodynamic intervention can prevent this patient's almost certain death. He also knows that saving her life in this way will violate Ms. Lawrence's deeply held religious convictions. What are the conflicting medical, legal, and ethical obligations? What is the role of the ethics committee in resolving this dilemma? What resources are available to help you?

Perhaps the threshold question that should begin our discussion is, What is bioethics and why does it matter? The short answer is that bioethics is the discipline that addresses the ethical issues that arise in the health care setting. As will become clear in the

following pages, however, bioethics does not lend itself to short answers, and further definition is necessary. The concerns of bioethics include the well-being and dignity of the patient; matters of choice and decision making; rights and responsibilities of the patient, family, and care team; access to care; and fairness and justice in health policy.

These matters are neither new nor exotic, but they have become more prominent. Health care has traditionally dealt with the profound moral issues of human existence, including life, self-determination, suffering, and mortality. What has changed are the complexity of medicine, the increased range of choices, and the way care is accessed and delivered. The ethical implications of these matters have attracted heightened attention, especially from those who make clinical and policy decisions. As applied ethics has become an integral part of the health care setting, institutional ethics committees have become increasingly visible and active in clinical and organizational decision making. The goal of this handbook is to help your committee be a knowledgeable, skillful, and effective ethics resource for your institution.

THE ROLE OF ETHICS IN CLINICAL MEDICINE

Ethics has a long and distinguished history grounding both the practice of medicine and the laws related to it. Society considers ethical principles so important that it gives them legal sanction in statutory and case law. Thus, ethical principles, such as respect for autonomy and privacy, are translated into laws about informed consent and confidentiality. It is important to note, however, that issues related to providing and forgoing medical treatment are governed almost exclusively by state law, creating wide variation in the way these matters are handled. For example, decisions about withholding or withdrawing life-sustaining measures might be very different if the patient were being treated in New York or New Jersey. For this reason, your ethics committee should have some familiarity with how your state laws and regulations address these issues.

Ironically, some of the most potentially beneficial developments have generated some of the most difficult ethical problems. In critical, acute, and long-term care settings, the very existence of new therapies often creates demand for their use, whether or not they are medically indicated or ethically appropriate. Clinical research raises issues of information disclosure, comparative levels of risks and benefits, and conflicts of interest. Budgetary pressures constrain the allocation of resources. Standing at the intersection of medicine, ethics, and law, bioethics provides a useful analytic framework for committees charged with helping to resolve these dilemmas.

ETHICS COMMITTEES IN THE HEALTH CARE SETTING

The development of bioethics as a powerful influence on the way health care is perceived and practiced was part of a larger social transformation. A hallmark of the latter

half of the twentieth century was the heightened notion of individual rights. Virtually every social sphere was affected by the effort to promote equality and redress inequities in race, gender, class, and education. In the context of the various rights movements, the ethical principle of autonomy became the major support for individual empowerment and self-determination in health care, most prominently in the doctrine of informed consent and refusal. In the process, patients became both partners in health care decision making and informed health care consumers.

Ethical, legal, and scientific developments created an obligation to evaluate critically the process of gathering scientific information, translating it into therapeutic applications, and using it responsibly. Advances in medical knowledge and skills generated a new array of treatment options, as well as the concern that the *ability* to intervene could become the *obligation* to intervene. For the first time, questions were raised not only about *how* and *when*, but *whether* to treat. Under what circumstances should therapies be withheld or withdrawn? When does the burden of an intervention outweigh its benefit? How should decisions be made about the allocation of limited medical resources? At the same time, the law was becoming involved in life-and-death matters that used to be confined to the doctor-patient interaction.

Bioethics as a discipline is generally considered to have developed between the 1960s and the 1980s as it became apparent that emerging issues could benefit from thoughtful analysis by people with both clinical and nonclinical perspectives. Philosophers, social scientists, theologians, legal scholars, and biomedical scientists increasingly focused their attention on clinical research, allocation of limited resources, transplantation of organs, reproductive technologies, genetic testing and treatment, terminal illness and end-of-life care, and the obligations in the clinical interaction. Of particular relevance to ethics committee background, these deliberations revealed that ethical analysis had practical application in the research and clinical settings.

The hospital ethics committee was an early institutional effort to bring a formal ethical perspective to the clinical setting, otherwise described as "a politically attractive way for moral controversies to be procedurally accommodated" (Moreno, 1995, pp. 93-94). Hospitals began to establish ethics committees during the mid-twentieth century to answer questions and help make decisions about health care issues with ethical dimensions. These committees had their roots in several types of small decision-making groups, each intended to address specific ethical problems. Sterilization committees, composed mainly of physicians with expertise in psychiatry and psychology, functioned mainly during the 1920s and 1930s to determine which individuals with mental disabilities should be involuntarily sterilized. Abortion selection committees functioned in many hospitals before the 1973 U.S. Supreme Court decision in *Roe v. Wade* legalized abortion. Beginning in 1945, their purpose was to evaluate the requests of women who wished to terminate their pregnancies and determine whether therapeutic abortions were indicated to preserve the life or health of the prospective

mother. Dialysis selection committees emerged during the early 1960s in response to the development of the dialysis machine, the first publicly recognized life-sustaining technology. Composed of lay members of the community, they were charged with choosing among the candidates with end-stage renal disease and determining who would receive chronic hemodialysis.

Beginning in the 1960s, institutional review boards (IRBs) responded to revelations of abuse in medical experimentation by reviewing all government-funded research using human subjects. The 1974 federal mandating of IRBs represented the first codified suggestion of institutional obligation to address ethical concerns. Prognosis committees were occasionally convened by the mid-1970s to assess the projected course of patients' illnesses. In its 1976 decision in *In re Quinlan*, the New Jersey Supreme Court referred to an article by Dr. Karen Teel and recommended that hospitals have an ethics committee to deal with termination of life-sustaining treatment for incapacitated patients. Although the court used the term *ethics committee*, it was actually suggesting a *prognosis committee* that would render opinions on the likely benefits of continued treatment for patients with grave and irreversible illness.

Infant care review committees began appearing in the wake of the 1982 "Baby Doe" ruling that permitted parents to approve withholding life-saving treatment from a neonate with Down's syndrome. These committees, which were intended to review care plans for severely disabled newborns, were also recommended by the President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research in 1983 and endorsed by the U.S. Department of Health and Human Services and the American Academy of Pediatrics.

Medical-morals committees met in Catholic hospitals to address sensitive issues, including those related to reproduction, analgesia, and extraordinary interventions at the end of life, in terms of Church doctrine.

Against this backdrop, clinical and administrative staffs began to meet for interdisciplinary deliberations about issues of high-tech care, undertook self-education, and exhibited a growing professional awareness of ethical implications. During the 1970s and 1980s, hospitals began to establish ethics committees to provide guidance about health care issues with ethical dimensions. Over time, these committees have taken on the additional functions of staff education, clinical guideline development, institutional policy advisement, and case review. Some ethics committees also advise on resource allocation and express or reinforce the institution's commitment to certain values.

Since 1992, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has required as a condition of accreditation that each health care institution have a standing mechanism to address ethical issues and resolve disputes. In addition, several states have passed statutes requiring hospitals to have ethics committees. The result is that almost all hospitals in the United States have ethics committees that meet on a regular basis.

As you read through this handbook, it is important to bear in mind that your committee does not own ethics in your institution. As discussed in the introduction, the committee should strive to develop ethics expertise, but it would be counterproductive to encourage the notion of ethics exclusivity and the perception that ethics resides only in a select group. Rather, one of your most valuable roles is that of a resource that, through education, policy development and consultation, helps clinical and administrative staff to integrate ethics knowledge and skills into their daily practice.

An important committee function is helping staff to identify ethical issues and conflicts, develop the skills to handle routine cases in ways that you have modeled in consultation on similar cases, and distinguish complex cases that require the attention of your consultation service. One mark of a successful ethics consultation is when you are stopped in the hall by someone who says, "Remember that case you consulted on two weeks ago? Well, we had another one just like it and we *didn't* have to call you. But now, we've got one that really has us stumped and we need your involvement again."

While your committee retains the responsibility to provide ethics expertise, education and guidance, it is important to reinforce the notion that the health care organization and all those who practice in it are moral agents with ethical obligations that cannot be delegated.

FUNDAMENTAL ETHICAL PRINCIPLES

As you no doubt expected, any discussion of applied bioethics must begin with a review of its theoretical underpinnings. Understanding the key concepts and how they relate to clinical practice is essential to the effective functioning of ethics committees.

The core ethical principles that support the therapeutic relationship and give rise to clinician obligations include

- respecting patient autonomy—supporting and facilitating the capable patient's exercise of self-determination in health care decision making
- beneficence—promoting the patient's best interest and protecting the patient from harm
- nonmaleficence—avoiding actions likely to cause the patient harm
- distributive justice—allocating fairly the benefits and burdens related to health care delivery

Respecting Patient Autonomy

Autonomy is the ethical principle widely considered most central to health care decision making because of its focus on self-governance and individual choice. Autonomy includes determination of health care goals, power over what is done to one's body, and control of personal information. Only when the individual cannot make decisions are others asked to choose. Autonomy gives priority to personal values and

wishes, supporting choices that are informed and uncoerced, and confers the professional obligation to respect patient privacy and confidentiality.

The significance of autonomy to health care decision making is seen in the ethical concepts of decisional capacity, informed consent and refusal, and truth telling. Patients exercise autonomy by making informed care decisions that reflect their goals, values, and preferences. Clinicians demonstrate respect for autonomy by providing information and guidance that enable patients to make knowledgeable decisions; honoring patient choices and implementing them in care plans; preserving patient confidentiality; and protecting the security of patient information.

It is important to recognize that the notion of autonomy encompasses a range of conceptions, some highly individualistic and somewhat isolating, others more relational and compatible with communitarian values. The heightened emphasis our society customarily places on individualism and independence is a largely Western phenomenon and not universally shared. Despite our prevailing focus on self-governance, not everyone is comfortable with or capable of pure autonomy. Patients with diminished or fluctuating cognition are likely to rely on spouses or adult children for help in care planning. Others may come from cultures that favor decision making by the family rather than the individual. For these patients, authentic decision making is an exercise shared with trusted others and reflects *supported* or *delegated* autonomy.

Ultimately, respecting patient autonomy does not mean elevating it to a position where it trumps all other considerations. While it is usually legally and ethically appropriate to honor the wishes of a capable patient, it is also necessary to consider the ethical principles that give rise to other, often competing, obligations.

Beneficence

The principle of beneficence underlies obligations to provide the best care for the patient and balance the risks or burdens of care against the benefits. Promoted goods typically include prolonging life, restoring function, relieving pain and suffering, and preventing harm. Beneficence is the principle with arguably the greatest resonance for caregivers, whose traditional mission is to heal and comfort, and notions of nurturing and protecting are reflected in caring for those who are most vulnerable. Perceptions of benefit and best interest are not purely scientific, however, but involve expectations, goals, and value judgments. Recognition that patients and their doctors may differ in these assessments has been at least partly responsible for the noticeable shift from physician paternalism to greater emphasis on patient choice.

Nonmaleficence

At the very core of the healing professions is the principle of nonmaleficence, captured in the ancient maxim, "First, do no harm." This principle grounds obligations to avoid the intentional infliction of harm or suffering, recognizing that conceptions of

harm, as of good, are inextricably tied to individual values and interests. Most, if not all, therapies carry the potential for some risk as well as benefit, and it would not be feasible to limit the therapeutic arsenal to treatments that are entirely benign. Nevertheless, the benefits of recommended treatments are expected to outweigh the possible harms, and physicians are required to discuss that calculus with their patients, comparing the burdens and risks to the anticipated goods. Likewise, the duty to prevent foreseeable harm requires investigators to disclose the benefits and risks of proposed research to potential subjects and institutional review boards.

Justice

Justice or equity refers to those principles of social cooperation that define what each person in the society or member of a group is due or owed—in short, what is fair. The several types of justice all share the basic notion of treating similar cases similarly and dissimilar cases dissimilarly. Most relevant to medical ethics is distributive justice, which concerns the norms and standards for allocating benefits and burdens across a given population. Distributive justice demands that the benefits, risks, and costs of actions—in this case, access to resources related to physical and mental health—be apportioned fairly and without discrimination on both societal and institutional levels. According to the principle of distributive justice, there should be ethically defensible reasons for why certain individuals or groups receive benefits or endure burdens that other individuals or groups do not.

■ The four ethical principles discussed above—autonomy, beneficence, nonmaleficence, and justice—have assumed a central place in much of bioethics literature, theory, and clinical analysis. Our very brief tour just touches the surface and you are encouraged to consult Beauchamp and Childress for an in-depth treatment. Because these principles have validity and can be useful in thinking through ethical issues, they are referred to frequently in the following chapters. As a cautionary note, however, it is important to resist the temptation to employ principles in a mechanical fashion. If applicable and used with judgment and sensitivity, they can inform sound ethical reasoning. If used rigidly without reference to context and narrative, principlist ethics can lead to a distorted and unhelpful analysis.

It is equally useful to consider clinical situations in terms of key ethical concepts, such as decisional capacity, power imbalances, decision-making authority, access to health care, pain and suffering, confidentiality, truth telling, informed consent, the family's role in decision making, the patient's best interest, forgoing treatment, and quality of life and death. These and other ethical issues will be referred to in analyzing clinical situations throughout the curriculum in part I and discussing the clinical cases in part II.

THE ROLE OF CULTURE, RACE, AND ETHNICITY IN HEALTH CARE

How people confront decisions about health care is shaped in large part by the beliefs, attitudes, and values inherent in the cultures with the greatest formative influence on them. Choices about advance care planning, approaches to decision making, disclosure of information, life-sustaining interventions, and palliation are often informed by culturally determined notions of self-governance and destiny, truth telling and protection from harm, the power of language to reflect or create reality, filial obligation, the meaning of suffering, religion and spirituality, historical discrimination, and mistrust of health care or the health care system.

The following brief examples are offered to illustrate how culture, race, and ethnicity can influence health care. Studies have found that European Americans, who tend to value independence and self-empowerment, are more likely than others to favor advance directives, full disclosure of health information, and limited treatment at the end of life. In contrast, African Americans have demonstrated reluctance to delegate decision-making authority through advance directives, objection to limiting treatment, and preference for aggressive life-sustaining technology, including cardiopulmonary resuscitation. Hispanics have been shown to defer to physician judgment, value decision making by the family rather than an appointed health care agent, and place great importance on how the family is affected by the patient's illness. Asian and Middle Eastern cultures typically prefer to protect patients from knowledge about serious illness or impending death, and favor family rather than individual decision making. Native American cultures tend to reject advance care discussions because they might bring on the envisioned health problems. Reports of these studies emphasize the need for balance in interpreting them. Overreliance on the findings risks cultural stereotyping, while indifference to cultural distinctions risks assuming that all patients share Western attitudes and values (Morrison and Meier, 2004; Kagawa-Singer and Blackhall, 2001; Hopp and Duffy, 2000; Blackhall et al., 1999; Shepardson et al., 1999; Morrison et al., 1998; Berger, 1998; Pellegrino et al., 1992).

The same commentators also point out that cultural determinants influence the values and attitudes of physicians as well as those of their patients. The result is the potential for misperception and miscommunication when the parties to the clinical interaction come from different cultural backgrounds. A valuable ethics committee function can be educating care providers about the personal and cultural differences that influence the clinical dynamic and affect patient care. Consider, for example, a series of grand rounds or in-service presentations on how cultural background can inform patient and provider comfort with notions of autonomy, privacy, advance directives, informed consent, and disclosure.

CONFLICTING OBLIGATIONS AND ETHICAL DILEMMAS

The several ethical principles discussed above confer on clinicians multiple ethical obligations—duties that are grounded in moral norms and must be fulfilled unless there are competing and more compelling obligations. Not surprisingly, these obligations frequently collide.

The tension between and among ethical principles may create dilemmas for clinicians when their obligations are in conflict. Ethical dilemmas usually occur in two types of situations. In some instances, an act can be seen as both morally justified and unjustified, but the arguments supporting each position are inconclusive. This troubling contradiction makes it difficult for the individual to determine the appropriate course of action. Examples would be abortion and assisted suicide, both of which invoke competing ethical norms. In other instances, an individual may be required to respond to different moral imperatives and cannot do one without violating the other. For example, care professionals are required to respect and promote the autonomy of their patients *and* to protect and enhance their well-being, to provide care to those who need it *and* to be responsible stewards of limited resources. Resolving these dilemmas requires clinicians and ethics committees to scrutinize carefully the competing interests and obligations, identify the likely consequences of the available choices, and weigh the benefits and risks to those involved.

Let us return to Ms. Lawrence, the patient who is refusing blood transfusion. The dilemma here concerns the tension between Dr. Thomas's obligation to honor his patient's autonomous decision about blood transfusion and his obligations to prevent harm and provide what he believes is the most beneficial care. On the surface, it seems that he cannot possibly meet one obligation without violating the others, yet he must take decisive action. Because the principles involved are so central to professional practice and the consequences in this case so profound, the goal must be to protect both Ms. Lawrence's rights and her well-being. The ethics committee member(s) can function usefully in a consultative role as these issues are considered.

The first responsibility is to confirm that Ms. Lawrence is capable of making decisions about her care and to ensure that she and Dr. Thomas have clarified the clinical situation, the care goals, the therapeutic options, and their likely consequences. As discussed in later chapters, the exercise of patient autonomy, through informed consent and refusal, depends on the patient's decisional capacity, the quality of the information provided by the physician, and the trust underlying the therapeutic relationship. An ethics consultation can create the opportunity for the patient and appropriate members of the care team to engage in these important discussions.

The next step is to consider the ethical issues, including Ms. Lawrence's right to make care decisions based on her goals and values, and confirm that her refusal is the product of her deeply held religious convictions, rather than coercion or misinforma-

tion about blood transfusions. The discussion should explore alternative options and resources, including nonblood therapies and transfer to other institutions that specialize in treatment without transfusion. Ms. Lawrence, her family, and the clinical team must be reassured that her refusal will in no way compromise the rest of her care.

Resolving the conflict between the obligation to respect the patient's autonomy and the obligations to promote her best interest and protect her from harm will require a careful collaborative assessment of her decision making, including how she weighs the benefits and burdens of the proposed treatment. While it is neither necessary nor appropriate to argue her out of her religious beliefs, the ethics consultant is obliged to be certain that her decision to forgo a life-saving intervention is informed, carefully considered, voluntary, and settled. If Ms. Lawrence genuinely believes that surviving with a blood transfusion would be morally unacceptable, then, for her, the benefits of the intervention would be significantly outweighed by the burdens of the outcome. Under those conditions, her refusal of transfusion should be honored while she receives all other appropriate care and support. In this time-consuming and exacting process, the ethics committee consultant is a valuable resource, providing all parties with information, ethical analysis, practical guidance, and support.

It should be remembered, however, that not only the patient's autonomy is at stake. Dr. Thomas and his colleagues also bring to this situation their professional obligations and personal values. Not unreasonably, surgeons and/or anesthesiologists in this circumstance are likely to be very uneasy about attempting surgery under conditions that restrict their ability to provide optimal care. Even though the patient has agreed to and assumed the risks of surgery without blood transfusions, the doctors will argue that they would be knowingly putting her at what they consider unacceptable risk. Doing so would erode both their competence and professional integrity. Under these restrictive conditions, many surgeons and anesthesiologists would prefer to transfer Ms. Lawrence to colleagues or other institutions more comfortable with her limitations, agreeing to operate only if alternatives were not available.

REFERENCES

- Ahronheim J, Moreno JC, Zuckerman C. 2000. *Ethics in Clinical Practice*. 2nd ed. Gaithersburg, MD: Aspen Publishers.
- Annas GJ. 1991. Ethics committees: From ethical comfort to ethical cover. *Hastings Center Report* May-June 21(3):18-21.
- Arras JD, Steinbock B, London AJ. 1999. Moral reasoning in the medical context. In Arras JD, Steinbock B, eds. *Ethical Issues in Modern Medicine*. 5th ed. Mountain View, CA: Mayfield Publishing Co., pp. 1-40.
- Beauchamp TL, Childress JF. 2001. *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press.
- Beauchamp TL, Walters L, eds. 2003. *Contemporary Issues in Bioethics*. 6th ed. Belmont, CA: Wadsworth-Thomson Learning.
- Berger JT. 1998. Culture and ethnicity in clinical care. *Archives of Internal Medicine* 158:2085-90.
- Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. 1999. Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine* 48:1779-89.
- Fletcher JC. 1991. The bioethics movement and hospital ethics committees. *Maryland Law Review* 50: 859-94.
- Hopp FP, Duffy SA. 2000. Racial variations in end-of-life care. *Journal of the American Geriatrics Society* 48(6):658-63.
- Jonsen AR. 1998. *The Birth of Bioethics*. New York: Oxford University Press.
- Joint Commission on Accreditation of Healthcare Organizations. 1999. *Comprehensive Accreditation Manual for Hospitals*. Oakbrook Terrace, IL: Joint Commission on Accreditation of Healthcare Organizations.
- Kagawa-Singer M, Blackhall LJ. 2001. Negotiating cross-cultural issues at the end of life: "You've got to go where he lives." *Journal of the American Medical Association* 286(23):2992-3001.
- Levine RJ. 2003. Informed consent: Some challenges to the universal validity of the Western world. In Beauchamp TL, Walters L, eds. *Contemporary Issues in Bioethics*. 6th ed. Belmont, CA: Wadsworth-Thomson Learning, pp. 150-55.
- Lo B. 2000. *Resolving Ethical Dilemmas: A Guide for Clinicians*. 2nd ed. Philadelphia: Lippincott Williams & Wilkins, pp. 140-46.
- Mappes TA, Degrazia D. 2001. *Biomedical Ethics*. 5th ed. Boston: McGraw Hill, pp. 1-55.
- Miller B. 1995. Autonomy and the refusal of life-sustaining treatment. In Arras JD, Steinbock B, eds. *Ethical Issues in Modern Medicine*. 4th ed. Mountain View, CA: Mayfield Publishing Co., pp. 202-11.
- Moreno JD. 1998. Ethics committees and ethics consultants. In Kuhse H, Singer P, eds. *A Companion to Bioethics*. Malden, MA: Blackwell Publishers, pp. 475-84.
- Moreno JD. 1995. *Deciding Together: Bioethics and Moral Consensus*. New York: Oxford University Press.
- Morrison RS, Meier DE. 2004. High rates of advance care planning in New York City's elderly population. *Archives of Internal Medicine* 164(22):2421-26.
- Morrison RS, Zayas LH, Mulvihill M, Baskin SA, Meier DE. 1998. Barriers to completion of health care proxies: An examination of ethnic differences. *Archives of Internal Medicine* 158(22):2493-97.
- O'Neill O. 2002. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press.
- Powell T, Lowenstein B. 1996. Refusing life-sustaining treatment after catastrophic injury: Ethical implications. *Journal of Law, Medicine & Ethics* 24:54-61.
- Pearson SD, Sabin J, Emanuel EJ. 2003. *No Margin, No Mission: Health-Care Organizations and the Quest for Ethical Excellence*. New York: Oxford University Press.
- Pellegrino ED. 1992. Intersections of Western biomedical ethics and world culture. In Pellegrino ED, Mazzarella P, Corsi P, eds. *Transcultural Dimensions in Medical Ethics*. Frederick, MD: University Publishing Group.
- Protection of Human Subjects, 45 CFR 47.107; see also 45 CFR 46.112 (1990).
- In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).
- Rosner F. 1985. Hospital medical ethics committees: A review of their development. *Journal of the American Medical Association* 253(18):2693-97.
- Ross JW, Michel V, Pugh D. 1986. *Handbook for Hospital Ethics Committees*. Chicago: American Hospital Publishing.
- Ross JW, Glaser JW, Rasinski-Gregory D, Gibson JM, Bayley C. 1993. *Health Care Ethics Committees: The Next Generation*. Chicago: American Hospital Publishing.
- Rothman DJ. 1991. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. New York: Basic Books.

- Schneider CE. 1998. *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*. New York: Oxford University Press.
- Shepardson LB, Gordon HS, Ibrahim SA, Harper DL, Rosenthal GE. 1999. Racial variation in the use of do-not-resuscitate orders. *Journal of General Internal Medicine* 14(1):15–20.
- Solomon MZ. 2005. Realizing bioethics goals in practice: Ten ways “is” can help “ought.” *Hastings Center Report* 35:40–47.
- Spencer EM, Mills AE, Rorty MV, Werhane PH. 2000. *Organization Ethics in Health Care*. New York: Oxford University Press.
- Teel K. 1975. The physician's dilemma: A doctor's view. What the law should be. *Baylor Law Review* 27:6–9.
- Thomasma DC. 1993. Assessing bioethics today. *Cambridge Quarterly of Healthcare Ethics* 2:519–27.
- Thomasma DC, Monagle JF. 1998. Hospital ethics committees: Roles, membership, structure, and difficulties. In Monagle JF, Thomasma DC, eds. *Health Care Ethics: Critical Issues for the 21st Century*. Gaithersburg, MD: Aspen Publishers, pp. 460–70.
- Toulmin S. 1981. The tyranny of principles. *Hastings Center Report* (December):31–39.
- Wear S, Katz P, Andrzejewski B, Haryadi T. 1990. The development of an ethics consultation service. *HEC Forum* 2:75–87.
- Wolf SM. 1991. Ethics committees and due process: Nesting rights in a community of caring. *Maryland Law Review* 50:798–858.

2

Decision Making and Decisional Capacity in Adults

Health care decisions and decision making

Decision-making capacity

Capacity and competence

Elements of decisional capacity

Decision-specific and fluctuating capacity

Assessment and determination of capacity

The importance of determining capacity

Who assesses decisional capacity?

Deciding for patients without capacity

Standards of decision making

Decision making for the formerly capacitated

Advance directives

Deciding for patients without capacity or advance directives

Decision making for patients who never had capacity

III Mrs. Klein is an 89-year-old woman admitted from home five days ago with cellulitis of the legs. Despite her discomfort, she has cooperated with her diagnostic work-up and treatment and consented to all interventions related to the cellulitis. She was able to provide accurate information about her medical history, which was corroborated by her niece. According to both women, Mrs. Klein has been very healthy and self-sufficient all her life, a state she attributes largely to “keeping my distance from doctors and hospitals.” Her goal, expressed repeatedly since admission, is “to go home and take care of my cats.”

Mrs. Klein's admission blood tests revealed anemia that suggests slow internal bleeding. Despite repeated attempts to explain the dangers of unchecked bleeding and the importance of identifying the source, she has consistently refused consent for a GI series. When asked why she is opposed to a diagnostic work-up, she replies, “Darling, you look, you'll find. No more tests or treatments. Just get me back on my feet so I can go home to my cats.”

After several days, the attending physician requests a psychiatric consult to do a capacity