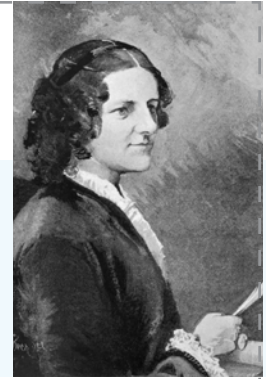


CHAPTER 2



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Values and Principles Confronting Our Health Care System

“Only ignorance! Only ignorance! How can you talk about only ignorance? Don’t you know that it is the worst thing in the world, next to wickedness?—and which does the most mischief heaven only knows. If people can say, ‘Oh! I did not know, I did not mean any harm,’ they think it is all right.”

— **Anna Sewell** (1820–1878), English author of *Black Beauty* (1877)

LEARNING OBJECTIVES

After completing this chapter, the reader should be able to:

1. Understand the role, responsibilities, and decision-making process of medical ethics committees in health care organizations.
2. Explain the difference between medical ethics committee decisions that are legal and those that are ethical.
3. Describe the values and principles that often govern and guide the decisions of medical ethics committees when ethical dilemmas are reviewed.

KEY TERMS

Adverse selection

American ethic

Autonomy

Autonomy from
government

Beneficence

Best interests standard

Chronic pain

Compassion

Competency

Corporate autonomy

Corporate practice of
medicine doctrine

Corporate well-being

Corrective justice

Economic utility

Emergency care

Enterprise liability

Entitlement spending

Equality of opportunity

Equitable access to health care	Medical futility	Public ethic
Ethical dilemmas	Medicare	Reasonable and necessary care
Fairness	Minimum coverage provision	Responsible corporate officer doctrine
Human dignity	Moral preferences	Risk pooling
Hyde Amendment	Negative law	Social contract
Individual responsibility	Negative moral rights	Social determinants of health
Informed consent	New federalism	Social justice
Joint Commission	No-fault insurance	Social risks
Justice	Non-maleficence	Truthfulness
Life-sustaining medical treatment	Personal autonomy	Universal values
Mature minor	Positive law	Vulnerable populations
Medicaid	Positive moral rights	
Medical ethics committees	Potentially avoidable events	
	Principles	

ETHICAL OR UNETHICAL DECISION

Balancing Values in Treatment Decisions by Medical Ethics Committees

Ethics Issue: *Should medical ethics committees balance their values with the values of patients and their families when treatment decisions must be made?*

In Brief: Marie-Eve Laurendeau and Stephane Mantha, parents of a severely disabled infant daughter, filed a \$3.5 million lawsuit against Montreal Children's Hospital for keeping their daughter on life support without their consent. Phebe Mantha was born in November 2007 at another Montreal hospital, where she suffered complications during birth. Phebe was transferred to Montreal Children's Hospital, where physicians told her parents she would never be able to breathe or feed on her own. The parents were told Phebe would be blind and deaf, and would never talk or walk. They were also told Phebe would have very little consciousness of life. The physicians recommended that Phebe's feeding tubes and ventilator support be withdrawn. Based on this prognosis, the parents agreed to withdrawal of Phebe's life support, believing this would avoid unbearable suffering for their daughter.

But the unexpected occurred: after Phebe was disconnected from the ventilator, she breathed on her own. The parents thought their decision meant that Phebe was to have her feeding tube removed. The hospital's medical ethics committee, without consulting either parent, ordered Phebe's feeding to continue. Phebe's physicians and her parents believed Phebe would die within hours after being disconnected from the ventilator even with a feeding tube.

Ten weeks passed before the hospital told the parents Phebe had to go home. The parents were trained and provided the equipment needed to keep Phebe alive. They had to attend to Phebe 10 to 20 times a day, feeding her and suctioning her airways and stomach. More than three years later, Phebe is in constant danger of catching a life-threatening illness and requires round-the-clock attention to survive; she is in constant pain, cannot walk or sit, cannot hold her head up all the time, and does not talk. No one knows how long Phebe will live.

— *Laurendeau v. LaSalle Hospital*, No. 500-17-048988-094 (Quebec Superior Court 2009). (See *Ethical or Unethical Decision* at the end of the chapter for discussion of this ethics issue.)

Introduction

Complex ethical situations occur on a regular basis in health care. Life and death decisions often involve **ethical dilemmas** where there are two or more valid positions being debated by the medical community and patients. **Medical ethics committees** (MECs) are the forum where many ethical dilemmas are resolved by multidisciplinary teams (**FIGURE 2-1**). These teams are commonly comprised of health care professionals from medicine, nursing, law, chaplaincy, and social work. MECs support and advise patients, families, and caregivers as everyone works together to reach the most ethical decisions possible.

Although many ethical issues in health care have gradually been redefined as legal issues (Weinberg, 2012), MECs often address the differences between what is legal and what is ethical when such differences arise. Sometimes it is not easy to tell them apart; sometimes they conflict; sometimes it is difficult to discern whether the differences even exist. What is legal is sometimes unethical; what is ethical sometimes is not legal; what is legal or illegal or ethical or unethical is sometimes not explicitly so. The effort of this text is to help provide deeper understanding of the topics where there is no clear consensus on what is legal and what is ethical. Although both the law and ethics come into play when ethical decisions are at stake, they are not the same. While the common law, and eventually statutory law, evolves from the common ethic, laws can be applied for good or to effectuate evil without regard to the implied ethics of situations; ethics, by definition, are directed toward the common good (Marcus, 2010; Smith, 2009a).

History of Medical Ethics Committees

In 1976, the New Jersey Supreme Court endorsed the creation of MECs as an alternative venue for resolution of **medical futility** disputes, which occur when medical treatment fails to end total dependence on intensive care, fails to result in any detectable improvement in or benefit to patient health, or only preserves permanent unconsciousness (Nachman, 2011). In one case, a New Jersey father was authorized, as guardian of his permanently unconscious daughter Karen Quinlan, to request termination of the **life-sustaining medical treatment** (LSMT) that was mechanically forestalling the moment of her death. LSMT refers to advanced medical technologies such as dialysis, feeding tubes to provide artificial nutrition and hydration, intravenous medications that maintain blood pressure, and mechanical



FIGURE 2-1 Multidisciplinary Medical Ethics Committee

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ventilators and respirators, that sustain life when the body is unable to do so by itself. The court suggested that the hospital MEC confirm Karen's prognosis before LSMT was withdrawn. In addition, the court granted immunity for the health care providers who honored LSMT refusals after the involvement of MECs. With this ruling, MECs were created as an alternative to the judicial system to help clarify ethical actions for health care providers. *See In re Quinlan*, 355 A.2d 647 (New Jersey Supreme Court 1976), *cert. denied*, 429 U.S. 922 (U.S. Supreme Court 1976).

Maryland followed New Jersey's lead in recognizing a role for MECs. Then in 1983, a presidential commission recommended that all hospitals create MECs to help resolve questions about foregoing LSMT (President's Commission, 1983). Following this development, other states mandated that hospitals establish MECs.

The most significant event in the history of MECs occurred in 1992, however, when having a MEC became a necessary condition for hospitals, nursing homes, and home care agencies seeking approval by the Joint Commission. An independent, not-for-profit organization, the **Joint Commission** is the nation's predominant standards-setting and accrediting body in health care. Joint Commission accreditation is required for Medicare and Medicaid certification and licensing in many states. Consequently, most health care organizations took action when the Joint Commission mandated that organizational policies had to be in place to address ethical issues. The creation of MECs was the most common response to this Joint Commission mandate. *See generally* Hester & Bjarnadottir, 2007.



ETHICS CASE

The Role of MECs in Deciding Patients' Right to Live v. Patients' Right to Die Disputes

Betancourt v. Trinitas Hospital

[Patient v. Hospital]

415 N.J.Super. 301 (Superior Court of New Jersey, Appellate Division 2010)

Facts: Rueben Betancourt, a 72-year-old patient at Trinitas Hospital, underwent surgery to remove a malignant tumor from his thymus gland. The surgery went well, but while Betancourt was recovering in the postoperative intensive care unit, the ventilation tube that was supplying him with oxygen became dislodged. As a result, his brain was deprived of oxygen, and he was left in a persistent vegetative state with no mental functioning. Ultimately, he required dialysis three times per week, was maintained on a ventilator, developed a staph infection, and was fed with a feeding tube. After various unsuccessful attempts to resolve the issue of LSMT with Betancourt's family, his physicians claimed that continued medical treatment would be futile and would violate the standard of care.

The hospital's MEC was consulted concerning the efficacy of continuing Betancourt's LSMT and it concluded that further medical treatment was futile. Continued LSMT would not end Betancourt's total dependence on intensive care; it would only mechanically preserve his permanent state of unconsciousness. Yet, Betancourt's family refused to cease LSMT. No other health care facility would accept Betancourt. Ultimately, the hospital acted unilaterally and placed a Do Not Resuscitate (DNR) order in Betancourt's chart and declined to provide further dialysis

treatment because, in the hospital's opinion, it only mechanically prolonged Betancourt's dying process.

Betancourt's family filed a lawsuit to stop the hospital from withholding LSMT based on their religious beliefs that their God should be permitted to decide the time of death. Within three months of reinstating LSMT, Betancourt died. Before his surgery, Betancourt had not executed an advance directive and had not designated a health care representative, nor had he memorialized specific wishes regarding the withholding or withdrawal of LSMT. By the time Betancourt died, his outstanding hospital bill was \$1.6 million.

Legal Analysis: At the onset, the court noted that while advanced medical technology to mechanically sustain human life has existed for more than 30 years, disputes about continuing LSMT that has no medical benefit do not frequently occur. The court distinguished between what constitutes medical futility for mentally incapacitated, yet medically stable patients, and mentally incapacitated patients facing imminent death. While there is no universal agreement about futile treatment for medically stable patients, the legislature defined medical futility for patients who are dying as any LSMT that fails to end total dependence on intensive care or that mechanically preserves permanent unconsciousness.

Defining what constitutes medical futility for mentally incapacitated, yet stable, patients is a profound and universal ethical issue; it warrants debate not in the context of litigation but rather by legislatures, as well as the executive branch of government, that both have responsibility for developing policies that impact the lives of everyone in society. Court-appointed guardians should presume that mentally incapacitated patients would choose the preservation of their lives; the exception to this presumption is when continued LSMT would merely artificially prolong the dying process.

Rule of Law: Although court-appointed guardians have the authority to make treatment decisions on behalf of patients legally incapable of making health care decisions, the parameters of what constitutes medically futile care for patients who are mentally incapacitated, yet stable, is a legislative, not judicial, issue when disputes arise.

Ethics Issue: What is the propriety of courts appointing guardians for patients who are legally incapable of making health care decisions when the issue of whether continued LSMT is medically futile is disputed?

Ethics Analysis: What constitutes medical futility is an ethical issue. Consistent with the terms of an advance directive, LSMT may be withheld or withdrawn from patients when continued treatment is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process.

One side of this debate holds that patients' right to forego LSMT is not absolute, but instead is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving patients' lives and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. Decisions to maintain medically appropriate LSMT must take precedence over other societal interests.

The other side of this debate acknowledges that setting limits fairly is a requirement of an ethical health care system. In this instance, medically futile care for patients on the verge of death cannot be justified. Justice demands a fair allocation of resources toward vital needs (Levine et al., 2007). At the same time, it would be unethical to forego LSMT for patients who are mentally incapacitated, yet stable.

Court's Holding and Decision: Near-universal rules to resolve medical futility disputes for patients who are mentally incapacitated, yet stable, are legislative decisions; such decisions should not be unilaterally decided by the courts or MECs.

See Pope, 2014 and 2014a (discussing this court decision).

Policy and Treatment Decisions Facing Medical Ethics Committees

While MECs serve as decision-makers for health care organizations, they also play an advisory role in ethics consultations for patients and their families. MECs also make decisions on behalf of incapacitated patients with no family or friends. Other times MECs adjudicate disputes and conflicts between providers and patients' families. Both in law and in practice, MECs have significant authority and responsibility to make decisions involving patients. State law generally defers to MECs to determine the course of treatment if there is a conflict; the exception is where the law is not clear. For instance, in the *Betancourt v. Trinitas Hospital* decision, state law failed to define what constituted medically futile care for a patient who was mentally incapacitated, yet medically stable.

When there are conflicts between providers and patients' families, MECs may adjudicate the disputes, but only the courts have the power to make decisions where competing interests cannot be reconciled to accept a MEC's advisory decision. MECs should not act unilaterally when family disputes arise. In every instance involving MECs, a fundamental value is patient self-determination, or the right of competent patients (or their legal representatives) to exercise control over their own medical futures (Maron, 2012). This value permeates the role of MECs.

Dealing with Ethical Dilemmas

The primary role of MECs is to work through ethical dilemmas. In many of these situations, the law is often not clear and the courts may be considering competing positions for the first time. The hope is that this text will help everyone, especially health care professionals serving on MECs, to make the most ethical decisions possible. When dealing with ethical dilemmas, it is best to determine and understand the factors, as illustrated in **FEATURE BOX 2-1**, that impact almost all decision-making and actions.

Decisions Confronting Medical Ethics Committees

The ethical dilemmas in this text, as illustrated in **FEATURE BOX 2-2**, are unresolved legal cases taken from the news headlines; they deal with topics that are part of the national debate on issues arising from circumstances in which the legal answers are not clear or are unknown. This occurs because there is simply not enough law to determine what course of conduct is clearly permitted or prohibited under every circumstance.

This text examines how to respond when situations are encountered for which the law fails to offer clear and precise solutions. The only thing that is clear is just how unclear and imprecise health care laws are. Given the increasingly complex medical and political environment of 21st-century health care in the United States, coupled with the potential life-or-death implications for specific patients, ethical discretion and personal values take on increased importance in decision-making. In addition, there is the complexity of choosing

FEATURE BOX 2-1

Factors Impacting Ethical Decision-Making

- Potentially competing sources of guidance in the law
- Rules of professional responsibility
- The complex dynamics of personal motivations
- The ethics of individual responsibilities and social obligations
- The primacy of universal and personal values

— Sources: AMA, 2012a; ASBH, 2010; Beauchamp & Childress, 2012; Moore, 1903/1998; Moulton & King, 2010; Percival, 1803/2002.

FEATURE BOX 2-2

Ethical Dilemmas

- Should lifestyle behaviors be taken into account in determining whether patients could be eligible for organ transplants?
- Under what circumstances should terminally ill patients have access to experimental medical technologies?
- How should health care professionals define medically unnecessary care and futile care for patients with terminal prognoses or seriously degenerative chronic conditions?
- Is it appropriate to withhold oral contraceptive prescriptions from women who have been informed of the risks involved and choose to forgo screening for unrelated health conditions?
- Should the administration of life-shortening analgesia be lawful in hospitals and hospice care?
- Does inappropriate use of curative treatment that fails to end total dependence on intensive care or that preserves permanent unconsciousness deprive patients of their fundamental rights to dignity and humane treatment?
- How should the interests of patients who refuse life-saving hydration and nutrition be balanced alongside their right to self-determination at the end of life?
- What could justify a medical team to withhold prognosis or treatment plan information from a **mature minor**, an adolescent who has the mental competence and intellectual capacity to make health care decisions?
- What is the proper balance between the rights of parents and the rights of minors to choose or refuse lifesaving medical treatment?

— Sources: AMA, 2012a; ASBH, 2010; Beauchamp & Childress, 2012; Moore, 1903/1998; Moulton & King, 2010; Percival, 1803/2002.

between two or more valid choices in many situations. The dynamic interplay with patients' lives and deaths has the potential to make various decisions highly subjective and resistant to codification, meaning no law could adequately address all such decisions, but the law at least has the potential to guide the making of ethical decisions.

Universal Values in Ethical Decision-Making

One responsibility of MECs is to help health care providers apply ethical principles to their actions (AMA, 2012). There are ten **universal values**, as illustrated in **FEATURE BOX 2-3**, which often govern and guide decisions when ethical dilemmas are reviewed. *Universal values* are personal **principles** that define what is ethical and right to do, or principles of a group (such as the universal values of physicians or nurses), or the principles of a nation (such as the fundamental principle of American democracy, and the principle that members of American society are valued and rewarded on the basis of their merit).

FEATURE BOX 2-3

Ten Universal Values in the American Ethic

- **Personal autonomy:** ensures that individuals have the right to make independent decisions about their own health care based on their own value systems. Burdens all stakeholders (patients and health care providers alike) to be well-informed regarding treatment decisions; involves more than simply protecting individuals' freedom to decide within the existing health care system. Presumably, such freedom in self-governance is always informed by moral preferences that are relevant considerations as opposed to transient arguments.
- **Beneficence:** promotes the well-being of others in ways that serve their best interests and are beneficial to them, all the while seeking to achieve the highest quality (not just high-quality) results on their behalf. Implies that one does not inflict harm but rather seeks to prevent harm.
- **Compassion:** one of the foundational principles of the emerging ethics of health care; requires health care professionals to respond to those suffering from disease or injuries with a deep awareness of patients' human dignity. Arises from the common humanity of everyone, especially the relationship between providers of health care and their patients. This ethical obligation is supported by economic and social considerations.
- **Equality of opportunity:** another foundational principle of the emerging ethics of health care; ensures that nearly all members of society have an equal claim to health care. Requires society to provide subsidies to help cover the health insurance costs of anyone who faces disproportionate health burdens from unavoidable ill health.
- **Fairness:** promotes giving to others what they are due or what they are properly owed. Requires that there be freedom from bias and injustice in the U.S. health care system so that patients in distress may receive the essential care they medically need while requiring those entrusted with governance of limited health resources act in a trustworthy and ethical manner.
- **Human dignity:** respects the inherent worth of everyone; requires a commitment to respond to everyone with mutual affinity, respect, and stateliness.
- **Individual responsibility:** emphasizes personal accountability for healthy lifestyles and preventable ill health. This ethical obligation is both a free choice and a personal and shared duty; assumes that avoidance of unhealthy day-to-day choices will help avoid preventable ill health from occurring or delay the onset of and the severity of symptoms from unpreventable aging and illness.

(continued)

- **Justice:** a foundational principle of health care ethics; fairness and equality in the way everyone is treated and decisions are made. Ensures access to affordable health insurance and the kinds of essential care that is owed. Depends on society's notion of what is right and fair and the allocation of shared societal resources for health care (which should incorporate precise measures of the total societal costs of preventable ill health and total societal benefits from health care).
- **Non-maleficance:** avoidance of harm; the opposite side of the coin of beneficence. Requires health care professionals to first do no harm, or if no good can be done without causing harm, then actions that have no curative effect or result should not be undertaken.
- **Truthfulness:** an overriding component at all levels of the U.S. health care system; takes an ongoing commitment to build and maintain with all stakeholders. Requires the medical products industry and other health care professionals to honestly and accurately report health information to patients; recognizes patients' right to know the truth of their health status. Trust and personal autonomy are compromised by withholding truth from patients.

— Sources: AMA, 2012a; Beauchamp & Childress, 2012; Kenny et al., 2010; Levine et al., 2007; Petrini & Gainotti, 2008; Post et al., 2006; Thayer, 2011; Thompson et al., 2006; Wiley, 2012; Nuttfield Council, 2007; Percival, 1803/2002.

When the subjective spiritual and emotional preferences of each member of society (defined here as **moral preferences**) are given social significance and made relevant, each person is connected to every other person in their community and together they are given human dignity that befits them to make decisions (Katz, 2010).

The American Ethic: An Evolving Public Ethic

The American ethic of health care has shared purposes and problems that are different from individual purposes and problems (Lee, 2012). A **public ethic** is often synonymous with universal values and refers to the state, its government, and its policies. In this instance, the American ethic is more than simply a collection of Americans with personal values (Lee, 2012). The **American ethic** is a combination of Americans' characters, their customs, norms, and traditions.

Universal principles cascade from universal values. This text, for instance, offers not a single theoretical approach to health care ethics; rather, it is an acceptance of pieces of numerous important philosophies of ethics and a theory of how they might be reconciled or utilized in a complementary manner when possible. Universal values and their cascading universal principles are put forth from this combination of ideas. This approach to ethics offers to knowledgeable and invested physicians, nurses, and other health care professionals (and students studying to become members of the health care profession) a set of guiding ethical principles that in turn provide consistency in ethical decision-making where there is currently great need and little concurrence (Baylis & Sherwin, 2008; Kenny et al., 2010). This approach also acknowledges a democratic and respectful pluralism (Jennings, 2009). It is a Rawlsian approach to accepting numerous distinct and seemingly

FEATURE BOX 2-4

Framework for Medical Decision-Making: Four Necessary Questions

- Which values and ethical principles apply?
- Which values should be applied for the most ethical decision?
- Are there other values and ethical principles that should be in place and, if so, what should they be?
- Which decision-making model(s) would best serve the applicable values and ethical principles?

— Sources: ASBH, 2010; Jaffe & Hope, 2010; Jennings, 2009; Kenny et al., 2010; Moulton & King, 2010; Nuttfield Council, 2007; Percival, 1803/2002; Petrini & Gainotti, 2008.

incompatible comprehensive doctrines (Rawls, 1971/2005 and 1993/2005). This approach to ethics also fits well in the U.S. political system, a system that prides itself on balancing respect for individuals with maintaining a society designed to advance the best in everyone (Lee, 2012).

Alignment of the American Ethic with Medical Decision-Making

Universal values and principles transcend and are embodied in the law; they do not give answers as to how to handle particular situations, but provide a useful framework for understanding conflicts and ethical dilemmas. When reviewing the topics in each chapter, four questions, as outlined in **FEATURE BOX 2-4**, should be considered.

Autonomy

Autonomy is the hallmark of health care ethics. As such, respect for autonomy is recognized in more health care situations than any other ethical principle (Beauchamp & Childress, 2012). The value of autonomy applies to individuals as well as to institutions.

Principles of Autonomy

There are three types of autonomy: personal, corporate, and governmental. Though often used interchangeably, their definitions are distinct. It is this principle which most hinders the pursuit of the common good.

Personal Autonomy: The Right to Self-Determination

Personal autonomy is significant in two respects: patient autonomy and the professional autonomy of physicians. Patient autonomy is rooted in respect for the right of patients to make independent decisions about their health care. Respect for patient autonomy incorporates at least two ethical principles: first, patients should be treated as autonomous agents; and second, patients with diminished personal autonomy are equally entitled to protection.

Patient autonomy thus divides into two separate ethical requirements: the requirement to acknowledge personal autonomy, and the requirement to also protect those with diminished personal autonomy. *See generally* Carnahan, 2011.

In addition to patient autonomy, physicians have always maintained their personal autonomy from corporations. This professional autonomy, however, is increasingly threatened by the rise of organized economic enterprises in the health care industry (Ameringer, 2011). Physicians are now accountable to the health insurance industry and to the government, and that external scrutiny has become the norm (Starr, 2013). The corporatization of medical services has led to closer scrutiny of physicians in order to mitigate against malpractice; this scrutiny is facilitated by gathering information about physician performance (Starr, 2013).

Corporate Autonomy: An Autonomous Economic Person

Corporate autonomy is about the right to self-governance of the health care industry; in other words, the right to be free from unwarranted interference by the government (Mansbach, 2011). Corporate autonomy extends to the right of the health care industry to freely make business decisions. Whereas personal autonomy generally encompasses the idea that patients should remain free from coercion, corporate autonomy means that organized economic enterprises should have autonomous corporate management. After all, health care corporations are but the formal organization of activities by physicians and other providers of health care.

Because corporations owe their existence to government as creatures of **positive law**, this means corporations only have the rights and privileges granted to them by the government. Therefore, the health care industry is subject to legitimate regulation of its corporate self-interests by the government. As such, corporations are autonomous, self-directed beings that are subject to regulation by the government against harmful activities (Goforth, 2010). For instance, when health care systems fail to meet their societal obligations, such as failing to provide health care to the sick and vulnerable, they may be regulated to do so as a condition of their corporate survival, particularly when they receive government funds or tax exemptions. Positive law can be compared to **negative law**, or what corporations cannot do. For instance, tax-exempt health care systems cannot neglect their charitable obligations and still maintain their exempt status.

Autonomy from Government

Autonomy from government assures that patients and the health care industry have the right to make decisions and act on them as free and independent moral agents. At the same time, there is a need for the federal government to have sufficient powers to promote the general welfare of all members of society, balanced against autonomous state and individual interests (Madison, 1788/1982). In health care reform, the role of the federal government depends as much on federalism as it does on the autonomy of its citizens and the states.

Application of the Value of Personal Autonomy and Self-Determination

Personal autonomy is a general indicator of health. Respect for the autonomous choices of patients upholds the ability of patients to make informed choices, and to take actions based on their personal values and beliefs (Fry-Revere et al., 2010).

Providing Women Their Rights to Reproductive Care

The right to women's reproductive care is subject to continuous challenge because positive moral rights are generally not recognized under the U.S. Constitution (Kinney, 2008). By definition, **positive moral rights** require action; one must act or others are obliged to act. Women's right to reproductive care is generally a negative moral right in the United States (*Harris v. McRae, et al.*, 448 U.S. 297 (U.S. Supreme Court 1980) (upholding the **Hyde Amendment** denying federal funding for abortions), *rehearing denied*, 448 U.S. 917 (U.S. Supreme Court 1980)). **Negative moral rights** permit inaction; one may refrain from acting or others may refrain from acting.

In other words, while the U.S. Supreme Court has told the government to let women alone and not interfere with their autonomous reproductive choices, the U.S. Constitution does not require the government to provide reproductive care or assist women to exercise their personal autonomy. For instance, Congress and state legislatures may not prohibit women from obtaining an abortion before their fetuses are viable, but the government does not have to provide funding for women who cannot afford the cost of an abortion. *See generally* Orentlicher, 2012.

Insuring Access to Health Care

Arguments for the right to health care parallel the arguments for women's right to reproductive care. Similar to the arguments for abortion, Congress and state legislatures may not prevent patients from receiving treatment for their illnesses or injuries, but nothing in the U.S. Constitution imposes a duty on government to ensure that patients can in fact obtain health care. In other words, a refusal to provide government health insurance coverage for a particular medical treatment can effectively mean a denial of health care. For instance, if Medicare decides not to reimburse hospitals for a particular treatment, the treatment will not be available for most patients with Medicare coverage unless they also have supplemental insurance policies. *See generally* Orentlicher, 2012.

Managing Medically Futile Care

Personal autonomy relates to the right of patients to choose their care and treatment, but many illnesses are characterized by the loss of personal autonomy. When physicians question whether to keep treating a patient, or nurses feel moral distress over a patient's unrelenting pain, or medical opinion is split, or a family wants to pursue medically futile care, MECs often become involved in care decisions (Adamy & McGinty, 2012). Treatment in these situations is arguably not preserving or respecting human life; it is delaying the natural process of death (Standley & Liang, 2011). MECs and physicians may determine, and then advise patients and their families, whether their choice of treatment requested or being provided is ethically appropriate.

Protecting Patients' Right to Informed Consent

Informed consent in this context is the voluntary, knowing, and competent decision of patients to accept or reject certain medical treatment. The requirement of informed consent functions as recognition of the right to protection of personal autonomy and integrity, yet it does not imply a waiver of patients' right to compensation in the event of injury from **potentially avoidable events** (or avoidable hospital acquired-conditions, including foreign objects retained after surgery, air embolisms, blood incompatibilities, stage III and IV pressure ulcers, falls and traumas, vascular catheter-associated infections, catheter-associated urinary tract infections, and manifestations of poor glycemic control)

(Beauchamp & Childress, 2012). Informed consent is based on respect for personal autonomy, self-determination, and fairness; consent embodies the need to respect the human dignity of patients and their autonomous decisions (Pike, 2012).

Application of the Value of Corporate Autonomy

A principle-based approach to decision-making as opposed to prescriptive rule setting is lacking within the U.S. regulatory space (Davis, 2009a). If it does not evolve, a bureaucratic mindset will likely usurp corporate autonomy to the ultimate disadvantage of patient safety and health care reform (Greenwood, 2012). The only purpose of government regulation is to assure that health care business decisions are ethical, especially because so many of them are government-funded; the health care industry (as all businesses) must seek to serve the common good of society and the best interests of everyone, ethically speaking. Because of the health care industry's unique relationship with its consumers, however, it must be held to the highest standards of fairness and justice.

Protecting the Well-Being of Health Care Institutions

Corporate autonomy is an indicator for the well-being of health care institutions that physicians, nurses, and other health care professionals are a part of (Tauber, 2005). Well-being, or corporate long-term financial health and stability, has implications for the personal ethics of individuals. While the aim of all health care decisions is to care for individual patients who will benefit from the care provided, at the same time, the health care facility providing the care must be cared for (Singer, 2010). The goal is to have everyone who requests care benefit from the facility's services. For instance, the principle of corporate autonomy could justify the admission policies of hospitals for upfront payments for care, such as payment of health insurance deductibles and co-payments, before care is received, or the requirement that patients make payment arrangements to pay for care before non-emergency care is received.

Regulating the Health Care Industry

Based on the principle of corporate autonomy, it is important that the United States have a sensible regulatory process that bases decisions on rational cost-benefit analysis, does not allow excessive delays in the time to make decisions, and lightens compliance burdens as much as possible (Goolsbee, 2010). Regulations with high costs relative to their benefits should be modified or eliminated. It is in everyone's interest to find ways to reduce compliance costs, and to eliminate or reconcile out-of-date and conflicting rules and regulations.

Application of the Value of Autonomy from Government

Autonomy from government, beneficence, fairness, justice, and non-maleficence are inter-related values (Fry-Revere et al., 2010; Karako-Eyal, 2011; Mansbach, 2011); all five arise out of the ethical principle of respect for human dignity (Carnahan, 2011). Respect for human dignity defines the framework for defining autonomy from government.

Accepting the New Federalism

A promising constitutional paradigm is emerging. Two competing visions of the value of autonomy from government are converging into a new federalism (Ryan, 2011). Under this **new federalism**, Congress is empowered to address any problem that the states are unable

to address separately (Lash, 2011). For instance, with the U.S. health care system suffering from adverse selection and cost-shifting in state health insurance markets, Congress has an ethical obligation to intervene to correct the interstate problem (Koppelman, 2011). At the same time, whenever a federal intervention imposes on personal autonomy, the states should retain primary regulatory authority, because state power better preserves individual liberty (Hills, 2006).

The new federalism balances two visions of personal autonomy with the mandate that nearly everyone have access to affordable health insurance; in this instance, the efficiency of national health care reforms converges with the liberties of state regulation of insurance. Under this new approach to federalism, the federal government has the best structures for regulatory efficiency, while state governments have the best structures to preserve individual liberty. In turn, efficiency and liberty serve as mutual constraints for one another. The goal of the U.S. federal system of government is to optimize the balance between the two visions of personal autonomy while preserving state and federal powers. *See generally* Moncrieff, 2012.

Safeguarding Federal and State Outlays for Health Care

With access to and the cost of care the subjects of considerable debate, a primary goal of health care reform is to slow the growth of health care costs. Even so, 10 percent of the patients with Medicare insurance coverage account for 64 percent of the federal government's hospital spending (CBO, 2008). A disproportionate share of health care costs occurs in the final year of life (CEA, 2009; Dartmouth, 2011). For instance, while nearly 7 percent of all hospital patients die every year, those 1.6 million patients account for almost one-fourth of total hospital costs (Adamy & McGinty, 2012). Clearly, to rein in cost growth, basic coverage for medical treatment for severe illness, especially near the end of life, must be expanded, regardless of whether it is someone who is actively dying or just eventually dying; namely, for everyone (Pope et al., 2011).

There are few processes for dealing with personal autonomy in end-of-life care decision-making. Informed consent to withhold or withdraw treatment is conditioned upon the requirement of predicting death, which is notoriously difficult, particularly when expensive LSMT holds out the promise of dying another day (Pope et al., 2011). Just because medical technology permits extending life, or prolonging death, does not necessarily mean that life should be extended at any cost (Fleck, 2011 and 2009).

Providing Access to Essential Health Care

In providing health care, physicians and MECs often advise boards of directors regarding treatment policies that involve modest sacrifices in the health care provided to individual patients for the common good of everyone served by their health care facility. Although health care providers will always have patients who need a disproportionate amount of resources, it is debatable whether such patients with bleak prospects should be kept alive without objective consideration of their survival chances or even the health benefit, if any, of consumption of such voluminous resources (Adamy & McGinty, 2012). If rising health care costs are ever to be controlled, the realities of terminal illness must be confronted (Pope, et al., 2011). For instance, a recent heart transplant case that resulted in a spiral of non-preventable infections at Johns Hopkins Hospital cost the public insurance programs more than \$4 million over a two-year period before the patient died; \$800,000 remained unpaid to Johns Hopkins Hospital (Adamy & McGinty, 2012). In this case, the issue was that the medical team could not agree whether treatment was futile, and the family wanted to pursue every possible treatment option.

ETHICAL DILEMMAS 2-1

1. Should the individual needs and desires of patients be the only consideration affecting the treatment decisions of MECs, or are there circumstances in which professional resources and the economic impact on the health care facility providing the care may be considered?

Although treatment decisions can be based on financial and professional resources of the health care facility they are made in, such as not performing any organ transplants, from an ethical perspective, financial considerations should not affect LSMT decisions. Decisions about LMST should always be based on clinical judgment and the autonomous right of patients, or their families or legal representatives when appropriate, to choose their care and treatment (Standley & Liang, 2011). At the same time, there is no ethical obligation to continue treatment when the medical team is unanimous about a patient's survival and no objective benefit will be had from continued care (Pope et al., 2011). Controversies arise when the medical teams, patients, or the family, as in the case at Johns Hopkins Hospital, disagree about the futility of continued care (Adamy & McGinty, 2012). If MECs cannot amiably resolve the competing interests, such controversies must be decided by the courts before any LSMT can be withdrawn. While respect for personal autonomy must be balanced with beneficence to prevent unnecessary and untimely deaths, a competent person's refusal of treatment must be respected even when the proposed treatment would probably be beneficial (Fenigsen, 2011). From an ethical perspective, truly informed consent helps to satisfy the dual goals of personal autonomy and beneficence (Conley et al., 2010).

Beneficence

Beneficence refers to actions that promote the well-being of others; it is one of the core values of health care ethics (Beauchamp & Childress, 2012). Personal autonomy and beneficence serve as the framework for medical decision-making and play a prominent role in assuring that everyone has access to health care (Noah, 2012). Beneficence is the value driving the United States' push toward universal health care.

Principles of Beneficence

The principle of beneficence holds that actions are moral, correct, and proper insofar as they are capable of achieving good results that are beneficial to individual or **corporate well-being** (Karako-Eyal, 2011). The American College of Physicians maintains that beneficence, promoting the medical good of patients, is indeed the only fundamental principle of health care ethics (Moulton & King, 2010). Possible benefits must be maximized and possible harms minimized under the principle of beneficence.

Application of the Value of Beneficence

Beneficence is about acting in ways that are beneficial to others. It involves the legal principles of providing competent health care, respecting the human rights of patients, protecting patient information, and maintaining the centrality of the physician's responsibility

to patients (Mansbach, 2011). This principle parallels the Hippocratic Oath by requiring providers of health care not only to refrain from injuring patients at all times, but also to advance the interests of their patients. Beneficence requires that treatments must be of the highest quality in order to serve the best interests of patients as defined by each patient.

Providing Access to Affordable Health Insurance

Although beneficence underlies the right to health care, beneficence also prompts considerations about economic utility. By definition, **economic utility** seeks to ensure that benefits are worth more than the harms caused. In other words, the benefits of providing access to affordable health insurance to nearly all members of society should be worth more than the costs of subsidizing insurance premiums for those unable to afford basic coverage for their health care.

Affording Access to Essential Health Care

The ethical obligation of beneficence justifies the part of the health care reform known as the **minimum coverage provision**, which requires nearly everyone to purchase basic coverage to help fund care for the sick, which is called risk pooling. **Risk pooling** involves a shifting of health care resources from the healthy to the sick. Risk pooling is a means to enable nearly all members of society to more equitably access health care on the basis of medical need, as opposed to on the basis of ability or willingness to pay (Hoffman, 2011).

The absence of a clear and robust consideration of beneficence undermines affordable access to quality care and the aims of health care reform (Clark, 2011). One example of beneficence can be seen in reforms linked to health insurers (public and private), and the providers that focus on reducing costly medication errors and potentially avoidable events in hospitals. In this instance, self-disclosure reforms are in the best interest of insurers, as they will not be required to reimburse hospitals for potentially avoidable events.

Balancing the Risks and Benefits of Medical Treatments

Beneficence requires physicians to provide a direct benefit to their patients while simultaneously balancing the benefits with the risks of producing the best overall outcome (Fry-Revere et al., 2010). Regrettably, there is often no consensus on what may always best help patients. Clinical evidence suggests that the number of patients undergoing surgeries would decline if more patients were fully informed; such failure to communicate the relevant risks, benefits, and alternatives of a medical procedure, including the option of doing nothing, violates the principal of beneficence (Moulton & King, 2010). Beneficence is violated whenever the potential harms exceed the potential benefits. In the instance of surgeries, although surgery may correct a medical condition, it may not always be necessary when medications or lifestyle changes may manage symptoms.

Physician recommendations and communication with patients are major driving forces of geographic variations in medical procedure rates for a wide range of health conditions in the United States, as opposed to clinical need or patient preference (Dartmouth, 2008). For instance, the variation in rates of intensive care unit use in the last month of life, chemotherapy in the last 14 days of life, deaths occurring in the hospital, and the use of hospice care (Dartmouth, 2012) all frequently reflect the tension between the traditional values of patient autonomy and the values of beneficence. It is important to recognize the difference between an ethical stance that views the role of physicians as non-directive and respectful of patient values, and the stance that accepts the active intervention of physicians in the decision-making of their patients for their greater good.

Protecting Human Research Subjects

Beneficence is also one of the pillars of clinical trials and the protection of human research subjects which requires researchers to minimize possible harms (Conley et al., 2010). This tension is most evident in the current controversy surrounding access to investigational medications by the terminally ill. Advanced medical technologies are arriving rapidly and with each innovation there are great promises for improvements to human health. Nevertheless, an ethical framework must be designed to promote the continued development of medical innovations while simultaneously providing early access to patients who would benefit from medical products or services in early clinical trials. To do nothing for the terminally ill who have no other treatment options jeopardizes medical innovations for patient care (Stein & Savulescu, 2011).

Preserving the Lives of Mature Minors

The legal principles surrounding mature minors emphasize beneficence above all other considerations. Mature minors' capacity to make autonomous treatment decisions is based on a **best interests standard** that is based on beneficence. In this instance, this standard refers to the highest quality care that will be administered to terminally ill and suffering minors at the end of their lives, not necessarily for the purpose of extending their biological lives for the longest time, but to offer compassion and pain control. Often, the best interests standard conflicts with the mature minors' personal autonomy. This conflict acknowledges that rational choice and competence exist in varying degrees in minors of the same or varying ages. As such, ethical decisions must ensure that when mature minors reject LSMT, they do so based on rational and defensible grounds. *See generally* Iyioha & Akorede, 2010.

Justifying Vaccinations

The principal justification for vaccination laws is to protect individuals against infections. Vaccinations are also justified by compelling societal interests: upholding herd immunity and protecting vulnerable members of society from vaccine-preventable illnesses (Parkins, 2012). While vaccines prevent harm to others by reducing the burden of health care costs caused by the infectious diseases prevented, the principal rationale for vaccination laws is beneficence: the avoidance of disease in vaccinated individuals outweighs the infringement upon personal autonomy (Shapiro, 2012).

Making Restitution for Gun Injuries

Ethically speaking, because manufacturers of firearms are the beneficiary of firearms sales, the firearms industry should arguably bear the burden of gun injuries as well (Ruttenberg et al., 2011). Restitution for the costs of environmental safety and gun injury prevention is justified by the duties of beneficence. Moreover, restitution reaffirms that individual interests matter, not just societal interests such as concerns about public safety (Goldberg, 2011).

Some states take a corrective justice approach to gun violence by providing gun injury victims with a legal right to restitution (Caldwell, 2011). **Corrective justice** in this instance is defined in terms of undoing a wrong or as giving rise to specific reasons for rectifying wrongs. Although state restitution laws would cover victims' losses from gun injuries, the federal Protection of Lawful Commerce in Arms Act of 2006 protects firearms manufacturers from civil actions seeking restitution for criminal acts of gun violence involving their products. All the same, when manufacturers purposefully design firearms with more harmful uses than beneficial ones and engage in distribution practices that encourage sales to

those who should not possess guns, they arguably cross the ethical line (Rutkow & Teret, 2011; Wagman, 2010). While beneficence is a cultural as well as ethical ideal, the nation needs to come to terms with the value of gun injury prevention in deciding what level of environmental safety is acceptable for everyone.

Compassion

The Hippocratic Oath requires members of the medical profession to adhere to the values of beneficence and compassion (Tames et al., 2011). Compassion is often part of individual healing in health care (Fichter, 2009). Defined as empathy for others and a truly humane attitude of caring or “being with the patient,” compassion enables physicians, nurses, and other health care professionals to respond to individual health needs.

Principles of Compassion

While physicians, nurses, and other health care professionals should treat patients with compassion, mercy, and respect for human dignity and rights, this is a subjective determination (Hethcoat, 2011). What is not subjective is the ethical and legal obligation to provide essential health care with some level of compassion to everyone (Baker, 2010). Neglect of the uninsured and underinsured must end if the United States is to live up to its own purported standards of compassion and human dignity and achieve the maximum use of its work force (Mauldin, 2011).

Application of the Value of Compassion

Compassion and benevolence for patients are often equated with treatment of illness and injuries, especially in medical or public emergencies (Sutton, 2010). Compassion and justice are also relevant to reducing the risk of malpractice as well as to the physician-patient relationship when medical errors occur. Compassion is one of the core values driving the nation’s health care reforms (AMA, 2012).

Administering Health Insurance Benefits

The principle of compassion lays an ethical framework for administration of health insurance benefits and provision of best practices for designing an ethical benefits program (AMA, 2012a). Compassion requires that health care benefits be flexible, responsive to individual values and priorities, and attentive to those with critical needs and special vulnerabilities. Above all, ethical decisions regarding benefit coverage should look toward the individual and not just the population base (Levine et al., 2007).

ETHICAL DILEMMAS 2-2

2. Should health care reform be spurred by limitless compassion, or should the compassion of human nature be checked as the values and ethical principles of compassion flow into national policies and opposing interests are balanced until a stable equilibrium emerges?

Designing Government Insurance Programs

Compassion was the normative principle underlying enactment of **Medicare** as a government health insurance program for people over 65 years of age and the disabled, along with **Medicaid**. Principles of compassion in Medicare and Medicaid health insurance were meant to focus on attentiveness, responsiveness to medical needs, and trust, as illustrated in **FEATURE BOX 2-5**. While government insurance programs are intended to show reasonable compassion for the truly needy, they are also designed to encourage self-reliance without impoverishing the federal and state governments or providing services beyond that affordable by the average taxpayer (Thayer, 2011).

Allocating Finite Health Care Resources to Preventable Disabilities and Health Conditions

American society is divided about compassion for others. While empathy and concern about injustice become more intense when people develop personal connections with those who have experienced hardship or injustice (Land, 2011), there is little compassion for individuals and families with preventable disabilities and ill health. For instance, Down syndrome (or Down's syndrome) is not a mysterious force but a prenatally diagnosable chromosomal abnormality detectable by a blood test during the first trimester; it evokes compassion in some and indifference in others (Caruso, 2010; WHO, 1994). Compassion often does not extend to families with children with Down syndrome who need shared societal resources to cover the costs of intensive therapeutic services and care of significantly burdensome concurrent health conditions (Odibo et al., 2005; Tyler, 2012). One reason for this divide in compassion is that the average cost of care for Down syndrome disease over a lifetime is \$57.5 million (Boulet et al., 2008; McGrath et al., 2011). In other words, when it comes to distributing finite health care resources, disabilities that are the result of a choice to carry a known abnormal pregnancy to term do not carry much weight compared to non-preventable health conditions, such as major birth defects that are non-detectable with current prenatal testing or that were not tested for because there was no personal or family

FEATURE BOX 2-5

Principles of Compassion in Medicare and Medicaid Insurance

- **Attentiveness:** Medicare and Medicaid were meant to be responsive to the special needs of everyone with government health insurance coverage.
- **Responsiveness to medical needs:** Preventive care was to be provided and where acute care was needed, it was supposed to be provided in response to what was deemed to be medically necessary.
- **Trust:** The federal government was to assume responsibility for paying for the health care of all members of society with government health insurance coverage without regard to the ability of the states or the willingness of American society to pay for government health insurance on a continuing basis.

— Sources: AMA, 2012a; President's Council on Bioethics, 2015; NICE, 2008.

history of a particular condition (*see* Farrell, 2013). In this instance, the abortion rate for prenatally diagnosed Down syndrome is more than half of such pregnancies (Dixon, 2008).

Authorizing Physician-Assisted Dying

Compassion and respect for patients' autonomous right to rationally decide if and how they will receive medical treatment at the end of their lives are the bases for physician-assisted dying legislation. It is often compassionate to terminate or refuse LSMT that merely prolongs the dying process of terminally ill patients; in many such instances, life is not being prolonged; rather, the process of dying with intractable pain and unnecessary human suffering is mechanically extended.

Each stage of the physician-patient interaction should be compassionate in physician-assisted dying. Physicians and terminally ill patients work together to create a means by which patients can control the time and manner of their deaths (Bostrom, 2010). Death can be a painless transition; it need not be faced with uncertainty and intractable suffering (Fenigsen, 2011). Analgesic medications can be compassionately administered to alleviate intractable pain.

Consenting to Non-Treatment of Chronically Irreversibly Comatose Children

There is a line of reasoning that would deny LSMT to severely disabled children as an act of compassion that is done in the child's best interests, thereby declaring that the value of human life can sometimes be superseded by other values (Fenigsen, 2010; Muller, 2011). For instance, when children have progressive degenerative diseases of the brain or severe chromosome disorders or suffer severe brain trauma and possess only the most basic form of consciousness or perception, treatment may be withheld. It is difficult to distinguish such cases from patients in a persistent vegetative state where treatment only prolongs their dying, except that rudimentary consciousness in children may be accompanied by the potential for pain and suffering, which is all the more reason for compassionate non-treatment (Fulginiti, 2010). Each and every medical problem requiring the exercise of medical judgment varies in complexity and severity, but what all cases have in common are patients who have a medical condition, the treatment or non-treatment of which must be evaluated with compassion (Summerhill & Chandler, 2009).

Equality of Opportunity

In the United States, the intersection between health and equality of opportunity is most often framed around access to essential health care (Tyler, 2012). Equality of opportunity recognizes that individuals must have the unfettered opportunity to achieve and maintain high levels of health. Health is necessary for a lifetime of well-being and human dignity, not to mention supporting oneself and one's family. Equality is essential for every U.S. resident to fulfill the American promise of life and the pursuit of happiness, and personal health is an essential ingredient to ensure equal opportunity (Levine et al., 2007).

Principles of Equality of Opportunity

Equality of opportunity does not equate with equality of results in the United States (Marshall, 2012). While access to health care does not necessarily include unfettered access to advanced care or to highly specialized physicians, it does provide access to medically

necessary care covered by basic health insurance. Whenever Americans do not have access to health care, equality of opportunity is compromised. Not receiving essential health care consistently leads to poor health outcomes and reduced ability to meaningfully contribute to society (Gratzer, 2008; Hyman, 2009).

Application of the Value of Equality of Opportunity

Physicians, nurses, and other health care professionals see firsthand the effects of inequalities and the social determinants of health on their patients' bodies and thus may be the first to detect the unmet needs and policy failures that harm health (Tyler, 2012). Despite increasingly complex laws, inequality has proved remarkably resilient, especially for the most marginalized groups, or **vulnerable populations**, in American society (poor and financially distressed people, children, the disabled, minorities, and the elderly). These social groups experience health disparities as a result of lack of access to health care and therefore face increased exposure to health risks (Landers, 2010).

Ensuring Universal Access to Affordable Health Insurance Coverage

Equality of opportunity does not easily permit other ethical values to be ignored, such as fairness and justice (Hart, 2012). For instance, just distribution of health care resources is made on the basis of fairness to everyone. Distributive justice allots health care benefits and burdens among all U.S. residents; such distribution is determined by the aggregate health risks, costs, and potential gains of everyone in society. This means some individuals may not be able to afford as comprehensive a health insurance plan as they desire because the cost is too great for them and they do not qualify for insurance subsidies. Injustice may involve unequal access to advanced care and highly trained specialists, as opposed to a lack of access to some extremely costly and at times futile health care with no proven evidence-based value (Beauchamp & Childress, 2012).

Providing Equitable Access to Reasonable and Necessary Care

The principle of equality of opportunity provides that **equitable access to health care** is more than simply access to **emergency care** in situations that pose an immediate threat to health; it is access to care that is reasonable and necessary based on medical need that might have serious implications for continued health and well-being. What constitutes **reasonable and necessary care** should be a socially determined allocation of health risks and insurance principles that pragmatically conforms to the values of compassion, fairness, and justice (Hoffman, 2011). Reasonable and necessary care does not mean that what is done for one person is owed to all others in similar circumstances. Rather, everyone has a legitimate expectation for appropriate diagnosis and treatment to improve their health outcomes, including the best that modern medicine has to offer when appropriate (AMA, 2012a; Pagan, 2007).

Implementing Lifestyle Employment Discrimination Practices

The idea of holding individuals responsible for their choices can be compatible with beneficence; after all, equality is respect for the inherent worth of every human. Giving each individual equal human respect means providing essential health care to everyone, even if

some people bear some responsibility for health conditions that are preventable (Fleischer, 2011). Although distinguishing choice from chance is complex and controversial, future health insurance might seek to promote health and financial security only with respect to health needs resulting from unavoidable harms (Hoffman, 2011). In other words, holding individuals responsible for their own poor choices serves the interests of others.

Providing for Pregnant Employees

The principle of equality of opportunity requires that reasonable accommodations be made for women who are pregnant; ethically speaking, women are entitled to the same workplace opportunities that employees who are not pregnant automatically enjoy (Weber, 2010). In this instance, what is ethically required is more than what current law requires. The law requires employers to provide necessary accommodations if they have chosen to provide them for other temporarily disabled workers with similar levels of incapacity. This legal principle is particularly deleterious for women in traditionally male-dominated occupations that are physically strenuous or hazardous, like emergency medical services (Grossman, 2010). Partially in response to these shortcomings, health care reform looks at health care as necessary to achieve fairness in the form of equality of opportunity (Satz, 2008).

Fairness

Fundamental fairness is included in the concept of justice and encompasses concepts of liberty, equality, and efficiency (Beauchamp & Childress, 2012). Fairness promotes giving to others what they are due (AMA, 2012a). Costs, as opposed to principles of fairness, have their limits in deciding what is right and what is wrong. Society is looking for fundamental fairness, but fairness is not always amenable to precise measurement of costs and benefits or even to measurement at all (Burlinson, 2011).

Principles of Fairness

Criticism of health care reform is often centered on the argument that costs unfairly outweigh benefits, but this economic argument can be countered with assurances that the costs of reform are generally low and will decrease over time as there is a paradigm shift to preventive care (Hoffman, 2011). In other words, costs are for the most part being redistributed as opposed to increased. Although economic arguments are constructive and significant, they cannot be the only indicator of how the U.S. health care system should be reformed to meet the social obligations owed to Americans (Rosenbaum, 2011).

Economic arguments alone cannot fully protect patient rights or uphold patient responsibilities. It is important to protect individuals in ways that go beyond economic efficiency. It is not sufficient to measure the success or failure of reform by financial terms only, to the exclusion of the American public ethic and its underlying values. It is ethical principles, not economic data, that will determine what is ethical or unethical. It is the ideals of fairness, compassion, equality of opportunity, and justice that the U.S. health care system values.

Moreover, there are costs for which society is willing to pay that can be extremely high. Yet, the fact that cost effectiveness does not ensure patients' right to health care indicates that economic reasoning is not the only basis for making health care decisions. This is not to say that fairness and economic efficiency are mutually exclusive goals. Health care resources are allocated based upon a combination of need and ability to pay. In the context of

fairness, equality of opportunity can be established by balancing efficiency and equity. See generally Burleson, 2011; Rawls, 1971/2005.

Application of the Value of Fairness

Objective judgment of what is fair comes into play when attending to the human rights and interests of stakeholders in the health care industry. Economic utility is not always the best justification for health care decisions because individuals place a significant value on fairness in deciding whether or not to accept health outcomes (Hollander-Blumoff, 2010). The difference between what people are willing to pay and the price they actually pay must be fair; in this instance, health insurance coverage must be worth more than the cost of the insurance (Kopson, 2010).

In addition, there are some economically rational health outcomes that sectors of the health care industry will not accept. The outcomes are rejected outright on the grounds that they are unfair. For instance, the health care reform measure limiting the administrative expenses of private health insurers is generally opposed by the insurance industry as being unfair (Bayly, 2012). Private health insurers want to pay executive salaries and returns to shareholders without limitation, as illustrated in **TABLE 2-1**. The principle of fairness, however, requires that insured patients in medical distress receive the care they need (Sage, 2014). Fairness requires that health insurance executives, who are entrusted with governance of limited health resources, act in a trustworthy and ethical manner and allocate resources to the insured in a fair manner, as opposed to serving their self-interests with extraordinary compensation to the detriment of what insured patients are due (see, e.g., Bayly, 2012; Osborn & Schoen, 2013). See generally Wharton, 2007a.

Reforming Regulation of Private Health Insurance

The private health insurance industry is questioning its need to comply with all the health outcomes metrics in the Affordable Care Act of 2010 (ACA). The industry maintains that some health outcomes are economically unfair to their business definition of value and their goals of solvency and fairness (Bayly, 2012). In particular, many private health insurers question the metrics requirements that limit their business's administrative costs as compared to their care costs, an outcome measure that is economically favorable to the U.S. health care system and the nation's need to ensure fair insurance pricing (NAIC, 2010).

Private health insurers maintain that limits to their administrative costs are not consistent with their business perceptions of fairness; insurers oppose the federal mandate

TABLE 2-1 Annual Compensation for Health Insurance CEOs

Aetna	\$30.7 million
Wellpoint	\$17.0 million
Centene	\$14.5 million
Cigna	\$13.5 million
United Health	\$12.1 million
Humana	\$8.8 million

Data from the 2013 Annual Proxy Statements submitted to the U.S. Securities and Exchange Commission.

— Source: SEC, 2014.

requiring that at least 80 percent of the health insurance premiums collected be used to pay for claims (Bayly, 2012). Compared to this new 20 percent federal mandate, for every dollar consumers of health care spent on private health insurance before the Affordable Care Act, 30 to 40 cents went toward administrative costs; profit and investment returns to shareholders were approaching \$90 billion annually before the health care reforms took place (SEC, 2011). Current debate is centered on the principle of fairness: is it fair to compare government health insurance with private market participation in health insurance in terms of administrative costs? An estimated 97 cents of each government health insurance dollar is put toward actual health care, compared to 60 to 70 cents of each private insurance dollar (Wharton, 2007).

Redistributing the Risk of Poor Health

One of the justifications for the minimum coverage provision is redistributive on of risk. The risk of poor health should arguably be shouldered fairly and more equally by everyone (Hoffman, 2011). Yet, the fairness of compelling the young and healthy to share responsibility for financing the health care of the not so young and perhaps not so healthy is a red herring used by both sides in the debate about health care reform (e.g., Majerol et al., 2015).

On the one hand, opponents' fairness argument diverts attention from insurers' need to protect their self-interests and maintain the status quo of fragmented insurance markets. Market fragmentation, in turn, serves to protect the inefficiencies of insurers' **adverse selection** practices. Adverse selection occurs when price increases or reduced benefits make health insurance no longer price-effective; those who make fewer and less expensive claims are taken out of the risk pool, leaving only higher-risk individuals. The result is that adverse selection prevents Americans from sharing broadly in the risk of poor health and, in doing so, entrenches a system where access to care remains tied to ability to pay and often mainly only benefits those who need it least, that is, those in good health (Hoffman, 2010).

On the other hand, health care reforms that move too far beyond underwriting risk undermining actuarial fairness, threatening the very idea of insurance (Bodaken, 2008). Supporters of health care reform, in contrast, view health insurance as simply a mechanism for financing health care; affordable health insurance should be available to nearly everyone because access to essential health care should be universally available (Mariner, 2010), perhaps even a human right (Daniels et al., 2009). Again, fairness and economic efficiency are not mutually exclusive goals. The argument has been persuasively made that providing a basic level of universal health care will improve the nation's economic prospects and ability to compete (Johnson, 2012).

Improving Fairness in Coverage Decisions by Health Insurers

Although difficult decisions regarding health insurance coverage will always have to be made, health care benefits should be administered with economic fairness and compassion. An ethical framework for the fair and consistent administration of health care benefits could markedly improve quality health care, while improving regulation of the insurance industry's self-interests (Levine et al., 2007). While costs and cost control must be considered in order to have a sustainable administration of insurance benefits, increased incorporation of principles of fairness in the business practices of private insurers could advance consumer satisfaction (Westfall, 2011).

Reorienting Insurance Incentives to Encourage Healthy Lifestyles

Traditional health insurance had no direct interest in favoring individual enrollees who assumed personal responsibility for maintaining their health and were committed to healthy lifestyles versus those who were not, such as smokers, the obese, and those who fail to adhere to their prescribed and agreed-upon treatment regimens (Marciarille & DeLong, 2012). Today, the issue is whether this impartial approach to health insurance coverage is fair to those who maintain healthy lifestyles.

Managing Hospital Readmissions

Hospital readmissions are prevalent and costly, with almost one-fifth of hospitalized government health insurance patients being readmitted within 30 days of their initial stay due to uncoordinated care following their discharge (Jencks et al., 2009). Hospitals have had little financial incentive to ensure that patients get the care they need once they leave, and in fact they benefited financially when patients did not recover and returned for more treatment (Rau, 2012). As part of health care reform, the amount government health insurance pays to hospitals with excess readmissions of patients will be reduced. Supporters of this reform maintain that it will save billions of dollars (CBO, 2010). Opponents maintain that the measure may unfairly decrease the quality of patient care and increase the financial distress of hospitals, including increased bankruptcies (Swider, 2012).

Responding to Selective Non-Treatment and Selective Abortion

Debate centers on a basic question about fairness and whether it is acceptable for prospective parents to choose death for their nascent offspring as opposed to life with a disability (Samaha, 2007). With regard to selective non-treatment, discrimination on the basis of disability, regardless of severity, is viewed as morally indefensible from birth; an infant's medical condition should arguably be the sole focus of treatment decisions (Muller, 2011). While there are parallels between selective non-treatment of neonates and selective abortion of fetuses, the focus has been on informed consent during prenatal testing when deciding whether it is acceptable to choose abortion (Dixon, 2008).

Improving the Fairness of Malpractice Compensation

Damages caps do not address the shortcomings of the current malpractice system regarding deterrence and fair compensation. A link has been demonstrated, however, between patient safety and malpractice claims (Greenberg et al., 2011). As patient safety outcomes improve, malpractice claims decrease. While damage caps could arguably decrease health care costs, with the priority health care systems placed on patient safety, malpractice claims have declined by half nationwide in the past 20 years (Kaiser, 2011). In turn, malpractice payouts have declined nationwide from \$8 billion to \$4 billion per year during the past decade (NPDB, 2012).

Proponents of a federal cap on non-economic damages of \$250,000, meant to compensate the patient for non-quantifiable harm such as pain and suffering, maintain that such a cap could significantly reduce total health care costs (CBO, 2009). These cost savings are separate from compensatory damage payouts, meant to reimburse actual costs to the patient, and punitive damage payouts, meant to deter future neglectful conduct. These

savings result primarily from a reduction in defensive medicine and avoidance of diagnostic procedures that are lacking in any benefit (or not likely to result in any further information that would contribute to an accurate diagnosis) (CBO, 2009a; Nelson et al., 2011). In contrast, opposition to damages caps is based on the view that caps unfairly penalize the most severely injured patients and are unlikely to reduce health care costs significantly (\$5.4 billion is less than 1 percent of the total health care costs). Moreover, medical accountability could be reduced and deterrence weakened by damage caps, resulting in an additional 4,800 patient deaths per year (Kaiser, 2011). In other words, it appears that damage caps disadvantage the most severely injured patients in return for the promise of only slightly lower health care costs for all (Nelson et al., 2011).

Compensating Participants Injured in Medical Research

The requirement of informed consent is based on fairness and respect for the personal autonomy of participants who volunteer to participate in medical research; consent embodies the need to respect participants and their autonomous decisions (Pike, 2012). Given the difficulties of compensating every injured research participant, along with the difficulty of recovering damages through the U.S. judicial system, plus the prevention of recovery altogether by research participants outside the United States, the result is substantial unfairness in the nation's clinical research sector. Moreover, the United States is a moral outlier in not mandating equitable and effective compensation to injured participants in medical research (Macklin, 2010). A fair and ethical medical research system would make injured participants whole in return for their contribution to the advancement of science (Pike, 2012).

Holding the Food Industry Responsible for Unsafe Food Products

With a general notion that the food industry is not doing enough to ensure safety of the nation's food supply, there is debate about the fairness or unfairness of holding individual executives responsible for food-borne illness, especially outbreaks resulting in deaths. Under the **responsible corporate officer doctrine**, there is no need to prove that executives actually knew that certain manufacturing activity violated the law; rather, the test is whether the executives were aware of the activity (Steinzor, 2010). One side of this debate maintains that the complexity of U.S. food regulations might result in inadequate food safety from honest mistake or confusion (Johnson, 2014). The other side maintains that food manufacturers' safety practices are not adequate to avoid unsafe food products that poison consumers (Cohoon, 2010), such as salmonella poisoning from improper testing and inspection at the manufacturing site (Pagnattaro & Peirce, 2010).

Neglect of food safety harms the nation by eroding public trust in the food industry as well as government regulatory agencies. It signals to those affected by unsafe, contaminated food products that the basic human needs of consumers matter less than the economic benefit of food manufacturers (Gostin et al., 2011). Society as a whole clearly has a stake in food safety.

Human Dignity

The U.S. Constitution seeks to enshrine human dignity as a national ideal; consequently, the worth and human dignity of everyone must be respected (Gerwint, 2011; President's Council, 2015). This focus on human dignity is premised on a belief that individuals are capable of exercising control over decisions that directly affect their lives and morally deserve to do so, as opposed to being subject to the whims of government (Shaub, 2012).

Debate often centers on how to respect human dignity involving end-of-life choices in a pluralistic society. There are at least two distinct approaches: let patients decide for themselves at what point their life is no longer worth preserving, or clarify the point after which there is no longer a social obligation to provide treatment, including LSMT (Fry-Revere, et al., 2010). Ideally, the two approaches to decision-making should converge and be balanced against one another.

Principles of Respect for Human Dignity

The principle of human dignity means a variety of things to different people, especially for end-of-life care that too often results in demeaning or humiliating care that reduces the sense of self-respect that is important to the integrity of everyone (Brownsword, 2007). While human dignity refers to respect for the inherent worth of others, it also involves shared decision-making. Respecting people's human dignity means respecting their competent decisions; disrespecting people's choices means showing disrespect to their human dignity and disrespecting their capacity to make decisions (Miola, 2006). In this instance and by definition, **competency** means someone has sufficient mental capacity to understand and voluntarily make knowing and informed decisions about his or her care, whether or not expedient.

Application of the Value of Respect for Human Dignity

Respect for human dignity is important in the interrelated legal doctrines of informed consent and the right to access high-quality health care (Fry-Revere et al., 2010; Karako-Eyal, 2011; Mansbach, 2011). These doctrines influence decisions about physicians' ethical obligations to their patients as well as patients' responsibilities in maintaining healthy lifestyles.

Honoring Patients' Consent to Non-Treatment

Human dignity has a much broader meaning than simply respecting individual patient autonomy. When patients lose their capacity to make decisions about their treatment, as in the case of Parkinson's or Alzheimer's diseases, the question of what constitutes essential human dignity arises. Forcing medical treatments on objecting people, even if they lack capacity, disregards their human dignity (Pleschberge, 2007). Providing life-prolonging treatments to individuals with borderline capacity, but who have always stated they did not want to live in a diminished state, shows a profound lack of respect for their inherent dignity as human people and their right to pursue a dignified death (Herring, 2008).

Consenting to Physician-Assisted Dying

The rights of human dignity and individual privacy, together, encompass the right of competent, terminally ill patients to consent to physician-assisted dying (Bostrom, 2010). Using the assistance of a physician to obtain a prescription for a lethal dose of medication that a patient may then decide to self-administer is ethical and legal in at least five states (Montana, Oregon, Vermont, and Washington, and one county in New Mexico). Although patients' right to die with human dignity is increasingly recognized, most states refuse to protect patients' physicians from sanctions (Tobler, 2010), maintaining that it is against public policy to permit physician conduct that results in harm. Yet, the unnecessary **chronic pain** of terminally ill patients, defined as pain lasting longer than three to six months, should be able to be treated by physicians for the sake of human dignity; intractable pain blocks

the aspiration of almost all other human values (Linares, 2012). Such treatment includes physician-assisted death under appropriate conditions.

Providing Incentives for Donation of the Human Body or Its Body Parts

The new legality of being able to donate bone marrow in return for compensation may begin to free the nation from the ethical fiction that donating human body parts for free is noble while accepting compensation is undignified (Schwark, 2011). While any attempt to assign a monetary value to the human body or its body parts, even in the hope of increasing organ supply, diminishes human dignity, the opposite is also true (Clark, 2006; Schwark, 2011). Allowing the donation of the human body and its parts increases human dignity and encompasses the value of human life. When donors give up a part of themselves in order to save the life of another, whom they may not even know, this is the very essence of valuing human life (Derco, 2010). Donors, in other words, should have the ultimate power to control what becomes of their body and its parts. To hold otherwise would be a conflict between medical progress and human dignity and privacy (Gatter, 2012).

Meeting the Need for Forcible Medication of Prison Inmates

Individuals should always have the right to protect their essential human dignity, including most instances in which criminal defendants are involuntarily subjected to antipsychotic medications for trial competence and prison safety. There is no agreement, however, on whether it is constitutional or ethical to forcibly medicate condemned death row inmates to restore their competence for execution (Sewall, 2010). The difficulty is that physicians are not actually harming criminal defendants physically, and may even be helping them under a narrow understanding of the meaning of beneficence. While the personal autonomy of criminal defendants is certainly being overridden, since the government has apparently carved out a specific exception to generally held notions of personal autonomy, much as it does with minors or the incompetent, it is not entirely clear that physicians who offer such care operate beyond the bounds of ethical medical practice and the principles of non-maleficence. *See generally* Appel, 2011. This is an instance in which the ethical values of physicians and prison inmates may differ from the ethical values of the government and the public, and may therefore differ from what is deemed ethical according to law.

Protecting the Human Rights of HIV/AIDS Patients

Health care reform measures are effective only within a human rights framework that respects human dignity and fundamental human rights (Wojcik, 2010). As a society, the question is whether, after the collection of personal health information reveals individual differences in health status, such as a positive test result for HIV, everyone should still continue to be treated the same. Some people, by virtue of their disabilities or illness, may have greater or lesser claims on society for support. Every effort should be made to ensure that HIV status information is not used for purposes that discriminate, or has the effect of infringing human rights, fundamental freedoms, or the human dignity of individuals that could lead to their stigmatization (Pompeo, 2011). All the while, there is vigorous debate over balancing human rights and individual responsibility and the right to the highest attainable standard of health, especially for people who are infected with HIV/AIDS (Kirby, 2009).

Individual Responsibility

Albert Einstein observed that the problems most individuals face cannot be solved at the same level of thinking they employed when they created them (Einstein, 1923/2015). Today, under the Affordable Care Act, a paradigm shift or change in U.S. health care is rapidly evolving. Nearly everyone now has to accept responsibility for obtaining and maintaining basic coverage.

While health has always been an individual responsibility in the United States (compared to other advanced economies where individual health is a shared ethical obligation), there is now a significant focus on prevention of disease as opposed to treatment of disease. Although individual responsibility for one's health has always been viewed as an unrestricted choice, the focus has recently shifted to emphasizing the ethical obligation to manage one's health, while stressing personal accountability for maintaining a healthy lifestyle and avoiding preventable ill health. With the newest health care reforms, the greatest power U.S. consumers of health care possess is their ability to choose healthy lifestyles (Kelly et al., 2007). At the same time, everyone is individually responsible for using preventive care services to prevent diseases from ever occurring or to delay their onset or reduce their severity (Berman, 2011).

Principles of Individual Responsibility and Self-Reliance

It is human nature to act and not be acted upon; by choosing how to respond to life, individuals can create the conditions of their lives (Covey, 1990/2014). In regard to health care, everyone has an individual and shared responsibility to make healthy decisions. Everyone is responsible for their health via their lifestyle choices, and often also responsible for their illnesses, suffering, and death. The vision of autonomous individuals is deeply ingrained in American culture; consequently, health care policies are generally framed around this individualistic archetype that anyone can do whatever they want regardless of the consequences to one's health (Berman, 2011).

Application of the Value of Individual Responsibility

The U.S. health care system defines itself in terms of health, individual responsibility, fairness, and equality (Copp, 2012). With 55 percent of health status determined by lifestyle choices, there is debate over whether health care costs should be imposed proportionately, based on one's health risks and day-to-day lifestyle choices (Davis, 2007; Solar & Irwin, 2007). Ethically speaking, the nation will be closer to achieving moral and economic fairness in health care when health status is more closely aligned with health care costs (Copp, 2012; Marmont & Wilkenson, 2005). The principles of fairness and justice require that individuals who are not compliant with their treatment regimes, who have casual sex with multiple partners, smoke tobacco, abuse medications and alcohol, refuse vaccinations, partake in dangerous activities such as extreme sports, and fail to maintain healthy weights must accept responsibility for the consequences of their day-to-day choices. These concepts of fairness and justice as they relate to health stem from notions of individual as opposed to social responsibility for individual, community, and population health.

Adopting Comprehensive Paradigms of Prevention

Health care in the United States is generally understood through the lens of American individualism. By contrast, other developed countries focus more on the **social determinants of health**, or the living conditions people experience: access to health care, early childhood

development, education, employment and working conditions, food security, housing, income and income distribution, social exclusion, social safety network, unemployment and job security, gender, race, and disability status. Social determinants are the primary factors that shape people's health, not medical treatments (IOM, 2011).

Although each individual bears personal responsibility for his or her own health, two different, but non-exclusive, paradigms of preventive health prevail in the United States. The public health paradigm focuses on population-based primary prevention by focusing on social determinants of health (Berman, 2011). Such interventions seek to prevent illness or injury from ever occurring by preventing public exposure to risk factors. For instance, food security is addressed by regulating the manufacturing of foods.

By contrast, the individual responsibility paradigm focuses on secondary and tertiary preventive health once an individual is ill (Tyler, 2012). Secondary prevention focuses on expanding access to health care by screening, testing, and detection of early risk factors in individuals before disease becomes symptomatic (such as hypertension), and early treatment (such as adherence to blood pressure treatment regimens). Tertiary prevention seeks to prevent a worsening of symptoms in individuals already suffering from a disease by encouraging healthy lifestyle choices and aggressive symptom management.

Choosing Healthy Lifestyles

The consensus holds that it is ethical to impose extra health care costs on individuals who choose unhealthy lifestyles that result in otherwise preventable health conditions (Marmont & Wilkenson, 2005). Nicotine addiction, obesity, and medication noncompliance are important societal issues that justify surcharges on anyone who smokes, or is obese, or refuses to adhere to their evidence-based treatment regimens. The roles of individual responsibility in sexually transmitted disease (STD) and immunization coverage are rapidly becoming lifestyle issues (Fan, 2012; Shapiro, 2012). When individuals make unhealthy choices that expose themselves and others to significant risk and then expect everyone else to pay for their lifestyle decisions, an expectation that is often met, this behavior creates incentives for others to act irresponsibly, or at least does not encourage others to act responsibly. It also violates the ethical standard of individual responsibility (Katz, 2010).

At the same time, and while the burden of preventable disease and illness brought on by poor lifestyle choices should be borne by the individual (Tyler, 2012), no one knows with certainty how much illness is due to a breach of individual responsibility and how much is unavoidable. For instance, no one knows how much obesity is due to a breach of individual responsibility and how much is due to or the result of blameworthy food industry practices, such as overeating of non-nutritious food, or even to biological or environmental factors, as science is beginning to investigate (Katz, 2010).

Considering Personal Responsibility Legislation

Maintaining good health is primarily an individual responsibility. Consistent with this principle is the perspective of today's health care reforms that Americans need to take increased personal responsibility for their health (Berman, 2011). At least 23 states have adopted personal responsibility laws forbidding lawsuits against the food industry, including the fast-food and the junk/snack sectors, for obesity-related harms attributed to overconsumption of food (Steinzor, 2010).

Regulating Non-Nutritious Foods

Debate over regulation of non-nutritious food is split. There is no consensus over the proper delegation of responsibility between individuals and society in general (Liu, 2012).

The issue is whether government intervention interferes with individual choice and informed decision-making.

On one side, the food industry ostensibly promotes public health solutions to obesity-related health conditions; such solutions focus attention on the choices of individual consumers and minimize the role of the food industry (Berman, 2011). The food industry maintains that restrictions on non-nutritious foods undermine individual responsibility while diminishing individual choice (Steinzor, 2010). The other side, while acknowledging the importance of individuals' responsibility for their own health, maintains that non-nutritious food advertising geared toward children is an appropriate target of regulation because of the predictable, negative impact it has on health at that population level (Berman, 2011; Liu, 2012). Today, there is a growing movement that emphasizes individual responsibility's role in the principle of justice, especially when safeguarding food products consumed by children.

Justice

This ethical value as it relates to health stems from notions of individual responsibility (as opposed to social responsibility) for individual or even population health (Tyler, 2012). The concept of justice requires that social benefits and social burdens be distributed in accordance with the demands of integrity. Justice details, at least in part, the means by which resources that are paid for are allocated (Fry-Revere et al., 2010). Justice usually involves respecting patient rights and acting fairly in the distribution of limited resources to individual patients (Mansbach, 2011).

Principles of Justice

The justice principle concerns the distribution of health care resources as well as policy decisions regarding who has access to health care. Efforts to reduce the federal deficit that could result in cuts to health care spending at the state level are not properly considering the principles of justice and compassion (Ravitch & Volcker, 2012). In this instance, many who oppose health care reform and express opposition to expansion of government health insurance because of its cost seem to be comfortable with the government's spending comparable, and often much larger, sums of money for other purposes (Dolgin, 2010).

Competing Interests: Justice and Compassion in State Medicaid Spending

Justice and compassion balance competing economic interests. On one side there is a health care system that demands fair compensation for the care it renders. On the other side are the human rights of patients who are demanding access to the U.S. health care system. Justice and compassion see the intertwined interests of the U.S. health care system and the cared-for patients as closely linked with each other. The principles of justice seek a fair resolution between these competing interests. Principles of compassion see the interests as importantly intertwined as opposed to simply competing. *See generally* Held, 2006.

The nation's failure to honor the historical enactment of Medicaid, where public health insurance was to assure equal access to high-quality care to everyone in need of it, has caused a degenerative effect in social justice. Many point to institutional failures as the problem with the U.S. health care system (Foster, 2010). One side cites a failure to understand public perceptions of justice and the other side cites the lack of commonly accepted principles of the ethics of compassion. Both sides are partially right. For instance,

the states' growing gaps between entitlement spending for government health insurance and tax revenue are becoming unsustainable (Ravitch & Volcker, 2012). Note, however, that **entitlement spending**, by definition, includes all tax expenditures, such as student loans and scholarship grants, home mortgage interest deductions, and failure to tax the earnings of qualified pension plans, not simply spending for government health insurance (Adamy & McGinty, 2012).

Nevertheless, the challenges of spending on health care are squeezing spending on education, infrastructure, and other government services (Corkery, 2012). While the principles of justice and compassion consider the limits that may be appropriate for government health insurance spending, neither principle can answer the question of whether taxes should be raised or cut, nor can propose specific spending cuts for the states (Ravitch & Volcker, 2012). Both ethical principles are ideal for a perfect world, but neither principle provides precise guidelines for living in an imperfect world in which the choices and decisions that must be made are seldom clear-cut (Held, 2006). Neither ethical principle provides clear answers on whether simply fixing taxes to raise more revenue can fix the government health insurance problem, nor whether there is a need for deep cuts to public benefits and entitlements (Corkery, 2012).

Intertwined Interests: Justice and Compassion in Malpractice

The principles of justice and compassion assume responsibility for reducing the risk of malpractice (Raper, 2011). Principles of justice extend compassion to patients harmed by medical errors, especially vulnerable populations. Principles of justice are used as a backdrop to consider questions about the law and its impact on patient compassion. Justice and compassion are both recognized as the foundation for remediation of malpractice claims (Pike, 2012).

Defining Malpractice in Terms of Compensatory, Distributive, and Social Justice

Social risks, the economic and societal conditions that affect everyone's health, such as the ability to access affordable health insurance, are shared by everyone. Under the principles of justice, compensating victims of medical errors is constrained by the requirements of distributive justice, which mandates that the needs and resources of society be taken into account when compensating malpractice claims (Smith, 2009).

At the same time, when medical errors are caused by fault-based conduct, victims who seek compensation through malpractice claims are constrained by the requirements of compensatory justice, which mandates that the resources of the culpable party be taken into account for compensation purposes, in contrast to the resources of society (Culhane, 2007). *Compensatory justice* is the form of justice that seeks to redress injury even when no fault or blame is associated with the injury (Pike, 2012). By definition, compensatory justice refers to the extent to which victims are compassionately, fairly, and justly compensated for their injuries. Just compensation is proportional to the harm inflicted.

The ethical principle of **social justice** seeks to redress medical errors that result in malpractice claims by focusing on systems-oriented solutions to patient safety (Raper, 2011). By definition, social justice refers to the idea of creating a society based on the principles of equality and social solidarity, that understands and values human rights, and that recognizes the dignity of every human being. The health care industry and the professionals who work in the U.S. health care system, by and large, strive to be an expression of this ideal.

Application of the Value of Justice

Justice is more than neutral application of the law. Comprehension of the law must be subservient to real life, rather than real life being subservient to the law (Crowe, 2010). In this instance, the animating principles of three of the kinds of justice are distinct, for while corrective justice applies only where a particular individual and action are identified, the principles of distributive and social justice apply in every circumstance (Culhane, 2007).

Providing Universal Access to Affordable Health Insurance

The nation's **social contract** is the U.S. Constitution, which binds American society together in the interests of not only justice but also compassion, equality of opportunity, and fairness (Rawls, 1993/2005). The submission of unbridled self-interests to "government of the people, by the people, for the people" informs the heart of American democracy (Lincoln, 1863/1953). The idea of this nation's social contract of "we the people" in the Preamble of the U.S. Constitution is that everyone places their interests under the direction of the general will, and the group receives each individual as an indivisible part of the whole (Rousseau, 1762/2012). The whole of American society is greater than any individual, and the whole has a social responsibility to each individual part.

The scope of this social contract was reexamined by the U.S. Supreme Court when the constitutional validity of the Affordable Care Act was initially decided. The validity of the health care reform law rested on whether Congress possessed the right to mandate that nearly everyone purchase and maintain health insurance. In 2012, the U.S. Supreme Court recognized the right of Congress to expand the role of the federal government in health care and to mandate that nearly everyone obtain health insurance. *See National Federation of Independent Business, et al. v. Sebelius, et al.*, 132 S.Ct. 2566 (U.S. Supreme Court 2012). In other words, Congress and the U.S. Supreme Court both recognized that improvement of the enduring and complex problems of the U.S. health care system is virtually impossible without a federal response (Gostin, 2008).

Almost half a century earlier, in 1965, the social contract was also examined when the constitutional validity of government health insurance was questioned by opponents of those programs. Then, the issue was whether Congress possessed the right to expand its Social Security legislation to include government health insurance coverage for the nation's most vulnerable populations. Since 1965, government focused on the consistent application of the ethical principles of justice in government health insurance (Held, 2006).

The principle of justice has always sought to focus on questions of equality of opportunity and fairness. Equality of opportunity means always asking whether patients with government health insurance have equal rights and equal access to the same level of care that is equal in scope to patients with private health insurance. Fairness, in contrast, means asking whether the provision of care is always impartial; are patients with private insurance favored over patients with government coverage? *See generally* Herring, 2008.

Today, health care laws and reform are changing the focus of health insurance. While accepting the relative rights arising from government insurance programs, the focus is now on social obligations that are undertaken for ethical reasons (Rawls, 1993/2005), ostensibly for the nation's common good. In other words, the right to access affordable health insurance is an entitlement that arose from the concept of human dignity and was freely granted by expansion of the nation's Social Security legislation. The principles of ethics surrounding what is owed to Americans are based on the values of justice that have been accepted by society to be legitimate for the past half-century. Health care laws and reform are not neutral;

both are directed toward justice. Today, health insurers are being forced to return to their role as social protectors (McKoy et al., 2005).

Setting Treatment Priorities

Issues regarding setting treatment priorities and allocating medical products and services fall under the justice principle (Katz, 2010). For instance, deciding whether to add newer medications in addition to older less expensive medications, as well as brand-name versus generic products to a hospital's formulary list for dispensing medications to patients, is influenced by the justice principle (Kesselheim, 2011). In addition, the justice principle is implicated when health insurers make decisions based on cost efficiency, such as requiring patients to try generic medications before agreeing to cover brand-name products. Like medication decisions, patients may not always be given the necessary information to decide whether they should select a more expensive medical device with a higher level of long-term safety versus a less expensive device with short-term benefits (Cornell, 2012).

While the justice principle is used in prioritizing patients in an emergency or in trauma settings or those on organ transplant wait lists, it also affects patients seeking preventive care, including the allocation of vaccines and the time of physicians (Wolfson, 2007). The justice principle also applies to patients who are not dying or comatose but who live with intractable pain, sometimes from the medications and technologies that are keeping them alive. In such cases, there may be a higher ethical obligation to provide end-of-life comfort care; the provision of such palliative care may often be more ethical than life-prolonging treatments.

Redressing Medical Errors

What the health care industry owes to patients who are the victims of medical errors is a controversial issue (Raper, 2011). Perhaps because the issue of malpractice seems too difficult to answer, most answers concerning the ethical obligation to assist injured patients focus on specific events, such as medication errors, misdiagnoses, or surgical blunders. Thus, debate surrounding this issue is often constrained or does not take into account the

ETHICAL DILEMMAS 2-3

3. Do MECs have the right to debate the merits of treatment decisions, or is this debate solely within the purview of individual patients and their families?
4. Should MECs develop information and guidelines, and offer support to physicians who are assisting individual patients and their families in deciding what probability of success determines whether a treatment is worth undertaking (a question of odds), and what quality of outcome is worth undertaking a treatment (a question of ends), or should MECs comment on such matters only after they are presented by medical professionals?
5. Should MECs be involved in decisions between physicians and individual patients and their families about when the benefits of treating terminal illnesses, such as end-stage cancer, with chemotherapy and radiation may outweigh the risks to quality of life, or should MECs comment on such matters only after they are presented by medical professionals?

broader social issues of justice and fairness to the needs and resources of society. Although this is understandable and perhaps even politically necessary, the question is whether the health care industry should settle for the results of a narrow approach to malpractice. See generally Culhane, 2007.

Using Alternatives to Litigation: No-Fault Malpractice Insurance

All three principles of justice would use a collaborative model to resolve successful malpractice claims, such as no-fault insurance as an alternative to the current litigation system. The central premise of the **no-fault insurance** model is that patients need not prove negligence to access compensation; they must prove only that they have suffered an injury, that it was caused by their medical treatment, and that it meets whatever severity or other threshold criteria apply, much like the workers compensation system. Compensation to injured patients is justified by all three principles of justice by positing consent to pay those harmed. Even though consents to compensation for medical errors might affect the financial interests of the government (through its government health insurance programs) and the health insurance sector (through its private health insurance), it would avoid requiring the malpractice insurance sector to resort to the legal system (Culhane, 2007). No-fault insurance may, however, be less able to satisfy the principles of non-malefeasance.

Non-Malefeasance

Non-malefeasance or *primum non nocere* (“first of all, do no harm”) imposes an ethical obligation not to inflict harm on others. Non-malefeasance designates the obligation of not doing harm to other people, whether deliberately or through negligence (Karako-Eyal, 2011). The principle of non-malefeasance may be combined with the principle of beneficence into a single principle where the principle of non-malefeasance is one of the components of beneficence. Although beneficence and non-malefeasance are similar and closely related, they are distinguished from each other and presented as two different principles so as not to obscure distinctions between the two (Beauchamp & Childress, 2012).

Principles of Non-Malefeasance

Non-malefeasance refers to the principle of doing no harm. Harmful care should never be prescribed; conversely, only care unlikely to be harmful should ever be prescribed (Beauchamp & Childress, 2012). At the very least, patients should understand the risks and benefits of any care; the likely benefits should outweigh the likely risks. In practice, however, most medical treatments carry some risk of harm. In some situations where the outcomes without treatment are life-threatening, risky treatments with a high chance of harm are justified, as the risk of not treating is also very likely to do harm (Ausiello, 2012). Clearly, non-malefeasance is not an absolute principle; it balances against the principle of beneficence (Beauchamp & Childress, 2012). In other words, the principle of beneficence declares that what is best for each person should be accomplished; the principle incorporates both the negative ethical obligation of non-malefeasance as well as the positive ethical obligation of beneficence, to do that which is good (Wright, 2006).

Application of the Value of Non-Maleficance

It is widely believed that anything done in the public interest is good for society and good for the individual members of society; when the “anything” involves people’s health, this belief is rapidly converted to law (Cooper, 1979). While the extent to which non-maleficance should be followed is often debatable because there is no agreement on what constitutes harm, the ethical principle generally accords with the traditional roles assigned to physicians.

Mandating Vaccinations against Infectious Disease

Non-maleficance is one of the cornerstones of individual health care decisions. For every individual right, there is, however, a corresponding responsibility to consider the needs of the common good. Often, the benefits and harms between rights and responsibilities are balanced when deciding what the most ethical decision should be. In the United States, this balancing of interests is often done within the framework of utilitarianism, where the ends justify the means. In this instance, the principle of non-maleficance requires compulsory vaccination in order to advance society’s common good and secure the public-at-large from exposure to the spread of infectious disease (Smith, 2009a).

Determining Best Courses of Treatment

The task of physicians, in conjunction with their patients, is to decide upon the best course of treatment for a specific medical need, using the principle of non-maleficance, as well as the principles of respect for personal autonomy, beneficence, and justice as guideposts as opposed to hard-and-fast rules (Fry-Revere et al., 2010). For instance, chemotherapy inhibits the growth of and ultimately kills cancerous tumors, but it also harms or kills healthy cells; the administration of oncology medications markedly harms (in the relative sense) patients. While the intended outcome of medical treatment is in the best interest of halting the growth of cancer, the action itself defies the ethical obligation to do no harm, because the effects of chemotherapy on the human body are devastating.

Protecting Patient Privacy and Confidentiality

Health care institutions and individual physicians, nurses, and other health care professionals who fail to protect patient privacy and confidentiality violate the principles of non-maleficance (Bauer, 2009). Violations of the principle of non-maleficance are especially problematic in the context of women’s reproductive choices, especially for women undergoing abortions in states requiring parental consent (Laufer-Ukeles, 2011). A second controversial area is the extent to which physicians may speak to patients about firearms and enter any solicited information into medical records (Hethcoat, 2011). Non-maleficance and preservation of personal autonomy support the need to protect patient health and welfare in both these instances.

Although unauthorized use of personal health information erodes public trust in the U.S. health care system, disclosure of individual patient information must be balanced against the principles of beneficence (the negative ethical obligation of non-maleficance) to protect the public’s health. For instance, states are authorized to review computerized databases to track prescription medications for controlled substances in an effort to identify and control drug abuse (Orentlicher, 2011) and conduct surveillance on STDs and HIV/AIDS (Fan, 2012).

In a U.S. Supreme Court decision reviewed in Chapter 4 of this text, the Court determined that the pharmaceutical industry may purchase certain physician-identifiable

prescription data without the consent of physician-prescribers for the purpose of marketing medications; the Court determined that this data-mining neither violates patient privacy and confidentiality nor harms individual patients (Boumil et al., 2012; *Sorrell, et al. v. IMS Health Inc., et al.*, 131 S.Ct. 2653 (U.S. Supreme Court 2011)). Thus, the principle of non-maleficence is not mutually exclusive from other ethical principles; rather, the challenge is figuring out what insight non-maleficence provides.

Truthfulness

Truthfulness, honesty, and transparency are key attributes of health care ethics. Truthfulness in this context includes honestly representing medical products, health care services, and health insurance coverage, including clear and adequate disclosure of all material terms. Health care providers and insurers must clearly disclose all that influences patients' treatment decisions with integrity and transparency.

Principles of Truthfulness

Consensus for health care reform need not be unanimous for it to be legitimate, although the higher the level of agreement the better. Each of the stakeholders in reform of the U.S. health care system should consider their respective interests and values. Health care industry leaders must develop a greater degree of genuine respect for government regulators and operate their organizations with integrity (Osborn, 2010).

To sustain an always fragile consensus on health care reform, supporters of reform, as well as opponents to reform, cannot obfuscate or manipulate the truth, lest either side find itself in opposition to the people upon whom they rely for legitimacy (Goolsbee, 2010). For instance, opponents of health care reform claim the law would add \$701 billion to the deficit, while supporters claim the law will save society \$1.3 billion (Annenberg, 2011). In this case, both sides are misrepresenting the fiscal effect of the Affordable Care Act (Foster, 2010); meanwhile, repealing the law would worsen the federal deficit over the next 10 years by \$230 billion (CBO, 2010a).

Application of the Value of Truthfulness

Benjamin Franklin explained his approach to making truthful decisions by describing what he did when he had a difficult decision to make. "To get over [any uncertainty] . . . my way is to divide half a sheet of paper by a line into two columns; writing over the one Pro, and the other Con. Then . . . I put down under the different heads short hints of the different motives . . . for and against the measure . . ." (Franklin, 1772/2012).

The U.S. health care system came under siege for its truthfulness and integrity when it was discovered that up to one-half of the nation's health care was devoted to medical treatments that did not improve health (IOM, 2011, 2011a, and 2009; Todd, 2011), was ineffective (Commonwealth Fund, 2011), and often made patients worse (Kimbuende et al., 2010). For instance, physicians are more likely to order diagnostic tests when they conduct the testing in their offices or have an ownership interest in the testing facility. Using the Franklin decision-making technique, some physicians are clearly more likely to take particular actions once they see how well they benefit from self-referrals. At the same time, threats to veracity and truthfulness can be occasions to define industry standards and regulations. Responsible behavior by individuals can be reinforced by the fair application of clear regulatory rules and prohibitions (Osborn, 2010).

Preventing Conflicts of Interest

Physicians should not allow conflicts of interest or bias to influence their decision-making (Sax, 2012). Above all, they must act with the highest levels of truthfulness and integrity in their relationships with patients so as to avoid even the appearance of impropriety (Osborn, 2010). While some conflicts are difficult to avoid, physicians have a responsibility to avoid entering such situations whenever possible. For instance, physicians are prohibited from referring patients for certain services to entities in which the physicians have a financial interest without self-disclosure to their patients (*see* CMS, 2011). Kickbacks and conflicts of interest affect the integrity of treatment decisions.

Another instance, based on current scientific data, is the removal of amalgam restorations from non-allergic patients for the claimed purpose of removing toxic substances from the body, when such treatment is performed solely at the recommendation or suggestion of a dentist. Such recommendations are unethical, because they stand to benefit only the dentist who is paid for the unnecessary care (Sfikas, 2005).

Licensing Physicians, Nurses, and Other Health Care Professionals

In addition to biological factors, illness can result from the loss of intrinsic values of any of the defining characteristics of humans, such as conscience and the instinct for truthfulness (Maslow, 1962/2011). Consequently, state boards may order medical evaluations when they have probable cause to believe that a licensed professional poses a risk to patient safety and well-being. When a conflict arises between a professional right to pursue a medical profession and the government's right to protect its citizenry, the professional right must yield to the state's power to prescribe reasonable rules and regulations in order to protect the state's people from unfit and dishonest physicians.

Eliminating the Corporate Practice of Medicine Doctrine

Good moral character, including simple honesty and truthfulness, is a requirement for licensed health care professionals. The **corporate practice of medicine doctrine** seeks to keep the economic and business incentives of corporations from interfering with the duties of licensed physicians (Hoffmann, 2010). Corporate enterprises cannot, under this doctrine, properly protect truthfulness because of their overriding concern with financial success. This predilection allegedly operates to slant conduct in favor of the corporation. Consequently, physicians maintain that it is inappropriate for corporations to attempt to practice medicine, a profession involving personal trust, truthfulness, and confidential relations (Sparks, 2012).

Nevertheless, as the retail clinic model for delivery of health care expands, like the walk-up clinics in CVS and Wal-Mart, the way Americans receive care is rapidly changing. While all business decisions affecting patients medically must still be made by licensed physicians in retail clinics, the professional autonomy of physicians from corporations that is framed around the value of truthfulness is quickly becoming obsolete (Ameringer, 2011). As retail clinics are more fully integrated into the medical community to help address the medical needs of all, the time is fast arriving to eliminate the corporate practice of medicine doctrine and adopt enterprise liability to better promote the efficiency and quality of U.S. health care (Ballerini, 2010). **Enterprise liability**, in this instance, is defined as the shifting of liability away from individual physicians, nurses, and other health care professionals and onto the corporate owners of retail clinics. *See generally* Hoffmann, 2010.

Reporting in Incentive-Payment Systems

Health care policy should create incentives for self-reform such as self-reporting of medication compliance, activity levels, and individual dietary regimes, as well as corporate reform, such as self-reporting of preventable or potentially avoidable events in hospitals. Yet, such individually reported conduct is dependent upon the truthfulness of individuals' self-reporting. Truthfulness and responsible behavior must be reinforced by the fair application of clear rules of reporting if incentive-payment systems are to succeed (Osborn, 2010).

How individuals and health care organizations should be allowed to reform themselves for incentive payments alone is debatable, as there are limits to the willingness of humans to credibly self-report discretionary behavior (Marciarille, 2011). The value of truthfulness and the human tendency to dissemble facts are important considerations in premium-oriented approaches to care, such as in care coordination of chronic diseases and in self-reporting of recidivism for hospital-acquired infections and other potentially avoidable events.

Prescribing Off-Label Medications and Other Medical Products

The value of truthfulness is related to other values such as professional competence and diligence in prescribing. Off-label prescribing, in particular, goes directly to the relevance of the truthfulness of medical and scientific information (Osborn, 2010). For instance, the medical products and services industry is prohibited from promoting off-label uses in any way, and physicians and other health care prescribers are increasingly being required to use evidence-based medicine in their treatment and prescribing decisions. This is so even where the accuracy and truthfulness of off-label use appears to be beneficial to patients. *Contra* Klasmeier & Redish, 2011 (advocating off-label prescribing).

Advertising Non-Nutritious Foods to Children

American consumers of health care have the right to demand safety and truthfulness in product labeling from the food industry. Ethically and by law, the food industry should truthfully label food products, lead efforts to recall unsafe foods, as well as restrict (or ban) non-nutritious food, especially food targeted to children (Zacher, 2011). Marketing directed at children, whether for foods purchased or purchasable by children, is analyzed from the perspective of children; truthfulness is measured by the impact on children, not others to whom the advertising is not primarily directed (Liu, 2012). When the food industry does not support healthy choices and induces children to request and think they prefer non-nutritious foods because of the use of cartoon characters and other promotions on packaging, this practice violates the value of truthfulness (Pomeranz, 2011).

Universal Principles of Ethics

People mistakenly think the world is how they perceive it and that universal values are, or should be, as they know them personally. Certain principles of ethics, as illustrated in **FEATURE BOX 2-6**, underlie most American values. With any principle, it is important to identify its core underlying values; when expressions of a principle are linked to universal values, the principle is more likely to gain acceptance (Noyes, 2012).

Each of these universal principles has underpinnings in the natural law. For instance, all societies emphasize the importance of compassion, and of sharing wealth with the most

FEATURE BOX 2-6

Eight Universal Principles in the American Ethic

- Ethical issues arise when actions or situations involve actual or potential harm to someone or something. Often these issues are also dilemmas that present two or more alternative solutions. An established and agreed-upon set of values and principles is needed to guide those who are charged with deciding so they can be confident in the ethical quality of their decision.
- The action that provides the greatest benefit is the most ethical. This principle prevents partiality and narrowness when deciding on a course of action. The greatest benefit also includes the *to the greatest number* principle, which further ensures an inclusive quality to decisions.
- All actions should strive for the highest quality outcomes, not just high-quality outcomes. Only the highest quality outcome can include the greatest benefit to the greatest number of stakeholders. It is the best course of action given the knowledge and resources available. For instance, a less than *highest quality outcome* decision will generally deprive patients from receiving appropriate and ethical care.
- Everyone must be accorded equal respect with regard to their status as human beings. Ethical courses of action may not intentionally harm one person while seeking to help another. Respect must embrace everyone, or it is not respect.
- Everyone must always be treated as an end, not merely as a means. To treat anyone as a means is to use them to advance self-interests, but to treat everyone as an end is to respect their human dignity by allowing them the freedom to choose for themselves.
- Everyone should be treated the same, unless they differ in substantive ways that are relevant to the situation in which they are involved. Each person and his or her health needs are different. However, respect for the value of each person must be equal, and the maximum good for each person must be included in ethical decisions.
- Whenever any member of society is treated unequally on the basis of arbitrary or material characteristics, his or her fundamental and innate human dignity is violated. The complexity of health care decisions is often overwhelming; the temptation is to take the most expedient course of action. Although practical decisions can appear to resolve the burden of the dilemma and relieve troublesome concerns, more fundamental values are needed to ensure ethical as opposed to inappropriate arbitrary decisions.
- All individuals, institutions, and the government have a responsibility to be compassionate. There exists an inherent ethical obligation to share wealth with the most vulnerable members of society, even if the less fortunate members have not always earned the wealth that is being shared. The inherent worth and human dignity of everyone must be respected; to respect some members but not others, is not human respect.

— Sources: AMA, 2012a; Beauchamp & Childress, 2012; Moore, 1903/1998; Percival, 1803/2002.

vulnerable populations of society, even if the less fortunate members have not always earned the wealth that is being shared. Only an American ethic of health care, a relatively specific set of shared ethical values such as personal autonomy, compassion, fairness, justice, and truthfulness, will in time be sufficient to support the positive and unifying forces operating

to reform the U.S. health care system (Musumeci, 2011). While individuals have moral responsibilities, the government also has moral responsibilities with respect to everyone (Noyes, 2012). Furthermore, the perceived benefit of universal principles also makes such principles human rights principles.

Difference between Legal and Ethical Decisions

Health care law and ethics, though distinct, are partners when MECs make difficult decisions and decide ethical dilemmas; neither is truly effective without the other. Both are grounded in the shared values of committee members serving on the MEC. Without grounding in generally accepted ethical principles, decisions by the MEC will ultimately be ineffective. Ethics, however, is not just important to effective decision-making; ethics is also the central intelligence for all decisions by the MEC. Ethics directs the MEC toward the common good. Ethics gives the MEC purpose and direction. Without ethics, MEC decisions would be without significance and lack meaning for the patients, families, and caregivers who work together with everyone to reach the best decisions possible. *See generally* AMA, 2012; Weinberg, 2012.

A number of issues in health care illustrate ethical dilemmas. As Tocqueville observed in his classic study of the United States, the law regularly resolves ethical differences (Tocqueville, 1835/2011). Yet, many legal issues that seem to be settled are not actually settled ethically. The continuing debates over women's reproductive rights and decisions about end-of-life care are instances where both the law and the ethics are unsettled. Although the law views the definition of conception as settled science, many ethicists accept philosophical and theological definitions of conception, not the scientific understandings of reproductive biology. Similarly, the law views the withdrawal of LSMT the same as the withholding of such treatment, and holds that withdrawing artificial nutrition and hydration is no different than withdrawing artificial ventilation; many ethicists find an ethical distinction between these actions (Orentlicher, 2010). An important goal of this text is to understand the nature of the distinctions between health care law and ethics, and to figure out how to recognize and possibly reconcile some of the differences that exist.

The Future: Socially Responsible Decisions

Although there is no commonly accepted definition of social responsibility for MECs, the expectation is that committee decisions will be socially responsible (ASBH, 2010). At its most basic level, social responsibility ensures that the policies governing MECs, as well as the decision-making processes behind the decisions they implement, are effectuated in a way that avoids harm.

Social responsibility is a key ethical obligation of MECs. If, however, notwithstanding the best of intentions, there are organizational constraints on the MEC's ability to always achieve socially responsible actions, then the definition of responsibility will have to be expanded. Social responsibility must always be about more than compliance with the law; it must also include efforts to improve the quality and equitable delivery of the health care being provided. In fact, the most critical dimension of social responsibility for MECs may well be the committee members' impact on policies affecting the organization's implementation of health care reforms. *See generally* Vogel, 2006.

ETHICAL OR UNETHICAL DECISION**Balancing Values in Treatment Decisions
by Medical Ethics Committees**

Ethics Issue: *Should medical ethics committees balance their values with the values of patients and their families when treatment decisions must be made?*

Ethics Analysis: No, MECs cannot impose their values on patients and their families; only courts have the power to overturn treatment decisions made by patients and their families when there is a conflict with what a MEC recommends. The MEC had no right to order life-sustaining feeding to continue after the ventilator was disconnected unless there was a treatment dispute with the parents of the infant; the committee overstepped its bounds by not allowing the infant to die.

Ethics Analysis: Yes, treatment decisions affecting infants are not about the values of families; they are about the human value of this particular infant and what was best for this particular infant. The MEC placed paramount value on the life of this particular infant and ordered life-sustaining feeding once the infant began to breathe on her own after being disconnected from a ventilator.

Settlement and Statutory Law: While none of the allegations in this case were proven in court before a settlement was reached, MECs are generally only consulted in situations where there is no agreement about a treatment decision. When the MEC overturned the parents' decision to withdraw life support, the MEC violated the law because only the courts have the power to do that.

— *Laurendeau v. LaSalle Hospital*, No. 500-17-048988-094 (Quebec Superior Court 2009).

CHAPTER SUMMARY

- MECs are the forum where many ethical dilemmas are reviewed and resolved by multidisciplinary teams comprised of health care professionals from medicine, nursing, law, chaplaincy, and social work.
- MECs often address the difference between what is legal and what is ethical and attempt to reconcile the two when possible.
- Laws can be applied for good or can effectuate evil. Ethics, by definition, is directed toward the common good.
- While MECs generally play an advisory role in ethics consultation for patients and their families, MECs are increasingly serving as decision-makers for health care organizations.
- MECs help health care providers develop the decision-making capacity to determine how ethical principles should be applied.
- There are ten values that often govern and guide the decision-making process of MECs when ethical dilemmas are reviewed: personal autonomy, beneficence,

compassion, equality of opportunity, fairness, human dignity, individual responsibility, justice, non-maleficence, and truthfulness.

- The expectation is that MEC decisions will be socially responsible, although there is no commonly accepted definition of social responsibility applicable to them.

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