The importance of bioethics and ethical decision making within the field of palliative care cannot be overstated. Proxy decision making, pain control, artificial nutrition and hydration, euthanasia, and withholding or withdrawing treatment all raise a variety of difficult ethical issues. Bioethics is a young, multidisciplinary field that focuses on the use of philosophical and principle-based theories to solve dilemmas in medicine and the life sciences.1 This chapter introduces the basic concepts of bioethics while focusing particular attention on practical ethical decision making at the bedside.

HISTORY OF BIOETHICS

Consideration of the moral obligations a physician has to his or her patient is by no means a recent phenomenon. In fact, medical ethics has existed since the inception of the medical profession itself. More than 4000 years ago, King Hammurabi of Babylon created the Hammurabi Code, which outlined proper conduct for physicians. Fifteen hundred years later, Greek physicians established the Hippocratic Oath, which served as the foundation for medical ethics in Western society and remains influential today.2 In 1803, the English physician Thomas Percival published one of the first secular works on medical ethics. However, Percival’s Code of Medical Ethics, which became an influential guide for Western physicians, was more of a guide to professional etiquette rather than a work focused on ethical decision making. His code employed an attitude of “what was good for the guild was good for the patient” and was guided by a paternalistic view of patient care.2 In 1847, the American Medical Association borrowed from Percival in creating its Code of Ethics, which remained largely unchanged for more than 100 years.2 However, this paternalistic view of the patient changed dramatically in the second half of the 20th century as research abuses, publications, social change, technological advances and seminal judicial opinions created a public outcry for greater patient autonomy and heralded the establishment of the field of bioethics.3,4

The roots of modern bioethics and the patient autonomy movement may be traced back to the Nuremberg trials of physicians and researchers for human subject research atrocities.5 These individuals had subjected concentration camp victims and prisoners of war to nonconsensual, harmful, and gruesome human experimentation. As a result of this trial, the first international code of research ethics—the Nuremberg Code—was created.5 The Code established that patient autonomy and voluntary decision making are integral to ethical human experimentation. Further, the Code stated that patient autonomy and voluntary decision making are integral to ethical human experimentation. Over the next 30 years, the field of bioethics was founded on several key works that included Morals and Medicine, by John Fletcher, and Patient as Person, by Paul Ramsey. These works focused less on Percival’s guild considerations and physician etiquette and more on the ethical justification of decisions, setting the stage for the development of bioethics as an independent field of scholarship.5

Key Advances

● In the 1960s, the civil rights movement created an outcry for “patients’ rights.”2–5 Adding to the force of this movement was the public disclosure of a series of human subject research abuses. In 1966, Henry Beecher published “Ethics and Clinic Research” in The New England Journal of Medicine. This seminal article
exposed several human research studies that had endangered subjects without appropriate clinical benefit or disclosure. These theoretical tests determine the morality of an action. One should “act only on the maxim whereby you can at the same time will that it should become a universal law.”

Deontological ethical theory. His theory states that there are absolute moral requirements on actions that can be determined through the use of certain categorical imperatives. These theoretical tests determine the morality of an action. Kant’s principle of universality states that one should “act only on the maxim whereby you can at the same time will that it should become a universal law.” This moral test requires that an action be applied to all persons in similar situations. If making a rule universal defeats its purpose,

### THEORIES OF BIOETHICS

Within the field of bioethics, there are several ways to approach ethical problems. Religious, philosophical, and principle-based considerations may be used in ethical decision making. To understand such ethical evaluations, it is important to be familiar with each of these various approaches. The following paragraphs provide a brief description of some of these considerations.

#### Utilitarianism

Utilitarianism is a consequence-based theory that advocates an analysis of the overall good achieved by a given action. The morality of an action is judged solely on its end result. This philosophical analysis had its origins in the writings of Jeremy Bentham (1748-1832) and John Stuart Mill (1806-1873) and advocated for maximizing the “good.” For Mill and Bentham, both utilitarians, the “good” meant maximizing pleasure or happiness. More generally, this theory asserts that all ethical decisions should entail a balancing of the costs and benefits of an action with an eye towards maximizing overall “happiness.”

Within this theory, there are two separate utilitarian schools of thought: rule utilitarianism and act utilitarianism. A rule utilitarian operates on precedent. Once it is established that a general rule serves the greater good, they advocate that such a rule should be adhered to regardless of individual consequences. An act utilitarian is more pragmatic. Rather than setting down broad social rules, this type of utilitarian advocates maximizing of the “good” in each separate situation. Thus, an act utilitarian does not adhere to strict rules of general good. For example, a rule utilitarian may advocate that a clinician should always be honest with patients. The justification may be that honesty in the medical profession is an important standard that generates patient trust and results in better patient disclosure and care. However, an act utilitarian may choose not to be honest in a given clinical situation if the beneficial consequences may be maximized by a lie.

#### Deontology and Kantian Thought

Deontology is a theory that is in almost direct opposition to utilitarian thought. This philosophical theory advocates that actions are morally right if they are consistent with a predetermined moral rule. Immanuel Kant (1724-1804), a German philosopher, established the most famous deontological ethical theory. His theory states that there are absolute moral requirements on actions that can be determined through the use of certain categorical imperatives. Kant’s principle of universality states that one should “act only on the maxim whereby you can at the same time will that it should become a universal law.” This moral test requires that an action be applied to all persons in similar situations. If making a rule universal defeats its purpose,
it is immoral. In the previous example, if deceiving patients were a universal rule, no patient would believe such deceptions, and any attempt to lie would fail. Therefore, Kant would hold that such an action (i.e., deceiving a patient) is empirically immoral because it cannot be universally applied. The problems with this strict theory are readily apparent. Many actions in the practice of medicine are pragmatic. As a result, it is doubtful that such a strict adherence to this rule would result in beneficial and appropriate results in all situations.

Perhaps the more useful theory for the ethical assessment of medical decision making and patient care is Kant’s second categorical imperative: “act in such a way that you treat humanity whether in our own person or in the person of another, always at the same time as an end and never simply as a means.” Applying this principle to the practice of medicine requires that clinicians treat patients as ends and not as means. Accordingly, although there may be clinical indications for diagnostic tests, procedures, and medical treatment, the patient’s outcome and perspective dictate that objective criteria are secondary to a patient’s informed wish. In this sense, the second categorical imperative can be applied to practical clinical decision making and bioethical deliberation. In contrast to both rule and act utilitarian thought, such a consideration appears to put more stock in the patient’s perspective.

Principle Theory

Beauchamp and Childress, in Principles of Biomedical Ethics, established a model for bioethical decision making that, although not a theory, incorporated some aspects of both utilitarian and deontological thought. This model, principlism, advocated the use of four basic considerations in ethical deliberation: respect for autonomy, beneficence, nonmaleficence, and justice. Each consideration is prima facie binding but may be overridden by another conflicting consideration for good reason. According to this model, clinicians should weigh each of these considerations in determining the appropriate action. This allows clinicians to exercise more discretion in decision making than in the more stringent philosophical models of utilitarian thought and deontology. However, this model does not always provide a single solution. Rather, it provides a checklist of ethical considerations, much like the clinician’s review of systems, which helps to ensure that all the relevant issues are considered.

Respect for Autonomy

The word autonomy is derived from the Greek autos (“self”) and nomos (“rule”) and therefore means “self-rule.” Autonomy is defined as an act or decision that a patient undertakes (1) intentionally, (2) with understanding, and (3) in the absence of controlling influences. If a patient acts intentionally, with understanding and without controlling influence, principlism considers this to be an autonomous act that should be respected by a provider.

Beneficence

The principle of beneficence refers to “a moral obligation to act for the benefit of others.” Such an obligation is the focus of utilitarian thought. Within principlism, it simply requires consideration of the beneficial outcomes of an action.

Nonmaleficence

The principle of nonmaleficence is closely associated with the well-known medical ethics maxim primum non nocere, or “first do no harm.” This doctrine has its foundation in the Hippocratic Oath. Essentially, consideration of this principle requires an assessment of the harm that may result from a decision.

Justice

Justice refers to consideration of distributive justice and fairness. Similar to rule utilitarian thought, justice considerations refer to balancing burdens and benefits in resource allocation. Such considerations reflect a desire to use limited medical resources to maximize patient benefit. In other words, the principle of justice requires that medical resources (e.g., costly treatments, scarce hospital beds) be allocated in a way that is based on clear criteria and equity.

Virtue Ethics

Unlike the rule-based, principle-based, and obligation-based theories, virtue ethics emphasizes the pursuit of virtuous characteristics by health care providers. Integrity, fidelity, respect, sympathy, fairness, skill, wisdom, and knowledge are characteristics to be aspired to by providers that guide appropriate behavior. This notion of ideal medical virtues is embodied in the Hippocratic Oath and dates back to Aristotle and Plato. In addition to ancient philosophers, modern medical practitioners such as Pellegrino advocate the importance of virtue ethics in modern biomedical ethics. Of note, this concept focuses on the appropriate motivation of a health care provider. Rather than imposing artificial imperatives, codes, and models, virtue ethics advocates that health care providers adopt virtuous characteristics that will, themselves, serve to guide practitioners to the appropriate ethical decisions.

Casuistry

A casuistic approach to biomedical ethics is a unique case-based consideration of ethical problems. This ethical theory was at its height in medieval and early modern philosophy but has experienced a recent revival. Casuistry uses history, past paradigmatic cases, and factual circumstances to determine appropriate decision making. It favors analogy over deductive reasoning and considers biomedical ethics in terms of past precedent. Like legal case law, a casuistic approach considers the specific facts of an ethical dilemma and compares them to past similar ethical cases in order come to a decision. Theories and rules serve as guidelines for a casuistic review that focuses on practical decision making.

Religious Considerations

An exhaustive treatment of religious beliefs is beyond the scope of this chapter. However, a brief consideration is essential. Of note, the major monotheistic religions—Judaism, Christianity and Islam—have key moral norms
that are absolute rules from above. Additionally, most of these religions include some form of the “Golden Rule.” The Golden Rule states that you should do unto others as you would have done unto you; that is, a physician should treat patients as he or she would want to be treated in a similar situation. Other religions, such as Buddhism, Hinduism, and Jainism, believe in concepts of karma or a cosmic moral order that create consequences for an action. Clinicians should be aware of cultural and religious beliefs that might influence a patient’s actions and decisions and be sensitive to these considerations. Although religious beliefs may appear to be in opposition to logic or appropriate care, they must nevertheless be respected as an autonomous wish.

DECISION MAKING

In recent years, autonomy has emerged as the single most important factor in practical clinical decision making. Though principlism remains a useful construct for evaluating the facets of an ethical case in an orderly manner, autonomy has been most emphasized by ethicists, courts, and clinicians. However, respect for autonomy reflects other ethical philosophies as well. Deontologic concerns for respect of the person are clearly considered by respecting patient autonomy. Additionally, autonomous decision making has aspects of virtue ethics as well. As outlined later, autonomous decisions can occur only when there is full disclosure and open communication. Effective disclosures often require physicians to foster an environment of integrity, fidelity, and trust between themselves and their patients. Such considerations are consistent with the teachings of virtue ethics. Finally, much of a patient’s or surrogate’s decision making may be guided by religious, faith-based beliefs. As a result, decision making may also encompass religious considerations.

In evaluating decision making, three basic categories of patients must be addressed: patients with the capacity to make medical decisions, patients who have lost that capacity, and patients who never had the capacity. A clinician must make a preliminary determination of the type of patient he or she is dealing with before an analysis may proceed. Once this is established, the clinician must employ a tailored assessment of decision making dictated by the type of patient.

Decision-Making Capacity

A prerequisite to informed consent is a patient’s intact capacity to make decisions. Evaluation of such capacity is a decision-specific determination that focuses on the patient’s ability to understand and communicate a rational decision. In complicated or difficult cases, a neurologist or psychiatrist should be consulted to make this assessment. The key considerations in an assessment of decision-making capacity are the following:

1. Ability to express a choice: The person must be able to express his or her choice and communicate that choice.
2. Ability to understand relevant information: The person must be able to understand information about the purpose of treatment, remember the information, and show that he or she can be part of the decision-making process.
3. Ability to appreciate the significance of the information and its consequences: The person must understand the consequences of treatment refusal and the risks and benefits of accepting or refusing treatment.
4. Ability to manipulate information: The person must be able to engage in reasoning as it applies to making treatment decisions (e.g., use logical processes, weigh treatment decisions, manipulate information about treatment decisions).

It is usually inappropriate to assume that a patient with mental pathology, sedation, or cognitive deficit lacks decision-making capacity. Instead, a formal evaluation is necessary.

Capacity is different from competence. Competence is determined by a court of law and uses issues of capacity in evaluating the legal ability to contract, write wills, or conduct one’s affairs. Because the standard of competence varies by jurisdiction, an exhaustive discussion of competence is beyond the scope of this chapter.

Patients with Decision-Making Capacity and Informed Consent

As noted earlier, self-determination and respect for a patient’s personal choice have become the guiding principles for physicians with regard to ethical issues. Patients who have decision-making capacity must give informed consent before most treatments or procedures may be performed. This informed consent standard has its roots in the common law of both England and the United States. Treatment of patients without such consent was and is considered a battery. In 1914, Justice Cardozo, in the often cited case of Schloendorff v. Soc’y of New York Hospital, stated that “Every human being of adult years and sound mind has a right to determine what shall be done with his own body: and a surgeon who performs an operation without his patient’s consent commits an assault for which he is liable.” This rule governing consent remains in the American and English common law today.

Within bioethics, respect for autonomy can be traced back to the Nuremberg Code, the Belmont Report, and principlism. Informed consent respects this concept by requiring a patient’s authorization of a medical intervention or involvement in research. Informed consent requires three basic elements: (1) disclosure of information, (2) comprehension, and (3) voluntariness. A patient must be informed of the risks, benefits, and alternatives of a procedure, and a clinician must ensure that the patient understands this information. Finally, a patient’s decision must be voluntary. Only decisions that are substantially informed and free of constraint or controlling influence are considered autonomous. Of course, no decision is ever truly free of influence or duress. Often, patients feel pressure from family, clinicians, careers, and social situations that influence their ultimate decision making. This is why an autonomous decision requires only that the patient be “substantially free of constraint” and not completely free (See Chapter 18 for a more extensive treatment of practical clinical considerations.)
Patients Who Lose Capacity

If a patient lacks decision-making capacity, other mechanisms for decision making must be explored. Currently, medicine has multiple mechanisms for respecting a patient’s autonomy in the face of mental incapacity. Living wills are one such mechanism. These written declarations are a type of advance care directive; they are created in anticipation of incapacity and may dictate which interventions a patient wishes to prevent or have performed16 (see Chapter 19).

By following the dictates of such documents, a health care provider respects a patient’s autonomous wishes. Do not resuscitate (DNR) orders are limited forms of living wills in which patients make decisions regarding future medical care. In addition to living wills, patients may execute durable powers of attorney. These legal documents give a proxy the power to make medical decisions once a patient loses decision-making capacity.16 Durable powers of attorney and living wills are both advance directives, but they are not mutually exclusive. An individual named under a durable power of attorney may use the patient’s living will to guide appropriate decision making.16 If patients do not have either a durable power of attorney or a living will, health care professionals should consult their local governmental rules and laws regarding appointment of proxy decision makers. In the United States, most states have family consent statutes or common law that specifies the appropriate proxy decision maker.16

Surrogate decision makers for previously competent patients exercise patient autonomy by making decisions based on the “substituted judgment” of the incapacitated patient.8,14,15 Typically, proxies are family members or close friends who are familiar with the incapacitated patient.15 Such individuals are most likely to understand the incapacitated patient’s preferences and accurately predict what the patient would decide if he or she were competent.13,15 In spite of this thinking, such substituted judgment decisions have been shown to be extremely inaccurate.19

However, there is arguably a morally defensible reason for following such surrogate decisions.13 First, respecting patient proxy decisions indirectly respects patient preference. In the study by Seckler and colleagues of surrogate decision making, 87% of surveyed patients believed that family members would make accurate or fairly accurate decisions.15 In spite of the poor correlation between surrogate decisions regarding substituted judgment and patient preference, such data imply patient confidence in family members’ ability to choose. This confidence may be illustrative of patient desire to transfer decision making to family members. Accordingly, respecting surrogate decision making may indirectly pay respect to an incapacitated patient’s preference. Additionally, other factors, such as a family member surrogate’s financial responsibility and vested emotional interest in a patient’s welfare, argue for respecting these surrogate decisions.15

In the United States, substituted judgment with respect to end-of-life issues has received tremendous attention in recent years. Since the landmark Quinlan case, two additional judicial opinions—in re Schiavo and Cruzan v. Director, Missouri Department of Health—have captured public attention and reinvigorated judicial interest in substituted judgment.15 Both of these cases dealt with surrogate decisions to withdraw nutrition and hydration from patients in a persistent vegetative state. In each case, removal of nutrition and hydration was based on the substituted judgment of the incapacitated patient. In determining the substituted judgment of these patients, the courts required a high standard of evidence to prove that the once-competent patient would have chosen to withdraw care. Arguably, such a high standard was required in these life-and-death decisions to ensure judicial accuracy.8,15 Although debate remains about the standard of “clear and convincing” evidence required by the courts, there is interdisciplinary consensus among bioethicists, clinicians, and jurists that “substituted judgment” is an appropriate mechanism for decision making on behalf of patients who lose decision-making capacity.14

Patients Who Never Had Capacity to Make Medical Decisions

Although the substituted judgment standard is useful if a patient has expressed previous wishes, often these wishes are not known. For instance, mentally retarded and pediatric patients who never had decision-making capacity must be subject to a different surrogate standard. “Substituted judgment” cannot be determined if the patient has never had capacity to make a decision. In these clinical situations, a “best interest” standard has been employed.20 In such cases, the risks and benefits of care are weighed, and appropriate care is determined by a proxy based on the best interest of the patient.14

Mentally Retarded Adults

In the United States, several judicial cases have dealt with never-competent patients.20 In Superintendent of Belchertown State School v. Saikewicz, the Supreme Judicial Court of Massachusetts considered the case of a 67-year-old institutionalized, mentally retarded patient. The patient was suffering from acute myeloblastic monocytic leukemia. In this case, the Massachusetts court decided to forgo chemotherapeutic treatment after weighing the benefits and burdens of treatment.18 The Court determined that the potential benefit of chemotherapy (i.e., extending the patient’s life), did not outweigh the burdens of treatment (i.e., discomfort, side effects). Such an evaluation of benefits and burdens is integral to a proper best interest evaluation. In contrast to substituted judgment, this standard focuses on an objective assessment of what is good for the patient rather than a consideration of what the patient would have wanted done.

One of the factors often considered in these best interest cases is the patient’s present quality of life; that is, whether the quality of a patient’s life warrants the risks of an intervention. However, such a consideration may be misguided (see “Common Errors”). Lloyd and associates recently published a survey study focused on patient decision making in seriously ill patients.21 The survey data showed no correlation between a patient’s current quality of life and decisions regarding future intensive care. Accordingly, determining whether a never-competent patient would desire a specific treatment based on his or her current quality of life may not be an accurate method.
of predicting a patient’s choice. Additionally, regarding mentally retarded patients, ethicists have noted that it would be difficult for a competent individual to envision the quality of life enjoyed by such a patient. Although the patient’s life may appear to be intolerably frustrating to a competent adult, it is unclear how a mentally retarded individual would rate his or her own quality of life.20

**Pediatric Patients**

Traditionally, parents of a pediatric patient have been given significant discretion to make decisions for their children.20 Minors in the United States are legally incompetent to make health care decisions or enter contracts, regardless of their capacity to understand. As a result, parents typically make their child’s health care decisions and wield significant discretion in this process.20 However, as in the Saikewicz case, the benefits and burdens of these decisions should be weighed to determine the best interest of the minor patient.22 As stated earlier, weighing such benefits and burdens to a patient is the essence of a “best interest” evaluation. Also of importance in such situations, surrogate decision makers must themselves have capacity to make health care decisions for their children. Any concern about the capacity of a surrogate decision maker should prompt investigation and consultation with appropriate personnel. Parents who lack capacity to make a decision are likely also not to be legally competent to make decisions for their child. Finally, although in the case of pediatric decision making parental discretion is significant, it can be overridden. Specifically, parental decisions that clearly are not in a child’s best interest may be overruled. A common example is in the case of Jehovah’s Witnesses: courts in the United States have ruled that parents may not prevent life-saving transfusions for minors. Such interventions are deemed to serve the best interest of a child and are de facto appropriate regardless of the religious beliefs of a parental surrogate.20

**Conclusion**

Bioethics is a young, multidisciplinary field that has become of integral importance to medicine and palliative care. End-of-life issues present many difficult decisions for health care providers and patients. Understanding the appropriate approach to these decisions, while respecting patient preference, is essential to providing proper care. Today, clinicians are expected to know more than the mere physical pathology and treatment of disease. Especially within the field of palliative care, clinicians must grapple with and understand ethical decision making and assist patients or proxies to make appropriate choices. As technology advances, ethical issues will continue to arise in medicine. The astute clinician will seek to learn not only how to correctly approach future ethical issues but also the reasoning behind such approaches. To this end, we hope this chapter has provided some guidance.

**References**


**Suggested Reading**