

# Chapter 1

## What Are Medical Ethics?

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### *In This Chapter*

- ▶ Defining medical ethics
  - ▶ Looking at common controversies
  - ▶ Moving medicine forward in research
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**D**o the right thing. It sounds so easy, but it isn't. Every time a story is written about any medical issue, whether it's abortion, end-of-life care, or multiple births, everyone has an opinion about what's right and what's wrong. We're bombarded with two or more opposing viewpoints, and each one sound reasonable. But which one is right?

And that's medical ethics in a nutshell. What's the right thing to do? How do we structure clinics, hospitals, and government so the most people benefit and patients are treated with respect and compassion? What should you, as the provider, do in certain situations?

There are guidelines and principles in place to help us make decisions, but sometimes those come into direct conflict with each other. When that happens, we need to use logical reasoning skills, ethical theories, and some tools of philosophy to balance and weigh our options. Even after all of that is done, there are still questions. Medical ethics gets into the gray areas of life. As you look at these issues in more depth, you realize there aren't many that are truly black and white.

In this chapter, we define medical ethics, look at the differences between ethical and legal behaviors, and explain the difference between patient rights and provider responsibilities. We need to understand the guidelines and guideposts to follow while treating patients in all stages of life. We look at some of the common and hot-button controversies and take a peek at the ethics of medical research, which is on the forefront of medicine.

## Defining Medical Ethics

Healthcare providers have always been respected and even revered. As societies were formed, ethical principles were developed by physicians and scholars from all walks of life. From Hippocrates to Muhammad ibn Zakariya ar-Razi to Thomas Aquinas, physicians and theologians have crafted guidelines to aid providers in their quest to help patients.

As a result, the American Medical Association has written a Code of Medical Ethics that covers most situations healthcare providers face in their careers. The Code is made up of guidelines and opinions written by ethical scholars and physicians. Whenever you have a question about an ethical issue, the Code will provide a good basis for your decisions. (See Chapter 2 for more on the AMA Code.)

In this section, we define the four principles of medical ethics. We also look at the differences between ethics and the law, and how you should reconcile patient care with ethical standards. One of the most important facts in medical ethics is that they are not static. Medical ethics have changed over the years and will continue to evolve as medicine advances.

### *What are ethics?*

Ethics and morality mean the same thing to many people, and they are similar. Morals are used to describe personal character, whereas ethics defines behavior in different situations. Morality refers to personal character, beliefs, and behavior; ethics is about the reflection on morality and deciding how to act as a person or a professional. An ethical person and a moral person are usually one and the same. We use *medical ethics* to refer to those guidelines and behaviors that we expect a medical professional with moral integrity to exhibit.

Ethics has developed over the centuries as a code of conduct, especially for professionals. Healthcare providers have so much knowledge about the human body, so much potential power over patients, and the ability to change and save lives. Because of these factors, the ethical bar is set very high, and providers have moral obligations to their patients.

The field of medical ethics is really about reflection on how to behave as a medical professional as well as the morality of particular medical interventions. Medical ethics are simply some key ethical principles applied to the practice of medicine. These principles are the bedrock of good clinical practice, and they are autonomy, nonmaleficence, beneficence, and justice. But they often come in conflict with each other as they are applied to a case. By using these principles in each individual case, it can be easier to make difficult decisions with your patients as you guide them through their care.

## *The four principles of medical ethics*

The four major principles of medical ethics are

- ✓ **Autonomy:** This principle is focused on the patient's independence or liberty. A competent adult has the right to make decisions about what happens to his body. The person must be capable of rational thought and not be manipulated or coerced into any decision. An adult can refuse medical care or treatment or accept treatment when his provider suggests it. That person then lives with the consequences of his decision.
- ✓ **Beneficence:** This principle states that a physician must act in the best interest of the patient. Providers are required to promote their patient's health and well-being. Most doctors agree that healing is the main purpose of modern medicine. Beneficence means providers must help their patients.
- ✓ **Nonmaleficence:** First, do no harm. Physicians must not harm a patient through carelessness, malice, vengeance, or dislike, or even through treatments intended to help the patient. This principle is balanced with beneficence in that any risks of a treatment or procedure to a patient must be outweighed by benefit. Some treatments always carry a risk of harm. But when the treatment is very risky, the benefit must be great, or the risk of not performing the procedure must be great.

*Double effect* is an offshoot of nonmaleficence. A treatment that is normally used to help someone may have an unintended negative effect. For instance, a vaccine used to prevent disease can, in rare cases, actually cause the infection it is intended to prevent. This principle provides specific guidance when determining when unintended effects are justified and when they are not.
- ✓ **Justice:** Justice refers to fairness with respect to the distribution of medical resources. This principle draws upon ethics, the law, and public policy. Who should receive scarce medical resources, and how should we distribute them in order to realize the best outcomes? Making the system as a whole more fair is one of the goals of justice.

There are two other values of medical ethics: truthfulness (or honesty) and dignity. Although these are important qualities, they are more standards of conduct, not overarching ethical principles.

These ethical principles all have merit, but they are not absolute and they are often in conflict. You will also see some tools of philosophy applied to some of the difficult ethical situations addressed in the upcoming chapters. *Deontology* states that some actions are, in and of themselves, good or bad, no matter if the end result is good. *Universality* is the concept that what is right or wrong for a person is right or wrong for all people in all places and at all times. *Consequentialism* holds that the consequences of any action determine

whether that action is just or right. And *utilitarianism* holds that the worth of any action is determined by the amount of good it produces.

Even with all of these principles and tools at our disposal, medical ethics can be complicated and messy. There will be times in your practice where you and your patient will simply not be able to decide on one course of action or agree about a treatment. Sometimes, all we can do is try to think clearly about what is ethical, then decide on a path, act, and hope for the best.

## *Differences between ethics and legality*

What is ethical is not necessarily legal, and vice versa. For instance, doctors have a fiduciary and ethical duty to their patients to do no harm, tell the truth, and treat patients with respect. The law does not demand that patients receive respect or compassion; it simply demands good medicine applied according to current standards. Some have said that good ethics begins where the law ends. In fact, ethical obligations often exceed legal standards.

The law is expressed in our society through court rulings and legislation. A statute sets a conduct standard that must be met, and a court ruling is binding on all relevant parties. Ethics, on the other hand, are guidelines. And breaches of ethics are usually not legally enforceable, although providers can be sanctioned by different medical institutions or boards if a serious breach occurs. The law does have some bearing on medical ethics in several different areas. For instance, laws, legal opinions, and court rulings affect

- ✓ **Informed consent:** A consent form is a legal document, which states that the patient has been informed about his condition and treatments, and that he understands and agrees to them.
- ✓ **Advance directives:** Directions for end-of-life care or care when the patient is incapacitated are legally binding. Although the patient doesn't need a lawyer to create an advance directive, it should be notarized or witnessed.
- ✓ **Abortion and birth control:** Countries and states have different laws regarding access to abortion and birth control. Doctors and providers must follow these laws depending on where they live.
- ✓ **Euthanasia:** Two states in the United States (Oregon and Washington) and some countries allow physician-assisted suicide. Those laws state specifically what providers are and aren't allowed to do for a patient.
- ✓ **Privacy and confidentiality:** In the United States, confidentiality laws and regulations are strictly enforced to protect the privacy of the patient at all times.
- ✓ **Access to medical care:** State-sponsored medical care, including Medicare and Medicaid, are laws that provide access to people who usually couldn't afford the care. Universal healthcare is provided in most countries around the world.



Medical ethics standards do have an effect upon the law. Many laws are devised and written based on the ethical codes of doctors and nurses. It is important that you, as a provider, know the laws in your state as well as understand the ethics guidelines that apply in different situations.

## *Reconciling medical ethics and patient care*

If you are in the medical profession, you do your best to become the kind of provider who is trusted by your patients. You want your patients to know that you have their best interests at heart, and you want to build relationships with your patients so you can give them the best care possible.

Medical ethics provide guidelines to becoming a better provider. Ethics can help you communicate better, be a better partner to your fellow doctors and nurses, reduce risk of errors, and increase job satisfaction. When you embrace ethics as simply doing the right thing, there will be few conflicts between medical ethics and good patient care.

In many cases, it may help to put yourself in your patient's shoes (or hospital slippers). What would you want if you were the patient? Would you want your doctor to be compassionate and caring? Would you want test results delivered to you quickly? Treating patients with a sense of courtesy comes first.



The Golden Rule applies in medical ethics. If you treat your patients as you would want to be treated, or as you would want someone to treat a cherished family member, you will provide good medical care.

## *Turning to ethical guideposts and guidelines*

If you have questions about a medical ethics issue, by all means turn to this book! But there are other sources for information, such as the Declaration of Geneva, an updated version of the Hippocratic Oath, or the AMA Code of Medical Ethics. If you work for a healthcare organization, your employer may have a code of ethics as well.



It's a good idea to read over an ethics code every now and then, not just when you have questions about issues. These codes aren't perfect or even enforceable, but taking the time to learn their principles and following the basic rules will help you enjoy your practice more, will result in more satisfying patient relationships, and will help make you a more effective provider.

## *Looking at the Common Medical Ethics Issues*

Medical ethics can be divided into five main areas of discussion: individual rights or privacy; beginning-of-life issues; end-of-life issues; access to health-care; and ethics in research are the main overarching areas that can generate the most need for medical ethics guidelines.

In this section, we look at each of the first four of these areas of ethics and talk a bit about how the four ethical principles can clash and intersect as people make decisions about their lives and providers make decisions about how to best help their patients. All four ethical principles apply to situations in these areas of ethics, and how a dilemma is resolved depends on which ethical principles you follow.

### *Privacy and confidentiality concerns*

Privacy and confidentiality go hand in hand with the principle of autonomy. In fact, because privacy upholds all four medical principles, it can be considered the cornerstone of your practice. Patient autonomy rules this issue because competent, informed patients can legally and ethically make all decisions about their care. It can be frustrating when a patient refuses treatment you know will help, but respecting his decisions, whether those decisions are made on personal, religious, or cultural grounds, is paramount.



Complying with federal regulations and putting safeguards in place in your office and clinic are important. It's also important to train your staff about privacy and confidentiality, as we discuss in Chapter 3. Running an ethical practice means respecting patient privacy at all times.

If a patient doesn't trust that you will keep their information private, he will be less likely to confide in you about matters that may be important in making the correct diagnosis.

Patient confidentiality demonstrates all of the medical ethics principles. Confidentiality is crucial to respecting autonomy because patients need to know that their decisions about their health and any diagnoses are being kept in a personal space. Nonmaleficence is important because if that information falls into the wrong hands, the patient can be hurt. Doing the best for your patient, or beneficence, means honoring the trust he places in you. And justice demands that confidential information be kept private because when others can learn information about intimate matters, patients can feel violated.

In Chapter 4, we take a detailed look at how to manage paperwork, deal with managed care situations, and handle sharing information with third parties,

particularly insurance companies. But complying with these standards is the bare minimum of keeping patient information confidential. It's important that you pay attention to what you are discussing with others and where, and what you communicate through the written and spoken word.



Most information about a patient, including test results, diagnoses, treatments, and vital statistics, can be shared only with others when the patient has given express permission for that release. That permission, when at all possible, should be in the written form.

When you have a system in place to comply with HIPAA (the Health Information Portability and Accountability Act), honoring confidentiality becomes second nature. Learning to not discuss patient information with anyone except other providers who are involved in the case or whom you are consulting is important. Practice it until it becomes second nature.



It's important to remember that in medical ethics, the law really is the lowest common denominator. Ethics goes above and beyond the law, from what is legal to what is right. So complying with the law is important, but to be the best healthcare provider, go beyond the law and add compassion, respect, and honesty to your practice. And speaking of honesty, medical errors do occur, and the best practice is to report them to your patient. We look at the best ways of disclosing medical errors in Chapter 5.

## *Reproduction and beginning-of-life issues*

Reproduction includes access to birth control, abortion, the right of a woman to choose or refuse care, the rights of the fetus, reproductive technologies, and access to care. Autonomy often comes into conflict with the other principles in reproductive issues simply because these matters are so personal.

For instance, a pregnant woman is allowed to refuse healthcare for her and her fetus up until the moment of birth. Respecting the woman's autonomy means that she is allowed to decide for herself what happens to her body, even when pregnant. In Chapters 9 and 11 we look at how to weigh the rights of a mother versus the rights of her fetus and pro-choice and pro-life stances on abortion. The definition of personhood also is explored as it relates to the rights of the fetus.

Access to birth control becomes an issue when minors request it. Because the law has decided that mature minors can have access to prescribed birth control, how do we respect a minor's privacy and autonomy while not interfering with the parent-child relationship? In Chapter 8, we take a look at adolescent patient's rights, emancipated minors, mature minors, and how to balance privacy with your obligations to your patient and her parents.

Finally, assisted reproduction can raise many ethical issues. In Chapter 10, we look at the ethics of artificial insemination, in vitro fertilization, surrogacy, and sterilization. How do we balance risk and harm to the mother and fetus? Who should receive genetic screening, and how do you prepare your patient for the results? What are your responsibilities toward your patient as you try to provide the best care?

## *End-of-life issues*

As at the beginning of life, the end of life raises many difficult ethical issues. With the advent of medical technology that is capable of supporting life far beyond what had once been possible, we need to understand anew when life ends. In Chapter 12, death is defined, and the rights of dying patients are discussed by looking at some landmark ethics cases. The physician's role in end-of-life cases is discussed, including the ethics of physician-assisted suicide.

We then look at honoring a patient's wishes at the time of death. Healthcare directives, or living wills, are addressed in Chapter 13 as vehicles for patient autonomy. How can we help patients die with dignity and as little suffering as possible? The rule of double effect (see the earlier section, "The four principles of medical ethics") is pertinent in this issue. Giving a patient drugs with the intent to make them comfortable can hasten death. Is that an ethical move?

Euthanasia and terminal sedation are hot-button topics. Who decides when it's someone's time to die? When it becomes obvious that life is ending, how much help should we offer someone who is suffering? One of medical science's advances is the ability to help relieve suffering. That's one of the greatest opportunities for beneficence. When someone is at the end of life, however, balancing beneficence and nonmaleficence can become tricky.

## *Access to care*

In the United States, universal healthcare has been in the news. Passionate supporters of this concept and equally passionate opponents have made their voices heard. But what's the reality of the situation? And what does medical ethics have to say about access to care? The principle of justice takes center stage with this topic.

Congress passed, and President Obama signed into law, the Health Care Reform Act of 2009. Because this act will take years to implement, there are still millions of Americans who are uninsured and underinsured, and no real guarantee that provisions of the act will ever be put into place. Thousands of Americans die every year because they don't have access to medical care, and thousands more go bankrupt because of the prohibitive cost of medicine.





The principle of justice is most applicable to this issue. As we discuss in Chapter 6, providing the basic minimum of care to the most people possible, while not reducing the standard of care enjoyed by others, is the balancing act. This fulfills a utilitarian approach to ethics by maximizing benefit to the greatest number of people. As a provider, you can help your patients by volunteering at free clinics, by prescribing generic drugs and less invasive and expensive procedures first, and by encouraging people to live healthy lifestyles. Respecting patient autonomy, guarding against harm (including financial harm), trying to do the best for your patient, and treating all patients equally is challenging but necessary in the current healthcare climate.

In Chapter 7, we look at integrating your patient's spiritual and cultural beliefs into their care as a way of enhancing treatment as well.

## ***Moving Medicine Forward: The Ethics of Research***

Medical research has brought great advances in the 20th and 21st centuries. The life span for the average American has increased from 49 years at the beginning of the 20th century to 77 years at the beginning of the 21st century.

But with this progress has come some dark days. We look at the Tuskegee syphilis study and the abuses of medical research during the Holocaust. Patients have been abused, hurt, and killed in the name of medical research before standards were put into place, as documented in Chapter 14. Even now, some researchers fail to follow guidelines and end up harming patients.

For example, in July 2010, media sources revealed that the drug manufacturer SmithKline Beecham hid results that showed Avandia, their successful diabetes medication, was harmful to the heart. Patients in the clinical trial had serious heart issues, including a significant risk of increased myocardial infarction, that weren't recorded in the tally of adverse events. The FDA is now deciding whether the drug should be withdrawn from the market. Clearly, if SmithKline Beecham knew about adverse side effects from this drug, they should have been made public. If true, this was a clear violation of nonmaleficence.

In Chapter 15, we look at the important components in an ethical clinical trial. This is vital information, whether you are a researcher or a caregiver of patients in the trials. In Chapter 16, we look at research in some special populations, such as animals, children, and psychiatric patients. Special care needs to be given to protect research subjects who cannot give full informed consent. And finally in Chapter 17, we look at the ethics of stem cell research and the controversies around genetic testing and cloning.

