CHAPTER e5

Ethical Issues in Clinical Medicine

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Physicians frequently confront ethical issues in clinical practice that are perplexing, time-consuming, and emotionally draining. Experience, common sense, and simply being a good person do not guarantee that physicians can identify or resolve ethical dilemmas. Knowledge about common ethical dilemmas is also essential.

FUNDAMENTAL ETHICAL GUIDELINES

Physicians should follow two fundamental but frequently conflicting ethical guidelines: respect patient autonomy and act in the patient's best interests.

RESPECTING PATIENT AUTONOMY

Treating patients with respect requires doctors to accept the medical decisions of persons who are informed and acting freely. Individuals place different values on health, medical care, and risk. In most clinical settings, different goals and approaches are possible, outcomes are uncertain, and an intervention may cause both benefits and harms. Thus competent, informed patients may refuse recommended interventions and choose among reasonable alternatives.

Informed consent

For patients to make informed decisions, physicians need to discuss with them the nature of the proposed care, the alternatives, the risks and benefits of each, and the likely consequences, and obtain the patient's agreement to care. Informed consent involves more than obtaining signatures on consent forms. Physicians need to educate patients, answer questions, make recommendations, and help them deliberate. Patients can be overwhelmed with medical jargon, needlessly complicated explanations, or too much information at once.

Nondisclosure of information

Physicians may consider withholding a serious diagnosis, misrepresenting it, or limiting discussions of prognosis or risks because they fear that a patient will develop severe anxiety or depression or refuse needed care. Generally, physicians should provide relevant information, while adjusting the pace of disclosure, offering empathy and hope, and helping patients cope with bad news.

In many cultures, patients traditionally are not told of a diagnosis of cancer or of other serious illness because such disclosure is believed to cause patients to suffer, while withholding information is believed to promote serenity, security, and hope. Patients should not be forced to receive information against their will, even in the name of promoting informed decisions. However, many individuals want to know their diagnosis and prognosis, even if they are terminally ill. Physicians, therefore, should ask patients how they want health care decisions to be made, adding that they usually provide information and make decisions together with patients, while offering patients the option not to receive information or to turn decision-making over to someone else.

Emergency care

Informed consent is not required when patients cannot give consent and when delay of treatment would place their lives or health in peril. People are presumed to want such emergency care, unless they have previously indicated otherwise.

Futile interventions

Autonomy does not entitle patients to insist on whatever care they want. Physicians are not obligated to provide futile interventions that have no physiologic rationale or have already failed. For example, cardiopulmonary resuscitation would be futile in a patient with progressive hypotension despite maximal therapy. But physicians should be wary of using the term *futile* in looser senses to justify unilateral decisions to forego interventions when they believe that the probability of success is too low, no worthwhile goals can be achieved, the patient's quality of life is unacceptable, or the costs are too high. Such looser usages of the term are problematic because they may be inconsistent and mask important value judgments. Several states have laws allowing physicians not to provide interventions that they deem futile or not medically indicated, provided they follow procedures such as obtaining the concurrence of the hospital ethics committee and giving the patient an opportunity to be transferred to another hospital.

Maintaining confidentiality

Confidentiality respects patients' autonomy and privacy, encourages them to seek treatment and discuss their problems candidly, and prevents discrimination. However, maintaining confidentiality is not an absolute rule. Confidentiality may be overridden in certain situations to prevent serious harm to third parties or to the patient. The law may require physicians to override confidentiality in order to protect third parties, as with reporting of tuberculosis and syphilis. In other situations, medical providers have a legal duty to report victims of elder abuse, child abuse, and domestic violence. These exceptions to confidentiality are justified because the risk is serious and probable, there are no less-restrictive measures to avert risk, the adverse effects of overriding confidentiality are minimized, and these adverse effects are deemed acceptable by society.

The Health Insurance Portability and Accountability Act (HIPAA) health privacy regulations have heightened awareness of the importance of confidentiality. These regulations are not meant to inhibit transmission of information needed for treatment: disclosure of patient information to other health care providers for the purposes of treatment without having the patient sign an authorization form is permissible.

Avoiding deception

Health care providers sometimes consider using lies or deception in order to protect the patient from bad news or to obtain benefits for the patient. Lying refers to statements that the speaker knows are false and that are intended to mislead the listener. Deception, which is broader, includes statements and actions that are intended to mislead the listener, whether or not they are literally true. For example, the health care provider may tell a patient that she has a "small growth" so that she does not think she has cancer. Or the provider may complete and sign a form for a patient to get a bus pass, even though he does not meet criteria for physical disability. Although such deception may be motivated by a desire to help the patient, it is ethically problematic. The person who is deceived cannot make informed decisions if he or she receives misleading information. Furthermore, deception undermines physicians' credibility and trustworthiness.

ACTING IN THE BEST INTERESTS OF PATIENTS

The guideline of beneficence requires physicians to act for the patient's benefit. Laypeople do not possess medical expertise and may be vulnerable because of their illness. They justifiably rely on physicians to provide sound advice and to promote their well-being. Physicians encourage such trust. Hence, physicians have a fiduciary duty to act in the best interests of the patient, which should prevail over physicians' self-interest or the interests of third parties, such as hospitals or insurers. These fiduciary obligations of physicians contrast sharply with business relationships, which are characterized by "let the buyer beware," not by trust and reliance. The guideline of "do no harm" forbids physicians from providing ineffective interventions or acting without due care. This precept, while often cited, provides only limited guidance, because many beneficial interventions also have serious risks.

CONFLICTS BETWEEN BENEFICENCE AND AUTONOMY

Patients' refusals of care may thwart their own goals or cause them serious harm. For example, a young man with asthma may refuse mechanical ventilation for reversible respiratory failure. Simply to accept such refusals, in the name of respecting autonomy, seems morally constricted. Physicians can elicit patients' expectations and concerns, correct misunderstandings, and try to persuade them to accept beneficial therapies. If disagreements persist after discussions, the patient's informed choices and view of his or her best interests should prevail. While refusing recommended care does not render a patient incompetent, it may lead the physician to probe further to ensure that the patient is able to make informed decisions.

JUSTICE

The term *justice* is used in a general sense to mean fairness: people should receive what they deserve. In addition, it is important to act consistently in cases that are similar in ethically relevant ways. Otherwise, decisions would be arbitrary, biased, and unfair. Justice forbids discrimination in health care based on race, religion, or gender and supports a moral right to health care, with access based on medical need rather than ability to pay.

PATIENTS WHO LACK DECISION-MAKING CAPACITY

Patients may not be able to make informed decisions because of unconsciousness, dementia, delirium, or other conditions. Physicians should ask two questions regarding such patients: Who is the appropriate surrogate? What would the patient want done?

ASSESSING CAPACITY TO MAKE MEDICAL DECISIONS

All adults are considered legally competent unless declared incompetent by a court. In practice, physicians usually determine that patients lack the capacity to make health care decisions and arrange for surrogates to make them, without involving the courts. By definition, competent patients can express a choice and appreciate the medical situation; the nature of the proposed care; the alternatives; and the risks, benefits, and consequences of each. Their choices should be consistent with their values and should not result from delusions or hallucinations. Psychiatrists may help in difficult cases because they are skilled at interviewing mentally impaired patients and can identify treatable depression or psychosis. When impairments are fluctuating or reversible, decisions should be postponed if possible until the patient recovers decision-making capacity.

CHOICE OF SURROGATE

If a patient lacks decision-making capacity, physicians routinely ask family members to serve as surrogates. Most patients want their family members to be surrogates, and family members generally know the patient's preferences and have the patient's best interests at heart. Patients may designate a particular individual to serve as proxy; such choices should be respected. Some states have established a prioritized list of which relative may serve as surrogate if the patient has not designated a proxy.

STANDARDS FOR SURROGATE DECISION-MAKING

Advance directives

These are statements by competent patients to direct care if they lose decision-making capacity. They may indicate (1) what interventions they would refuse or accept or (2) who should serve as surrogate. Following the patient's advance directives, the surrogate respects the patient's autonomy.

Oral conversations are the most frequent form of advance directives. While such conversations are customarily followed in clinical practice, casual or vague comments may not be trustworthy. Living wills direct physicians to forego or provide life-sustaining interventions if the patient develops a terminal condition or persistent vegetative state. Generally patients may refuse only interventions that "merely prolong the process of dying."

A health care proxy is someone appointed by the patient to make health care decisions if he or she loses decision-making capacity. It is more flexible and comprehensive than the living will, applying whenever the patient is unable to make decisions.

Physicians can encourage patients to carry out advance care planning, which might include clarifying values and priorities, identifying unfinished goals, and addressing spiritual concerns. Such discussions often facilitate completion of advance directives. In discussions with patients, physicians can ensure that advance directives are informed, up-to-date, and address likely clinical scenarios. Such discussions are best carried out in the ambulatory setting. The federal Patient Self-Determination Act requires hospitals and health maintenance organizations to inform patients of their right to make health care decisions and to provide advance directives.

Substituted judgment

In the absence of clear advance directives, surrogates and physicians should try to decide as the patient would under the circumstances, using all information that they know about the patient. While such substituted judgments try to respect the patient's values, they may be speculative or inaccurate. A surrogate may be mistaken about the patient's preferences, particularly when they have not been discussed explicitly.

Best interests

When the patient's preferences are unclear or unknown, decisions should be based on the patient's best interests. Patients generally take into account the quality of life as well as the duration of life when making decisions for themselves. It is understandable that surrogates would also consider quality of life of patients who lack decision-making capacity. Judgments about quality of life are appropriate if they reflect the patient's own values. Bias or discrimination may occur, however, if others project their values onto the patient or weigh the perceived social worth of the patient. Most patients with chronic illness rate their quality of life higher than their family members and physicians do.

Legal issues

Physicians need to know pertinent state laws regarding patients who lack decision-making capacity. A few state courts allow doctors to forego life-sustaining interventions only if patients have provided written advance directives or very specific oral ones.

Disagreements

Disagreements may occur among potential surrogates or between the physician and surrogate. Physicians can remind everyone to base decisions on what the patient would want, not what they would want for themselves. Consultation with the hospital ethics committee or with another physician often helps resolve disputes. Such consultation is also helpful when patients have no surrogate and no advance directives. The courts should be used only as a last resort when disagreements cannot be resolved in the clinical setting.

DECISIONS ABOUT LIFE-SUSTAINING INTERVENTIONS

Although medical technology can save lives, it can also prolong the process of dying. Competent, informed patients may refuse life-sustaining interventions. When patients lack decision-making capacity, such interventions may also be withheld on the basis of advance directives or decisions by appropriate surrogates. Courts have ruled that foregoing life-sustaining interventions is neither suicide nor murder.

MISLEADING DISTINCTIONS

People commonly draw distinctions that are intuitively plausible but prove untenable on closer analysis.

Extraordinary and ordinary care

Some physicians are willing to forego "extraordinary" or "heroic" interventions, such as surgery, mechanical ventilation, or renal dialysis but insist on providing "ordinary" ones, such as antibiotics, IV fluids, or feeding tubes. However, this distinction is not logical because all medical interventions have both risks and benefits. Any intervention may be withheld, if the burdens for the individual patient outweigh the benefits.

Withdrawing and withholding interventions

Many health care providers find it more difficult to discontinue interventions than to withhold them in the first place. Although such emotions need to be acknowledged, there is no logical distinction between the two acts. Reasons that justify withholding interventions, such as refusal by patients or surrogates, also justify withdrawing them. In addition, after an intervention has been started, new data may indicate that it is no longer appropriate. The intervention may prove unsuccessful, or it may be learned that the patient did not want the intervention. If interventions could never be discontinued, patients and surrogates might not even attempt treatments that might prove beneficial.

DO NOT ATTEMPT RESUSCITATION (DNAR) ORDERS

When a patient suffers a cardiopulmonary arrest, cardiopulmonary resuscitation (CPR) is initiated unless a DNAR order has been made. Although CPR can restore people to vigorous health, it can also disrupt a peaceful death. After CPR is attempted on a general hospital service, only 14% of patients survive to discharge, and even fewer in certain subgroups. DNAR orders are appropriate if the patient or surrogate requests them or if CPR would be futile. To prevent misunderstandings, physicians should write DNAR orders and the reasons for them in the medical record. "Slow" or "show" codes that merely appear to provide CPR are deceptive and therefore unacceptable. Although a DNAR order signifies only that CPR will be withheld, the reasons that justify DNAR orders may lead to a reconsideration of other plans for care. Many hospitals have standardized order forms that specify whether other life-sustaining interventions, such as intubation and mechanical ventilation, are to be administered or withheld.

ASSISTED SUICIDE AND ACTIVE EUTHANASIA

Proponents of these controversial acts believe that competent, terminally ill patients should have control over the end of life and that physicians should relieve refractory suffering. Opponents assert that such actions violate the sanctity of life, that suffering can generally be relieved, that abuses are inevitable, and that such actions are outside the physician's proper role. These actions are illegal throughout the United States, except that physician-assisted suicide is legal in Oregon and Washington under restricted circumstances. Whatever their personal views, physicians should respond to patients' inquiries about these actions with compassion and concern. Physicians should elicit and address any underlying problems, such as physical symptoms, loss of control, or depression. Often, additional efforts to relieve distress are successful, and after this is done patients generally withdraw their requests for these acts.

CARE OF DYING PATIENTS

Patients often suffer unrelieved pain and other symptoms during their final days of life. Physicians may hesitate to order high doses of narcotics and sedatives, fearing they will hasten death. Relieving distressing symptoms in terminal illness and when patients forego life-sustaining interventions such as mechanical ventilation enhances patient comfort and dignity. If lower doses of narcotics and sedatives have failed to relieve suffering, increasing the dose to levels that might suppress respiratory drive or lower blood pressure is ethically appropriate because the physician's intention is to relieve suffering, not hasten death. Such palliative sedation is distinguished ethically and legally from active euthanasia, which is administering a lethal dose with the intention of ending the patient's life. Physicians can also relieve suffering by spending time with dying patients, listening to them, and attending to their psychological distress.

CONFLICTS OF INTEREST

Acting in the patient's best interests may conflict with the physician's self-interest or the interests of third parties such as insurers or hospitals. The ethical ideal is to keep the patient's interests paramount. Even the appearance of a conflict of interest may undermine trust in the profession.

FINANCIAL INCENTIVES

The 2010 health care reform law includes pilot programs that offer physicians financial incentives to improve the quality and efficiency of care. There are concerns that pay-for-performance incentives may lead physicians to avoid sicker, more complicated patients or to focus on benchmarked interventions even if they are not in the best interests of an individual patient. In contrast, physicians have incentives to provide interventions regardless of the probability or magnitude of benefit when they receive fee-for-service reimbursement or when they refer patients to laboratory or imaging facilities in which they have a financial stake. Regardless of financial incentives, physicians should recommend available care that is in the patient's best interests, no more and no less.

RELATIONSHIPS WITH PHARMACEUTICAL AND DEVICE COMPANIES

Financial relationships between physicians and industry are under increasing scrutiny. Gifts from drug and device companies may create an inappropriate risk of undue influence, induce subconscious feelings of reciprocity, impair public trust, and increase the cost of health care. Policies at many academic medical centers and companies have eliminated pens, notepads, and meals to physicians. Under new federal sunshine requirements, companies must disclose publicly the names of physicians to whom they have made payments together with the amount of payment. It will be a challenge to structure such disclosure to distinguish between payments for scientific consulting, contracts, and grants—which are consistent with professional and academic missions and need to be encouraged—from promotional speaking and consulting whose goal is to increase sales of company products.

■ OCCUPATIONAL RISKS

Some health care workers, fearing fatal occupational infections, refuse to care for persons with HIV infection or multidrug-resistant tuberculosis. Such fears about personal safety need to be acknowledged, and health care institutions should reduce occupational risk by providing proper training, protective equipment, and supervision. To fulfill their mission of helping patients, physicians should provide appropriate care within their clinical expertise, despite some personal risk.

■ MEDICAL ERRORS

Errors are inevitable in clinical medicine. They may cause serious harm to patients or result in substantial changes in management. Physicians and students may fear that disclosing such errors could damage their careers. Without disclosure, however, patients cannot understand their clinical situation or make informed choices about subsequent care. Furthermore, patients are often outraged when physicians do not acknowledge and apologize for errors. Several states have enacted laws that allow physicians to say they are sorry for errors without increasing legal liability. Similarly, unless attending physicians are informed of trainees' errors, they cannot provide optimal care and help trainees learn from mistakes.

■ LEARNING CLINICAL SKILLS

Learning clinical medicine, particularly learning to perform invasive procedures, may present inconvenience or risk to patients. To ensure patient cooperation, students may be introduced as physicians or patients may not be told that trainees will be performing procedures. Such misrepresentation undermines trust, may lead to more elaborate deception, and makes it difficult for patients to make informed choices about their care. Patients should be told who is providing care, what benefits and burdens can be attributed to trainees, and how trainees are supervised. Most patients, when informed, allow trainees to play an active role in their care.

■ IMPAIRED PHYSICIANS

Physicians may hesitate to intervene when colleagues impaired by alcohol abuse, drug abuse, or psychiatric or medical illness place patients at risk. However, society relies on physicians to regulate themselves. If colleagues of an impaired physician do not take steps to protect patients, no one else may be in a position to do so.

■ CONFLICTS FOR TRAINEES

Medical students and residents may fear that they will receive poor grades or evaluations if they act on the patient's behalf by disclosing mistakes, avoiding misrepresentation of their role, and reporting impaired colleagues. Discussing such dilemmas with more senior physicians can help trainees check their interpretation of the situation and obtain advice and assistance.

ALLOCATING RESOURCES JUSTLY

Access to needed care still remains a moral aspiration in the United States, even after the passage of health care reform laws in 2010. Physicians caring for underserved populations must act ethically in a health care system that has serious ethical shortcomings in access to and quality of care. Some patients with a clear need for medical care cannot pay for medications, tests, or hospitalizations, or the insurer may deny coverage. If this occurs, physicians should advocate for patients, trying to help them obtain needed care. Doctors might consider, or patients might request, using lying or deception to help them gain such benefits. However, avoiding deception is a basic ethical guideline that sets limits on advocating for patients. Allocation of health care resources is unavoidable because resources are limited. Ideally, allocation decisions should be made as public policy, with physician input. Allocation of resources at the bedside on an ad hoc basis is problematic because it may be inconsistent, unfair, and ineffective. At the bedside, physicians generally should act as patient advocates within constraints set by society, reasonable insurance coverage, and evidence-based practice. For example, a patient's insurer may have a higher copayment for nonformulary drugs. It is reasonable for physicians to advocate for nonformulary drugs only if there are compelling reasons for an exception, as when the formulary drugs are ineffective or not tolerated.

ASSISTANCE WITH ETHICAL ISSUES

Discussing perplexing ethical issues with other members of the health care team, colleagues, or the hospital ethics committee often clarifies issues and suggests ways to improve communication and to deal with strong emotions. When struggling with difficult ethical issues, physicians may need to reevaluate their basic convictions, tolerate uncertainty, and maintain their integrity while respecting the opinions of others.

FURTHER READINGS

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