CLINICAL ETHICS

A PRACTICAL APPROACH
TO ETHICAL DECISIONS
IN CLINICAL MEDICINE

Eighth Edition

Albert R. Jonsen Mark Siegler William J. Winslade



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A Practical Approach to Ethical Decisions in Clinical Medicine

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Introduction

This book is about the ethical issues that clinicians encounter as they care for patients. In order to practice excellent clinical care in modern medicine, clinicians must understand ethical issues such as informed consent, decisional capacity, surrogate decision making, truth telling, confidentiality, privacy, the distinction between research and clinical care, and end-of-life care. Clinicians must apply this knowledge each day in their practices. By clinicians we mean not only physicians but also nurses, social workers, psychologists, clinical ethicists, medical technicians, chaplains, and others responsible for the welfare of patients. We include, as well, students who are preparing to enter these professions. It is our hope that this book will be particularly helpful to those who serve on hospital ethics committees as they deliberate about appropriate action in difficult ethical cases.

Ethical issues are embedded in every clinical encounter between patients and clinicians. The technical and moral aspects of patient care are inseparable. The central feature of the clinical encounter is the therapeutic relationship between clinicians and patients—a relationship that is permeated with ethical responsibilities. Physicians enter the doctor-patient relationship with a professional identity that obliges them to give priority to the patient's interests, to devote themselves to the competent care of the patient, to preserve confidentiality, and to communicate honestly and compassionately. Physicians must aim, in the words of Hippocrates, "to help and do no harm," an admonition that is not as simple as it seems within the complexities of contemporary medical science and practice.

In the usual course of a therapeutic relationship, clinical care and ethical imperatives run smoothly together. The reason for this is that generally the patient and clinician share the same goal, namely, to resolve the medical problems and needs of the patient. For example, a patient

presents with a distressing cough and wheezing and wants relief: a physician responds to the patient and utilizes the correct means to diagnose and treat. In this situation, the treatment for, say, a mild asthma attack, is effective and the patient is satisfied. In other cases, this simple scene becomes complicated. The patient's wheezing may be caused by a tumor obstructing the airway. This disease may be life threatening; the treatment may be complex and may prove unsuccessful. On other occasions, the smooth course of the doctor-patient relationship may be interrupted by what we call an ethical question: a doubt about the right action when ethical responsibilities conflict or when their meaning is uncertain or confused. For example, the physician's duty to cure is countered by a patient's refusal of indicated treatment, or the patient's need for treatment cannot be met because of inability to pay. The principles that usually bring the clinician and the patient into a therapeutic relationship seem to collide. This collision blocks the process of deciding and acting required for clinical care. Sometimes, confusion and conflict can become extreme and distressing for all parties. This book aims to elucidate the ethical dimensions of clinical care when doubt about right action blocks decisions. In such cases, we attempt to formulate recommendations about how that doubt might be resolved.

This book is titled *Clinical Ethics*. *Clinical ethics is a structured approach to ethical decisions in clinical medicine*. Clinical ethics is part of the discipline called bioethics. Bioethics is an academic enterprise that draws upon various disciplines such as moral philosophy, cognitive psychology, communication skills, clinical medicine, and health law. The scholars called bioethicists must master this interdisciplinary field. Clinicians in their daily practice of medicine need not become bioethics scholars; they usually can manage with a basic understanding of certain key ethical issues like informed consent, surrogate decision making, and end-of-life care. They should be able to identify the ethical question and to reach a reasonable conclusion and recommendation for action. In this book, we provide a method to identify the ethical dimensions of patient care and to analyze and resolve ethical problems. This method is useful for structuring the questions faced by any clinician as she or he cares for patients.

Jonsen AR. The Birth of Bioethics. New York, NY: Oxford University Press, 1998.

Jonsen AR. A Short History of Medical Ethics. New York, NY: Oxford University Press, 1999.

THE FOUR TOPICS

Every clinical case presents an extensive variety of medical facts and details which the clinician must interpret in order to carry out the reasoning process necessary for diagnosis and treatment. Every clinician learns early in training a standard pattern for organizing that mass of factual detail: they are taught to review in order the chief complaint, history of the chief complaint, general medical history of the patient, results of physical diagnosis, and results of laboratory studies. The data that are sorted into these patterns lead the clinician to decisions about diagnosis and treatment.

Just as clinical cases require a method for sorting data, so too ethical cases must have some method to collect, sort, and order the facts and opinions raised by the case. We have developed such a method. We propose four topics for organizing ethical reasoning: medical indications, patient preferences, quality of life, and contextual features. Our four topics provide a pattern for collecting, sorting, and ordering the facts of a clinical ethical problem. Each topic can be filled with the actual facts of the clinical case that are relevant to the identification of the ethical problems. The contents of all four topics viewed together form a comprehensive picture of the ethical dimensions of the case. Clinical reasoning begins with the facts of the case and moves toward a presumptive diagnosis by sorting those facts into reasonable patterns of causality. Similarly, clinical ethical reasoning starts with the facts. A statement of the ethical problem in a case follows a clear and complete collection of the facts of the case.

Bioethics scholars generally identify four ethical principles that are particularly relevant to medical care: the principles of beneficence, of nonmaleficence, respect for autonomy, and justice. Some bioethicists would add to these four principles others such as empathy, compassion, fidelity, integrity, and other virtues. The bioethical literature explains these principles at length (see Beauchamp, Childress below). In this book, we explain them only briefly. We direct our reader's attention to how these general principles relate to the concrete circumstances of a clinical case, and how they serve as guides to action in specific circumstances.

Our four topics constitute the essential ethical structure of every clinical encounter. This book devotes one chapter to each topic. They can be seen schematically in the chart on page 9 and on the tearout page at the back of the book. Those charts display the particular questions that can be raised about each of the topics and that can be asked to determine the circumstances of each clinical case. Because the charts display these topics in quadrants, many users of this book have come to speak of "THE FOUR BOXES."

We accept that terminology because it helps to explain how the four topics should be used in a clinical consultation. Each topic is, in a way, a "box" into which the circumstances of the case can be sorted and evaluated.

The four topics or boxes are: (1) Medical indications (MI) refer to the diagnostic and therapeutic interventions that are being used to evaluate and treat the medical problem in the case. (2) Patient preferences (PP) state the express choices of the patient about their treatment, or the decisions of those who are authorized to speak for the patient when the patient is incapable of doing so. (3) Quality of life (QL) describes the degree of satisfaction, pleasure, and well-being or the degree of distress and malfunction that people experience in their life prior to and following treatment. (4) Contextual features (CF) identify the social, institutional, financial, and legal settings within which any particular case of patient care takes place, insofar as these influence medical decisions.

ETHICAL REASONING IN CLINICAL ETHICS

The subtitle of our book states that clinical ethics is a "practical" approach. This implies that the approach must go beyond simply identifying the problem by collecting and sorting the facts of the case. As "practical," the approach must guide practice, that is, it must lead from identification of the ethical problem to decisions about how to manage the problem. It must show the clinician how to manage those obstacles to decision making that the ethical problem had posed. Clinical ethics is seldom a matter of deciding between what is right versus what is wrong; rather it involves finding the better, more right, and more reasonable solutions among several options. Our approach seeks to guide the clinician and others involved in the case toward such resolutions.

Good ethical deliberation must go beyond gathering of information about the case. It must sort that information into the relevant and irrelevant, the important and unimportant. The boxes help to do this sorting. The boxes, however, must be fitted into a form of moral reasoning that can produce some closure to the deliberation. That closure is a resolution, a judgment that one course of action among the range of options is most probably the right one. We admit, before going on, that there are moral problems that do not seem to allow resolution (these are often called "dilemmas"). We do not believe that every moral problem, even the most complicated, is a dilemma. We propose a method of "weighing" the information sorted into the boxes so that a resolution can be reached and

formed into a recommendation which a clinician or an ethicist might offer to a patient or to a colleague who is perplexed by the moral problem at hand.

The term "weighing" appears frequently in writings about ethics. We are asked to weigh norms and principles against each other in order to discern their superiority or ability to "trump" in an argument. The most celebrated moral theory of recent years, *Theory of Justice* by John Rawls, elaborates "reflective equilibrium," which implies a balancing. The major textbook of bioethics, *Principles of Biomedical Ethics* by Beauchamp and Childress adapts this method for biomedical ethics. Our proposal for "weighing" and "balancing" of moral considerations is not as elaborate, or deeply philosophical as the approach posed by these authors, but it is, we believe, more easily used by clinical ethicists and clinicians. We do not seek any sort of equilibrium; clinical medicine is too messy to offer ideal solutions. Rather we are looking for the set of circumstances that draw down the scale toward one or another option. In other words, we search for a reasoned conclusion based on medical facts and ethical considerations that leads to a good or better decision, all things considered.

There are clearly some very important ethical principles, such as benevolence/nonmalevolence and respect for persons. It might be said that they are very "weighty." However, we do not believe that a principle or norm in itself has "weight." Rather, we propose that principles "gain weight" in application to the ethical reasoning about a particular case. Thus, while beneficence/nonmaleficence, the primary ethical principles of medical indications, is a very "weighty" or highly important principle—as its endurance throughout medical history demonstrates—it carries much less "weight" in a case where no known form of treatment can effect a cure. Or, more precisely, its weight is converted from the heavy obligation to apply curative interventions to the duty of providing comfort as an enhancement of quality of life.

All four topics and the principles associated with them contribute to the resolution of the problem. It is a mistake to leap into one topic or to grasp one principle as the obvious solution: all elements of the case, that is, all relevant circumstances and principles, are weighed. The resolution is always formulated "on the whole" or "all things considered." It is also "probably the right course," but its probability is tested by this weighing process. We are constantly reminded of Dr. William Osler's sage observation, made more than 100 years ago but still relevant: "medicine is a science of uncertainty and an art of probability."

Cases that present ethical problems may originate as disagreements between parties who all seek the best outcome for the patient, rather than

adversarial opposition. These disagreements can often be settled by quiet, thoughtful exchange of views. In our experience, a simple checklist will aid clinicians to uncover the source of disagreement: (1) Have I failed to communicate effectively with the patient and family? (2) Has communication with patient and family been muddled by diverse providers? (3) Is the patient's decisional capacity compromised by fear or pain? (4) Does the patient lack trust in me as an individual or toward medicine and its institutions? (5) Are the patient's values and beliefs so different than mine that we are not pursuing a common goal? If still unable to reach agreement, it may be useful to resort to explicit mediation techniques.

Dubler NN, Liebman CB. *Bioethics Mediation: A Guide to Shaping Shared Solutions*. New York, NY: United Hospital Fund of New York; 2004.

One final step remains in our practical approach. After an ethical problem is identified and assessed, a resolution must be reached. This resolution usually takes the form of a considered opinion by the clinician that can be formulated into a recommendation to the patient or other decision makers in the case. The resolution will be based on an assessment of the facts of the case in relation to the ethical principles relevant to the case. However, this assessment can also be tested by comparing it with similar cases. It is certainly true that in medicine every case is unique. and every patient "a statistic of one." Nevertheless, the case at hand will have similarities with other cases. The other cases may have been thoughtfully considered-and even adjudicated in the law-and may provide guidance for assessing the present case. Such cases are called "paradigm cases." Reference to paradigm cases does not prove that a case is correctly assessed; rather paradigm cases are examples of serious assessments in prior, similar cases, to which the current case can be compared, in order to guide the clinician in this case. The present case may have circumstances that make it more complex than previous cases; or it may represent a novel problem due to innovative technology. Clinical ethicists should be familiar with these paradigm cases and be able to discern how they differ from or agree with the current case.

Each chapter of this book begins with some general considerations about the topic and the ethical principle most relevant to that topic. Then, the clinical situations that generate ethical problems associated with that topic are stated and illustrated by cases. A short distillation of current opinion on this problem from the bioethical literature follows.

We conclude with a recommendation that the three authors formulate from our extensive experience as clinicians and clinical ethics consultants.

RESOURCES IN CLINICAL ETHICS

In each section that discusses a clinical-ethical problem, we provide capsules of essential information about common problems, such as orders not to resuscitate or withholding life support. The issues that we treat in capsule form have been discussed and debated in the ever-widening literature of bioethics. We refer readers to certain sources where they can find more extended discussions and references. The major reference work in medical ethics is Jennings B (ed), Bioethics, 4th ed, Macmillan Reference USA, 2014 (formerly The Encyclopedia of Bioethics). In this work, the major concepts of bioethics are explained in scholarly articles. The standard textbook of bioethics is Tom Beauchamp, James Childress, Principles of Biomedical Ethics (Oxford University Press, 7th ed, 2013). Three books are particularly useful for more detailed treatment of issues that we treat in capsule form: Bernard Lo, Resolving Ethical Dilemmas: A Guide for Clinicians (Lippincott Williams & Wilkins, 5th ed, 2013), Peter Singer, AM Viens (eds), The Cambridge Textbook of Bioethics (Cambridge University Press, 2008) and Steinbock B, ed. The Oxford Handbook of Bioethics. New York, NY: Oxford University Press, 2009.

An extensive ethics literature can be found in bioethical and medical journals. Because it is fast growing and of varying quality, we have decided to limit our references to the journal literature. We do cite articles when they are "classic" or when they provide what we judge to be a particularly helpful discussion of some issues. The principal bioethics journals are: Hastings Center Report, American Journal of Bioethics, Journal of Medical Ethics, Cambridge Quarterly for Healthcare Ethics, Theoretical Medicine, and Journal of Clinical Ethics, of which the latter is most relevant for clinical ethics. Papers on ethical issues in the standard medical journals are indexed and sometimes summarized in PubMed (www.ncbi.nlm.nih.gov/pubmed). Several dedicated Web sites provide extensive bioethical resources, particularly National Reference Center for Bioethics Literature at Georgetown University (www.georgetown. edu/research/nrcbl/orgs.htm) and Clinical Ethics Center of the National Institutes of Health (www.nih.gov/sigs/bioethics).

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The Four Topics Chart

Medical Indications

Miculai Indications

- The Principles of Beneficence and Nonmaleficence
- 1. What is the patient's medical problem? Is the problem acute? chronic? critical? reversible? emergent? terminal?
- 2. What are the goals of treatment?
- 3. In what circumstances are medical treatments not are the probabilities of success of various treatment options?
- 5. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

Preferences of Patients

The Principle of Respect for Autonomy

- 1. Has the patient been informed of benefits and risks of diagnostic and treatment recommendations, understood this information, and given consent?
- 2. Is the patient mentally capable and legally competent or is there evidence of incapacity?
- 3. If mentally capable, what preferences about treatment is the patient stating?
- 4. If incapacitated, has the patient expressed prior preferences?
- 5. Who is the appropriate surrogate to make decisions for an incapacitated patient? What standards should govern the surrogate's decisions?
- 6. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

Quality of Life

The Principles of Beneficence and Nonmaleficence and Respect for Autonomy

- What are the prospects, with or without treatment, for a return to normal life and what physical, mental, and social deficits might the patient experience even if treatment succeeds?
- 2. On what grounds can anyone judge that some quality of life would be undesirable for a patient who cannot make or express such a judgment?
- 3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life?
- 4. What ethical issues arise concerning improving or enhancing a patient's quality of life?
- 5. Do quality-of-life assessments raise any questions that might contribute to a change of treatment plan, such as forgoing life-sustaining treatment?
- 6. Are there plans to provide pain relief and provide comfort after a decision has been made to forgo life-sustaining interventions?
- 7. Is medically assisted dying ethically or legally permissible?
- 8. What is the legal and ethical status of suicide?

Contextual Features

- The Principles of Justice and Fairness
 - Are there professional, interprofessional, or business interests that might create conflicts of interest in the clinical treatment of patients?
 - 2. Are there parties other than clinician and patient, such as family members, who have a legitimate interest in clinical decisions?
- 3. What are the limits imposed on patient confidentiality by the legitimate interests of third parties?
- 4. Are there financial factors that create conflicts of interest in clinical decisions?
- 5. Are there problems of allocation of resources that affect clinical decisions?
- 6. Are there religious factors that might influence clinical decisions?
- 7. What are the legal issues that might affect clinical decisions?
- 8. Are there considerations of clinical research and medical education that affect clinical decisions?
- 9. Are there considerations of public health and safety that influence clinical decisions?
- 10. Does institutional affiliation create conflicts of interest that might influence clinical decisions?



Medical Indications

his chapter treats the first topic relevant to any ethical problem in clinical medicine, namely, the indications for or against medical intervention. In most cases, treatment decisions that are based on medical indications are straightforward and present no obvious ethical problems.

EXAMPLE. A patient complains of frequent urination accompanied by a burning sensation. The physician suspects a urinary tract infection, obtains a confirmatory culture, and prescribes an antibiotic. The physician explains to the patient the nature of the condition and the reason for prescribing the medication. The patient obtains the prescription, takes the medication, and is cured of the infection.

This case exemplifies clinical ethics because it demonstrates the bioethical principles commonly considered necessary for ethical medical care, namely, respect for autonomy, beneficence, nonmaleficence, and justice. The symptoms are sufficiently clear for the physician to make a diagnosis and prescribe an effective therapy in order to benefit the patient. The patient's preferences coincide with the physician's recommendations. The patient's quality of life, presently made unpleasant by the infection, is improved. Medications are available, insurance pays the bill, and no problems with family or hospital complicate the situation.

This case represents the ethical practice of medicine because each of the fundamental principles is fulfilled. It would become an ethical problem if one or more of these principles could not be fulfilled because several principles appeared to conflict or draw the decision in different directions. For example, if the patient stated that he did not believe in antibiotics, or if the urinary tract infection developed in the last phase of a terminal illness, or if the infection was associated with a sexually transmitted disease where sexual partners might be endangered, or if the indicated medication was in short supply and needed to be rationed. Sometimes, these problems