Introduction

THE FOUR TOPICS: CASE ANALYSIS IN CLINICAL ETHICS

Clinical ethics is a practical discipline that provides a structured approach for identifying—,analyzing, and resolving ethical issues in clinical medicine. The practice of good clinical medicine requires a working knowledge about ethical issues, such as informed consent, truth telling, confidentiality, end-of-life care, pain relief, and patient rights. Medicine, even at its most technical and scientific levels, i.s an encounter between human beings, and the physician's work of diagnosing disease, offering advice, and providing treatment is embedded in a moral context. The willingness of physician and patient to endorse moral values, such as mutual respect, honesty trustworthiness, compassion, and a commitment to pursue shared goals, usually ensures that significant conflicts between physician and patient rarely occur. Occasionally, physicians and patients may disagree about values or may face choices that challenge their values. It is then that ethical problems arise. Clinical ethics concerns both the ethical features that are present in every clinical encounter and the ethical problems that occasionally occur in those encounters. Clinical ethics relies on the conviction that, even when perplexity is great and emotions run high, physicians, nurses, and patients and their families can work constructively to identify, analyze, and resolve many of the ethical problems that appear in clinical medicine.

The authors have two purposes in writing this book: first, to offer an approach that facilitates thinking about the complexities of the problems that clinicians actually face and, second, to assemble concise representative opinions about typical ethical problems that occur in the practice of

medicine. We do not, however, merely give answers to the ethical questions. Instead, our goal is to help clinicians understand and manage the cases they encounter in. their own. practices. Every clinician should recognize that ethics is an inherent aspect of good clinical medicine. Our book is intended not only for clinicians and students who provide care to patients, but also for other individuals, such as hospital administrators, hospital attorneys, members of institutional ethics committees, quality reviewers, and administrators of health plans, all of whose work requires an awareness and sensitivity to the ethical issues in clinical practice. In the complex world of modern health care, all of these persons are responsible for maintaining the ethics that lie at the heart of quality care.

Many books onhealth care ethics are organized around ethical principles, such as respect for autonomy, beneficence, nonmaleficence, and fairness, and cases are analyzed in the light of those principles. Other books consist of essays on particular problems, such as informed consent or forgoing life support. Our book is different. Clinical situations are complex, because they involve a wide range of medical facts, a multitude of circumstances, and a variety of values. Often, decisions must be reached quickly. The authors believe that clinicians need a straightforward method of sorting out the pertinent facts and values of any case into an orderly pattern that facilitates the discussion and resolution of ethical problems. Our book, therefore, brings together those principles and circumstances that comprise a method to facilitate the analysis of cases involving ethical issues. This technique, in our view, corresponds to the way clinicians analyze actual cases.

We suggest that every clinical case, especially those raising an ethical problem, should be analyzed by means of the following four topics: (1) medical indications, (2) patient preferences, (3) quality of life, and

(4) contextual features, defined as the social, economic, legal, and administrative context in which the case occurs. Although the facts of each case can differ, these four topics are always relevant. The topics organize the various facts of the particular case and, at the same time, call attention to the ethical principles appropriate to the case. It is our intent to show readers how these four topics provide a systematic method of identifying and analyzing the ethical problems occurring in clinical medicine.

Clinicians will recall the method of case presentation that they learned at the beginning of their professional training. They were taught to "present" a patient by stating in order (1) the chief complaint, (2) history of the present illness, (3) past medical history, (4) family and social history,

(5) physical findings, and (6) laboratory data. These are the topics that an experienced clinician uses to reach a diagnosis and to formulate a plan for management of the case. Although the particular details under each

of these topics can differ from patient to patient, the topics themselves are constant and are always relevant to the task of arriving at a management plan. Sometimes one topic, for example, the patient's family history or the physical examination, may be particularly important or, conversely, may not be relevant to the present problem. Still, clinicians are expected to review all of the topics in every case.

Our four topics help clinicians understand how the ethical principles connect with the circumstances of the clinical case. For example, a patient comes to a physician, complaining of feeling ill. Medical indications include a clinical picture of polydipsia and poly uric, nausea, fatigue, and. some mental confusion, with laboratory data indicating hyperglycemia, acidosis, and elevated plasma ketone concentrations. A diagnosis of diabetic ketoacidosis is made. Fluids and insulin are prescribed in specific doses and volumes. These clinical actions are all intended to benefit the patient. However, an ethical problem would occur if, after hearing the physician's recommendations, the patient rejects further medical attention. In these circumstances, the principle of beneficence, that is, the clinician's duty to assist the patient, and the principle of autonomy that is, the duty to respect the patient's preferences, come into conflict with each other. As the case is described, circumstances accumulate under all four of the topics and affect the meaning and relevance of the ethical principles. It is advisable to review all four topics together to see how the principles and the circumstances together define the ethical problem in the case and suggest a resolution. Good ethical judgment consists in appreciating how ethical principles should be interpreted in the actual situation under consideration. We hope our method helps practitioners to do just that.

We divide the book into four chapters, each one devoted to one of the four topics. These four chapters define the major concepts associated with each topic, present typical cases in which the topic under discussion plays a particularly important role, and critically review the arguments commonly offered to resolve the problem. For example, the case of a Jehovah's Witness patient who refuses a blood transfusion will demonstrate how the topic of patient preferences functions in the analysis of the ethical problem presented by a patient's refusal of an indicated medical treatment. At the same time, we suggest a resolution of the case that reflects both the current opinion of medical ethicists on cases involving Jehovah's Witnesses and our own judgment. Thus, for this particular example, a reader can use this volume as a reference book, by looking up "Refusal of treatment" or "Jehovah's Witnesses" in the Locator at the back of the book and reading the several pages devoted to that issue in Chapter 2.

Those readers who use the book as a reference will find concise summaries of current opinion on the ethics of certain typical cases, such as those involving refusal of care or a diagnosis of persistent vegetative state. This information may be all that they need at the moment. However, the actual cases that clinicians encounter in practice will be a combination of unique circumstances and values. The four topics can be considered as signposts that guide the way through the complexity of real cases. Thus, using the book's four-part method as a part of clinical. reasoning will serve th.e reader better than using it for occasional reference. The clinician will gain an appreciation of how an actual ethical case fits into the general understanding of such cases and how to reach an opinion suited to the actual case. We strongly suggest that readers read the book from beginning to end to get the full understanding of th.e method. We hope they will become adept at bringing the method to bear on their own clinical cases.

This book was originally written for physicians specialized in internal medicine, and it concentrated on the ethical problems encountered by those making clinical decisions for patients in their practice. In subsequent editions, the scope was broadened to adult medicine in :general, and then also to pediatrics. The sections particularly relevant to pediatric ethics have the letter P after their numbers in the text. Also, it became obvious to the authors that many other health care providers, nurses, social workers, medical technicians, as well as chaplains and administrators, found our method useful. In this fifth edition, the original emphasis on clinical decisions made by physicians remains, but we believe that others can fit the particular concerns and values of their own professions into the topics of the book. Unfortunately this book cannot address the ethical issues in reproductive medicine and obstetrics; the problems there involve an enigmatic third party, the fetus, and thus, they require a more complex approach than this book provides.

The method presented in this book is not only useful for clinical decision making. It also provides a simple way to determine the ethical dimensions of a patient's care. For example, the four topics might serve as the outline for a discussion between providers, patient, and family at the time of admission to an extended-care facility or to hospice care. A copy of the four topics could be given to patient and family; various questions could then be asked, and the answers recorded. This initial record could be reviewed as the patient's situation changes and as particular decisions must be made. We believe that this book, despite its use of medical language, can benefit every person who will some day be a patient, or who has family and friends who are now patients. The structured framework can guide all parties through otherwise confusing situations.

Dax's Case. We can illustrate our method by a brief summary of a case familiar to many who have studied medical ethics, namely, the case of Donald "Dax" Cowart, the burn patient who related his experience in the videotape *Please Let Me Die* and the documentary Dax's *Case.'*

In 1973, "Dax" Cowart, aged 25 years, was severely burned in a propane gas explosion. Rushed to the Burn Treatment Unit of Parkland Hospital in Dallas, he was found to have severe burns over 65% of his body; his face and hands suffered third-degree burns, and his eyes were severely damaged. Full-burn therapy was instituted. After an initial period during which his survival was in doubt, he was stabilized and underwent amputation of several fingers and removal of his right eye. During much of his 232-day hospitalization at Parkland, his few weeks at The Texas institute of Rehabilitation and Research at Houston, and his subsequent 6-month stay at University of Texas Medical. Branch in Galveston, he repeatedly insisted that treatment be discontinued and that he be allowed to die. Despite this demand, wound care was continued, skin grafts were performed, and nutritional and fluid support were provided. He was discharged totally blind, with minimal use of his hands, badly scarred, and dependent on others to assist in personal functions.

Discussion of the ethics involved in a case like this can begin by asking any number of questions. Did Dax have the moral or the legal right to refuse care? Was Dax competent to make a decision? Were the physicians paternalistic? What was Dax's prognosis? All these questions, and many others, are relevant and can result in vigorous debate. However, we suggest that the ethical analysis should begin by an orderly review of the four basic topics. We recommend that the same order be followed in all cases; that is, (1) medical indications, (2) patient preferences, (3) quality of life, and (4) contextual features. The use of this procedure will lay out the ethically relevant facts of the case (or show where further information is needed) before debate begins. This order of review does not constitute an order of ethical priority. The determination of relative importance of these topics will be explained in the four chapters.

Medical Indications. This topic includes the usual content of a clinical discussion: the diagnosis, prognosis, and treatment of the patient's medical problem. "Indications" refers to the diagnostic and therapeutic interventions that are appropriate to evaluate and treat the problem. Although this is the usual material covered in the presentation of any patient's clinical problems, the ethical discussion reviews the medical facts and evaluates them in the light of the fundamental ethical features of the case, such as the possibility of benefiting the patient and respecting the patient's preferences.

In Dax's case, the medical indications include the clinical facts necessary to diagnose the extent and seriousness of his burns, to make a prognosis for survival or restoration of function, and to determine the options for treatment, including the risks, benefits, and probable outcomes of each treatment modality. For example, certain prognoses are associated with burns of given severity and extent. Various forms of treatment, such as fluid replacement, skin grafting, and antibiotics are associated with certain probabilities of outcome and risk. After initial emergency treatment, Dax's prognosis for survival was approximately 20%, but the quality of life after his survival was likely to be greatly diminished by blindness, disability, and deformity After 6 months of intensive care, his prognosis for survival improved to almost 100%. If his request to stop wound care and grafting during that first hospitalization had been respected, he would almost certainly have died. A clear view of the possible benefits of intervention is the first step in assessing the ethical aspects of a case.

Patient Preferences. In all medical treatment, the patient's preferences that are based on the patient's own values and personal assessment of benefits and burdens are ethically relevant. In every clinical case, certain questions must be asked: What does the patient want? and What are the patient's goals? The systematic review of this topic requires the following additional questions: Has the patient been provided sufficient information? Does the patient comprehend? Does the patient understand the uncertainty inherent in any medical recommendation and the range of reasonable options that exist? Is the patient consenting voluntarily? and Is the patient coerced? In some cases, an answer to these questions might be: "We don't know because the patient is incapable of formulating a preference or expressing one." If the patient is mentally incapacitated at the time a decision must be made, we must ask: Who has the authority to decide on behalf of this patient? What are the ethical and legal limits of that authority? and What is to be done if no one can be identified as surrogate?

In Dax's case, his mental capacity was questioned in the early days of his refusal of care. Had the physical and emotional shock of the accident undermined his ability to decide for himself? Initially, it was assumed that he lacked the capacity to make his own decisions, at least about refusing life-saving therapy. The doctors accepted the consent of Dax's mother in favor of treatment over his refusal of treatment. Later, when Dax was rehospitalized in the Galveston Burn Unit, a psychiatric consultation was requested, which affirmed his capacity to make decisions. Once that capacity was established, the ethical implications of his desire

to refuse care became central. The following ethical questions immediately had to be considered: Should his preference be respected? Did. Dax appreciate sufficiently the prospects for his rehabilitation? Are physicians obliged to pursue therapies they believe have promise over the objections of a patient? Would they be cooperating in a suicide if they assented to Dax's wishes? Any case involving the ethics of patient preferences relies on clarification of these questions.

Quality of Life. Any injury or illness threatens persons with actual or potentially reduced quality of life, manifested in the signs and symptoms of their disease. One goal of medical intervention is to restore, maintain, or improve quality of life. Thus, in all medical situations, the topic of quality of life must be considered. Many questions surround this topic: What does this phrase "quality of life" mean in general? How should it be understood in particular cases? How do persons other than the patient perceive the patient's quality of life, and of what ethical relevance are their perceptions? Above all, what is the relevance of quality of life to ethical judgment? This topic, important as it is in clinical judgment, opens the door for bias and prejudice. Still, it must be confronted in the analysis of clinical ethical problems.

In Dax's case, we note the quality of his life before the accident. He was a popular, athletic young man, just discharged from the Air Force, after serving as a fighter pilot in Vietnam. He worked in a real estate business with his father (who was also injured in the explosion and died on the way to the hospital). Before his accident, Dax's quality of life was excellent. During the course of medical care, he endured excruciating pain and profound depression. After the accident, even with the best of care, he was confronted with significant physical deficits, including notable disfigurement, blindness, and limitation of activity. During most of his hospital course, Dax had the capacity to determine what quality of life he wished for himself. However, in the early weeks of his hospitalization, he may have suffered serious deficits in mental capacity at the time critical decisions had to be made. Others would have to make quality-of-life decisions on his behalf. Was the prospect for return to a normal or even acceptable life so poor that no reasonable person would choose to live, or is any life worth living regardless of its quality? Who should make such decisions? What values should guide the decision makers? The ethical controversy occurred because Dax believed, even though his mother and physicians did not, that he had the capacity and the right to make his own quality-of-life decisions, including the right to refuse all treatment. The meaning and import of such considerations must be clarified in any clinical ethical analysis.

Contextual Features. Preferences and quality of life bring out the most common features of the medical encounter. However, every medical case is embedded in a larger context of persons, institutions, and financial and social arrangements. The possibilities and the constraints of that context influence patient care, positively or negatively. At the same time, the context itself is affected by the decisions made by or about the patient: these decisions may have psychological, emotional, financial, legal, scientific, educational, or religious impact on others. In every case, the relevance of the contextual features must be determined and assessed. These contextual features may be crucially important to the understanding and resolution of the case.

In Dax's case, several of these contextual features were significant. Dax's mother was opposed to termination of his medical care for religious reasons. The legal implications of honoring Dax's demand were unclear at the time. The costs of 16 months of intensive burn therapy were substantial. Dax's refusal to cooperate with treatment may have influenced the attitudes of physicians and nurses toward him. These and other contextual factors must be made explicit and assessed for their relevance.

Rules and Principles. These four topics are relevant to any clinical case, whatever the actual circumstances. They serve as a useful organizing device for teaching and discussion. Some clinicians have even found them useful for organizing a plan for patient management. A review of these topics can also help to move the discussion of an ethical problem toward a resolution. Any serious discussion of an ethical problem must go beyond merely talking about it in an orderly way: it must push through to a reasonable and practical resolution. Ethical problems, no less than medical problems, cannot be left hanging. Thus, after presenting a case, the task of seeking a resolution must begin.

The discussion of each topic includes certain standards of behavior that are ethically appropriate to the topic. These can be called ethical principles or ethical rules. For example, one version of the principle of beneficence states, "There is an obligation to assist others in the furthering of their legitimate interests." The ethical rule, "Physicians have a duty to treat patients, even at risk to themselves," is a specific expression of that broad principle, suited to a particular sphere of professional activity, namely, medical care. The topic of medical indications, in addition to the clinical data that must be discussed, includes the additional questions, "How much can we do to help this patient?" and "What risks of adverse effects can be tolerated in the attempt to treat the patient?" Answers to these questions, arising so naturally in the discussion of medical indica-

tions, can be guided by familiar historical rules of medical ethics such as, "Be of benefit and do no harm" or "Risks should be balanced by benefits." Rules such as these reflect in a specific way the broad principle that the philosophers have named beneficence. Similarly, the topic of patient preferences contains rules that instruct clinicians to tell patients the truth, to respect their deliberate preferences, and to honor their values. Rules such as these fall under the general scope of the principles of autonomy and respect for persons.

Our method of analysis begins, not with the principles and rules, as do many other ethics treatises, but with the factual features of the case. We refer to principles and rules as they become relevant to the discussion of the topics. In this way, abstract discussion of principles is avoided, as is also the tendency to think of only one principle, such as autonomy or beneficence, as the sole guide in the case. Ethical rules and principles are best appreciated in the specific context of the actual circumstances of a case. For example, a key issue in Dax's case is the autonomy of the patient. However, the significance of autonomy in Dax's case is derived not simply from the principle that requires we respect it, but from the confluence of considerations about preferences, medical indications for treatment, quality of life, decisional capacity, and the role of his mother, the doctors, the lawyers, and the hospitals. Only when all these are seen and evaluated in relation to each other will the meaning of the principle of autonomy be appreciated in this case.

Research in Medical Ethics. Competence in clinical ethics depends not only on the ability to use a sound method for analysis, but also on a familiarity with the literature of medical ethics. Some readers will seek further elaboration of the issues dealt with so briefly in this book. We rarely cite articles (except those that we quote), because the literature in bioethics is extensive and in constant evolution. Instead, we refer, when useful, to the most widely used general text in bioethics, Beauchamp and Childress, *Principles of Biomedical Ethics.*[2] We also reference the Special Issues and Special Sections of three principal American journals in bioethics, Hastings *Center Report,*[3] *Journal of* Clinical Ethics,[4] and *Cambridge Quarterly of Healthcare* Ethics.' These special issues and sections provide broad views of particular issues with bibliographies of the current literature. Readers seeking the most current articles may search in the annual publication The *Bibliography of Bioethics.*[6] This source is available on-line as Bioethicsline, through the National Library of Medicine's MEDLARS. There are also many useful Web sites, such as those of the Clinical Ethics Center of the National Institutes of Health, http ://www. nih . gov/sigs/bioethics.

***Four* Cases.** Four clinical cases will reappear throughout this book as our major examples. The patients in these cases are given the names Mr. Cure, Ms. Care, Ms. Comfort, and Mr. Cope. These fictional names are chosen to suggest certain prominent features of their medical condition. Mr. Cure suffers from bacterial meningitis, a serious but curable acute condition. Ms. Comfort has breast cancer that has metastasized, for which there is a low probability of cure even under a regimen of intensive intervention. Ms. Care has multiple sclerosis, a disease that cannot be cured but whose inexorable deterioration can be managed by continual care. Mr. Cope has a chronic condition, insulin-dependent diabetes, that requires certain medical assistance but depends heavily on the patient's active involvement in his own care. Details of these cases will occasionally be changed to illustrate various points as the text proceeds. Many other shorter case examples will appear in which the patients will be designated by initials.

Case I. Mr. Cure, a 24-year-old man, has been brought to the emergency room by a friend. Previously in good health, he is complaining of severe headache and a stiff neck. The results of the physical examination and laboratory studies, including spinal fluid examination, suggest a diagnosis of pneumococcal pneumonia and pneumococcal meningitis.

Case II. Mr. Cope is a 42-year-old man with insulin-dependent diabetes. His diabetes was first diagnosed at age 18. He complied with an insulin and dietary regimen quite faithfully. Still, he experienced frequent episodes of ketoacidosis and hypoglycemia, which necessitated repeated hospitalizations and emergency room care. For the last few years, his diabetes has been controlled, and he required hospitalization only once for ketoacidosis associated with acute pyelonephritis. Twenty-one years after the onset of diabetes, he appears to have no functional impairment from his disease. However, fundoscopic examination reveals a moderate number of microaneurysms and urinalysis shows persistent proteinuria. He has no neurologic symptoms or abnormal physical findings.

Case *III*. Mrs. Care, a 44-year-old married woman with two children, was diagnosed with multiple sclerosis (MS) 15 years ago. Over the past 12 years, the patient has experienced progressive deterioration. She developed severe spasticity in both legs, requiring canes, then a walker, and finally full use of a wheelchair. She is now blind in one eye, with markedly decreased vision in the other. For the past 2 years, she has required an indwelling Foley catheter because of an atonic bladder. In the last year, she has become profoundly depressed, is uncommunicative even with close family, and refuses to rise from bed.

Case IV Ms. Comfort is a 58-year-old woman. She has had a mammogram yearly for the past 6 years. Eight months after her last mammogram, she noted a rapidly enlarging right breast mass. She was seen by her primary care physician and referred to a surgeon who performed a breast biopsy that confirmed the presence of an infiltrating ductal adenocarcinoma. She underwent a modified radical mastectomy with reconstruction. Dissected nodes revealed metastatic disease. She received a course of chemotherapy and radiation.

On page 12, a chart depicts the four topics in quadrants. This chart can serve as a convenient way to record the facts of a case in an orderly way However, it has a much more important purpose as a guide for ethical deliberation about a case. The many facts do not remain isolated in their respective quadrants. Rather, once they are displayed, the ethical task begins: to evaluate the facts in relation to each other and in light of the principles. In some cases, once the facts are clear, it also becomes clear that the issue is easily resolved: confusion about the facts or failures in communication may have obscured the obvious priority of one or another principle. In other cases, reflective balancing of the principles is required, so as to reveal which principle should take priority. Finally, there are cases where the facts and the principles may be clear, but a genuine ethical dilemma may remain. We are aware that there are such dilemmas in clinical medicine, but we are convinced that many ethical problems can be reasonably resolved. When value conflicts are encountered, reasonable persons should make choices only after careful, honest consideration of the ethical aspects and the facts of the situation. We hope that this book will assist persons in doing just that.

EFERENCES

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■ MEDICAL INDICATIONS

The Principles of Beneficence and Nonmaleficence

I. What is the patient's medical problem? history? diagnosis? prognosis?

2. Is the problem acute? chronic? critical? emergent? reversible?

3. What are the goals of treatment?

4. What are the probabilities of success?

5. What are the plans in case of therapeutic failure?

6. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

■ QUALITY OF LIFE

The Principles of Beneficence and Nonmaleficence and Respect for Autonomy

I. What are the prospects, with or without treatment, for a return to normal life?

2. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?

3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life?

4. Is the patient's present or future condition such that his or her continued life might be judged undesirable?

5. Is there any plan and rationale to forgo treatment?

6. Are there plans for comfort and palliative care?

■ PATIENT PREFERENCES

The Principle of Respect for Autonomy

I Is the patient mentally capable and legally competent? Is there evidence of incapacity?

2. If competent, what is the patient stating about preferences for treatment?

3. Has the patient been informed of benefits and risks, understood this information, and given consent?

4. If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision making?

5. Has the patient expressed prior preferences, e.g.,Advance Directives?

6. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

7. In sum, is the patient's right to choose being respected to the extent possible in ethics and law?

■ CONTEXT AL FEATURES

The Principles of Loyalty and Fairness

I. Are there family issues that might influence treatment decisions?

2. Are there provider (physicians and nurses) issues that might influence treatment decisions?

3. Are there financial and economic factors?

4. Are there religious or cultural factors?

5. Are there limits on confidentiality?

6. Are there problems of allocation of resources?

7. How does the law affect treatment decisions?

8. Is clinical research or teaching involved?

9. Is there any conflict of interest on the part of the providers or the institution?