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INTRODUCTION

WHEN A THERAPIST and a patient meet to address the needs created by mental disorder, their developing relationship is bounded by rules that determine the appropriateness of interventions considered and performed. These rules are based not only on knowledge about the biological and psychological bases of disorder, but also on values which, like the therapies that can be employed, not only provide a range of alternatives, but also set limits on actions.

This book is about a particular subset of values dealing with ethics. Ethics is a discipline concerned with understanding the right-making and wrong-making characteristics of actions. The practitioners who analyze the ethical dimensions of human thought and interaction must examine deeply held beliefs derived from personal experience concerning right and wrong, cultural mores founded on the conventions of tradition, values received from and embodied in decisions of courts and legislatures, historical conventions developed by the health care professions over time and embodied in documents such as ethical codes, and scholarly works on ethics.

In this book, we approach ethics through case studies. Our goal is to present case material that can provide clinicians with a basis for learning and reflection, preferably in interaction with their colleagues. The cases used are real and are derived from clinical situations and consultative experiences of the authors, and their colleagues. The use of the case method, as applied to problems of mental illness, was developed by the authors at the Massachusetts Mental Health Center, where ethics rounds were begun in 1979 and continue in the present. The essays in the first part of this volume place the ethical problems of treating mentally ill people in the context of the health care ethics movement and traditions of ethical decision making. The essays as
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NEW PROBLEMS, NEW ETHICS:
CHALLENGING THE VALUE
STRUCTURE OF HEALTH CARE

IN THE MIDDLE of the 1960s, a revolution took place that pushed away the veil shrouding the ethical dilemmas of health care. It exposed not abuse, but misunderstanding, and a widespread unawareness of the ethical context of the relationships among medical personnel, patients, and society. Without some knowledge of this revolution in general medicine, the related developments in mental health cannot be fully understood.

HEALTH CARE AS A RIGHT

The ethics movement was the outcome of multiple events, linked by their focus on rights. Particularly important was the effort at the beginning of this century to equalize the quality of care among the diverse strata of American society.

A traditional attitude in the United States toward social provision of health care had been that meeting the basic needs of life was the responsibility of the individual. Society would intervene when an illness posed a long-term threat to a person's health, the care for the disease was time-consuming and placed substantial burdens on the family, or the disease posed a danger to the community. By these definitions, persons afflicted with tuberculosis, mental illness, and retardation were candidates for social support, and many hospitals were built during the 19th and 20th centuries to treat these disorders. Society also responded to the general medical needs of the poor by constructing institutions for their care: Indigency was a condition that legitimized social intervention.

The movement to give people broad access to health care, regardless of their specific illness or financial state, met with continued
resistance from the time it began in the early 20th century right up to 1960. Then, the rising cost of medical care dovetailed with a growing conviction that a particular segment of the population, the elderly, was particularly vulnerable to both illness and the large medical bills now accompanying it. The Democratic Party, with John F. Kennedy as its presidential nominee, caught wind of an emerging national consensus, which favored social assumption of the health care of the elderly, and supported a government-financed insurance scheme that would give this age group medical access and protection. This scheme was embodied in the 1965 Medicare Act. In the wave of social activism that was the hallmark of the Great Society, Medicaid legislation in 1966 consolidated the federal government’s medical assistance plans for the poor.

Although the magnitude of this commitment of health service delivery by the federal government represented a policy departure, in essence, tradition was maintained. Once again, the country had opted to provide health care rights to well-defined groups having special needs and had rejected a policy giving broad health care coverage to all.

However, in the 1960s the fact that millions had acquired the right to health care resources through Medicare and Medicaid dramatically changed the government’s view of its responsibility to oversee the nation’s health. The government was no longer a bystander, but had become a responsible party with major obligations. For the first time in American history, “right to health care” was a familiar phrase in the political dialogue.

CIVIL RIGHTS FOR WOMEN AND ABORTION

Simultaneously with these events, a large civil rights movement, with significant origins in the 1950s, began to influence women’s views of their position in society. In the early 1960s women began to ask, in an increasingly public and forceful manner, why the barriers to equal opportunity with men in all spheres of life should not be taken down.

A central question of interest to this movement was how women could approach their function as the bearer of children and yet retain a capacity for equal participation with men in the opportunities and rights of American society. This raised into the social consciousness
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of the 1960s the long-debated question of what the status of the fetus was and whose views — those of its mother, father, the state, or religion — should take precedence in deciding this question.

A strong argument was presented that a woman’s central role in the process of fetal maturation and birth should make her the predominant figure in this decision. This debate generated one of the most prolonged, socially open, and productive discussions ever held on abortion. Difficult questions were raised concerning the meaning of personhood, the right of individuals to adjudicate decisions about their own biologic functions, and the right of the state to intervene in such matters.

Often the discussion was charged with great emotion. For those who believed the fetus was a person from the moment of conception, abortion represented killing. Others considered the viewpoints about the fetus to be so philosophically conflicting and bound in untestable religious tenet, that it seemed socially and morally desirable to give individuals relative freedom in deciding how to regard the fetus. This was the essential position taken by the U.S. Supreme Court in 1972 in Roe v. Wade. It permitted the woman and doctor to determine jointly whether abortion was reasonable during the first trimester of pregnancy. In the second trimester, the state was given the prerogative to protect the health of the mother. In the final trimester, the state might pass laws to protect the fetus.

By posing such questions in the 1960s, the debate on abortion led clinicians, among others, to analyze the meaning of personal rights, the definition and consequences of autonomy, and the boundaries of state power to intervene in decisions involving the body of the individual.

Technology and ethics

Complementing these social movements in the 1960s was a technologic revolution in medicine, unparalleled in its breadth and complexity. This revolution affected attitudes toward three issues in particular: the allocation of resources, the definition of death, and the dilemma of justifying cessation of aggressive, life-sustaining therapy.

In 1944, Willem Kolff, a physician in Holland under Nazi oc-
cupation, used human beings to test a machine that cleansed the blood of toxic products accumulating as a result of kidney failure. The device was make-shift and intended only to assist the body’s toxic waste disposal needs for a short period, during episodes of acute renal failure. It was ineffective in the first 14 patients tested. For the 15th patient, a woman, it proved to be a life-saving device.

By 1961 the machine was clinically perfected, with the addition of a shunt allowing the patient and machine to be connected for prolonged periods and filters to remove waste from the blood in a more effective way than in the past. Furthermore, drugs had been developed to prevent clotting when blood flowed through the system. Thus technically improved, the artificial kidney appeared at the Dialysis Center in Seattle, Washington. With thousands of people in the United States in the final stage of renal disease, the demand for therapy rapidly exceeded the supply of machines and the personnel to run them. The hospital staff was faced with the ethical problem of how to distribute a life-saving technological resource among desperate claimants, a type of situation Americans had not faced since World War II.

Those charged with making these choices decided to empanel an ethics committee composed of medical personnel and community representatives to develop guidelines for allocation, and to act on them. The rules they adopted to choose one person over another – particularly those aspects that weighed social merit and ability to pay – seemed unsatisfactory to social and medical critics. This committee labored mightily, under much stress, navigating in uncharted waters. Yet, in retrospect, it is clear that making choices of this sort using such guidelines is extremely difficult. Some critics began to urge that greater randomness be introduced into the process. Others called for a national program to support the financial needs of those in renal failure who were candidates for dialysis and transplantation. In 1972, such a program became law, eliminating the need to choose among patients having kidney disease. This legislation shifted the problem from the patient and ethics committee to society, which now contributes more than $2 billion in annual costs to support this program.

The artificial kidney was but one of a cohort of new technologies introduced into medicine in the 1960s that staved off death in the face of massive physiological collapse. These technologies included
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artificial respirators, monitoring machines, and more effective drugs, all of which gave medical staffs undreamed of power to keep the human body alive. These devices challenged the intellectual constructs medicine had fashioned to deal with death. To a physician or a nurse in the early 1960s death was simple and unequivocal—it was defined as the cessation of heart and lung functions and the absence of pupillary contraction in the presence of bright light. The tools used to diagnose this condition were simple—a stethoscope and a flashlight. However, once the technology was available to sustain these functions, such strategies and tools became obsolete. New concepts and other machines were needed. They emerged in 1966 in the notion of brain death and in the growing reliance on the electroencephalograph (EEG) to determine this condition. Death was now defined by criteria involving neurologic and brain function, partly viewed through the wave-form evidence of the EEG. The paradox of the heart and lungs working while the person who housed them was brain dead presented surreal images to medical staffs and families of the patients.

This new approach to death raised complex ethical questions concerning not only the definition of death itself, but also the nature of the medical heroics appropriate to life-threatening crises. In the past, the issue of whether to restrain therapy had been a subject of medical concern and debate. The ancient Greek dictum urging physicians “to help, or at least to do no harm,” implied that the unrestrained use of medical force could lead to much suffering for the patient. Not harming, in this formulation, was as much a good as helping.

Although physicians and patients in previous ages grappled with this question, their engagements were sporadic and of short duration. The illness, usually unyielding to therapeutics if it was serious and acute, ended after a not too prolonged course. The therapeutics of the 1960s changed this pattern significantly. Strengthened by the advances of science, the new therapeutics, with the technology of rescue in its vanguard, fought off illness and staved off death. But at a high price. For those who did not begin to recover their normal functions within the space of weeks, each day increased the likelihood that the patient would not return to normal. If not recovery, if not death, what then? Linger. Patients lingered in the twilight life of vital function, continuing without hope or even consciousness. And
while they lingered, staff and family grew uneasy, perplexed, and embittered about the machines that at first were seen as agents of rescue.

This situation generated calls for reflection on the ethics of the matter and for action. Any action that would bring about some resolution seemed preferable to the waiting and the hopelessness that grew with it.

With the repeated occurrence of such events over a range of medical disasters, from accidents to cancer, many turned to the theory and practice of ethics for an approach that would reconfirm the validity of initially applying the new technological marvels to these disorders. It became clear that only a rational approach with an ethical basis for withdrawing therapy would deliver the relief to patients and families that medicine was expected to bring.

EXPERIMENTATION AND THE RIGHTS OF SUBJECTS

An event that dovetailed in the 1960s with the debate on therapeutics had to do with the science used to generate them. Experiments that used human subjects to test the effects of new therapies had taken place throughout medical history. What was new in this decade was the influence of experiments performed on humans by the Nazis in World War II, which drew attention to the dangers for the subjects in experimental investigations and to the obligations of scientists to guard against them. To this was added a growing sensitivity to ethical questions in medicine in general, which increased the scrutiny to which research on human subjects was subjected.

The outcome of the judicial deliberations concerning experimentation on human beings during World War II was the formulation of ten standards, known as the Nuremberg Code, that were to be observed in this activity. These standards were established in recognition of the need to inform subjects fully about the possible outcomes of their participation, and to make certain that investigators were morally obligated to ensure the subject’s safety, independent of the consent process.

The standards helped investigators to clarify their obligations. But they were not by themselves adequate to prevent subjects from being harmed. In the late 1950s and 1960s, several widely publicized cases
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involving unethical practices in human studies led the U.S. Public Health Service to issue a regulation in 1966 requiring all hospitals and other medical institutions conducting research on human subjects to empanel committees of medical staff and laymen. Their purpose was twofold: to evaluate all human studies and ensure that they were designed so as to minimize harm to subjects; and to provide subjects with a full view of the possible dangers as well as benefit, so that their decision to enter a trial was “informed.”

One of the cases that brought attention to the need for additional safeguards occurred in an institution for the mentally retarded called the Willowbrook State School. There, in the late 1950s, newly admitted children were fed hepatitis virus in an experiment designed to investigate the circumstances under which the disease occurred, evaluate the cogency of gamma globulin in reducing its occurrence, and test the induction of immunity by feeding hepatitis virus to gamma globulin-protected persons. The investigators justified the experiment on the basis of their experience that most of those entering the school got the infection, that it was a benign disease in children, that facilities were available at the school to provide good medical care in an isolation unit, that the experimentally induced disease would be milder than the natural infection (this turned out to be the case), and that consent for the study had been gained from parents of the subjects involved. Was such a proxy consent adequate? Should people such as children or the mentally retarded, who cannot give their own consent, be provided with additional procedural safeguards? What ethics should be guiding the research on such people (1)? The Willowbrook case stirred such questions.

Consent of the subject had been a central feature of the Nuremberg Code. However, since 1966 – when it was stipulated that all investigators must consider this issue before their research is approved – investigators have come to better understand and become more sensitive to their obligations to and the rights of subjects.

THERAPEUTIC ACTIVITIES AND THE RIGHTS OF PATIENTS

The focus on consent and the autonomy of the subject in experimentation stimulated investigators to explore these issues in relation
to the therapeutic activities of medicine. In the 1960s clinicians began to examine how they treated the passage of information to patients. In the 1970s there emerged a consensus that doctors had withheld too much from patients in the past and that the patients had a right to participate in important decisions affecting them.

This concern was reflected in a document published in 1973 by the American Hospital Association, *Statement on a Patient's Bill of Rights*. It emphasized the right of patients to have complete and clear information concerning diagnosis, prognosis, and therapy. It called on physicians to obtain the informed consent of patients before the start of any therapy; that is, it asked them to stipulate the risks and the expected length of incapacitation, and to let patients know about the availability of significant alternative therapeutic options. Rights to refuse treatment and to privacy and confidentiality were enumerated, along with information about bills and hospital rules. In essence, the document represents an important and explicit public statement concerning the enhanced role of patients in deciding the terms of medical care.

**THE ETHICS MOVEMENT IN MENTAL HEALTH**

The ethics movement in health care also led those charged with treating patients suspected of or having diminished capacity to evaluate the therapeutic alternatives, to review more critically than they had in the past the terms under which they exercised paternalistic oversight. Nowhere in health care was this more significant or difficult than in the field of mental health. Psychiatrists, social workers, psychologists, and other mental health therapists began, as never before, to question the ethical values under which they developed relationships with patients, colleagues, society, and the state (2). A number of issues were central to this discourse. One dealt with the psychiatrist as “double-agent” (3). This issue in particular received publicity in the early 1970s, as news reached the West of the use of Soviet psychiatrists and psychiatry to quell political dissent by linking it to mental illness and committing dissenters to mental hospitals as patients. Other circumstances in which mental health therapists felt