STRANGERS AT THE BEDSIDE

A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING

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CONTENTS

INTRODUCTION

Making the Invisible Visible

BEGINNING in the mid-1960s, the practice of medicine in the United States underwent a most remarkable—and thoroughly controversial—transformation. Although the changes have altered almost every aspect of the relationship between doctor and patient—indeed, between medicine and society—the essence can be succinctly summarized: the discretion that the profession once enjoyed has been increasingly circumscribed, with an almost bewildering number of parties and procedures participating in medical decision making. As late as 1969, the philosopher Hans Jonas could assert that "the physician is obligated to the patient and to no one else. . . . We may speak of a sacred trust; strictly by its terms, the doctor is, as it were, alone with his patient and God."[1] But even as he wrote, the image of a physician alone with a patient was being supplanted by one of an examining room so crowded that the physician had difficulty squeezing in and of a patient surrounded by strangers.

Well into the post–World War II period, decisions at the bedside were the almost exclusive concern of the individual physician, even when they raised fundamental ethical and social issues. It was mainly doctors who wrote and read about the morality of withholding a course of antibiotics and letting pneumonia serve as the old man's best friend, of considering a newborn with grave birth defects a "stillbirth" and sparing the parents the agony of choice and the burden of care, of

experimenting on the institutionalized retarded to learn more about hepatitis, or of giving one patient and not another access to the iron lung when the machine was in short supply. Moreover, it was usually the individual physician who decided these matters at the bedside or in the privacy of the hospital room, without formal discussions with patients, their families, or even with colleagues, and certainly without drawing the attention of journalists, judges, or professional philosophers. And they made their decisions on a case-by-case basis, responding to the particular circumstances as they saw fit, reluctant by both training and practice to formulate or adhere to guidelines or rules.

By the mid-1970s, both the style and the substance of medical decision making had changed. The authority that an individual physician had once exercised covertly was now subject to debate and review by colleagues and laypeople. Let the physician design a research protocol to deliver an experimental treatment, and in the room, by federal mandate, was an institutional review board composed of other physicians, lawyers, and community representatives to make certain that the potential benefits to the subject-patient outweighed the risks. Let the physician attempt to allocate a scarce resource, like a donor heart, and in the room were federal and state legislators and administrators to help set standards of equity and justice. Let the physician decide to withdraw or terminate life-sustaining treatment from an incompetent patient, and in the room were state judges to rule, in advance, on the legality of these actions. Such a decision might also bring into the room a hospital ethics committee staffed by an unusual cadre of commentators, the bioethicists, who stood ready to replace bedside ethics with armchair ethics, to draw on philosophers' first principles, not on the accumulated experience of medical practice.

Were all these participants not company enough, the physician in the ordinary circumstances of daily practice often encountered a new type of patient, particularly among young and better educated men, and even more frequently, women, who had assimilated a new message: rather than comply dutifully with your doctor's orders, be "alert to your responsibility in the relationship, just as you would in any other adult relationship where you are purchasing services."[2] In the 1950s,

popular health care guides had carried such titles as "What to Do Until the Doctor Comes." The updated version might well be called: "What to Do After the Doctor Comes."

Without putting too fine a point on it, the critical period of change was 1966 to 1976. The transformation began when in 1966 a Harvard Medical School professor, Henry Beecher, exposed abuses in human experimentation. Then, in 1973, Congress, under the leadership of senators Walter Mondale and Edward Kennedy, established a national commission to explore medical ethics. The period closed with the New Jersey Supreme Court ordering doctors to yield to parental requests to remove twenty-two-year-old Karen Ann Quinlan from a respirator. The impact of these events, most generally framed, was to make the invisible visible. Outsiders to medicine—that is, lawyers, judges, legislators, and academics—penetrated its every nook and cranny, in the process giving medicine an exceptional prominence on the public agenda and making it the subject of popular discourse. This glare of the spotlight transformed medical decision making, shaping not merely the external conditions under which medicine would be practiced (something that the state, through the regulation of licensure, had always done), but the very substance of medical practice—the decisions that physicians made at the bedside.

The change was first manifested and implemented through a new commitment to collective, as against individual, decision making. There were standing committees to ensure that a researcher who would experiment with human subjects was not making a self-serving calculus of risks and benefits, and standing committees to review whether the physician who would withdraw treatment from a gravely ill newborn or, for that matter, from a terminally ill adult, was not idiosyncratic in his or her calculus of medical futility or judgment about a life not worth living. Second, a new formality came to characterize decision making. Written documentation was replacing word-of-mouth orders (or pencil notations to be erased later), as in the case of coding a patient DNR (do not resuscitate) so that if his heart stopped, the team would not make every last effort (through chemical and electrical stimulation) to revive him. This formality transformed the medical chart from an essentially private means of communication among doctors to a public piece of evidence that documented what the doctor had told, and heard from, the patient. Third, in a more subtle but no less critical

fashion, outsiders now framed the normative principles that were to guide the doctor–patient relationship. The critical pronouncements no longer originated in medical texts but in judicial decisions, bioethical treatises, and legislative resolutions. Outsiders, not doctors, defined the moral codes that were to guide physician behavior.

The causes and consequences of these extraordinary changes are the core concerns of this book. How did it happen that physicians, who had once ruled uncontested over their domain, came to confront committees, forms, general principles, and active patients? What were the roots of the idea, not very long ago unheard of, that "there is need to involve not only the medical profession, but lawyers, sociologists, moralists, and society at large" in the effort to resolve "complicated [medical] issues," for "the solutions will come only if society is willing to support the formal investigation by physicians, lawyers, sociologists and moralists"?[3] Why did this line become repeated so often and in such a variety of contexts as to become almost a truism? In a phrase, what brought new rules and new players to medicine?

In answering these questions, it will often be useful to contrast the perspectives and goals of physicians and nonphysicians, or outsiders as I call them. The designations are obviously broad, and for some purposes no doubt too broad. Medical specialists have often differed on policy issues from general practitioners, as anyone familiar with the history of the American Medical Association recognizes. And from 1966 to 1976, physicians were divided (albeit not evenly) among themselves on many of the substantive matters explored in this book. In almost every instance, it was physicians who assumed the role of whistleblowers and invited outsiders in. For example, Henry Beecher, a physician, exposed the abuse of discretion by individual researchers, and physicians such as Raymond Duff and William Bartholome lifted the curtain that surrounded neonatal decision making. But that said, in the debates over ruling medicine, the great majority of physicians who went on record, including the whistle-blowers, were deeply troubled about a loss of doctors' authority at the bedside and the expanded prerogatives of outsiders. The changes that came to medicine generally came over the strenuous objections of doctors, giving the entire process an adversarial quality.

On the other side, the outsiders who entered medicine ranged from lawyers to legislators to religion and philosophy professors. Although one would not have anticipated prior agreement among them on most subjects, they shared a goal of bringing new rules to medicine. Whether drawing on a tradition of predictability (in the law) or of first principles (in philosophy or religion), they joined together to create a new formality and impose it on medicine, insisting on guidelines, regulations, and collective decision making. They concurred on the need to reduce physicians' discretion and enhance patients' autonomy.

Given such disparate views and intentions, a twofold classification of doctors and outsiders makes sense. Although it can mask important distinctions, it helps us capture and explain the essence of a decade-long conflict. It conveys an image of a relatively well drawn battle line—which fits with the contours of the events.

I am also comfortable maintaining an insider–outsider distinction because in 1983 I became Professor of Social Medicine at Columbia's College of Physicians and Surgeons, even as I continued as professor of history in the university. My mandate from the medical school was to bring the methods and materials of the humanities and social sciences into its research and teaching curriculum. In a very personal way, then, I crossed the boundary and entered the world of medicine, in the process coming to appreciate just how different a world it is.

My assignment has been both exciting and difficult. Medicine has its own language, and it was disconcerting, almost humiliating, to arrive and listen to a group of twenty-six-year-olds carry on a conversation I could barely understand. "Dropping a crit," "flipping t waves," and "running v tach" were actions whose significance I neither recognized nor appreciated. Medicine also has its own brand of shoptalk; as I describe later, a first exposure to the "interesting case"—almost certain to involve devastating disease for the patient and many unknowns for the physician—was, even for someone who had investigated institutions for the retarded and prisons, emotionally draining and often too painful to share, at least with nonphysicians. But these experiences taught me firsthand that illness is highly segregated in this society, as are those who treat it.

I was struck again and again by the vast ignorance of colleagues and

friends about the world of medicine. Although I was accustomed to exploring institutions that were sealed off from the general public, I had not imagined that hospitals belonged in this category. I was frequently asked questions that revealed a startling degree of distance and unfamiliarity: "Is an operating room really a theater, with rows of seats going up?" (No) "Do surgeons bring tape decks with them?" (Sometimes) "What do you wear on rounds?" (A suit, not a white coat)—and on and on, as though my questioners had never been inside a hospital or spoken to a doctor outside of an examining room. Of course, they had read all about respirators, transplants, and other high-technology interventions. But what they lacked was a feel for the enterprise, a sense of the actors and the routines. To judge from their reactions, I was a throwback to the anthropologists of the 1920s, an explorer of foreign parts, as though 168th Street in northern Manhattan was at one with the South Seas.

In truth, I sometimes shared this sensation. Surprise was, and remains, a constant feature of going on rounds. At one of my first sessions, I was startled to hear a resident inform a senior physician, just before we entered a patient's room, that the patient had "died" yesterday, but after having had his medications adjusted, was doing much better. Later that morning she related that another patient was making good progress: he had not "died" even once, and she was confident about his prospects. Surely I was on a magic island if death was reversible and resurrection commonplace. And even after I learned that to "die" was to suffer a cardiac arrest and undergo resuscitation, not all of the sense of mystery disappeared.

I was also unprepared for the grueling and continuous pace of medical practice, a pace that helps isolate physicians in their own universe. The day starts early (seven o'clock meetings are not uncommon), and ends late; one female physician confessed to me that she considered herself only part-time because family responsibilities (raising three children) allowed her to work only a forty-hour week. And time not devoted to practice or teaching is often spent keeping pace with the latest research findings in the medical journals; nothing is more common on rounds than for attending physicians or house staff to cite a recent article on the advantages and disadvantages of a particular drug or procedure. The physicians are alert to numbers, and findings from

random clinical trials carry critical authority. But numbers alone do not rule, which brings us back to the issues at hand in the control of medicine.

Perhaps the most remarkable feature of clinical decision making is the extraordinary reliance on a case-by-case approach. No two patients, after all, are exactly alike; symptoms do not appear in the same pattern in the course of disease, and the results of tests do not always fall unambiguously into one category or another. Thus, medicine is as much art as science, and the clinical anecdote becomes highly relevant to treatment decisions. Because of uncertainty, clinicians value experience highly and are prepared to make decisions on the basis of a trial of one—that is, a patient treated some ten years ago whose case resembles the one today and who improved on a particular regimen. It is this resort to the anecdote that gives physicians the air of artists, even of magicians. In the face of confusing and contradictory symptoms, physicians can pull from a hat some case from the past and make their recommendation, often leading to the patient's recovery, albeit a baffling one.

Physicians, as I have learned, frequently bring this case-by-case approach into the consideration of social and ethical issues. Offer them a principle to consider (for example, that patients have the right to know their diagnosis), and they will often come up with a case (drawn from experience) that they believe undercuts and thereby negates the principle (for instance, the seeming inappropriateness of informing a seventy-five-year-old woman about to go off to her grandchild's wedding that she has an inoperable and slow-growing brain tumor). Describe a case in the ethics of decision making at the end of life that occurred at another hospital, and the physicians initially will try to obviate the problem by claiming that those doctors made egregious errors in their treatment (for example, this patient should never have needed a respirator in the first place). It is as though their ability to resolve the incident at hand absolves them of the need to formulate or respect general principles. If they can cite a case in which the proposed rule does not hold, then they have ostensibly discredited not only the rule but the search for rules. In short, clinicians start with the case at hand, and if they have their way, stop with the case at hand.

Outsiders from various disciplines seem far more prepared to seek out the general principle in deciding social and ethical questions. A

legal, as opposed to medical, mind-set is much more likely to search for the rule that should be imposed on a particular case than to see how the case can be resolved without it. Those trained in history or in other disciplines in the humanities and social sciences share this orientation. The end point is not the individual case but the light it can shed on general phenomena. In history this often prompts an impatience with biography, at least to the degree that it invokes the details of one person's life that are irrelevant to the larger social or political context. Medicine, by contrast, is closer to biography than to history, or to put this point in medicine's language, to the case history. Most of what physicians write for lay audiences, whether it is a neurologist on aphasia or a surgeon on transplants, follows this pattern—focusing on the one exciting case, or a series of cases, and letting the one instance represent all.

Clinicians appear to be as uncomfortable with sociological analyses of the collective aspects of medical decision making and the structural underpinnings of medical institutions as they are with the humanists' search for general principles. Consider, for example, the case of infants who are being treated even when the overwhelming majority of physicians and nurses do not believe treatment should continue. Tell the head of a neonatal unit that such practices persist not because of some error or breakdown in communication but because of a collective ethos that is protreatment; explain that this structural element, not the particulars of each case, is probably shaping the treatment decision, and you probably will hear a firm denial that such a process could occur. The very idea that some underlying mechanisms might constrain or dictate action is altogether alien to a perspective that insists that each case is, and must be, considered on its own merits.[4]

This perspective is transmitted from one generation of physicians to the other, not in so many words but in the very organization of medical school education. In clinical teaching the case approach is sacrosanct, and anyone who would bring social and ethical issues into the curriculum must adopt the same style. To begin with the general (What does "patient autonomy" mean?) and then move down to the particular (What are the implications for terminating treatment?) is to lose one's audience at the outset. Rather, one must start with the particular, with the specifics of a case and hope (distractions fielded) that one gets to

the general point. In fact, many medical schools long resisted the formal teaching of ethics, not because they believed that ethics could not be taught, but because it had to be taught at the bedside, by starting with the individual case. This type of approach, which I call *bedside ethics*, essentially meant teaching by example, by role modeling, by students taking cues from practicing physicians. Students were not to learn ethics by studying principles but by watching senior physicians resolve individual situations and then doing likewise. It is as though medical decision making begins and ends (or more precisely, should begin and end) with the dyad of the doctor and the patient alone in the examining room.

These biographical details and disciplinary outlooks help explain my approach in this book. They suggest, first, how alien rules are to medical decision making and how dogged and persistent an effort to alter this orientation would have to be. Second, although a doctor–outsider distinction may seem rudimentary, both scholarship and experience have persuaded me how real and powerful it is—so much so that in some ways this book represents my attempt to understand why a medical school would ask me (and the requests now extend, obviously, to many others) to cross over and enter its domain.

Perhaps most important, these observations make clear that from the start my own predilection strongly favored bringing rules to medicine. What I did not, however, fully appreciate at the outset was that by 1983 many of the critical battles had already been fought and a number of victories won. Thus, I immediately became a member of the institutional review board to oversee the conduct of human experimentation; I helped the medical director of the neonatal unit organize a bioethics committee, on which I took a seat; I helped a team of physicians who were conducting in vitro fertilization set up guidelines; and I sat with the heart transplant team as they pondered procedures for selecting recipients. Of course, I and the other committee members encountered resistance from colleagues. But it soon became apparent to me that what was needed most was not an insistence on bringing rules to medicine but a careful analysis of how the transformation in medical decision making had occurred.

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The causes of this sweeping transformation are as far-reaching as its implications. To understand the origins and outcomes of the disputes over ruling medicine requires tracing developments within both medicine and society, a reckoning that takes into account physician behavior and more diffuse public attitudes. For in many ways, the conflicts come down to an erosion in trust, to a decline in the deference given to doctors and to their professional judgments. To grapple with such delicate and elusive sentiments as trust and deference requires scrutinizing both sides of a relationship—what doctors did and what outsiders did—to make traditional ties and procedures seem inadequate and obsolete.

Surprisingly, the story opens in the laboratory, not the examining room. A series of exposés of practices in human experimentation revealed a stark conflict of interest between clinical investigators and human subjects, between researchers' ambitions and patients' well-being. This perception undercut an older confidence in the exercise of medical discretion and gave the regulation of clinical research a special prominence on the public agenda. The ethics of experimentation attracted the concern not only of those within medicine (particularly at the National Institutes of Health and the Food and Drug Administration), but an array of outsiders, most notably politicians and academics (law professors, philosophers, and sociologists), who had previously paid scant attention to medical issues. In fact, the agitation over human experimentation quickly became linked to the rights movements that were gaining strength in the 1960s, largely because the great majority of research subjects were minorities, drawn from the ranks of the poor, the mentally disabled, and the incarcerated. This linkage ensured that the rights of research subjects (or, conversely, the felt need to restrict the discretion of the researcher) would not only capture but hold public attention.

The result was an entirely new system of governance for human experimentation. Federal regulations required mechanisms for collective decision making, thereby abridging the once considerable freedom of the investigator. No less important, human experimentation gave an entirely new weight to the idea of consent, to making certain that the subject understood the nature of the experiment and voluntarily agreed to participate. This unprecedented reliance on the mechanism of consent reflected not so much an abstract commitment to the importance