
Prologue

Practically every development in medicine in the post–World War II period distanced the physician and the hospital from the patient and the community, disrupting personal connection and severing the bonds of trust. (Rothman 1991, 127)

Health care in the United States is going through a period of self-examination, and all signs point to a malady. The debate, of course, swirls around defining the ailment. One component, and the one on which this book is focused, concerns the relationship of doctor and patient. And the prescription, at least that offered by the governing boards of medical education, is an infusion of a newly defined professionalism. Medical schools and residency training programs are increasingly aware of public expectations that physicians exhibit humane qualities in dealing with their patients. A major expansion of competencies beyond technical knowledge is now part of training programs to specifically include interpersonal skills and a professionalism that promotes behaviors designed to scrupulously protect human dignity. Indeed, the signs of a growing awareness that the profession must provide more humane care are, literally, everywhere.

In June 2004, I happened to be walking on the UCLA medical campus and wandered alongside a construction site for an expanded pediatrics hospital. There, on the fence separating the construction from the pedestrian walkway, were various “advertisements” about the new facility. One caught my eye in particular:

The UCLA medical staff and faculty are dedicated to building and sustaining an ethical environment supported by values: respect, honesty, integrity, compassion, fairness, innovation, and stewardship of our resources.

I had a mixed response. On the one hand, I was gratified to see this pronouncement, for I was certain that behind that fence resided an honest intention to fulfill this commitment. On the other hand, I recognized these words as a public relations effort to reassure a disgruntled public. The hospital administration justified the expensive expansion precisely on the promise of humane care, not only on the technological prowess of contemporary clinical science and its products. And well might they remind the professional health-care providers of this ethical dimension of care.

The dual demands of achieving technical proficiency and the unrelenting pressures of managing patients leave doctors in training and their mentors with precious little time to carve out another niche for humane medicine. Indeed, physicians are literally torn between the demands of efficiency and personalized care. The balance is difficult to achieve and remains a symptom of a divided agenda driven by very different values. Howard Spiro (1993, 8–9), a gastroenterologist from Yale, is particularly forthright in his characterization: “During medical education, we first teach the students science, and then we teach them detachment. To these barriers of human understanding, they later add the armor of pride and the fortress of a desk between themselves and their patients. . . . Students begin their medical education with a cargo of empathy, but we teach them to see themselves as experts, to fix what is damaged, and to ‘rule-out’ disease in their field.” In short, the casualty of professional training is lost empathy. Unfortunately, Spiro’s observation is amply supported by various studies, which have uniformly shown that as the process of professionalization progresses, sensitivity toward patients decreases (e.g., Self et al. 1993).

Despite the best intentions and attempts to counter these professional lessons, with their attendant loss of humane values, the forces restricting the expression of an enhanced empathy are powerful, and seemingly forbidding. Doctors have learned how to cope with the huge demands on their time and energies, and too often they simply cannot address all of the ethical concerns that arise in the care of their patients. Some blame the system, and others simply defend themselves behind the shield of professionalism. Accordingly, medicine is dedicated to treating disease; physicians are trained experts essentially committed to addressing the

biomedical problems at hand; as time allows, as others fill in, the more peripheral concerns of care will be “covered.” Is this a “straw man” easily blown away? Yes and no. Health-care providers, by and large, harbor abundant moral sensitivity, but to function effectively in the contemporary environment of health care, they must learn how to deal with schedules that are too busy, comply with administrative details that are too taxing, cope with a reward system that suffers glaring inequalities, and function within an economy that has reduced the hospital and clinic to something like a glorified buttons factory. These are pervasive determinants of how medicine is practiced in the United States. Few are satisfied with the present state of affairs. Indeed, the profession has chafed at its lost autonomy and its inability to modify the practice of medicine in accord with its own aspirations: competency and humane care. All too often professional conduct is defined as efficient in terms set by the market, and under the mask of efficiency, humane intentions are compromised. So while efficiency may define a sense of effectiveness, the ten-minute visit robs physicians of the resources from which they draw their empathy, compassion, and patience.

Unfortunately, there are no simple formulas or prescriptions for how to better balance the demands of corporate medicine and the calls for empathy in a medical marketplace that is driven by economic forces conspiring against a more intimate relationship between doctor and patient. For me, the key challenge in clinical practice is how to capture that intimacy and make it work toward better care—that is, effective (as measured by scientific and economic parameters) and humane. More specifically, I seek the basis for strengthening the *moral intimacy* between doctor and patient. I reject an intrusive attitude, one that many might construe as invasive to personal privacy and misdirected to the doctor becoming a “friend” or “confidant.” Instead, I seek the means and justification whereby a physician intimately understands and acknowledges the values and goals of the patient’s moral universe.

I suggest the most sympathetic to my orientation are those who find that the most interesting fact about contemporary medical ethics is that it exists at all. These “innocents”—of whom I am proud to be counted—still wonder how and why we face the moral predicament of a strained doctor-patient relationship and then ask why, given the strong sentiment

to “fix” the problem, it is so hard to do so. What are the tensions and where do they come from? Of course, we have explanations, but at a deeper level a sense of denial—perhaps a naive moral outrage—turns these questions into rhetorical, ironic dismay.

To begin to unravel these perplexing questions and to find a way they might be answered in terms that offer the hope of change, we must recall the history of bioethics and, in particular, the milieu in which complex social forces demanded medicine’s reform about thirty years ago. The initial concerns of bioethics (of which medical ethics is a subset) reflected tumultuous reappraisals, all of which seemed to converge on a newfound suspicion of authority and a reawakened sense of classical Hippocratic ethics (Do no harm!). Regarding the first issue, the Vietnam era was marked by the unsettling of confidence in government, education, business, and medicine, and the activism of the period culminated in the ascendancy of a rights-based culture different from any era preceding our own (Sandel 1996). On this interpretation, although presumably committed to traditional democratic ideals, judicial interpretations were radically altered to reflect a changing political environment and social values. This is clearly appreciated when we examine how clinical medicine itself was caught up in the rights-based movements of the 1960s, which borrowed models of autonomy (drawn by the legal and political claims of the period) to ground its own ethics. The second tributary, alarm over dehumanizing patients and making them subject to an intimidating technology, was easily coupled to suspicions of authority. Together, they combined to create bioethics, a potent antidote that defended patients and placed respect for persons front and center in health care.

Medical ethics thus became the articulation of an ancient moral philosophy governing the doctor-patient relationship, beneficence, and a new demand concerning the respect of patient autonomy in the guise of informed consent. In the explicit elaboration of these principles, their interaction and balance, bioethicists found themselves embroiled in debate as to what, indeed, medicine’s ethics might be. Dominant voices advocated patient autonomy, not only because it was the most easily extrapolated from our rights-based politicojudicial culture, but because it offered a plain antidote for a pervasive mistrust. Whereas trust had

hitherto been the implicit moral understanding governing physician behavior and patient delegation of authority, in the age of Johnson and Nixon, patient confidence required both new definition and novel substitutes. In short, medical ethics generally, and patient autonomy in particular, filled an ethical lacuna left by the erosion of patient trust, and thus patient autonomy became the sacrosanct principle governing medical ethics.¹

From this perspective, medical ethics is very much of one piece with the deep moral crisis Americans face in the beginning of the twenty-first century. The balance between individualism and communal concerns is no less than the search for the social glue that ties us together in a highly pluralistic culture. On this view, medical ethics provides a lens by which we may peer into the American moral psyche to refract a pervasive problem besetting a culture that increasingly is alarmed at the loss of social cohesion and social capital. In seeking an ethical medicine, we find many points of stress clearly demarcated in the dramatic setting of illness and death, and the prescriptions for both how to understand and how to address our predicament remain elusive.

The underlying rationale of this book is that if a realignment of patient and caregivers is sought, the profession must revise its own standards and better align itself with more traditional and fundamental values of patient care. Most directly, this book is a reflection on the moral crisis faced by all physicians who are caught in a vise of multiple responsibilities that demand different kinds of responses beyond a focus on the ethics of caring for patients. After all, doctors are accountable not only to their patients but to their employers, managed-care plans and insurance companies, and hospitals and professional associations. Overriding each of these domains, the government monitors professional competence, legal and ethical conduct, and adequacy of access (Emanuel and Emanuel 1996). As if these diverse domains of accountability were not enough, there are at least three models in which these relationships are enacted: a professional model, which answers the demands of professional services to provide patient care (e.g., licensure, certification, malpractice, and so on); an economic model, which defines health care as a commodity with certain performance standards and financial expectations and restrictions; and finally a political model,

where policy decisions concerning health-care delivery are made and executed (Emanuel and Emanuel 1996). Situated within the matrices of these interacting systems reside the various components of the intimate doctor-patient relationship. This last domain cannot be circumscribed, as might the others, but instead fills in the spaces between them to hold in place (or cohere) the social, economic, and political influences that so powerfully affect the character of health care.

Each of these contending points of view describes, and ultimately redefines, the doctor's professional identity from one characterized by simple (perhaps naive) responsibility for patient care to one that reflects the complexity of our contemporary health-care system. What has been lost as a result of the growing dominance of the corporate structure of health-care delivery? How do, or should, physicians respond to the mixed responsibilities to their employers or payers on the one hand, and to their patients, on the other hand? With this "splitting" of professional focus, something crucial seems to be missing. The debate swirls and critics abound to address the discord—both patient mistrust arising from perceived physician conflicts of interest (e.g., Mechanic 1996; Mechanic and Schlesinger 1996; Kao et al. 1998b; Shortell et al. 1998; Jacobson and Cahill 2000) and physician behaviors that undermine corporate strictures on care (Kao et al. 1998b; Kao et al. 1998a; Freeman et al. 1999; Wynia et al. 2000). (Conversely, physicians not infrequently deny patients possibly useful choices because their medical insurance does not cover such services or medications (Wynia et al. 2003).) But the managed-care setting presents only the most obvious example of the shifting relationships between patients and their caregivers. I maintain that a more general ambiguity has replaced the traditional trust characterizing the patient-doctor dyad, and the sources of this misalignment lie deeply embedded in contemporary society.² To understand the quandaries of health care, we must dig deeper into the shifting sands of identity politics and philosophical notions of personhood.

During the past twenty years, commentators from sociology and psychology have highlighted a contemporary fact of American life: mistrust has assumed greater prevalence in all spheres of our social interactions. Indeed, I regard the quest for patient autonomy as a symptom of the more general realignment of relationships, which reflect a less cohesive

society and a more self-protective posture of its citizens. Many factors have conspired to alter the communal character of American life, and in medicine, the commercialization of care has had a particularly powerful disruptive effect on traditional trust. With managed care, a contract model has become prominent at the expense of an older covenant. Contracts define obligations and minimize risk. To the extent they are specified and enforced, the concerned parties are protected. The principal difference from the covenant model of care is this substitution of explicit rules for the implicit expectations governed by an ethics of responsibility. Whereas traditionally, patients might expect to have their best interests protected, when health care is just another commodity, services are specifically limited and the older ethic of care is replaced with a market model of goods and services purchased and provided by defined business arrangements. This rich mulch for patient dissatisfaction allowed mistrust to grow, and bioethics was, in part, a response to new demands for physician accountability.

Most would agree that contemporary medical ethics has successfully offered a scaffold for understanding how ethical decisions are made at the bedside and in the clinic. By using various strands of moral reasoning required for thoughtful decision making and legal case-law precedents, a vibrant partnership between philosophy and the law has improved medical practice, which prior to the age of informed consent, allowed doctors to govern the profession without due regard for the full dimensions of patient autonomy. Their failures gave rise not only to a deepened awareness of professional responsibility on the part of doctors, but in addition, to the adoption of a more reflexive stance toward their own professional behavior. This is the arena in which moral philosophy is contributing to medical practice.³

Patient Autonomy and the Ethics of Responsibility probes the underlying ethical implications of shifting professional allegiances and thereby continues the discussions initiated in my *Confessions of a Medicine Man* (1999a), which was also concerned with defining the physician's identity. The earlier book, which portrayed the relational ethics between doctor and patient, elaborated an *ethical metaphysics*; here I am engaged in defining a *moral epistemology*. (Note that this is not the characteristic use of the term; moral epistemology typically addresses the epistemic

status and relations of moral judgments and principles—for example, justification of statements or beliefs, in epistemology, or validation of judgments or actions, in ethics.) The difference is telling, but both books reach the same philosophical spot, albeit in very different ways. *Confessions* described the implicit responsibility physicians have for their patients by extending a general ethical position to the domain of clinical medicine. Contemporary medical ethics only tangentially appeared, and instead, the discussion situated itself in the tradition of dialogical philosophy. That project might fairly be characterized as an ethical metaphysics because it argued for the primacy of ethics—that is, medicine was fundamentally ethical and its science and technology were in the employ of its moral agenda.

Perhaps because I ventured into such thin airs, I remained dissatisfied with *Confessions* as everyday concerns continually beckoned to me as a practicing physician and educator. Moreover, one might well want a more direct line from medicine's technical and scientific practice to its ethics. Others (Whitbeck 1981; Porn 1984; Seedhouse 1986; Nordenfelt 1995; Richman 2004) have provided such a rationale, effectively arguing that the criteria of health are inseparable from the goals and values of the patient, and thus for medicine to perform its own technical duties, these human ends require an awareness of the patient's moral universe. On this instrumentalist account, the doctor is committed to forging a link between the science and the ethical concerns of care:

Talking to patients about their goals is an absolutely central part of responsible health care. Medical science and biology may discover the means to reach our personal goals, but they tell us little about what those goals are or should be. For this reason, physicians and other HCPs [health care providers] cannot know what will improve the health of any individual considered as a *person* [emphasis added] without substantial information about that individual's goals [and values]. . . . This is not due to ethical worries about patient autonomy, but to metaphysical issues surrounding what it means to be healthy. (Richman 2004, 57)

I have assumed this instrumentalist position, and I too reject the present dominance of autonomy as the premier principle guiding medical ethics. Much of what follows deals with how the preoccupation with patient autonomy arises from outside medicine and why the ethical basis of care must instead grow from medicine's own philosophical roots. To this

extent, I nod to my instrumentalist predecessors as forming a kindred group, but I begin from a different place and follow a different philosophical path.

This book seeks to construct a philosophical portrait of the doctor-patient relationship by starting with medicine's epistemology. By showing the value-laden character of the clinician's knowledge, I argue that the ethics naturally follow; indeed, the moral and the epistemological are inseparable. Thus I adopt the designation *moral epistemology*—moral, because clinical evaluation and care are value-laden, and epistemological, because medicine expresses and employs a form of knowledge. The argument begins with a discussion of medicine's epistemology as a product of dual concerns: establishing facts and applying values. The ideal of separating facts and values into different domains is contested and once the dichotomy is appreciated as false and collapses, clinical epistemology is opened to an expanded view of scientific facts, whose ultimate meanings are determined by the biopsychosocial context of the patient. That diffusion of values into the domain of facts is expressed in every facet of care, and in recognizing the impact of values on therapeutic options, the doctor-patient relationship then may be characterized in a more complete fashion. In short, the ethics governing clinical medicine rests on two pillars: the primacy of responsibility (*Confessions*) and the structuring imposed by a moral epistemology.

Balancing Facts and Values

Because of its multifarious activities, conceptual approaches, and moral demands, it seems self-evident that medicine rests on various philosophies. But if one tried to arrive at a singular viewpoint to tie the various elements and approaches together, I submit the answer is not to be found only in medicine's epistemology, its forms of knowledge and manner of understanding, but rather in some synthesis that must include its moral philosophy as well. If we expand the idea of knowledge and form a synthesis between two branches of philosophical discourse—the moral and the epistemological—provocative alternatives appear. Although epistemology and moral philosophy are generally regarded as separate sub-disciplines of philosophy, I combine them: any form of knowledge, no

matter how objective and divorced from subjective bias, is still imbued with value. And here, value is construed as moral.

Morality is not simply about good and evil, but is more generally concerned with values—that is, how values are used to judge choices and actions. Values presuppose judgment, and in this sense ethics is based on structures of values. Even objective science is ordered by its own values: objectivity, coherence, predictability, comprehensiveness, simplicity, and so on (Putnam 1990, 2002). At least since the 1840s, these values, have given a particular cast to scientific knowledge, a form of positivism, which assumes that objective facts are freed of bias, subjectivity, and value. Positivists would not deny the utility of such values, and consequently the door is left ajar for considering how facts and values may be linked. But they do restrict the kind of value allowed to participate in the scientific endeavor: objectivity divorced from personal value is embraced precisely because such knowledge is regarded as making facts universal. Indeed, it is the universality and impartiality of scientific knowledge that confer its authority.

I would hardly argue against science's successes, and indeed, who could quarrel with the triumphs of such an approach? To be sure, science is governed by its own values, and these have served medicine well. However, these values, while necessary, are insufficient for clinical medicine. For the view from nowhere, the absent perspective, is not only inappropriate for medicine, it is unattainable as well. Indeed, medicine's epistemology is thoroughly embedded in *nonpositivist* values and these competing values reflect a moral structure that ultimately orders and defines clinical science. Clinical science scrutinizes and treats the disease and the doctor treats the person; this difference is what makes medicine more than a natural science, for its practitioners must synthesize the various strands of its faculties in the service of the patient. In short, I maintain that the glue holding together the various epistemological strands of contemporary medicine is of a *personal* moral character, and what we seek is a better understanding of medicine's moral epistemology as it is guided by responsibility, namely, an ethics of care. What this means is the subject of this book.

Two components are intertwined here. The first is the ethical thesis that, simply stated, argues that the practice of medicine employs certain

tools—scientific and technological—to fulfill its moral mandate, the care of the person. That entity—the person—defines an ethical response, as opposed to only a strict attention to the *disease*. The second component concerns scientific practice and scrutiny, which highlights the integrative character of clinical science. After all, the organism as an integrated, functioning entity frames all approaches to the patient. Clinical science is, by its very character, holistic in orientation, endeavoring to address all systems at once and to enable the full function of each. This requires a global view of function, from molecule to intact organism. So we witness a synthesis supporting a unified vision of the patient: the orthodox moral calling—the responsibility of care—and the character of clinical science both point to a holistic medicine.

Neither position goes uncontested. The drive toward molecularization has dominated recent biomedicine, and the power of that approach is indisputable. But the trend toward a reductive biochemical and genetic characterization of disease often eschews the problems of complex organization and regulation. As I discuss in later chapters, reductionism requires hybridization with a science that is able to effectively put the components back together into functioning systems. New advances in bioinformatics, modeling of the nervous and immune systems, and ambitious programs to decipher metabolic and genetic organization herald a new science focused on regulation of complex systems. Medicine will be the beneficiary of the expected advances in this new field of “systems biology.”

The moral character of medicine is also disputed. Consider these radically different views from respected medical academicians:

I believe medicine is inherently a moral profession. . . . The practice of medicine—caring for the sick—takes what are presumed to be facts about the body and disease and on the basis of that technical knowledge does something for a person. In that sense it can be seen in the same light as any moral behavior—moral because it has to do with the good and welfare of others. (Cassell 1976, 87)

Is medicine a “moral enterprise”? I doubt it, any more than plumbing or auto repair is. Physicians rarely cure or save lives, and spend most of their time trying to provide some comfort, relieve symptoms and perhaps prolong life. The moral issues seldom come up in situations that constitute physicians’ practice. The dramatic life and death issues . . . are difficult, but relatively uncommon occurrences of the typical physician. (Lasagna 1977, 44)

For Eric Cassell, even the ordinary acts of medicine are fraught with ethical import; physicians, self-consciously aware or not, are engaged in a profound moral enterprise; and the values governing their behavior are demanding and extraordinary. Louis Lasagna takes a more relaxed approach in seeing physicians as engaged in an ordinary profession. I side with Cassell's view of health-care providers. While it is true some situations are agonizingly complex and others reasonably simply, *all* clinical encounters are value-laden and reflect an array of moral choices.

The implications of assuming this ethical attitude are far-reaching. The most fundamental question asks, How morally reflexive should a physician be? The answer, not surprisingly, is that it depends on the context. Scenarios range widely: vexing end-of-life decisions; clinical rationing of scarce resources; fidelity to patients' self-interest, and so on. Obviously, most encounters are ethically "neutral" or ordinary, while others are demanding, if not excruciating. Much depends on the clinical setting in which care is delivered, the therapeutic options available, the contingencies of personal histories, and so forth, but what strikes me as glaringly obvious is the *depth* of the moral challenge beyond the ordinary identification of ethical issues.

The reified model of disease is aligned with the conversion of patients to consumers, to clients, to covered lives. Each is, in different ways, "objective," but now defined by statistics or a bureaucratic designation instead of by molecules or genes or laboratory data. I believe that in making complex choices from among conflicting data and value judgments, health-care policymakers face challenges similar to those faced by physicians in advocating particular options for the care of individual patients. The dimensions are different and the terms of choice are clearly disparate, but the underlying negotiation of facts and values remains constant, albeit on different coordinates: policymakers factor quality (value) elements into the complex calculus of care, just as physicians do in following clinical strategies. Consequently, health care that forfeits moral self-consciousness, whether regarded from the abstract reaches of public policy or the immediacy of the individual patient, is incomplete.

We *know* this moral fact, but a deep tension remains between our aspirations for an objectivity and efficiency and the demands for humane care. Why are these so difficult to reconcile? Part of the answer is that

these goals call on different justifications, which are too often in conflict with one another. To simultaneously observe the patient objectively, *as well as* empathetically, calls on two attitudes that at present are too often regarded as conflicting: one persona peers out, dissociated and removed, while the other looks reflectively within. A physician must do both and become, in effect, a modern Janus.

My vision of an ethical medicine hinges on the free movement of a swinging door that opens easily into two domains: the scientific and the moral. Physicians stand in this portal and with an objective eye place clinical facts within the patient's psychosocial context. The door might close with the practitioners' gaze fixed on the clinical science, and at other times they will be focused on the ethical concerns of the patient, but in the end, a synthesis must occur. Atomistic patients with isolated pathologies, are, in fact, ill persons. Although patients are often reduced to entities, which clinical science defines as disease, malady, disorder, ailment, and pathology, such transfigurations must be "corrected," by putting the findings of a critical science into a larger moral framework.

My organizing question concerns how we are to understand the moral agency of patients in a manner that best protects a humane identity in a factual universe. I pose two contrasting possibilities: the first (presented in more detail below), and the one dominant in contemporary America, is the atomistic model. From that understanding of persons as self-reliant, self-governing, and fundamentally alone, individualistic autonomy arises. In the world of clinical medicine, this conception involves situating persons in a world of neutral fact. Concern with multidimensional identity is moot and even inimical to the positivist approach to disease: as isolated entities, the objective stare is unencumbered by psychosocial complexities, and the physician may proceed with her scientific gaze and technological tools oblivious to the personal context that remains dormant or hidden from such consideration. In short, autonomy as configured in its individualistic stance facilitates the isolation required for positivism to operate freely. As an alternative formulation, a relational understanding of persons permits the doctor and patient to engage on a larger playing field: with such an orientation, disease becomes illness and a cooperative venture replaces the social and psychological dissociations arising from clinical scrutiny. The desired outcome is to shift

patients from their dissociated state (induced by organic dysfunction and social designation of sickness) to one in which integrated participation supports trust.

At the heart, then, of what I am calling a moral epistemology is the quest for an elusive synthesis of the “personal” and the “objective”—a search for their common foundation (Tauber 1996, 2001). By showing the interplay of facts and values, we might regard medicine as a crucible in which their enigmatic and elusive synthesis is being forged with particularly intriguing consequences. And perhaps more saliently, the health-care crisis is shown to include a moral quandary that regards the economic and political issues currently dominating public debate from a different perspective, one that shifts those dollar-dominated choices into a different currency (Tauber 2003c). The conclusion: we require a medical philosophy that throws its net wider than to cover the “thin” debates currently dominating the discourse of medical ethics (Evans 2002). Pursuing “thicker” concerns will bring renewed attention to philosophy’s contributions and better fulfill the ethicists’ original promise.⁴

Sick Autonomy

To the trained eye, every patient presents an ethical problem.

—Frost 1976, 3

The desire for autonomy is a powerful antidote to the threats to personhood that result from being ill, by offsetting the power of those who define identity by defining disease. Physicians achieved power by tapping into two large reservoirs of belief. The first is the primordial human concern with illness and death. The mystifying power of the shaman (and doctor) over life forces evokes an entire universe of primitive fears and hopes. To be subject to forces beyond normal control places the individual in a highly charged, dependent position. Technology powerfully transforms patients into objects of a science with a new authority to define the normal and the pathological (Canguilhem [1966] 1989). The second array of beliefs arise from the application of this biological template to the self-assessment of who we are and what we might do by con-

ferring identity in terms of health and disease. This occurs in both obvious and more obscure ways. Consider how physical fitness is regarded as a source of fulfillment. Ordinary health confers energy levels for work and play; youth and vigor are championed; extraordinary physical abilities are rewarded as heroic from the sandlot to the professional athletic arena. Americans, obese and underexercised, denigrate themselves for their laxity and feel they have fallen short precisely to the extent that they fail to meet cultural health norms. By any standards, health is an ideal that comprehensively defines cultural status. And correspondingly, in western culture the ill, those with disabilities, and the elderly are compromised precisely because of their physical ailments and dysfunctions. Maintaining autonomy allows people to claim control and retain choices in the face of the medicalization of personal identity—in other words, to resist being reduced from persons to patients.

Within this context, protecting patient autonomy has been at the heart of medical ethics in the United States since the late 1960s as a consequence of the dual assaults of an unleashed technology and a mass-market medicine, each of which dehumanizes and manipulates patients. Indeed, according to virtually all students of the discipline, “autonomy” has dominated the debate on the moral foundations of clinical practice and research. Whether presented as the basic ethical principle or one of several, the recurrent questions seem always to be, Where and how does patient autonomy fit into the framework of bioethics? I take this question as central to my own investigation.

To understand the crucial role of autonomy in medical ethics, we must decipher the other roles it might be playing on the stage of biomedicine and within the even vaster drama of Western moral philosophy and culture. After all, clinical medicine is not an isolated enclave but is practiced in our social midst, and the rules of governance apply there as in every other domain of the community. I think it no accident that the moral philosophy that informs and directs American liberal, democratic society, where respect for the individual dominates judicial and political precepts, was so readily transferred to the medical arena. But I maintain that this extrapolation is exactly that, an extension from one domain to another—one, despite its power and importance for our political and social life, that still may not be altogether appropriate.

The cultural preoccupation with individual autonomy is a distinctly post–World War II social phenomenon, and medicine has been caught in a massive social realignment that reflects this increasingly important personal value (Sandel 1996). Contemporary American bioethics developed in that milieu (Jonsen 1998). The early founders of the discipline, Joseph Fletcher (1954) and Paul Ramsey (1970), held the sanctity of life and the dignity of persons paramount and autonomy thereby became a derivative principle, which reflected their basic humanitarianism as theologians. Indeed, autonomy had little philosophical support in their writings, and by not delineating how this principle competed with other moral tenets, these early discussions obscured the complexity of medicine’s moral universe.

Indisputably, autonomy serves a vital judicial-legal function in our system of medical law, and this may account for its continued importance, but it is more likely that the pervasiveness of our respect for persons reflects a deeper commitment to Western religious roots (Thomasma 1984; Engelhardt 1996). Our care of the ill is based on a metaphysical response to the other, a reaction that generates *responsibility* (Tauber 1999a), or put differently, “respect for the person” (Ramsey 1970). For theologians as well as nonbelievers, the sanctity of life—essentially a religious principle—remains paramount even as it has been secularized into the political principle of autonomy (Callahan 1969; Jonsen 1998, 337ff.).

Ironically, theologians, poised and ready to engage in a discourse they had already developed for their own purposes, soon found themselves on the outside looking in as the secular philosophers articulated moral principles shorn of their religious trappings. The theological insights (and ideologies) of a rich intellectual and religious heritage (Lammers and Verhey 1987; Verhey and Lammers 1993; Camenisch 1994) did influence the development of contemporary judicial and philosophical medical ethics, but the calculus had shifted: instead of social justice and communal caring serving as the dominant orienting principles, autonomy assumed supremacy. Medical ethics moved from being an ethics dominated by religious and medical traditions to one increasingly shaped by philosophical and legal concepts. The consequence has been a model of public discourse that emphasizes secular themes: universal rights, indi-

vidual self-direction, procedural justice, and a systematic denial of either a common good or a transcendent individual good (Callahan 1990, 2). Yet despite this secularization, a deep commitment to care underlies recent medical developments, and we could regard clinical medicine's interpersonal ethical commitment as an unquestioned presupposition.⁵

But if we probe a bit, we will see that although autonomy carries the ancient banner of life's sanctity, its secularized meaning and applications have made new allegiances. So when this political and judicial principle is extended to medical ethics, the law accompanies the ill to the clinic and hospital to protect *citizens*. Due to this legal extrapolation, the traditional basis of the doctor-patient relationship must accommodate an orientation different in kind and purpose from the older ethic of caring. I have previously argued that bioethics functions too often as applied jurisprudence, reflecting a parallel legal ethos rather than effectively asserting its own agenda (Tauber 1999a). This is hardly a novel observation; while some see this as a problem, others remain unapologetic.⁶

The "moral space" in which patients reside is not necessarily coincident with that of autonomous *citizens*. While their respective moral identities overlap, they nonetheless are distinct because patients, while carrying their rights as citizens into the clinic, exercise those rights by essentially delegating them. The patient, at least in the autonomy model, receives medical attention only to the extent that his or her rights as an autonomous citizen are respected. This is problematic in as much as autonomy is a product of the milieu of advocacy and conflict, dynamics foreign to medicine (O'Neill 2002, 25). In the medical setting such a construction is at odds with the moral concerns of caring. Let us now delve into this issue.

Balancing Rights and Responsibilities

In facing the growth of patient autonomy, clinical medicine is confronted with a reexamination of its moral foundation, for "autonomy" is an interloper, a new principle that has encroached on the doctor-patient engagement, which is based on trust. At least traditionally, clinical care has been built on trust (the expectation that the patient's best interests would be ministered to) and trustworthiness (the commitment of

physicians to achieve those ends). Accordingly, doctors and nurses have a primary ethical obligation to be beneficent (Pellegrino and Thomasma 1988) or, from a different standpoint, to be responsible (Tauber 1999a). And thus the two ethical approaches may clash.⁷

Autonomy is inadequate, by itself, to account for medicine's moral calling because of two failings. First, from the patient's perspective, autonomy is frequently diminished in the clinical setting (Schneider 1998; O'Neill 2002). Patients necessarily relinquish their autonomy to experts, and in this regard, they cannot make truly autonomous, that is, self-reliant, fully informed decisions, and must instead rely on the competence and goodwill of their health-care providers to promote their best interests. Second, autonomy as a construct cannot account for the ethical responsibilities of the caregiver (Pellegrino and Thomasma 1988; Tauber 1999a). The sense of responsibility exhibited by physicians and nurses arises from their sense of care for others, not primarily from a set of rules designed to protect patient autonomy. Respect for the person in this setting is implicit in their professional role, a role characterized by a profound sense of commitment to their charge. This ethic of care regards autonomy as only one of a number of moral principles governing the doctor-patient relationship, and it finds in beneficence a more resonant expression of clinical medicine's fundamental ethos. In short, we require a better balance of patient rights and physician responsibilities.

Intimate trust, the product of a relational ethics, permits patients to exercise their autonomy by relinquishing some decision-making power to those with the expertise to care for them. Physicians then act as entrusted fiduciaries. While I reject a return to paternalism, I do believe that physicians may, and should, assume more active advocacy for their patients' interests by helping them identify not only the clinical choices but also the moral issues they face. While time-consuming and often at odds with current rewards for professional effort, I regard such efforts as the most viable local responses to a medical crisis engendered by a distortion of personhood in the name of science on the one hand, and sociopolitical atomism, on the other.

Several conceptualizations of this relationship have been proposed. Perhaps the best known is Edmund Pellegrino and David Thomasma's notion of "beneficence-in-trust" (1988, 55–58). In their construction,

medical care is ethically based primarily on physician beneficence, which seeks to protect patient autonomy and, indeed, advocate for the patient's best interests. Beneficence in their view, and mine, is not in conflict with autonomy (paternalism is, however), but rather is a powerful means of supporting autonomy and preserving the dignity of patients.

I enthusiastically join those promoting beneficence-based ethics, which struggles to reorient professional attitudes, to define those new obligations, and then to offer a way to fulfill them. This endeavor is not an "either-or" choice—autonomy or beneficence. The principles "sit" in a weblike structure, where one principle may pull the others toward its concerns in a particular case, and a different principle achieves dominance in another (Kenneth Richman, personal communication, 2004). No principle stands alone, but each must adjust to the demands of the others (analogous to Quine's holistic "web of beliefs"). Indeed, on this view, patient autonomy can become an integral part of an ethics of responsibility when we better balance its claims against those of beneficence. In short, medical ethics must align facts and values, and rights and responsibilities, on coordinates that have been configured by an ethics of care. Although responsibility and beneficence have lost ground as medicine's guiding principles,⁸ I propose how they may be reasserted *in alignment with the claims of patient autonomy*.

Plan of the Book

I begin in chapter 1 with a historical survey of how the values governing science have competed with the values of patient care. When allopathic medicine assumed the mantle of the natural sciences, and thereby achieved a legitimacy that set it apart from all other contenders for health-care dominance, it did so at considerable cost. Pretensions to radical objectivity compromised clinical care by allowing a powerful scientism to obscure medicine's older ethical heritage. Specifically, a science concerned exclusively with facts shrank from the messier realm of values. Notwithstanding the protests of a few stalwart humanistic physicians, the profession marched forward with little concern for the ethics of care and was only brought up short by the birth of medical ethics and a new public fury in the form of malpractice suits in the early 1970s. The

history of the fact-value distinction, which underlies this social development, begins with the origin of positivism in nineteenth-century science and its philosophical sources in the eighteenth century. Chapter 1 surveys the conceptual issues underlying medicine's scientific epistemology and shows how and why medicine continues to be only in part a scientific enterprise.

Chapter 2 explores how the ethical thread of care is inextricably woven into medicine's epistemological project with a historical review of the doctor-patient relationship and the attendant patient rights movement. Underlying this social-legal history are shifting understandings and assumptions about personhood, which strongly influence patient identity. The discussion then delves more deeply into the historical layers of the concepts of autonomy, selfhood, and individualism. Most saliently, this historical overview shows how medicine's own ethics reflect the underlying philosophical and social tenets of interpersonal relationships, with their attendant obligations and rights. Analysis of the past offers a perspective on our own rapidly changing culture and the difficulties we encounter in an increasingly pluralistic society.

Chapter 3 develops a "topology" of autonomy by considering how underlying notions of selfhood shape various understandings of autonomy, and how "reason" plays its role in distinguishing autonomous choices and behaviors from heteronomous ones. From Locke to Kant, from Hume to Mill, the overview presented here describes how autonomy has been contested and, more saliently, provides the groundwork for the application of this moral principle to patients. We seek a definition of patient autonomy that is appropriate to the moral universe of the sick, whose needs and expectations are not necessarily the same as those of citizens in other settings. In short, we must preserve autonomy and at the same time find a means for its best expression in a setting that challenges the very notion of self-governance.

This historically oriented discussion frames the question, What role does autonomy play in the care of the patient? This question is addressed in chapter 4, where I explore various ways autonomy might be preserved in the challenging setting of the hospital or clinic. Once I have presented a philosophical strategy for protecting autonomy, I will be in position to directly address the problematic status of freedom of choice in the clin-

ical setting. My goal is to contribute a response to the basic challenge American medical ethics faces: how to conceptualize autonomy and trust so that they are mutually supporting.

Chapter 5 considers how physician beneficence and patient autonomy need not compete but rather may converge toward the same ethical ideal, the preservation of the personal dignity of the patient. To accomplish this task, we need to heal a weakened social bond. I argue for what some would say is a quixotic ideal: medicine must reassert its covenant with the patient, albeit in the face of powerful social and economic forces impeding that effort. Arising from the ethics of care, autonomy might recede from its defensive posture if physicians are to reclaim their identification as trustworthy and thus avoid the corruption of relationships so prevalent in our era. Admittedly, the tenor of this essay moves against a social reality that has made too many patients angry and defensive. My arguments may seem hollow to those who have suffered or know others who have been mistreated because of the insensitivity or incompetence of their doctors. I have sprinkled through the text several case studies from my own experience to illustrate both the variety of interpretations autonomy lends itself to and perhaps to remind myself, and my readers, that the physician-advocacy model presented here is not necessarily appropriate and may easily be misapplied. Consequently, my attempt to place more responsibility on the physician, when so much evidence points to the need for patients to remain vigilant with respect to their own interests, requires support beyond slogans and general pronouncements.

The concluding chapter charts a strategy by offering practical ways that trust might be better established between physician and patient. An ethics of trust requires a patient-centered approach that takes into account the complex experience of illness and thus factors in relevant social and psychological issues. Seeking to account for the psychosocial dimension in patient care is not to abandon the power and effectiveness of current reductive strategies of biomedicine, but rather to expand clinical care to more effectively include humane concerns as well. So, while medicine prides itself on its scientific character and technical virtuosity, physicians must always synthesize a reductionist approach to disease with a holistic one that regards the patient not only as an organic entity

but also as a person with psychological, social, and historical natures besides the strictly organic. Ultimately, if we seek to balance the moral principles vying for dominance, the care of the patient must be informed and guided by complex values—both those of the ill and those of the physician.

A patient-centered medicine directs clinical attention beyond the scientific and technocratic aspects of treating disease to a more comprehensive psychosocial appreciation of illness. This has become an often-cited slogan for reform, and few would oppose such an ideal, but the obstacles for its implementation are formidable. I believe much resistance may be attributed to the power of a philosophical misunderstanding: the radical separation of facts from values. If facts and values are deliberately integrated and seen as influencing each other, a more comprehensive clinical epistemology beckons. If the values of human suffering are deliberately included in the program of care, a more comprehensive medicine would result. This is the purported aspiration of contemporary medicine, but the resistance is strong. One strategy is to understand how an integrated fact-value epistemology may be adopted as a legitimate basis for medicine, and so we bring the beginning and concluding chapters into juxtaposition.

To achieve this goal, I consider how medical education might be expanded from its narrow scientific focus to a more expansive humanism or, more specifically, propose a program that trains doctors to be morally self-reflexive. Again, this discussion brings us back to the earlier consideration of the fact-value relationship in clinical medicine. To embrace their intimate connection, we have to engage the unity of medicine's science and its ethics. But the debate regarding the place of medical ethics training is still unresolved. Can the teaching of ethics and other humanities subjects revive the compassion that too often is displaced because of the demands of time and because of resistant professional attitudes? Given the subjective nature of this goal, how can success even be measured? Are reformers aiming at the proper target, and which arrows should be chosen? There are no clear answers to these questions, but it seems self-evident that classroom pedagogy is not sufficient to offset the professional ethos that champions the aloof technocrat and the time constraints of a corporate medical system. Moral attitudes are ingrained in

professional practice. Despite new directives from various medical education governing boards, the failure to adequately address ethics education or moral issues continues to plague clinical practice despite repeated calls for reform over the past three decades. These issues are reviewed here.

Reflecting my own impatience, I am proposing a new addition to medical record keeping, which, in effect, is a reflection of physician reasoning. An *Ethical Concerns* section of the medical record would provide for a synthesis of personal, social, and ethical matters related to patient care. There, physicians would self-consciously address problems that range from decision making in crisis to the mundane details of support for the ill during the hospital stay and after discharge. In making deliberate efforts to identify such questions, the doctor effectively addresses those concerns often closest to the patient's own experience of illness. More than a scientific and legal document, the medical record might then become a more comprehensive construction of a person's illness, and perhaps more to the ethical point, the physician, in composing this narrative, must critically evaluate her own values and negotiate them with the patient. In this way, a moral dialogue is initiated and sustained.

Overview and Final Comment on Method

I seek an ethical ideal by showing how a renewed commitment to expanded responsibility might be achieved. As philosophy, the analysis of autonomy, responsibility, and trust is shown to illustrate the nodal points of medicine's conceptual framework (e.g., the formulation of selfhood as a foundation for notions of individual autonomy or the understanding of the fact-value distinction and how it plays into medicine's epistemology and ethics). But more than an academic exercise, the reconfiguration of autonomy and responsibility points toward an ethical reform, toward what I call an "ethics of responsibility." In this sense, the idealistic moral portrait of the physician serves as a sketch of what ought to be, not what necessarily is. I am not daunted by protestations that my position is impractical or that its expectations are exaggerated. I reply that the philosophical exercise is to identify the weaknesses of the conceptual apparatus that supports current practice; to argue for

reformulations that allow reform; to present a moral compass to find our way in a social system of extraordinary complexity. Defending medicine's deepest moral commitments against the competing demands and power of current economic and political forces requires such a philosophy. To settle for less is to misconstrue what philosophical discourse is about. This last issue is addressed in the epilogue and represents my reiteration of Galen's (1884, 1) admonition: "The best physician is also a philosopher."

This book, at first glance, reflects two general attitudes, one philosophical, the other practical. But the point of my exercise is, in fact, to show how these attitudes are inseparable. In framing the practicalities of the clinical encounter by moral reflections, the reader might feel somewhat pitched and tossed—moving from epistemology, to historical surveys, to ethics, to sociology, to education. I plead guilty. But I remain unrepentant. The issues require no less. With its subject matter refracted from various perspectives, and synthesized by an overarching moral vision, I can only hope this eclectic book, which has drawn on several literatures and employs several modes of analysis, offers the reader a sense of medicine's multilayered philosophy. Indeed, the physician cannot be guided by a single point of view. Instead, she practices at the nexus of many different sociologies and epistemologies and thus confusion will reign without a clear understanding of goals and priorities. To see clearly, we must don our moral spectacles, wipe off the smudges and dust, and peer around with keen sight and heightened awareness. If we fail to do so, already-entrenched developments will become irretrievable: health care will become just another commodity; patients will become consumers; and providers, business entrepreneurs . . . a sorry state for a society that champions the individual.

One last comment on method: while I am very sympathetic to the case made by casuists (Jonsen and Toulmin 1988) and even to a Wittgensteinian abandonment of formal medical ethics (Elliott 1999), the discussion adopted here is one framed by a principle-based discourse (Beauchamp and Childress 2001). I am not altogether pleased with the ground rules so applied for two main reasons: First, in structuring my argument on a tension between "autonomy" and "beneficence," I am in danger of being accused of remaining within the confines of what is often

regarded as an oversimplified dichotomy. But I am concerned with beneficence in the service of autonomy, for the true obstacle to autonomy is paternalism (Pellegrino and Thomasma 1988, 57). As we define the various conceptions of selfhood and moral agency, as well as probe the philosophical problem of trust in the doctor-patient dyad, these distinctions will become apparent and crucial in transforming the apparent opposition of autonomy and beneficence into a pattern of mutual support. Second, hidden within the principles approach is a formalism that supports a legalistic construction of medical ethics, and this most readily favors a rights-based philosophy extrapolated from our legal system. But principlism has become the preferred theoretical structure of medical ethics, and while I am not necessarily satisfied with this construction, I have organized my own argument with the aid of this template.⁹ I do so because, if “autonomy” is the focus of debate, then the issue becomes, How is “autonomy” understood?

The strategy employed here is to move the rights-dominated arguments into a different framework, where moral relations between atomistic individuals are configured not as the rights of those in conflict but rather as the responsibilities of persons in mutually supporting relationships. Thus, utilitarian, feminist, communitarian, and virtue ethics figure prominently in this account, which would replace the ethical scenario of parties in competition with one based on a covenant. Such an ethics of care better captures the obligations of physicians to their patients and thereby protects the moral intimacy of the doctor-patient relationship. This is the ethics I, like many others, seek to promote.