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THE ROLE OF THE HORRIBLE IN UNDERSTANDING MEDICINE: A MEDITATION ON DAVID ROTHMAN'S *STRANGERS AT THE BEDSIDE*

Edward P. Richards, III*

I. INTRODUCTION

Unconscious bodies wheezing away on mechanical ventilators, unknowing patients injected with cancer cells, unfeeling physicians prolonging the death agony of hopelessly premature babies—these are some of the horrors that shape contemporary medical policy.

These horrors make medicine a uniquely alien world to outsiders such as the lawyers, ethicists and other non-medical personnel discussed by Professor David Rothman in his excellent book, *Strangers at the Bedside*.¹ Professor Rothman dares to discuss the underlying politics of the bioethics movement, questioning its overall benefit to patients. In this essay I test the proposition that the bioethics movement has, on balance, contributed to a decline in patient autonomy.

I do not suggest that bioethicists have acted improperly or dishonorably. Nor do I suggest that physicians, left on their own, will always protect their patients' interests. My thesis is that the horrible facts of medical practice, combined with its scientific basis, lead outsiders into misunderstandings that ultimately harm patients. To make my bias clear, I write as a quasi-insider. I am a law professor and lawyer, but I am trained in medical science and research. I am periodically involved in scientific research² and routinely involved in medical decision-making. I write extensively for physicians and biomedical engineers.

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1. DAVID J. ROTHMAN, M.D., *STRANGERS AT THE BEDSIDE* (1991) [hereinafter ROTHMAN].

2. Arnold Miller et al., *Birth Clustering*, 1990 PROC. OF THE AM. STAT. SOC'Y, (forthcoming 1992); Barry B. Bounds & Edward P. Richards III, *Using Objects to Communicate Legal Information*, COMPUTER SOC'Y PRESS OF THE IEEE, 9 PHOENIX CONF. ON COMPUTERS AND COMM. 766-771 (1990); Arnold R. Miller & Edward P. Richards III, *Statistical Analysis of Medical Malpractice Costs: Analysis of Incident Reporting Times*, PROC. OF THE BUS. AND ECON. STAT. SEC. OF AM. STAT. SOC'Y, 327 (1989); R. R. Sharp, III & Edward P. Richards III, *Molecular Mobilities of Soluble Components in the Aqueous Phase of Bovine Chromaffin Granules*, 497 BIOCHIMICA AND BIOPHYSICA ACTA 260 (1977); R. R. Sharp, III & Edward P. Richards III, *Analysis of the Carbon 13 and Proton NMR Spectra of Bovine Chromaffin Granules*, 497 BIOCHIMICA AND BIOPHYSICA ACTA 14 (1977); R. R. Sharp III & Edward P. Richards III, *NMR Evidence for an Acetylcholine ATP Complex*, 64, #3 BIOCHEMICAL AND BIOPHYSICAL RES. COMM. 851 (1975).

I believe that most bioethicists have been distracted by horrible facts, allowing themselves to be blinded to the profound ethical implications of the organizational and financial shifts that are fundamentally changing the physician-patient relationship.³ While ethicists are increasingly concerned with rationing medical care and the perverse impact of third-party payors providing incentives to physicians who provide less care to their patients, this concern comes many years too late.

The 1970s saw medicine become a capital intensive business. The 1980s saw competition and entrepreneurship become watchwords for medical practice. During the same period, legal academics and bioethicists focused on topics such as informed consent and right to die. These are important issues, but their true significance is as symptoms of the structural changes in medical practice. Focusing on these surface issues inadvertently provided ethical cover for third-party payors and governmental entities⁴ that use issues such as right to die to manipulate public opinion regarding access to care for the elderly and the seriously ill.⁵

This essay begins with the genesis of Professor Rothman's book. I then explore why medicine is an alien culture to non-physicians. While this essay is not meant to be a comprehensive review of *Strangers at the Bedside*, I do track Professor Rothman's presentation of different examples of bioethical reforms, extending his historical analysis with a discussion of how these reforms are co-opted by the marketplace. This discussion centers on how patient empowerment has failed as an effective philosophy for assuring ethical decision-making. I conclude with suggestions for rethinking the role of ethicists and other strangers at the bedside.

II. THE ORIGIN OF *STRANGERS AT THE BEDSIDE*

Professor Rothman is a narrative historian who writes on contemporary medical topics. He is an excellent scholar who is not reluctant to advocate his views of right and wrong.⁶ *Strangers at the Bedside* grew out of an invitation by the Columbia School of Medicine to have Professor

3. Ironically, traditional physician-dominated ethical codes were concerned with the financial conflicts inherent in practicing medicine: "What a far cry from the days when medical 'ethics' consisted of condemning economic improprieties such as fee splitting and advertising." ROTHMAN, *supra* note 1, at 200.

4. For example, the Oregon Plan for health care rationing has been favorably received in much of the media, despite its fundamental unfairness to poor women and children. See David J. Rothman, *Rationing Life*, 39 *NY NEW YORK REVIEW OF BOOKS*, Mar. 5, 1992, at 32.

5. Many physicians are deeply suspicious of ethicists:

In a brief period, the professional ethicist has become a fixture on the medical scene. At the moment ethicist is a self-descriptive term, and any entrepreneur can claim the title. Remember that the authority and social acceptance of phrenologists in the early nineteenth century was such that the faculty of a famous American university discussed the establishment of a department of phrenology, and eventually rejected it by a margin of only one vote. Whatever the competence of ethicists as a group, physicians must not allow themselves to be on the sidelines on matters that directly affect their relations with patients.

George A. Silver, *Ethicists in Medicine*, 338 *LANCET* 1325 (1991).

6. David J. Rothman, *M.D., Doesn't Mean 'More Deaths'*, *N.Y. TIMES*, Apr. 20, 1991, § 1, at 23.

Rothman join their ranks.⁷ This invitation allowed Professor Rothman to become deeply involved in the process of delivering medical care and performing medical research. The resulting book is deeply skeptical of many aspects of established medicine. It also reflects, however, some of the complexity of medical practice and is perhaps equally skeptical of the simplistic solutions being proposed for reforming the medical care system.

Strangers at the Bedside is subtitled, "A history of how law and bioethics transformed medical decisionmaking." This theme is developed through an analysis of three areas: 1) medical experimentation; 2) refusing care for severely impaired newborns; and 3) terminating lifesupport and substituted decisionmaking for the terminally ill. The common thread in each example is a highly publicized horror story that precipitates a legislative or judicial revision of existing practices. In every case, the physician's power was reduced and third parties to the physician-patient relationship gained a right to intervene in the decision-making. Patients gained real power in some cases, theoretical power in others and lost power in a few.

Professor Rothman humanizes the physicians involved in some of these horrible situations by recognizing that there are alternative perspectives that make otherwise brutal behavior explicable.⁸ In doing so, he steps into dangerous territory. The great power of the horrible anecdote as a rhetorical device is the ease with which persons who attempt to mitigate the horror are painted as condoning the behavior in question. Medical care and research is fraught with horrible situations and competing interests. Recognizing competing interests, even accepting that the competing interests are compelling, is not the same as denying the horror of the situation.⁹

III. THE TWO CULTURES PROBLEM

For those who work with medical policy issues, Professor Rothman's discussion of his socialization into the medical school culture may be the most fascinating part of his book.¹⁰ Medicine is an alien culture for non-physicians.¹¹ The most difficult problem for outsiders working in alien cultures is achieving a proper balance between gaining enough knowledge and empathy to accurately portray the culture, and going native.¹²

In general, science-based cultures are fundamentally alien to persons without scientific training. C. P. Snow called this the "two cultures"

7. ROTHMAN, *supra* note 1, at 5.

8. ROTHMAN, *supra* note 1, at 218.

9. Laurie Zoloth-Dorfman & Bridget Carney, *The AIDS Patient and the Last ICU Bed: Scarcity, Medical Futility, and Ethics*, 17 QRB 175-81 (1991).

10. ROTHMAN, *supra* note 1, at 135, *see* text surrounding note.

11. While not meant to denigrate the knowledge and understanding of the nursing profession, the primary legal relationship is between physician and patient. This is based on the physician's sole authority to make medical decisions as defined in most state licensing acts.

12. Going native, in the context of writing about medicine, usually means an uncritical acceptance of the norms of the particular medical group studied. In the case of physicians and scientists turned ethicists and philosophers, however, it frequently means a wholesale rejection of scientific values in favor of vaguely spiritual "individual centered" philosophies.

problem;¹³ the difficulty of communication between persons enculturated in the sciences or engineering and persons in the humanities. The blame for this failure to communicate rests on both cultures.

Scientific disciplines, medicine in particular, train and reward for narrow technological expertise.¹⁴ With the demise of traditional liberal education in the universities, many of these practitioners have focused on the sciences since the beginning of high school. This focus is often to the exclusion of other life activities essential to emotional maturity and understanding of the human condition.¹⁵ Scientific and technical training also inculcates a belief in knowledge and progress as unalloyed goods, irrespective of their impact on society.¹⁶

In turn, persons with only humanities training are often profoundly illiterate in the maths and sciences.¹⁷ This illiteracy impedes their reading and evaluating primary scientific material. Scholars who confine themselves to secondary sources, such as journalist popularizations,¹⁸ lay-oriented simplifications¹⁹ and articles that themselves are based only on secondary sources, are handicapped in their appreciation of the complexity and nuances of scientific and medical problems. This may manifest as either romantic, superficial generalizations of scientific ideas, or as a lumping together of well-reasoned research and National Inquirer hysteria-mongering.²⁰

13. C. P. SNOW, *THE TWO CULTURES AND THE SCIENTIFIC REVOLUTION* (1959).

14. J. Allan Hobson, Symposium, *Psychiatry as Scientific Humanism: A Program Inspired by Roberto Unger's Passion*, 81 NW.U.L.REV. 791 (1987).

15. The image of the callous physician, locked in perpetual adolescence, is a perennial literary theme. W. Somerset Maugham, who was qualified as a surgeon, wrote an early classic, *Of Human Bondage* (1915). A more contemporary view can be found in SAMUEL SHEM, *HOUSE OF GOD* (1978).

16. In Ibsen's *Enemy of the People*, we see a physician crushed by the discovery that his fellow citizens would rather not know that the spa that provided the economic base for their town was contaminated by dangerous bacteria.

17. This, of course, only applies to those who shun the sciences in their formal education. Even those without formal scientific training, given an interest in a scientific area, may systematically educate themselves if they are willing to invest the time to learn the necessary background materials. Such self-education is different, however, from the superficial glibness that lawyers are taught to develop to advocate a client's narrow interests in a specific case. The lawyer's task is to appear convincing to a jury or judge, not to understand the complexities of a discipline. In some ways, the lawyer who is ignorant of the discipline is at an advantage. A lawyer skilled in the underlying area must put aside the complexities and ambiguities to be an effective advocate; and must sometimes even wrestle the ethical question of when oversimplification becomes fraud. Lawyers who only know superficial oversimplifications are less often chafed by the ethics of dissembling.

18. This is not to diminish the value of such popularizations. As an example, James Gleick's book, *Chaos* (1987), provided an excellent, though simplified, introduction to the particular problem posed by non-linear systems such as weather forecasting. This provided a gateway into the primary sources for individuals who had not known of the chaos theory, but were willing to investigate these sources. It is the primary sources, however, that present both the complexity and the limitations of the theory. For example, Gleick at 79, discusses how chaos theory can help to understand the dynamics of epidemics such as AIDS. The primary sources, such as Hebert W. Hethcote & James A. Yorke, *Gonorrhea Transmission Dynamics and Control*, in *LECTURE NOTES IN BIOMATHEMATICS* (S. Levin ed. 1984) illustrate that while epidemiological systems are non-linear, chaos theory only plays a limited role in understanding their dynamics.

19. This genera is typified by Scientific American. While skillfully written, these articles often ignore inconvenient facts that get in the way of the flow of the story.

20. This is, of course, not limited to non-scientists. Both scientists and non-scientists were represented in the proliferation of articles and theories to explain crop circles.

IV. THE SPECIAL PROBLEM OF MEDICINE

Of all the science-based systems, medicine is at once the most familiar and the most alien. It is the most familiar because its concerns are those of every person: life, death, and, most importantly, health. The notions of healing, the province of medicine,²¹ are embedded in every culture. Even in the United States, the world leader in high technology medical care,²² a substantial part of the population relies on non-scientific²³ and lay healers.²⁴ The persistence of these healers testifies to both the enduring belief that healing is a natural activity that does not require university training and the real limitations in medical treatment.

Medicine is the most alien of sciences for three reasons. First, it demands objectivity in the face of human suffering. Objectivity is difficult in all disciplines.²⁵ Pure objectivity, the ability to judge facts on their own, without reference to outside, non-factual considerations, is impossible. Objectivity is most difficult in medicine because of the unavoidable identification of physicians, as fellow humans, with their patients. Financial and emotional considerations²⁶ make even relative objectivity difficult in medicine. These considerations delay acceptance of new knowledge by established physicians²⁷ and encourage other physicians to be overly eager to adopt unproven ideas.²⁸

Second, medicine is a relatively young discipline. We see an enormous medical research establishment and forget that while scientific medicine may have its roots in Paracelsus's studies of pharmacology,²⁹ it did not

21. The late Ruel Stallones, M.D., M.P.H., founding Dean of University of Texas School of Public Health, was always careful to talk about medical care and medical care delivery. He believed that it was critical for medical policymakers to understand that we do not care for health, nor do we deliver health. We care for disease and we deliver disease care.

22. High technology in medical care is not limited to the use of machines on patients. The most pervasive use of technology is pharmaceuticals, which now account for approximately 15% of the medical care dollar.

23. Chiropractors are the most numerous and powerful of these practitioners.

24. Many of these people reject physician care for non-financial reasons. In some parts of the south, the lay midwife (midwives with no formal medical training, as distinguished from nurse midwives) movement is religiously-based and is targeted toward middle class suburban women.

25. The relevant comparison in law is not with jurisprudential theories, but with the management of conflicts of interest. The diffusion of alternative dispute resolution and preventive law into traditional litigation-oriented law practice and teaching is a good parallel with the problems of paradigm shift in science.

26. The human genome project is a good example. Every scientist involved in the project has a substantial financial interest in its progress. Even the usual interests of university researchers in federal grant money is now complicated by their simultaneous holding in private genetic technology concerns.

27. The classic work is THOMAS S. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* (2d ed. 1972). The relevant point is that scientists' reputations and personal psychologies become dependant on the validity of the theories with which they are identified. This undermines their willingness to accept new scientific knowledge.

28. Two dangerous manifestations of this are the rush by physicians to be "first on the block" with trendy new therapies and the willingness of "alternative healers" to promote quasi-mystical nonsense.

29. Paracelsus (1493-1541) broke away from the Galenic tradition and used empirical studies to determine the effects of drugs.

begin to flower until the work of Pasteur³⁰ and Semmelweis³¹ in the later part of the 1880s. It was not until sometime after 1900 that going to a physician increased a patient's chances of survival. Medicine as a hospital-based, capital intensive business, epitomized by the research medical center, is a product of the 1950s and 1960s.

The values that shape the contemporary physician-patient relationship were formed before medicine had effective treatments. The great historical tradition of medicine is, at best, one of dedicated emotional support for patients. At worst, it is a history of fraud and deception. Physicians are expected to practice a discipline that has changed fundamentally during one practice lifetime. It is not surprising that traditional medical values have failed to provide clear guidance for solving the problems of modern medical practice.

Third, and most critical, physicians must deal with horrible facts. The scientific details seem the most difficult barriers for non-scientists seeking to understand medical practice. Yet medical practice is just as difficult to understand for persons skilled in other branches of the life sciences, for whom the science of medicine is perfectly comprehensible. What is most alienating for both groups is that the objective facts of much of medical practice are horrifying. The process of surgery is the cold-blooded rending of flesh and tearing of organs. Chemotherapy is the systematic poisoning of the patient in hopes of killing the tumor faster than the patient. The management of chronic diseases such as renal failure, AIDS and other HIV-related diseases, diabetes, congestive heart failure, and untold others, is not one of cure, but of slowing and mitigating death.

Appreciating and accommodating this horror is a major part of the training of physicians and, as Professor Rothman found, those who would understand the complexities of medical ethics. Medical training is often criticized for its inhumanity.³² It is questionable, however, how humane medical training can be and still prepare physicians to deal with inhumane situations. This is not a question of becoming "hardened" to human

30. Pasteur's work on the biological origin of disease was the foundation of modern medical science. Interestingly, Pasteur's work was widely accepted precisely because he was a chemist with strong political supporters outside of organized medicine.

31. Semmelweis was the first to use statistical analysis when he studied the incidence and cause of childbed fever. Unlike Pasteur, he was a physician and thus subject to the sanctions of the medical profession. While he was able to reduce the mortality of the disease from 12% to 1.5% of pregnant women, his work was ignored and he was driven from practice in Vienna. His sin was to show that childbed fever was an iatrogenic illness, spread by the very physicians from whom the women sought relief.

32. Some of these criticisms are well taken. John M. Colford, Jr., M.D., & Stephen J. McPhee, M.D., *The Ravelled Sleeve of Care; Managing the Stresses of Residency Training*, 261 JAMA(R) 889-93 (1989). The best founded of these objections is to the long hours demanded in many training programs. Alan D. Bedrick, M.D., *The Eighty-Hour Workweek; Residency Friend or Foe?* 144 AM. J. DIS. CHILD. 857 (1990). These take an unacceptable toll on both the physicians and the patients. David A. Asch, M.D., & Ruth M. Parker, M.D., *The Libby Zion Case: One Step Forward or Two Steps Backward?* 318 NEW ENG. J. MED. 771-75 (1988); Kenneth E. Thorpe, Ph.D., *House Staff Supervision and Working Hours; Implications of Regulatory Change in New York State*, 263 JAMA(R) 3177-81 (1990).

suffering, although a certain degree of detachment is fundamental to a physician's emotional survival. Physicians, and those who would understand medical practice, must learn not to let the horror of individual suffering blind them to the best medical decision-making for that individual.

This is best understood in the context where physicians themselves recognize that they are unable to be sufficiently objective. It is considered bad practice, if not unethical, for physicians to treat members of their own families. Traditionally, physicians have treated their colleagues' families without charge to discourage the physicians from treating their own families.³³ Termed professional courtesy, this practice recognizes that objective decision-making is impossible when the physician is emotionally involved with the patient. Contrary to the usual assumption that patients would get better medical care if physicians only cared more about them, caring a lot about patients as individuals is very destructive to the patient's medical care. When a physician cares deeply about an individual, that physician is torn between undertreatment because of denial and overtreatment because of fear.

A. Do Horrible Facts Make Physicians into Strangers?

Professor Rothman addresses the role of horrible facts in his chapter entitled "The Doctor as Stranger." The most powerful paragraph in this chapter, and, in my view, one of the most insightful in the literature of cross-discipline studies of medical practice, deals with Professor Rothman's internalization of the significance of horror in isolating physicians from society:

Physicians' shoptalk is not so much boring as it is filled with tales that would strike outsiders as tragic and gruesome, stories that no one else would want to hear around a dinner table, or for that matter, anywhere else. Let one personal experience clarify the point. No sooner did I join a medical school faculty than I met with the chairman and chief of service of various clinical departments (pediatrics, medicine, and so on) to explore what interest each department might have in social medicine. The sessions were informal, but much of these first conversations turned on "interesting cases," which typically involved descriptions of devastating illness. . . . At first I thought these stories were an initiation ritual — was a historian trained to do archival work up to the stuff of medicine? But I slowly learned that this was not a right of passage but a sharing of anecdotes and gossip; they assumed that because I was part of the faculty, I, too, would be fascinated by the shoptalk. Then, in turn, when friends asked about these meetings, I would share the stories; but as I watched their faces get tense and drawn, I learned to put aside the question and change the subject. The substance of medicine, I was learning, was easiest talked about with medical people, not because of its technical or dry qualities, but because of its scariness in exposing the frailty of human beings and the dimensions of suffering.³⁴

33. Richard C. Wasserman, M.D., et al, *Health Care of Physicians' Children*, 83 PEDIATRICS 319-22 (1989).

34. ROTHMAN, *supra* note 1, at 135.

This description of Professor Rothman's internalization of the significance of horrible facts is doubly compelling. First, Professor Rothman was not unfamiliar with horrible facts in related contexts. In particular, his studies of asylums for the mentally ill forced him to confront suffering and helplessness in the face of disease.³⁵ Yet the horrors of his research into asylums did not prepare him for the pervasive impact of horror in the routine practice of medicine. While not discussed by Professor Rothman, it is possible that a key difference between his approach to his asylum research and his initiation into medical culture was an assumption that the conditions in asylums were improper and should be fixed.

One can imagine one's non-medical friends (or oneself) earnestly discussing the horrors of asylums in the way that persons discuss problems in society that can be fixed, even if they are not being fixed; "If people were just more dedicated, if we would just spend more money, if we would just listen to the experts . . ." Such caring, but detached, discussion is possible because the problems seem tractable, at least theoretically. Most importantly, the problems of asylums are not deeply disquieting because they are other people's problems; few people see themselves as potential inmates in asylums. The horrors of medical practice cannot be escaped because they are the horrors of life itself.

Professor Rothman's account is also compelling because he articulates how this initiation separated him from non-physicians. His realization of the effects of his stories on his non-medical colleagues is a profound insight for those, enculturated into the medical ethos, who would bridge the gap between medical and non-medical worlds. Professor Rothman uses this insight as part of his persuasive picture of the physician as a stranger to society.³⁶ He leaves unanswered the question as to the extent that this is a societally-imposed, as well as self-imposed, separation.

Professor Rothman's personal solution was to change the subject, rather than to discuss difficult medical cases with his non-physician colleagues. This raises the critical question: was this a decision on Professor Rothman's part to avoid a discussion which made him uncomfortable,³⁷ or does it reflect his realization that he would be ostracized by his non-medical colleagues if he continued with his tales of horror?

I cannot answer this question for Professor Rothman's colleagues. I find most persons without medical training profoundly uncomfortable when confronted with specific, graphic discussions of medical facts. Many

35. The overcrowding was desperate - beds jammed one next to the other in the wards and along the hallways - and the filth ubiquitous, so that virulent intestinal diseases like shigella spread through the population. Staffing was minimal, one attendant to fifty or sixty inmates, and injuries common, with residents abusing themselves or assaulting others.

DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBROOK WARS*, at 15 (1984).

36. This extends to the estrangement of many physicians from their families and, given their community standing and wealth, their relative lack of involvement in politics. ROTHMAN, *supra* note 1, at 133-37.

37. A decision which was available because as an insider/outsider, he could move on to his outsider interests.

law students have difficulty in dealing with realistic discussions of the medical facts in torts cases. More troubling are medical law and policy experts who are emotionally unprepared to face the detailed factual analysis that is necessary to understand certain difficult medical problems.³⁸ This is not limited to squeamishness over unpleasant physiological phenomena. It extends to an unwillingness to confront situations where ethically proper decisions conflict with generally accepted notions of individual liberty.³⁹

This unwillingness to face horrible facts often manifests as a schizophrenic combination of vilification and sentimentalization of medical issues. It also leads outsiders to fixate on issues that pose fascinating ethical questions, but have de minimus impact on medical practice. As discussed later, this becomes destructive when general medical policy is determined by these aberrant anecdotes.

B. The Importance of Shared Knowledge

Professor Rothman was struck by the use of case-based, or, as he puts it, "case-by-case" reasoning in clinical decision-making.⁴⁰ He sees this as resolving cases without rules and believes that persons with a legal mind-set are 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."⁴¹ He is troubled because he sees this case-based reasoning used to avoid general ethical rules by finding exceptions that undermine the proposed rule:

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 experience⁴²) 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 will initially 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

38. Feeling revulsion does not, in itself, discredit a scholar's work. There are subjects, such as the Nazi concentration camp medical experiments, that properly horrify all who study them. Horror of the subject of inquiry is only relevant when it distorts the scholarship. One must attempt to understand the rational behavior behind even horrible acts such as the Nazi death camps.

39. RAE J. ISAAC & VIRGINIA C. ARMAT, *MADNESS IN THE STREETS* (1990).

40. "Perhaps the most remarkable feature of clinical decision making is the extraordinary reliance on a case-by-case approach." ROTHMAN, *supra* note 1, at 7.

41. ROTHMAN, *supra* note 1, at 8.

42. What many outsiders do not realize is that physicians use medical hypotheticals just as law professor's use legal hypotheticals. It matters less that the counter-example be real as that it could be real. In many cases, clinical hypotheticals are composites, drawn from the physician's own practice, the practice of colleagues, and the general medical mythology.

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.⁴³

Medicine does use case-by-case reasoning. There is an old joke, however, that whenever a physician begins a sentence with "in my clinical experience," you should be prepared for a statement that contradicts common-sense, if not physical law. Outsiders often misunderstand this process, however, because they do not appreciate physicians' shared background. No other graduate and post-graduate education is so consistent between schools. This is due to comprehensive accreditation requirements and to a shared belief in what a physician should know. While not all medical schools have the same curriculum, and many medical educators disagree on what medical education should be, these differences are insignificant compared to the tumult in disciplines such as law.

As an example, my greatest surprise in moving into law teaching was that there were no requirements on the content of required courses. As long as your course has the proper title, no one inquires into what you teach. I soon had the second surprise of finding that law school accreditation requirements make minimal demands on what courses must be required, irrespective of their content. This combination of idiosyncratic course content, and limited accreditation requirements on required courses, allows students from the same law school to graduate with little shared knowledge. This is exacerbated when comparing the shared knowledge of students from different law schools.⁴⁴

There are pedagogic reasons why a lock-step curriculum is not desirable in law⁴⁵ (and history, sociology, etc.). This does not obviate the cultural gulf between persons educated under such broad disciplines and physicians. When an outsider sees physicians making what appear to be ad hoc, case-by-case decisions, the reality is often profoundly different. Medical students and residents are as rule-oriented as law or philosophy students. The cases they discuss are often exceptions to an unarticulated rule unknown to the outsider, or are surrogates for complex rules in a shorthand discussion of which theory should govern the patient's care.⁴⁶ This is especially likely

43. ROTHMAN, *supra* note 1, at 7.

44. It might be expected that the bar examinations would force a great degree of homogeneity on law school teaching. This does not happen, however, because in each state a private company runs a comprehensive, lengthy bar review cram course to give all students the minimal knowledge necessary to pass the state's bar examination. Given the limited focus of the bar examinations, it is an open question whether the average law school admittee could do equally well on the bar examination by skipping law school and taking the bar review course.

45. Most important is that law is not a well-defined subject, changing from state to state and from case to case. Law students are taught to analyze problems and to look up the relevant law. This assumes that the lawyer has the time to investigate the facts and do detailed research on the law. Physicians are seldom able to make decisions at such a leisurely pace. Edward P. Richards, *Living with Uncertainty: Information Theory and Clinical Decision Making*, 5 J. INTENSIVE CARE MED. 91 (1990).

46. There is another old joke on the mystery created by shared background: A sociologist visits a prison warden to discuss the possibility of doing research in the prison. The warden takes her on

when the outsider only sees the "interesting cases;" those brought to the attention of ethics committees, those used as teaching material, or just those that are unusual enough that they are discussed around the department coffee pot.

V. MEDICAL EXPERIMENTATION

No area of bioethical inquiry is more thoroughly grounded in horrible facts than is medical research. Modern bioethics, as it concerns medical experimentation,⁴⁷ begins with the Nuremberg trials and the resulting Nuremberg Code.⁴⁸ Of all the atrocities of the Nazi concentration camps, perhaps the most disturbing were the medical experiments. This was not due to their brutality alone, for in the context of the death camps, relative brutality is meaningless. The medical experiments were abhorrent because they were performed by physicians, mocking the expected dedication of physicians to their patients' well-being.⁴⁹

The Nuremberg Code arose from the trial of Karl Brandt. It was intended to be a code of ethics governing human experimentation, but its emphasis on patient autonomy was the first major break from the paternalistic model for the physician-patient relationship.⁵⁰ It was generally ignored, however,⁵¹ because most physicians saw the Nuremberg Code as irrelevant to their practices: the acts of monsters such as Dr. Mengele

a tour of the cell-block. As they pass the cells, they hear a prisoner call out "47!". This is immediately followed by guffaws of laughter. Soon another prisoner calls out "53", which is also followed by laughter. The sociologist, baffled, asked the warden what was going on. He replied that the prisoners all knew the same jokes, so they had numbered them to make it easier to tell them in the confusion of the cellblock. Calling out the number was telling the joke. (The joke continues that the sociologist calls out a number and is greeted by silence. The warden explains that the humor is all in the delivery.)

47. For a broad investigation of human experimentation, including social science research, see JAY KATZ, *EXPERIMENTATION WITH HUMAN BEINGS* (1972).

48. *Nuremberg Code*, 2 TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 181-82 (1949) reprinted in ROBERT J. LEVINE, *ETHICS AND REGULATION OF CLINICAL RESEARCH* 425 (1981).

49. Less well known, but perhaps more disquieting, physicians were well represented in the SS itself. In general, see ROBERT J. LIFTON, *THE NAZI DOCTORS: MEDICAL KILLING AND THE PSYCHOLOGY OF GENOCIDE* (1986).

50. a. The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent: should be so situated as to be able to exercise free power of choice without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

Nuremberg Code, 2 TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 181-82 (1949) reprinted in ROBERT J. LEVINE, *ETHICS AND REGULATION OF CLINICAL RESEARCH* 425 (1981).

51. For a fascinating history of the Nuremberg Code and legal decisions on medical experimentation, both pre-Code and post-Code, see George J. Annas, *Mengele's Birthmark: The Nuremberg Code in United States Courts*, 7 J. CONTEMP. HEALTH L. & POL'Y 17 (1991).

were too far removed from clinical research in the United States.⁵² Ironically, the horror of the Nazi death camp experiments was so great that physicians distanced themselves from it in the same way that non-physicians distance themselves from the horrors of routine medical practice. It was more than fifteen years after the promulgation of the Nuremberg Code before the ethics of medical research in the United States was seriously questioned.

Professor Rothman begins his discussion of medical research with the end of the "golden age" — the publication of *Ethics and Clinical Research* in 1966.⁵³ In this article, Professor Beecher discussed twenty-two examples of unethical conduct by medical researchers.⁵⁴ The conduct decried by Beecher was described by the scientists themselves in their articles and was approved by the peer-reviewers who approved the articles for publication. All the studies were performed after the promulgation of the Nuremberg Code and would have been difficult or impossible to perform if the provisions of the Code had been followed.

The unethical conduct complained of in most of these experiments was a failure to obtain a proper consent from the patients who participated. This was not a mere formality. A number of the experiments posed substantial risks to the patients. In some cases, the risks were such as to make the experiment ethically questionable, irrespective of patient consent.⁵⁵ Beecher makes clear, however, that the unethical conduct in most of these experiments was the result of "thoughtlessness and carelessness, not wilful disregard for the patient's rights"⁵⁶

52. It is not a fictional villain but a flesh-and-blood murderer, Josef Mengele, who sets the modern standard for experimentation atrocities. By almost any measurement, Mengele, the "Angel of Death," was one of the most notorious of the Nazi physicians. Eyewitness accounts summarize the cold brutality and murder of this M.D.-Ph.D. "man of science." Some of his most horrifying work involved genetically-related experiments performed on children who were twins, many of whom he personally murdered. In an affidavit, one of his prison assistants, Dr. Miklos Nyiszli, describes how Mengele once killed fourteen Gypsy twins himself:

In the work room next to the dissecting room, fourteen Gypsy twins were waiting and crying bitterly. Dr. Mengele didn't say a single word to us, and prepared a 10 cc and a 5 cc syringe. From a box he took Evipal and from another box he took chloroform, which was in 20 cc glass containers, and put these on the operating table. After that the first twin was brought in . . . a fourteen year old girl. Dr. Mengele ordered me to undress the girl and put her head on the dissecting table. Then he injected the Evipal into her right arm intravenously. After the child had fallen asleep, he felt for the left ventricle of the heart and injected 10 cc of chloroform. After one little twitch the child was dead, whereupon Dr. Mengele had her taken into the corpse chamber. In this manner all fourteen twins were killed during the night.

Id.

53. Henry K. Beecher, *Ethics and Clinical Research*, 274 NEW ENG. J. MED. 1354 (1966).

54. *Id.* at 1355-59.

55. While each of the experiments posed a substantial risk to the patients involved, there were few serious injuries. In only one case was there clear evidence that the experiment caused the death of an otherwise healthy person. In this experiment, a malignant melanoma (a fast growing and deadly skin cancer) was transplanted into a healthy volunteer. The callous disregard for the patient in this experiment approached the level of that displayed in some of the Nazi experiments. *Id.* at 1359.

56. *Id.* at 1356.

Having started with Beecher's 1966 article, Professor Rothman jumps back to turn of the century and presents an excellent history of medical research in the United States.⁵⁷ He reviews the development of medical research in the United States. The purpose of this review is to demonstrate the development of the arrogance and self-assurance of the medical research community that led to the thoughtlessness and carelessness observed by Beecher.

Professor Rothman successfully conveys the development of the mindset that puts research progress ahead of patient well-being. He then demonstrates how abusive medical experiments were publicized to marshal popular and legislative support for restrictions on human experimentation. Most of these experiments were indefensible, justifying the call for more effective regulation of human experimentation.⁵⁸ Professor Rothman documents the resulting reforms, including stringent requirements on informed consent,⁵⁹ limitations on research on children and bans on research involving prisoners.

He also recognizes that these regulations, born of a fear of sinister researchers conducting horrible experiments, have two central weaknesses. First, the primary vehicle for enforcing the regulations is the Institutional Review Board (IRB), a committee appointed by the institution performing the research. Institutions are free to appoint anyone to an IRB, they may remove troublesome members from the IRB and a few IRBs are empowered to determine whether the experimenters actually follow the informed consent protocols approved by the IRB.⁶⁰

As Professor Rothman makes clear, the operative assumption behind the reform of rules governing human experimentation is that scientists cannot be trusted.⁶¹ Yet, in most cases, persons who distrust scientists are not opposed to medical research. The most obvious examples are ACT UP⁶² and other victims advocacy groups who decry current research efforts while demanding more research into their ailment. This leads to the second problem with these regulations:

On the balance, however, the procedures to protect human experimentation are so firmly entrenched that the central issue now, in view of the AIDS crisis, is not how to protect the human subject from the investigator but how to ensure that all those who wish to be human subjects have a fair

57. ROTHMAN, *supra* note 1, at 15-79.

58. One of the worst was the Tuskegee syphilis experiment. This study on the long-term consequences of syphilis infection began in 1932. A large group of black men infected with syphilis were followed to determine the natural history of the disease. This was questionable in 1932. It was inexcusable in 1946 when penicillin became generally available to treat syphilis. See JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981); *Pollard v. United States*, 69 F.R.D. 646 (M.D. Ala. 1976).

59. See Protection of Human Subjects; Informed Consent; Standards for Institutional Review Boards for Clinical Investigations, 56 Fed. Reg. 28,025 (1991) (to be codified at 21 C.F.R. pt. 51, 56).

60. ROTHMAN, *supra* note 1, at 252.

61. ROTHMAN, *supra* note 1, at 100.

62. AIDS Coalition to Unleash Power, the advocacy group founded by author Larry Kramer.

opportunity to enter a protocol. The nightmare image has shifted from an unscrupulous researcher taking advantage of a helpless inmate to a dying patient desperate to join a drug trial and have a chance at life. The backlash against the IRB is spurred not by researchers' impatience with bureaucratic delays but by patients who want to make their own calculations of risks and benefits and to decide for themselves, without the veto power of the IRB, whether a protocol is worth entering. Although this reorientation in large measure reflects the grim fate confronting persons with AIDS, it also testifies to how effectively the IRBs have trained, really tamed, the researcher.⁶³

"Trained and tamed." Precisely correct, but incomplete. In their zeal to eliminate horrible experiments, reformers ignored a critical issue: why do great scientists do research and what happens if they stop? This is critical because of the tension between limiting the prerogatives of scientists while trying to encourage medical research. Having been involved in medical research and having served on IRBs, I believe that there have been profound changes in medical research, but that IRBs have been almost irrelevant to this change.

The best science is driven by a lust for knowledge and the all-consuming excitement that comes with doing productive research on important problems. Where ethicists and lawyers see horrible things being done to patients without their informed consent, researchers see a path to an important discovery, perhaps the cure to a scourge afflicting millions of people. A prime motivation of great scientists is the thrill of solving difficult problems and explicating the laws of the universe.

While bioethicists see the increased protection of human subjects as the central change in medical research, the most important change has been in funding priorities and grant oversight. IRBs are only a small part of the bureaucratization of science. In general, reformers of science, including bioethicists and lawyers, see science as a commodity. If you believe that science is a commodity, then it is reasonable that you can direct scientific discoveries by how you allocate grant money. This process started with the "war on cancer."

The war on cancer dictated that federal research funds be reallocated to scientists working on cancer cures. In following the war metaphor, money was also shifted into giant research organizations, aping the Manhattan Project's approach to building the atomic bomb. Biomedical scientists had to work on cancer-related projects or lose their funding. The directors of large laboratories became increasingly powerful, at the expense of individual scientists. As grants became much larger, Congress demanded increasing oversight of grant funds. Grant applications required massive paperwork that specified in detail what the scientist expected to accomplish and how the money would be spent.

The war on cancer failed. Some incremental progress was made, but no magic bullet was found. While it should have been clear that the grand experiment of checkbook science had failed, it became impossible to go

63. ROTHMAN, *supra* note 1, at 252.

back. Great scientists had been turned into laboratory directors responsible for obtaining grants to pay the salaries of tens to hundreds of people. Having sold their souls to build research empires, they found they could no longer do research.⁶⁴ They had become full-time fund-raisers. They were tamed by the federal regulations on obtaining and spending grant money, not by IRBs.

This taming of the medical research establishment, with all its costs in lost creativity and careers ruined by arbitrary changes in federal grant priorities, did not greatly decrease unethical research. The reason is simple: formal medical research has always been a very small part of medical practice. Most medical research, including some of the most abusive, masquerades as patient care. Treating physicians trying "something new" have always posed far greater risks than the most determined medical scientists.

These abuses are greatest for medical and surgical procedures.⁶⁵ Paradoxically, we have created a system where there is little or no regulation of unproven or even previously untried procedures. As long as physicians performing procedures charge the patient for the procedure and call it therapy, they are immune from IRB review and most other restrictions on human experimentation.⁶⁶

The most extreme result of this immunity from review is that major medical industries will develop around unproven treatments. Once such treatments are institutionalized, they are almost impossible to dislodge. While there have been many examples of treatments adopted without proper proof of their efficacy,⁶⁷ all pale before the coronary artery bypass (CAB) industry. Approximately 15 years elapsed between the introduction of CABs and the results of the first controlled clinical trials of their efficacy. During this period CABs became a multi-billion dollar a year business, and many of the CAB surgeons became millionaires.

Perhaps most importantly, this period saw a million or more, mostly middle and upper class, white men undergo the procedure. Anyone

64. The story of Faust's bargain with the devil remains the classic picture of scientific curiosity combined with ambition. JOHANN GOETHE, *FAUST: A TRAGEDY* (C. Thomas ed., 1892).

65. "Procedure" is used as a general term for invading the patient's body with various instruments. At one time, most procedures were performed by surgeons and involved what is traditionally thought of as surgery. Most specialties have developed an armamentarium of invasive procedures. These include cardiologists doing angiography and angioplasty, internists doing endoscopy and surgical procedures through the endoscope, to gynecologists performing lyposuction. Procedures generate a lot of money for a limited amount of patient contact time. An hour spent doing a detailed medical history and counseling a patient might only generate a \$40-\$100 fee, while an hour spent performing a procedure can generate a \$2000 fee. This is in addition to equal or higher charges by the hospital or outpatient surgical center for the equipment and support team.

66. How can this be? Unlike drugs and medical devices, which must be declared safe and effective by the U.S. Food & Drug Administration, the decision to adopt a new surgical procedure—whether RK or coronary bypass—is left in the hands of those who perform it. "The only effective regulation is after-the-fact malpractice," says George J. Annas, professor of health law at Boston University.

Karen Freifeld, *Myopic Haste? (100,000 plus have had new eye surgery)*, *FORBES*, May 6, 1985 at 95(2).

67. For an excellent chronicle of medical fads, see CHARLES L. BOSK, *FORGIVE & REMEMBER: MANAGING MEDICAL FAILURE* (1979).

challenging the appropriateness of this treatment would face the wrath of both a well-financed medical lobby and these "satisfied customers." Understandably, these patients would be unwilling to confront the reality that they might have undergone unnecessary, expensive and dangerous surgery. Even today, after many studies have demonstrated that the procedure is only beneficial in limited circumstances,⁶⁸ many persons still undergo unnecessary CABs.

While CABs are the biggest success story in the sell-it then test-it school of medical progress, the most outrageous attempt to prevent the investigation of an unproven procedure was mounted by a group of ophthalmologists. These ophthalmologists performed radial keratotomies, a procedure where the cornea is sliced to change its optical properties. The procedure was developed in the Soviet Union and introduced into the United States without clinical trials. This is a quick procedure and one that, in its height, would net its practitioners about \$1000 an eye. A physician who could recruit enough business could do several of these a day for all the working days in a year.

When the National Eye Institute set up a study panel to determine if this procedure was safe and effective, the physicians participating in the study panels found themselves the target of a lawsuit by the ophthalmologists performing the procedure.⁶⁹ The complaint alleged that the panel members conspired to interfere with the businesses of the ophthalmologists performing the procedure. What was the interference? The panel called the procedure experimental, thus raising a question about whether insurers should pay for the procedure.⁷⁰

The use of legal process by a well-financed group to prevent the investigation of an unproven treatment is the logical extension of a regulatory system that makes it difficult to perform research while not addressing unethical practices by non-scientist physicians. Ironically, this happens because even unethical researchers work in the open. Beecher's pioneering article and investigation of unethical research practices was only possible because researchers must publish their work to survive. This makes researchers easy targets for bioethicists and lawyers who fasten onto the horrible facts in printed accounts to shape regulatory policy. In contrast, unethical practitioners offering unproven procedures as therapy are carefully shielded from scrutiny by privacy laws developed to protect patients.

VI. PARENTS v. CHILDREN — BABY DOE AND NANCY CRUZAN

One of the most difficult problems in bioethics is the conflict of rights between family members, in most cases, rights of children and their

68. Eugene Braunwald, *Effects of coronary-artery bypass grafting on survival: Implications of the randomized coronary-artery surgery study*, 309 NEW ENG. J. MED. 1181-84 (1983).

69. *Schachar v. American Academy of Ophthalmology, Inc.*, 870 F.2d 397 (7th Cir. 1989); *Vett v. Waring*, 565 F. Supp. 674 (N.D. Ga. 1983).

70. Colin Norman, *Clinical Trial Stirs Legal Battles: Legal Disputes in Atlanta and Chicago Over Surgery for Myopia Raise Issue of How Controversial Surgical Techniques Should be Assessed*, 227 SCIENCE 1316 (1985).

parents. The context of these conflicts changes throughout the life cycle: starting with abortion; moving through duties to protect the fetus; the right to refuse medical care for a severely impaired newborn; the duty to properly care for children; the right of minors to independent medical care including abortion; decision on the termination of lifesupport for children; and, ultimately, the decision to terminate lifesupport for one's parents.

Most bioethicists have tried to resolve these conflicts by appeals to autonomy: whoever has the right to autonomy wins. This is a circular solution, however, because they have not articulated a clear rule that establishes who should get autonomy. They are left to resolve inconsistencies through ad hoc decisions and silence. The hardest of these inconsistencies is treatment for damaged newborns, where the rights of the parents, the newborn and the disabled collide.

A. The Baby Doe Regulations

Professor Rothman illustrates this collision by his account of the political maneuverings leading to the Baby Doe rules.⁷¹ The Baby Doe rules⁷² mandated that severely impaired newborns be given all indicated medical treatment, irrespective of parental wishes. The regulations were inspired by Section 504 of the Rehabilitation Act,⁷³ which outlaws discrimination against the handicapped.

Parents of severely impaired newborns told horrifying stories of children condemned to lives of hopeless despair.⁷⁴ Bioethicists, focusing on these horror stories, bitterly opposed the Baby Doe rules for interfering with the parents right of self-determination.⁷⁵ In doing so, however, they ignored the message implicit in allowing these parents to choose to withhold care.

Allowing parents to withhold care from defective newborns was at odds with efforts to protect children from abuse and neglect and with ethical arguments made on behalf of the handicapped that their lives were fully as valuable as those of the non-handicapped. Advocacy groups for the handicapped raised a very difficult issue: Was it so very wrong for a severely disabled person, making the most of his or her abilities, to protest when an equally disabled baby is allowed to die because its parents see its life as a burden to the child and to themselves? This question has gone unanswered, continuing to poison the debate over the rights of the disabled versus their parents.

Outside of the abortion debate, the conflict of rights between parents and children has been the most bitter of the debates over limiting the

71. ROTHMAN, *supra* note 1, at 190-221.

72. Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-05 (1984).

73. Rehabilitation Act of 1973, § 7(7)(B)(ii)(codified as amended at 29 U.S.C.A. § 706(8)(B)(ii)(West Supp. 1992)).

74. ROBERT AND PEGGY STINSON, *THE LONG DYING OF BABY ANDREW* (1983).

75. See Stephen A. Newman, *Baby Doe, Congress and the States: Challenging the Federal Treatment Standard for Impaired Infants*, 15 AM. J.L. & MED. 1 (1989).

freedom of pregnant women in order to protect their unborn children. In this debate, which archetypically involves a pregnant woman abusing illegal drugs, the ethically approved view is that the pregnant woman's rights completely trump any right of society to protect the fetus.⁷⁶

This is a logical approach if the underlying agenda is to protect a woman's right to chose abortion: if abortion is always assumed to be available, then it is illogical to restrict the rights of a woman if she can always end the restrictions by aborting the fetus.⁷⁷ It is in conflict, however, with the efforts to protect the child's rights that begin immediately at the birth of the child, at least with the birth of a perfect child. Trying to make the moment of birth a mystical dividing line between absolute rights of mother and child is inviting legal disaster. The Supreme Court and many legislatures abhor legal asymmetries. If they are confronted with an argument that birth is magic because prior to birth the woman has a right to abortion, then they are more likely to limit that right of abortion than to accept a system that allows a pregnant crack-head to injure her baby.

B. The Right to Die

These conflicts and the inconsistencies in their resolution by bioethicists become most obvious in the debates over the right to die. No issue has preoccupied bioethicists more than the right of a patient to refuse medical care, particularly in the face of a terminal illness. Professor Rothman presents a concise, if traditional, history of the problem.⁷⁸ His discussion is centered on the *Quinlan* case,⁷⁹ *Cruzan*⁸⁰ not having been decided when he completed his manuscript.

I do not intend to review the right to refuse medical care debate in this article.⁸¹ I will focus, instead on two unpleasant points that are generally ignored by bioethicists: 1) the hypocrisy in simultaneously vili-

76. J. Gallagher et al., *Court-Ordered Obstetrical Interventions*, 316 NEW ENG. J. MED. 1192-96 (1987); G.J. Annas, *The Impact of Medical Technology on the Pregnant Woman's Right to Privacy*, 13 AM. J.L. & MED. 213-32 (1989); D. Johnsen, *The Creation of Fetal Rights: Conflicts With Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L. J. 599-625 (1986); M.A. Field, *Controlling the Woman to Protect the Fetus*, 17 LAW MED. HEALTH CARE. 114-29 (1989); A.C.L.U. *Criminal Prosecutions for Fetal Abuse Increasing at Alarming Rate*, 1 Reprod Rights Update 2 (Sept. 1, 1989); Note, *Maternal Rights and Fetal Wrongs: The Case Against the Criminalization of 'Fetal Abuse'*, 101 HARV. L. REV. 994 (1988).

77. This is also an appealing position for physicians, partly because it respects the traditional patient's rights, partly because it does not require the physician to get involved in nasty legal disputes over the woman's care. See American Medical Association, *AMA Board of Trustees Report - Legal Interventions During Pregnancy; Court-Ordered Medical Treatments and Legal Penalties for Potentially Harmful Behavior by Pregnant Women*, 264 JAMA 2663-70 (Helene M. Cole, ed., 1990).

78. ROTHMAN, *supra* note 1, at 222-46.

79. *In re Quinlan*, 355 A.2d 647 (1976), cert. denied, 429 U.S. 922 (1976).

80. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc), *aff'd sub nom. Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).

81. See Edward P. Richards, *Making Sense of Cruzan: Implications of the Supreme Court's Right to Die Decision*, 5/6 J. INTENSIVE CARE MED., at 241-45 (1990); Edward P. Richards, *Ethical Considerations in Non-Judicial Termination of Life-Support Decisions*, 5/6 J. INTENSIVE CARE MED., at 193-96 (1990).

fying and sentimentalizing the family, depending on the legal issue; and
2) the economics of death.

C. Cutting Families to Fit the Conclusions

The hypocrisy is best illustrated in the contrast between two dissenting Supreme Court opinions filed on the same day. The first was in a case contesting Ohio's requirement that minors seeking abortion must either tell their parents or get the approval of a judge.⁸²

Sadly, not all children in our country are fortunate enough to be members of loving families. For too many young pregnant women, parental involvement in this most intimate decision threatens harm, rather than promises comfort. The Court's selective blindness to this stark social reality is bewildering and distressing. Lacking the protection that young people typically find in their intimate family associations, these minors are desperately in need of constitutional protection. The sexually or physically abused minor may indeed be "lonely or even terrified," not of the abortion procedure, but of an abusive family member. The Court's placid reference to the "compassionate and mature" advice the minor will receive from within the family must seem an unbelievable and cruel irony to those children trapped in violent families.⁸³

I believe that this is an accurate statement of the situation of some minors seeking abortion. Even though many may have supportive parents, it is unreasonable for the court to assume that all parents will unselfishly put their child's interests first. In contrast, however, is the dissent from *Cruzan*, decided on the same day:

The majority justifies its position by arguing that, while close family members may have a strong feeling about the question, "there is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been had she been confronted with the prospect of her situation while competent." I cannot quarrel with this observation. But it leads only to another question: Is there any reason to suppose that a State is more likely to make the choice that the patient would have made than someone who knew the patient intimately? To ask this is to answer it. As the New Jersey Supreme Court observed: "Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but also because of their special bonds with him or her. . . . It is . . . they who treat the patient as a person, rather than a symbol of a cause." The State, in contrast, is a stranger to the patient.⁸⁴

If this romantic picture of the family were transposed to the *Akron* decision, it would be a persuasive argument for the state's right to require parental notification, if not parental consent. I believe that the dissent in *Akron* is correct, but I do not believe that bioethicists and liberal supreme court justices can have it both ways. While some scholars attempt to distinguish *Akron* from *Cruzan* by stressing that Nancy Cruzan was

82. *Ohio v Akron Cntr. for Reprod. Health*, 497 U.S. 502 (1990).

83. *Akron*, 110 S. Ct. at 2991-92 (citations omitted).

84. *Cruzan*, 110 S. Ct. at 2877.

incompetent, this seems irrelevant to the question of family good will and motivation.⁸⁵

VII. The Economics of Death

As a teacher of medical law, I find my students least objective about the financial aspects of medical care delivery. Even when they believe that physicians are motivated only by money, they are unwilling to accept the logical consequences of that assumption. So it is with the right-to-die controversy. First, it is important to remember that the vast majority of right-to-die decisions involve persons over sixty-five who are covered by Medicare. Young persons in persistent vegetative states are so rare as to have a de minimus impact on the medical system.

In simple terms, prior to 1983 physicians and hospitals made money by keeping patients alive. The more machines the patient was connected to, the more tests that were ordered, the more days that patient was in the hospital, the more money the government paid the physicians and the hospital. Putting aside the very real emotional concerns about physicians being unwilling to face death, about the technological imperative and all the other psychological games associated with pulling the plug on patients, it was extremely profitable to keep patients around.

In 1983 the game changed. Medicare instituted a prospective payment system based on diagnosis related groups (DRGs). Under DRGs, the government pays hospitals a fixed amount for each patient, based on that patient's diagnosis. For example, the government might pay the hospital \$10,000 to care for a patient with pneumonia. The hospital would receive the same amount of money, irrespective of the patient's hospital course. If the patient had a simple, uncomplicated recovery, he or she might be discharged in a few days, with a net profit to the hospital. On the other hand, if the patient developed severe complications and was in the hospital for 3 weeks, the hospital would still receive only \$10,000. In this case, the hospital would lose money.

DRGs turned medical finance on its head.⁸⁶ Suddenly physicians who had been the darlings of the hospital because of their lengthy hospitalizations and profligate ordering of tests became menaces to the hospital's bottom line.⁸⁷ Physicians were suddenly under pressure to provide less care and to get the patients out of the hospital faster.⁸⁸ It was not lost on hospital administrators that if a patient refuses care and dies on day

85. What if the state allowed the parents of an incompetent pregnant minor (perhaps injured in an auto accident) to decide whether the minor could be aborted while she slept?

86. K.E. Powerly & E. Smith, *The Impact of DRGs on Health Care Workers and their Clients*, 19 HASTINGS CENTER REP. 16 (1989).

87. It comes as a shock to many law students that hospitals maintain elaborate records of the profitability of each physician on their medical staffs.

88. The current law assigns the liability for premature discharge to the physician. Irrespective of the hospital's threats, which can include termination of medical staff privileges, the physician cannot plead duress in a medical malpractice lawsuit based on a premature discharge. See Wickline v. California, 228 Cal. Rptr. 661 (2nd Dist. 1986). See also Thomas H. Boyd, *Cost Containment and the Physician's Fiduciary Duty to the Patient*, 39 DEPAUL L. REV. 131 (1989).

two, the hospital makes even more money than if the patient has a quick recovery.

In my work with legal issues in critical care medicine, most of the physicians I encounter are faced with pressures to deny appropriate care much more frequently than they see disputes on the right-to-die. I find it interesting that there has been almost no discussion in the ethics literature of the benefit to the government and other insurers in frightening the elderly and the infirm into refusing care.⁸⁹ Many who criticize physicians as too ready to compromise their patients' interests for money seem ready to assume that this motivation somehow does not apply to right-to-die decisions.

VIII. CONCLUSIONS

In his epilogue, Professor Rothman asks whether bioethics is unduly focused on the rights of individuals, without proper concern for the good of society in general. While a defender of individual rights, Professor Rothman points out that they do have a cost.

I propose that, on balance, patients' real gains from the involvement of outsiders in medical decision-making have been more than offset by the losses in autonomy due to managed care and other changes in medical care finance. Moreover, outsiders have exacerbated this loss of patient autonomy by decrying the motives and sincerity of those physicians who have tried to act as advocates for their patients' rights.

Ethicists and lawyers must be more sensitive to the unintended consequences of their rules. This is especially important as private health insurers and the government attempt to reduce the cost of medical care. It is much more important to protect the rights of all patients to quality care than to focus on horrible facts that have little significance in routine medical practice.

89. For a refreshingly contrary view, see Nat Hentoff, *Deciding Who Dies*, THE WASHINGTON POST, Oct. 26, 1991, at A21; Nat Hentoff, *When a Hospital Goes to Court to End a Life*, THE WASHINGTON POST, Sept. 28, 1991, at A27; Nat Hentoff, *Who Really Won the Cruzan Decision?*, THE WASHINGTON POST, July 14, 1990, at A19; Nat Hentoff, *The Quality of Life — and Death*, THE WASHINGTON POST, March 17, 1990, at A29; Nat Hentoff, *Two Cheers for the ACLU*, THE WASHINGTON POST, March 3, 1990, at A25; Nat Hentoff, *Right to Die? Isn't It Really About the Right to Live?*, THE WASHINGTON POST, Nov. 25, 1989, at A23; Nat Hentoff, *Not a 'Hopeless Case' After All*, THE WASHINGTON POST, April 29, 1989, at A25; Nat Hentoff, *Let Her Die? Or Make Her Die?*, THE WASHINGTON POST, Dec. 31, 1988, at A19; Nat Hentoff, *Euthanasia: Another Warning From the Surgeon General*, THE WASHINGTON POST, April 11, 1987, at A21.