1991

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Dena S. Davis
Cleveland State University, d.davis@csuohio.edu

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Original Citation
SLIM JUST LEFT TOWN: DECISIONMAKING ON AN INTENSIVE CARE UNIT

Dena S. Davis*

The title of this paper comes from an incident that occurred while I was participating in morning rounds on the pediatric and surgical intensive care unit of a large, midwest tertiary care center. The patient under discussion was an eight-week-old girl who had been born without kidneys, and who had been cared for on the unit for seven weeks. In the previous week, the baby's condition had gone steadily downhill, as she experienced one medical catastrophe after another. One of the nurses asked the staff doctor who was leading rounds that morning, "What are the baby's chances?" The physician replied, "Her chances are slim." To which one of the young residents immediately answered, "Slim just left town."

This essay will analyze the process of making health care decisions when patients' chances are slim. I look at recent legal tools that purport to enhance patients' control over their own care, and conclude that they are rarely efficacious. Because all medical decisions are based on prognosis, and because prognosis is ineluctably subjective, the doctor retains almost total control of the decisionmaking process.

I. Responses to the Problem of Overtreatment

A great deal of energy in medicine, law, and ethics has been devoted to the choices that face us when "Slim leaves town." Before World War II, there were fewer dilemmas because medicine had fewer interventions to offer. After the war, as the "wonders of modern medicine" exploded into a society ill-prepared to deal with the resulting social ramifications, the paradigmatic dilemma involved allocating a scarce medical resource among a competing number of needy patients.

* Assistant Professor of Law, Cleveland-Marshall College of Law. I am grateful for the support of the Cleveland Clinic Foundation, where I was a Fellow in Bioethics in 1989. Rebecca Dresser, James Orlowski, and Jacquelyn Slomka were generous and patient in answering questions and reading drafts; their contributions did much to strengthen this essay.
Perhaps the classic example of an allocation dilemma is that of kidney dialysis: when it first became possible, there were many more candidates than machines. Hospitals had the hard task of deciding which candidates would be accepted; ethicists had a field day discussing their decisions. Today the dilemma of scarcity remains with us, but it has been joined by an equally thorny problem: a culture of medicine that does not know when to stop. Now that dialysis machines are ubiquitous, the problem is not the patient who needs treatment and cannot get it, but the patient who cannot benefit from treatment and gets it anyway.

Overtreatment that merely serves to extend the dying process is an ethical problem from three perspectives. The principle of beneficence is abrogated when a patient is subjected to burdensome procedures that have scant hope of a good outcome. The principle of distributive justice is at issue when scarce and expensive resources are spent upon patients whom these resources are unlikely to help. The principle of respect for autonomy is threatened when patients become the objects of medical care that they or their agents have attempted to reject (or when patients and their agents have been left out of the decisionmaking process altogether).

At least since the Quinlan case, the problem of overtreatment has increasingly become a focus of legal attention. Patients, their agents, and hospital administrators have faced off in court over the issue of withdrawing unwanted treatment. Groups such as the Hemlock Society and the Society for the Right to Die have been organized, offering support for those who wish to retain control over the manner of their dying. In a recent case in Chicago, the father of a young boy who had been kept alive in a comatose state for eight months after a tragic accident, marched into the hospital room, kept medical personnel at bay with a gun, and unplugged his son from his life support systems. A grand jury refused to indict.2

One tenet on which all observers agree is that courts are not the best arena for deciding these cases. Perhaps society needs paradigmatic cases like Quinlan to create landmarks; the large number of these cases, however, and the necessity to decide them quickly, require that they normally be resolved between the doctor, patient, and family, without constant resort to the courts.

The responses to the problem of overtreatment constitute a patchwork of policy, legislation, and case law. Three approaches that attempt to deal with the problem proactively are: various forms of advance directives or so-called “Living Wills,” durable powers of attorney, and hospitals’ do not resuscitate (DNR) policies. In one way or another, supporters of each of these approaches claim that these approaches will empower patients and their agents to regain control over life-and-death decisions.

“Living Wills,” in which a person makes a statement about when he or she would want certain kinds of treatment withdrawn, have captured the imagination of many people. “Dear Abby” reports tens of thousands of requests for living wills each time she deals with the subject. The New York group, Concern for Dying, has distributed millions of them. In 1976, California became the first state to recognize statutorily the existence of such documents in its “Natural Death Act”; many states have followed suit. But California’s experience suggests that these documents are more helpful in sparking discussion between family members and physicians than in actually directing withdrawal of specific treatment. Even when the document is signed (or updated) after the person received a terminal diagnosis, the document cannot help but remain vague. Thus, living wills have been criticized as returning too much discretion to the physician. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research agreed with this assessment, noting that a decision not to follow an advanced directive may sometimes be justified even when it would not be acceptable to disregard a competent patient’s contemporaneous choice. Such a decision would most often rest on a finding that the patient did not adequately envision and consider the particular situation within which the actual medical decision must be made.

For this reason, the Commission concluded that “[d]urable powers of

3. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment 140 (1983) [hereinafter Deciding to Forego Life-Sustaining Treatment].
4. Id. at 139.
5. Id. at 137.
6. Id. at 145 & n.73.
8. Deciding to Forego Life-Sustaining Treatment, supra note 3, at 137.
attorney are preferable to 'living wills' since they are more generally applicable and provide a better vehicle for patients to exercise self-determination, though experience with both is limited."

In a durable power of attorney, a person designates an agent (often, but not necessarily, a family member), who is legally empowered to act for her. The advantages over a "living will" are obvious: the agent is "on the spot," making contemporaneous decisions, able to modify those decisions as new medical information becomes available.

Reacting to a legal and social climate in which end-of-life decisions have moved into the spotlight, many hospitals have enacted in-house DNR policies. Until recently, physicians were often reluctant to enter an explicit "no-code" order on a patient's chart; instead, they resorted to a system of colored dots decipherable only by hospital staff, or to verbal instructions to nurses to "walk slowly" if a certain patient was in arrest. Even worse was the designation of "show code," in which a sham attempt at resuscitation was conducted for the benefit of the family. But as courts have upheld the appropriateness of withholding cardiopulmonary resuscitation (CPR) from some patients, physicians have grown more comfortable with entering a "no-code" on a chart. Unfortunately, recent studies have shown that patients and families are often not consulted or told that a no-code order has been entered. For example, a 1985 study found that of seventy-one patients who were designated DNR, written justification was given for only forty-one. In only fifteen per cent the of cases were patient wishes given as a reason for DNR.

II. CASE STUDIES OF HOSPITAL DECISIONMAKING

These approaches are largely cosmetic. Patients and their families, sometimes even doctors, nurses, and hospital ethicists, may believe that these tools restore decisionmaking to the patient, but in fact they

9. Id. at 5.
10. The term "durable" refers to the fact that the usual power of attorney is for a discrete transaction such as selling a house and ceases automatically if the principal becomes incapacitated. See G. Alexander, Writing a Living Will 49-50 (1988).
11. Emergency "codes" define the procedures followed by hospital personnel under various circumstances. "Code Blue," for example, might signal that a patient had stopped breathing, allowing immediate response by hospital staff without alarming other patients and visitors.
14. Id.
merely constitute a new set of rituals, token sacrifices at the paper altar of patient autonomy. Power remains firmly in the hands of the physician, although the physician herself may be so mesmerized by chanting the mantra of “informed consent” that she fails to realize this.

To illustrate my argument, let me present the following four true cases (with names and identifiers changed), based on my experience as a Fellow in Bioethics in a large, tertiary care center.

A. Anthony Cooper

Mr. Cooper was a seventy-three-year-old white male, who had spent five weeks in the intensive care unit (ICU) following cardiac surgery. His problems included “cold leg,” (implying some circulatory failure) and decreasing liver, kidney, and respiratory function. He had not been conscious for some time. The staff physician in charge of the ICU wrote the following note in Mr. Cooper’s chart:

Long discussion with patient’s wife and son. They were very explicit that, based on patient’s statement and attitudes in the past, he would not want to be maintained in this condition. They ask we withdraw all active therapy, and just keep him comfortable. Although this is earlier in the course of a fatal illness than we would normally take these measures, I think we should agree with their wishes based on the ethical principle of autonomy. Statistically, there is very little chance of recovery from respiratory, hepatic, and renal failure after five weeks in an ICU.

The following day, the physician ordered that Mr. Cooper be taken off TPN (total parenteral nutrition, delivered through an intravenous line). Although the patient continued to be intubated and on a respirator, the machine was turned to room air; no extra oxygen was provided. Mr. Cooper died peacefully the next day.

B. Nikki Galvanis

Nikki was a six-week-old Greek child from a family of recent immigrants. Only his father spoke English with any fluency. Nikki had been born in a community hospital, where he had initially been healthy, but he began to have severe seizures on his third day of life. Medical management of these seizures was unsuccessful. After four weeks during which there was no improvement, the baby was transferred to a tertiary care center for a magnetic resonance imaging
Three days after his transfer, he was intubated and placed on a ventilator. He had a poor sucking reflex, and was receiving nutrition and hydration by means of a nasogastric tube.

A meeting of the hospital ethics committee was called because Nikki’s parents had indicated that they did not want to continue aggressive treatment if there was no chance that their son would ever breathe on his own. At the community hospital where Nikki had been born there had been an understanding between the family and the staff that if there were no hope of the baby’s recovery, they would take the baby home and keep him comfortable for his remaining days. His transfer to the tertiary care center, accompanied by a number of communication gaps between the two hospitals and exacerbated by the family’s poor grasp of English, had resulted in an aggressive level of care for Nikki that the parents had never wanted.

In the opinion of Nikki’s primary physician, a pediatric neurologist, Nikki was suffering from a rare disorder known as myoclonic encephalopathy. All the babies cited in the medical literature concerning this disorder had died before their first birthday, most considerably sooner. The physician explained that his confidence in this diagnosis was only about ninety-five percent sure, but that his prognosis of death in infancy was completely certain.

Nikki’s parents were invited in. They explained, through the father and a translator, that they wanted their baby to live, but not “if he can’t breathe on his own.” The committee, without dissent, agreed that there was strong ethical support to remove Nikki from his various tubes and lines so that his mother could hold him without impediment. The family understood that Nikki might die immediately, or that he might be able to go home with them and survive for weeks or even months. The next day, the hospital chaplain’s office found a Greek priest who came in and prayed with the family in Nikki’s room. A resident removed Nikki’s respiratory tube and placed the baby in his mother’s lap. Nikki died immediately.

C. Deborah Cook

Deborah arrived at the tertiary care center at one week of age. At the community hospital where she was born, she had been diagnosed as having no kidneys. The cause was unknown. She vomited anything she

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15. MRI scans generate medically diagnostic images, similar in nature to a CAT scan, but using magnetic fields rather than X-rays. TABER’S CYCLOPEDIC MEDICAL DICTIONARY 1226 (16th ed. 1989).
ate or drank, and it was assumed that she had some kind of intestinal blockage. She also could not breathe without the aid of a ventilator. When the community hospital first called the tertiary care center, seeking to transfer the baby to the care of its pediatric nephrologist, the latter responded that he would not take the baby if she were not breathing on her own; he did not think that the odds justified trying to treat a newborn with failure of two systems. The community hospital managed to extubate Deborah, who breathed independently for a few days, allowing the nephrologist to accept her for admission. Deborah was then intubated “temporarily” for a minor procedure, but all subsequent efforts to wean her from the ventilator proved futile.

Deborah’s entrance into the unit was heralded with tension and conflict; many of the personnel—staff, residents, and nurses—felt that this was a futile endeavor that would only cause suffering for everyone. There were frequent emotional references to another newborn who had been on the unit for nearly a year before finally dying, a traumatic experience no one wished to repeat. Senior staff physicians felt discouraged and frustrated at Deborah’s lack of progress, but were unwilling to challenge the optimism of the primary physician. Nurses were angry at the senior staff for not “standing up” to the primary physician. There was much disagreement, never fully aired, about the adequacy of the measures taken to control the baby’s pain.

Deborah’s primary nurse called a “team consult” after two weeks, ostensibly as a routine move with a long-term patient but, in fact, to try to resolve some of these conflicts. At the meeting, the pediatric nephrologist reiterated his plan for Deborah: to continue to dialyze by means of continuous peritoneal dialysis (CPD); to support nutritionally through TPN; and to try to wean her from the ventilator, all in the hope of achieving a weight of ten pounds, the minimum at which a kidney transplant could be contemplated. Based on the experience of two medical centers with a total of twenty babies, he estimated her chances of getting to transplant at seventy percent, and her chances of a successful transplant at eighty percent. Despite the fact that nurses, residents, and senior staff had been muttering that these were wildly optimistic projections, no one challenged the nephrologist.

The social worker and Deborah’s primary nurse reported on the family situation. Deborah’s mother had two children by a previous...
marriage; her father was a salesman and out-of-town for long periods. They were committed to Deborah, came to visit as often as their difficult circumstances allowed, and were thinking ahead to the rigors involved in doing CPD at home. The family was described as living from crisis to crisis but managing always to survive. Their attitude toward Deborah was that as long as there was hope, they wanted everything done.

During the two long months of Deborah's life, the family's attitude was consistently presented as the main ethical defense for continuing treatment. When I spoke privately with the pediatric nephrologist, he related that when he had first examined Deborah, he had explained to the parents that the choice whether or not to treat aggressively was theirs, that he would be very supportive if they decided to move the baby to a regular nursing floor and give her comfort measures until she died. During rounds, as nurses and others asked, "Why are we doing this?" the answer was always, "The parents want to treat."

Eventually, Deborah's problems overwhelmed her. She developed a strangulated hernia. Abdominal surgery made it impossible to continue with CPD; dialysis was achieved temporarily with slow continuous ultra-filtration (SCUF). It was at this point that the resident observed that "Slim just left town," because it was highly unlikely that Deborah could survive on SCUF until her abdominal difficulties cleared up enough to reinstitute CPD. Meanwhile, her respiratory and nutritional capabilities were declining rapidly. Her parents were consulted and agreed to make Deborah DNR, meaning simply that no chest compression would be done if she were to undergo cardiac arrest; all other treatment measures remained in place. Nine days after the abdominal surgery, Deborah died.

D. Esther Stephens

Ms. Stephens was a twenty-six-year-old woman who had an aneurysm burst in her brain two weeks after delivering her second child. After six weeks on the neurological intensive care unit, Ms. Stephens remained in a coma, unresponsive to her surroundings, incapable of purposeful movement. She was breathing on her own, but had a fever that was tentatively diagnosed as a staphylococcal infection. Her husband reported that in the course of their six-year marriage, his wife had often expressed the wish never to live in less than a fully cognitive state. In fact, a few years earlier a close friend had suffered a ruptured aneurysm after giving birth, and throughout the course of the friend's
illness and eventual death, Ms. Stephens had repeatedly exhorted her husband never to let her remain alive in such a condition.

An ethics consultation was suggested by Ms. Black, the nurse who worked with Ms. Stephens's primary physician, a neurologist named Dr. Lopez. Ms. Black, Ms. Stephens's social worker, and various other nurses had unofficially confided to staff ethicists that Dr. Lopez "never gives up," and never admits to a bleak prognosis. The social worker was concerned because Mr. Stephens was becoming angry and frustrated that his wife was being treated in a way that went against her expressed wishes. He repeatedly said that Esther would not want to live if she were to remain in a nursing home.

Mr. Stephens, Ms. Black, the social worker, and three ethicists were present at the ethics consultation. Dr. Lopez was not there, but sent a resident in his stead. The resident reiterated Dr. Lopez's position: "Until Esther's fever is resolved, it is imperative to continue to treat aggressively." Mr. Stephens tried to elicit a clearer prognosis, but to no avail. One ethicist tried to push the resident to consider what options would be available once the fever resolved, privately thinking that if Esther's alternatives were death from infection or life in a nursing home, Mr. Stephens's only chance to carry out her wishes might be to insist that antibiotics be withdrawn. The resident refused to foreclose the possibility of a future in which Ms. Stephens returned home a functioning person. The nurse and social worker, who had been vocal in their concern privately, remained silent.

The meeting ended with Mr. Stephens's expressed acceptance of continued treatment, based on the open prognosis, and with the understanding that there would be another consultation in a few weeks, when the fever resolved. The second consultation never took place. With the resolution of her fever, Esther's condition did not improve, but she was no longer in danger of dying. She was sent to a regular nursing floor, and at this writing plans are being made to send her to a rehabilitation facility with a coma stimulation program.

III. THE ELEMENTS OF PROGNOSIS

The reason power remains with the physician is that all of these approaches are, and in the nature of things must be, dependent on the medical prognosis. Very few people have an aversion to a particular medical intervention in and of itself. Most people will agree to almost any procedure if there is a good enough chance of a positive outcome. Depending on particular values and "risk budget," one person may de-
cide on surgery if there is even a remote possibility of success while requiring a much greater chance to undergo the rigors of chemotherapy. Likewise, people differ markedly in what they consider a “successful outcome” or an acceptable quality of life. But most people are “balancers”; few are like Jehovah’s Witnesses, prepared to say that a specific medical treatment is always unacceptable in any context.

The wording of the three methods for addressing the problem of overtreatment discussed in this Article all indicate a dependence on medical prognosis. Thus, the typical living will begins “If there is no reasonable chance of my recovery . . . .” A hospital policy statement on DNR orders entitled, “A Statement of Policy on Care of the Hopelessly Ill,” explains, “Hopelessly ill patients have an irreversible disease where death will be the outcome.” Where the patient has executed a durable power of attorney, the designated agent must make decisions based on risk/benefit analyses in which the patient’s prognosis is probably the most important factor.

If arriving at a prognosis were a mechanical exercise in which all the relevant factors were fed into a computer that responded with a single numerical projection with which everyone agreed, there would not be a problem. Unfortunately, the ambiguities of prognosis are myriad.

(1) Each person presents a unique combination of strengths and weaknesses. An allergy to an important drug may complicate an otherwise bright prognosis; a strong heart may pull one patient through an episode of kidney failure that would be fatal to most.

(2) Two physicians, depending on personal experience, knowledge, and personality, could interpret the same data in two different ways, or at least with different nuances.

(3) With new forms of therapy, for example organ transplants, much may depend on the institution. One transplant center may have a success rate of sixty percent, while another has a rate of seventy percent (but perhaps the first institution takes riskier cases).

(4) With very new therapies the data base may be extremely small, or survivors may not yet have lived long enough to give much information about long-range outcomes. There are, in addition, many factors related to outcome that we do not understand.

17. See supra notes 3-14 and accompanying text.
In addition to these relatively "objective" problems with prognosis, there are a number of "subjective" problems as well:

(5) The primary physician is performing a number of different functions simultaneously. She is (ideally) the patient's ally and supporter, sensitive to the patient's need for hope and reassurance, but she must also be the hard-headed scientist who can present the diagnosis and prognosis in an unbiased way. She needs to engender patient confidence in her abilities, but also must admit to doubt. She needs to be encouraging, but also honest. In their theoretical study of prognosis in medicine, Hilden and Habbema point out that "there are sometimes rational or semi-rational grounds for the doctor to withhold some information or understate the uncertainty" but that this conflicts with the goal of allowing the patient to assess the merits of each treatment. To allow the patient to make such an assessment, "the doctor would have to explain carefully and honestly each action-specific prognosis and ask the patient to imagine the decisions he would make if that particular action were taken."\(^\text{20}\)

(6) Physicians tend to be extremely uncomfortable sharing their uncertainty with patients, so much so that they can deceive themselves about their own level of certainty. Hilden and Habbema list this problem as one of the sources of "tension and distrust" between doctors and patients:

The public tends to think that the medical profession can make much more precise predictions than is actually the case; so do, by the way, the doctors themselves. To preserve the image of the profession, and in view of the undesirability of uncertainty as such . . . , the clinician may be inclined to understate the amount of prognostic uncertainty, and perhaps sometimes justifiably so.\(^\text{21}\)

Jay Katz, in his poignantly titled book, *The Silent World of Doctor and Patient*,\(^\text{22}\) asks why principles of medical ethics have never urged doctors to share decisionmaking with patients. "We need to inquire why physicians have been so insistent in their demand that all authority be vested in one party—the doctor."\(^\text{23}\) He finds part of the answer in

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21. Id. at 358.
23. Id. at xvii.
physicians' discomfort with uncertainty:

One important reason for this insistence is physicians' unfamiliarity with and embarrassment over conversing with patients about medical ignorance and uncertainties that can so decisively affect choice of treatment. This problem has become more acute during this century, due to physicians' increased capacities to distinguish knowledge from ignorance and uncertainty. Revelation of such uncertainties is difficult and disquieting. Learning to live more comfortably with uncertainty, however, has also been impeded by other strongly held, although largely unexamined, professional beliefs, that patients are unable to tolerate awareness of uncertainty, and that faith in professionals and their prescriptions makes a significant contribution to the optimal treatment of disease.\(^{24}\)

In contrast, philosopher/physician Eric Cassell states that "the hallmark of physicians is their ability to tolerate uncertainty,"\(^{25}\) and points out that uncertainty in medicine arises from two "unresolvable" sources:

The first is that all medical actions are about the future and the future is ineluctably unknowable. The other fundamentally important source of uncertainty is that all systematic knowledge is generalized to one degree or another and every decision is about a particular patient. There will always be uncertainty about the applicability of general knowledge to a patient—it cannot be otherwise. . . . In medicine as in clinical ethics a basic tension exists. Withdrawal from the patient is rewarded with certainty and punished by insufficient knowledge, the move towards the patient is rewarded with knowledge and punished with uncertainties. The fact remains, however, that to disengage from the patient is to lose the ultimate source of knowledge in medicine.\(^{26}\)

One argument physicians make for not sharing their uncertainty with patients is that medical authority has a powerful placebo effect, what Cassell calls "the healing property of confidence."\(^{27}\) This is an

\(^{24}\) Id.


\(^{26}\) Id.

\(^{27}\) Id.
important point, because it is clear that there is a placebo effect on human physiology; in other words, the old assumption that because a sugar pill worked the condition was “all in the patient's head,” is unfounded. Katz muses:

If physicians themselves are the placebos, then they are powerful therapeutic agents in their own right. . . . Deep in patients’ unconscious, physicians are viewed as miracle workers, patterned after the fantasied all-caring parents of infancy. Medicine, after all, was born in magic and religion, and the doctor-priest-magician-parent unity that persists in patients’ unconscious cannot be broken. The placebo effect therefore attests to the power of the unconscious. Yet, patients are defined by their consciousness as well. On a conscious level, patients are aware of the limitations of medicine and physicians. They have learned of these limitations from personal suffering, from illnesses and deaths of loved ones. Patients know that miracles are only occasionally the lot of mankind. They may hope for miracles, but they are also resigned to the reality of their rarity.28

Katz acknowledges that “expressions of hope and reassurance” augment the placebo effect, but he is unwilling to jettison the principles of truth-telling and patient autonomy. He expresses the hope that acknowledgement of limitations does not necessarily diminish the placebo effect, because it is possible to admit to uncertainty and still convey a message of hope and reassurance. Katz hopes that by demonstrating honesty, physicians will prove their trustworthiness in ways that will increase the placebo effect, not diminish it. He further argues that deception on the part of the physician inevitably leads to a generalized lack of communication between doctor and patient, “for the withholding of crucial information compromises intimacy, and physicians and patients can engage only in arm’s-length transactions.”29

(7) Even in cases where the medical facts are clear and the prognosis relatively certain, there can be enormous ambiguity about what the prognosis means. In Katz’s book, the doctor who hesitates to perform a radical mastectomy on “Iphigenia” is reluctant because she is “young and attractive.”30 Why does he assume that in an older or ug-

29. Id. at 193.
30. Id. at 90-93.
lier woman, the radical surgery would be less unwelcome? To the doctor, a diagnosis of diabetes may carry a prognosis that can be expressed in scientific terms; to the patient, what is paramount may be fears about sexual functioning and independence. The question, “But will my spouse still want to make love to me?” is also a request for prognosis, but one no doctor can answer.31

(8) The way people react to probability is often irrational, as evidenced by the number of people who do not bother to use seatbelts, or teenagers who have unprotected intercourse and are then astonished to discover that they have become pregnant. An encounter with a single “living statistic” can often seem much more meaningful than a host of numbers; candidates for cardiac transplant whom I have interviewed have usually been more influenced by the one or two healthy survivors they have spoken with than by the official seventy-percent success rate. Almost every medical geneticist has a story about a couple who, after extensive education about the one-in-four risk of having a child with a particular recessive trait, will then volunteer, “Well, the risks are fifty/fifty; either the child has the trait or it doesn’t.” In the recent Pennsylvania lottery people spent thousands of dollars and drove across the country to buy tickets at odds of 9.6 million to 1.32

(9) Taking into account just these factors (and there are many more, for example in cross-cultural contexts)33 it is apparent that “the prognosis” presented by the physician is in fact the result of a choice, conscious or otherwise, to present a certain picture to a certain patient. The same patient might elicit a very different prognosis from another doctor. Even the doctor who strives to present the most objective pic-

31. I am indebted to David Barnard for some of these insights.
32. USA Today, Apr. 26, 1989, at 1A.
33. Notions of etiology and cure of disease (and even of what constitutes a disease) vary widely across cultures. In many ethnic groups in North America, beliefs about illness and healing can be very different from those of mainstream medicine. When health care personnel are not aware of these differences, they “may be unable to respond appropriately to the personal needs of patients for information, reassurance, and effective treatment.” Harwood, Introduction to Ethnicity and Medical Care 1 (A. Harwood ed. 1981). Different concepts of disease affect evaluation of symptoms, utilization of “alternative” practitioners and “folk” remedies, and compliance with mainstream treatment regimens. Id. at 9. Among the Navajo, for example, modern medicine is used as a way to alleviate symptoms. To actually cure the disease, the patient turns to the traditional healing ceremonies. Thus, “Anglo” treatments that give quick relief, such as stitching wounds or setting bones, are easily accepted, but diagnostic procedures and surgery are often resisted. Kunitz & Levy, Navajos, in Ethnicity and Medical Care, supra pp. 337, 382.

In many developing countries, moreover, the germ theory of disease is not accepted, “particularly among the not-so-educated members of the population.” Ekunwe & Kessell, Informed Consent in the Developing World, 14 Hastings Center Rep., June 1984, at 22, 23.
ture possible, allowing the patient to fill in the subjective shadings himself, is forced to use words like "pain" and "fatigue," which resist quantification. Furthermore, doctors differ radically in such characteristics as pessimism and optimism, risk aversion, and sensitivity to pain. Therefore, a patient (or a patient's agent) who is trying to decide whether the time has come to deescalate therapy, ask for a DNR order, or try an experimental treatment, is so dependent on the doctor's subjective presentation of the prognosis, that a decision that appears to be the patient's is in reality dictated almost totally by the doctor's presentation.

IV. HOW PROGNOSIS AFFECTS PATIENTS' DECISIONS

It is possible to shuffle the small deck of cases discussed above in a number of ways. In two cases, the goal of a "dignified death" was achieved. In all cases, the appropriate decisionmakers were identified and their wishes followed. It is notable that two of the cases involved an ethics committee or its consult team. The language of the note in Mr. Cooper's chart, referring to the "principle of autonomy," shows the sophistication of the physician about ethical concepts. In short, these decisions appear to be made in an environment where there is a high level of awareness of biomedical ethics, and in which informed consent is a reality.

But if we shift our angle of perspective, it becomes clear that every one of these cases was decided by one person: the primary physician. Patients or their surrogates appear to be making the decisions, surrounded by the impressive trappings of ethics committees and the like, but in fact they are making the decisions that the physician directs by the manner in which she conveys the prognosis. As long as Dr. Lopez refuses to "give up hope" for Esther Stephens, her husband will be effectively blocked from carrying out her wishes by demanding an end to treatment. The process looks respectful of the Stephens's rights, but only because a face-off has been sidestepped.

Mr. Cooper's wishes, as relayed by his wife, were respected because the physician had decided that the prognosis was so poor that survival was extremely unlikely. It is true that had Mrs. Cooper con-
veyed her husband’s wishes for more aggressive treatment, the physician would have complied (up to a point). Likewise, had Nikki’s parents wished, he would have been given full respiratory and nutritional support until his death (Nikki’s doctor remarked privately later that that is what he would have done had Nikki been his child). The parents were allowed to make the choice because the doctor had determined that Nikki’s prognosis was dismal. What if the pediatric neurologist had been a more “optimistic” personality, more like Dr. Lopez? What if he had thought to himself, I am only ninety-five percent certain that Nikki has myoclonic encephalopathy, and if he does have some other disease there is always the outside chance that he will survive, so he had told the parents that “there is always hope, we mustn’t give up”?

The clearest example of the overwhelming power of the primary physician is in the case of Deborah Cook. At every juncture, treatment was justified verbally by the fact that the parents wanted to “go for it.” When I spoke with the primary physician, I asked him if he had shared with the Cooks the fact that his optimism was definitely a minority opinion. He had not done so. The nurses and doctors on the ICU had also not expressed their discomfort to the Cooks, although they saw them almost daily. When I asked why, I was told that it was wrong to give the family “mixed messages.” To this observer, it was clear that Deborah and her parents were on an express train driven by the primary physician alone.

In today’s sophisticated ethical climate, it is no longer acceptable to justify end-of-life choices because the doctor made them and “doctor knows best.” Today we want to know that the person’s own values have been respected; if the patient is incapable of making those values known, we want to know that an appropriate surrogate has spoken for him. The nephrologist’s statement to the parents that a decision not to treat would be respected, shows a sensitivity to the current climate. But by telling them only his optimistic prognosis, and not telling them of his colleagues’ concerns, he made the decision for them as surely as if he had brushed them aside in the first place.

Looking at these cases further, it is clear that neither advance directives nor durable powers of attorney would have changed the course of events, even in the two cases involving adults. In the case of Esther

38. See supra Part II(B).
39. See supra Part II(C).
Stephens, her explicit statements to her husband were as clear as a written advance directive; imagine further that the Stephenses had taken the precaution of executing a durable power of attorney for Esther, with her husband as attorney-in-fact. And posit as well that the state in which this took place had passed legislation giving legal status to advance directives and durable powers of attorney for health care. Would Ms. Stephens's case have turned out any differently? No. Mr. Stephens, trying to fulfill his responsibilities to his wife, would have pressed to discontinue treatment if there were no reasonable chance of recovery. Dr. Lopez would have continued to hold out hope that recovery was possible, thereby sidestepping an open confrontation. The ambiguity of the word "recovery" in this context would have contributed to Mr. Stephens's frustration, as Dr. Lopez would have refused to be pinned down to an explicit description of what Esther's capabilities were likely to be. The nurses, social workers, and residents would have continued to remain quiet. The result would have been the same: Ms. Stephens would have spent the rest of her life in a nursing home, the one fate that she had so clearly wished to avoid.

The role of the hospital DNR policy in these cases is actually quite small. The policy is enabling, in that it allows the physician to remove the option of CPR from a patient if the physician chooses. But the existence of a DNR policy does nothing to change the basic dynamics of the physician/patient relationship; it merely allows the physician, once she has decided that the medical prognosis warrants it, to remove an inhumane and useless treatment.

Advance directives, durable powers of attorney for health care, and DNR policies are helpful in cases where families and physicians agree that further treatment is only prolonging the dying process. These procedures can help all parties feel more comfortable with their actions when the case for withdrawal of treatment is clear. The advance directive can reassure the family later, when doubts may set in, that they were acting as the patient wanted and not out of selfish reasons (e.g., to "get it over" or to avoid expense). A durable power of attorney can help resolve some conflicts among family members, and reassure the doctor that the person who is speaking for the patient is the appropriate one to do so. A DNR policy reassures hospital staff that their actions are "normal" and "reasonable." These are important gains.

Where the doctor is "aggressive" and "optimistic," however, all the legal strategies discussed here become merely window dressing. The
doctor will give up when he or she is ready to give up, and only at that point will the patient or family have any real say. But this truth is hidden by the cosmetic effect of ethics committees, living wills, durable powers of attorney, and DNRs.

V. RECOMMENDATIONS

(1) Because the physician retains almost complete control, we must concentrate on physician education, including helping physicians to be more comfortable sharing uncertainty with patients.

(2) In other consumer areas we educate ourselves gradually, so that we are relatively experienced when we have to cope with big decisions. For example, we work up to the rigors of choosing and financing a home by making increasingly more important purchases over the course of years, beginning with our grade-school pocket money. If health care professionals took the trouble to invite patients into the decisionmaking process during routine medical events (and if clients insisted on doing so) this practice might pay off when big decisions need to be made. Clients would learn that even routine decisions are based on probabilities, and that there are hidden value choices in routine care that they may wish to consider explicitly.

(3) We must challenge the convention that only one perspective on prognosis is to be shared with the family. Granted, a family in stress does not need a dozen people pulling it in a dozen directions, but neither are people so fragile that they must always be shielded from controversy. In other areas of life, people can cope with uncertainty. Why not expand the “team approach” to prognosis, where a range of perspectives is shared with the patient and family?

(4) Hospital ethicists must encourage other health care providers (nurses, technicians, residents) to speak up, especially when there is near-consensus among them that the primary physician is being unrealistic. Ethicists can be heartened in this endeavor by the new mood of professionalism and autonomy in the nursing profession. Although working behind the scenes to encourage and empower others is probably best, there will be times when the ethics consult team or hospital ethicist must openly challenge the perspective of the primary physician and insist that the family be exposed to other views. Since Ms. Stephens and Baby Deborah were real patients, it is impossible to pre-

40. To some extent, we see this in women's health care, as women have insisted on educating themselves and on expanding the choices in areas like childbirth and breast cancer. See Annas, Breast Cancer: The Treatment of Choice, 10 Hastings Center Rep., April 1980, at 27-29.
dict with certainty what would have happened had the ethicists been able to do this, but it appears likely that the outcomes would have been better. Families would have acted in a more "informed" manner, and needless suffering might have been avoided. The legal maxim that a person has the right to decide what happens to his or her body would have been more clearly honored. If the ethicist does not bring a conflict over prognosis into the open when she knows it exists, then she becomes merely another passenger on the doctor-driven express train, one of the amenities offered by the hospital, but one which makes no real difference in the end.