

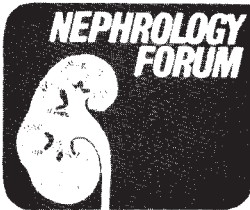
Withdrawal from dialysis: An ethical perspective

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DR. JEROME P. KASSIRER (*Associate Physician-in-Chief, New England Medical Center, Boston, Massachusetts*): We depart today in more ways than one from our usual format. Instead of presenting a patient whose findings illustrate some pathophysiologic principles relevant to the practice of nephrology, we present a patient whose behavior evoked an ethical dilemma. Instead of inviting an academic nephrologist to be the principal discussant, we have asked the patient's physician, an experienced practicing nephrologist in Atlanta, to do so. To enrich the discussion, we have enlisted two experts in medical ethics. The discussion centers around the practical, legal, and ethical problems raised by the patient who wishes to withdraw from dialysis.

Case Presentation

DR. DAVID C. LOWANCE (*Nephrologist, Atlanta, Georgia*): The patient is an unmarried 36-year-old male with congenital vesicoureteral reflux, which led to total renal failure, thus requiring the initiation of dialysis when he was 28 years old. In

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some respects he has been the ideal dialysis patient during the 6 years he has been dialysed in our unit: blood pressure, fluid balance, dietary compliance, and phosphorus regulation have been without problem. He has been a productive staff member of a national organization. Psychosocial problems and behavioral inconsistencies have been apparent, however. He has never forgiven his deceased parents for letting him develop end-stage renal disease (ESRD) by their not taking him to doctors earlier. His attitude toward dialysis personnel has been demanding. Periodically he has appeared late for dialysis, asking to receive full treatment at the expense of personnel and other patients, and on occasion he has been verbally abusive. He has received psychiatric counseling intermittently. As I said, however, he has been productive and is in very good physical condition. Approximately one year ago, he had threatened to cease dialysis but was convinced to continue. He has declined renal transplantation on the basis that it is not a perfected science. In short, he is not an atypical dialysis patient.

The current saga evolved over several days and, although the story is divided into separate segments for presentation and discussion, many of the encounters occurred simultaneously. For approximately 10 days prior to the present confrontation, the patient talked with dialysis personnel about discontinuing dialysis. Because of access problems, one dialysis was missed, and the patient was rescheduled for the following day. He did not keep the appointment. He did not answer telephone calls to his apartment and did not appear for work. His brother and sister were contacted and it was determined that the patient again was expressing a desire to discontinue dialysis. The patient's siblings were asked to talk with him. Attempts by dialysis and professional personnel to bring him to the dialysis center were unsuccessful.

The patient's sister went to his apartment, determined he was inside, and with the aid of the building manager, entered the apartment against the patient's wishes. He refused to leave and threatened legal action against his sister by himself or his estate if she again entered his apartment against his will. He expressed a desire to stop dialysis and to die.

The patient did agree to talk to people by telephone. There then began a 2-day barrage of telephone calls to the patient from friends, dialysis personnel, and family members. Six days following his last treatment, it was thought that more aggressive

action was needed because the patient showed no inclination to change his course of action. The family sought court orders to declare the patient incompetent and to allow the family to enter his apartment to meet with the patient. Several lawyers and judges advised the family that neither of these avenues was possible without legal risk to themselves. Telephone appeals to the patient continued.

The patient remained adamant. Legal counsel again advised against entering the patient's apartment. It was determined that if a lawsuit declaring the patient mentally incompetent were filed, he would be served notice to appear in court. If he did not appear in court, he probably would be declared incompetent in absentia by the judge, because only testimony relating to his alleged incompetence would be presented. The family chose this avenue and retained a lawyer.

The patient was notified by the court to appear, and he sought legal counsel, who advised the patient to appear in court. By this time, 7 days had elapsed since his last dialysis, and an emergency hearing was scheduled.

I was present when the lawyer briefed the patient. The lawyer, previously an accident victim himself, understood both physical and emotional suffering. He repeatedly advised his client not to stop dialysis but agreed to represent the patient if he chose to do so. I served as a technical advisor to the patient's lawyer. I was advised by his lawyer not to divulge specific information about the patient's condition to his siblings' counsel. I heeded that advice.

At the trial, the family's lawyer argued to have the patient declared incompetent so dialysis could be ordered and psychiatric care sought. The patient's lawyer contended that the patient was competent to make an appropriate decision and that to declare him incompetent would violate his right to self-determination.

When it appeared that the court might not declare the patient incompetent, the family (a brother) testified that the suit had been filed only to demonstrate to the patient how much he was loved, and that the family would withdraw the suit to allow the patient the freedom to make his own choice. The case was closed.

At that time the family believed that the patient would agree to one or two dialysis treatments to allow them time to talk with him. After several minutes of conversation following the trial, however, the patient restated his desire not to restart dialysis and to go home to die.

I was asked to drive him home, and after the patient parted tearfully from his family, he and I left. In the car, we talked extensively about his decision and how it would encourage other patients to make decisions for themselves. I expressed regret about his choice but acknowledged his right to make the decision.

Rather than drive the patient home, I drove him to a bus stop. By doing so I hoped to demonstrate to the patient that our system of care, although imperfect in his mind, would continue to provide for others and would be there for him if he chose to reenter the system. I informed the patient that we would be happy to reinstitute dialysis should he change his mind.

Discussion

The foregoing presentation and following discussion encompass two problems encountered frequently by the practicing

nephrologist. The first problem, that of dealing with a patient who wishes to cease dialysis, was highlighted recently by Kjellstrand [1]. Clearly, many patients choose not to live on dialysis, and we accept this decision when it appears appropriate to us. The second problem, discussed frequently as the "right of patient refusal," is more complex and contains few definitive solutions. In a more general sense, however, this aspect of the problems raised by our patient may be viewed simply as the right of a patient to choose a course of action different from that recommended or deemed appropriate by the physician. It is not in the scope of this discussion to review all the problems one encounters in dealing with such a patient. Rather, my purpose is to explore, against the background of this particular instance, how a practicing physician must influence and guide patients and families through a maze of unfamiliar technologies, uncertain outcomes, and periods of emotional turbulence. Indeed, we often are asked to deal with issues for which there are no simple answers and with issues for which the right complex answers vary among individuals. Few of us are blessed with enough time to examine prospectively the details of the motives on which each decision is made or advice given and their likely consequences. It is usually in retrospect, often while we lay awake at night, that we begin to ask ourselves why we behaved in a certain way and whether our responses were appropriate. A forum such as today's affords us the opportunity to reflect on some of the principles that direct our actions and which therefore help us identify a basic structure about which "appropriate behavior" or "ethical decision-making" take place daily.

Decision analysis is a useful clinical tool and has been popularized by many [2]. Its success is predicated on our ability to utilize experiences and facts, assign numerical values to them, and use the information in a predictive fashion to make clinical medicine cost-effective and efficient [2]. Many persons might arrive at the same conclusion by different routes, but if properly utilized, branched-chain decision-making might be considered the "straightest line" between a hypothetical point A and point B. An advantage the "craft" or "science" of medicine enjoys is that point B frequently is an agreed-upon goal; for example, a serum sodium of 140 mEq/liter is more desirable than a serum sodium of 120 mEq/liter. Quantitative decision-making and other decision aids, whether in a computer, a journal, or in the physician's mind, can help determine how the sodium concentration varied from normal and how best to return it to normal. I would like to reiterate that the one fact allowing the science of medicine to utilize this simple straightforward method of problem-solving is that the goal, "point B," is a commonly agreed-upon beneficial target point. The science of medicine also lends itself to this approach because the utility assigned to each segment in the decision process can usually be agreed upon or mathematically derived.

Contrary to the advantage that the "science" of medicine enjoys is the disadvantage with which the "art" of medicine struggles. This disadvantage is epitomized by the case we are discussing today: the patient and the physician perceived point B entirely differently. The patient perceived point B as withdrawal from dialysis, whereas the physician perceived point B as continuation of dialysis while helping the patient cope with the emotional and physical stresses associated with dialysis. Furthermore, it would be virtually impossible to assign agreed-

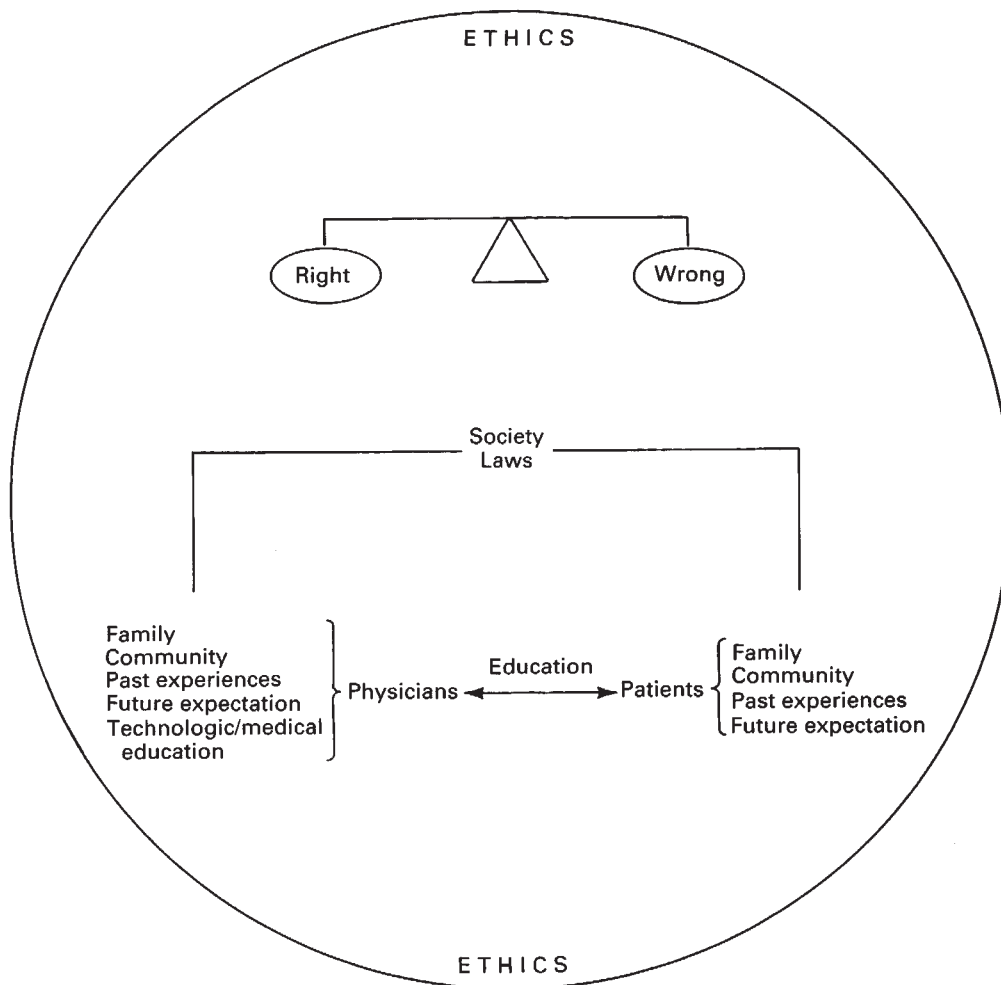


Fig. 1. Factors influencing doctor-patient decision-making.

upon numerical values to the segments in either the patient's or physician's minds that led to disparate perceptions of point B. This inability highlights the difference between a science that lends itself to quantification versus an art that deals with less-tangible feelings and emotions. These disparate perceptions have clearly defined outcomes; one is final.

In such settings, who is empowered to make the final decisions? What should the physician's role be? Again, we have no simple answers to these questions. Each of us must have a framework within which to work. The structure in Figure 1 is the one in which I perceive myself as operating daily.

Ethics can be defined as the "discipline of dealing with what is good and bad or right and wrong or dealing with moral duty and obligation" [3]. In practice, we all consider ethics as a code of behavior that underlies the manner in which we deal with one another. All of society is influenced by ethical principles that have evolved through time and that are considered appropriate. These ethical principles have produced the laws by which we govern ourselves. My own belief is that ethics is a relative science operating between two extremes, right and wrong. Consequently, one can easily understand how the moral codes of behavior vacillate between these two opposite poles. Our

ethical stance influences the laws society makes, so it is not surprising that laws change as we alter our perception of good and bad. The questions regarding our right to live, right to die, legalized abortion, passive euthanasia, and active euthanasia all reflect changing behavior and are relatively "modern" inquiries.

All the participants in the schema proposed in Figure 1 have their own interpretations of the current ethical environment, and each participant has different exposures to the same environment, according to differences in experience, education, community, and family history. Society will write laws and establish behavior codes deemed appropriate for governing itself. These laws will be influenced by our collective perception of good and bad.

As I stated earlier, my perception of what was best for my patient was the opposite of what he perceived as best. Again, we can ask, who is empowered to make the decision, and what is our obligation to the patient and to ourselves when a situation such as this arises? Obviously, different individuals will give different answers to this question, so what I say must be construed as personal opinion. On the other hand, I hope that our common social and medical milieu has influenced me

sufficiently to allow my personal opinion to lie somewhere "inside the 95% confidence bands" for opinions generated by members of our profession.

Why was the patient's perception of point B different from ours? Why couldn't we convince him of what we believed to be right? What is our obligation to such a patient? How can similar situations be avoided in the future? None of these questions has simple answers. I have no idea why we could not persuade him to our way of thinking. We certainly tried, his family tried, and his "society" tried. Despite our efforts, his interpretation of many of the environmental influences in Figure 1 led him to a different conclusion from ours as to what was best for him. We failed to recognize this fact early enough to prevent a crisis. Earlier recognition of this difference and earlier discussion with the patient regarding our differences might have averted the crisis.

How can we avoid this type of crisis in the future? I believe the answer rests in better education of ourselves and our patients. We must continually seek to identify and understand patients' needs and to offer patients alternatives insofar as medically possible. We should acknowledge that sometimes we will fail in bridging the gap in opinion between ourselves and our patients. But this failure should never be allowed to interfere with our continued pursuit of a mutually acceptable and appropriate solution to the patient's problem.

While pursuing these goals, we must remember one important fact. In the final analysis, medical decisions are too important to be made solely by doctors. The decisions are too personal, too complex, and not merely scientific decisions. Because of this, these decisions must be made *with* the patient and not *for* the patient. Our role remains both educator and student: we must give the patient technical advice and we must provide guidance based on our own experience, education, and community and family influences. While doing so, we must always remember that our patients react to our advice within their own personal sphere of influences. We must be willing to listen to their interpretations of what we say and modify our approach depending on their needs. If we perceive that our patients do not agree with our opinions, it is not our job to become angry and forceful or to withdraw from caring for them. Rather, we should support the patients' decisions; it might be the only "right" decision for the individual patient. If after educating our patients about all possible options, we find that they *still* reach different conclusions than we would for ourselves, our job remains that of an advisor and friend.

The patient discussed today presents the practicing nephrologist with the challenge quite analogous with that confronting the academic nephrologist in the conduct of a research project. One should not embark on a research project unless one is committed to discovering the truth. In the laboratory, this endeavor entails creating an environment in which the laws of nature dictate the outcome of an experiment. In the practice of clinical medicine, this endeavor entails educating both ourselves and our patients to a level of mutual understanding that allows the patients to make decisions correct for their needs. As physicians, we can work only to create the appropriate environment in both instances. We have no right to manipulate the environment to force results we prefer. Our preference for what is right just might be wrong.

I have left one word out of today's discussion intentionally.

The word is *compassion*, defined as sharing or having a deep feeling of someone else's suffering. None of us can adequately feel someone's else's suffering. This basic problem creates many of the ethical dilemmas we face in medicine today. Yet we have a continuing obligation to try to understand the patient's difficulties. At best, our efforts will be incomplete. Nonetheless we must continually try to understand and support our patients in their struggles to decide what is best for themselves.

Forum commentary

DR. PETER A. SINGER (*Fellow, The Center for Clinical Medical Ethics, University of Chicago, Chicago, Illinois*) and DR. MARK SIEGLER (*Director, The Center for Clinical Medical Ethics, University of Chicago*): Should the physician accede to the request of an apparently competent 36-year-old man with end-stage renal failure to discontinue dialysis? What do we know empirically about treatment refusal and stopping dialysis? How have the courts dealt with treatment-refusal cases? How should the physician ethically respond to instances of treatment refusal? We shall examine refusal of treatment, in the context of this case, from three separate frameworks: epidemiology, the law, and ethics. These approaches inform in different ways. Epidemiology captures the existing patterns of patient-doctor interactions. The law ratifies social norms of ethical behavior. Ethics delineates what ought to be done for the finest discharge of human behavior.

The epidemiologic framework

The refusal of treatment is a frequent and serious problem in the clinical setting. In a recent study of the epidemiology of treatment refusal in medical hospitals, Applebaum and Roth reported that the incidence of refusal was 4.6 per 100 patient days [4]. Of 242 patients cared for on a medical ward during an 8-week observation period, 45 (19%) refused at least one treatment or diagnostic procedure. Fifteen percent of refusals were potentially life-threatening. Reasons for refusal were usually multifactorial, but the most common primary causes were: organic brain syndromes, character type, and failure to inform the patient about the purpose of the treatment or procedure. The most common physician responses to refusal were: reinforcing patients (28%), forcing treatment in incompetent patients (14%), permitting proper refusals (12%), and forceful persuasion or coaxing (10%). The most common outcomes of refusal were: no treatment given (34%), delayed acceptance (31%), and forced treatment (17%). Physicians' responses tended not to relate to the specific reasons for the patients' refusal: "Physicians often seemed too ready to concede patients' 'right to refuse' rather than to recognize the clinical problems that lay at the bottom of the refusal (e.g., poor or inconsistent communication) and to take steps to remedy them."

Neu and Kjellstrand reported that stopping long-term dialysis is not uncommon: 9% of 1766 dialysis patients died because dialysis was stopped [1]. Stopping dialysis accounted for 22% of all deaths and, after vascular causes, was the second most common reason for death [5]. Stopping dialysis was more common in older patients and in patients whose rate and severity of complications were increased. Approximately one-half of the patients who stopped dialysis were competent; most of them made their own decision to stop. About one-half were

incompetent; the decision to stop was initiated by the physician or the family. The mean duration of treatment before discontinuation was 30 months, but 10% discontinued after 3 years, and 3% discontinued after 9 years of dialysis. Some authors have corroborated [6, 7], whereas others have disputed [8], these results.

The legal framework

Since the seminal Quinlan case in 1976, the courts have heard many cases involving the withdrawal of life-sustaining treatment. Because of the number of cases, we will limit our presentation to those involving competent patients like the one under discussion, although we recognize that many principles developed in cases involving incompetent patients can be applied to competent patients. We will attempt to highlight cases dealing with the discontinuation of dialysis.

The law distinguishes between patients who are terminally ill and those who are not. In the case of terminally ill patients, the law upholds the right of competent patients to forego life-sustaining therapies. For example, *Satz v. Perlmuter*, a 1980 decision by the Supreme Court of Florida, upheld the right of a competent 73-year-old man with advanced amyotrophic lateral sclerosis and ventilatory failure to discontinue mechanical ventilation [9]. This decision was reaffirmed in the 1987 Farrell case, in which the Supreme Court of New Jersey upheld the right of a 37-year-old, competent, terminally ill woman with the same disease to discontinue mechanical ventilation [10]. The 1982 Cinque case, heard by the Supreme Court of New York, involved a patient's request to stop dialysis [11]; he was a competent 41-year-old man with long-standing, insulin-dependent diabetes mellitus complicated by blindness and bilateral amputation of the lower extremities due to neuropathy and peripheral vascular disease. The court found that he was terminally ill (his estimated life expectancy on dialysis was 6 months according to the treating nephrologist) and, citing the "constant and severe pain caused by his multiple debilitating irreversible and terminal conditions," upheld Cinque's right to stop dialysis.

Statutory law, in the form of natural-death legislation, also recognizes the right of terminally ill patients to forego life-sustaining therapy. For example, the California Natural Death Act declares that "adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition [12]." The definition of "terminal condition" is "an incurable condition. . . which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient."

The courts also have permitted the discontinuation of life-sustaining therapy in competent patients who are not terminally ill (and who may even have a prolonged life expectancy with treatment). In the 1984 Bartling case, the California Appellate Court upheld the right of a competent 70-year-old man with lung cancer and emphysema (and an estimated life expectancy of one year) to discontinue mechanical ventilation [13]. In the 1986 Bouvia case, the same court upheld the right of a competent, 28-year-old, quadriplegic woman with cerebral palsy (and an

estimated life expectancy of 15 to 20 years) to refuse nasogastric feeding [14]. The courts have upheld the right of Jehovah's Witnesses to refuse blood transfusion and the right of competent patients to refuse limb amputation.

In 1979, the Supreme Judicial Court of Massachusetts considered the request of Kenneth Meyers to stop dialysis [15]. Meyers was a competent 24-year-old prisoner with end-stage renal failure due to glomerulonephritis. He refused dialysis as "a form of protest against his placement in a medium, as opposed to minimum, security prison." He would be able to live "an otherwise normal and healthy life" if he continued dialysis. Although the court compelled treatment because "the State's interest in upholding orderly prison administration tips the balance in favor of authorizing treatment without consent," it found that "given the magnitude of the medical invasion occasioned by dialysis. . . the defendant's interest in refusing dialysis is strong enough, despite the positive prognosis, to counterbalance the State's usually predominant interest in the preservation of life."

The legal reasoning of these treatment-refusal cases involves a balancing act between individual and state interests. The individual interests are (1) the common-law right of informed consent ("the right not to be treated without consent is the same as the right not to be treated at all" [16]) and (2) the constitutional right to privacy ("the privacy of one's person and body ought to be protected by the Constitution against unwanted intrusions by the state" [17]). The countervailing state interests are: (1) the preservation of life; (2) the prevention of suicide; (3) the safeguarding of the ethical integrity of the medical profession; and (4) the protection of innocent third parties [18]. The judicial cases listed here illustrate that the interests of the individual generally outweigh the interests of the state.

The ethical framework

Should the physician accept outright and without discussion a patient's treatment refusal? How should the physician assess the quality of a treatment refusal? If, after discussion, the patient and physician continue to disagree, how should the physician respond? We will argue that physicians and patients should always discuss the refusal of important treatment choices to ensure both that the patient has adequate decision-making capacity and that the communication between patient and physician fosters that capacity. We will identify the considerations germane to the evaluation of treatment refusals. Finally, we will examine the physician's appropriate responses when patient and physician continue to disagree after adequate discussion has occurred.

Discussion between patient and physician serves as the procedural underpinning of "shared decision-making" (the ethical equivalent of the legal doctrine of informed consent), the components of which are disclosure, voluntariness, and decision-making capacity. Patients, like the man under discussion, must have decision-making capacity if their treatment refusals are to be considered valid. Decision-making capacity is the ethical equivalent of the legal notion of competence; in law, there is a presumption of competence, which can only be reversed by a court. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter referred to as the President's Commission)

recommended that assessments of decision-making capacity be based on “the person’s actual functioning in situations in which a decision about health care is to be made” [19]. The Commission identified the elements of decision-making capacity as (1) possession of a set of values and goals; (2) the ability to communicate and understand information; and (3) the ability to reason and to deliberate about one’s choices [20]. It is evident that discussion between patient and physician is required to ensure that patients who refuse treatment have adequate decision-making capacity.

Decision-making capacity not only must be possessed by the patient, it also must be supported by patient-physician communication. Jay Katz, in *The Silent World of Doctor and Patient*, puts it this way:

Ignorance, misconceptions, exaggerated fears, and magical hopes about matters such as diagnostic tests and therapeutic interventions, as well as about what patients and physicians want and are able to do for one another, can decisively influence choice. The danger is great that patients’ and doctors’ choices will be distorted by such internally and externally engendered mistaken ideas. Thus, conversation will have to be more extensive and more searching if one believes that such distortions affect choice and that they can and must be sorted out [21].

The physician must ensure that the patient has decision-making capacity and that the patient-physician communication fosters this capacity. Therefore, one should never accept a patient’s refusal of treatment without discussion.

How should the physician assess the quality of a treatment refusal? There are no established clinical rules here; the physician must rely on a type of clinical judgment known as “moral discernment” [22]. Patients must be able to understand the nature of their medical problem and be able to express the medical treatment alternatives (including no treatment) along with their consequences (the “communicate and understand information” requirement of the President’s Commission). They must retain intellect and rationality sufficient to choose among the alternatives (the “reason and deliberate” requirement of the President’s Commission), and the choice should not be merely a reaction to the pain, fear, and uncertainty of disease. The choice must be authentic (the “possession of a set of values and beliefs” requirement of the President’s Commission). It must be “consistent with the ‘kind of person’ this patient is. . .with [his] enduring values. . .previous choices. . .[and] the convictions he has previously asserted and defended” [22]. There are several ways that authenticity can be validated, including living wills and durable powers of attorney for health care, but perhaps the best way is a long-standing doctor-patient relationship within the context of which issues of life-sustaining therapy have been discussed.

The difficulty of formulating general rules that apply to particular cases might explain why no consensus exists regarding the standard that patients must meet for their decision-making capacity to be considered adequate. We make determinations of decision-making capacity in clinical practice to avoid two types of error: treating incompetent individuals as competent (an approach that exposes them to the potential bad outcomes of an unwise choice), and treating competent individ-

uals as incompetent (a posture that limits their exercise of self-determination). The ethical principles of beneficence, which directs that physicians seek to promote their patients’ best interests (that is, health), and autonomy, which directs that individuals have the right to form, revise, and pursue personal plans for life, often conflict. The balancing of these ethical principles must incorporate the specific risk-benefit ratios of individual cases.

Certain factors should predispose physicians to accede to patients’ treatment refusal: (1) if the disease is chronic (because the patient is familiar with the quality of life associated with at least one of the treatment options, and the authenticity of the choice is easier to validate); (2) if the disease is terminal (because the treatment refusal affects the timing rather than the fact of death); or (3) if the treatment will result in permanent disability (because patients must decide what quality of life they would be willing to accept). Other factors should predispose physicians to resist the treatment refusal: (1) if the disease is acute or the patient rejects discussion about the treatment refusal (because the decision-making capacity of the patient and the authenticity of the refusal are difficult to judge); (2) if the extent of bodily invasion occasioned is small; or (3) if treatment offers prolonged survival and the consequences of non-treatment are fatal (because the condition is reversible).

Advocates of maximal autonomy will be disenchanted with this model of the physician as judge. However, when practiced in good faith by the discerning physician, this role represents the best compromise between medical beneficence and the protection of individual rights. The more difficult task is not the grounding of individual rights, but their protection from abridgment in actual practice. Our assumption is that an explicit consideration of criteria for acceding to or resisting treatment refusal will result in the abridgment of fewer rights than in the current standard of practice, wherein ethical decisions are made implicitly and on unclear grounds. Another response to the criticism of physician as judge is captured below:

It is true that the determination both of rationality and of authenticity is made by the physician. Many critics of medicine would prefer that the patient’s condition—i.e., his rationality or competence or authenticity—rather than the physician’s judgment of his condition, actually control whether a physician overrides a patient’s wishes. This notion is unworkable. Rationality, competence and authenticity are not absolute standards such as ‘Middle C.’ Rather, they are states of mental responses that must be construed. While one would hope for a rule of action that would eliminate subjectivity and avoid wrong decisions, we have seen why conceptually neat alternatives—either libertarianism or an all encompassing medical paternalism—are even more unacceptable [22].

Patients and physicians, after discussion, agree about the treatment choice in most instances. But no doubt in a minority of cases, fundamental and intractable disagreements will persist even after discussion. How is the physician to respond to these instances of “ethical impasse?” The spectrum of potential responses includes abandonment of the patient, gentle verbal persuasion, and frank coercion. Some would argue that the physician should refrain from responding at all out of respect

for patient autonomy. But the mere invocation of the principle of autonomy is insufficient; patients as well as physicians possess autonomy in the patient-doctor relationship; and autonomy is the constraint upon, not the goal of, the relationship:

[T]he invocation of the concept of autonomy fails to provide sufficient practical guidance to morally conscientious physicians and patients to enable them to determine where on a spectrum of paternalism/ consumerism or dependence/independence their professional relationship will and ought to stabilize [23].

The central moral and practical dilemma facing concerned patients and conscientious physicians. . . is to balance the rights of patients and the responsibilities of physicians—and the rights of physicians and the responsibilities of patients. . . [23].

Autonomy constrains and limits the negotiations and the activities of both [the physician and the patient]: neither party may violate the autonomy of the other or use the other merely as a means to an end. But respecting autonomy as a constraint or a limit does not imply seeking it as a goal or praising it as an ideal [24].

This model of bilateral autonomy as constraint on behavior can ground the physician's response to treatment refusal. This approach would prohibit the physician from abandoning the patient or from compelling or coercing the patient into accepting or continuing treatment. It would not prevent the physician from withdrawing from the patient's care after suitable alternative arrangements had been made or from attempting to gently persuade the patient to accept or continue treatment. Admittedly, the distinction between persuasion and coercion is not always clear in practice and requires more discussion and research. In the words of Dr. Kassirer, such a model would prevent physicians from "adding insult to injury" by "usurping patients' prerogatives" [25].

Conclusion

The decision made by the patient under discussion to stop dialysis is not unusual. Like him, 50% of the patients who discontinue dialysis are competent, and most make the decision themselves. He is younger, has been on dialysis longer, and has fewer complications than does the average patient who stops dialysis. We are unsure of his reasons for wishing to discontinue dialysis, just as we are unclear of the rationale in many patients who refuse medical treatment. The patient is a competent, non-terminally ill adult without dependents. Based on the cases of Peter Cinque and Kenneth Meyers, and the parallels in the Bouvia, Jehovah's Witness, and amputation cases, we conclude that the courts would likely uphold his right to discontinue dialysis.

The physician and dialysis team did not accept outright and without discussion the patient's refusal of dialysis, but made multiple attempts to contact him by telephone. We are not given specific details of discussions between physician and patient; perhaps such discussions did not occur because of the patient's general reluctance to talk to anyone. The factors that weaken the treatment refusal (the patient's rejection of discussion, and prolonged survival with treatment versus certain death without

treatment) seemed to outweigh the factors that strengthen it (chronic condition) in the mind of the treating physician in this case. But despite his conceptual rejection of the treatment refusal, the physician chose neither to abandon the patient nor to coerce him to continue dialysis—the doctor left an open door and a cordial invitation to the patient to re-initiate treatment.

Refusal of treatment in general, and of dialysis in particular, is not uncommon; physicians' responses to treatment refusal are often nonspecific, without regard to the reasons why a patient refuses treatment. The bulk of judicial opinion upholds the right of competent patients, even if non-terminally ill, to forego life-sustaining therapies, including dialysis; this can be viewed as the courts' ratification of social norms of ethical behavior. Physicians should always discuss treatment refusals with their patients; they should develop and use in good faith explicit criteria for assessing the quality of treatment refusals. In instances of intractable disagreement or "ethical impasse," they should encourage, but never coerce, their patients to accept treatment.

DR. LOWANCE: Here is the epilogue to our case presentation. The following morning, the patient called the unit and requested dialysis. His blood urea nitrogen was greater than 180 mg/dl, creatinine greater than 20 mg/dl, and potassium greater than 7.0 mEq/liter. Successful dialysis was accomplished. Currently he is in psychiatric counseling and has returned to work. He remains a productive member of society. The decision to return to dialysis was his, a decision we gladly supported.

Questions and answers

DR. JEROME P. KASSIRER: My first question relates to the stability of patients' preferences over time. It occurs to me that the problem in dealing with some of these ethical dilemmas and that of carrying out formal decision analysis in individual patients is similar. In some decision analyses, the patient's preference is a predominant factor in the outcome of the analysis [25]. When incorporating patients' preferences into any utility function in decision analysis, it is essential that any utility adjustment for the quality of the patient's life must be as accurate a reflection of the patient's feelings as possible. The problem with these quality adjustments is that they may not be stable: patients have one view of how they feel about a given state on one occasion and another view on a later occasion. Indeed, such was the case in the patient we are discussing today. How can we deal with the shifting sands of such personal assessments?

DR. LOWANCE: Patients' attitudes do frequently change. This is one of the reasons that assigning utility to these values will frequently be less precise in the "art" than in the "science" of medicine. Indeed, this patient had decided to stop dialysis once before, had changed his mind, and now was reverting to his previous position. Because he was so knowledgeable about the technical and scientific aspects of his disease, my scientific expertise was of little value. An attempt to educate myself to his personal needs, and to then educate him to the fact they could be met, became my major endeavor. Again, as demonstrated in Figure 1, a continued, open dialogue between the physician and patient is essential for appropriate patient management. It is possibly the only way this "soft" value of attitude can be handled. In some interchanges the difference between the two participants is small, so the bidirectional education is quick and

easy. In other instances, as in this case, the differences are large and the process is complex and demanding.

DR. KASSIRER: Here is another knotty problem. Some patients have been known to refuse certain essential treatments, such as blood transfusions, have been forced by the courts to accept the treatment, and later have expressed gratitude that they were forced to take the life-saving treatment. When such legal coercion occurs, what is the aftermath?

DR. SIEGLER: This is a difficult question to answer because two important studies have not been done: (1) the assessment of whether people whose wishes are overridden retrospectively approve of their care, and (2) whether a person's stated wish at time zero persists at 6 or 12 months with regard to the same type of decision. In essence, do people mean what they say? In an attempt to answer these questions, our group currently is conducting a study in patients with amyotrophic lateral sclerosis (ALS) to determine whether patients' wishes remain constant over time or whether they change.

DR. JOHN T. HARRINGTON (*Chief of Medicine, Newton-Wellesley Hospital, Newton, Massachusetts*): Dr. Siegler, you indicated that we need to know whether patients always mean what they say. Dr. Lowance's experience shows that at least some patients don't. My experience with another difficult patient also supports the contention that they do not always mean what they say. This man has been taken care of by me and other members of this audience for many years. Eight years ago, he expressed a desire to stop dialysis and, in fact, his case went to court. The court refused his petition because he was at that time a prisoner. Yet today he is alive and doing well with a serum creatinine of 1.8 mg/dl, having undergone successful cadaveric kidney transplantation. That patient clearly did not mean what he said in his lawsuit, that is, that he wanted to stop dialysis and die. I suspect that he simply was trying to get better prison facilities during the time he was being dialyzed.

My specific, and unrelated, question is, how does one know whether a patient is severely depressed, as are many suicidal patients? If today's patient was, shouldn't we have treated his depression as well as his renal failure?

DR. LOWANCE: I think everybody is hitting on salient points about the motives behind this patient's behavior. I actually did allow him to ride a bus home and I did that intentionally because to the end, my perceived job and my goal was to do what I thought best for him. Rightly or wrongly, I believed my "point B" was better for him than his "point A." In dealing with this patient over a number of years, I have learned he needed reinforcement in believing that our system of care was solid. He periodically needed constraints placed on his ability to manipulate the system. He periodically needed to be told that beyond a certain point, manipulation became destructive to everybody working in the system. One of the points I tried to make to him was that I had other patients to see and other responsibilities to discharge and that we had done all we could for him. It was now time for him to decide whether or not he could conform to the rules of our system. We had done all we could do. At that time, it was becoming detrimental to our system to allow him to consume as much time and effort as he did. I do not think that he ever wanted to die. I think that, in fact, one of the things he wanted to do was to see exactly how much people cared about him. His parents had died at an early age, he had been reared by his siblings, and he wanted once

again to assess exactly how far people were willing to go to express love and appreciation for him. He is periodically depressed and is treated for that depression. It is a depression that on occasions creates erratic behavior. The courts, however, would not order psychiatric care, because they perceived him as competent to make decisions for himself.

DR. MICHAEL GRODIN (*Director, Program in Medical Ethics, Boston University Schools of Medicine and Public Health, Boston*): I am quite concerned about the nature, scope, and justification of the argument presented with regard to treatment refusal. I will take as a given that an adult, competent, informed, and understanding patient has the absolute right to refuse any and all medical therapies. My concern relates to your criteria and methods for assessing competence. I think the appropriate sphere for the discussion of competence lies within the nuances of the physician-patient clinical encounter. The questions are when and how we assess whether people mean what they say and say what they mean. Specifically, when do we recognize a red flag that suggests the need for further exploration and elucidation of a patient's understanding and intent? The patient who refuses to even enter into a dialogue poses a particular dilemma, but I am concerned also with the patient who does respond to probing. What are the limits or boundaries of such discourse? When do you believe the patient? What questions do you ask and what answers are you looking for? I am concerned, Dr. Lowance, that you focused on the specific explanations or reasons given by the patient and disregarded the fact that the patient had explored and responded to the question. In other words, I fear that in this interchange, the physician worried more about receiving the answer he was looking for than on being satisfied with the encounter itself. When a patient gives the "right" answer, the physician might respond, "That's fine; you need not respond further. We will honor your wishes." If the patient does not give the "right" answer, however, the physician might respond, "I did not find your answer acceptable. Let's probe further and push the encounter along until I'm satisfied." Of course, competence is an independent assessment and does not depend on a patient's specific response. Unfortunately, one questions competence when a patient refuses therapy but rarely when a patient accepts a physician's course of action. I might equally suspect as incompetent anyone who accepts a life with dialysis. Patients are either competent or incompetent, but not incompetent just because they refuse therapy. I grant that a clinical encounter is necessary for assessment of the patient's ability to competently understand the risks, benefits, alternatives, and consequences of a specific decision, but my question relates to the end-point of the encounter. Even if the physician disagrees with the patient's decision, and even if it might appear at initial assessment that the decision is a "bad" one, at some point the clinician must accept the patient's response and discontinue debate. Dr. Lowance and Dr. Siegler, would you comment please?

DR. LOWANCE: As I discussed, I believe our obligation is to educate the patient to a level of understanding that allows him to make a reasoned personal decision. I think this notion is different from pushing a patient to do what we want him to do. Admittedly, some of us may be better or more forceful educators than others. On the other hand, if we do our job properly

the process will be one of education through dialogue and not one of coercion.

DR. SIEGLER: I did not mean to suggest that the patient's goals have to coincide with mine. A patient could have several possible goals: the right to die, the right to refuse treatment, the right to make a political statement about rights, secondary gains—there are a whole variety of potential goals. It would help a lot, I think, for the physician at least to be made aware of which goal or goals the patient is pursuing. It makes it easier to acknowledge and respect a wish if patients are willing to clarify their goals. Surely this does not mean that a patient who is totally unwilling to make such a clarification is by definition incompetent and ought to be treated despite his or her refusal. You are obviously right that non-hospitalized patients frequently vote with their feet in a variety of ways, for example, by not seeking our attention, by not coming back to see us, or by disappearing from the health care system.

I am in total sympathy with the notion that patient goals and prerogatives ultimately reign supreme. Within the clinical encounter, within an ongoing, established doctor-patient relationship in which a patient is making demands without explaining the goals that he or she is pursuing, and without giving reasons for the demands, I think it is appropriate in that context to push the patient harder—not to get agreement with your goal, but to get a clarification and understanding of the patient's goal.

There are ethicists in this country who would place the presumption in such an encounter at a very different level from the level at which I have just placed it. For me, the presumption in a relationship between a physician and a patient is that the mutual interaction should be uncoerced and voluntary but, as Dr. Lowance suggested, based on mutual understanding. Discussion of goals is a very important ingredient in that understanding. Now there are ethicists, supporters of the autonomy school in particular, who would say that any effort on the part of a physician or others in the health care system to ask a person to explain anything is absolutely outrageous. I know you did not say that. Presumably, all you want is for people to make decisions for themselves. But you are concerned that anything a physician says may be coercive and that therefore the physician ought not to say anything except offer neutral, value-free options. Are you attacking me for the line I have tried to establish?

DR. GRODIN: I am concerned about whether the answer that the patient gives determines how you proceed. It seems to me that the specifics of the patient's response did make a difference to you, Dr. Siegler. I am not sure whether that is appropriate. Such a demand extends beyond the need for probing within the encounter to assure that the patient has at least thought about and rationally analyzed the situation. To push this point further, Dr. Singer and you even had suggested the notion of authenticity or consistency as criteria for assessing competence. I find such a test disturbing. Clearly, if someone who has been well maintained on dialysis for a number of years suddenly proclaims, "I want to stop," the physician might think, "This sudden change of heart seems out of character" and might then initiate a discussion with the patient about what appears to be a decision based on confusion. On the other hand, after exploring the decision with the patient, the physician might discover that the patient has had a sudden rational and reasoned, albeit radical, change in treatment goal or life expectancy. At least in

the case of the patient presented today, I am reassured that the patient's physician has cared for this patient over an extended period, and such continuity can lend insight into the clinical encounter. The question is whether patients who are less well known to their doctors are given more or less credibility with regard to the authenticity of their decisions. I want to know whether it is the answer itself that determines how far you probe the patient, or what point in the clinical encounter will be sufficient for you to say, "This patient's decision is authentic and consistent, and therefore I will accept the decision to refuse therapy."

DR. SIEGLER: Authenticity is not the sole ethical basis for accepting or rejecting a patient's wishes. What Dr. Singer and I have tried to suggest is that the clinical factors in a case, the nature of the person, the quality of the reasons, and the quality of the justification are all legitimate factors to take into account. For example, if a patient who has behaved in a certain way over time suddenly behaves in a totally different way, the physician is presented with a clinical clue. Is it right for the physician to pursue that clinical clue to figure out why a patient, whom the physician thought he or she understood, is suddenly making decisions and behaving in different ways, or is it the physician's role to say, "Oh yes, I understand that you behaved one way during the past 9 years that we have worked together, and you are now behaving differently and that is your prerogative." I say the change in behavior is an important clinical clue to pursue. If one finds that the patient's change in behavior is the result of encephalopathy, a psychiatric change, or an emotional crisis that might otherwise have gone unrecognized, then those are important clinical data. The clinical examination of the patient's authenticity is a legitimate part of the clinical process. I'm not saying that people cannot change their minds. People do change their minds for a lot of reasons. They do it over time; surely the concept of authenticity would not prevent people from changing their minds.

DR. GRODIN: How we feel about the decision a patient makes is an important area of exploration, but such feelings must be carefully separated from respect for the absolute right of the patient to be the final appropriate authority for decision-making. It is quite clear, however, that you feel much better now that the patient has agreed to continue his therapy. It is interesting what role emotions play in the moral life and how significant it is to "feel right" about "doing right."

DR. RONALD PERRONE (*Division of Nephrology, New England Medical Center*): I wanted to respond to the point Dr. Grodin made. You objected to pushing patients too hard and said that we push until we hear the answer we want to hear. As a physician I would feel terrible having let a patient make an irreversible and fatal decision based on a temporary or transient problem and inspired by a poorly thought-out series of actions. For example, the patient that Dr. Lowance described sounded like an angry fellow: he was angry at his parents for not having had his disease diagnosed early enough; he probably was angry at his brother and sister because they were rich and he was not. It appeared that he was angry at the dialysis staff because they did not accommodate his demands. I wouldn't have any problem "pushing" such a patient; I would not bring him into the dialysis unit and strap him down, but I would push him as hard as I could and not feel bad about that. I think a relevant example is attempted suicide. In my experience, people don't wake up

and say, "You s.o.b., you kept me alive." Generally they are grateful. That doesn't mean that they live the rest of their lives feeling that way. But I think that as a physician, you really need to "push hard" when it is reasonable to do so. I would not push a diabetic with amputations, neuropathy, and blindness, who had decided to discontinue dialysis, to continue therapy. That's different. In a patient who is otherwise healthy, I would have no hesitation in pushing as hard or even harder than Dr. Lowance did.

DR. GRODIN: In my view your example is a clear case of unwarranted patient coercion. Although you believe that your paternalistic stance warrants your decision-making for the patient who thanks you after the fact, this is a dangerous justification for such coercive action. One must remember that your experience "after the fact" is limited to patients who, through your "pushing harder," have either ultimately been coerced or who have sought another physician. The patients who are dead don't come back to object or acquiesce to your paternalism. I am concerned that your post-facto analysis is based on patients who are still living because they either have been coerced successfully or they have changed their minds.

DR. PERRONE: People who really want to commit suicide do so, whereas those who are more ambivalent often place themselves in situations from which they can be rescued.

DR. GRODIN: Obviously you are taking away some decisional autonomy from patients. I agree that our goal as medical practitioners is not just to protect the rights of patients. We don't want to use consent as a shield from patient encounter by saying, "I'm just here to protect your right of autonomy, so here's all the data, now you make your decision." I am concerned not only with protecting patients' rights but also in ensuring their welfare. The question at hand is, at what point does the notion of a patient's welfare extend to a justified paternalistic stance that leads one to declare, "I truly know what's in your interest better than you do"? This vital clinical judgment ultimately will define the limits of the physician-patient encounter. I also would feel uncomfortable accepting such a radical treatment refusal without probing for the patient's justification. But I am less concerned with the answer itself than that some rationale exists. My fear is that you go too far in probing for answers. If the patient ultimately agrees with you, you continue treatment; if the patient persists in refusing therapy, you push further. In this sense it is the answer itself that determines the end-point.

DR. SIEGLER: Dr. Grodin, what would you have done with Dr. Lowance's patient? Would you have gone as far as he did? Less far? Further?

DR. GRODIN: Actually, I was impressed by the appropriate level of discourse in this case. I am still concerned, however, about who was determining the end-point or goals of the clinical encounter. My notion of the physician-patient relationship is one in which the patient determines its ends or goals. The physician and patient then work together in an attempt to accomplish that mutual task. This is not to suggest that the physician is the agent of the patient. Rather, I perceive a mutual respect for the roles and responsibilities of the parties, but the final decision and ultimate assessment of the "good outcome" resides with the patient. If a physician cannot tolerate a patient's final decision, the patient must never be abandoned, but rather transferred to the care of another physician.

It seems to me that a reasonable dialogue was established with Dr. Lowance's patient. Obviously I am concerned that the probing went too far, but I was not there and do not have the benefit of having had a continuing relationship with the patient. How far do you go? This is part of the art of medicine. But I maintain that the answer should be determined by how comfortable you feel that the patient really understands what is going on.

DR. KASSIRER: The problem of patient autonomy and independence in decision-making must be even more complex in adolescents. Suppose a 15-year-old patient similarly requests that dialysis be discontinued. How much more complicated is the analysis and assessment of an adolescent compared with an adult? An 18-year-old is considered competent for the purposes of treatment refusal until proven incompetent, yet a 17-year-old is considered incompetent for the purposes of treatment refusal until proven competent. How would a pediatric nephrologist handle an adolescent who refuses dialysis?

DR. JOHN T. HERRIN (*Chief, Pediatric Nephrology, Massachusetts General Hospital, Boston*): In caring for children and adolescents, the spectrum of decision-making differs in that the patient has a legal and ethical surrogate, namely, parents or guardians, natural or court-appointed. Further, variations in maturity provide a range in the appreciation of the concept of "present pain for future gain." For these reasons, we must include patient, caregiver, and surrogate in treatment plans. Adolescents' exaggerated involvement with personal freedom and body image, together with their tendency to engage in reckless testing and inconsistent behavior, make intrusive or restrictive therapy (diet, exercise, dialysis) especially challenging and frustrating [26-28]. As adolescent patients mature, they should be integrated into decision-making regarding therapy, providing that full explanations are given and that options are offered where possible to return some degree of control to the teenager.

Adolescents need to balance the gains from dialysis with the potential embarrassment, pain, and change in body image. They also need to review the cosmetic changes from potential drug therapy in the event of future transplantation. Changes in appearance from steroid therapy and cyclosporine frequently cause difficulties in compliance after transplantation [29, 30]. The anger, negativism, testing, depression, or self-destructive behavior of adolescence are most often manifest as refusals to accept medications or fluid or dietary restrictions, or to cooperate during dialysis treatments [28, 29]. Attempts by family and caretakers to integrate limits for adequate treatment with support and understanding are necessary. Under most circumstances, the younger child's or adolescent's family decides to initiate or continue therapy, and this "adult" decision imposes treatment on the child or adolescent. I find it helpful to begin education for the child and family early in the disease process to allow the child to develop an understanding of the course of the disease and to have a voice in the family's decision for treatment. Such early education and integration of the child into therapeutic regimens, such as giving the patient the responsibility for taking medication, obviate the tendency toward contrary views and "testing" behavior of the adolescent.

DR. SIEGLER: In deciding to withdraw from dialysis, do adolescents follow the behavior pattern described by Kjellstrand?

DR. HERRIN: It is hard for a child to withdraw from dialysis by "walking away" and not returning for treatment. Parents or guardians tend to coerce the child to come back. I have one adolescent patient, a ward of the state, who refused dialysis for 6 days while attempts were made to find her. On the advice of the hospital's legal counsel, we appealed to the mass media and, with community help, she was located and returned to the custodial institution and to dialysis. Her expression of anger and frustration was an adolescent reaction and followed frequent mood swings and episodes of manipulative behavior. Like Dr. Lowance's patient, she had made a statement so that her needs and frustrations would be recognized. With increased support, she continued dialysis until she received a renal transplant. A similar pattern of fluctuating response was shown by a 16-year-old male high school student who asked to be taken off the transplant list on five separate occasions. All episodes were at times of dialysis-access difficulty. In this case, negativism, anger, and frustration followed painful invasive therapy, which changed his "baseline" desire for further therapy. During adolescence, problems of motivation and difficulties relating to therapy are heightened. I was willing to acquiesce to his desires and allow him some measure of control, and then to work with the family to restore his confidence in himself and his treatment. With younger children, such reasoning is not possible; for humane reasons we physicians must show these patients consistency and try to foster a caring and supportive atmosphere during therapy for parents and caregivers.

DR. PAUL KURTIN (*Chief, Division of Pediatric Nephrology, New England Medical Center*): Dialysis capabilities are not unlimited, and it is sometimes said that some patients are never offered dialysis. I think this is particularly true in the population of patients with acquired immune deficiency syndrome. What is your opinion on the legalities and ethical issues of a physician not offering a patient dialysis?

DR. SIEGLER: Inclusion and exclusion criteria for a variety of medical technologies change over time. Are you asking whether it is ever permissible to withhold dialysis from patients with full-blown, stage-IV, symptomatic AIDS?

DR. KURTIN: Yes.

DR. SIEGLER: You could always base the withholding of a lifesaving intervention on the notion that such interventions are futile. If one is dealing with a disease that is going to result in death in a week, two weeks, or a month, that might be grounds for withholding expensive and invasive technologies. If, however, one is dealing with diseases of a more uncertain prognosis in which the withholding of the therapy inevitably will result in the death of the patient in a short time, and if the therapy is being withheld for discriminatory reasons, I think one would want to speak out strongly against such behavior. My feeling is that life-prolonging interventions should not be denied for non-terminally ill people on grounds other than real futility or the wishes of the patient not to receive therapy.

DR. SINGER: I think it is worthwhile to ask: What is the goal of a discussion like the one in which we are engaged today? Why should we make explicit an ethical notion like decision-making capacity or treatment refusal? We can draw a useful analogy to decision analysis here. Decision analysis does not claim that the clinical decision-making it describes did not occur before the decision-analysis model was designed. It merely

claims that there is some value in making explicit the decision-making process. The thrust of our commentary has been the same contention for the realm of clinical ethics. There is no question that these decisions, like the decision under discussion today to stop dialysis, are made every day in clinical practice. However, they are made implicitly. We are suggesting that there is value in making explicit the clinical-ethical decision-making process. As we mentioned in our commentary, it is easier to talk in the language of "rights" than to prevent their abridgment in clinical practice. To improve patient care, we must examine our "ethical standard of practice." Our explicit consideration of clinical-ethical decision-making approaches not only the goal of clinical medical ethics, but also the goal of medicine itself. To be clear, the goal of clinical medical ethics is to improve the quality of patient care and the quality of the patient-physician interaction. As we attempt to explicate complex notions like decision-making capacity or treatment refusal, we come one small step closer to this goal.

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