

implies that any dollar amount imposed by a court will be arbitrary and thus violate the basic requirement that a law applied against someone be fair. But this would be a rash conclusion. Arbitrariness in this variety of case can be limited by judges who review damage awards to assure their consistency with comparable cases. It can be further limited by assuring that the level of damages is not ordinarily so high as to pose a threat to the vitality of a normally functioning firm.

Even if we limit arbitrariness in oil spill cases, we cannot eliminate it. Attaching monetary value to non-market goods will always have some measure of arbitrariness. But it would be presumptuous to suppose that all arbitrariness can be removed from the law. Adopting any legal rule involves settling on a convention and sticking with it, a process that necessarily contains an arbitrary component. Moreover, even if burdens imposed by law contain a degree of arbitrariness, they may nonetheless serve to limit the arbitrariness of other burdens people confront. Accidents themselves are deeply arbitrary, instances of bad luck to their victims and of things gone wrong in ways outside the plans of people who cause them. In the case of oil spills, there is no reason that the weight of the arbitrary

should fall entirely on the shoulders of the public. By imposing liability for compromising nonuse values on firms like the Exxon Corporation, we do not mete out an excessive burden, and the burden of arbitrariness is more fairly shared.

— Alan Strudler

Sources: Exxon Valdez Oil Spill Trustee Council, *Draft Exxon Valdez Oil Spill Restoration Plan* (November 1993); Keith Schneider, "Exxon is Ordered to Pay \$5 Billion for Alaska Spill," *New York Times* (September 17, 1994); *Reuters Business Report* (November 16, 1994); *The Economist* (August 17, 1991); Thomas A. Campbell, "Natural Resource Damage Assessments: A Glance Backward and a Look Forward," *Baylor Law Review*, vol. 45 (Spring 1993); Peter A. Diamond and Jerry A. Hausman, "Contingent Valuation: Is Some Number Better than No Number?," *Journal of Economic Perspectives*, vol. 8, no. 4 (Fall 1994); Michael Lemonick, "Alaska's Billion-Dollar Quandary," *Time* (Sept. 28, 1992); Jerry A. Hausman, ed., *Contingent Valuation: A Critical Assessment* (North-Holland, 1993); *Federal Register*, vol. 58, no. 10 (January 15, 1993).

Futile Treatment and the Ethics of Medicine

Ryan Nguyen was born six weeks prematurely on October 27, 1994, with a weak heartbeat and poor blood flow to his organs. His physicians at Sacred Heart Medical Center in Spokane, Washington, employed heroic measures to revive him. A few weeks after his birth, it became clear to Ryan's doctors that the aggressive medical interventions keeping him alive were futile and should be withdrawn. Ryan had multiple medical problems including kidney failure, bowel obstruction, and brain damage. To survive, he would require kidney dialysis for approximately two years followed by a kidney transplant, a feat most consulting experts on kidney disease agreed was "virtually impossible to pull off." According to one consultant, a professor of pediatrics and director of the kidney program at Children's Hospital and Medical Center in Seattle, "long-term dialysis would not only be inap-

propriate, but would be immoral . . . it would prolong pain and agony in a child that has no likelihood of a good outcome."

As is often the case, some physicians could be found who disagreed with generally accepted practice standards. When Nghia and Darla Nguyen, Ryan's father and mother, rejected the Sacred Heart doctors' prognosis for their baby, they sought out such physicians. Denying that Ryan had brain damage and believing that his kidneys were getting better, the Nguyens approached four other medical centers requesting dialysis and other life-prolonging treatments for Ryan. Each time, they were turned down on the ground that aggressive lifesaving measures were futile.

The Nguyens' search continued. A self-described "pro-life attorney," Russell Van Camp, agreed to represent them. Mr. Van Camp accused the Sacred Heart

physicians of acting from questionable motives. The doctors were withholding treatment, he charged, because Ryan's parents were unemployed and on Medicaid, and also because the baby "doesn't have blond hair and blue eyes" (Ryan's mother is an American Indian and his father is a Vietnamese refugee). In other statements, Mr. Van Camp accused the doctors of trying to kill Ryan, perhaps as a way of covering up medical mistakes made during the baby's delivery. Through their lawyer, the Nguyens sought a permanent injunction that would force the Sacred Heart doctors to treat Ryan unless another hospital accepted him. The Nguyens obtained a temporary restraining order requiring Ryan's doctors at Sacred Heart to resume kidney dialysis, which had been stopped without the parents' consent in order to allow Ryan to die a comfortable death.

During their ordeal, Ryan's parents kept a diary of their baby's travails, depicting the medical and legal battles they overcame on their son's behalf and including signatures from television and newspaper reporters who interviewed the family. They steadfastly maintained, "He'll make it, if we can find a doctor who cares."

Eventually, a physician at Legacy Emanuel Children's Hospital in Portland, Oregon, Dr. Randall Jenkins, read news accounts of the case and agreed to admit Ryan to Emanuel's kidney program. Once at Emanuel, Ryan's condition improved. He was taken off a ventilator and began to breathe independently. He underwent surgery to correct a bowel obstruction. When doctors removed him from dialysis, he was able to urinate on his own.

As this article goes to press, Ryan is being discharged from the hospital. According to Dr. Jenkins, the baby's kidneys are functioning at about three fourths of normal capacity. Since, at this level of functioning, his kidneys will "wear themselves out," he will eventually require a kidney transplant. Ryan continues to rely on tube feeding, and his long-term prognosis remains unclear with regard to possible cerebral palsy, muscle impairment, and brain damage. Still, Ryan's physicians and parents are grateful that he has made enough progress to leave the hospital, and everyone hopes he will do well in the future.

Questions about Futility

The case of the so-called "Spokane baby" is at the heart of a larger debate now raging within medical centers around the country over the use of medically futile interventions. Among the questions Ryan's case raises are the following. In light of the uncertainty associated with any medical decision, how can members of a health care team ever justify withholding or withdrawing a futile intervention? How can society prevent the sort of situation alleged by the Nguyens'

lawyer, in which claims of medical futility provide a smoke screen for invidious racial or other prejudice? How can physicians avoid "imposing" their values upon patients and families? Once doctors determine that a treatment is futile, must they find another institution willing to provide it if the patient or family insists? Finally, should it make a difference if patients have the ability to pay for futile treatment? If insurers are willing to reimburse doctors for futile interventions, is there anything wrong with doctors offering such treatments?

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Dealing with Uncertainty

Public perceptions about medical futility are undoubtedly colored by the fact that the media are more likely to report rare medical successes than routine medical failures. The public is thereby encouraged to ascribe God-like powers to physicians, and to expect "medical miracles" to occur. And in Ryan's case, it is true that despite a consensus of opinion that dialysis and other life-prolonging treatments would be futile, the patient has made considerable progress.

Most health care professionals who have practiced for any length of time are familiar with cases of this kind, where a patient with a dismal prognosis "beats the odds." Indeed, doctors and nurses learn early in their training never to say "never." Medicine, after all, is an empirical science. No matter how many times a treatment has failed in the past, there is always a *chance* that the next time it is used it will succeed. There will always be instances where a futile treatment works, just as there will always be instances where a recommended treatment fails. This hardly shows that medical judgment is worthless. Nor does it show that patients should always be treated irrespective of expected outcomes. The real question health care providers face is, How many times must they observe a treatment to fail before calling it futile for a given category of patients?

In trying to address this question, we should think about the term "futility" as marking a point along a probability continuum at which the likelihood of benefiting the patient is exceedingly poor. Specifically, it has been argued that we should call a treatment *quantitatively* futile when the chance that it will benefit the patient is less than 1 in 100. If a treatment is futile in this sense, it will occasionally succeed: Ryan, for example, did better than expected. Yet this does not estab-

lish that physicians should use life-prolonging treatments in future cases resembling Ryan's. Most babies in his situation will not do well. Moreover, institutional policies that routinely sanction futile treatments will condemn many patients to suffer needlessly. Therefore, general standards of medical practice require justifying the use of painful and invasive technologies by showing that they hold a reasonable prospect of helping the patient.

There is another way in which the term "futility" is used. Even in cases where the likelihood of benefiting the patient is relatively good, the quality of benefit may nonetheless be exceedingly poor. In such instances, treatment may be considered *qualitatively* futile. For example, the kidney specialists asked to consult on Ryan's case agreed not only that Ryan was doomed to die, but also that the quality of outcome Ryan would gain from dialysis was very bad. That is, it was widely held that Ryan was suffering greatly as a result of dialysis and other life-prolonging interventions.

Preventing Abuses

To the extent that health care providers openly discuss medical futility, and to the extent that health care institutions develop explicit policies about the withholding and withdrawal of futile interventions, abuses involving assertions of medical futility are less likely to occur. If a hospital has a policy in place carefully defining medical futility, then it cannot mean whatever the doctors in a given case decide it means. Nor can futility be invoked as a subterfuge for discrimination based on race, socioeconomic status, or other factors that should be irrelevant to medical decision-making. In short, the judgment of medical futility should not rest with individual physicians at the bedside, but should instead reflect a more general professional and societal consensus.

Such a consensus has been emerging gradually over the past several years. This is apparent in the public pronouncements of influential medical organizations, such as the American Medical Association and the American Hospital Association, among others, and in public statements from bioethical organizations, such as the Hastings Center and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.

Local consensus is also developing in places such as Denver, where area hospitals have jointly developed criteria for deciding that a treatment is futile. Such guidelines establish, for example, that aggressive treatments, such as CPR, are futile and generally should not be provided for patients who are bedfast with metastatic cancer, or patients with HIV who have had two or more *Pneumocystis carinii* pneumonia episodes, or patients with multiple organ system failure with no improvement after three days of intensive care. Other

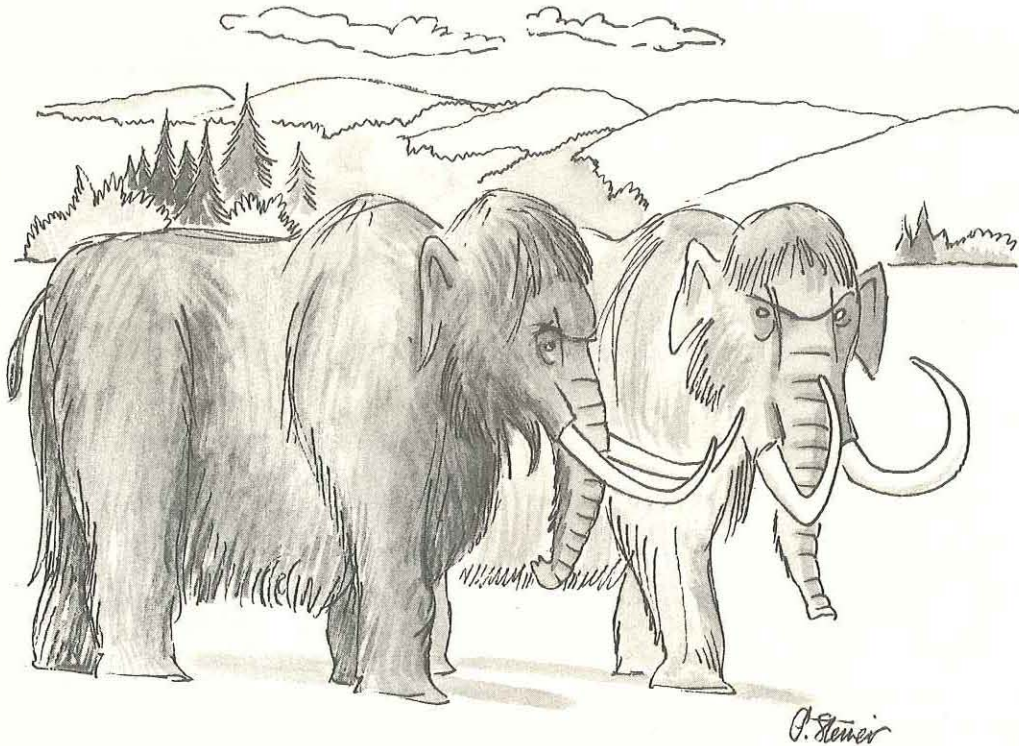
institutions, such as Santa Monica Hospital Medical Center, have defined futility more broadly to refer to "any clinical circumstance in which the doctor and his or her consultants, consistent with the available medical literature, conclude that further treatment (except comfort care) cannot, within a reasonable possibility, cure, ameliorate, improve or restore a quality of life satisfactorily to the patient." A generally worded policy can be useful so long as it specifies, as this one does, a relevant procedure or set of standards for evaluating judgments of medical futility. Here, consensus and consistency with medical literature are required, and futile treatment is carefully distinguished from caring efforts which should continue to be provided when treatment is futile. Such a policy provides institutional support to individual practitioners who face difficult choices. In addition, courts look to an institution's standards of care to determine the reasonableness of medical decisions in particular cases.

Those who oppose allowing health care providers to withhold or withdraw futile treatments may argue that such decisions are moral or ethical in nature, and that providers have no business imposing their values on patients and families. After all, medical school trains doctors only in medicine, not in ethics; therefore, physicians (and other health care providers) can claim no special expertise in ethics. In response, it can be said that value judgments are an inevitable part of practicing medicine. In Ryan's case, for example, providing dialysis as the Nguyens requested would not have enabled the medical team to escape making a value judgment. To the contrary, both *refraining from* interventions to keep Ryan alive and *employing* such interventions involved a value decision.

Referring Patients Elsewhere

Were Mr. and Mrs. Nguyen entitled to a referral? Were the Sacred Heart physicians obligated to find an institution willing to take Ryan, despite the fact that pediatric kidney experts agreed about the futility of dialysis? There are at least three different answers one might give. First, it might be argued that physicians have a duty to refer patients (and their families) to someone else who is willing to provide futile treatment. This answer implies that futile medical treatment is analogous to services such as abortion that fall within the range of ordinary medical services but which individual physicians may object to on the basis of personal conscience. The problem with this reply is that futility judgments reflect more than the personal beliefs of individual providers. Properly understood, they reflect general professional standards of care.

Second, it might be claimed that refusing to provide futile treatments is analogous to refusing to provide lifesaving medical care to a brain-dead patient. Just as we do not say to a family who requests continued ven-



"I hear they can freeze you until they discover a cure."

*Drawing by P. Steiner; © 1992
The New Yorker Magazine, Inc.*

tilator support for a brain-dead patient, "I don't treat the dead, but I know someone who does," so the Sacred Heart doctors should not say to the Nguyens, "We don't offer futile treatment at this hospital, but we know another hospital that does." According to this view, just as there is a generally accepted definition of death, so too there are generally agreed-upon standards governing medical futility. In Ryan's case, all the pediatric nephrologists Sacred Heart consulted agreed that dialysis was futile. Although there was some opposition at the margin, there is also opposition at the margin for the Uniform Death Act, and this hardly renders it invalid.

There is a final answer one might give to the question of whether physicians have a duty to refer patients elsewhere for futile treatments. It holds that although consensus about medical futility is in the process of developing, a truly stable and informed consensus takes time and builds slowly. Consensus, Daniel Yankelovich suggests, begins with dawning awareness of an issue, moves to a sense of urgency and discovery of choice, then to a more mature stage of taking a stand intellectually and integrating that stand with moral and emotional judgment. Although there may never be a national futility policy, in many areas of the country there is a fairly well-developed consensus, including explicit public guidelines govern-

ing futile treatment. In other areas, this process has hardly begun to occur. In light of this, it might be argued that to the extent that a stable consensus about the futility of a particular intervention is not forthcoming, health care professionals cannot appeal to professional standards to back the futility judgments they make. In such situations, providers are obligated to refer patients elsewhere for treatments that they cannot in good conscience provide. Ryan's case hardly fits this description, however, as there was general agreement among both the Sacred Heart doctors and medical experts across the country that dialysis was not medically indicated.

The Bottom Line

Some commentators may argue that so long as insurers are willing to pay for futile treatment, futile treatment should continue to be available. Such an argument assumes that most of the medical and ethical issues surrounding futile treatments can be resolved satisfactorily if physicians simply provide whatever services are in demand. This is an ethically dubious proposition, however. It is tantamount to saying that doctors are justified in doing anything for money.

In fact, the long-standing tradition of ethics in medicine prohibits physicians from using futile interventions. Medicine, the Greek physician Hippocrates reportedly

said, exists "to do away with the sufferings of the sick, to lessen the violence of their disease," but also "to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless." Socrates apparently offered a sharp warning to doctors who were tempted by money to prescribe futile interventions. He warned that they may suffer the same fate as Asclepius, a reputable physician who was killed by lightning after being "bribed with gold to heal a rich man who was already dying."

Although modern doctors sometimes encourage the false perception that medicine can perform miracles, the ethical standards of modern medicine are increasingly judging such actions harshly. Even if Ryan survives to lead a reasonable life, this hardly refutes the judgment made earlier by the Sacred Heart doctors. They correctly judged that the odds of dialysis benefiting Ryan were exceedingly slim and the odds of causing Ryan significant pain were overwhelming.

Caring for Patients

The Nguyens stated more than once that they longed for a physician who "cared." Yet painful, futile treatments are a poor substitute for genuine caring. When lifesaving interventions are futile, caring is best expressed by doctors and nurses who reaffirm to patients and families that they will not be abandoned, and that everything possible will be done to minimize the patient's suffering. Undoubtedly, some families will reject these overtures and continue to insist on

futile interventions. Yet far too often, demands for futile treatment arise not because the family has been offered other options and rejected them, but because the choice the medical team presents is between futile treatment or "doing nothing." By redoubling their efforts to care for patients and families, providers can make the process of acknowledging futility a more acceptable and humane prospect.

— Nancy S. Jecker

Nancy S. Jecker is associate professor in the Department of Medical History and Ethics, University of Washington, and coauthor (with Lawrence Schneiderman) of *The Wrong Medicine: Doctors, Patients, and Futile Treatment* (Johns Hopkins University Press, forthcoming). Sources: Gina Kolata, "Battle over a Baby's Future Raises Hard Ethical Issues," *New York Times* (December 27, 1994); J. Todd Foster, "Parents, Hospital Battle over Fate of Sick Infant," *Spokane Spokesman Review* (December 13, 1994); Lawrence Schneiderman, Nancy Jecker, and Albert Jonsen, "Medical Futility: Its Meaning and Ethical Implications," *Annals of Internal Medicine*, vol. 112 (1990); Daniel Yankelovich, *Coming to Public Judgment* (Syracuse University Press, 1991); Jeanette White and J. Todd Foster, "The Struggle over Baby Ryan," *Spokane Spokesman Review* (December 26, 1994); Nancy S. Jecker, "Knowing When to Stop: The Limits of Medicine," *Hastings Center Report* (May-June, 1991); Hippocrates, "Art"; Plato, *Republic*, Book III.

Science and Social Harm: Genetic Research into Crime and Violence

A variety of current research programs investigate genetic influences on violent, impulsive, aggressive and criminal behavior. Some attempt to tease out genetic from environmental influences through the study of twins and adoptees; others utilize the latest genetic technology to search for markers, and ultimately genes, associated with crime and violence. Still others are laboratory and clinical studies of the neurobiology of human behavior. While they differ greatly in method and ambition, these programs share the assumption that it makes scientific sense to look for

genetic influences on morally or legally significant categories of human behavior.

Vigorous objections have been raised against funding such research. As a liberal academic and criminal defense lawyer, I have become well-acquainted with these concerns, having spent much of the last three years organizing, then defending, then reorganizing, an interdisciplinary conference on the research and its social, legal, and ethical implications. Opponents of genetic research into crime and violence have argued that it promotes racism, diverts resources and atten-