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MEDICAL FUTILITY

Robert D. Truog*

CASE: SUN HUDSON

Wanda Hudson gave birth to a boy, whom she named Sun, on September 25, 2004, at St. Luke's Hospital in Houston, Texas. She had received no prenatal care before giving birth, so she was unaware that her baby would be born with significant physical and mental disabilities. When Sun was born, he had dwarf-like features, with very short appendages and an enlarged head, and he experienced significant respiratory distress from the moment he was delivered. He was immediately transferred and admitted to Texas Children's Hospital's Level III neonatal intensive care unit (NICU), the largest in the nation. He was placed on a ventilator and a feeding tube was inserted.

Genetic tests showed that Sun was born with thanatophoric dysplasia, which is a rare, fatal condition. While this lethal form of dwarfism causes severe mental and physical disabilities, what ultimately contributes to death is an abnormally narrow chest cavity that restricts the baby's ability to breathe. The chest cavity does not grow normally, so the baby's breathing problems only worsen until the baby suffocates to death. Most babies affected with this disorder die within a few hours or days after birth of respiratory insufficiency.

Ms. Hudson claimed that the sun was the boy's father and that he was normal and just needed time to develop. She insisted that intensive care continue to be provided to Sun. Physicians and other hospital personnel thought that she was incompetent to make decisions for Sun's care and that further care was futile and medically inappropriate and should be withdrawn. The Children's Bioethics Committee agreed. This was the first case to arise under the Texas Advance Directives Act, and the hospital provided Ms. Hudson with

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independent legal counsel as the case was filed in court. On March 14, 2005, nearly six months after Sun's birth, the probate judge hearing the case found there was no alternative provider willing to continue care for Sun and lifted the court's injunction and allowed the hospital to withdraw life-sustaining treatment from Sun. Ms. Hudson came to the hospital the following day and was holding Sun when he died shortly after treatment was withdrawn.¹

Cases like that of Sun Hudson's are among the most frustrating encountered by physicians and nurses in medicine today. As technology has become increasingly effective at prolonging life, the dark side of this success has emerged in the demands of families to use this technology to sustain life in situations that at best offer no hope of meaningful existence, and that at worst subject patients to unconscionable pain and suffering. As one of the most important functions of the law is to ensure due process, the temptation in this essay is to elaborate upon the strengths and weaknesses of the various procedural approaches that have been developed in attempts to resolve these disputes.

Although I will return to this issue at the end of the manuscript, I will begin by taking a step back from the usual discourse that surrounds this topic and provide what might be called a "differential diagnosis" of the concept of futility. In medical parlance, a differential diagnosis is a list of the possible conditions that could be causing the patient's signs and symptoms. In this context, it pertains to those sociological, psychological, and financial issues that often play a determinative role in how these conflicts are framed and resolved. My differential diagnosis is built around the issues of power, trust, hope, money, and suffering.²

1. Lance Lightfoot, *Incompetent Decision Makers and Withdrawal of Life-Sustaining Treatment: A Case Study*, 35 J.L. MED. & ETHICS 851, 851-52 (2005).

2. John D. Lantos, *Futility Assessments and the Doctor-Patient Relationship*, 42 J. AM. GERIATRICS SOC'Y 868, 868-70 (1994).

I. POWER

The first element in the differential diagnosis is power. While many scholars have attempted to define medical futility, my favorite description comes from the cartoonist Gahan Wilson in the *New Yorker Magazine*, who penned a scene of a browbeaten physician kneeling before a tombstone in a cemetery, anxiously fiddling with his stethoscope over the grave. Standing behind and over him with an intimidating expression is someone we take to be the wife of the deceased, seemingly demanding that the physician perform a miracle. All the physician can do is submissively look back over his shoulder and apologetically explain, "I'm afraid there is really very little I can do"³

This cartoon successfully captures the essence of the futility debate as it is experienced by clinicians. Fundamentally, the debate over medical futility can be summed up in the questions: "Who has the power to demand treatment, and who has the power to say no?" In this sense, these questions have taken a 180-degree turn over the last few decades. During the 1970s and 1980s, the debate was about the rights of patients to refuse medical treatment. Whereas today we recognize broad rights for patients to refuse unwanted therapy, during the past two decades the central question has shifted to the rights of patients and families to demand medical treatment, and here we have little, if any, consensus.

As bioethicist John Lantos has observed, how one views the debate hinges to a large extent on how one frames the issues. So, for example, those who ask, "Do patients and families have a right to force doctors to squander scarce time and resources on therapies that have no benefit in order to satisfy their irrational wishes?" will likely come to different conclusions from those who ask, "Do doctors have a right to arbitrarily ignore the values and preferences of patients and

3. Gahan Wilson, *I'm Afraid There Is Really Very Little I Can Do*, THE NEW YORKER, Feb. 15, 1999, http://www.thenewyorkerstore.com/product_details.asp?sid=40848.

families using their own value systems to make life and death decisions for others?”⁴

Bioethicist Art Caplan has helpfully characterized this as a debate about “odds and ends,” with conflicts about futility being defined by how one answers the questions: “What chance or probability of success is ‘worth it’?” (a question of odds) and, “What quality of outcome is ‘worth it’?” (a question of ends).⁵ Throughout the years there have been many attempts to define futility in terms of medical criteria, thereby placing it squarely within the medical domain and implicitly empowering physicians with the authority to decide what is futile and what is not. Yet despite the wish to fence these judgments within the realm of medical expertise, even casual reflection reveals that physicians did not learn in medical school the answers to questions such as: “Is a one in a thousand chance of success ‘worth it’?” or, “Is a life with moderately severe cognitive disabilities ‘worth it’?” As I will discuss in more detail below, although the Texas Advance Directives Act (TADA) does not explicitly endorse the decision-making power of physicians over patients, it has stacked the deck in such a way so as to give them virtually absolute authority.

II. TRUST

The second element in the differential diagnosis is trust. Articles about futility rarely explore the fact that these conflicts do not arise randomly. Although there are some notable exceptions, futility cases most commonly involve patients and families from the more marginalized and disadvantaged segments of our society. These are families who have lived on the outskirts of our healthcare system, and who have frequently been denied or perceive that they have been denied, care that is beneficial. Now they are, once again, being told that they cannot have a treatment that may not only be beneficial but actually life-sustaining. Why should they believe physicians who tell

4. *Id.* at 868.

5. Arthur L. Caplan, *Odds and Ends: Trust and the Debate over Medical Futility*, 125 ANNALS INTERNAL MED. 688 (1996).

them that the use of this treatment would be futile? In point of fact, research actually shows that their skepticism may be justified. Numerous studies demonstrate that “evidence-based” predictors of mortality are highly unreliable for individual patients.⁶

III. HOPE

Third on the list is hope. Hope is not constrained by rationality. No one thinks that someone is crazy just because they are hoping for something that is very unlikely. One of the most important sources of revenue in many states is the lottery, and its success is of course a reflection of the very large number of people who buy tickets. Given that lotteries have been accurately described as a tax on those who are not very good at math, how should one account for their considerable success? The answer, I think, is that when the payoff is big enough, many people are willing to take unreasonable and irrational risks. This is just human nature. For those who are desperately ill in the hospital, where death may be the only alternative, is any chance of success too small to hope for?

As the poet Maya Angelou said, “In order to survive, a human being needs to live in a place furnished with hope.”⁷ Many compassionate clinicians have learned that patients and families can evolve through terminal illness to see their hopes transformed from a wish for cure and recovery to hopes for peace and closure. But it does not always work this way. Abigail Zuger wrote of her experience as a resident in internal medicine caring for Jerry, a patient with terminal AIDS.⁸ Day after day, she went into his room trying to persuade him to accept a do-not-resuscitate (DNR) order, explaining that any

6. See Sonia Frick, Dominik E. Uehlinger & Regula M. Zuercher Zenklusen, *Medical Futility: Predicting Outcome of Intensive Care Unit Patients by Nurses and Doctors—A Prospective Comparative Study*, 31 CRITICAL CARE MED. 456, 456–61 (2003); see also Pedro A. Mendez-Tellez & Todd Dorman, *Predicting Patient Outcomes, Futility, and Resource Utilization in the Intensive Care Unit: The Role of Severity Scoring Systems and General Outcome Prediction Models*, 80 MAYO CLINIC PROC. 161, 161–63 (2005); John Rapoport, Daniel Teres & Stanley Lemeshow, *Can Futility Be Defined Numerically?* 26 CRITICAL CARE MED. 1781, 1781 (1998).

7. Interview by Oprah Winfrey with Maya Angelou in Chicago, Ill. (2003).

8. Abigail Zuger, *High Hopes*, 262 J. AM. MED. ASS'N 2988 (1989).

attempts at resuscitation were bound to be futile, leading only to pain and suffering that would end in death. Each day he resisted, feeling confident that a cure was “just around the corner” and could happen any day. But eventually he got the picture, reason prevailed, and he signed his DNR order. But she closes her essay with a moving and ambivalent observation on the “success” of her counseling to have Jerry forego intensive care and resuscitation: “Which was, in fact, the greater cruelty? Was it the one she avoided, which would have condemned Jerry to a protracted death in the intensive care unit, all blood and tubes and pain? Or was it the one she committed, sitting on Jerry’s bed, holding his hand, and methodically erasing all the hope from his eager eyes?” Reason and rationality have their place, but they also have their price.

IV. MONEY

One of the most complex and confusing elements of the differential diagnosis is the role of money, and in particular the way that judgments about futility have been conflated with judgments about the fair allocation of scarce resources, or rationing. The work of Larry Schneiderman and his colleagues has been very clear on this point: “rationing refers to the allocation of beneficial treatments among patients; [whereas] futility refers to whether a treatment will benefit an individual patient.”⁹ In other words, denying futile care to patients and families should have nothing to do with saving money through the fair allocation of scarce resources. If a treatment is futile, it is not worth doing, no matter how much it costs, no matter how little it costs—indeed, futile treatments are not worth doing even if they are free.

While this point is well-accepted within the academic community and the literature on this topic, the truth is that actual futility cases are almost always intertwined with questions about saving money and

9. Lawrence J. Schneiderman & Nancy S. Jecker, *Medical Futility: Response to Critiques*, 125 ANNALS INTERNAL MED. 670, 673 (1996).

cutting costs. Consider, for example, that questions of futility rarely arise around treatments that are cheap or easy to provide. For example, if a patient with widely metastatic breast cancer demands to be provided with vitamin C in the belief that it will be beneficial, I suspect that few would object. After all, it costs almost nothing and is safe—who cares if it does not work, as long as it makes the patient feel good? On the other hand, if this same woman demands treatment with high-dose chemotherapy followed by a bone marrow transplant based on the same belief that it may be beneficial, most would refuse, on grounds that convincing research has demonstrated that such treatment offers no benefit and is futile. So even if one were to agree that futility judgments should be isolated from financial considerations, in the real world these judgments tend to be applied primarily in situations that are resource-intensive.

The reasons for this provide some insight into the psychology of futility determinations. As demonstrated by our recent healthcare debates, most Americans are allergic to the concept of rationing in healthcare. Yet everyone seems to understand that healthcare expenditures are rising at an unsustainable rate. One strategy for seeking to save money while refusing to acknowledge the need to ration is to claim that all will be well if we simply stop providing treatments that are futile. In this way, the concept of futility serves as an end-around approach to rationing and saving money. In other words, if we can label some treatments as futile, we can successfully deny marginally beneficial treatments to patients and families without having to acknowledge that we are really rationing.

This strategy has two significant problems. In the broadest sense, fair allocation of resources requires us to separate those treatments that are cost-effective from those that are not (within any defined global budget for healthcare). But any fair approach to separating cost-effective from non-cost-effective treatments must be willing to look across the entire spectrum of all healthcare expenditures.

Consider, for example, the case of Avastin.¹⁰ Initially approved for treatment of advanced colon cancer, this drug can cost as much as \$100,000 per year, and in 2007 Genentech reported \$2.3 billion in sales in the United States alone—all of this for a drug that prolongs life for patients with colon cancer by only a few months, at best (recent studies suggest that its true effect may be even less). Furthermore, Avastin was approved by the FDA this past February for patients with metastatic breast cancer, against the recommendation of its own advisory panel, and despite no evidence of prolonged survival or improved quality of life in patients who receive the drug.¹¹

Now if Avastin were a unique example of an arguably non-cost-effective treatment which is routinely made available to patients, both on- and off-label, then the problem might be limited, but in fact the Avastin example is not at all unusual, and indeed much of the new drug development that is occurring in this country shares many of the same problems.

So the issue is as follows: if one were to look at the definitions of medical futility that have been developed over the years, Avastin would surely seem to fit into that category, particularly for breast cancer. If the goal is to provide only cost-effective care, then why are policymakers not turning a critical eye on the many treatments that are like Avastin? Could it be because elimination of these drugs would significantly impact the profit margins of the pharmaceutical companies and deny treatments (that offer more hope than benefit) to the relatively few fortunate patients who are able to pay for them? Why do we single out for elimination cases like that of Sun Hudson, seeking to deny life-sustaining treatment under conditions that are highly contentious, divisive, and fraught with difficulties in terms of jeopardizing trust within the patient-physician relationship?

10. See Dan W. Brock, *How Much Is More Life Worth?* 36 HASTINGS CENTER REP. 17, 17–19 (2006); see also Gina Kolata & Andrew Pollack, *Costly Cancer Drug Offers Hope, but Also a Dilemma*, N.Y. TIMES, July 6, 2008, at A1.

11. See Kolata & Pollack, *supra* note 10.

Not only is it unfair to target cases like that of Sun Hudson rather than Avastin, but it is also ineffective. Evidence shows that refusing to provide life-sustaining treatments under conditions of futility will not save very much money. This point is counterintuitive to most clinicians, because everyone who has practiced in hospitals can remember horrendous cases, like that of Sun Hudson, that seem like an enormous waste of money and resources. Yet there is a powerful recall bias that is operative here; these cases seem to stick in our memories for reasons that are out of proportion to their true impact. Several lines of research all point to the conclusion that elimination of treatments that meet any reasonable definition of futility will not save very much money. Consider, for example, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a study of more than 4,000 critically ill patients.¹² Of these patients, 115 were predicted to have less than a 1% chance of surviving two months. Of these, all but one died within 6 months, and most died within 5 days. If the clinicians had decided that further treatment for these 115 patients was futile, and if they had stopped treatment immediately, \$1.2 million would have been saved. Not only is this a relatively small amount of money in the context of 115 patients, but the majority of the money would have been saved in the context of only 12 patients, 6 of whom were under 51 years of age, one of whom lived for 10 months, and all of whom had religious convictions not to have life support withdrawn. In other words, \$1.2 million could have been saved, but almost certainly at the price of considerable conflict, emotional angst, and potentially costly litigation.

Other research using different methodologies has arrived at similar conclusions. For example, a research group in Houston, Texas that performed a retrospective review of patients in their adult intensive care unit and examined the likely financial impact of refusing care

12. Joan M. Teno et al., *Prognosis-Based Futility Guidelines: Does Anyone Win?* 42 J. AM. GERIATRICS SOC'Y. 1202, 1202-07 (1994).

they determined to be futile.¹³ They concluded that “[t]he frequency of futile interventions appears to be low unless one is willing to accept a definition that includes patients who could survive for many months. . . . [T]his suggests the concept of futility will not play a major role in cost-containment.” A similar study in a Pediatric Intensive Care Unit (PICU) reached essentially the same conclusion: “Despite our use of broad definitions of medical futility, relatively small amounts of resources were used in futile PICU care. . . . Attempts to reduce resource consumption in the PICU by focusing on medical futility are unlikely to be successful.”¹⁴ Willie Sutton astutely robbed banks “because that’s where the money is”¹⁵—one could ask why those who seek to save healthcare dollars seem to persevere around highly contentious disputes involving the use of life-sustaining therapies rather than focusing more productively on the widespread use of extremely expensive, low-benefit treatments like Avastin?

In sum, the debate about medical futility has been confused by those who want to use the concept as a “back-door” way of rationing resources, by denying marginally beneficial care to some patients without having to acknowledge that it has anything to do with rationing. This is wrongheaded first because it targets a generally marginalized population rather than spreading the burdens fairly across everyone in society, and second, because it addresses a problem where the cost savings would be modest while ignoring the need to ration or eliminate treatments that are equally ineffective and where the cost savings would be quite substantial.¹⁶

13. Amir Halevy, Ryan C. Neal, Baruch A. Brody, *The Low Frequency of Futility in an Adult Intensive Care Unit Setting*, 156 ARCHIVES INTERNAL MED. 100–04 (1996).

14. Ramesh C. Sachdeva, Larry S. Jefferson, Jorge Coss-Bu, & Baruch A. Brody, *Resource Consumption and the Extent of Futile Care Among Patients in a Pediatric Intensive Care Unit Setting*, 128 J. PEDIATRICS 742, 742 (1996).

15. Steve Cocheo, *The Bank Robber, THE QUOTE, and the Final Irony*, http://www.banking.com/aba/profile_0397.htm.

16. Martin L. Smith et al., *Texas Hospitals’ Experience with the Texas Advance Directives Act*, 35 CRITICAL CARE MED. 1271 (2007).

V. SUFFERING

The fifth and last element in the differential diagnosis for futility is that of suffering. Suffering is an issue for everyone involved—patients, families, and providers. My first point is that I do not think we have been serious enough about preventing the suffering of patients. When family members insist upon treatments that are causing pain or suffering, we need to be much more proactive in challenging their role as surrogate decision makers, and we need to seek to have them replaced by a guardian ad litem, if necessary. In comments before the President’s Council on Bioethics in September 2008, legal scholar Thaddeus Pope noted that the courts recently have been more willing to take this approach than they have been in the past, particularly in situations where the surrogate does not seem capable of fully appreciating and responding to the medical needs of the patient.¹⁷

Judgments about suffering are subjective and do have some pitfalls, however. For example, when children are admitted to the intensive care unit in which I work, parents often ask if their child will suffer. We are quick to reassure them, telling them that we take great pride in using sedatives, analgesics, and other techniques to assure that suffering is minimized or eliminated for the patients under our care. However, days or weeks later, when the child has not improved as we had hoped, we will often sit with the same parents and recommend withdrawal of life support, sometimes supporting this recommendation with the statement, “Your child has already suffered so much.” To be clear, I think this is perfectly understandable, and I am not criticizing the practice per se (I have said things like this on many occasions), but the point I want to make here is that in the context of futility we cannot ask the word “suffering” to mean whatever we want it to mean in order to suit our purposes at the moment. The truth is, many times the patients

17. Thaddeus Mason Pope, Remarks Before the President’s Council on Bioethics, Medical Futility: Institutional and Legislative Initiatives (Sept. 12, 2008), <http://www.bioethics.gov/transcripts/sept08/session5.html>.

involved in futility disputes are either so severely neurologically damaged or so deeply sedated that the possibility of pain and suffering is remote. Under these circumstances, suffering is not an issue.

The concerns about the suffering of caregivers are very different but no less important. I will not explore them in detail in this essay, but only note that issues of moral distress and burnout are of increasing concern among intensive care unit (ICU) clinicians, and especially among nurses. Three brief quotations from a paper that deals with the problem of burnout among ICU nurses around providing futile care give a flavor of the magnitude of the problem:¹⁸

- “I often equate my job with ‘keeping dead people alive.’ On these days, I dread coming to work.”
- “I’m scared that I’m causing undue pain and suffering, and this causes me great distress.”
- “Some days I feel (physically) sick.”

VI. RESOLVING FUTILITY DISPUTES

From all that has been written above, one might conclude that I oppose futility policies and futility judgments, and indeed that is how my views have often been characterized. But although I have many concerns about the way that futility determinations are made, I do recognize that unilateral judgments by physicians to deny treatments that are inappropriate are ubiquitous in medicine. For example, one of the technologies we have in the ICU is a form of cardiopulmonary bypass called ECMO (extracorporeal membrane oxygenation). With ECMO physicians can, quite literally, keep almost anyone alive. And yet intensivists are highly selective in its use, reserving this expensive and invasive therapy only for situations where we expect a patient’s cardiac or respiratory failure to be quickly reversible. When this is

18. Ellen H. Elpern, Barbara Covert, & Ruth Kleinpell, *Moral Distress of Staff Nurses in a Medical Intensive Care Unit*, 14 AM. J. CRITICAL CARE 523, 525–27 (2005).

not the case, I do not believe I have an obligation to offer ECMO to patients and families or even an obligation to discuss it with them, and I would refuse inappropriate demands from family members to place a patient on ECMO.

What is the difference between the use of ECMO for patients with irreversible cardiorespiratory failure and the use of mechanical ventilation for patients like Sun Hudson? I will not pretend that there is a clear and bright line here, and in both cases I think a good argument can be made for unilateral refusal to provide life support. The difference, I suggest, is in the nature of the process that must be followed before such refusal is recognized as ethically and legally legitimate. Though value judgments are present in both situations, they are much more narrow and constrained in the ECMO case than in the case of Sun Hudson. Life on ECMO is essentially life under general anesthesia—when treatments are truly a “bridge to nowhere” it is hard to imagine any worldview or set of values that could justify a demand for this therapy. While some might see Sun Hudson’s life in the same terms, the fact is that many would judge life on a ventilator, even if of poor quality and short duration, as valued and worth living. In my mind, this puts decisions about life-support in cases like that of Sun Hudson’s in a different category from those about the use of ECMO for irreversible cardiorespiratory failure.

The process for adjudicating these disputes is therefore central to evaluating the legitimacy of how they are resolved. In the late 1990s, the Council on Ethical and Judicial Affairs of the American Medical Association (AMA) endorsed a procedural approach to futility determinations, stating that judgments of futility cannot be made by reference to rules or definitions but must be determined on a case-by-case basis.¹⁹ In this, it echoed an insight from U.S. Supreme Court Justice Potter Stewart in his comments on pornography, when he wrote, “I shall not today attempt further to define . . . [pornography]; and perhaps I could never succeed in intelligibly doing so. But I

19. Charles W. Plows et al., *Medical Futility in End-of-Life Care*, 281 J. AM. MED. ASS’N 937, 939 (1999).

know it when I see it.”²⁰ In other words, futility and pornography are both “all things considered” types of judgments that cannot be adequately captured by rules or definitions. Instead, one must develop a fair process for evaluating these conditions and then make determinations on a case-by-case basis.

VII. FUTILITY POLICIES: CHILDREN’S HOSPITAL BOSTON VERSUS THE TEXAS ADVANCE DIRECTIVES ACT

Finally, then, I turn to two procedural approaches for determining futility and compare their strengths and weaknesses. The first is the futility policy at Children’s Hospital Boston, which I helped develop more than ten years ago,²¹ and the second is the Texas Advanced Directives Act (TADA), which has been in place since 1999.²² Both approaches essentially conform with the process that was recommended by the AMA, in that both require consultation from an ethics committee or medical review committee as well as attempts to resolve the conflict by transfer of the patient to other willing providers. Finally, both endorse cessation of the futile intervention if the conflict remains intractable and if all opportunities for resolution have been exhausted.

Under either approach, the process could reach a point when clinicians inform the family that their demands for life-sustaining treatment will no longer be honored. If the treatment is mechanical ventilation, then the decision could be quite decisive and dramatic, as in the clinicians’ stating, “On Friday afternoon at three o’clock we will withdraw the ventilator, and we anticipate that your relative will die within minutes.”

The two policies differ substantially, however, about the options available to the family after the judgment of futility is made. At

20. *Jacobellis v. Ohio*, 378 U.S. 184, 197 (1964).

21. Jeffrey P. Burns & Robert D. Truog, *Futility: A Concept in Evolution*, 312 CHEST 1987, 1987–93 (2007).

22. See generally TEX. HEALTH & SAFETY CODE ANN. §§ 166.001–166.166 (Vernon 2000); Robert L. Fine, *The Texas Advance Directives Act of 1999: Politics and Reality*, 13 HEC FORUM 59, 59–81 (2001).

Children's Hospital Boston, the family would be told that if they disagreed with the decision, they would have the option of seeking a court order to prohibit the physicians from withdrawing treatment. Furthermore, if the family wanted to seek legal involvement but could not afford the cost of legal representation, the hospital would offer to cover those costs.

Has the policy at Children's Hospital Boston been effective in resolving futility disputes? While we do not keep precise records, the policy has been invoked on several occasions. Nevertheless, all of these cases have been resolved without having to resort to unilateral decision-making. Some view this as a failure of the policy, but I would disagree. Before we had the policy, clinicians were very reluctant to bring futility cases before the ethics committee because they knew that the committee had no mechanism for overriding the demands of parents. Now that we have a mechanism—a policy requiring consultation with the committee and respect for the parents' alternatives, including their option to pursue legal injunction—these cases are brought to the committee and undergo intensive efforts to achieve resolution. In some cases, the clinicians conclude that the harms of unilaterally refusing treatment are greater than the benefits of doing so. In other cases, the parents welcome the judgment of the committee as taking the burden of decision-making off of their shoulders, as if they were saying, "We could not have made this decision on our own, but since the doctors and nurses feel so strongly that this is the right thing to do, we will accept this judgment and not continue to resist their recommendations." Although we have not yet had a case that failed to reach resolution, if in the future such a case does arise, there is no reason to believe that the clinicians and the hospital administration would not follow through with a unilateral decision to withdraw life support, in accord with our policy.

In contrast, under the TADA, the families' options are much more limited. Under the Texas law, the physician's refusal to treat must first be reviewed by the hospital's ethics or medical review committee. The family must be given forty-eight hours' notice and be invited to participate in the process. The hospital must make

reasonable efforts to transfer the patient's care to others (which is usually not possible, because other institutions are very reluctant to take on cases already engulfed in anger and conflict). If no provider can be found in ten days, treatment may be unilaterally withdrawn. The family may request a court-ordered extension, which a judge should grant only if there is a reasonable chance of finding a willing provider. Finally, the treatment team is immune from civil or criminal prosecution.

My objections to the Texas law center around its approach to due process.²³ The TADA seeks to incorporate a due process standard by insisting that all allegations of futility go forward only after they have been reviewed and approved by the hospital ethics committee or a medical review committee. In such situations, the ethics committee is acting, under Texas law, as a surrogate judge and jury, with the statutory power to authorize clinicians to take life or death actions against the wishes of a patient or family. But whereas the judicial system assures Americans of access to a "jury of peers" or at least an impartial judge, hospital ethics committees are not held to this standard. Although it is true that most committees include one or two members of the community (often grateful patients of the hospital), most members are physicians, nurses, and other clinicians from the hospital staff. Without in any way calling into question their motivations or intentions, one must recognize that they are unavoidably "insiders," completely acculturated to the clinical world and its attendant values. This is hardly an impartial tribunal for many, indeed probably most, of the patients who are subject to these decisions. The TADA thus relies on a due process approach that is more illusory than real and that risks becoming a rubber-stamp mechanism for systematically overriding families' requests that seem unreasonable to the clinicians involved. During a two-year period at Baylor, for example, the ethics committee agreed with the clinical team in forty-three out of forty-seven cases.²⁴

23. Robert D. Truog, *Tackling Medical Futility in Texas*, 357 NEW ENG. J. MED. 1, 2 (2007).

24. Robert L. Fine & Thomas W. Mayo, *Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act*, 138 ANNALS INTERNAL MED. 743, 745 (2003).

Furthermore, while we proudly look to our courts as the guarantors of due process, under the Texas law judges have no latitude to overrule or even amend the decisions of the physicians and the hospital ethics committees. Judges are only empowered to extend the ten-day waiting period, and even then only if there is a reasonable chance of finding a willing provider, which is usually very unlikely. Although it would be interesting and helpful to know the number of times that the policy has been invoked and to be able to review the specifics of the cases, the Texas law inexplicably includes no provisions for such data collection or review (compare this, for example, with the physician-assisted suicide law in Oregon, which requires meticulous tracking of all cases). Indeed, Thaddeus Pope, a legal scholar who has been otherwise supportive of the Texas law as a model for other states, nevertheless commented in his recent testimony before the President's Council on Bioethics that "it's extremely unlikely the Texas statute will last another six months. . . . It doesn't comport with the requirements of Constitutional procedural due process." He went on to say that "[a] process-based approach may be the way to go, but we have to attend to procedural fairness. They've been around for thirty years, but health care ethics committees are not ready. They don't have the competence[;] they don't have the neutrality to exercise the sort of decision-making authority that the Texas statute has given them."²⁵

A historical analogy is useful here. In the 1970s, the parents of Karen Ann Quinlan, a young woman in a persistent vegetative state, argued that mechanical ventilation was futile and should be discontinued. Her physicians disagreed, arguing that it would not be ethical to discontinue a life-sustaining treatment. Had this case gone to an ethics committee, one could easily imagine that the committee would have sided with the clinicians. But her parents had access to the courts, and in what is now regarded as a landmark case, the court

25. Pope, *supra* note 17.

decided in favor of the rights of families to refuse unwanted medical treatments.²⁶

Are there ways that the Texas law could be improved? One possibility would be to “level the playing field” by giving this powerful authority over life-and-death decision making to another committee without the conflicts of interest that are inherent to hospital ethics committees. In Boston, for example, the Harvard teaching hospitals have supported the creation of a community ethics committee, composed of individuals from diverse backgrounds who do not have financial or social ties to the hospitals. This group has already produced white papers on several controversial policy issues, but it is not currently empowered to comment on individual clinical cases. If thoughtfully structured and utilized, however, community ethics committees could be educated around key aspects of medical care at the end of life and could provide a forum for deliberation about such cases that would be much freer from the biases and conflicts of interest that, in my mind, plague the Texas approach.

On the other hand, the availability of a fair and neutral decisional process is precisely what our judicial system has been designed to provide, and it has the benefit of more than two hundred years of development and refinement. We should consider carefully whether the creation of a “shadow” judicial system through the use of community ethics committees is likely to offer substantial improvements over the mechanisms already in place.

In sum, therefore, although I support a fair process approach to futility determinations and agree that under some circumstances it is ethical to unilaterally withdraw life support from patients against the wishes of their families, I believe the Texas approach is seriously flawed, and I believe any fair system must have some recourse to the traditional protections of the courts.

26. *In re Quinlan*, 355 A.2d 647 (N.J. 1976); Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J.L. MED. & ETHICS 182, 182–96 (2001).