



Tackling Medical Futility in Texas

Robert D. Truog, M.D.

For several weeks this spring, national attention was focused on a mother's struggle to prevent the Children's Hospital of Austin from withdrawing life support from her infant son. Emilio Gonzales

was an 18-month-old boy who had Leigh's disease, a progressive and fatal neurometabolic disorder. He had been on life support in the intensive care unit for 5 months. The hospital had invoked the Texas Advance Directives Act, which authorized it to withdraw life support if an ethics committee had determined that further life support was medically inappropriate and provided the hospital gave the family 10 days' notice and attempted to transfer Emilio to an alternative provider (see box). With the support of lawyers and a coalition of advocacy groups, Ms. Gonzales had successfully obtained extensions of the deadline, but Emilio died before the judge issued a final ruling on the case.

The Gonzales case is the most recent in a series of famous "futility" cases, including those of Helga

Wanglie, Baby L, and Baby K. All are stories about families' insisting on the continued use of life-sustaining treatments that physicians consider to be medically inappropriate. Many of these cases are the product of a severe breakdown of trust in the relationship between the clinicians and the patient's family. Even in the best circumstances, physicians often communicate poorly, and this deficiency is exacerbated when the communication must occur across the gaps created by language, class, and culture. Improvement of physicians' communication and conflict-resolution skills would no doubt go a long way toward preventing such cases from occurring.

But even impeccable communication and relational skills may not resolve conflicts that arise from fundamental differences in

values between families and clinicians. In such situations, clinicians often justify their efforts to override the requests of family members by claiming that the continued use of life support is causing the patient unwarranted suffering or is contributing to an undignified death. Though sometimes valid, these arguments are difficult to sustain in cases like that of Emilio. First, patients who require mechanical ventilation can always be made comfortable with sufficient doses of sedatives and analgesics, since the ventilator prevents the consequences of the respiratory-depressant effect of these medications. Second, paradoxically, as Emilio's neurologic condition worsened, his capacity to feel pain and to suffer actually diminished, reducing the moral force of this concern. Finally, regardless of whatever objections the clinicians may have had about the dignity of his death, his mother and others who spent time at his bedside clearly felt that his life was still dignified.

Although the clinicians in Aus-

Key Provisions for Resolving Futility Cases under the Texas Advance Directives Act.*

1. The physician's refusal to comply with the patient's or surrogate's request for treatment must be reviewed by a hospital-appointed medical or ethics committee in which the attending physician does not participate.
2. The family must be given 48 hours' notice and be invited to participate in the consultation process.
3. The ethics-consultation committee must provide a written report detailing its findings to the family and must include this report in the medical record.
4. If the ethics-consultation process fails to resolve the dispute, the hospital, working with the family, must make reasonable efforts to transfer the patient's care to another physician or institution willing to provide the treatment requested by the family.
5. If after 10 days (measured from the time the family receives the written summary from the ethics-consultation committee) no such provider can be found, the hospital and physician may unilaterally withhold or withdraw therapy that has been determined to be futile.
6. The patient or surrogate may request a court-ordered time extension, which should be granted only if the judge determines that there is a reasonable likelihood of finding a willing provider of the disputed treatment.
7. If the family does not seek an extension or the judge fails to grant one, futile treatment may be unilaterally withdrawn by the treatment team with immunity from civil and criminal prosecution.

* The list is adapted from Fine and Mayo¹ and Okhuysen-Cawley et al.² The full text of the law is available at <http://tlo2.tlc.state.tx.us/statutes/docs/HS/content/htm/hs.002.00.000166.00.htm>.

tin consistently denied that they were motivated by financial considerations, concern about excessive expense may be an ethically legitimate reason to refuse continued treatment to patients like Emilio. Health care is not an unlimited resource, and physicians have an ethical obligation to ensure that it is distributed fairly. Unfortunately, the United States has been reluctant to adopt a systematic approach to allocating resources across the health care spectrum. Although futility cases may seem like an obvious target for cost cutting, the evidence suggests otherwise. Even if life support were consistently denied to patients whose situations met common definitions of futility, the monetary savings would be trivial.^{3,4} This counterintuitive finding results from the facts that such cases are relatively rare (despite attracting considerable attention) and that the patients usually die within a short period, even when the requested life support is continued.

Aside from considerations of suffering, dignity, and money, clinicians may justify their refusal to treat on the basis of their right to refuse to participate in medical in-

terventions that they believe violate their moral integrity. The moral distress associated with providing futile care has been cited as an important source of burnout among critical care nurses.⁵ But though these concerns can sometimes be ethically legitimate, they are questionable in cases like that of Emilio. The claim that continued life support for Emilio was morally objectionable was nothing more than an assertion that the values of the clinicians were correct while those of Ms. Gonzales were wrong.

So what is the answer? In cases of intractable conflict, the American Medical Association and others have recommended an approach based on due process as a fair method for reaching resolution. The gold standard of the due-process approach is an honest judicial system. The Texas Advance Directives Act 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. 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 actions against the

wishes of a patient and family, with protection against civil and criminal liability. But whereas the judicial system assures Americans of having a "jury of peers," 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, we must recognize that they are unavoidably "insiders," completely acculturated to the clinical world and its attendant values. This is hardly a "jury of peers" for a low-income woman of color and her infant son.

Of course, we could do better. Some have suggested setting up ad hoc ethics committees with a membership that truly represents the diversity of the local population, without any financial or social ties to the hospitals they serve, specifically to offer a more legitimate sounding board for difficult cases in which the hospital ethics committee could be seen as having a conflict of interest or a biased perspective.

But even this solution is not sufficient. As a liberal society, we take pride in protecting the rights of minorities against the tyranny of the majority. Of all the unpopular values and preferences that we might respect, should not we favor those that have life-or-death consequences for the persons involved? Families live with the memories of the death of a loved one for years; certainly their religious, cultural, and personal preferences during that process should be honored, or at least tolerated, whenever possible.

The principal advantage of the Texas Advance Directives Act is that it provides a path for resolving intractable dilemmas in situations in which clinicians may feel compelled to do whatever patients and families demand. The law may therefore serve a useful purpose when patients are subjected to unwarranted pain and suffering or

when clinicians have defensible claims that these demands compromise their moral integrity.

On the other hand, the Texas law's effectiveness as a mechanism for reaching closure in difficult cases is also what makes it most problematic. It 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 2-year period at Baylor Health Care System, for example, the ethics committee agreed with the clinical team's futility assessment in 43 of 47 cases.¹ Although there may be cases in which the law should be used to trump the demands of patients and families, it is doubtful that the Gonzales case was one of them. Rather than jeopardize the respect we hold for diversity and minority viewpoints, I believe that

in cases like that of Emilio Gonzales, we should seek to enhance our capacity to tolerate the choices of others, even when we believe they are wrong.

Dr. Truog is a professor of medical ethics and anesthesia (pediatrics) in the Departments of Anesthesia and Social Medicine at Harvard Medical School and the Division of Critical Care Medicine at Children's Hospital Boston — both in Boston.

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The Art of Letting Go

Ranjana Srivastava, F.R.A.C.P.

“Is there any money we need to pay? Is that why you won't treat him?”

Her face wears a hunted expression; her slender frame is weighed down by fatigue and untold distress. In her native country, people died for lack of sufficient funds for treatment.

“No, no,” I hurry to reassure her. “This has nothing to do with money. Health care is free here. It is just that he is not well enough to have treatment.”

“Anything, doctor — we will do anything to make him better. We have three young children.”

“I know.”

She walks down the corridor, whispering a prayer. I feel sick with the unfairness of life.

Her husband felt well 2 months ago. Last month, he developed an irritating cough that would not resolve with multiple courses of antibiotics. A CT scan of his chest revealed some suspicious opacities. When he rapidly became anemic, he was immediately admitted to the hospital for further tests. A gastroscopy uncovered a sinister gastric carcinoma, and further staging demonstrated the involvement of multiple lymph nodes. Simultaneously, his liver function started to deteriorate. The medical unit requested an oncology consultation. The entire sequence of events took place within a matter of days.

I met the patient and his wife on the medical unit. He walked

in slowly, holding onto an IV pole with a saline bag on it. His skin was jaundiced, his face filled with telltale signs of sleepless nights. Small pieces of cotton-wool marked failed attempts at venipuncture. “He has lost a lot of weight, and his back hurts,” his wife offered. “I am tired and sweating a lot,” he added. I was not surprised at the revelation. The cancer was highly catabolic. His hematologic reserve was dissipating every day; he had already required transfusion support. The skyrocketing liver-function readings beggared belief. The diagnosis of metastatic gastric carcinoma had been clearly established but for an unexpected occurrence — repeated imaging failed to