

# When Parents Request Seemingly Futile Treatment for Their Children

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## Abstract

This paper reviews the development of the concept of medical futility, particularly as it applies to pediatrics. It discusses the difference between technical considerations and value considerations in futility determinations, and then breaks down the concept of futility into four components—power, money, trust and hope.

**Key Words:** Futility, doctor-patient relationship, power, economics, trust.

THE TOPIC OF MEDICAL FUTILITY is difficult to address concisely. So much has been written about it over the past decade that it has become complex, arcane, and stale all at the same time. Furthermore, as a practical matter, as opposed to a theoretical one, I think it is virtually a non-issue in pediatrics today. That is because, as a practical and legal matter, the controversy has been essentially resolved. There are virtually no situations in which courts will give permission to doctors to withhold or withdraw treatment that parents request. Instead, courts have allowed parents to demand intubation of anencephalic babies and continued home ventilation of brain-dead children. Courts will, on occasion, forgive doctors who withhold or withdraw therapies over parental objections, but, in order to get that forgiveness, doctors need to take the risk that punishment, rather than forgiveness, may come their way. Most doctors are not willing to do that or, if they are, soon come to realize that they must overcome not just parents but their own legal counsel as well.

Conversely, courts rarely allow parents to opt for treatment withdrawal if doctors think treatment is indicated. So it appears that the current working policy in the US is that there must be consensus among doctors and parents in order to stop treatment, and that disagreement always leads to continued treatment. It is interesting to speculate about how things got this way. My own explorations of the futility issue over the years, which include inconsistencies, twists and turns, mirror the national debate so, to review the national debate, I will review some of my own past speculations on the issue.

I first started thinking about futility after the Baby Doe controversy in the mid-1980s (1). I was a fellow in clinical medical ethics at the University of

Chicago, and was puzzling over the explanatory guidelines that were published after Congress passed amendments to the Child Abuse and Treatment Act (1). These guidelines incorporated within them the moral outrage that followed the death of a baby with Down syndrome because his parents refused to consent to surgery for an easily correctable esophageal anomaly. The goal of these guidelines was to limit the situations in which such parental refusals had to be complied with. In other words, they addressed situations that were the opposite of the typical “futility” controversies. (Today, we are talking about situations in which parents want something done that doctors think is futile. In that situation, the doctors desperately wanted to treat the baby and even sought a court order to do so, but the parents did not want treatment.)

The guidelines may have been the first to incorporate within them the concept of medical futility. Interestingly, they didn't use it as it has come to be used since then—to define situations in which doctors are justified in not providing treatment (or, according to some formulations, obligated not to provide the treatment.) Instead, they used it to define situations in which it was permissible for parents to refuse treatment without being judged neglectful. Those were situations in which the treatment was either “futile” or, in the memorable words of the guidelines, “virtually futile and inhumane.” None of these three concepts—futile, virtually futile, or inhumane—was defined.

This definitional ambiguity in guidelines that were meant to resolve ambiguity led me to take up two projects. The first was an empirical study. Working at The University of Chicago with neonatologist Bill Meadow, I started with the intuition that cardiopulmonary resuscitation (CPR) might be futile for certain very sick premature babies. The intuition was based upon our understanding that CPR was often provided to such babies for multi-system organ failure—and the recognition that CPR had not been designed for this sort of problem or for this patient population. We studied outcomes after CPR was given to those babies and found that for a

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subset, namely those babies who received CPR outside the delivery room—that is, after the first minutes of life, when many had a transitory cardiac or respiratory depression—and within the first three days of life, none of the 39 babies survived (2). Our statistical analysis showed that, because of our small sample size, the confidence interval on our 0% survival rate went up to 7%. That is, the most we could scientifically claim was that the survival rate was likely to be very low, but we couldn't say with statistical certainty that it was zero. We also showed that, given the nature of statistics and confidence intervals, it would be difficult to ever do a study large enough to get the confidence interval small enough to prove that a particular treatment was absolutely futile. Instead, we raised the question of whether this sort of finding might satisfy the Baby Doe criteria, i.e., that the treatment could be considered “futile.” This would mean that it was one that parents might be legally permitted to refuse.

At the same time, we started a completely different sort of inquiry into the nature of medical futility. Working with the fellows and faculty of The University of Chicago's MacLean Center for Clinical Medical Ethics, we conducted an historical inquiry into the concept of medical futility and a theoretical analysis of the content of the concept (3). Interestingly, at that time, a search of Medline, the National Library of Medicine's database, turned up no articles that used the concept of futility in its modern context. That is, there were no papers published between 1966 and 1984 that discussed the ethical implications of futile medical treatments. It seemed to be a non-issue. There were several ancient discussions: Hippocrates, for example, warns physicians not to treat patients who have been “overmastered by their disease”; Jewish tradition considers how the moral obligations of patients to preserve their own lives (and loved ones and physicians to help them) shifts when death is imminent; and the traditional Catholic distinction between ordinary and extraordinary treatments may have an element of futility implicit within it. But doctors in the 1960s and 1970s didn't seem to worry much about futility. The only hits we had in Medline using “futility” as a keyword were for the psychiatric literature and articles discussing feelings of futility as a component of some depressive syndromes. So we thought we were the only ones thinking about it. (How wrong we were!)

Our paper (3) argued that there were two components to any futility determination. First, someone must determine the goals of treatment. If, for example, the goal of insulin therapy is to cure diabetes, then the therapy is futile. It can only control the disease, not cure it. If, however, the goal is to prevent hyperglycemia, insulin is quite effective. If the goal

is to prevent the long-term complications of diabetes, then insulin is only partially effective. For CPR, a similar sort of analysis might start with several possible goals. CPR could be intended to provide temporary oxygenation and circulation, to restore a spontaneous heart rate, or to lead to a full cardiovascular and neurological recovery from a cardiac arrest. CPR cannot be said to be “effective” or “futile” until its goals are defined. Once the goals are defined, there is a second element of any assessment of futility: the likelihood that the treatment will succeed in reaching those goals. The first component, we argued, properly belonged to the patient, not the doctor. The second component was the proper domain of the doctor, or, more accurately, the medical profession and its health services researchers, clinical epidemiologists, and statisticians. The first component was more value oriented, the second more quantitative. Both incorporated significant uncertainties. We suggested that both must be considered in any determination of futility.

In the meantime, the field of futility studies took off. Over the next ten years, hundreds of articles and numerous books appeared about medical futility. Hospitals developed and tried to implement futility policies. There were numerous court cases testing the limits of doctors' authority to make unilateral determinations of medical futility, thus overriding patients' or their surrogates' demands for continued treatment. All this sudden attention seemed curious to me. Why is it that nobody seemed to care about medical futility until 1985, and then suddenly it was the hottest issue in medical ethics? The answer seemed to be tied in with both the scientific and the political developments of the time. Scientifically, we were just starting to understand the implications of some of the technologies that had been developed over the previous decades. For example, renal dialysis first became widely used in the 1960s, long-term mechanical ventilation did not become practically effective until the 1970s, and solid organ transplantation was really a technology of the 1970s. The 1980s saw the first trials of an artificial heart. By the 1980s, people were starting to realize just how complicated were the decisions arising from these “half-way” technologies, these treatments that could sustain biological or physiological life but might not lead to improvement or cure. At the same time, the political environment was changing. Concern about expanding access had dominated health policy in the sixties. By the eighties, cost containment was the primary political concern, and Congress enacted a new payment method for Medicare.

I started working with a colleague, neurologist Bob Taylor, who was then a fellow at The MacLean Center, on a paper in which we argued that there was a fundamental economic element to futil-

ity determinations (4). This economic element became salient after the implementation of diagnostic-related groups (DRGs), when the financial incentives for doctors and hospitals shifted from rewarding excessive treatment toward rewarding the limitation of treatment. The shift was from a reimbursement system based upon doctors' charges—whatever doctors and hospitals charged is what they got paid—to a reimbursement system based on calculations of what the average cost of treatment for any particular diagnosis ought to be. Under a prospective payment system, hospitals received a set fee for the treatment of, say, a myocardial infarction, septic shock, or a motor vehicle accident victim with head trauma. Clearly, under this new system, it was in the interest of doctors and hospitals to limit treatment and get patients out of the hospital quickly and efficiently; and this, we argued, was the underlying stimulus that led doctors to rediscover the ancient concept of medical futility. We concluded that futility cases were really about money, and that they quickly came to be about power and trust.

My final try at an analysis of the issues found in futility controversies was an attempt to assess the whole topic in the late 1990s, after ten years had passed. Working with Mark Siegler and oncologist Paul Helft, I reviewed what we called “the futility movement” (5). We characterized that movement as an attempt to change public policy and local hospital policy in order to empower doctors to override patients' requests, or demands, for treatments that the doctors thought were futile. We argued that most futility policies that tried to thus empower doctors were, essentially, bluffs. The policies were written in such a way as to acknowledge that, if disagreements persisted, the cases would ultimately have to be resolved by courts. And we showed how reluctant most judges were ever to permit such prospective futility determinations by doctors to override the wishes of patients and family members. Many such cases had reached the courts. In such cases, different courts used all sorts of reasoning but generally came up with similar answers—that patients' or families' demands would override doctors' refusals. The only exceptions were the cases that reached the courts after a doctor had already imposed a futility determination, the patient did die, and the family then sued. In those cases, the courts generally did not hold the doctors liable. In short, courts seemed unwilling to give permission for prospective futility determinations but somewhat willing, on occasion, to offer forgiveness to doctors who made such determinations.

Why did it come out this way? Well, partly because of the issues that we raised in that early paper, where we broke futility up into its components—

the goals of treatment and the likelihood of success. The courts were reluctant to cede authority for the first to doctors and were, it seems, not particularly willing to ignore the confidence intervals, the rare chances of success in even the most unlikely situations. Put another way, they seemed to recognize that unilateral futility determinations were usually either one of two things. One, they could be masked quality-of-life determinations. For example, when doctors say that mechanical ventilation for a patient in a persistent vegetative state is futile, they don't really mean that mechanical ventilation will not sustain the patient's life. Instead, they fear that it will work—it will sustain biologic life but life of a quality that they deem insufficient to warrant the effort. To the extent that futility determinations are, in essence, such quality-of-life assessments, they should be identified as such and dealt with as such.

Alternatively, futility determinations can be probabilistic assessments that success is extremely unlikely. But in such situations, the only downside to trying a treatment that is unlikely to work is economic. It will be a wasted expenditure. To the extent that this is the case, futility determinations collapse into rationing decisions.

So the domain of true futility—that is, situations that are neither disguised quality-of-life assessments nor disguised rationing decisions—is extremely small, perhaps non-existent.

All this is not to say that the concept of medical futility is not a useful or important one. It is important, there are situations in which treatment is futile, and they can often be identified prospectively. Generally, in such situations, doctors explain this to the patients or their surrogates, the latter understand and accept the situation, and treatment is withheld or withdrawn. The concept of futility, in those cases, has a moral role in helping absolve patients or surrogates of the moral obligation to continue treatment. Futility has not, however, been as useful as a moral trump card to resolve intractable disagreements. Instead, it is, as it should be, a concept to be used judiciously and with trepidation, to help patients or family members identify and shift their perception of their own moral obligations.

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