

# How Can Hospital Futility Policies Contribute to Establishing Standards of Practice?

LAWRENCE J. SCHNEIDERMAN and ALEXANDER MORGAN CAPRON

## Introduction

A few years ago a battered infant was admitted to a California hospital. After a period of observation and testing, the physicians concluded that the infant had been beaten so badly that his brain was almost completely destroyed, leaving him permanently unconscious. The hospital had just adopted a policy specifying that life-sustaining treatment for permanent unconsciousness was futile and, therefore, not indicated. According to this policy, after suitable subspecialty consultations and deliberations, including efforts to gain parental agreement and documentation of unanimous ethics committee support, the patient's physician had the authority to discontinue life-sustaining treatment. The infant's physician wished to do this. The mother, however, who was the prime battery suspect, insisted that the baby be kept alive.

In dealing with this conflict, the ethics committee members were mindful that the case might serve to test the hospital policy in court, if it came to that. The committee members reasoned that the hospital could anticipate a sympathetic response from a jury because the diagnosis and prognosis were not disputed by any of the medical staff and it seemed evident that the mother was not acting in her baby's best interests, but only in her own interest, namely to avoid a murder charge.

Right at that time, however, the U.S. Court of Appeals for the Fourth Circuit handed down an opinion that seemed to support parents who insisted on continuing treatment even when their child's physicians thought it was futile. In that case, a Virginia hospital, where an anencephalic baby (known in the court as Baby K) had twice been resuscitated, sought a judicial declaration that it was not required to provide respiratory support if Baby K returned to its emergency room a third time.<sup>1</sup> Although Baby K's father and guardian *ad litem* agreed that CPR would be "medically or ethically inappropriate" (the terms used by a state statute which said that physicians were not required to provide such treatments), the court, by a vote of 2 to 1, sided with the mother who wanted life support continued. The court ruled that under the Federal Emergency Medical Treatment and Active Labor Act (EMTALA),<sup>2</sup> the hospital had to provide mechanical ventilation for Baby K if that was what it would do for other patients with comparable respiratory problems. We believe this was a misapplication of EMTALA, which was really intended to stop hospitals from

---

The conference was supported by grants from the Agency for Health Care Policy and Research, the Walter and Elise Haas Fund, and the Whitehill Foundation. The administrative assistance of Sharyn Manning is gratefully acknowledged.

“dumping” indigent emergency patients. As the dissenting member of the Fourth Circuit panel said in the case of *Baby K*, “even in its weakest moments,” Congress “would not have attempted to impose federal control in this sensitive, private area.”<sup>3</sup>

*Baby K* actually provides no judicial guidance on the legality of ceasing treatment deemed to be futile.<sup>4</sup> Indeed, the Fourth Circuit court itself ruled in a subsequent decision that *Baby K* “turned entirely on the substantive nature of the stabilizing treatment that EMTALA required for a particular emergency medical condition.” Once a patient has been admitted, a hospital is not obligated by EMTALA to continue any particular treatment indefinitely. EMTALA, the court ruled, “cannot plausibly be interpreted to regulate medical and ethical decisions outside [the emergency room] context,” thus leaving the futility issue to be resolved under state law.<sup>5</sup> Nonetheless, the *Baby K* decision captured much attention and had a chilling effect on hospitals’ willingness to implement futility policies.

For example, shortly after *Baby K* was decided, a lawyer who had helped to write an *amicus* brief on behalf of the American Academy of Pediatrics supporting the Virginia hospital’s position, paid a visit to the California hospital. On his advice the hospital administration rescinded the futility policy and refused to allow the withdrawal of life support on the battered, unconscious infant. This baby died five and a half years later without ever regaining consciousness.

At least one hospital has been willing to terminate life support on futility grounds, despite objections from the patient’s next of kin, and then face a suit for damages in court. Following advice from the chair of the hospital’s ethics committee, physicians at the Massachusetts General Hospital overrode the objections of the family of Catherine Gilgunn (a comatose 71-year-old patient who suffered from many medical complications) and removed her respiratory support. After her death, the patient’s daughter who served as her surrogate decisionmaker sued the hospital and two physicians, but the jury rejected her claim of negligent infliction of emotional suffering.<sup>6</sup> The defense argued to the jury that CPR would not only have been ineffective in prolonging the patient’s life but would actually have been harmful to this dying patient.

One of us (AMC) has argued that this is the weak version of futility—not the position that physicians are entitled to withhold care that does not offer sufficient likelihood of producing a “meaningful” existence, but only that treatment may be forgone when the impairment is beyond reversal or, in the words of the expert witness in the Massachusetts case, the treatment “could not produce the desired physiological change.”<sup>7</sup> One of us (LJS) believes that a major import of the jury decision is that it provides evidence that society is quite receptive to the notion that physicians are not obligated to provide treatments judged to be futile. Both of us agree that the outcome in *Gilgunn* remains ambiguous, given that no appellate review of the trial court’s judgment has occurred.

Despite the outcome in the *Gilgunn* case, many healthcare professionals do not feel they will be supported by their institution if they act according to what they perceive to be their professional values. This was strikingly revealed in a survey of representatives of all 43 children’s hospitals in the country conducted after the *Baby K* decision.<sup>8</sup> Although the respondents unanimously condemned the efforts to keep alive the anencephalic *Baby K* (who survived over two years), almost all acknowledged that their own hospital would probably yield

to demands for life-sustaining treatment in a similar case because of fears of lawsuits and bad headlines.

This apparent disparity between professional values and professional actions led us to explore whether it would be possible to develop a consensus on institutional futility policies that would ensure sensitivity to patients' values, as well as recognition of professional obligations and limits, and serve as a basis for standards of practice when conflicts occur over end-of-life medical treatment.

Seventy-four participants, consisting of 30 MDs, 15 attorneys, 5 judges, and 24 others, including nurses, members of the clergy, social workers and community representatives, including 53 ethics committee members from 39 hospitals, attended a day-long conference, which took place in San Diego on February 20, 1998. Exemplary cases were discussed and 26 hospital futility policies were critiqued. The participants were not chosen randomly, but rather to provide diverse viewpoints in a forum of manageable size. They came from Northern and Southern California, from religious and secular institutions, from academic, managed care, and community hospitals, and from within and without the healthcare profession. All the California university medical centers (UCSD, UCLA, UCI, UCD, USC, UCSF, Stanford, Loma Linda, King-Drew) were represented by participants and/or policies. The community hospitals represented were: Alexian Brothers Hospital, Alvarado Hospital and Medical Center, Kaiser Permanente, Scripps Memorial Hospitals (Encinitas and Chula Vista), and Scripps Clinic-Green Hospital, Enloe Hospital, Santa Barbara Cottage Hospital, Paradise Valley Hospital, Long Beach Memorial Medical Center, Hoag Hospital, Palomar Hospital, Little Company of Mary Hospital, San Bernardino Hospital, St. John's Medical Center, Tri-City Hospital, Cedars-Sinai Medical Center, Santa Monica Medical Center, and Fountain Valley Hospital. The Santa Clara Medical Society was also represented.

### Summary of Hospital Policies

Without exception, all 26 hospital policies endorsed the present ethical and legal standard that adult decisionally capacitated patients may refuse any treatment, even life-sustaining treatment. Variations occurred with respect to treatments demanded by patients, however. One hospital policy stated that physicians "should act to support the patient's life," without further qualification. All but two hospital policies specifically defined circumstances in which treatments should be considered nonobligatory even if requested by a patient or patient representative. In describing such treatments, 15 hospital policies used the term "futile" and five hospital policies used the term "inappropriate." Six hospitals used other terms: "nonbeneficial," "no longer obligatory or ethically mandated," "ethically objectionable," "irreversible and incurable," and "not medically indicated."

All but two hospital policies defined the nonobligatory treatment in terms that were benefit based rather than physiology based. For example, many hospital policies made clear that patient awareness and potential for appreciating the benefit of the treatment were the criteria for judging a treatment. Fourteen policies provided specific examples of clinical conditions that did not warrant life support because of lack of patient awareness or benefit. The most common examples were permanent unconsciousness (12 policies), permanent dependence for survival on treatment available only in the Intensive Care Unit

(ICU) (8 policies), severe and irreversible dementia (4 policies), and irreversible multi-organ failure or end-stage illness (6 policies).

All of the hospital policies cited the necessity for dispute resolution but were limited in describing the procedures. They all described, albeit sometimes briefly, a role for an ethics committee in dealing with such matters. Twelve policies specifically referred to comfort/palliative care as an alternative to futile treatment within the context of end-of-life management.

With respect to who makes the final treatment decision after all efforts to resolve disputes have failed, the hospital policies took varied positions. Sometimes the position was not clearly spelled out. Nine (or possibly ten) policies assigned the final decisionmaking authority to the responsible physician. Seven policies specifically stated the patient or patient representative had the final decisionmaking authority. Others assigned the decision elsewhere, for example to an intra-institutional Optimum Care Committee (one), the court (one), or the chief of staff (one). Three listed various combinations of providers, ethics committees, court, hospital administration, and patient/surrogates without specifying the ultimate decisionmaker.

### **Establishing Standards of Practice**

Although society regulates the professions and the organizations where they provide care, the setting of professional standards is typically left to the professions themselves. Through various oversight mechanisms, society either accepts or rejects these standards—and sometimes leads the way by pushing for adjustment in professional norms that have lagged behind changing public expectations.<sup>9,10</sup> Those with long experience in public opinion research point out that achieving societal consensus is a gradual and evolving process.<sup>11</sup> It begins with public awareness of an issue; proceeds to understanding by working through the issue, including changing unrealistic expectations; leading finally to resolution on cognitive, emotional, and moral levels. This long process, which involves landmark judicial decisions, has been required to evolve contemporary standards of practice for care at the end of life and is now under way regarding futile medical treatment.

In the past half-dozen years, working groups of professional and laypersons throughout the country have started to develop consensus-based futility hospital policies.<sup>12,13,14</sup> Also, the American Medical Association's *Code of Medical Ethics* presents guidelines on "Medical Futility in End-of-Life Care" which propose that: 1) All healthcare institutions, whether large or small, should adopt a policy on medical futility; and 2) Policies on medical futility should follow a due process approach.<sup>15</sup> The *Code* outlines a seven-step sequence involving efforts at dispute resolution, including negotiation, and offering patient transfer to another physician or institution. In the end, the limit to the physician's obligation is clearly stated: "If transfer is not possible, the intervention need not be offered."<sup>16</sup>

Futility policies, like all institutional policies, attempt to bridge the gap between the cultures of medicine and the law—doctors trying to say legal things, lawyers trying to say medical things. At the California conference, healthcare providers, wanting to avoid doing things to patients that they judge to be futile, inappropriate, or burdensome,<sup>17,18</sup> tended to seek specific and descriptive *definitions* of these kinds of treatments. By contrast, lawyers and judges were more

concerned about putting in place detailed *procedures* that will protect vulnerable patients.

When cases come to court, and on appeal to higher courts, it will be judges who decide whether professional judgment is in line with society's expectations. Because the general language of statutes dealing with disability, rehabilitation, child abuse, and emergency treatment gives the courts substantial discretion in interpretation, judges will ask: Where does the medical profession stand on these difficult matters? What standards does it profess? And, most tellingly, how does it behave?

In response to these questions it would seem essential that healthcare institutions develop futility policies that contribute toward an acceptable standard of practice. The drafters—who should include other healthcare professionals (besides physicians) and some lay members—need to begin by examining the principles involved, recognizing that particular care is needed to resolve the hard issues that arise when these principles conflict. For example, when patient self-determination conflicts with professional autonomy, can the range of issues in dispute at least be narrowed if both are seen as negative rights—that is, patients may refuse *unwanted* interventions and physicians may refuse to provide *inappropriate* interventions? If so, a physician could not simply abandon a patient but neither could a patient command a course of treatment that lacks a medical rationale. In our opinion, policies on futility should provide both specific definitions and a well-described dispute-resolution process that will bear scrutiny by outside, impartial observers. It is noteworthy that most of the futility policies of the participating institutions succeeded in addressing both these components.

Contrary to an opinion rendered by the American Medical Association Council on Ethical and Judicial Affairs claiming that the concept of futility “cannot be meaningfully defined,”<sup>19</sup> many of the participating hospitals independently crafted common definitions of the term. In our view, even the approach advocated by the Council—namely, determining futility on a case by case basis<sup>20</sup>—requires thoughtful and specific definitional grounding and endpoints to avoid arbitrary and unfair decisions. For if limits to physicians' obligations are not defined, end-of-life outcomes are likely to be determined less by medical circumstances and justifiable standards and more by individual healthcare providers' tolerance for risk, patients' and families' varying degrees of knowledge and rhetorical skills, and economic considerations.

In this regard, a multi-institutional collaborative futility policy issued by most of the major hospitals in the greater Houston area, although detailed with respect to dispute resolution procedures, lacks, in our opinion, a well-defined rationale and justification for the procedures.<sup>21</sup> The framers of that policy, while rejecting any substantive definition of futility as “unworkable,” provided only vague terms like “harms without compensating benefits” and “provision of unseemly care” to describe circumstances that justify a physician's forgoing futile treatment. It is hard to imagine a physician facing a jury trying to use “unseemly care” as a justification for withdrawing life support.

At the California conference, participants concerned with the rights and welfare of minority and disabled patients were worried about the potential for physicians to regard a medical treatment as futile because of prejudices about the value of the lives of certain persons. Therefore, any credible dispute-resolution process necessarily involves a variety of lay community representa-

tives (including perhaps representatives of the disabled) to give confidence that the decisions reached have been subjected to the values of the community and are not self-serving acts of healthcare professionals.

Hospitals are likely to find the legal system willing (and even eager) to defer to well-defined and procedurally scrupulous processes for internal resolutions of futility disputes.<sup>22</sup> Although courts are capable of providing due process protections, judges are largely unfamiliar with the substance of medical treatment and are neither expected nor even able to follow up medical outcomes once they have entered judgment. In years past, when physicians insisted on providing life-prolonging treatment over the objections of patients or their next of kin, critics pointed out that it was the patients and their kin—not the physicians—who would bear the burdens associated with long-term survival. This circumstance was often cited to reinforce the principle that decisions about life-sustaining treatment ought usually to be made by patients or their surrogates.

Similarly, one might argue that it is the physicians seeking to cease futile treatment—and not the judges who are called on to rule on the case—who have to live with the decision. For example, a judge who orders that a severely disabled child be kept alive rarely sees firsthand the long-term consequences of that decision, which remain a continuing vivid experience for the health professionals who must provide care for the child.

The parallel is not perfect, of course, because patients have a right to seek, and courts have an obligation to provide, due process in the resolution of disputes and, in particular, protection of the right of medical self-determination. This right of medical self-determination is not limitless, however. As previously noted, patients have a right to refuse any treatment; they do not have a right to demand any treatment. Until considerably more test cases have been reviewed by appellate courts or until relevant legislation has been adopted, uncertainties remain and not all cases will be able to be resolved without seeking judicial guidance on how the conflicting rights and responsibilities of patients and healthcare providers should be balanced.

Neither the policies themselves nor the conference participants reached a consensus on how to handle futility issues, and a follow-up survey one year after the conference revealed very few changes in the hospital futility policies. Does that mean that the questions, “Where does the medical profession stand on these difficult matters? What standards does it profess?” cannot be answered? Is it necessary that there be unanimous agreement in order to establish a professional standard of practice? Not at all, given that the law does not demand unanimous agreement among professionals regarding issues that are matters of professional judgment. Differing standards are acceptable when some physicians hold one view and others another view, provided each is held by at least a “respectable minority” and not just an individual practitioner.

No data exist on futility policies adopted by hospitals in California, much less across the nation. Most of the futility policies in the diversely representative but nonrandom sample reviewed in this conference agree that physicians are not obligated to continue life-sustaining treatment of patients who have reliably been determined to be permanently unconscious. If this standard were urged on the California courts, it would need to be acknowledged that at the very least a “respectable minority” of hospitals have not adopted such an explicit policy statement.

These latter hospitals, however, should consider the obligations and actions associated with their position. Is it a position or merely the absence of a position? Specifically, are these hospitals willing to accept the transfer of a permanently unconscious patient or others for whom another hospital has deemed further life-sustaining treatment futile? If so, disputes over end-of-life treatments could be resolved without requiring hospitals to go to court.

If successful transfer cannot be achieved, however, physicians and hospitals face a hard choice because of the finality of treatment withdrawal. The courts have usually espoused the view that all parties should err on the side of continuing life support. Physicians should not expect the courts to give them prior permission to forgo futile treatment because the courts will want the opportunity to examine all the facts *after* the action is completed in order to judge the rightness or wrongness of that action. Indeed, "physicians are likely to get better legal results when they refuse to provide nonbeneficial treatment and then defend their decisions as consistent with professional standards than when they seek advance permission to withhold care."<sup>23</sup>

If the decision to forgo treatment has been reached by a process that is careful both in medical and procedural terms, including full discussion (where possible) with patient or family, ethics committee review, and adequate aid to the patient and family in seeking care elsewhere, there may be no need for the healthcare providers to seek prior permission from the courts to carry out their professional duties. If the rightness of that action is questioned after the fact, judges will want to know the answer to the third question, "How does the medical profession behave?" Thus, healthcare professionals need not only to develop policies but also to act in accordance with their policies. They also need to justify, through discussion and publication, their conduct in dealing with situations that have presented the issue of the limits of professional obligations when treatment does not yield results that would be regarded as beneficial by most patients and consistent with the goals of medicine.<sup>24</sup>

## Notes

1. In re Baby "K," 16 F.3d 590 (4th Cir.), *cert.denied*, 513 U.S. 825 (1994).
2. Emergency Medical Treatment and Active Labor Act (EMTALA), 42 U.S.C.A. #139dd (West 1992).
3. See note 1.
4. Capron A. Medical futility: strike two. *Hastings Center Report* 1994;24(5):42-3.
5. *Bryan v. Rectors and Visitors of the University of Virginia*, 95 F.3d 349 (4th Cir. 1996). The court affirmed the trial court's dismissal of Bryan's suit, which had been brought in federal court under EMTALA, yet recognized that a state tort law action might lie.

Such reprehensible disregard for one's patient as Bryan hypothesizes would not constitute the "dumping" at which EMTALA aims but the well established tort of abandonment, which the states may expand or constrict as they deem just but which Congress evidenced no desire to federalize. Presumptively aware of this feature of state tort law, Congress did not address a hypothetical problem that was not before it but addressed a national scandal that was: emergency rooms turning away patients at the door for inability to pay or other similar reasons.

*Id* at 352.

6. Kolata G. Court ruling limits rights of patients: care deemed futile may be withheld. *New York Times* 1995;22 Apr:6.
7. Capron A. Abandoning a waning life. *Hastings Center Report* 1995;25(4):24-6.

## Hospital Futility Policies and Standards of Practice

8. Schneiderman LJ, Manning S. The Baby K case: a search for the elusive standard of medical care. *Cambridge Quarterly of Healthcare Ethics* 1997;6:9-18.
9. Schneiderman LJ, Jecker NS. Futility in practice. *Archives of Internal Medicine* 1993;153:437-41.
10. Annas GJ. Asking the courts to set the standard of emergency care: the case of Baby K. *New England Journal of Medicine* 1994;330:1542-5.
11. Yankelovich D. *Coming to Public Judgment: Making Democracy Work in a Complex World*. Syracuse: Syracuse University Press, 1991.
12. Halevy A, Brody BA. A multi-institution collaborative policy on medical futility. *JAMA* 1996;276:571-4.
13. Murphy DJ, Barbour E. GUIDe (Guidelines for the Use of Intensive Care in Denver): a community effort to define futile and inappropriate care. *New Horizons* 1994;2:326-31.
14. Bay Area Network of Ethics Committees (BANEC) Nonbeneficial Treatment Working Group. Nonbeneficial or futile medical treatment: conflict resolution guidelines for the San Francisco Bay Area. *Western Journal of Medicine* 1999;170:287-90.
15. American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations*. Chicago: American Medical Association, #2.037 (adopted Dec. 1996. 1998:10.
16. See note 14, BANEC Nonbeneficial Treatment Working Group 1999.
17. Solomon MZ, O'Donnell L, Jennings B, et al. Decisions near the end of life: professional views of life-sustaining treatments. *American Journal of Public Health* 1993;82:14-25.
18. Wilkinson JM. Moral distress in nursing practice: experience and effect. *Nurse Forum* 1987-88; 23:16-28.
19. American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations*. Chicago: American Medical Association, #2.035 (issued June 1994).
20. American Medical Association, Council on Ethical and Judicial Affairs. Medical futility in end-of-life care. *JAMA* 1999;281:937-41.
21. See note 11, Yankelovich 1991.
22. National Center for State Courts, Coordinating Council on Life-Sustaining Medical Treatment Decision Making by the Courts. *Guidelines for State Court Decision Making in Life-Sustaining Medical Treatment Cases* 2nd ed. St. Paul, Minn.: West Publishing Co., 1993.
23. Alpers A. Respect for patients should dominate health care decisions. *Western Journal of Medicine* 1999;170:291-2.
24. Schneiderman LJ, Jecker NS. *Wrong Medicine: Doctors, Patients, and Futile Treatment*. Baltimore: Johns Hopkins University Press, 1995.