

A history of resolving conflicts over end-of-life care in intensive care units in the United States*

John M. Luce, MD, FCCM

Objectives: To present a case of conflict over end-of-life care in the intensive care unit (ICU) and to describe how such conflicts have been resolved in the United States since the inception of ICUs.

Data Sources: A nonsystematically derived sample of published studies and professional and lay commentaries on end-of-life care, ethical principles, medical decision-making, medical futility, and especially conflict resolution in the ICU.

Study Selection: Some of those studies and commentaries dealing specifically with conflicts over end-of-life care in the ICU and their resolution.

Data Synthesis: An historical review of conflict resolution over end-of-life issues in U.S. ICUs.

Results and Conclusions: Conflict at the end of life in ICUs in the United States is relatively rare because most families and

physicians agree about how patients should be treated. Nevertheless, conflict still exists over some patients whose families insist on care that physicians consider inappropriate and hence inadvisable, and over other patients whose families object to care that physicians prefer to provide. When such conflict occurs, mediation between families and physicians is usually successful in resolving it. Consultation from ethics committees also may be helpful in achieving resolution, and one state actually allows such committees to adjudicate disputes. Physicians who act unilaterally against family wishes run the risk of malpractice suits, although such suits usually are unsuccessful because the physicians are not shown to have violated standards of care. (*Crit Care Med* 2010; 38:1623–1629)

KEY WORDS: palliative care; intensive care units; medical futility; medical ethics; decision making; resource allocation

I recently encountered a case of conflict over care at the end of life that is similar to others that occur, albeit uncommonly, in the United States. It involved an 86-year-old man named James McGilvray (I have changed the patient's name and several details of his history to avoid his being identified) from San Francisco. Mr. McGilvray had chronic hypertension, heart failure, and vascular dementia, in addition to the new onset of acute myelogenous lymphoma. At his request and that of his spouse and adult son, he was treated with conventional chemotherapy by a community oncologist after being deemed ineligible for experimental protocols at a nearby university medical center.

After several months, Mr. McGilvray no longer responded to chemotherapy, and he and his family was informed that

his lymphoma could never be controlled. Nevertheless, he was admitted by his oncologist to an intensive care unit (ICU) for respiratory failure caused by tumor infiltrates in his lungs. An intensivist treated Mr. McGilvray with noninvasive ventilation delivered through a face mask. Mr. McGilvray's thinking had clouded by this point. He could no longer make medical decisions, and he had never prepared an advance directive to assist others in making them.

During this hospitalization, Mr. McGilvray's wife and son were advised by his oncologist and intensivist that it would be best not to intubate him if could not be maintained on noninvasive ventilation because he would soon die of his lymphoma. They also advised the family that he not undergo cardiopulmonary resuscitation (CPR) in the event of a cardiopulmonary arrest. The family rejected this advice on the grounds that Mr. McGilvray was "a fighter" who would want full support. The family also stated that every day Mr. McGilvray lived was a blessing bestowed by God.

One night as his respiratory status was declining, presumably because of progressive tumor infiltration, his family was told by a physician covering the ICU that Mr. McGilvray could maintain adequate

oxygenation only if his trachea was intubated. The family requested this procedure. During intubation, however, Mr. McGilvray suffered a cardiopulmonary arrest. It took half an hour of CPR to restore his heartbeat, after which he was placed on the ventilator in an unconscious state.

After performing a thorough neurologic examination the next morning, Mr. McGilvray's intensivist concluded that he had suffered severe hypoxic-ischemic brain damage. She then advised the family that he was unlikely to regain consciousness and asked that the mechanical ventilator be removed. The family refused, insisting that he would recover, even if "a miracle" were required. The intensivist then met with the hospital ethics committee, a representative of which tried to convince the family that further treatment could not benefit Mr. McGilvray and that he might not want the treatment his family requested for him if he were able to speak for himself.

The family was not persuaded by the ethics committee representative, and mechanical ventilation was continued. Mr. McGilvray's intensivist tried to interest other physicians in assuming his care but was unsuccessful. After another week in the ICU, during which he received full

***See also p. 1742.**

From the Departments of Medicine and Anesthesia, University of California, San Francisco, and San Francisco General Hospital, San Francisco, CA.

The author has not disclosed any potential conflicts of interest.

For information regarding this article, E-mail: jluce@medsfgh.ucsf.edu

Copyright © 2010 by the Society of Critical Care Medicine and Lippincott Williams & Wilkins

DOI: 10.1097/CCM.0b013e3181e71530

support (including vasopressors, antibiotics, fluids, and nutrition) but never regained consciousness, Mr. McGilvray suffered another cardiopulmonary arrest and could not be resuscitated. The family subsequently sued the hospital and Mr. McGilvray's oncologist and intensivist for alleged medical malpractice, claiming that they had not "done everything to save him."

From what I know of Mr. McGilvray's case, communication between his family and physicians was excellent, as it was between the family and the ethics committee representative. Nevertheless, the family members never accepted the prognosis offered them and insisted on life-sustaining therapy until Mr. McGilvray died. End-of-life care is not contentious for most ICU patients because their families and physicians usually agree on a plan of treatment. Nevertheless, Mr. McGilvray's case is a reminder that seemingly unsolvable conflicts still occur despite extensive negotiations and, like conflicts in other arenas, may ultimately be played out in the legal system.

In this article, I trace the history of how conflicts over care at the end of life have been dealt with in American ICUs since their inception and discuss several court cases involving such conflicts. In the process, I explore the ethical principles that underlie end-of-life care in the ICU and other settings. I do not discuss the financial implications of such care in detail, because this complex and important topic deserves an independent review.

The Early Years of the ICU

ICUs were created in the United States and other developed countries in the 1950s and 1960s to provide physiologic monitoring and potentially life-saving medical interventions such as mechanical ventilation. At the time, biomedical ethics in and outside the ICU was dominated by the principles of beneficence, under which physicians, nurses, and other caregivers are expected to benefit patients, including keeping them alive in most situations; and its corollary, non-maleficence, under which they should "do no harm" (1, 2).

Most caregivers and medical institutions assumed that ICU interventions were potentially life-sustaining and that patients would naturally want them. Reflecting this assumption, and using what might be called a paternalistic model of

medical decision-making, physicians frequently applied therapies even in non-emergency situations without obtaining informed consent from patients and families. Similarly, hospitals required that CPR be performed on all patients, and patients who were started on mechanical ventilation usually were ventilated until their deaths could no longer be forestalled (2).

Physicians and nurses who performed CPR in the ICU came to realize that it was effective in restoring life in only a small minority of critically ill patients (3). Furthermore, caregivers encountered patients and families who did not want this treatment if their wishes were sought. Nevertheless, withholding CPR from patients was considered unethical, if not illegal, and it conflicted with hospitals' universal resuscitation policies. A popular and unethical way of feigning compliance with institutional policies was to resuscitate patients in a delayed or intentionally ineffective fashion. This procedure was called the "slow code" (4).

One reason that mechanical ventilation was continued in most patients was that the withdrawal of this therapy was regarded as homicide, even if done with the permission of the patient and family (5). An ethical and legal rationale for withdrawing the ventilator was provided in 1968, when the Ad Hoc Committee at Harvard (6) created criteria for brain death that circumvented the issue of homicide in patients who met these criteria and, after changes in state laws, allowed their organs to be transplanted. Nevertheless, withdrawal of mechanical ventilation from patients who did not meet brain death criteria continued to be called either "killing" or "euthanasia" by many caregivers.

Key Legal Decisions

In the 1970s, the father of Karen Ann Quinlan, a young woman who was unconscious following a drug overdose, requested that a trial court in New Jersey name him her guardian with the expressed purpose of removing her from mechanical ventilation. He was opposed by his daughter's physicians and the hospital in which his daughter was cared for on the grounds that removing life-sustaining therapy from her would be both illegal and unethical. After the trial court turned down his request, Mr. Quinlan took his case to the Supreme Court of New Jersey.

In its *in re Quinlan* (7) decision in 1976, the New Jersey Supreme Court reasoned that, were she somehow to return to consciousness momentarily, Ms. Quinlan probably would refuse further treatment that could not provide a sentient existence. The Court also stated that she had a constitutional right of privacy to make such a refusal. Since Ms. Quinlan could not exercise that right on her own, the Court appointed her father to make decisions for her. It also declared that Ms. Quinlan's physicians and the hospital were not liable for her death if an ethics committee agreed that she could not regain consciousness despite further therapy.

In the 1980s, the parents of Nancy Cruzan, who remained unconscious months after an automobile accident, asked a trial court in Missouri to allow their daughter's feeding tube to be removed over the objections of the state hospital in which she was housed. Although the trial court allowed the tube to be removed, the Supreme Court of Missouri ruled that such removal required clear and convincing evidence – for example, a written advance directive – of Ms. Cruzan's wishes before she became incapacitated. Ms. Cruzan's parents then asked the U.S. Supreme Court to determine whether the Missouri Supreme Court's decision violated their daughter's right of privacy by imposing the evidentiary requirement.

In *Cruzan v. Director, MO Department of Health* (8), which was decided in 1990, the U.S. Supreme Court accepted the principle that patients capable of making medical decisions have a right to refuse any and all medical treatment. However, because it believed that not all families know their members' wishes or represent them adequately, the court permitted states to require clear and convincing evidence of such wishes before life support is withdrawn at a family's request. During the same year, Congress passed the Patient Self-Determination Act, which mandates that health facilities inquire whether patients have prepared advance directives regarding end-of-life issues before admission and, if they have not, help them to prepare directives if they so request (9).

Taken together, the *Quinlan* and *Cruzan* decisions permitted patients with decision-making capacity to refuse any and all treatment, including that which was potentially life-sustaining. They also allowed families to refuse treatment

when patients lacked capacity, with clear and convincing evidence of previous patient wishes in states required in states such as Missouri and New York. Nevertheless, the legal decisions did not give patients or families the right to expect that their demands for treatment would be met in all circumstances. Nor did *Quinlan* or *Cruzan* assert that physicians and other caregivers could decide to treat or not to treat certain patients against the wishes of their families.

In the years following these two cases, when physicians sought judicial approval to withhold or withdraw life support over family objections, as in *the Matter of Baby K* (10), judges sided with families. Yet, in *Gilgunn v. Massachusetts General Hospital* (11), the courts did not penalize the hospital or its physicians when they removed mechanical ventilation over family members' objections. *Gilgunn* illustrated that physicians are more likely to get better legal results when they refuse to provide treatments they consider nonbeneficial than they do when they seek advance permission to do so. This is because then, as now, the only test of physician behavior in not acceding to patient and family requests for or against treatment is that of medical malpractice, in which physicians and other caregivers can be successfully sued only if plaintiffs prove they have violated professional standards (12).

The Ascendance of Autonomy

The *Quinlan* and *Cruzan* decisions were historic in that they helped establish respect for autonomy as the dominant ethical principle in American medicine (1, 2). One aspect of the ascendancy of autonomy was increased willingness of physicians to obtain informed consent under what came to be called a shared medical decision-making model. American hospitals discontinued their universal resuscitation policies, and physicians who had not done so already were asked to solicit patient and family wishes regarding CPR on admission to health care institutions. As a result, the do-not-resuscitate (DNR) order became commonplace in hospitals and nursing homes.

Reflecting these trends, Smedira and colleagues (13) reported in 1990 that the majority of patients dying in ICUs at the University of California, San Francisco and San Francisco General Hospital did so during the withholding and withdrawal of life-sustaining therapy with

DNR orders in place. Due to their underlying diseases and the psychoactive drugs they were receiving, none of the patients could decide on their own to limit treatment. Instead, families made decisions for them either before or after physicians recommended that they do so, rarely guided by advance directives. Physicians made decisions by themselves only for patients who lacked families.

This study and others (14, 15) like it were historically important primarily for two reasons. First, the studies demonstrated that withholding and withdrawal of life support had become common practice in ICUs in the U.S. Second, the studies showed not only that most families approved of this practice, but also that they and physicians usually worked together in deciding whether or not to treat critically ill patients. The studies thereby advanced the concept of shared decision-making while not drawing attention to the relatively rare cases in which families, physicians, and institutions disagreed about end-of-life care.

Some of these disagreements were similar to those in the *Quinlan* and *Cruzan* cases in that physicians and hospitals insisted on treating patients against family wishes. Other disagreements involved families, such as Mr. McGilvray's, that requested treatments that physicians were loath to provide for ethical reasons. Although the latter cases were the exception and not the rule, most intensivists had some experience with them. This experience was unsettling in that it reminded the physicians that the ascendance of respect for autonomy as an ethical principle infringed upon their traditional prerogative to treat or not treat patients on the basis of what they considered beneficial (2).

The Rise of the Futility Movement

One response to this perceived infringement on professional prerogatives was what has been called "the rise of the futility movement" during the 1990s (16). The futility movement was an attempt to convince fellow caregivers and the public that physicians should use their professional judgment and empirical evidence to determine which interventions were futile and thereby not worth providing from the physicians' point of view. If such a determination was made, the physicians then should be allowed to withhold or withdraw the

treatment, even over patient and family objections. Ideally, physicians would be legally protected for such actions, if only because they were acting within what were or might become generally accepted standards (16).

Essential to the futility movement were attempts to define "futile," a word that literally means "incapable of being accomplished." Perhaps the best known attempt, that of Schneiderman and colleagues (17), offered quantitative and qualitative definitions. In their scheme, an intervention was quantitatively futile if "physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of published empirical data) that in the last 100 cases a medical treatment had been useless." Qualitative futility was defined as that which "merely preserves unconsciousness or fails to end a patient's total dependence on intensive medical care."

While definitions of futility were being created, intensivists also were developing prognostic scoring systems, based on physiologic data and other variables, to determine the severity of critical illness and the likelihood of surviving ICU admission. Perhaps the best known of these systems was the Acute Physiology and Chronic Health Evaluation (APACHE) of Knaus and colleagues, the second iteration of which was reported in 1985 (18). Several years later, these investigators (19) suggested that APACHE and similar systems could provide objective probability estimates for predicting when intensive care was futile in individual patients and using such predictions in clinical decision-making. The estimates "can also form the basis of more equitable comparative entitlement determinations in response to scarce resources" and thereby could influence institutional or national resource allocation policies.

Prognostic scoring systems proved to be useful in stratifying patients according to severity of illness in clinical investigations (20) and in contrasting ICU admitting practices in various countries after adjusting for case mix (21), among other things. In addition, the comparability of caregivers' predictions of hospital mortality with that estimated by APACHE II was verified (22). At the same time, however, the scoring systems were shown to have limited positive and negative predictive value (23). They therefore remained only adjuncts to less rigorous physician prognostication in clinical decision-making. They also were not used in resource allo-

cation policies, which never became popular in the United States.

The interest of intensivists in prognostic scoring systems and their involvement in the systems' development were due in large part to the intensivists' familiarity with the poor outcome of many ICU patients and the high cost of treating them. Some of the intensivists served as medical directors of ICUs. In this role, they appreciated the frequent shortage of ICU beds and were asked by hospitals to influence other physicians to use these beds and other medical resources wisely. Although motivated primarily by the principles of beneficence and nonmaleficence, these physicians also were influenced by the ethical principle of distributive justice: the fair allocation of medical resources (1). This principle was cited by Knaus and colleagues (19) in their assessment of the potential usefulness of prognostic scoring systems such as APACHE in making futility determinations.

In 1991 the Bioethics Task Force of the American Thoracic Society (ATS) (24), which included several ICU directors, stated that "a life-sustaining intervention may be withheld or withdrawn from a patient without the consent of the patient or surrogate if the intervention is judged to be futile. A life-sustaining intervention is futile if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for that patient. Here, meaningful survival specifically refers to a quality or duration of survival that would have value to that patient as an individual. Survival in a state with permanent lack of consciousness (i.e., completely lacking cognitive or sentient capacity) may be generally regarded as having no value for such a patient."

In 1997, the ATS Bioethics Task Force (25) advanced the idea that the principle of distributive justice supported the position that "marginally beneficial ICU care may be justifiably limited on the basis of a social consensus that its cost is too high relative to the value of its outcome." The ATS also noted that "decisions to limit care on this basis should not be made covertly by individual health care providers but only be explicit institutional policies that reflect a social consensus in support of the limitation. The following categories can be considered as candidates for exclusion from ICU care on this basis: patients highly unlikely to survive their acute illness or injury, even with

ICU care; those facing imminent death due to a fatal untreatable underlying disease; and those who are permanently unconscious or irreversibly lack all cognitive function."

Futility Policies

Although it did not claim that social consensus had been achieved regarding the high cost of certain ICU patients, the ATS statement sanctioned the use of what came to be called futility policies, which might allow physicians to limit potentially life-sustaining therapy with institutional support. One such policy was reported as a guideline by the San Francisco Bay Area Network of Ethics Committees (BANEC) (26) in 1999. The BANEC guideline policy defined nonbeneficial treatment, allowed primary physicians to determine what was nonbeneficial, and created a procedure for dealing with cases in which physician and family disagreed over the benefits of care.

The BANEC procedure included consultation with a second physician who, if she or he agreed with the primary physician, could approach the family and seek agreement. If agreement was not reached, the primary physician would present the case to a hospital ethics committee. If the committee disagreed with the primary physician, the patient could be transferred to another physician at the same or at another institution. On the other hand, if the committee agreed with the primary physician that care was nonbeneficial, it would so inform the family. The family could either seek a court order to continue treatment or request that the patient's care could be transferred to a physician at another hospital. If transfer could not be arranged, "a plan for withholding or withdrawal of nonbeneficial treatment may ethically be made."

Although the BANEC guideline policy was adopted by several hospital ethics committees in the Bay Area, no published evidence demonstrates that the guidelines were endorsed or implemented by a majority of the hospitals themselves. Furthermore, a survey (27) from San Francisco General Hospital, a BANEC member, indicated that most physicians would offer CPR to a hypothetical patient whom they thought could not benefit from attempted resuscitation, or to the patient's family, despite a futility policy that allowed them to do otherwise. Whether these physicians actually disagreed with the policy, felt a personal obligation to

offer CPR to patients whom they considered unlikely to benefit, assumed that patients or families would refuse their offer of CPR, or were concerned about the possible medical-legal ramifications of not offering CPR was not determined in this survey.

Also in 1999, Halevy and Brody (28) described to a wider readership a multi-institutional policy in Houston that also employed ethics committees to manage conflicts over limiting life-sustaining treatments if the conflicts were not resolved after second physician consultation. The Houston policy was similar to that of BANEC in that patients whose treatment was considered nonbeneficial by an ethics committee could be transferred to another hospital if that was possible; if it was not, further treatment could be withheld or withdrawn. Three hospitals, including Baylor, the investigators' parent institution, had approved the Houston policy at the time it was reported. However, no cases had been adjudicated by their ethics committees, probably because most cases were resolved at an earlier stage.

Problems With Futility

Although futility policies were being developed across the United States in the 1990s, the policies and the futility movement itself came under increased criticism. For example, one commentator (29) noted that the BANEC guidelines unfairly favored physicians' interests over those of patients and families. Similarly, Younger (30) stated that most medical interventions achieve some physiologic results and that treatments physicians consider nonbeneficial may be valuable to patients and their families. Finally, Truog and colleagues (31) argued that because what physicians may consider futile might be seen as beneficial by patients and families, futility determinations are inherently value-laden. When physicians make them, the determinations often seem to be a covert way of allocating medical resources. A more straightforward approach, Truog and colleagues argued, would be to face overtly the issue of resource allocation, which they considered an ethically and socially appropriate concern.

In keeping with this viewpoint, the Ethics Committee of the Society of Critical Care Medicine (SCCM) (32) stated in 1999 that "treatments should be defined as futile only when they will not accom-

plish their intended goal. Treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile. Futile treatments constitute a small fraction of medical care. Thus, employing the concept of futile care in medical decision-making will not primarily contribute to a reduction in resource use."

The SCCM Ethics Committee statement regarding problems with the concept of futility helped discourage the use of the term as a rationale for limiting life-sustaining therapy. Yet one might argue that the SCCM Ethics Committee was merely substituting "inappropriate" for "futile" and that the committee was ducking the issue of how to resolve conflicts between physicians and families who disagreed about which therapies were "inappropriate and hence inadvisable." Furthermore, although some commentators (16) heralded "the fall of the futility movement" on the heels of the SCCM Ethics Committee statement, events would soon indicate that the movement was still alive.

The Texas Experiment

In 1999, the American Medical Association (AMA) (33) opined that "since definitions of futile care are value-laden, universal consensus on futile care is unlikely to be achieved," in keeping with the SCCM Ethics Committee statement. However, at the same time, the AMA allowed futility to be operationally defined at the local level, thereby supporting the concept that futility was an actual condition. The organization also endorsed what it termed a "due-process approach" to futility determinations based on the Houston model that also had been adopted by BANEC. In so doing, the AMA sanctioned the use of ethics committees to resolve conflicts over end-of-life care.

That same year, the due-process approach was adopted by Texas as an amendment to the Texas Advance Directives Act (TADA), which originally was written to prompt physicians to honor patient and family refusals of life-sustaining therapy (34). The TADA allowed a physician to request ethics committee review of proposed treatment that the physician considered to be nonbeneficial. If the committee agreed with the physician, life support could be withheld or withdrawn if the patient could not be

transferred within 10 days. A judge could extend this period only if there was a reasonable expectation of finding a willing provider.

In 2000, Fine (35) described how the due-process approach had been used with a patient at Baylor who died during the 10-day waiting period. In a subsequent report, he and Mayo (36) noted that six cases of presumed inappropriateness had been pursued through the conflict resolution process at Baylor since passage of the TADA amendment. In those six cases, three families agreed to the withdrawal of life-sustaining treatment shortly after receiving an ethics committee opinion. In two cases, the patient died during the 10-day waiting period without an alternative provider having been located. Although an alternative provider was found in one case, the patient died awaiting transfer.

In 2007, M. Smith and colleagues (37) reported a survey of hospital members of the Texas Hospital Association performed in 2004. Only 40 of the 409 hospitals surveyed provided useful data on cases involving end-of-life care conflicts that had been reviewed by their ethics committees in keeping with the TADA. In 70% of these cases, the committees agreed with the attending physicians that the treatment requested by a patient or family was inappropriate; in 30% of cases, the committees sided with the patients and families. After learning the committees' decisions in support of physicians, 40% of patients or families agreed to discontinue treatment. Another 44% of the involved patients died during the 10-day waiting period pending transfer; 17% were transferred to other physicians and facilities; and eight patients improved and continued to receive life support.

In the most widely-publicized case, which was not included in the survey of Smith and colleagues, a hospital ethics committee in Austin invoked the TADA in deciding to remove mechanical ventilation from a 16-month-old child named Emilio Gonzales who had a progressive and uniformly fatal congenital disease. The family challenged the constitutionality of the TADA, but a federal judge refused to hear the case and referred it to a local court. The court issued a restraining order preventing the ventilator from being removed and scheduled a hearing to discuss the case. The Gonzales child died before the hearing, having spent 5 months in the ICU before he died.

In reviewing the Gonzales case in 2007, Truog (38) noted that although financial issues had not been raised by the ethics committee in Austin, such issues were worthy of consideration. Nevertheless, the due-process approach under Texas law that empowered ethics committees such as the one in Austin to be surrogate judges and juries in authorizing physicians to take actions against patients and families was one-sided because ethics committees are dominated by hospital staff members, usually contain few community representatives, and "are acculturated to the clinical world and its clinical values." Regarding the Gonzales family, Truog stated, the ethics committee was "hardly a 'jury of peers' for a low-income woman of color and her infant son."

In 2009, in a published point-counterpoint debate with Fine (39), Truog (40) also noted that the TADA "is implemented most often in urban hospitals, which serve the majority of the uninsured, underinsured, and socioeconomically deprived. The law may therefore be disproportionately applied to people who have been denied, or at least believe they have been denied, beneficial treatments that are available to others. These families may believe that, once again, they are being deprived of treatment that is not only beneficial, but indeed life sustaining."

To put the debate over futility determinations under TADA in historical context, Truog reminded readers that in the 1970s, the father of Karen Ann Quinlan had argued that mechanical ventilation was futile for his daughter and should be discontinued. Her physicians argued to the contrary, and had her case gone to an ethics committee similar to those in Texas today, such an ethics committee might well have sided with the physicians. But Mr. Quinlan had access to the legal system, and the Supreme Court of New Jersey ultimately decided in favor of families having the right to refuse unwanted therapies.

The Future of Futility

To date, the constitutionality of the TADA has not been determined at a state or national level. Nevertheless, the due-process approach used under the Act and with the AMA's endorsement has been adopted by many American hospitals. For example, according to Truog (40), the Children's Hospital Boston has developed a policy that permits withdrawal of life-

sustaining therapy physicians consider futile after ethics committee review. Unlike the TADA, and similar to the policy guidelines developed by BANE, the Children's Hospital policy advises families that they have a legal right to seek a court order to prevent unilateral withdrawal of life support. Given the results of cases like *Baby K* in Virginia (10), judges in Massachusetts probably would support the families in these situations, but whether they have had an opportunity to do so is unclear.

It also is uncertain what has happened across states like California, whose probate code (41) allows caregivers and health care institutions to decline to provide "medically ineffective care" but does not define such care or specify a conflict resolution mechanism. In a half-dozen California cases in which I have served as an expert witness, claims filed by families such as Mr. McGilvray's who allege that physicians have committed malpractice in not following their wishes have been dismissed because the plaintiffs were unable to secure experts who would state that the defendants violated professional standards. L. Smith and I are reviewing legal databases to identify similar malpractice cases in California. So far, we have documented as many cases in which physicians refused to withhold or withdraw therapies that families considered futile as we have cases in which physicians withheld or withdrew treatments they considered futile over the objections of families (L Smith, JM Luce; unpublished data).

That physicians and families still disagree about providing end-of-life care suggests that little has changed since *Quinlan*. Yet such a suggestion overlooks the relatively uncommon nature of such disagreements and the increasingly wide use of the shared decision-making model in either preventing or ameliorating them. As described by White and colleagues (42), physicians using this model are expected to discuss the nature and likely outcome of a given illness, explore the ramifications of forthcoming decisions, determine patient values, confirm that patients or families understand the information provided them, discuss preferred roles in decision-making, and achieve consensus about treatment courses that are most consistent with patient values.

Although not all physicians employ the shared decision-making model or do

so expertly, recent studies have demonstrated how its use can be improved upon. For example, these studies have shown that many families appreciate extra time to make decisions for patients at the end of life (43), that physicians may not present prognostic estimates in a fashion that families can understand and incorporate (44), that families value such estimates even though they often disagree with them (45), that better communication during family conferences can enhance decision-making (46), and that facilitative but not proscriptive ethics committee consultations can provide a similar enhancement (47).

Burns and Truog (48), who have chronicled the futility movement, believe that attempts to define futility and develop procedural approaches have failed due to the lack of national agreement on "what constitutes beneficial treatment." These investigators predict that the movement's next phase will focus on communication and negotiation at the bedside. When communication and negotiation fail, as they did in the case of Mr. McGilvray, Burns and Truog recommend that caretakers find ways of supporting one another in providing care they disagree with rather than overriding families' requests.

Of course, not all physicians will agree with the recommendations of Burns and Truog. Some, in fact, will refuse to accede to family requests and will withhold or withdraw life-sustaining therapy from patients overtly or covertly, as has been described previously (49). Mr. McGilvray's physicians did what his family requested; he died despite receiving full support; and his physicians were sued nonetheless. Although the legal aspects of Mr. McGilvray's case are highly unusual, his death after a prolonged ICU stay is not. Indeed, his case in California and that of Emilio Gonzales in Texas remind us that even in states where caregivers are not required to provide treatments they consider futile, end-of-life conflicts between families and physicians may not be resolved until—or after—patients die.

ACKNOWLEDGMENTS

I thank Judith A. Luce, MD, and three anonymous reviewers for their editorial suggestions.

REFERENCES

1. Beauchamp TL, Childress JF: Principles of Biomedical Ethics. Fifth Edition. Oxford, Oxford University Press, 2001
2. Luce JM, White DB: A History of ethics and law in the intensive care unit. *Crit Care Clinics* 2009; 25:220–237
3. Bedell SE, Delbanco TL, Cook EF, et al: Survival after cardiopulmonary resuscitation in the hospital. *N Engl J Med* 1983; 309: 569–576
4. Gazelle G: The slow code – should anyone rush to its defense? *N Engl J Med* 1998; 338:467–469
5. Truog RD: Brain death – too flawed to endure, too ingrained to abandon. *J Law Med Ethics* 2007; 273–280
6. Ad Hoc Committee of the Harvard Medical School: A definition of irreversible coma, report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. *JAMA* 1968; 205:337–340
7. *In re Quinlan*, 755 A2A 647 (NJ), cert denied, 429 70 NJ 10, 355 A2d 647 (1976)
8. *Cruzan v. Director, Missouri Dept. of Health* 1990; 110 S Ct 2841
9. Omnibus Budget Reconciliation Act of 1990; Public law no: 101-508
10. *In the Matter of Baby K* 16 F3d 590 (4th Cir 1994)
11. *Gilgum v. Massachusetts General Hospital*. No 92-4820 (Mass Super Ct Civ Action Suffolk So April 22, 1995)
12. Luce JM, Alpers A: Legal aspects of withholding and withdrawing life support from critically ill patients in the United States and providing palliative care to them. *Am J Respir Crit Care Med* 2000; 162:2029–2032
13. Smedira NG, Evans BH, Grais LS, et al: Withholding and withdrawal of life support from the critically ill. *N Engl J Med* 1990; 322: 309–315
14. Prendergast TJ, Luce JM: Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997; 155:15–20
15. Prendergast TJ, Claessens MT, Luce JM: A national survey of end-of-life care for critically ill patients. *Am J Respir Crit Care Med* 1998; 158:1163–1167
16. Helft PR, Siegler M, Lantos J: The rise and fall of the futility movement. *N Engl J Med* 2000; 343:293–296
17. Schneiderman LJ, Jecker N, Jonsen AR: Medical futility: Its meaning and ethical implications. *Ann Intern Med* 1990; 112:949–954
18. Knaus WA, Draper EA, Wagner DP, et al: APACHE II: A severity of disease classification system. *Crit Care Med* 1985; 13: 818–825
19. Knaus WE, Wagner DP, Lynn J: Short-term mortality predictions for critically ill hospitalized adults: Science and ethics. *Science* 1991; 254:389–394
20. Wachter RM, Russi MB, Bloch DA, et al: Pneumocystis carinii pneumonia and respiratory failure in AIDS: improved outcomes

- and increased use in intensive care units. *Am Rev Respir Dis* 1991; 143:251–256
21. Zimmerman JE, Knaus WA, Judson JA, et al: Patient selection for intensive care: A comparison of New Zealand and United States hospitals. *Crit Care Med* 1988; 16: 318–326
 22. Kruse JA, Thill-Baharozian MC, Carlson RW: Comparison of clinical assessment with APACHE II for predicting mortality risk in patients admitted to a medical intensive care unit. *JAMA* 1988; 260:1739
 23. Luce JM, Wachter RM: The ethical appropriateness of using prognostic scoring systems in clinical management. *Crit Care Clin* 1994; 10:229–241
 24. American Thoracic Society Bioethics Task Force: Withholding and withdrawing life-sustaining therapy. *Am Rev Respir Dis* 1991; 144:726–731
 25. American Thoracic Society Bioethics Task Force: Fair allocation of intensive care unit resources. *Am J Respir Crit Care Med* 1997; 156:1282–1301
 26. Bay Area Network of Ethics Committees Nonbeneficial Treatment Working Group: Nonbeneficial or futile medical treatment: Conflict resolution guidelines for the San Francisco Bay Area. *West J Med* 1999; 170: 287–290
 27. Swig L, Cooke M, Osmond D, et al: Physician responses to a hospital policy allowing them to not offer cardiopulmonary resuscitation. *J Amer Geriatr Soc* 1996; 44:1215–1219
 28. Halevy A, Brody BA: A multi-institution collaborative project on medical futility. *JAMA* 1996; 276:571–574
 29. Rubin SB: Why futility policies are not the answer. *West J Med* 1999; 170:291
 30. Younger SJ: Who defines futility? *JAMA* 1988; 260:2094–2095
 31. Truog RD, Brett AS, Frader J: The problem with futility. *N Engl J Med* 1992; 326: 1550–1564
 32. The Ethics Committee of the Society of Critical Care Medicine: Consensus statement of the SCCM's Ethics Committee regarding futile and other possible inadvisable treatments. *Crit Care Med* 1997; 25:887–891
 33. Council on Ethical and Judicial Affairs, American Medical Association: Medical futility in end-of-life care: Report of the Council on Ethical and Judicial Affairs. *JAMA* 1999; 281:937–941
 34. Texas Health and Safety Code, Chapter 166
 35. Fine RL: Medical futility and the Texas Advance Directives Act of 1999. *Proc (Bayl Univ Med Cent)* 2000; 13:144–147
 36. Fine RL, Mayo TW: Resolution of futility by due process: Early experience with the Texas Advance Directives Act. *Ann Intern Med* 2003; 138:743–746
 37. Smith ML, Gremillion G, Slonka J: Texas hospitals' experience with the Texas Advance Directives Act. *Crit Care Med* 2007; 35: 1271–1276
 38. Truog RD: Tracking medical futility in Texas. *N Engl J Med* 2008; 357:1–3
 39. Fine RL: Point: The Texas Advance Directives Act effectively and ethically resolves disputes about medical futility. *Chest* 2009; 136: 963–967
 40. Truog RD: Counterpoint: The Texas Advance Directives Act is ethically flawed. *Chest* 2009; 136:968–971
 41. State of California. Probate Code, Sections 4374–4376
 42. White DB, Braddock CH III, Berekniiyeu S, et al: Toward shared decision making at the end of life in intensive care units: Opportunities for improvement. *Arch Intern Med* 2007; 167: 461–467
 43. Gerstel E, Engelberg RA, Koepsell T, et al: Duration of withdrawal of life support in the intensive care unit and association with family satisfaction. *Am J Respir Crit Care Med* 2008; 178:798–804
 44. White DB, Engelberg R, Wenrich M, et al: Prognostication during patient-family discussions about limiting life support in intensive care units. *Crit Care Med* 2007; 35:442–448
 45. Evans LR, Boyd EA, Malvar G, et al: Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty. *Am J Respir Crit Care Med* 2009; 179:48–53
 46. Lilly CM, DeMeo DL, Sonna LA, et al: An intensive communication intervention for the critically ill. *Am J Med* 2000; 109: 469–475
 47. Schneiderman LJ, Gilmer T, Teetzel HD, et al: Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: A randomized controlled trial. *JAMA* 2003; 290:1166–1172
 48. Burns JP, Truog RD: Futility: A concept in evolution. *Chest* 2007; 132:1987–1993
 49. Asch DA, Hansen-Flaschen J, Lanken P: Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: Conflicts between physicians' practices and patients' wishes. *Am J Respir Crit Care Med* 1995; 151:288–292