10-1-2006

Who Decides Whether a Patient Lives or Dies?

Diane E. Hoffmann
University of Maryland School of Law, dhoffmann@law.umaryland.edu

Jack Schwartz

Who decides whether a patient lives or dies?

DIANE E. HOFFMANN AND JACK SCHWARTZ

Whether patients choose life-sustaining medical treatment or prefer to forgo it, they and their families sometimes clash with health care providers. In resolving these disputes, courts are facing tough questions of life and death.

Eighty-year-old Mary Wohlford had strong views about life-sustaining medical treatment (LSMT). When the time came for her to die, she did not want interventions to interrupt the dying process. She communicated her wishes as clearly and bluntly as she could imagine: with a tattoo on her chest that read, "DO NOT RESUSCITATE."[1]

Although few people go as far as Wohlford to express their wishes, many share similar feelings about the use of resuscitation techniques, ventilators, feeding tubes, and other life-sustaining measures when death is approaching. Others, of course, have precisely the opposite preference and want whatever interventions modern medicine can devise to try to extend life. Either way, patient preferences about end-of-life care can be frustrated by health care providers.

When this happens, patients or their families may seek legal representation. If the dispute over care is ongoing, the remedy sought may be an injunction requiring compliance with the patient's wishes. If unwanted interventions have already occurred, or if requested interventions have already been withheld, the patient, or others on his or her behalf, may seek damages.

The legal basis for claims against health care providers in these contexts is the right of informed consent. Arising out of "our Anglo-American legal tradition of personal autonomy," this common law principle vests in a competent patient "the right of self-determination" about proposed invasions of the body.[2] Informed consent to treatment implies a "logical corollary" that the patient generally possesses "the right not to consent, that is, to refuse treatment."[3]

The right of informed consent or refusal applies whether the treatment in question is aimed at curing a condition or at maintaining vital functions when a disease cannot be cured. For example, a patient with end-stage renal disease may accept dialysis or decline it. The fact that the consequence of declining is likely to be death underscores the need for a careful informed consent process, but it does not remove the decision from the patient.[4]

Patients who lack the capacity to engage in the informed consent process, however, present special challenges. Many people nearing the end of life have impairments from the terminal illness itself or from secondary disorders, such as clinical depression. Sometimes, decisional incapacity results from medical treatments (for example, the sedative effect of strong analgesics) or even the medical environment (for example, "ICU psychosis," in which acute-care patients develop a syndrome involving impaired intellectual functioning[5]). Whatever the cause, decisional incapacity threatens the control over end-of-life interventions that the informed consent doctrine seeks to ensure.

While decisional incapacity theoretically does not negate the patient's underlying right,[6] it does mean that the issue of end-of-life interventions must be addressed differently. When the patient is incapacitated, the physician must conduct the informed consent process with a proxy decision-maker who has the re-

sponsibility to decide on the patient's behalf, sometimes with the aid of a living will or similar advance medical directive. State law defines the circumstances under which a living will may be used to determine preferences about end-of-life care after a patient's loss of capacity. State law also secures a patient's right to identify a preferred proxy and, in most states, establishes next-of-kin decision-making authority without resort to guardianship.

Unwanted treatment

Most disagreements about the care of a dying patient are resolved without resort to the courts.[7] Nevertheless, from perhaps the earliest end-of-life case, *In re Quinlan*,[8] courts have issued declaratory or injunctive relief against health care providers who refuse to carry out a decision to forgo further use of LSMT. Of course, this decision must be based on sufficient evidence that it reflects the patient's wishes or promotes the patient's best interest. If such evidence is presented, courts give practical effect to the informed consent doctrine by ordering the treatment stopped.[9]

Much more problematic, from a plaintiff's perspective, is obtaining damages after the fact. For example, in *Anderson v. St. Francis-St. George Hospital*, a nurse successfully resuscitated a patient, despite a "do not resuscitate" (DNR) order issued at the patient's request.[10] Two days later, the patient suffered a stroke, leaving him partially paralyzed. He sued the hospital for negligence and battery.

The Ohio court readily acknowledged the legal wrong: "Whether intentional or negligent, interference with a person's legal right to die would constitute a breach of that duty to honor the wishes of the patient."[11] Nevertheless, the claims failed. Discerning no evidence that the resuscitation was negligently performed or was itself the cause of the stroke, the court ruled that the negligence claim amounted to one for "wrongful living," an unacceptable attempt to win damages for the ills of life that followed the successful resuscitation.[12] On the battery claim, because the resuscitation was physically harmless (involving no broken bones or other injuries, as sometimes occurs), only nominal damages were possible and had not been sought by the plaintiff.

This case illustrates a fundamental problem with the right to decline life-sustaining treatment: Although the legal right is well-established and generally can be translated into an injunction requiring health care providers to comply with a refusal, tort law is a doubtful means of redress when unwanted life-sustaining treatment has already been administered. Depending on the facts, the elements of battery, intentional infliction of emotional distress, or negligence might appear to be satisfied. Yet, as one leading treatise observes, "Despite the apparent ease of stating a . . . claim, the courts display extreme reluctance to penalize health care providers for rendering life-sustaining treatment to patients even if the patients did not want it."[13]

Courts are wary of determining that a person's life was "unnecessarily prolonged," as an Indiana court put it, and translating the extended life into damages. In *Taylor ex rel. Taylor v. Muncie Medical Investors, L.P.*,[14] the patient's living will rejected "extraordinary means" to prolong her life once she was in a terminal condition.[15] Her family understood the document to mean no use of a feeding tube, which a nursing home nevertheless inserted. After the patient died, her family brought both negligence and intentional tort claims.

Affirming the trial court's grant of summary judgment for the defendants, the appellate court held that "the family could have challenged the actions of [the patient's] physicians . . . in court at any time to enforce their decisions regarding [the patient's] care."[16] That, however, was their only remedy, because the court declined to recognize what it called "a new cause of action for wrongful prolongation of life."[17]

Other cases illustrate how the path to recovery can be blocked. In *Wright v. Johns Hopkins Health Systems Corp.*, an AIDS patient signed a living will directing health care providers to forgo LSMT, including resuscitation efforts, after two physicians had certified that he was in a terminal condition.[18] While in the hospital to get a blood transfusion, the patient suffered cardiac arrest. He was resuscitated and died 10 days later. His family's negligence claim for violation of the living will was defeated because, although they argued that he was in a terminal condition following the cardiac arrest, two physicians had not certified this, and so the living will did not apply.

The fact that the consequence of declining dialysis is likely to be death underscores the need for a careful informed consent process, but it does not remove the decision from the patient.

In *Allore v. Flower Hospital*, the patient, who suffered from asbestosis, executed a living will declining life-sustaining treatment when he was admitted to the hospital in June 1994. Two months later, he was readmitted and, during an episode of respiratory distress, was intubated and placed on a respirator. After he died, his family's battery claim for violation of the living will failed because, although the patient's primary physician knew of the living will, those who performed the resuscitation did not.[19]

Blouin v. Spitzer, a New York case, involved a claim for intentional infliction of emotional distress against state lawyers who had insisted on medically contraindicated and physically harmful artificial feeding.[20]

The patient, with serious mental and

DIANE E. HOFFMANN *is a law professor and director of the law and health care program at the University of Maryland School of Law.* JACK SCHWARTZ *is an assistant attorney general and director of health policy development with the Maryland Attorney General's Office.*

physical impairments since infancy, was near death in a state university hospital. By agreement of the family and the treatment team, interventions to prolong life were forgone in favor of palliative care, which succeeded in keeping the patient comfortable. However, lawyers from the attorney general's office, asserting that only a competent patient could lawfully decline artificial nutrition and hydration, insisted that the patient be given an intravenous nutrition solution. After more than a month of this treatment, which the patient's physicians noted was worsening her condition and causing increased suffering, a court (over the attorney general's office's opposition) authorized a return to the original palliative-care plan despite the evident harm to the patient.

The case was dismissed because the lawyers had not acted "beyond all possible bounds of decency," a nearly insurmountable standard.[21] The lawyers were also protected by public-official immunity. Similarly, a California court broadly construed a statutory immunity provision to shield from damages health care providers who kept a patient alive against family requests to withdraw life support.[22]

In short, although physicians may fear liability for tort claims of this kind and some settlements have been reported,[23] the odds are against a substantial recovery.

Treatment withheld

While physicians often err on the side of providing LSMT, even when it is against a patient's wishes, in some cases they have terminated life support despite a request from the patient's family members that doctors do everything possible to keep the patient alive. In those cases, physicians often believe that continued life-saving treatment would be "medically inappropriate" or "futile." These cases highlight tensions between the authority of patients and their surrogates to obtain wanted care and the domain of physicians to determine what types of care are medically appropriate. A few have resulted in litigation.

In cases brought for failure to provide LSMT consistent with patient or proxy wishes, the patient is typically severely disabled and very close to death. In the few cases that have been brought, plaintiffs have sought recovery based on theories of negligent or intentional infliction of emotional distress, lack of informed consent, or failure to treat under two federal statutes: the Emergency Medical Treatment and Active Labor Act (EMTALA)[24] and the Rehabilitation Act of 1973.[25] The first two types of claims may be viable, but so far, courts have rejected the statutory claims when brought to obtain damages.

Although the legal right to refuse treatment is well established, tort law is a doubtful means of redress when unwanted life-sustaining treatment has already been administered.

Emotional distress. In *Rideout v. Hershey Medical Center*, the parents of two-year-old Brianne Rideout, who suffered from a brain-stem tumor, sued the hospital where Brianne was removed from a ventilator without their consent.[26] Her physicians believed that she would not survive the tumor and that the ventilator was prolonging her death. Even so, her parents favored aggressive chemotherapy treatment.

Brianne's attending physician, with the support of the hospital's ethics committee, wrote a DNR order without the parents' consent. The Rideouts were told that in the event of cardiac arrest, Brianne would not be resuscitated but that "no support would be withdrawn."[27]

Brianne remained in the hospital for weeks, and her parents were told that their health insurance coverage "might soon be exhausted and that medical assistance would be needed to cover her medical costs."[28] Since Brianne was stable, the hospital sought to place her in home care or a chronic-care facility; however, there was no placement available at the time and none likely to be available for several months.

After Brianne had been in the hospital for more than three months, her condition deteriorated significantly. Her attending physician felt that continued LSMT was futile and inappropriate. Without the Rideouts' consent, he shut off Brianne's ventilator.

At the time, her parents were in the office of the hospital's patient advocate, hoping to prevent or stall the physician's actions. They heard the hospital's chaplain, who was in Brianne's room, announce over the hospital's intercom: "They turned her off, they turned her off!" They rushed to Brianne's bedside "hysterically crying and screaming that their child had been murdered."[29] Brianne's father was so upset "that he suffered an acute asthma attack." Despite being disconnected from the ventilator, Brianne was able to breathe on her own. However, two days later, unable to get enough oxygen, she "succumbed to cardiopulmonary failure and died in the presence of her parents."[30]

The Rideouts sued the hospital, alleging, among other things, negligent and intentional infliction of emotional distress. The hospital asserted that they could not satisfy the elements of each claim under Pennsylvania common law or the *Restatement (Second) of Torts*, but the court determined that the Rideouts did sufficiently allege claims for both torts.

Another case alleging intentional infliction of emotional distress, *Estate of Bland v. Cigna Healthplan of Texas*, involved an AIDS patient who died after he was taken off a respirator against his wishes. Family members sued his health care providers and the chair of the hospital's ethics committee.[31] The suit was settled, and it is not clear whether the family would have prevailed if the case had gone to trial. However, several facts appeared to make the actions of the health care providers particularly egregious.

Bland, a registered nurse who was

close to death, was admitted to a Houston hospital's ICU. At the hospital, he was placed on a respirator and given a paralytic drug to make him comfortable. Because he was afraid of suffocating if he was taken off the respirator, "he asked his physician to allow him to die peacefully while being ventilated."[32] His family agreed to a DNR order on the condition that Bland be kept on the respirator.

Bland's primary care physician, who was part of a Cigna managed care plan, questioned whether he needed to remain in the ICU. Allegedly in response to these concerns, the hospital's ethics committee chair intervened without consulting Bland's family, and "the patient was removed from the respirator by a respiratory therapist and died shortly thereafter."[33]

Few courts have specifically addressed the issue of futility of medical treatment, and those that have considered it have reached inconsistent conclusions.

Informed consent. In addition to emotional distress claims, the *Rideout* plaintiffs brought a series of claims based on lack of informed consent. They were grounded in common law as well as constitutional provisions because the defendant was a state institution. Regarding the common law claim, the court relied on Pennsylvania case law holding that "where a surgical procedure is performed upon an incompetent, the physician must obtain consent by way of the patient's surrogate."[34] The court gave little weight to the hospital's argument that removal of the ventilator was not a surgical procedure and concluded that it was premature to dismiss the claim.

Statutory claims. Although the Rideouts' emotional distress and informed consent claims survived summary judgment, their case shows the obstacles facing claims based on violations of EMTALA or the Rehabilitation Act.

The court determined that the hospital had not violated EMTALA by discontinuing Brianne's ventilator. It distinguished the case from *In re Baby K*,[35] in which the Fourth Circuit had held that EMTALA required a hospital to provide ventilatory support to an infant with anencephaly when the infant was brought to the hospital's emergency room, despite the hospital's view that "such treatment was unethical and inappropriate."[36] The *Rideout* court held that Brianne had received "appropriate medical screening, and her emergency medical condition was properly stabilized for approximately three months."[37] In addition, the court found that because of her condition, discharge or transfer from the hospital was unlikely.

Finally, the court determined that the facts of the case did not support a claim alleging violation of the Rehabilitation Act. To be successful under §504 of the act, a plaintiff must show that a person with a disability is "otherwise qualified" for the benefit sought and that he or she was discriminated against solely because of the disability. Brianne, the court determined, "was not 'otherwise qualified' to receive mechanical ventilatory support absent her disabling condition since that condition (brain-stem cancer) was related to the condition to be treated (lack of oxygen)."[38]

In another unsuccessful EMTALA case, *Bryan v. Rectors & Visitors of the University of Virginia*, Cindy Bryan brought suit against the university on behalf of Shirley Robertson, a 53-year-old patient who was transferred to the university hospital after surgery at a regional hospital to treat an ulcer.[39] Her condition after surgery was very poor, and a CT scan "revealed a massive left cerebrovascular stroke. In addition, her multiple infections were not responsive to antibiotics, and she had massive subcutaneous emphysema and kidney failure."[40]

Although her family asked her health care providers to do everything possible to keep her alive, including administering CPR in the event of cardiac arrest, her doctors determined that CPR would be "ethically and medically inappropriate." After consultation with members of the hospital's ethics committee and several other physicians not involved in the case, the attending physician wrote a DNR order. Eight days later, Robertson had a heart attack and died.

The plaintiff argued that under EMTALA the hospital had an obligation not only "to admit Mrs. Robertson for treatment of her emergency condition"—respiratory distress—"but thereafter continuously to 'stabilize' her condition no matter how long treatment was required to maintain that condition."[41] The Fourth Circuit disagreed, holding that "EMTALA seeks to achieve the limited purpose of its enactment by requiring that the hospital provide limited stabilizing treatment to or an appropriate transfer of any patient that arrives with an emergency condition" and that the stabilizing requirement does not apply in the context of the patient's long-term care in the facility.[42]

Intentional tort. In at least two cases, plaintiffs have characterized the wrong as an intentional tort and argued that the claim was not subject to the state's procedural requirements under its medical malpractice statute. The courts in both cases disagreed.

In *Causey v. St. Francis Medical Center*, the family of a 31-year-old comatose, quadriplegic patient in end-stage renal failure sued the hospital and the patient's physician for intentional battery after the physician withdrew the patient's LSMT against the family's wishes.[43] The Louisiana Court of Appeal affirmed the trial court's decision that withdrawal of medical treatment without consent requires a determination of the relevant standard of medical care. As a result, the court said, the claim falls under the state's Medical Malpractice Act and should have been submitted to a medical review panel before being filed in court.

Similarly, in *Litz v. Robinson*, the Idaho Court of Appeals held that the plaintiff's claim of intentional infliction of emotional distress for wrongful withholding of life-saving treatment was, in essence,

a medical malpractice claim. Therefore, it had to comply with the state's requirements for malpractice actions, including the production of expert testimony.[44]

The question of futility

In each of these cases, the health care provider's general defense is that the demanded medical treatment would have been medically inappropriate or futile. Few courts have specifically addressed the issue of futility, and those that have considered it have reached inconsistent conclusions.

In *Causey*, the court examined the concept of futility in some detail, distinguishing between care that is medically or physiologically futile and care that is futile on "philosophical, religious, or practical grounds."[45] The court asserted that "futility is a subjective and nebulous concept which, except in the strictest physiological sense, incorporates value judgments."[46] To focus on a definition of "futility," it said, "is confusing and generates polemical discussions." As a result, the court characterized the issue as one of the appropriate standard of care; it went on to say that a physician has no obligation to "provide interventions that in his view would be harmful, without effect, or 'medically inappropriate.'"[47]

In *Gilgunn v. Massachusetts General Hospital*, a jury rejected claims by Catherine Gilgunn's daughter, Joan, that the hospital and two of its physicians were guilty of negligence and infliction of emotional distress.[48] Catherine was a 71-year-old comatose patient with multiple health problems and extensive brain damage from a series of seizures. Despite her daughter's claims that Catherine had said she wanted everything done to keep her alive, her physicians wrote a DNR order asserting that CPR in her case would be "medically contraindicated, inhumane, and unethical."[49] The jury agreed with the physicians.

In these cases, health care providers allege that "doctors are not required to provide a treatment simply because it is demanded by patients or their surrogates."[50] On the other hand, patients and their advocates argue that these cases are about "how society protects its most vulnerable members and how it decides

which lives are worth preserving."[51]

It is not hard to understand why judges might be uneasy deciding these life-and-death matters, especially given the lack of consensus on the definition of "futile" medical treatment and a process for determining it. There is also an unstated concern that health care costs are driving these decisions.[52] In both *Rideout* and *Bland*, for example, it is unclear whether the termination of life support was motivated by cost concerns or by the patient's status.

This confusion may rightly give judges pause, and some may decide that the validity of a "futility defense" is a matter that should be addressed by the legislature rather than the judiciary. At least one state government has attempted to help judges in this regard. In 2003, the Texas legislature added a provision to its advance directive law that requires review by an ethics or medical committee when an attending physician refuses to comply with a patient's or surrogate's request for LSMT because the doctor believes the treatment would be medically inappropriate. If the committee agrees with the physician, the patient must be given LSMT while efforts are made to transfer the patient to a willing provider.[53] If a willing provider cannot be found within 10 days of the committee decision, the treatment may be withdrawn or withheld unless a court has granted an extension.

The statute provides a framework for resolving these disputes outside the courtroom, although it has not prevented litigation.[54]

Plaintiffs who seek damages for the harm of unwanted LSMT are largely fighting an uphill battle. Courts have reaffirmed the right to refuse this treatment, but generally they perceive a damages remedy as a "wrongful living" claim, which they are unwilling to endorse. Plaintiffs who seek damages for the withholding or withdrawal of requested life-saving treatment may fare better, especially where the facts indicate egregious conduct by hospital personnel or where there is some indication that a hospital is motivated by cost concerns—but they face uncertainty when health care providers defend their action on futility grounds.

Plaintiffs are more likely to achieve their goals in futility cases if they seek a remedy before life support is terminated. Courts may be more willing to order the provision of care consistent with a patient's wishes when he or she is still alive than to award damages after a patient has died. ■

Notes

1. Ken Fuson, *Iowan Spells Out Wishes for Caregivers*, Des Moines Register 1A (May 16, 2006), www.desmoinesregister.com/apps/pbcs.dll/article?AID=/20060516/LIFE02/605160389.
2. *Thor v. Superior Court*, 855 P.2d 375, 380 (Cal. 1993) (quoting *In re Gardner*, 534 A.2d 947, 950 (Me. 1987)); *In re Conroy*, 486 A.2d 1209, 1223 (N.J. 1985).
3. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261 (1990).
4. *See e.g. State v. McAfee*, 385 S.E.2d 651 (Ga. 1989).
5. *See* Mary M. Tess, *Acute Confusional States in Critically Ill Patients: A Review*, 23 J. Neuroscience Nursing 398 (1991).
6. *See e.g. In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976).
7. *See In re Spring*, 399 N.E.2d 493, 499 n. 9 (Mass. App. 1979), *rev'd*, 405 N.E.2d 115 (Mass. 1980).
8. 355 A.2d 647.
9. *See e.g. McConnell v. Beverly Enter.-Conn., Inc.*, 553 A.2d 596, 604-05 (Conn. 1989).
10. 671 N.E.2d 225 (Ohio 1996).
11. *Id.* at 227.
12. *Id.* at 228-29.
13. Alan Meisel & Kathy Cerminara, *The Right to Die* §11.02[A], 11-14 (3d ed., Aspen Publishers 2004).
14. 727 N.E.2d 466, 470 (Ind. App. 2000).
15. *Id.*
16. *Id.* at 472.
17. *Id.* at 471.
18. 728 A.2d 166 (Md. 1999), *superseded by statute, Plein v. Dept. of Labor*, 800 A.2d 757 (Md. 2002).
19. 699 N.E.2d 560 (Ohio App. 6th Dist. 1997). The court's decision creates an incentive for poor communication among health care providers about an advance directive.
20. 213 F. Supp. 2d 184, 197 (N.D.N.Y. 2002), *aff'd on other grounds*, 356 F.3d 348 (2d Cir. 2004).
21. *Id.* at 197.
22. *Duarte v. Chino Community Hosp.*, 85 Cal. Rptr. 2d 521 (Cal. App. 4th Dist. 1999).
23. *See* Mark Crane, *The Latest Malpractice Risk: Saving Your Patient's Life*, 75 Med. Econ. 226 (1998).
24. 42 U.S.C.A. §1395dd (West Supp. 2006).
25. 29 U.S.C. §§701-796l (2000).
26. 30 Pa. D. & C. 4th 57 (Dauphin Co. Ct. Com. Pleas 1995).
27. *Id.* at 61.
28. *Id.* at 63.
29. *Id.*
30. *Id.*
31. No. 93-52630 (Harris County Tex., 11th Dist. 1995).
32. *Introduction to Clinical Ethics* 273 (John C. Fletcher & eds., 2d ed., U. Publg. Group 1997).
33. *Id.* at 273, 285 n. 80.
34. 30 Pa. D. & C. 4th at 72.
35. 16 F.3d 590 (4th Cir. 1994).
36. 30 Pa. D. & C. 4th at 89 (quoting *In re Baby K*, 16 F.3d at 593).
37. *Id.* at 90-91.
38. *Id.* at 93.
39. 95 F.3d 349 (4th Cir. 1996).
40. *Introduction to Clinical Ethics*, *supra* n. 32, at 271.
41. *Bryan*, 95 F.3d at 350.
42. *Id.* at 352. In *Causey v. St. Francis Med. Ctr.* (719 So. 2d 1072, 1075 n. 2 (La. App. 2d Cir. 1998)), the court considered a similar EMTALA claim and followed the reasoning in *Bryan*, holding that EMTALA was not applicable.
43. 719 So. 2d at 1073.
44. 955 P.2d 113 (Idaho App. 1997).
45. 719 So. 2d at 1074.
46. *Id.* at 1075.
47. *Id.* This was also consistent with La. Stat. Ann. §40:1299.58.1 (2001).
48. No. 92-4820 (Mass. Super. Apr. 21, 1995).
49. Alexander Morgan Capron, *Abandoning a Waning Life*, 25 Hastings Ctr. Rep. 5 (July/Aug. 1995).
50. Gina Kolata, *Withholding Care from Patients: Boston Case Asks, Who Decides?*, N.Y. Times A1 (Apr. 3, 1995).
51. *Id.*
52. *See e.g.* Ruth Sorelle, *Mercy or Money?: Suit Focuses on How Much Pressure Health Plans Put on Doctors' Decisions*, Hous. Chron. A1 (Oct. 11, 1993).
53. Tex. Health & Safety Code Ann. §166.052 (Supp. 2005).
54. *See e.g. Hudson v. Tex. Children's Hosp.*, 177 S.W.3d 232 (Tex. App. 2005).