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# The Case of Baby K: Exploring the Concept of Medical Futility

Mark A. Bonanno\*

## INTRODUCTION

Withholding and withdrawing medical treatment near the end of life is a constant source of legal and ethical debate. In the 1970s and 1980s, a steady stream of “right-to-die” and “right to refuse treatment” actions brought physicians and patients into courtrooms across the country.<sup>1</sup> The question in these cases was whether the interest of a patient in refusing life-saving medical treatment was superior to the interests of health care providers and the interests of states in steadfastly preserving life. With some exceptions, patients prevailed.<sup>2</sup> Now the theoretical question has been turned around: whether the interest of a patient in demanding life-saving medical treatment is to be honored when health care providers decide such treatment is medically not beneficial or warranted. In the most recent conflicts, patients demanding treatment face resistance from physicians seeking to withhold or withdraw medical care.<sup>3</sup> Relying on the principle of patient autonomy, the patient or a surrogate family member instructs the doctor to continue administering medical care, such as cardiopulmonary resuscitation (CPR) or mechanical ventilator assistance, because even though the chance for survival is

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1. See, e.g., *Cruzan v. Missouri Dep't of Health*, 497 U.S. 261 (1990); *In re Quinlan*, 355 A.2d 647 (N.J.), cert. den., 429 U.S. 922 (1976); *Brophy v. New England Sinai Hosp.*, 497 N.E.2d 626 (Mass. 1986); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (1986); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977).

2. Although the Court in *Cruzan* recognized that a person could refuse life-saving medical treatment, it held that clear and convincing evidence was required of an incompetent's wish to withdraw treatment, a procedural requirement that Nancy Cruzan's parents did not meet. *Cruzan v. Missouri Dep't of Health*, 497 U.S. at 280.

3. See, e.g., *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), aff'd, 16 F.3d 590 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994) (considering declaratory action to refuse life-supporting care to anencephalic infant).

minimal, there is value to each additional moment of the patient's life.<sup>4</sup>

A physician may seek to terminate treatment as medically futile because in his or her opinion the additional procedures or tests will yield no net benefit to the patient.<sup>5</sup> In extreme cases, health care providers are asking courts to decide whether or not treatment may be withheld from a patient.<sup>6</sup> From scant opinions, courts are inclined to rely on the wishes of a patient or surrogate family member.<sup>7</sup> These decisions are being criticized because, as current political consensus builds toward the development of a health care system that secures universal access to medicine within economic constraints, the provision of treatment that is not beneficial is closely questioned.<sup>8</sup>

In October of 1992, a baby girl was born in Virginia who unknowingly became a symbol of medical futility.<sup>9</sup> Baby K was anencephalic,<sup>10</sup> and as a result should have died a few days after

4. In the Baby K case, an anencephalic baby's mother did not want ventilator treatment discontinued because she believed that "all human life has value, including her anencephalic daughter's life." *Id.* at 1026.

5. Robert M. Veatch & Carol Mason Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15, 16 (1992) (describing the concept of medically futile care).

6. See, e.g., *In re Baby K*, 832 F. Supp. 1022.

7. See, e.g., *In re Wanglie*, No. PX-91-283 (Prob. Ct. Hennepin Co., Minn. 1991), reprinted in [1991 Transfer Binder] II BioLaw (Univ. Pub. Am.) U:2161, U:2164; John J. Paris et al., *Physician's Refusal of Requested Treatment: The Case of Baby L*, 322 NEW ENG. J. MED. 1012, 1013 (1990).

8. See Ann MacLean Massie, *Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide*, 35 ARIZ. L. REV. 173 (1993); see also Ann Alpers & Bernard Lo, *Futility: Not Just a Medical Issue*, 21 L. MED. & HEALTH CARE 327 (1992); Lance K. Stell, *Stopping Treatment on Grounds of Futility: A Role for Institutional Policy*, 11 ST. LOUIS U. PUB. L. REV. 481 (1992); Edward B. Hirshfeld, *Should Ethical and Legal Standards for Physicians Be Changed to Accommodate New Models for Rationing Health Care?*, 140 U. PA. L. REV. 1809 (1992).

9. See 832 F. Supp. 1022. Generally, the debate surrounding medical "futility" is a medical, legal, and ethical debate that pits a patient's desire to receive treatment against the physician's medical judgment that no benefit would be achieved. In other words, the expenditure of medical resources toward a goal of improving the health status of a patient is thought to be futile. However, the public has voiced its views as well. See, e.g., *Dateline Feedback; Response from Viewers on Whether Baby Born with No Brain Should Be Kept Alive* (NBC television broadcast, Mar. 28, 1995). Baby K died on April 5, 1995. See Marylou Tousignant & Bill Miller, *Death of "Baby K" Leaves a Legacy of Legal Precedents*, Apr. 7, 1995, at B03.

10. Anencephaly is a medical condition characterized by an incomplete brain; that is, the brain is "entirely or substantially absent." PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL AND LEGAL ISSUES IN TREATMENT DECISIONS* 202 (1983) [hereinafter PRESIDENT'S COMM'N]. Specifically, anencephaly is defined as a congenitally

birth. However, when she began having trouble breathing, physicians provided her with assistance through the use of a machine called a ventilator. At the insistence of her mother, ventilator treatment was administered in subsequent episodes of difficult breathing and, remarkably, this cycle of medical care kept her from dying for over two years.<sup>11</sup> Her physicians believed the continued provision of this kind of treatment was futile because she had no chance for a conscious life. Thus, they recommended that the hospital seek a court order allowing them to refuse ventilator treatment during a future episode of difficult breathing.<sup>12</sup> The district court said refusing to provide treatment would violate federal law;<sup>13</sup> seven months later the Fourth Circuit agreed.<sup>14</sup> Consequently, the case has fueled a growing debate in the medical and legal communities about a patient's right to demand medical treatment that a physician does not want to provide.<sup>15</sup>

This article discusses the manner in which courts have responded to the medical futility debate by highlighting the *Baby K* decisions and their effect on the practice of medicine. The following questions are then considered. Should a medical or legal definition of medical futility be developed for use in hospitals and courts? While general agreement exists that a patient may refuse treatment in life-threatening situations, may a patient similarly demand treatment even though the physician believes treatment is not warranted, especially when the result will most likely be death? May health care providers simply respond

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defective development of the brain, with absence of the bones of the cranial vault, the cerebral and cerebellar hemispheres, a rudimentary brainstem, and traces of basal ganglia. *STEDMAN'S MEDICAL DICTIONARY* 75 (25th ed. 1990).

11. See Marylou Tousignant & Bill Miller, *Baby K's Mother Gives Her the Prayer That Many Deny She Has*, *WASH. POST*, Oct. 7, 1994, at A01.

12. The hospital involved in the litigation is Fairfax Hospital located in Falls Church, Virginia. Linda Greenhouse, *Court Order to Treat Baby with Partial Brain Prompts Debate on Costs and Ethics*, *N.Y. TIMES*, Feb. 20, 1994, at 20.

13. 832 F. Supp. at 1031.

14. 16 F.3d 590 (4th Cir), *cert. denied*, 115 S. Ct. 91 (1994).

15. "The case of 'Baby K' . . . has become an emotional tug of war over issues such as parents' rights, medical ethics and who should decide what is proper medical treatment for a patient." Bill Miller & Marilou Tousignant, *Mother Fights Hospital to Keep Infant Alive*, *WASH. POST*, Sept. 25, 1993, at A01. "Under [the court's definition of disabled] a hospital or doctor could be guilty of discrimination if they refused to perform brain surgery on the baby just because she didn't have a brain. There is a difference between discrimination and medical judgment." Ellen Goodman, *The Shift from Dr. Partner to Dr. Provider*, *BOSTON GLOBE*, Oct. 24, 1993, at 85; Linda Greenhouse, *Hospital Appeals Ruling on Treating Baby Born with Most of Brain Gone*, *N.Y. TIMES*, Sept. 24, 1993, at A10 (describing opposing views on the court decision).

to patients that a certain medical procedure will not be provided because "we don't do that here"?<sup>16</sup>

Section I provides a brief overview of the futility debate by reporting on variations in definitions, and then looking at the application of the concept from medical and legal perspectives. Section II discusses the most recent case law entering the debate, and focuses on the controversial *Baby K* opinion, which appears to stifle physician decision making in the doctor-patient relationship by granting broad patient authority to dictate the course of medical treatment regardless of the benefit provided. Section III examines the reasoning of the court opinions, and further analyzes medical futility in the context of providing health care services in the United States. Given the recent call for national health care reform, there may be a conflict unfolding between protecting the rights of individual patients such as *Baby K* and achieving societal goals of maintaining a health care system that is cost effective, of high quality, and universally accessible. Finally, Section IV attempts to clarify some of the confusion stemming from the *Baby K* decision, and offers a few suggestions for better resolution of these cases without resorting to litigation.

## I. DEFINING MEDICAL FUTILITY: NOT A SIMPLE TASK

Medical futility—an imprecise term wielded by doctors, bioethicists, and lawyers to classify the justification for terminating medical treatment that is not beneficial—has emerged from our current struggle to create a comprehensive health care system, and challenged the notion that patients should be given all therapies medicine has to offer without regard for cost or anticipated quality of life. While the concepts underlying the futility debate may be traced to an earlier patients' rights movement in right-to-die cases, the issue is more complex because a consensus about denying patients medical treatment they desire (rather than refuse) is much harder to achieve.<sup>17</sup> Our reliance on life-saving technology to produce miracles, together with a steady erosion of doctor decision-making authority, and societal pressure to contain health care costs all lurk in the background of this discussion.

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16. John J. Paris et al., *Beyond Autonomy—Physicians' Refusal to Use Life-Prolonging Extracorporeal Membrane Oxygenation*, 329 *NEW ENG. J. MED.* 354, 357 (1993).

17. Veatch & Spicer, *supra* note 5, at 16.

Drafting a medical or legal definition of futility may avoid confusion in deciding when treatment should be withheld, but fashioning terminology for physicians to point to as authority for denying care may decrease patient involvement in medical decision making. Futility is moving from hallway consultations on hospital rounds into the courtroom; consequently, these legal decisions will most likely reshape the nature of the concept.

### A. *Origins of the Futility Debate*

Patient contradiction of a physician's futility decision is not surprising given the evolution of medicine from a simple relationship between the doctor and patient to our current complex health care system of doctors, allied health professionals, hospitals, public and private insurers, ethics committees, the patient, and the patient's family members; each potentially engaged in decision making regarding an episode of medical care.<sup>18</sup> This challenge to physician authority was readily apparent in *Bouvia v. Superior Court*, where a patient suffering from a severe form of cerebral palsy wanted to die.<sup>19</sup> Her physicians insisted on care, but the court held she could forgo artificial hydration and nutrition even though such action would result in her death.<sup>20</sup> In contrast, the futility debate puts a physician in the position of refusing to provide treatment, contrary to the patient's desire to attempt to prolong life.<sup>21</sup> However, the well-founded principle of patient autonomy indicates that any such unilateral decision attempted by a health care provider will be challenged.<sup>22</sup>

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18. In the early 1980s, Paul Starr observed that "[e]merging developments [in medicine] now jeopardize the profession's control of markets, organizations, and standards of judgment. The profession has benefited from state protection and political accommodation of its interests, but government is no longer so sympathetic and physicians are no longer the single, dominating claimant in the medical industry." PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 421 (1982).

19. 225 Cal. Rptr. 297 (1986); see also KENNETH R. WING, *THE LAW AND THE PUBLIC'S HEALTH* 102-107 (3d ed. 1990 & Supp. 1990) (discussing right-to-die cases).

20. 225 Cal. Rptr. at 301, 306 (stating that this right of a competent adult to refuse medical treatment, including that which would prolong or save the person's life, is one that is basic and fundamental).

21. "Suddenly we see a reversal. A patient or family says, 'Do everything,' while the physician says, 'Stop.'" E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 33, 33.

22. Marcia Angell, *The Case of Helga Wanglie—A New Kind of "Right to Die" Case*, 325 NEW ENG. J. MED. 511, 571 (1991) (arguing that futility conflicts are a form of earlier right-to-die cases because they affirm the right of the family to make decisions about life-sustaining treatment); see Troyen A. Brennan, *Physicians and Futile Care: Using Ethics Committees to Slow the Momentum*, 21 L. MED. & HEALTH CARE 336, 337-38 (1992) (futility debate is a side effect of the right-to-die movement).

In addition to roots in right-to-die principles, technological innovation that sustains body functions for longer periods has played a role in shaping the futility concept. Patients, and even doctors, expect modern medicine to cure every ailment.<sup>23</sup> Medicine offers us life extension through high technology procedures such as organ transplantation and gene therapy.<sup>24</sup> As a result of the narrow focus on sustaining a patient for days or even months, both health care providers and families may disregard quality of life considerations when patients are unable to make their own choices.<sup>25</sup> This distinction between quantity and quality in defining life, which medical technology makes us contemplate, is apparent when patients demand futile treatment.<sup>26</sup> Further, the modernization of medicine from the private interpersonal house call to an efficient production-line office visit has led to an erosion of the doctor-patient relationship, and, conse-

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23. See DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* 16 (1987) (discussing our reliance on medical technology); GEORGE J. ANNAS, *STANDARD OF CARE: THE LAW OF AMERICAN BIOETHICS* 215 (1993) (stating we have been taught to demand medical technologies that are touted as miracles that can cure us); ALAN D. LIEBERSON, *ADVANCE MEDICAL DIRECTIVES* 30 (1992 & Supp. 1994) (doctors trained that death is the enemy); Mildred Z. Solomon, *How Physicians Talk About Futility: Making Words Mean Too Many Things*, 21 J.L. MED. & ETHICS 231, 236 (1993) (we believe medical progress will alleviate all human ills).

24. See generally LIEBERSON, *supra* note 23, at 26 (discussing the technology explosion). In addition to more complex technologies, more common procedures may be culprits as well. Recent commentary suggests that medical futility arose out of studies demonstrating the inefficacy of cardiopulmonary resuscitation. See also Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. a Physician's Professional Conscience*, 44 HASTINGS L.J. 1241, 1253-54 (1993); Arthur L. Kellermann et al., *Predicting the Outcome of Unsuccessful Prehospital Advanced Cardiac Life Support*, 270 JAMA 1433 (1993) (prehospital advanced cardiac life support); Marni J. Bonnin et al., *Distinct Criteria for Termination of Resuscitation in the Out-of-Hospital Setting*, 270 JAMA 1457 (survival rates for out-of-hospital cardiac arrests) (1993); William A. Gray, *Prehospital Resuscitation: The Good, the Bad, and the Futile*, 270 JAMA 1471, 1472 (1993) (recommending systematic changes in termination of prehospital unsuccessful resuscitation); Don Colburn, *Futile Care in Cardiac Arrest Cases; When Heart Can't Be Restarted on the Scene, There's Little More a Hospital Can Do*, WASH. POST, Oct. 5, 1993, at Z07.

25. See ANNAS, *supra* note 23, at 216-17.

26. Death is a technical phenomenon obtained by a cessation of care, a cessation determined in a more or less avowed way by a decision of the doctor and the hospital team. Indeed, in the majority of cases the dying person has already lost consciousness. Death has been dissected, cut into bits by a series of little steps, which finally makes it impossible to know which step was the real death, the one in which consciousness was lost, or the one in which breathing stopped.

LIEBERSON, *supra* note 23, at 29-30; Thomas Wm. Mayo, *Constitutionalizing the "Right to Die,"* 49 MD. L. REV. 103, 154 (1990) (quoting PHILLIPE ARIES, *WESTERN ATTITUDES TOWARD DEATH: FROM THE MIDDLE AGES TO THE PRESENT* 88-89 (1974)).

quently, an emerging distrust of doctors making medical decisions.<sup>27</sup> Because patients have been empowered with more decision-making authority in medical treatment, doctors may be looking for ways to retain control by hanging treatment decisions on the concept of medical futility. With the treatment labeled as futile, the physician preempts further communication with the patient or family members about how the patient will die. Finally, in the background and possibly foreground of this debate are financial concerns, as we face the challenge of developing a cost-efficient health care system. Compared with the right-to-die issue, the emerging futility debate appears to be more complexly motivated.<sup>28</sup>

### B. Formulating a Medical or Legal Definition

In general, the concept of medical futility is poorly defined and frequently misused in the clinical setting.<sup>29</sup> Various commentators have described the futility discussion: "an elusive concept,"<sup>30</sup> "a war of words,"<sup>31</sup> "the problem-without-a-name,"<sup>32</sup> "the newest addition [ ] to the lexicon of bioethics,"<sup>33</sup> and "a highly dangerous concept."<sup>34</sup> The problem with developing a standard clinical definition of medical futility is that the concept contains value judgments about the quality of the patient's life. As a consequence, what may be considered by one physician to be futile may not be to the patient or even another physician.<sup>35</sup>

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27. LIEBERSON, *supra* note 23, at 574 (quoting Alan Meisel, head of the Medical Ethics Center at the University of Pittsburgh, who stated that increasing antagonism between health care providers and patients is evidence of the deterioration of the doctor-patient relationship).

28. ALAN MEISEL, *THE RIGHT TO DIE* (1989 & Supp. 1994).

29. Ronald Cranford & Lawrence Gostin, *Futility: A Concept in Search of a Definition*, 20 L. MED. & HEALTH CARE 307, 307 (1992).

30. John D. Lantos et al., *The Illusion of Futility in Clinical Practice*, 87 AM. J. MED. 81, 83 (1989).

31. Morreim, *supra* note 21, at 33.

32. Daniel Callahan, *Medical Futility, Medical Necessity: The Problem-Without-a-Name*, HASTINGS CENTER REP., July-Aug. 1991, at 30, 30.

33. Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560 (1992).

34. Cranford & Gostin, *supra* note 29, at 309.

35. Solomon, *supra* note 23, at 232, 235. This difficulty with agreeing on a futility definition was readily apparent at the Washington Hospital Center's Seventh Annual Bioethics Conference in 1993. Seventh Annual Bioethics Conference, *Medical Futility: Is There Consensus?*, Washington Hospital Center, Washington, D.C. (Oct. 20, 1993). During one part of the conference, attendees were asked to develop a process for determining medical futility. A mix of physicians, nurses, social workers, clergy, legislators, attorneys, administrators, psychologists, and clinical staff noted much debate in coming to an agreement on a working definition of futility, or even what crite-



In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research reported on issues arising from the decision to forgo life-sustaining treatment.<sup>36</sup> In its discussion about seriously ill newborns, assessments were made regarding the forgoing of treatment for certain types of conditions. "When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates and providers not to try predictably futile endeavors is ethically and legally justifiable."<sup>37</sup> While there was apparent agreement that "futile endeavors" should not be carried out, there did not appear to be much guidance addressing what was actually futile. Currently, there are few statutory guidelines on making futility decisions other than state-level "do not resuscitate order" or "advance medical directive" legislation.<sup>38</sup> Much debate has surfaced over whether or not to develop criteria for allowing physicians to withdraw treatment based on futility.

Those supporting the concept of medical futility generally argue that physicians must be able to make medical judgments about the course of patient care. To yield to the demands of patients, or more likely their families, when treatment is judged of "no benefit" would undermine medical ethics and lessen the dignity of the dying patient.<sup>39</sup> "Do we not recognize the author-

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ria should go into a determination of futility in the clinical setting. As one lecturer commented, this issue is probably like pornography in that you simply know it when you see it. Robert M. Arnold, Address at the Seventh Annual Bioethics Conference, Medical Futility: Theory v. Practice, Washington Hospital Center, Washington, D.C. (Oct. 20, 1993); see also Trug et al., *supra* note 33, at 1560 (1992) (stating futility may be like pornography in that clinicians may not be able to define it, but they know it when they see it).

36. PRESIDENT'S COMM'N, *supra* note 10.

37. *Id.* at 219.

38. Both Georgia and New York attempted to define the term "medically futile" in respective "do not resuscitate" statutes. New York defines the term similarly to Georgia: medically futile "means that cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs." GA. CODE ANN. § 31-39-2 (1993); N.Y. PUBLIC HEALTH LAW § 2961 (McKinney 1994).

39. Is there a right on the part of a competent, but dying, patient to vigorous life-extending treatment when there is little medical reason to think it will be efficacious? That would be a strange claim. A patient has a right only to ask medicine to do that which is compatible with its proper goals. Those goals cannot encompass an effort to extend a life in the face of a wholly bleak medical prognosis: health cannot thereby be promoted. Discretion and sensitivity in the doctor-patient relationship will be required in a refusal to provide wanted though useless treatment. The physician should make clear that he or she cannot provide useless or inappropriate care which will neither do the patient any good nor bring honor to the practice of medicine.

ity of the physician to place at least some limitations on patients' demands for treatment? . . . [P]hysicians must be able to employ reasonable, socially validated value judgments to restrict the alternative offered to patients, for the sake of both physician integrity and patient autonomy."<sup>40</sup> In extreme cases, as with anencephaly, the physician should not feel obligated to provide cure-oriented care and should simply respond "we don't do that here."<sup>41</sup>

On the other hand, some are skeptical about defining medical futility. Their main fear is that physicians should not be allowed to unilaterally forgo medical treatment when the decision is largely based on a value judgment rather than concrete medical criteria or statistics.<sup>42</sup> Patients are just as qualified to make these value-laden determinations.<sup>43</sup> "When the alternative is death, the question of whether going for a long-shot chance of recovering consciousness is worth it is quite obviously a question of values, rather than a technical medical question doctors are especially professionally qualified to decide."<sup>44</sup> The term itself is arguably too vague,<sup>45</sup> and some urge that we move beyond the narrow futility discussion because the problems of setting limits in health care are societal decisions.<sup>46</sup>

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CALLAHAN, *supra* note 23, at 176-77.

40. Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276, 1277 (1990).

41. Paris et al., *supra* note 16, at 357. In light of a growing consensus for national health reform, the futility debate also may represent the fray of discussion about affording accessible and affordable basic medical care. That is, "[w]e could not afford a universal health care system based on patients' demands. Such a system would irrationally allocate health care to socially powerful people with strong preferences for immediate treatment to the disadvantage of those with less power or less immediate needs." Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512, 514 (1991).

42. See Barbara Springer Edwards, *Deciding What was Best for Baby Rena*, WASH. POST, Aug. 1, 1991 at A14 (Letters to the Editor) (we should not allow physicians to impose their own views and biases on the patient and family).

43. Veatch & Spicer, *supra* note 5, at 36.

44. Felicia Ackerman, *The Significance of a Wish*, HASTINGS CENTER REP., July-Aug. 1991, at 27, 27.

45. Solomon, *supra* note 23, at 231 (should not be used to guide decision making near the end of life); Cranford & Gostin, *supra* note 29, at 307 (no consensus on a definition).

46. LIEBERSON, *supra* note 23, at 573 (quoting Susan M. Wolf, an ethicist at New York's Hastings Center, who stated society should set the limits); Robert D. Truog, *Beyond Futility*, 3 J. CLINICAL ETHICS 143, 144 (1992) (futility is one new buzzword we would be better off without); Morreim, *supra* note 21, at 33 (calling the futility debate largely futile).

Because there is no definitional consensus and because patients will disagree with physicians, the issue of medical futility will be deliberated in the courts. Arguments on both sides of the debate are reflected in preliminary case law analyzing the denial or withdrawal of care deemed medically futile by the health care provider.

## II. FUTILITY IN THE COURTS: THE CASE OF BABY K

Currently, only a few cases of health care providers seeking to withhold medical care contrary to patient demands have reached the courtrooms. One of the first cases involved an elderly woman who tragically suffered a heart attack soon after hospitalization for a hip fracture.<sup>47</sup> She never regained consciousness, and lived for over a year in a persistent vegetative state.<sup>48</sup> The hospital asked the court to appoint a guardian—other than the patient's husband—so that an objective determination could be made about the course of medical care.<sup>49</sup> The court refused because it determined the husband was the best person to be her guardian. As a result, the woman died still supported by a ventilator.

In another case, a two-year-old girl with severe neurological injury was being kept alive by mechanical ventilation and cardiovascular support.<sup>50</sup> Physicians and hospital personnel agreed that aggressive medical intervention was not in the baby's best interests; however, the mother demanded treatment.<sup>51</sup> Before the probate court, the hospital challenged the mother's decision. Even though the judge indicated a preference to comply with the mother's interests, the case became moot when the baby was transferred to a hospital willing to provide care.<sup>52</sup>

In a recent situation, parties asked the court to decide what medical treatment physicians were obligated to provide to Baby

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47. *In re Wanglie*, No. PX-91-283 (Prob. Ct. Hennepin Co., Minn. 1991), reprinted in [1991 Transfer Binder] II BioLaw (Univ. Pub. Am.) U:2161, U:2166.

48. *Id.*

49. The hospital did not ask the court to consider the legal obligation to continue treatment that physicians concluded was not beneficial. If an independent guardian had determined respirator treatment was not beneficial, then a second hearing probably would have been convened about the legality of withholding treatment. Miles, *supra* note 41, at 513.

50. Paris et al., *supra* note 7 at 1012.

51. *Id.* at 1013.

52. *Id.*

K.<sup>53</sup> Both the federal district court opinion and court of appeals panel decision illustrate how judicial intervention responded to the issue of medical futility.

Baby K was born on October 13, 1992 and Fairfax Hospital immediately provided her with mechanical ventilator treatment to assist her breathing.<sup>54</sup> After a few days, hospital physicians recommended that the mother allow ventilator treatment to be stopped and a “do not resuscitate order” to be issued on the basis that such treatment was “medically unnecessary and inappropriate” due to the baby’s anencephalic condition.<sup>55</sup> The mother refused the recommendation.

The physicians and the hospital then pursued an alternative route—other than consent through the mother as a surrogate decision maker—to discontinue treatment. First, they consulted with the hospital ethics committee, which concluded that treatment should end because “such care is futile” and if the family insisted on treatment the hospital should go to court. Second, they transferred Baby K to a nursing home at a time when she did not require the ventilator, but stipulated to treating her if difficult breathing resumed.<sup>56</sup> Third, the hospital sought appointment of a guardian ad litem, who concluded treatment should be withheld. Finally, the hospital turned to the court seeking a declaratory judgment to determine their rights and obligations in rendering medical care to Baby K.<sup>57</sup>

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53. *In re Baby K*, 832 F. Supp. 1022, 1026 (E.D. Va. 1993), *aff’d*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

54. 832 F. Supp. at 1025. “Baby K was diagnosed prenatally as being anencephalic. Despite the counselling of her obstetrician and neonatologist that she terminate her pregnancy, Mrs. H. refused to have her unborn child aborted.” *Id.*

55. *Id.* The court used the following description of Baby K’s condition:

Anencephaly is a congenital defect in which the brain stem is present but the cerebral cortex is rudimentary or absent. There is no treatment that will cure, correct, or ameliorate anencephaly. Baby K is permanently unconscious and cannot hear or see. Lacking a cerebral function, Baby K does not feel pain. Baby K has brain stem functions primarily limited to reflexive actions such as feeding reflexes (rooting, sucking, swallowing), respiratory reflexes (breathing, coughing), and reflexive responses to sound or touch. Baby K has a normal heart rate, blood pressure, liver function, digestion, kidney function, and bladder function and has gained weight since her birth. Most anencephalic infants die within days of birth.

*Id.* Under a do not resuscitate order, if Baby K went into respiratory or cardiac arrest no ventilator treatment or cardiopulmonary resuscitation would be provided.

56. Baby K was transferred from the nursing home back to the hospital twice from November 30, 1992 through April 13, 1993. The second time she received a tracheotomy to install a tube in her neck so that ventilator treatment would be easier. *Id.* at 1026.

57. *Id.* at 1027.

Judge Claude Hilton heard evidence and arguments, and then proceeded to whittle away at the hospital's request for declaratory relief from the application of federal and state laws relating to the delivery of health care. First, the hospital wanted assurance that refusing ventilator treatment would not violate the federal Emergency Medical Treatment and Active Labor Act (EMTALA).<sup>58</sup> Under the statute, if an individual arrives at a hospital with an emergency medical condition, treatment must be provided or the individual stabilized for transfer to another facility.<sup>59</sup> Based on the hospital's admission that Baby K meets the statute's criteria when she arrives at the hospital in respiratory distress, Judge Hilton concluded that refusing to care for her difficult breathing by withholding ventilator treatment would violate EMTALA.<sup>60</sup> Tersely, the judge dismissed the hospital's position that an exemption from the statute should be made when treatment is futile: "The plain language of the statute requires stabilization of an emergency medical condition. The statute does not admit of any 'futility' or 'inhumanity' exceptions. Any argument to the contrary should be directed to the U.S. Congress, not to the Federal Judiciary."<sup>61</sup>

The judge considered two federal statutes protecting the handicapped and disabled.<sup>62</sup> First, under the Rehabilitation Act of 1973, any discrimination against a handicapped individual based solely on that handicap is impermissible.<sup>63</sup> Because an infant born with a congenital defect is included in that statute's definition of "handicapped," Baby K is protected by the statute.<sup>64</sup> Therefore, the judge concluded that the hospital could not withhold treatment solely because of Baby K's anencephalic condition.<sup>65</sup> Second, withholding ventilator treatment would vi-

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58. *Id.* at 1026. See 42 U.S.C. § 1395dd (1988 & Supp. 1993).

59. 42 U.S.C. § 1395dd(b)(1).

60. 832 F. Supp. at 1027.

61. *Id.* In dicta, the judge stated that ventilator treatment was not futile in relieving respiratory difficulty because this was the emergency condition that must be treated. Further, "[t]o hold otherwise would allow hospitals to deny emergency treatment to numerous classes of patients, such as accident victims who have terminal cancer or AIDS, on the grounds that they eventually will die anyway from those diseases and that emergency care for them would therefore be 'futile.'" *Id.*

62. *Id.* at 1026.

63. 29 U.S.C. § 794(a) (Supp. 1993).

64. 832 F. Supp. at 1027 (citing *Bowen v. American Hosp. Ass'n*, 476 U.S. 610, 624 (1986)).

65. "Just as an AIDS patient seeking ear surgery is 'otherwise qualified' to receive treatment despite poor long term prospects of living, Baby K is 'otherwise qualified' to receive ventilator treatment despite similarly dismal health prospects." *Id.* at 1028.

olate the Americans with Disabilities Act of 1990 (ADA).<sup>66</sup> In general, the ADA prohibits discrimination against the disabled; services offered for public accommodation, such as hospital services, cannot be denied on the basis of a disability.<sup>67</sup> Judge Hilton reasoned that Baby K is disabled because of her anencephalic condition, and that denying the benefits of ventilator services to anencephalic babies as a class of disabled individuals is not permitted.<sup>68</sup>

The court dismissed consideration of the Child Abuse Amendments of 1984<sup>69</sup> as a state agency must bring suit in cases of child abuse and neglect, and there is no private cause of action under the statute. In this case, the Virginia Child Protective Services was not joined as a necessary party.<sup>70</sup> Similarly, the court declined to “elbow its way” into Virginia medical malpractice law because Virginia courts and the legislature had not addressed the standard of care for anencephalia.<sup>71</sup> This federal court believed there were significant state interests in allowing Virginia to settle the issue for itself.<sup>72</sup> Finally, Judge Hilton analyzed constitutional and common law issues, and determined that the hospital must establish by “clear and convincing evidence” that it should interfere with the mother’s “treatment decision.”<sup>73</sup> “In this case, where the choice essentially devolves to

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66. 42 U.S.C. §§ 12101-12213 (Supp. 1993).

67. *Id.* § 12112.

68. 832 F. Supp. at 1029.

69. 42 U.S.C. §§ 5101-5119 (Supp. 1993).

70. 832 F. Supp. at 1029.

71. *Id.* at 1029-30.

72. *Id.* at 1030. In general, federal district courts have “a duty to adjudicate controversies properly brought before them.” *Jones v. Griffith*, 688 F. Supp. 446, 452-53 (N.D. Ind. 1988). Under the doctrine of abstention, for a district court to decline jurisdiction is an extraordinary and narrow exception. *Colorado River Water Conservation Dist. v. United States*, 424 U.S. 800, 813 (1976) (quoting *County of Allegheny v. Frank Mashuda Co.*, 360 U.S. 185, 188-89 (1959)). Usually, an appropriate circumstance for abstention is “where there have been presented difficult questions of state law bearing on policy problems of substantial public import . . . .” *Id.* at 814. *Compare Jones v. Griffith*, 688 F. Supp. at 454 (questions relating to standard of care in a medical malpractice action brought by wife of deceased patient not of substantial public importance).

73. 832 F. Supp. at 1031. In this case, the source of the clear and convincing standard for the hospital is vague, and the court seems to arrive at the standard through a brief discussion of the First and Fourteenth Amendment rights of Baby K and her parents. First, the court stated the Free Exercise clause of the First Amendment was applicable because the mother had a strong religious belief in protecting life. *Id.* at 1030. In addition, the court seemed to apply a Fourteenth Amendment substantive due process analysis by referencing the *Cruzan* test of clear and convincing evidence, which has been applied in right-to-die cases. *Id.* at 1031. In *Cruzan*, however, the

a subjective determination as to the quality of Baby K's life, it cannot be said that the continuation of Baby K's life is so unreasonably harmful as to constitute child abuse or neglect."<sup>74</sup> The hospital appealed.

The Fourth Circuit simply reviewed the district court's analysis of EMTALA and affirmed.<sup>75</sup> Like Judge Hilton, Judge Wilkins focused on whether difficulty with breathing qualified as an emergency medical condition triggering the duty of the hospital to stabilize under EMTALA. The hospital admitted ventilator treatment was necessary to stabilize Baby K when she was brought back to the hospital in respiratory distress, and failure to treat would cause "serious impairment to bodily functions," which would trigger the duty to stabilize the infant or provide for transfer.<sup>76</sup> Because the mother objected to transfer and no other facility would agree to admit Baby K, the hospital was thus forced to treat.<sup>77</sup> "In sum, a straightforward application of the statute obligates the Hospital to provide respiratory support to Baby K when she arrives at the emergency department of the Hospital in respiratory distress and treatment is requested on her behalf."<sup>78</sup>

Recognizing its hands were tied, the hospital tried to argue around the language of the statute. First, it argued that EMTALA only requires uniform treatment of all patients with the

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Supreme Court required that the parents offer clear and convincing evidence of their adult daughter's wishes to withdraw treatment. Absent such evidence, the parents could not request that the treatment be terminated. Unlike *Cruzan*, the issues in *Baby K* involve an infant and a parent's demand for medical treatment. There does not appear to be a standard for this novel situation, but Judge Hilton thought the hospital needed to come forward with clear and convincing evidence that ventilator treatment could be withheld against the mother's wishes. *Id.* at 1031. In medicine, absent a legal obligation, there is no duty to treat. *ANNAS, supra* note 23, at 121. Once the doctor-patient relationship is established, the obligation exists, but whether a physician must render care that is not beneficial (futile) is not so clear. Because a determination of what is futile medical care involves physician judgment, perhaps shifting the burden of the clear and convincing test from the parents (or surrogate decision maker) to the health care provider will safeguard patients' interests in these unique situations.

74. 832 F. Supp. at 1031.

75. 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). The panel did not consider all the issues posed in the district court because once it concluded "that the Hospital has a duty to render stabilizing treatment under EMTALA, we need not address its obligations under the remaining federal statutes or the laws of Virginia." *Id.* at 592 n.2.

76. *Id.* at 594.

77. *Id.*

78. *Id.* at 594-95.

same condition.<sup>79</sup> In this case, uniform treatment of anencephalic infants was supportive care in the form of warmth, nutrition, and hydration. The court disagreed because it thought the hospital's argument for "uniform treatment" conflicted with EMTALA's requirement for "stabilizing treatment." The court concluded that it is respiratory distress that brings Baby K to the hospital, not anencephaly, and this is the medical condition that must be treated.<sup>80</sup> In its second argument, the hospital contended that the standard of care for anencephaly was warmth, nutrition, and hydration, and ventilator assistance was not consistent with this standard.<sup>81</sup> Again, the court dismissed the argument by relying on respiratory distress as the emergency medical condition. Third, the hospital argued EMTALA must yield to Virginia law, which permits physicians to refuse medical care determined to be "medically or ethically inappropriate."<sup>82</sup> The court refused to apply this statute as EMTALA preempts any state law conflicting with the requirement for stabilizing treatment. Finally, the hospital urged that the requirement of "stabilizing treatment" only applies if the baby is to be transferred to another facility.<sup>83</sup> The court disagreed with this interpretation of EMTALA, relying on precedent and holding patients with an emergency medical condition must be treated or transferred.<sup>84</sup> Finding the hospital's arguments "unavailing," the court affirmed.<sup>85</sup>

Judge Sprouse dissented. EMTALA was designed to prevent hospital dumping of indigent or uninsured patients presented at the emergency room; therefore, he disagreed with the application of the statute in this situation because there was "no sugges-

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79. *Id.* at 595.

80. *Id.* at 596.

81. *Id.*

82. Health Care Decisions Act, VA. CODE ANN. § 54.1-2990 (Michie Supp. 1993).

83. 16 F.3d at 597.

84. *Id.* at 598 (quoting *Bruditt v. U. S. Dep't of Health & Human Servs.*, 934 F.2d 1362 (5th Cir. 1991)).

85. *Id.* at 595. The court refused to consider ethical standards when interpreting statutory language and congressional intent.

EMTALA does not carve out an exception for anencephalic infants in respiratory distress any more than it carves out an exception for comatose patients, those with lung cancer, or those with muscular dystrophy—all of whom may repeatedly seek emergency stabilizing treatment for respiratory distress and also possess an underlying medical condition that severely affects their quality of life and ultimately may result in their death.

*Id.* at 598.



tion of patient dumping.”<sup>86</sup> Further, he agreed with the hospital’s argument that anencephaly was the “relevant condition” to be reviewed under EMTALA.<sup>87</sup> As a result, no violation would occur by withholding ventilator treatment because that medical decision—if determined to be the appropriate standard of care for the condition—would apply to all anencephalic infants.<sup>88</sup>

### III. SEARCHING FOR A STANDARD

The *Baby K* opinions highlight the various standards applied in making decisions about providing futile care. In general, when courts examine the appropriateness of medical care, they apply a legal standard that has both common law and statutory origins. There is a legal duty placed on health care providers to render reasonable care, which arises out of common law negligence actions; there are also legislatively imposed standards such as those required under EMTALA. Some courts may inquire into medical standards and practice guidelines, which may differ from legal standards, indicating that medical and legal standards do not always correlate. Other courts may impose a different standard when they consider the standard of care inappropriate, or hold that an alternative medical standard is reasonably supported.<sup>89</sup> Finally, courts may consider ethical principles. In end-of-life cases, however, courts are not likely to “devolve[ ] to a subjective determination . . . .”<sup>90</sup> Analysis of ethical principles is a source of circular debate, as like minds can disagree when determining the “right” thing to do regardless of legal or medical standards.<sup>91</sup> As a result, courts almost always rely on legal standards and ignore ethical arguments unless they are somehow incorporated into the law in question.

In *Baby K*, the district and appellate courts stuck to their task of statutory interpretation, holding legal standards above ethical principles and to some extent medical standards. While this is a defensible and predictable outcome for the case, the courts

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86. *Id.*

87. *Id.* at 599.

88. Therefore, challenges to the medical decision or standard of care should be through state malpractice actions. *Id.*

89. See Morreim, *supra* note 21, at 38 (courts should grant ample leeway on both sides); see also *Helling v. Carey*, 519 P.2d 981, 983 (Wash. 1974).

90. 832 F. Supp. at 1031.

91. WING, *supra* note 19, at 13 (defining ethics as formal principles of conduct recognized and enforced by sanctions employed by professional peers).

could have used ethical and medical principles to determine a standard that supported refusal of ventilator assistance treatment for anencephalic newborns. Judges Hilton and Wilkins, however, were averse to engaging in an arguably legislative function. Hilton stated the statute did not “admit of any ‘futility’ . . . exception,” and any such argument was for the legislature.<sup>92</sup> Similarly, Wilkins agreed that the statute should apply broadly and no exception should be made for anencephalic infants.<sup>93</sup>

On the other hand, Judge Sprouse in his dissent showed a willingness to engage in a case-by-case analysis for extremely narrow circumstances such as anencephaly. He disagreed that withholding ventilator assistance from Baby K was akin to the “‘dumping’ of indigent or uninsured emergency patients,”<sup>94</sup> the primary evil EMTALA was meant to thwart. Yet, this case was not about access to emergency care because Baby K’s mother was covered by Kaiser Permanente, a health maintenance organization, which agreed to cover the cost of treatment.<sup>95</sup> The only apparent basis for the resulting conflict between the health care providers and the mother was a disagreement over making an end-of-life decision. It is difficult to imagine that a federal regulatory scheme governing patient dumping should apply to “the sensitive decisionmaking process between family and physicians at the bedside of a helpless and terminally ill patient . . . .”<sup>96</sup>

Another concern for the district court was the apparent discrimination against Baby K due to her anencephalic condition. Judge Hilton compared anencephalic infants to AIDS patients, stating that because an AIDS patient may receive ear surgery “despite poor long term prospects of living,” an anencephalic infant is similarly entitled to ventilator treatment.<sup>97</sup> While anencephaly falls into a category of disabled or handicapped, the condition cannot be compared to AIDS. An AIDS patient may tragically have a shorter than expected life span, but it is generally a fully conscious life. Further, there remains hope that a treatment of a suppressed immune system is possible. In contrast, Baby K was not able to hear, see, think, or interact with

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92. 832 F. Supp. at 1027.

93. 16 F.3d at 598.

94. *Id.*

95. Greenhouse, *supra* note 12.

96. 16 F.3d at 598.

97. 832 F. Supp. at 1028.

others.<sup>98</sup> There is no cure that could have replaced her missing brain to provide a chance of any sort of conscious life.<sup>99</sup> This does not mean that anencephalic infants should be denied medical treatment. On the contrary, the point is that perhaps a standard of care that dissuades aggressive technological intervention for anencephalic infants should be recognized by the courts.

Finally, a more theoretical argument supposes that courts and judges must protect the rights of individuals from majoritarian rule making, and in this case Judges Hilton, Wilkins, and Williams were simply applying that principle. Judge Hilton stated that "the Hospital must establish by clear and convincing evidence that [the mother's] treatment decision should not be respected because it would constitute abuse or neglect of Baby K."<sup>100</sup> Further, Judge Wilkins remarked that "[t]he terms of EMTALA as written do not allow the Hospital to fulfill its duty to provide stabilizing treatment by simply dispensing uniform treatment. Rather, the Hospital must provide that treatment necessary to prevent the material deterioration of each patient's emergency medical condition."<sup>101</sup>

Admittedly, it is unclear whether the standard of care for anencephalic newborns is to withhold ventilator assistance. Nevertheless, even if hospital physicians considered such a course the standard of care, there is always a chance a court would apply an alternative standard and ignore the prevailing standard of care.<sup>102</sup>

#### IV. ALTERNATIVE CONSIDERATIONS

Currently, health care providers and insurers are looking to a delivery system with stricter cost controls. It is probably not a coincidence that the futility debate has emerged to rekindle issues such as patient autonomy, physician power in decision making, rationing, technology utilization, defining life, and confronting death. So far, *Baby K* teaches us that physician medical

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98. 16 F.3d at 599.

99. *Id.*

100. 832 F. Supp. at 1031.

101. 16 F.3d at 596.

102. See generally *Helling v. Carey*, 519 P.2d 981 (Wash. 1974). In *Helling*, the court applied its own reasonableness standard rather than that of the medical profession. Disregarding the apparent standard for ophthalmology, which did not require glaucoma testing for patients under the age of 40, the court held as a matter of law that the reasonableness standard required administration of the eye test to the patient in that case. *Id.* at 983. Notably, the court's conclusion was based, in part, on the fact that glaucoma tests were simple and relatively inexpensive.

judgment must yield to the demands of the patient or the family member. Even if other courts decide similar conflicts differently, the case readily illustrates that we have yet to seriously consider setting limits to our health care system.

From a policy perspective, the futility debate includes all the difficulties present in delivering medical services. It challenges our political desire to create a system that is affordable, provides quality medicine, and is accessible to everyone. If a primary goal of health care reform is universal access to medical care within limited financial constraints, then policy discussions about futility must address resource limits or, in the alternative, we must be prepared to pay higher costs.<sup>103</sup> To argue that economics should be left out of the debate because health care providers should not be elevating financial motivation over dutiful patient care incorrectly denies that financial considerations are central to this discussion.<sup>104</sup> Any reform initiatives calling for universal medical care coverage or tighter cost controls will consequently heighten the controversial futility debate.

In order to avoid unpleasant courtroom battles like *Baby K*, a consensus needs to be reached about the meaning of medical futility. Both health care providers and the general public need to be involved in accepting standards that discourage aggressive medical care for certain conditions unless we accept unilateral decision making by physicians at the bedside.<sup>105</sup>

Arguably, patient autonomy principles and the doctrine of informed consent suggest a consensus approach because much of the futility debate may be circumvented by improved doctor-patient communications about the goals of medical treatment.<sup>106</sup> Too often, provider interaction with the patient centers on treat-

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103. See ANNAS, *supra* note 23, at 216-17 (stating that it is not possible to contain costs unless we come to grips with our mortality; no plan is economically feasible without limits, and no limits are feasible without recognition that quality of life is more important than length of life). Cf. Miller & Touseignant, *supra* note 15 (quoting Arthur Caplan, Director of the Center for Biomedical Ethics, University of Minnesota: "The [P]resident and Congress are saying we must restrict our costs, and the court is saying . . . we will allow a single mother to defy the opinion of doctors and continue care in what must arguably be the most hopeless of circumstances.").

104. Veatch & Spicer, *supra* note 5, at 36 (arguing allocation decisions are not for physicians but society).

105. Brennan, *supra* note 22, at 336 (resisting unilateral decision making about futile care).

106. Stuart J. Youngner, *Futility in Context*, 264 JAMA 1295, 1296 (1990) (physicians should inform patients and families about futile care decisions in order to resolve the problem at bedside); Truog et al., *supra* note 33, at 1562 (communication should resolve many of the conflicts).

ment of a specific condition, and the patient becomes simply an organ or body system. As a result, it may be difficult for the doctor to discuss overall treatment goals with the patient, and couching decisions in vague terminology such as 'it would be medically inappropriate to proceed with that course of treatment' allows physicians to avoid discussions about how a patient wants to or is going to die.<sup>107</sup>

Here, ethics committees or medical ethicists could play a role in educating attending and resident physicians about the value of early communication with patients. This could preempt later liability-motivated decision making, and preserve patient input into the course of the patient's own medical treatment.<sup>108</sup>

While educational efforts offer long-term solutions, interim incentives are needed to stimulate doctor-patient discussion about futile care. Such methods to encourage earlier communication with patients about end-of-life decisions include setting restrictive practice guidelines for physicians to follow in difficult cases;<sup>109</sup> amending ethical standards and hospital protocols to create community-wide agreement on treatment practices;<sup>110</sup> and reimbursement for documented quality-of-life patient visits,

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107. "Terms that signal to patients that 'there is nothing more medically to be done' make discussion of tough value questions unnecessary and help physicians avoid painful explorations with their patients." Solomon, *supra* note 23, at 235-36; Mildred Z. Solomon et al., *Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments*, 83 AM. J. PUB. HEALTH 14 (1993) (demonstrating inadequate communication between doctors and patients in advance of crises and inadequate documentation of patient preferences).

108. Solomon et al., *supra* note 107, at 19 (patient preference documentation inadequate); Solomon, *supra* note 23, at 234 (lack of knowledge about ethics and law creates exaggerated concern about liability); Brennen, *supra* note 22, at 336 (use ethics committees to educate providers and the public); Stell, *supra* note 8, at 497 (involve ethics committees to resolve clashes with patients).

109. Miles, *supra* note 41, at 513 (practice guidelines); Clark C. Havighurst, *Practice Guidelines as Legal Standards Governing Physician Liability*, LAW & CONTEMP. PROBS., Spring 1991, at 87 (on development of clinical practice guidelines).

110. Alpers & Lo, *supra* note 8, at 328 (calling for more societal input before letting physicians make futility decisions). Some health care communities are trying to reach a consensus on the standard of care for futile medical conditions. For example, a novel project is under way in Denver to create and implement a community standard for treating futile medical conditions. The project, Guidelines for Use of Intensive Care in Denver (GUIDE), is bringing together hospital and community leaders in an attempt to reach a consensus on how to treat, or rather not treat, certain medical conditions that most people would consider inappropriate. See *Definition of Futility No Longer a Purely Medical Decision*, HOSP. ETHICS, Nov.-Dec. 1993, at 5. By including the public in the discussions, the hope is to create a policy that will be accepted as the standard for the community. *Id.*

which utilizes more persuasive financial incentives to alter physician behavior.<sup>111</sup>

In theory, a refusal of care is effortless, but at the patient's bedside with family members present, the physician faces a much harder task. In its current form, the use of the term medical futility is inappropriate because it allows physicians to withdraw from these interpersonal confrontations with the patient and family, and make private, unilateral decisions about the course of treatment.<sup>112</sup> Such practice should not occur because it ultimately pits the physician against patient. A better approach counsels physicians to interact earlier with patients in end-of-life decisions in an attempt to reach a consensus on appropriate medical care.<sup>113</sup>

### CONCLUSION

Where tension exists between physicians making medical judgments and patients demanding treatment, the patient apparently will prevail. As the *Baby K* opinions suggest, courts are compelled to favor individual rights under current federal statutes and case law. In addition, while earlier right-to-die decisions revealed that courts were willing under limited circumstances to let individuals refuse life-sustaining medical treatment, here, judges were not willing to let physicians refuse to provide treatment contrary to the patient's or surrogate's wishes. Arguably, withdrawing or refusing a life-saving treatment is a form of passive suicide. However, perhaps nontreatment for certain diagnoses should be adopted as the standard of care. That is, health care providers or the legislature should be permitted to develop criteria for making end-of-life decisions, which would allow physicians—in an extremely narrow case such as anencephaly—to decide that aggressive treatment is not the best course of therapy.

To the best of our knowledge, Baby K could not think or feel, and her ability to survive was uncertain even with periodic ventilator intervention.<sup>114</sup> In similar instances, should a court allow

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111. Allowing the doctor to bill the patient's health insurance company for discussions about what type of care the patient will receive should effect some basic communication about making end-of-life decisions. See Solomon et al., *supra* note 107, at 21.

112. Solomon, *supra* note 23, at 235-36.

113. See Lantos et al., *supra* note 30, at 83 (framework for these determinations should be one of shared decision making).

114. See The Medical Task Force on Anencephaly, *The Infant with Anencephaly*, 322 NEW ENG. J. MED. 669 (1990).

physicians to refuse mechanical ventilation, or must it defer to the wishes of the infant's parent and mandate treatment? The issues are dying and who should control the decision of how and when death will occur.<sup>115</sup> Perhaps, in this limited context, medical judgment or a consensus of decision makers such as an ethics committee should be favored. If not, legislatures must become involved in the difficult task of setting limits to our health care system unless we are willing to spend unlimited financial resources preserving a tragically ill patient for whom no known treatment exists.

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115. See, e.g., Kathryn A. Koch et al., *Analysis of Power in Medical Decision-Making: An Argument for Physician Autonomy*, 20 L. MED. & HEALTH CARE 320, 322 (1992) (describing the power struggle at the bedside).