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## Medical Futility: A Futile Concept?

Keith Shiner

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# Medical Futility: A Futile Concept?

Keith Shiner\*

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Do not go gentle into that good night,  
 Old age should burn and rave at close of day;  
 Rage, rage against the dying of the light.

— Dylan Thomas\*\*

### I. Introduction

Are patients raging too much against the dying of the light? After courts established patients' rights to withdraw life-sustaining treatment,<sup>1</sup> are patients<sup>2</sup> now demanding continuation of inappropriate treatment that should be withdrawn and forcing physicians to continue treatment that the physicians consider unethical<sup>3</sup> and medically futile? Several recent cases<sup>4</sup> and

\*\* DYLAN THOMAS, *Do Not Go Gentle Into That Good Night*, in THE POEMS OF DYLAN THOMAS 207 (Daniel Jones ed., New Directions Publishing Corp. 1971) (1952).

1. Courts have established the right to refuse life-sustaining treatment based upon a constitutional right of privacy, a liberty interest protected by the Fourteenth Amendment, and the common-law right to informed consent. The seminal case of *In re Quinlan* grounded Karen Quinlan's right to refuse treatment in a federal constitutional privacy right. *In re Quinlan*, 355 A.2d 647, 662-64 (N.J.), cert. denied, 429 U.S. 922 (1976). Subsequently, most courts based the right to refuse treatment on the common-law right to informed consent, either alone or in combination with the constitutional privacy right. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 271 (1990).

2. The patients discussed in this Note are not competent and are unable to make decisions for themselves because of their status on life support. The patient's surrogate makes the life support decisions discussed in this Note instead of the patient. However, because the patient's interests and life are at issue, this Note will refer to the "patient" as decisionmaker. The analysis does not change by referring to the patient instead of the surrogate.

3. Treatment can be considered "unethical" for several reasons. First, patients could pursue treatment towards ends for which medical treatment should not be employed. Second, the treatment could violate a particular physician's personal ethics. Third, the treatment could not be the best use of society's scarce health care resources. This Note considers unethical treatment primarily under the first and third conceptions. See *infra* notes 199-207 and accompanying text (discussing ways in which treatment can be considered unethical).

4. See *infra* notes 77-92, 98-140 and accompanying text (discussing futility cases).

research<sup>5</sup> suggest that patients may be.

Since the New Jersey Supreme Court held in 1976 that Karen Ann Quinlan's right to privacy included the right to have life-sustaining treatment withdrawn,<sup>6</sup> families, hospitals, physicians, and courts increasingly have faced decisions concerning the withdrawal or withholding of life-sustaining treatment. Approximately eighty percent of the deaths each year in the United States occur in hospitals or nursing facilities, and seventy percent of these deaths result from decisions to withhold or withdraw treatment.<sup>7</sup> Initially, physicians and hospitals resisted terminating treatment for patients who were not brain dead, predominantly out of fear of criminal or civil liability.<sup>8</sup> Consequently, many individuals feared living — and dying — as "prisoners" of life-sustaining technologies.<sup>9</sup> The cause for these fears has

5. See generally Jeremiah Suhl, M.D. et al., *Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support is Unreliable*, 154 ARCHIVES INTERNAL MED. 90 (1994) (examining agreement between patient responses to questionnaire for preferences for life support treatment in four scenarios and substituted judgment of patient's surrogate). The authors' coma scenario elicited preferences for resuscitation from 16% of the patients despite a less than 1% chance of awakening. *Id.* at 92. Further, the authors found that surrogate disagreement with patients' true preferences as expressed in the questionnaire was twice as likely to favor life support that patients did not want than to favor less treatment than patients wanted. *Id.* at 93-94. The authors cite another study finding that spouses also overestimated patients' desires for life support. *Id.* at 94 (citing R.F. Uhlmann et al., *Physicians and Spouses' Predictions of Elderly Patients' Resuscitation Preferences*, 43 J. GERONTOLOGY 115 (1988)). However, one recent study does suggest that physicians and surrogates are already acknowledging the futility of some treatments. See Joan M. Teno et al., *Prognosis-Based Futility Guidelines: Does Anyone Win?*, 42 J. AM. GERIATRICS SOC'Y 1202, 1205-06 (1994) (suggesting acknowledgment of futility by physicians and surrogates).

6. See *In re Quinlan*, 355 A.2d 647, 662-64 (N.J.) (holding that Quinlan's right to privacy included right to withdraw life support treatments and that her father may assert her right to privacy in her behalf), *cert. denied*, 429 U.S. 922 (1976).

7. See Lance K. Stell, *Stopping Treatment on Grounds of Futility: A Role for Institutional Policy*, 11 ST. LOUIS U. PUB. L. REV. 481, 493 (1992) (citing Helen B. Lipton, Ph.D., *Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications, and Outcomes*, 256 JAMA 1164, 1168 (1986)). Justice Brennan cited similar figures in *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 302-03 (1990) (Brennan, J., dissenting).

8. See *Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (1983) (finding that doctor's cessation of life-sustaining treatment upon family's request, though intentional and with knowledge that patient would die, was not unlawful failure to perform legal duty); E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 33, 33 (noting previous physician resistance to removing life-sustaining treatment stemming from concerns over being sued or indicted for murder).

9. See B.D. COLAN, *HARD CHOICES: MIXED BLESSINGS OF MODERN MEDICAL TECHNOLOGY* 248 (1986) (noting public reaction to Quinlan case, in which woman lived in coma for more than decade). "The thing the Quinlan case has done for most people is kind of set up a paradigm . . . . People say, 'I don't want to die like Karen Ann Quinlan.'" *Id.* at 249 (quoting

eased in the last twenty years, as courts and commentators have developed a general consensus that patients have the right to terminate life-sustaining treatment upon request.<sup>10</sup> The proliferation of living will and surrogate decisionmaking statutes affirms this consensus.<sup>11</sup>

A "turf battle"<sup>12</sup> has now developed and some physicians and commentators believe that patient autonomy has gone too far and that patients and their surrogates demand too much. They believe that patient autonomy has intruded too far into physician integrity — both as a matter of professional judgment and as a matter of professional ethics. Thus, in several recent cases, physicians and hospitals have argued that certain treatments were futile and have sought to remove or withhold life-sustaining treatment against the wishes of surrogates.<sup>13</sup> These cases raise the issue of whether a physician's or hospital's determination that certain requested treatment is medically or ethically inappropriate should override the patient's demand for such treatment. Although courts thus far have denied the physician and hospital

George Annas, professor of health law at Boston University's schools of medicine and public health). Cf. Lawrence J. Schneiderman, M.D., *The Futility Debate: Effective Versus Beneficial Intervention*, 42 J. AM. GERIATRICS SOC'Y 883, 886 (1994) (stating, in context of argument that medicine's goal is to benefit patient, rather than merely to affect body, that "[p]atients and families who demand that 'everything be done' may well be expressing a subtext: 'Do not abandon me'").

10. The right to withdraw life-sustaining treatment originally grew out of the constitutional right of privacy, but has since been stated more often in terms of a constitutional liberty interest or in terms of an autonomy interest as developed in informed consent doctrine. See *infra* notes 44-63 and accompanying text (discussing patient autonomy).

11. See Daniel R. Mordarski, Note, *Medical Futility: Has Ending Life Support Become the Next "Pro-Choice/Right to Life" Debate?*, 41 CLEV. ST. L. REV. 751, 778 (1993) (noting that every state and District of Columbia have legislation concerning individual's right to accept or reject life-sustaining treatments and establishing procedures for surrogate decision-makers); *id.* at 778 n.197 (compiling list of relevant state statutes).

12. See Joseph J. Fins, *Futility in Clinical Practice: Report on a Congress of Clinical Societies*, 42 J. AM. GERIATRICS SOC'Y 861, 864 (1994) (stating that "[t]he debate over futility has become, in essence, a question of turf"); Morreim, *supra* note 8, at 35-36 (arguing that coercion, instead of futility, is central issue of debate).

13. See, e.g., *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993) (denying hospital's request for order that it is not required to provide continued life-support to anencephalic infant), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994); *In re Jane Doe*, No. D-93064 (Sup. Ct. Fulton County, Ga. Oct. 17, 1991) (denying hospital's request to allow de-escalation of treatment for 13-year-old girl and entry of Do Not Resuscitate order without consent of both parents), *aff'd*, 418 S.E.2d 3 (Ga. 1992); *In re Wanglie*, No. PX-91-283 (Hennepin County, Minn., P. Ct. June 28, 1991), *reprinted in* 7 ISSUES L. & MED. 369 (1991) (denying hospital's request to appoint independent guardian and appointing husband of 86-year-old woman in persistent vegetative state as guardian in her best interests to direct life-sustaining treatment).

requests in every case, the courts have focused on the question of who should decide whether to continue treatment instead of addressing the futility question.

Many commentators support the decisions in these cases and criticize the idea of recognizing medically inappropriate, or futile, treatment that physicians can withhold or withdraw against patients' wishes. These commentators raise concerns such as whether futility arguments are really physicians' attempts to regain power from patients,<sup>14</sup> whether physicians will remove patients or their surrogates from the decisionmaking process,<sup>15</sup> and whether physicians will use the futility argument to deny treatment to certain population groups.<sup>16</sup> They also question the extent to which economic concerns are motivating the futility debate<sup>17</sup> and the amount of money that

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14. See Alexander M. Capron, *In re Helga Wanglie*, HASTINGS CENTER REP., Sept.-Oct. 1991, at 26, 27-28 (discussing *Wanglie* case as it relates to power issue); Morreim, *supra* note 8, at 35 (stating that practical moral dilemmas of futility debate concern coercion, not futility or value of life).

15. See Capron, *supra* note 14, at 28. See generally Alexander M. Capron, *Medical Futility: Strike Two*, HASTINGS CENTER REP., Sept.-Oct. 1994, at 42 [hereinafter Capron, *Medical Futility*] (discussing futility after *In re Baby K*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994)). Indeed, the case of Catherine F. Gilgunn suggests that physicians have already removed patients and their surrogates from the decisionmaking process. See generally Gina Kolata, *Withholding Care from Patients: Boston Case Asks, Who Decides?*, N.Y. TIMES, Apr. 3, 1995, at A1 (reporting suit against hospital and two physicians by daughter of elderly woman after physicians allegedly entered Do Not Resuscitate order for elderly woman, leading to woman's death, against wishes of guardian daughter). The jury verdict in the Gilgunn case for the hospital and physicians may suggest that society is ready to accept some notion of futility. See Alexander M. Capron, *Abandoning a Waning Life*, HASTINGS CENTER REP., July-Aug. 1995, at 24 (reporting jury verdict for hospital and physicians in Gilgunn suit and discussing significance of Gilgunn verdict). Further, a recent national survey suggested that 80% of physicians surveyed had withdrawn care that they considered futile, nearly one-quarter having acted without family consent, and 3% having acted contrary to family wishes for continued treatment. See Richard A. Knox, *Suit Centers on Ethics of Life Support; MGH, Physicians Named in Action*, BOSTON GLOBE, Apr. 4, 1995, at 26 (discussing poll results in relation to Gilgunn case). The physician who conducted the survey stated that "[w]hen you get patients to agree, there's so much subtle or not so subtle coercion . . . . Patients are sold something. We all know doctors who are particularly good at quote getting the [Do Not Resuscitate] order . . . ." Kolata, *supra*, at A1.

16. See *Baby K*, 832 F. Supp. at 1027 (suggesting that allowing futility exception to Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd (1994), would allow hospitals to deny emergency treatment to accident victims with terminal cancer or AIDS); see also Erich H. Loewy, M.D. & Richard A. Carlson, M.D., *Futility and Its Wider Implications: A Concept in Need of Further Examination*, 153 ARCHIVES INTERNAL MED. 429, 430 (1993) (noting danger that futility poses to elderly, poor, or other relatively powerless population groups).

17. See John D. Lantos, M.D., *Futility Assessments and the Doctor-Patient Relation-*

the recognition of futility could save by eliminating needless, but expensive, treatment from dying patients.<sup>18</sup> Apparently acting contrary to the commentators' criticism of futility, Virginia and Maryland recently amended their health care decisions acts such that the acts do not require physicians to provide treatment that the physicians determine to be medically or ethically inappropriate. These states thus seem to acknowledge the validity of the futility concept.<sup>19</sup>

Therefore, the time has come for the law to address the issue: Can a physician refuse to provide life-sustaining treatment that the physician deems medically inappropriate or futile against a patient's request that the treatment continue?<sup>20</sup> For example, may a physician unilaterally withdraw life-sustaining treatment from an elderly patient in a persistent vegetative state?<sup>21</sup> May a physician refuse on the grounds of futility to provide requested resuscitation for an anencephalic baby?<sup>22</sup> Further, is it wise to allow physicians this futility "trump card"? Or does respect for patient autonomy require physicians to continue providing life support, despite the physicians' judgment that the treatment is futile? These questions are important because they address issues concerning the meaning that we attach to life, particularly diminished life;<sup>23</sup> self-determination;<sup>24</sup> the nature of the physician-patient

*ship*, 42 J. AM. GERIATRICS SOC'Y 868, 869 (1994) (noting physicians' interest in futility after development of prospective payment systems and noting that although medical futility for patients is not clearly definable, financially futile care for hospitals is clearly definable).

18. See Capron, *Medical Futility*, *supra* note 15, at 43 (discussing *Baby K* and status of futility debate); Michael A. Rie, *The Limits of a Wish*, HASTINGS CENTER REP., July-Aug. 1991, at 24, 26-27 (discussing economic conflicts that can arise in case like *Wanglie*); see generally Teno et al., *supra* note 5 (investigating potential savings from elimination of futile care).

19. See *infra* notes 27-37 and accompanying text (providing amendments and discussing their provisions).

20. For a recent British case in which the Court of Appeal seemed to recognize a physician's authority to declare treatment futile, see *Re J (a minor)*, [1992] 4 All E.R. 614 (C.A.), in which the court held that it would not exercise its inherent jurisdiction over minors to order a physician to provide life-sustaining treatment to a severely handicapped, microcephalic minor in a manner contrary to the physician's clinical judgment of the minor's best interests.

21. See *infra* notes 77-92 and accompanying text (discussing such case).

22. See *infra* notes 98-108 and accompanying text (discussing such case).

23. See generally COLEN, *supra* note 9 (1986) (discussing ethical problems created by technology). Colen states:

Indeed, it is not at all uncommon when a[n anencephalic baby] is born for the physician to place the infant in a tray in a corner of the delivery room and simply cover the tray with a towel and walk away. In a short time the infant is dead and the parents are told that the mother delivered a stillborn, badly malformed infant.

*Id.* at 178.

24. See THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING

relationship;<sup>25</sup> and the just allocation of scarce health care resources.<sup>26</sup>

This Note considers the issue of medically futile treatment from several perspectives. Part II introduces medical futility by discussing recent amendments to the Virginia and Maryland health care decisions acts as legislative responses to medical futility. Part III presents the background principles of respect for life and patient autonomy and the right to direct the use or nonuse of life-prolonging treatment upon which the futility debate lies. Part IV presents the various medical conditions and cases in which physicians and hospitals have raised the futility issue and discusses various conceptions of futility. It also presents an argument for the legal recognition of futility and discusses the policy considerations germane to the futility debate. Finally, Part V presents recommendations for how the legal system should respond, arguing for a rejection of medical futility as a general concept, but arguing for a limited, case-by-case recognition of physician authority to declare treatments futile.

## II. Amendments to Virginia and Maryland Health Care Decisions Acts

At least two states, Virginia and Maryland, have attempted to address the futility issue by amending their health care decisions acts.<sup>27</sup> In 1992, the

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TREATMENT AND THE CARE OF THE DYING 19 (1987) (noting patients' rights to make important decisions about their lives, including what happens to their bodies and use of life-sustaining treatment).

25. See Edmund D. Pellegrino, M.D., *Ethics*, 270 JAMA 202, 203 (1993) (discussing changes in physician-patient relationship). Pellegrino states that "[t]his issue must be confronted as we enter more closely into managed health care systems in which cost containment, allocation decisions, and societal benefit are reshaping the fiduciary relationship of physician and patient." *Id.* Further, Pellegrino argues:

[The futility debate is] useful . . . because it exposes the need for carefully weighing the limits of both physician and patient autonomy, the explicit meaning of "participation," and the relative reliability and moral weight of "objective" medical and "subjective" value determinations. Underlying these issues are deeper philosophical questions about the nature of medical knowledge, the relationship between fact and value, and the moral status of the physician's conscience in a pluralistic and democratic society like ours, which so highly prizes individual autonomy.

*Id.*

26. See Daniel Callahan, Ph.D., *Necessity, Futility, and the Good Society*, 42 J. AM. GERIATRICS SOC'Y 866, 867 (1994) (discussing pressures of economic scarcity); Rie, *supra* note 18, at 26-27 (discussing economic conflicts that can arise in futility cases).

27. See MD. CODE ANN., HEALTH-GEN. § 5-611 (1994 & Supp. 1995) (providing that ethically inappropriate or medically ineffective treatment is not required); VA. CODE ANN. § 54.1-2990 (Michie 1994) (providing that Health Care Decisions Act does not require medically unnecessary treatment).



Virginia General Assembly amended its Health Care Decisions Act (VA-HCDA)<sup>28</sup> and affirmed that the right to request treatment does not create an obligation for a physician to provide treatment that the physician deems medically or ethically inappropriate. The amended VA-HCDA provides, in Section 2990, that "[n]othing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate."<sup>29</sup>

In 1993, Maryland amended its Health Care Decision Act (MD-HCDA) to provide that the MD-HCDA requires the provision of neither ethically inappropriate nor medically ineffective treatment.<sup>30</sup> The amended MD-HCDA provides in Section 5-611:

(a) Ethically inappropriate treatment not required. — Except as provided in section 5-613(a)(3) of this subtitle, nothing in this subtitle may be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be ethically inappropriate.

(b) Medically ineffective treatment not required. — (1) Except as provided in § 5-613(a)(3) of this subtitle, nothing in this subtitle may be construed to require a physician to prescribe or render medically ineffective treatment.<sup>31</sup>

Section 5-613(a)(3) requires a transferring provider to comply with a patient's treatment instructions pending a transfer of the patient to a health care provider who will comply with the instructions willingly when failure to comply with the instructions would likely result in the patient's death.<sup>32</sup> The MD-HCDA defines medically ineffective treatment to mean that "to a reasonable degree of medical certainty, a medical procedure will not (1) [p]revent or reduce the deterioration of the health of an individual; or (2) [p]revent the impending death of an individual."<sup>33</sup>

These legislative responses signal a willingness to deal with the problem of medical futility. However, the legislative responses are incomplete. For example, Virginia does not define "medically or ethically inappropriate" treatment. Also, although both statutes provide for transfer of the patient when physicians determine that requested treatment is inappropriate,<sup>34</sup> neither statute provides for situations in which no transferee hospital is

28. VA. CODE ANN. §§ 54.1-2981 to -2993 (Michie 1994).

29. *Id.* § 54.1-2990.

30. *See* MD. CODE ANN., HEALTH-GEN. § 5-611 (1994 & Supp. 1995) (providing that ethically inappropriate or medically ineffective treatment is not required).

31. *Id.* § 5-611(a), (b)(1).

32. *Id.* § 5-613(a)(3).

33. *Id.* § 5-601(n).

34. *Id.* § 5-613; VA. CODE ANN. §§ 54.1-2987, -2990 (Michie 1994).

willing to accept the patient and to provide the treatment deemed "medically or ethically inappropriate." The MD-HCDA does provide that, pending transfer, health care providers must comply with a patient's instructions regarding treatment if failure to comply with the instruction would likely result in the patient's death,<sup>35</sup> but still avoids the situation in which a willing transferee is not available. Finally, although the MD-HCDA acknowledges the concept of medically ineffective treatment, the MD-HCDA does not authorize action contrary to expressed wishes of the patient.<sup>36</sup> The patient's known wishes presumably include wishes expressed through surrogates.<sup>37</sup>

### III. Background Principles

#### A. Respect for Life

A convincing argument that physicians should have the authority to declare certain life-sustaining treatments futile must overcome a presumption in favor of life because, in essence, the futility concept suggests that the law should allow physicians to determine that some patients should die. Courts have been reluctant to impose a "duty to die" on patients.<sup>38</sup> Indeed, the principal concern underlying and limiting the right of a patient to withdraw or withhold life-sustaining treatment, particularly through a surrogate, is a respect for life — both the sanctity of life in general and preservation of the life of the particular patient.<sup>39</sup> Thus, courts will err on the side of preserving life.<sup>40</sup> The Supreme Court grounded its holding that a state may require clear and convincing proof of an incompetent individual's intent before a surrogate may withdraw life-sustaining treatment on the state's interest in

35. MD. CODE ANN., HEALTH-GEN. § 5-613(a)(3) (1994 & Supp. 1995).

36. See *id.* § 5-611(e)(2) (providing that "[n]othing in this subtitle authorizes any action with respect to medical treatment, if the health care provider is aware that the patient for whom the health care is provided has expressed disagreement with the action").

37. See *id.* § 5-605 (providing for surrogate decisionmaking).

38. See *In re Jane Doe*, No. D-93064, slip op. at 21-22 (Sup. Ct. Fulton County, Ga. Oct. 17, 1991) (stating that requiring removal of life-sustaining treatment from patients when physicians decide there is no hope for "meaningful recovery" approaches imposing duty to die on terminally ill patients — one duty that this society does not impose).

39. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 425-27 (Mass. 1977) (identifying preservation of life and prevention of suicide as among four state interests that could overcome patient's wish to withdraw life-sustaining treatment).

40. See *In re Conroy*, 486 A.2d 1209, 1233 (N.J. 1985) (stating that "[w]hen evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if at all, in favor of preserving life"); *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 273 (1990) (citing *Conroy* for same proposition).

life.<sup>41</sup> The Court recognized the presumption in favor of life by noting that an incorrect decision not to end life merely preserves the status quo, allowing for possible developments that may correct or ameliorate the effect of the erroneous decision.<sup>42</sup> However, because an incorrect decision to withdraw life-sustaining treatment results in death, it is impossible to correct the decision or limit its effects.<sup>43</sup>

*B. Patient Autonomy and the Right to Direct the Use  
or Nonuse of Life-Prolonging Treatment*

Although courts acknowledge the importance of life, they recognize that a state's interest in life "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims," and a patient's right to privacy and self-determination then prevails over the state's interest in life.<sup>44</sup> Courts and legislatures have established that the patient, rather than the physician, has the authority to decide the course of treatment for that patient at the extremes of life.<sup>45</sup> Courts and legislatures have placed

41. See *Cruzan*, 497 U.S. at 281-87.

42. *Id.* at 283.

43. *Id.*

44. *In re Quinlan*, 355 A.2d 647, 664 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

45. In chronological order, the leading cases discussing the circumstances under which a patient may refuse life-sustaining treatment that will not cure the patients underlying condition include: *In re Quinlan*, 355 A.2d 647, 662-64 (N.J.) (affirming privacy right to withdraw life-sustaining treatment), *cert. denied*, 429 U.S. 922 (1976); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 431-32 (Mass. 1977) (applying substituted judgment doctrine and finding that patient, if competent, would not want chemotherapy); *In re Dinnerstein*, 380 N.E.2d 134, 139 (Mass. App. 1978) (declaring that law does not require prior judicial approval in order to withdraw resuscitation in appropriate cases); *In re Spring*, 405 N.E.2d 115, 120, 122-23 (Mass. 1980) (finding that probate judge correctly found that treatment should be withdrawn but disapproving of court's decision to delegate decision concerning life-sustaining treatment to ward's wife and son when probate court had found that ward would have refused such treatment if competent); *In re Storar*, 420 N.E.2d 64, 70-73 (N.Y.) (approving, in one case of consolidated appeal, order to remove respirator of incompetent patient because maintaining patient in vegetative coma by use of respirator was inconsistent with patient's repeated, stated wishes while competent, but, in other case, concluding that application for permission to continue transfusions for never-competent patient should have been granted over surrogate's wishes that transfusions cease), *cert. denied*, 454 U.S. 858 (1981); *Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983) (concluding that doctor's cessation of life-sustaining treatment upon family's request, though intentional and with knowledge that patient would die, was not unlawful failure to perform legal duty); *Bartling v. Superior Court*, 209 Cal. Rptr. 220, 224 (Cal. Ct. App. 1984) (holding that competent adult patients with incurable, but not terminal, illnesses have right to withdraw life-sustaining treatment against physician's objections); *In re Conroy*,

the decisionmaking authority with patients primarily out of respect for autonomy or self-determination. Thus, an argument that physicians have the authority to declare certain requested treatments futile must overcome patients' autonomy rights as courts have developed them over the last twenty years<sup>46</sup> and demonstrate why physicians have a greater authority to decide the use of care at the extremes of life.

A competent individual generally has the right to control what is done with his or her body.<sup>47</sup> Courts base this right upon various grounds, but they generally rely on either the common law of informed consent or on a constitutional privacy right. The common law of informed consent generally

486 A.2d 1209, 1242-44 (N.J. 1985) (finding evidence insufficient — under subjective, limited-objective, or pure-objective tests — to establish incompetent patient's wish to terminate life-sustaining treatment); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 306 (Cal. Ct. App. 1986) (holding that competent woman's right to refuse medical treatment entitled her to removal of nasogastric feeding tube inserted against her will despite life-sustaining nature of treatment and that hospital may not deny her relief from pain and suffering because of her choice); *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626, 639-40 (Mass. 1986) (upholding judgment honoring substituted judgment of patient in persistent vegetative state to withdraw artificial nutrition and hydration and, although agreeing with hospital that hospital itself can refuse patient's request to withdraw life-sustaining treatment, ordering hospital to assist guardian in transferring patient to facility that will withdraw treatment); *In re Jobs*, 529 A.2d 434, 447-50 (N.J. 1987) (holding that, under circumstances, nursing home could not refuse to participate in patient's withdrawal of artificial nutrition by continuing to treat patient until patient was transferred); *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 280 (1990) (holding that Missouri could require clear and convincing evidence of patient's intent to withdraw life-sustaining treatment before surrogate could exercise authority to remove treatment). See George P. Smith, II, *All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?*, 22 U.C. DAVIS L. REV. 275, 384-408 (1988) (characterizing these cases, except yet-to-be-decided *Cruzan*, as leading precedents and discussing them at length).

46. See cases cited *supra* note 45 (providing leading end-of-life cases).

47. See *Schloendorff v. Society of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (stating that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages") (Cardozo, J.). Further, as *Cruzan's* dissenting opinion explains:

It is 'a well-established rule of general law . . . that it is the patient, not the physician, who ultimately decides if treatment — any treatment — is to be given at all . . . . The rule has never been qualified in its application by either the nature or purpose of the treatment, or the gravity of the consequences of acceding to or foregoing it.'

*Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 306 (1990) (Brennan, J., dissenting) (quoting *Tune v. Walter Reed Army Medical Hosp.*, 602 F. Supp. 1452, 1455 (D.C. 1985)).

includes an individual's right to informed refusal of unwanted medical care,<sup>48</sup> including life-sustaining treatment.<sup>49</sup> Courts have also grounded the right to refuse unwanted medical treatment upon constitutionally protected privacy<sup>50</sup> and liberty interests.<sup>51</sup> However, courts have relied upon the constitutional rationales less frequently in recent years and have generally grounded the right to refuse treatment solely upon common-law informed consent or informed consent in combination with a privacy right.<sup>52</sup>

Incompetent patients have the same rights to refuse unwanted medical treatment as do competent patients.<sup>53</sup> Incompetent patients exercise those rights either through some form of advance directive or other expression of wishes,<sup>54</sup> or through a surrogate.<sup>55</sup> Individuals may appoint their own

48. See *Cruzan*, 497 U.S. at 277 (stating "the common law doctrine of informed consent is viewed as generally encompassing the right of a competent individual to refuse medical treatment"); cases cited *id.* at 269-77.

49. See *Bartling v. Superior Court*, 209, 224 Cal. Rptr. 220 (Cal. Ct. App. 1984) (considering whether competent patient has right to have life-support equipment disconnected over objections of physicians despite fact that such removal will hasten death and finding that patient's right to self-determination outweighs any state interests).

50. See *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 306 (Cal. Ct. App. 1986) (holding that competent woman's right to refuse medical treatment as part of fundamental privacy right entitled her to removal of nasogastric feeding tube inserted against her will despite life-sustaining nature of treatment and holding that hospital may not deny her relief from pain and suffering because of her choice); *In re Quinlan*, 355 A.2d 647, 662-64 (N.J.) (holding that Karen Quinlan had constitutionally protected privacy right to remove respirator), *cert. denied*, 429 U.S. 922 (1976).

51. See *Cruzan*, 497 U.S. at 278 (stating that "[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions"); *Washington v. Harper*, 494 U.S. 210, 221-22, 229 (1990) (recognizing liberty interest in refusing unwanted antipsychotic drugs); *Vitek v. Jones*, 445 U.S. 480, 494 (1980) (recognizing more general liberty interest in refusing unwanted medical treatment); *Parham v. J.R.*, 442 U.S. 584, 600 (1979) (same).

52. See *Cruzan*, 497 U.S. at 271 (recognizing informed consent, alone or combined with privacy right, as most frequent basis for courts upholding right to refuse treatment).

53. See *Quinlan*, 355 A.2d at 662-64 (analyzing comatose woman's right to privacy and finding "only practical way" to prevent loss of right was to allow family to decide "whether she would exercise it in these circumstances"); *In re A.C.*, 573 A.2d 1235, 1237 (D.C. 1990) (holding that when pregnant woman is incompetent to give informed consent to medical treatment, her decision must be ascertained through substituted judgment).

54. A patient can make a formal advance directive, *see, e.g.*, VA. CODE ANN. §§ 54.1-2981 to -2993 (Michie 1994), or a patient can express his or her wishes informally, *see In re Eichner*, 420 N.E.2d 64, 68, 72 (N.Y. 1981) (finding sufficient evidence of patient's wishes to allow removal of respirator from prior expressions, which occurred during religious group's discussion of Quinlan case, that favored nontreatment).

55. See VA. CODE ANN. §§ 54.1-2983 to -2984 (Michie 1994) (providing that individu-

surrogates,<sup>56</sup> or if an individual does not appoint a surrogate, a court may appoint a surrogate — commonly a family member — for the individual.<sup>57</sup> For example, parents have a fundamental constitutional right to direct the care of their children<sup>58</sup> and courts presume that parents generally, though not always, act in the best interests of their minor children when making medical decisions.<sup>59</sup>

Courts determine a surrogate's authority to exercise an incompetent patient's rights on the basis of the evidence available concerning the now-incompetent patients' wishes regarding treatment when formerly competent. The decisionmaking process involves, first, making a substituted judgment for the patient by deciding what the patient would have wanted — a surrogate may withhold or withdraw life-sustaining treatment when it is clear that the patient would have refused the treatment under the circumstances.<sup>60</sup> Courts use a second criterion to guide decisionmaking when some evidence exists that the patient would have refused the treatment and the surrogate decides that the burdens of the patient's continued life with the treatments clearly outweigh the benefits of that life — the patient's best interests.<sup>61</sup> The best interests standard also guides surrogate decisionmaking in a third situation — when no evidence exists of the patient's wishes, such as when the patient has left no prior clues regarding the patient's wishes or when the patient has always been incompetent. In such a case, a surrogate may direct the withholding or withdrawal of life-sustaining treatment if the surrogate decides in the patient's best interests that the burdens of the patient's continued life with the treatments clearly outweigh the benefits of that life.<sup>62</sup> States

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als may appoint agent to make health care decisions in accordance with advance directive).

56. *Id.*

57. *See id.* § 54.1-2986 (providing following people as authorized decisionmakers, in order of preference, in absence of advance directive expressing patient's wishes or naming agent: guardian of patient, patient's spouse, adult child of patient, parent of patient, adult sibling of patient, other relative of patient in descending order of blood relationship).

58. *See Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (providing cardinal principle that custody, care, and nurture of children reside primarily in parents).

59. *See In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) (recognizing that "natural bonds of affection lead parents to act in the best interests of their children") (quoting *Parham v. J.R.*, 442 U.S. 584, 602 (1979)).

60. *See In re Conroy*, 486 A.2d 1209, 1229 (describing subjective test for terminating life-sustaining treatment).

61. *See id.* at 1232 (describing limited-objective test, which combines patient's best interests with some evidence of patient's wishes).

62. *See id.* (discussing pure-objective test and noting its propriety in instances when "the recurring, unavoidable and severe pain of the patient's life with the treatment [are] such that the effect of administering life-sustaining treatment would be inhumane").

have also incorporated the best interests test into their health care decisions acts to guide appointed surrogates in the absence of any evidence of the patients' wishes, preferences, or beliefs.<sup>63</sup>

#### IV. Futility Presented

##### A. *Medical Conditions and Cases in Which Physicians and Hospitals Have Attempted to Withdraw Life-Sustaining Treatment Against Patients' Wishes*

Against the background of a respect for life and patient autonomy, physicians have raised the notion of futility in medical conditions involving irreversible unconsciousness, severe pain that physicians cannot alleviate, or both. To understand physicians' calls for recognition of futility, one must understand the medical conditions in which physicians consider treatment futile. Several cases in recent years involved physicians' attempts to remove life-sustaining treatment from patients in these medical conditions against the wishes of those making decisions for the patients. While these cases likely deviate from many other patient scenarios in which physicians and surrogates come to consensus about the proper course of treatment or withdrawal of treatment,<sup>64</sup> they nevertheless demonstrate the difficult questions and conflicting interests that arise when physicians and surrogates disagree over whether particular treatment is worthwhile or effective at achieving appropriate therapeutic goals.

##### 1. *Irreversible Unconsciousness*

The conditions of "persistent vegetative state" (PVS) and anencephaly present two common examples of irreversible unconsciousness that pose the futility question.<sup>65</sup> For example, the President's Commission for the Study

63. See, e.g., VA. CODE ANN. § 54.1-2986(A) (Michie 1994) (providing decision criteria for persons authorized to consent to provision, withholding, or withdrawal of treatment in absence of advance directive). The decisionmakers authorized by § 2986 must ascertain the religious beliefs and basic values of the patient and base their decisions on those values unless the beliefs and values are unknown, in which case the decisionmakers must decide based upon the patient's best interests. *Id.*

64. See Teno et al., *supra* note 5, at 1205-06 (providing evidence that physicians and surrogates may already be reaching much agreement about withdrawing treatment or not pursuing "futile" measures). But see The SUPPORT Principle Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients*, 274 JAMA 1591, 1596 (1995) [hereinafter SUPPORT] (finding that enhanced opportunities for physician-patient communication did not change established physician practice patterns that included major shortcomings in care of seriously ill, hospitalized patients).

65. See generally The Medical Task Force on Anencephaly, *The Infant with Anen-*

of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission) suggests that treatment may be futile in cases of permanent unconsciousness because the treatment cannot confer the ordinary benefits of medical treatment.<sup>66</sup> Thus far, however, courts have not recognized as futile the treatment of patients in states of irreversible unconsciousness in the cases in which physicians have made futility claims.

*a. Persistent Vegetative State: In re Wanglie*

The Multi-Society Task Force on PVS<sup>67</sup> (PVS Task Force) defines the vegetative state as "a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain-stem autonomic functions."<sup>68</sup> The PVS Task Force characterized the distinguishing feature of the vegetative state as a cyclic, irregular state of sleeping and waking with no detectable expression of self-awareness, recognition of external stimuli,

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*cephaly*, 322 NEW ENG. J. MED. 669 (1990) [hereinafter Anencephaly Task Force] (presenting consensus of medical views on anencephaly in fetuses and infants from organizations of physicians caring for such patients and comparing anencephaly with persistent vegetative state). Anencephaly is similar to the persistent vegetative state in that both conditions are states of permanent unconsciousness including "a loss or absence of all cerebral cortical function"; both involve reflexive responses to pain, presumably without suffering; and both involve cycles of sleeping and waking. *Id.* at 672. Anencephaly differs from persistent vegetative state in that anencephaly occurs at birth rather than developing over time or resulting from trauma; clinicians can observe the extent of neurological damage more easily in anencephaly and can diagnose anencephaly with more certainty than persistent vegetative state; and patients in persistent vegetative state generally live much longer than anencephalic infants. *Id.*

66. See PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE SUSTAINING TREATMENT: ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 181-82 (1983) [hereinafter PRESIDENT'S COMM'N]. The President's Commission states:

[T]reatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible.

*Id.* (quoted in *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 310 (Brennan, J., dissenting)).

67. See generally The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State*, 330 NEW ENG. J. MED. pt. 1, at 1499, pt. 2, at 1572 (1994) (summarizing current knowledge on medical aspects of persistent vegetative state).

68. *Id.* pt. 1, at 1500.



or learned response.<sup>69</sup> Because PVS, by definition, includes unconsciousness, adult PVS patients cannot experience pain and suffering;<sup>70</sup> however, newborn PVS patients may have the potential to experience pain and suffering because of their different pain responses.<sup>71</sup> The diagnosis of a *persistent vegetative state* requires the condition to last from at least a few weeks to a month or more.<sup>72</sup> The prognosis of *permanent vegetative state* results when the chances for recovery from the vegetative state become small enough to consider the condition irreversible.<sup>73</sup> The PVS Task Force reports that the mortality rate for adults and children diagnosed with PVS is eighty-two percent at three years and ninety-five percent at five years.<sup>74</sup> Therapy cannot reverse the persistent vegetative state.<sup>75</sup> In 1990, the American Medical Association estimated that there were between 15,000 and 25,000 PVS patients in the United States.<sup>76</sup>

*In re Wanglie*,<sup>77</sup> the first case to confront the issue of physicians seeking withdrawal of futile care against a surrogate's wish, provides an example of

69. *Id.* The PVS Task Force also presented criteria for diagnosing the vegetative state:

(1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brainstem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes.

*Id.*

70. *See id.* pt. 2, at 1576 (distinguishing between responses to noxious stimuli and conscious, self-aware perceptions of pain and suffering).

71. *Id.* at 1577.

72. *Id.* pt. 1, at 1501.

73. *Id.*

74. *Id.* pt. 2, at 1575.

75. *Id.* at 1577. The PVS Task Force identified four levels of treatment:

high-technology "rescue" treatments, such as mechanical ventilation, dialysis, and cardiopulmonary resuscitation; medications and other commonly ordered treatments, including antibiotics and supplemental oxygen; hydration and nutrition; and nursing or home care to maintain personal dignity and hygiene.

*Id.*

76. Council on Scientific Affairs & Council on Ethical and Judicial Affairs, Am. Medical Ass'n, *Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support*, 263 JAMA 426, 427 (1990).

77. No. PX-91-283 (Hennepin County, Minn., P. Ct. June 28, 1991), *reprinted in 7 ISSUES L. & MED.* 369 (1991).

the futility question in the context of PVS.<sup>78</sup> The issue before the probate court concerned who would serve Helga Wanglie's best interests as her guardian — her husband, Oliver Wanglie, or a stranger nominated by the hospital that was treating her.<sup>79</sup> In December 1989, Helga Wanglie, an 86-year-old woman in Minnesota, fractured her hip and was hospitalized. Mrs. Wanglie later suffered a cardiorespiratory arrest and never regained consciousness.<sup>80</sup> She eventually became ventilator dependent and was fed by intubation.<sup>81</sup> Doctors diagnosed her as being in an irreversible persistent vegetative state.<sup>82</sup> Physicians suggested withdrawing the life-sustaining treatment because it was not benefitting Mrs. Wanglie.<sup>83</sup> Mrs. Wanglie's husband and children refused consent to withdrawal of the treatment.<sup>84</sup> Mr. Wanglie further stated that his wife had never expressed her preferences with respect to life-sustaining treatment.<sup>85</sup> Thereafter, a new attending physician confirmed the diagnosis of persistent vegetative state and concluded that the respirator was "non-beneficial" because it could not heal her, palliate her pain, or allow her to enjoy life.<sup>86</sup> He informed the family that he would no longer continue the respirator treatment.<sup>87</sup>

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78. *In re Wanglie*, No. PX-91-283 (Hennepin County, Minn., P. Ct. June 28, 1991), reprinted in 7 ISSUES L. & MED. 369, 372, 377 (1991) (concluding that best interests of woman in persistent vegetative state required appointing her husband of fifty-three years as her guardian). Although the *Wanglie* case is generally acknowledged as a futility case, the court expressly stated in a memorandum attached to the opinion that "[n]o Court order to continue or stop any medical treatment for Helga Wanglie has been made or requested at this time." *Id.*, reprinted in 7 ISSUES L. & MED. at 377. Nonetheless, the case exists because of the conflict between the physicians and family over the effectiveness or futility of Mrs. Wanglie's treatment.

79. *Id.*, reprinted in 7 ISSUES L. & MED. at 376.

80. *Id.*, reprinted in 7 ISSUES L. & MED. at 374.

81. *Id.*, reprinted in 7 ISSUES L. & MED. at 374.

82. *Id.*, reprinted in 7 ISSUES L. & MED. at 375.

83. Steven H. Miles, M.D., *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512, 513 (1991). Steven Miles served as the ethics consultant for the hospital during the Wanglie case. *Id.* At the time of the hospital's request, Mrs. Wanglie suffered from irreversible persistent vegetative state; aortic insufficiency murmur; congestive heart failure; chronic, recurrent pneumonias secondary to underlying lung disease, unconsciousness, and recumbency; bilateral atelectasis and calcified lung disease; and irreversible, chronic respiratory insufficiency with dependence on mechanical ventilation. *Wanglie*, reprinted in 7 ISSUES L. & MED. at 375.

84. Miles, *supra* note 83, at 513.

85. *Id.*

86. *Id.* The physician did not characterize the ventilator as "futile" because it could prolong her life. *Id.*

87. *Id.* The ethics consultant concurred. *Id.*

After Mr. Wanglie refused proposals to transfer his wife or to seek a court order mandating treatment, the hospital informed the family that the hospital would seek court direction on whether the hospital must continue the treatment.<sup>88</sup> From February to May 1991, the family tried unsuccessfully to transfer Mrs. Wanglie.<sup>89</sup> In May 1991, the hospital petitioned the court seeking first, appointment of an independent conservator to determine whether the ventilator was providing a benefit, and second, if the ventilator was not providing a benefit, a hearing to decide whether the hospital was required to continue providing the respirator.<sup>90</sup> Relying upon Minnesota guardianship law, which requires appointment of the person who will act in the best interests of the incapacitated person, the court found that the evidence clearly and convincingly supported the conclusion that the appointment of Mr. Wanglie as guardian of Mrs. Wanglie's person and estate was in her best interests.<sup>91</sup> Ironically, Mrs. Wanglie died three days after the court entered its order; the family praised the medical care that Mrs. Wanglie had received.<sup>92</sup>

*b. Anencephaly: In re Baby K*

Anencephaly is a congenital abnormality in which an infant lacks a functional cerebral cortex and is permanently unconscious.<sup>93</sup> Depending

88. *Id.*

89. *Id.*

90. *Id.*

91. *In re Wanglie*, No. PX-91-283 (Hennepin County, Minn., P. Ct. June 28, 1991), reprinted in 7 ISSUES L. & MED. 369, 372, 377 (1991). The court found that Mrs. Wanglie did not have a living will; Mrs. Wanglie shared devout religious beliefs with her husband of 53 years, Oliver Wanglie; Mr. Wanglie was the closest person to Mrs. Wanglie and was fully capable of understanding her medical situation and needs; occasionally, Mrs. Wanglie discussed with her husband and son the meaning of life and the use of life-sustaining treatments, but no evidence suggested she ever contemplated her condition in a persistent vegetative state or ventilator dependency. *Id.*, reprinted in 7 ISSUES L. & MED. at 370-71.

92. Miles, *supra* note 83, at 513.

93. See Anencephaly Task Force, *supra* note 65, at 669 (presenting consensus of medical views on anencephaly in fetuses and infants from organizations of physicians caring for such patients). "Anencephaly is a congenital absence of a major portion of the brain, skull, and scalp . . . [resulting in] a hemorrhagic, fibrotic mass of neurons and glia with no functional cerebral cortex." *Id.* Clinicians can diagnose anencephaly

with virtual certainty when all the following criteria are met: (1) A large portion of the skull is absent. (2) The scalp, which extends to the margin of the bone, is absent over the skull defect. (3) Hemorrhagic, fibrotic tissue is exposed because of defects in the skull and scalp. (4) Recognizable cerebral hemispheres are absent.

upon the extent of brain-stem damage, anencephalic infants may respond to noxious stimuli, exhibit feeding and respiratory reflexes, and interact through facial expressions and eye movements.<sup>94</sup> However, the Medical Task Force on Anencephaly (Anencephaly Task Force) reports that anencephalic infants presumably cannot suffer.<sup>95</sup> Anencephalic infants generally die within days of birth.<sup>96</sup> The Anencephaly Task Force estimates that slightly over 1000 infants per year are born with anencephaly.<sup>97</sup>

*In re Baby K*<sup>98</sup> provides an example of the futility question in the context of anencephaly. In *Baby K*, the United States District Court for the Eastern District of Virginia considered whether a hospital would violate federal and state law by refusing to provide requested life-sustaining treatment for an anencephalic infant that the hospital and its physicians considered medically and ethically inappropriate.<sup>99</sup> The *Baby K* court also considered whether the request for continued treatment by the infant's mother was so unreasonable that it constituted abuse or neglect; if the request constituted abuse or neglect, the court would not have to respect the mother's constitutional and common-law rights to decide treatment for her child and the hospital would not have to comply with the request.<sup>100</sup> *Baby K* was born in October 1992 with anencephaly. The hospital initially

*Id.* at 670.

94. *Id.* at 671-72.

95. *Id.* at 672.

96. *Id.* at 671. The Anencephaly Task Force notes that three large surveys reported survival beyond one week at 0%, 5%, and 9% and reports an outside survival limit of two months according to the Task Force's diagnostic criteria. *Id.* (citations omitted). *But see*, Marylou Tousignant & Bill Miller, *Baby K's Mother Gives Her the Prayer That Many Deny She Has*, WASH. POST, Oct. 7, 1994, at A1 (reporting continued survival after two years of anencephalic infant at issue in *In re Baby K*).

97. Anencephaly Task Force, *supra* note 65, at 671.

98. 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

99. *In re Baby K*, 832 F. Supp. 1022, 1026-30 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). The court considered the hospital's requests for declarations that its refusal to treat *Baby K* would not violate the Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd (1994) (EMTALA); Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1988 & Supp. V 1993); Section 302 of the Americans with Disabilities Act, 42 U.S.C. §§ 12102, 12181, 12182 (1994) (ADA); the Child Abuse Amendments of 1984, *Id.* §§ 5101-5106, 5111-5113, 5115 (1994); and the Virginia Medical Malpractice Act, VA. CODE ANN. §§ 8.01-581.1 to 581.20 (Michie 1992 & Supp. 1995). *Baby K*, 832 F. Supp. at 1026-30.

100. *Baby K*, 832 F. Supp. at 1030-31. If the court had found abuse or neglect, it could have overcome the constitutional and common-law presumption that the mother should decide *Baby K*'s treatment. *Id.* at 1031.

stabilized Baby K, and Baby K's physicians advised Ms. H (Baby K's mother) of the infant's diagnosis and prognosis.<sup>101</sup> The physicians recommended providing only supportive care of warmth, nutrition, and hydration and entering a "Do Not Resuscitate Order,"<sup>102</sup> but Ms. H insisted on mechanical breathing assistance for Baby K. Believing that such care was medically and ethically inappropriate, the hospital attempted to transfer Baby K, but no other hospital would accept her.<sup>103</sup> The hospital subsequently stabilized Baby K and transferred her to a nursing home, after which the hospital readmitted Baby K three times between January and March of 1993 for respiratory failure, each time stabilizing her and returning her to the nursing home.<sup>104</sup>

After Baby K's second re-admission, the hospital brought a declaratory judgment action to determine whether the hospital was required to continue providing emergency medical treatment that it deemed medically and ethically inappropriate.<sup>105</sup> The United States District Court for the Eastern District of Virginia denied the hospital's requests for declaratory judgments.<sup>106</sup> Relying on the mother's constitutional and common-law rights as a parent to make medical decisions for Baby K, and the presumption in favor of life, the court found the mother to be the appropriate decisionmaker for Baby K's treatments.<sup>107</sup> The Fourth Circuit affirmed the district court's decision by finding that the plain language of the Emergency Medical Treatment and Active Labor Act required the hospital to treat Baby K.<sup>108</sup>

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101. *See id.* at 1025.

102. *Id.* A "Do Not Resuscitate Order" is a signed order directing that CPR not be performed in case of cardiac or respiratory arrest. THE HASTINGS CENTER, *supra* note 24, at 140.

103. *In re Baby K*, 16 F.3d 590, 593 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

104. *Id.*

105. *Id.*

106. *In re Baby K*, 832 F. Supp. 1022, 1026-30 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). The district court relied upon the plain language of EMTALA to decide that EMTALA "does not admit of any 'futility' or 'inhumanity' exceptions." *Id.* at 1027. The district court found that Baby K's anencephaly qualified the infant for protection under both the Rehabilitation Act and the ADA. *Id.* at 1027-29. The district court did not consider the hospital's argument under the Child Abuse Amendments because the hospital failed to join a necessary party, nor did it consider the hospital's argument under the Virginia Medical Malpractice Act because Virginia courts have not yet addressed the appropriate standard of care for anencephalic infants. *Id.* at 1029-30.

107. *Id.* at 1030-31.

108. *In re Baby K*, 16 F.3d 590, 598 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994). Finding that Congress rejected a case-by-case approach to determining what emergency treatment hospitals must provide and to whom, and relying upon the plain language of

2. *Severe Pain with No Chance of Recovery: In re Jane Doe; Baby L; Baby Rena*

Physicians have also raised the notion of futile treatment in instances in which they have treated patients who experienced severe pain with no chance of recovery. For example, in *In re Jane Doe*,<sup>109</sup> the court considered the case of Jane Doe, a thirteen-year-old girl in an "irreversible" condition with no hope of "meaningful recovery" whose parents disagreed as to whether to de-escalate her treatment or to enter a Do Not Resuscitate order.<sup>110</sup> One of Jane Doe's physicians described the lack of hope as meaning that the girl may recover enough to respond only to deep pain, but not beyond that.<sup>111</sup> Jane Doe had no self-awareness or capacity to relate to others.<sup>112</sup> One physician testified that the treatments used to sustain Jane Doe's life themselves might have caused her pain.<sup>113</sup> Another of her physicians concluded that continued treatment would be "abusive and inhumane."<sup>114</sup> Despite the physicians' claims, the court found no evidence of abuse, neglect, or abandonment.<sup>115</sup> The court acknowledged that a move away from a "paternalistic view of what is 'best' for a patient" and toward the principle of individual autonomy undermined the hospital's authority to decide treatment for patients and supported the parents' authority.<sup>116</sup> "[A]bsent severe neglect, abuse or a stance that clearly endangers the child," the parents had the authority to decide treatment.<sup>117</sup> The court relied on the

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EMTALA, the Fourth Circuit found no exception to EMTALA's duties to provide emergency treatment when physicians determine that the treatment is futile. *Id.* at 592-98. Senior Circuit Judge Sprouse dissented on the grounds that Congress did not intend for EMTALA to apply as the majority applied it to the case and endorsed a case-by-case approach of applying state malpractice law as the proper method for determining the appropriate care in situations such as Baby K's. *Id.* at 598-99.

109. No. D-93064 (Sup. Ct. Fulton County, Ga. Oct. 17, 1991), *aff'd*, 418 S.E.2d 3 (Ga. 1992).

110. *In re Jane Doe*, No. D-93064, slip op. at 2-3, 7, 9 (Sup. Ct. Fulton County, Ga. Oct. 17, 1991), *aff'd*, 418 S.E.2d 3 (Ga. 1992). The court identified three competing interests: the fundamental rights of each of the parents, the responsibilities of the state, and the best interests of the child. *Id.* at 9.

111. *Id.* at 3 n.1.

112. *Id.* at 4.

113. *Id.* However, another physician testified that she was not conscious of any pain or suffering. *Id.* at 5.

114. *Id.*

115. *Id.* at 8.

116. *Id.* at 15-16.

117. *Id.* at 19.

fundamental right of parents to direct medical treatment for their children and on the presumption in favor of life in its ruling that the hospital could not de-escalate Jane Doe's treatment or implement the Do Not Resuscitate order absent the consent of both parents.<sup>118</sup>

In 1990 the *New England Journal of Medicine* reported what the authors called the first physician refusal of "potentially life-prolonging medical treatment for a patient in acute crisis."<sup>119</sup> Baby L was born prematurely after a complicated pregnancy; physicians resuscitated her and weaned her from mechanical ventilation, but her "extensive neurological deficits" did not improve, and she responded only to pain.<sup>120</sup> Over the next twenty-four months, physicians performed three major operations on Baby L, including a gastrostomy and tracheostomy, and repeatedly hospitalized Baby L for recurrent pneumonia, septic shock, and cardiopulmonary arrests.<sup>121</sup> Baby L's mother continually insisted that everything possible be done to save Baby L.<sup>122</sup> The hospital physicians, nurses, ethics committee members, and counsel met and unanimously agreed that further medical intervention was not in Baby L's best interests because intervention would only inflict pain on the child without improving the possible outcome.<sup>123</sup> The mother rejected the proposal and contacted an attorney who arranged a hearing in probate court.<sup>124</sup> A pediatric neurologist contacted by Baby L's guardian *ad litem* agreed that Baby L was severely ill and capable of experiencing pain and that it was questionable whether she would survive even with full intervention.<sup>125</sup> Nevertheless, the consultant agreed to accommodate the mother's wishes and Baby L was transferred to the consultant's care, rendering the legal dispute moot.<sup>126</sup>

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118. *Id.* at 12-19. The court also recognized several other factors that weighed in the court's decision of Jane Doe's best interests: the father's freedom of religion, the "devastating effects" on the family of an order to terminate life support, and a reluctance to impose a "duty to die" on Jane Doe. *Id.* at 20-22.

119. See John J. Paris, S.J., Ph.D. et al., *Physicians' Refusal of Requested Treatment: The Case of Baby L*, 322 NEW ENG. J. MED. 1012, 1013 (1990).

120. *Id.* at 1012-13.

121. *Id.*

122. *Id.* at 1013.

123. *Id.*

124. *Id.* In response to questioning from the judge, the attorney for the physicians indicated that the physicians would not follow a court order to continue mechanical ventilation because the physicians felt that it would violate their ethical obligations to Baby L. *Id.*

125. *Id.*

126. *Id.* Baby L was still alive two years after the reported incidents, but remained deaf, blind, and quadriplegic. *Id.* She is fed through the gastrostomy, averages a seizure a day,

The case of Baby Rena provides perhaps the most compelling example of physicians' calls for withdrawing futile treatment because of the severe pain it imposes.<sup>127</sup> Baby Rena was born on October 10, 1989, at George Washington University Hospital in Washington, D.C., weighing just four pounds and twelve ounces; she was infected with HIV, the virus that causes AIDS.<sup>128</sup> Her mother abandoned her, but a hospital employee and his wife soon "adopted" Baby Rena and became her volunteer foster parents, allowing the District of Columbia to continue acting as Baby Rena's legal guardian.<sup>129</sup> Physicians eventually placed Baby Rena on a respirator and diagnosed her with pneumocystis carinii pneumonia, a leading complication caused by AIDS.<sup>130</sup> Baby Rena's condition gradually improved enough for physicians to remove her from the respirator, artificial feeding, and most of her medications, and she left the hospital at nine months of age.<sup>131</sup> However, Baby Rena suffered cardiac failure with respiratory distress in January 1991, and physicians placed her back on the respirator.<sup>132</sup> In February, a new physician took over Baby Rena's care and concluded, after several failed therapies, that she could survive on the respirator, but would never improve.<sup>133</sup>

Thereafter, the physician and foster parents met with the ethics committee several times to discuss the option of withdrawing treatment from Baby Rena. The physician described Baby Rena's hopeless condition and explained that she would die soon, but the foster parents, hoping for a miracle, insisted on continuing the life-sustaining care and resuscitation.<sup>134</sup> Baby Rena was in constant pain and anguish. The physicians continually increased her medication to keep her sedated and free from agitation; she

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requires sixteen hours of daily intensive home nursing, and retains the mental status of a three-month-old. *Id.*

127. See generally Benjamin Weiser, *The Case of Baby Rena: Who Decides When Care Is Futile?*, WASH. POST, July 14, 1991, pt. 1, at A1, July 15, 1991, pt. 2, at A1 (describing life and treatment of baby girl with HIV).

128. *Id.* pt. 1, at A18.

129. *Id.* Thus, the volunteer foster parents had no legal standing. *Id.* pt. 2, at A1.

130. *Id.* pt. 1, at A18.

131. *Id.* at A19.

132. *Id.*

133. *Id.* The physician stated that Baby Rena's situation was "different than just the loss of personhood, which is the usual dilemma of someone in a persistent vegetative state. This child was suffering, and she was suffering for a cause that we felt we couldn't fulfill." *Id.*

134. *Id.* The District of Columbia, which had become Baby Rena's guardian when her mother abandoned her at birth, also refused permission to withdraw the respirator. *Id.* pt. 2, at A1.



was fed intravenously; attempts to wean her from the respirator had failed; and she suffered from chronic diarrhea.<sup>135</sup> One physician suggested that the physicians unilaterally withdraw the care.<sup>136</sup> The foster parents eventually agreed to attempt weanings, but insisted upon replacement of the respirator should the weanings fail; several weanings succeeded for only a couple of days before Baby Rena again required the respirator.<sup>137</sup> On March 25, 1991, the physicians determined that Baby Rena would die imminently from multiple organ system failure initiated by AIDS and recommended no further interventions.<sup>138</sup> The foster parents again rejected the prognosis and left the hospital thinking that Baby Rena's condition would improve.<sup>139</sup> Baby Rena died later that afternoon.<sup>140</sup>

### B. Defining Futility

Commentators have provided many definitions of "futile" care, but have not produced a common conception.<sup>141</sup> The conceptions that they have produced may not be sufficiently precise for a legal definition. In particular, the probabilistic nature of medicine and the value judgments inherent in evaluating any probability create problems and confusion.<sup>142</sup>

One must define futility in terms of the futility of achieving specific ends.<sup>143</sup> Thus, one must first distinguish between "medical futility" — whether the benefit of the treatment is worthwhile to the individual<sup>144</sup> — and "economic futility," or rationing — whether the benefit is worthwhile to

135. *Id.* pt. 2, at A6.

136. *Id.*

137. *Id.*

138. *Id.*

139. *Id.* at A6, A7.

140. *Id.* at A7.

141. *See infra* notes 143-87 and accompanying text (discussing futility definitions).

142. *Compare* Robert D. Truog, M.D. et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561 (1992) (arguing that physiological futility is at least close to being value free) *with* Schneiderman, *supra* note 9, at 883 (asserting that limited goal of providing physiological effects is value choice that radically changes nature of patient-centered ethic of medicine).

143. *See* Stell, *supra* note 7, at 490 (defining futility as "end-related concept"); *see also* Truog et al., *supra* note 142, at 1561 (noting that one must ask "Futile in relation to what?" when discussing futility).

144. *But see* Loewy & Carlson, *supra* note 16, at 429-30 (noting that treatment may be futile for patient but have social value to family, and approving of extension of treatment for reasonable time to allow family and others concerned to come to terms with situation, provided treatment causes patient no suffering).

society.<sup>145</sup> One author has also described "financial futility" in reference to care or cases in which hospitals are reasonably assured of losing money under operative prospective payment systems.<sup>146</sup> Although this Note concerns only individual situations and the issue of whether physicians may decide that care is futile for a particular patient, the larger social problems involving rationing and a just allocation of resources ultimately affect the futility debate.<sup>147</sup>

One can consider two broad conceptions of futility: (1) care that produces no effect (physiological or quantitative futility), and (2) care that produces an effect, but offers no benefit (qualitative futility).<sup>148</sup> The discussion below provides an example of each of the categories of futility and evaluates whether the conception can provide a sufficient basis for a legal recognition of futility. A new definition of death that includes permanent unconsciousness, although not precisely a futility concept, also could help resolve some aspects of the futility debate.

### 1. *Physiological or Quantitative Futility*

The first broad conception of futility includes what Robert Veatch and Carol Spicer, two medical ethicists at Georgetown University's Kennedy Institute of Ethics, refer to as care that produces no physiological effect at a given level of probability.<sup>149</sup> Allowing for a given level of probability that a given treatment will produce a therapeutic benefit recognizes the inherent

145. See Nancy S. Jecker, Ph.D. & Lawrence J. Schneiderman, M.D., *Futility and Rationing*, 92 AM. J. MED. 189, 192-94 (1992) (discussing differences between concepts of futility and rationing and noting that futility refers to "specific cause-and-effect relationship[s]" while rationing refers to distributive choices); see also Stuart J. Younger, M.D., *Who Defines Futility?*, 260 JAMA 2094, 2095 (1988) (noting that, until social consensus occurs, individual physicians must distinguish between concerns for patients and more global economic and policy concerns).

146. See Lantos, *supra* note 17, at 869 (discussing links between prospective payment systems and futility debate and citing four studies demonstrating scenarios generating net losses for hospitals under prospective payment systems).

147. See Callahan, *supra* note 26, at 867 (discussing pressures of economic scarcity); Rie, *supra* note 18, at 26-27 (noting economic concerns in case of Helga Wanglie); see generally Teno et al., *supra* note 5 (investigating potential savings from elimination of futile care).

148. See Schneiderman, *supra* note 9, at 884-85 (discussing conceptions of futility); Robert M. Veatch, *Why Physicians Cannot Determine If Care Is Futile*, 42 J. AM. GERIATRICS SOC'Y 871, 871 (1994) (distinguishing between two types of futility).

149. See Robert M. Veatch, Ph.D. & Carol M. Spicer, M.A., *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15, 16-20 (1992) (discussing futility of care that produces no effect at chosen level of probability).

uncertainty resulting from the empirical nature of medical practice.<sup>150</sup> Other commentators sometimes refer to this broad category as "physiological futility"<sup>151</sup> or "quantitative futility."<sup>152</sup> Veatch and Spicer provide as an example of this type of futile care cardiopulmonary resuscitation (CPR) performed on a patient who last breathed three hours prior to administering the care.<sup>153</sup> They cite the use of antibiotics for the common cold as another example of this type of physiological futility.<sup>154</sup> Lawrence Schneiderman and his colleagues, leading physician commentators in the futility debate,<sup>155</sup> have proposed as a definition of futility that if a treatment has proved ineffective in the last one hundred cases, it is futile.<sup>156</sup> Schneiderman and his colleagues use the outcomes from the last one hundred cases as a method of measuring the probability of success in the next case.<sup>157</sup> Schneiderman defines ineffective treatment as "treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care."<sup>158</sup>

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150. See Nancy S. Jecker, Ph.D. & Lawrence J. Schneiderman, M.D., *An Ethical Analysis of the Use of 'Futility' in the 1992 American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiac Care*, 153 ARCHIVES INTERNAL MED. 2195, 2197 (recognizing quantitative component of futility).

151. See Younger, *supra* note 145, at 2094 (1988) (arguing that physicians should not offer physiologically futile care).

152. See Schneiderman, *supra* note 9, at 884 (discussing quantitative futility).

153. Veatch & Spicer, *supra* note 149, at 18.

154. *Id.* (citing Tom Tomlinson, Ph.D. & Howard Brody, M.D., Ph.D., *Futility and the Ethics of Resuscitation*, 264 JAMA 1276, 1277 (1990)).

155. See generally Jecker & Schneiderman, *supra* note 145 (comparing and contrasting different concepts of futility and rationing); Lawrence J. Schneiderman, M.D. & Nancy S. Jecker, Ph.D., *Futility in Practice*, 153 ARCHIVES INTERNAL MED. 437 (1993) (discussing how to define futility); Lawrence J. Schneiderman, M.D. et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990) (proposing that if care is ineffective in last 100 cases, it is futile).

156. See Schneiderman et al., *supra* note 155, at 951 (proposing conception of futility). The authors state that "when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases a medical treatment has been useless, they should regard that treatment as futile." *Id.*

157. See Schneiderman, *supra* note 9, at 884 (noting that if care did not work in previous 100 cases, it is almost certain to fail if tried again). Schneiderman acknowledges that society or the medical community could fix the probability of success higher or lower than the level suggested by his last-100-cases test, but asserts that the probabilistic nature of medicine requires fixing some probability level where absolute certainty is impossible. *Id.*

158. Schneiderman et al., *supra* note 155, at 952.

Those who support physiological futility would allow physicians to withhold or withdraw care that physicians determine is physiologically futile; for example, Veatch and Spicer acknowledge, at least as a strong presumption, that physicians can determine instances in which care will have no effect and in which physicians, therefore, can refuse to provide such procedures.<sup>159</sup> Schneiderman similarly would allow physicians to refuse to provide treatment under circumstances of quantitative futility.<sup>160</sup> In a report on the ethics of providing life-sustaining treatment, the Hastings Center, a leading bioethics institution, also suggests that physicians may refuse to provide physiologically futile care.<sup>161</sup>

Some commentators argue that physiological futility presents a value-free concept.<sup>162</sup> That is, the question of what care is effective for achieving a given physiological result is largely a question of medical science and judgment.<sup>163</sup> However, commentators such as Schneiderman dispute the notion that physiologic futility is value free: They note that medicine's objectives extend beyond producing physiologic effects to include healing the person.<sup>164</sup>

This conception of futility is not controversial; most commentators would not require physicians to provide care that is physiologically or quantitatively futile.<sup>165</sup> However, this conception of futility is of limited use

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159. Veatch & Spicer, *supra* note 149, at 19-20.

160. See Schneiderman, *supra* note 9, at 884 (suggesting that physicians' obligations do not require offering quantitatively futile treatment).

161. See THE HASTINGS CENTER, *supra* note 24, at 19 (stating that physicians may provide futile treatment, particularly when it offers psychological benefit, but noting that there is no obligation to provide futile treatment).

162. See Truog et al., *supra* note 142, at 1561 (arguing that physiological futility is at least close to being value free). But see Veatch & Spicer, *supra* note 149, at 18-20 (arguing that fact/value distinction is not always clear and that physiological futility thus presents questions of values).

163. See Veatch & Spicer, *supra* note 149, at 18 (noting that question concerns whether treatment will produce relevant effects).

164. See Lawrence J. Schneiderman, M.D. et al., *Beyond Futility to an Ethic of Care*, 96 AM. J. MED. 110, 112 (1994) (stating that "[t]he objective of medicine is not to achieve a simple physiologic effect . . . , but to heal ('make whole') the patient"). Schneiderman has asserted elsewhere that assigning medicine the limited goal of producing physiological effects on organ systems, instead of healing the whole patient, is itself a value choice that radically changes the patient-centered nature of medicine. Schneiderman, *supra* note 9, at 883.

165. See Veatch & Spicer, *supra* note 149, at 20 (noting that few people would question physicians' ability to refuse to provide such treatments). Physiological futility is controversial only to the extent that some people would limit the scope of physician authority to physiological futility, but others would extend the authority beyond that.

beyond recognizing a limited area of professional judgment. For example, Veatch and Spicer note that Helga Wanglie's husband and physicians disputed the benefit of her treatments, not the effects of those treatments.<sup>166</sup> Thus, this notion of futility would have been of little use to the court in deciding the fate of Helga Wanglie.<sup>167</sup> Also, courts in the recent futility cases, thus far, have not considered the fact that other practitioners agreed with the physicians who sought to end treatment that the requested care was futile,<sup>168</sup> perhaps because the treatment was effective at sustaining life. That is, the real futility question in the cases concerned the benefit of the effects created by sustaining life, instead of a medical judgment about whether the treatments could effectively sustain life.

## 2. Qualitative Futility

The second broad conception of futility — qualitative futility — concerns care that produces effects that physicians perceive to be of no benefit.<sup>169</sup> Futility in this sense is at the heart of the futility debate because it conflicts directly with the established notion of patient autonomy: It allows physicians to determine the benefits of a particular treatment and to evaluate those benefits for the patient. However, some physicians argue that physicians should have this authority as a matter of professional judgment falling within medicine's directive to act in the patient's best interests.<sup>170</sup> For example, the medical effects of providing Helga Wanglie with a respirator were not disputed — the respirator maintained her in a vegetative state;<sup>171</sup> Baby K's emergency care had the effect of prolonging her life,<sup>172</sup> and Baby Rena's care similarly had the effect of prolonging her life.<sup>173</sup> Despite the

166. See *id.* at 21 (noting that *Wanglie* dispute did not concern medical facts, but rather concerned value of preserving Helga Wanglie in vegetative state).

167. See *supra* notes 77-92 and accompanying text (discussing *Wanglie*).

168. See *In re Baby K*, 16 F.3d 590, 598 (4th Cir.) (noting that no other facility would accept Baby K — arguably representing consensus by medical community that care was futile — yet declining to order that treatment was not required), *cert. denied*, 115 S. Ct. 91 (1994).

169. Veatch & Spicer, *supra* note 149, at 16.

170. See generally Howard Brody, M.D., Ph.D., *The Physician's Role in Determining Futility*, 42 J. AM. GERIATRICS SOC'Y 875 (1994) (arguing for expanded physician role in determining futility).

171. See Veatch & Spicer, *supra* note 149, at 21 (noting that dispute concerned value of preserving vegetative life and did not concern medical facts); *supra* notes 77-92 and accompanying text (discussing *Wanglie*).

172. See *supra* notes 98-108 and accompanying text (discussing *Baby K*).

173. See *supra* notes 127-40 and accompanying text (discussing case of Baby Rena).

undisputed effects of treatment in these cases, physicians claimed that the treatments were futile because the physicians perceived the effects to be of no benefit.

Schneiderman provides as an example of qualitative futility the case in which the best outcome resulting from care is that the patient will be kept "perpetually prisoner in the Intensive Care Unit."<sup>174</sup> Schneiderman regards such an outcome as a "failure to achieve the goals of medicine."<sup>175</sup> Thus, he assigns to the medical profession part of the responsibility for determining the benefits of treatment and frames the qualitative futility issue in terms of a question concerning the proper role of medicine. He considers a denial of physician authority to declare certain treatments futile a radical change in the nature of medicine, reducing physicians to mere technicians whose only function is to provide any treatment that produces an effect that the patient considers a benefit.<sup>176</sup>

Lance Stell, a professor of clinical ethics at Carolinas Medical Center in Charlotte, North Carolina, provides another example of this type of futility.<sup>177</sup> He discusses futility in terms of "nested" ends for diagnostic and therapeutic efforts.<sup>178</sup> Patients value certain preliminary ends of treatment only because they promote more advanced ends. When the treatment cannot achieve the higher ends, the preliminary ends lose their value.<sup>179</sup> For example, although CPR may achieve a limited end of restoring heart and lung function, patients and physicians should devalue this limited end when the chances of a fuller recovery diminish. Thus, physicians need not perform CPR when the chances of fuller recovery are diminished because the CPR is futile at achieving the greater end of recovery.<sup>180</sup>

174. Schneiderman, *supra* note 9, at 885.

175. *Id.*

176. *Id.* at 883 (stating that "specify[ing] narrow physiological objectives as the goals of medical practice is not *value neutral*, but a *value choice* that is, in my opinion, about as far from the patient-centered tradition of the medical profession as it is possible to be").

177. See Stell, *supra* note 7, at 490-91 (discussing futility as "end-related concept").

178. See *id.* (noting relationship between means chosen and likelihood of achieving ends desired in determining value of means).

179. See *id.* at 491 ("Lower-order ends are worthwhile in so far as they promote higher-order or ultimate ends. When higher-order ends cannot be achieved, their subordinate ends lose status as ends unless other suitably related higher-order ends are substituted.").

180. *Id.*; see also John J. Paris, S.J., Ph.D. et al., *Beyond Autonomy — Physicians' Refusal to Use Life-Prolonging Extracorporeal Membrane Oxygenation*, 329 NEW ENG. J. MED. 354 (1993) (discussing futility in context of change in treatment goals after initial trial therapy proves ineffective).

Others, however, insist that questions about the benefits that certain treatments provide are the province of patients and their families or surrogates who have knowledge of the patients' values.<sup>181</sup> Thus, they contend that "the important category of 'care that produces an effect, but one believed to be of no benefit,' should not be referred to as futile on *medical* grounds."<sup>182</sup> They contend that futility in this sense involves value judgments concerning the *benefits* of treatment, for which the physician has no particular skill.<sup>183</sup> Accordingly, these commentators argue that physicians should not have the authority to withdraw or withhold life-sustaining treatment against a patient's direction.<sup>184</sup> The effect-but-no-benefit conception also requires evaluation of a patient's quality of life, a task that courts have avoided.<sup>185</sup> To date, courts have respected the move away from paternalistic standards under which physicians could determine the benefits of treatments and toward the principle of individual autonomy,<sup>186</sup> thus agreeing with these latter commentators.<sup>187</sup>

### 3. Brain-Dead Patient as Paradigmatic Case of Futility

David Blake, a lawyer and professor of philosophy, discusses futility by positing the brain-dead patient as the "paradigmatic" case of futility.<sup>188</sup> He suggests evaluating new cases for probable futility by examining how closely

181. See James L. Nelson, *Families and Futility*, 42 J. AM. GERIATRICS SOC'Y 879, 880 (1994) (discussing authority of family).

182. Veatch & Spicer, *supra* note 149, at 16-17.

183. See *id.* (arguing that futility judgments cannot properly be made solely by physicians, particularly when treatment produces physiological effects).

184. *Id.* at 17.

185. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 282 (1990) (noting that states may properly decline to judge quality of life of particular individual).

186. See *In re Jane Doe*, No. D-93064, slip op. at 15-16 (Sup. Ct. Fulton County, Ga. Oct. 17, 1991), *aff'd*, 418 S.E.2d 3 (Ga. 1992) (noting move away from paternalistic standards and toward individual autonomy).

187. See *supra* notes 77-92 and accompanying text (discussing *Wanglie* case, in which court denied hospital's request to appoint guardian for purpose of withdrawing allegedly futile treatment and instead appointed woman's husband as guardian); *supra* notes 98-108 and accompanying text (discussing *Baby K* case, in which court refused to allow hospital's determination of futility to justify withdrawal of care); *supra* notes 109-18 and accompanying text (discussing *Jane Doe* case, in which court refused to allow entry of Do Not Resuscitate order against wishes of minor's parent).

188. See David C. Blake, *Bioethics and the Law: The Case of Helga Wanglie: A Clash at the Bedside — Medically Futile Treatment v. Patient Autonomy*, 14 WHITTIER L. REV. 119, 126 (1993) (noting that "medical intervention . . . , in this society, is most obviously and consistently viewed as 'futile' . . . [in] the case of the brain-dead patient").

they resemble the circumstances of the brain-dead patient.<sup>189</sup> Thus, a redefinition of brain-death to include permanent unconsciousness would place patients in a persistent vegetative state and infants with anencephaly within Blake's paradigmatic case of futility.<sup>190</sup>

The currently accepted standard for defining death is the "brain death" standard,<sup>191</sup> which requires the loss of all brain functions.<sup>192</sup> Some authors have proposed new definitions of death based upon the permanent loss of only higher brain functions — a definition that would include persistent vegetative state and Anencephaly.<sup>193</sup> Those calling for such a change in the definition of death base their proposals on their assertion that "[t]he death of the higher brain is the death of what makes us human."<sup>194</sup> Many of the situations in which the question of futility arises concern patients in a persistent vegetative state.<sup>195</sup> Because a dead person has no right to treatment, such a change in definition would resolve some of the debate, at least in cases involving patients in persistent vegetative states or patients with

189. *Id.* at 127. Blake proposes four categories for comparison: (1) the neurological and other life functions of the patient; (2) the degree of inevitability and timing between the patient's condition and cessation of all biological functions; (3) the patient's self-understanding of the condition; and (4) the position of the treatment within the overall health care picture. *Id.*

190. See *supra* notes 65-76, 93-97 and accompanying text (discussing persistent vegetative state and anencephaly and noting that both conditions involve permanent unconsciousness).

191. See Robert M. Veatch, Ph.D., *The Impending Collapse of the Whole-Brain Definition of Death*, HASTINGS CENTER REP., July-Aug. 1993, at 18, 18.

192. See UNIFORM DETERMINATION OF DEATH ACT § 1, 12 U.L.A. 441, 443 (Supp. 1995). The Uniform Act provides: "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards." *Id.* Thirty-one states, the District of Columbia, and the Virgin Islands have adopted the Act. *Id.* at 441.

193. See, e.g., Daniel Callahan, Ph.D., *Pursuing a Peaceful Death*, HASTINGS CENTER REP., July-Aug., 1993, at 33, 37 (stating that "we must have a general social agreement on the right of physicians to withhold medical treatment from persons in the persistent vegetative state"); Veatch, Ph.D., *supra* note 191, at 23 (proposing that "[a]n individual who has sustained irreversible loss of consciousness is dead"); Gina Kolata, *Ethicists Debate New Definition of Death*, N.Y. TIMES, Apr. 29, 1992, at C13 (discussing proposed new definitions of death).

194. Kolata, *supra* note 193, at C13 (quoting Dr. John Fletcher, ethicist at University of Virginia).

195. For example, Helga Wanglie was in a persistent vegetative state. *In re Wanglie*, No. PX-91-283 (Hennepin County, Minn., P. Ct. June 28, 1991), reprinted in 7 ISSUES L. & MED. 369, 375 (1991).



anencephaly.<sup>196</sup> However, because society is not yet ready to declare that people with beating hearts and open eyes are dead,<sup>197</sup> a change in the definition of death is not imminent,<sup>198</sup> which leaves the futility question in place, at least for the time being.

### C. *An Argument for the Legal Recognition of Futility*

#### 1. *Respect for the Ethical Integrity of the Medical Profession Supports the Recognition of Futility*

Maintaining the ethical integrity of the medical profession is one of the principal considerations involved in decisions regarding the use of life-sustaining treatment.<sup>199</sup> Requiring physicians to provide certain treatment can violate the ethical integrity of the medical profession and the integrity of the profession's judgments in several ways. First, patients could pursue treatment toward ends for which medical treatment should not be employed. Schneiderman has argued that such an ethical violation occurs when medicine is used merely to sustain biological functions instead of healing the patient.<sup>200</sup> A patient's request for treatment that a physician considers to be medically inappropriate and a court requiring the physician to honor that request also undermine the integrity of the medical profession's judgments.<sup>201</sup>

196. See Blake, *supra* note 188, at 127 (suggesting that legal definition of death "is in effect a strong and persistent consensus regarding futile medical treatment").

197. See Kolata, *supra* note 193, at C13 ("It is pretty horrifying and psychologically jarring, to say the least, to look at someone whose eyes are open and say they are dead.") (quoting Dr. Ronald Cranford, neurologist and chair of ethics committee of American Academy of Neurology).

198. See *id.* (noting fears of (1) declaring individuals with diminished mental capacities dead and (2) diagnosing persistent vegetative state inaccurately).

199. See THE HASTINGS CENTER, *supra* note 24, at 19-20 (identifying ethical integrity of health care professionals as underlying ethical value in decisions about use of life-sustaining treatment).

200. See Schneiderman, *supra* note 9, at 883 (arguing that pursuit of narrow physiological goals is not value neutral).

201. Medical societies generally justify the physician's authority to declare treatment futile based upon some notion of a physician's judgment to determine "medically indicated" treatments. See Council on Ethical & Judicial Affairs, Am. Medical Ass'n, *Fundamental Elements of the Patient-Physician Relationship*, 264 JAMA 3133, 3133 (1990) (noting physician obligation to cooperate in provision of medically indicated treatments); see also James J. Murphy, Comment, *Beyond Autonomy: Judicial Restraint and the Legal Limits Necessary to Uphold the Hippocratic Tradition and Preserve the Ethical Integrity of the Medical Profession*, 9 J. CONTEMP. HEALTH L. & POL'Y 451, 467-70 (1993) (discussing various medical associations' views of physician's role in determining appropriate treatment).

Physicians contend that they have an obligation to exercise learned judgment for their patients and that shifting that responsibility to patients would be a "misguided attempt to respect autonomy."<sup>202</sup> Others have argued that such treatment is also unethical because it misleads patients and their families and produces false hope, ultimately undermining physician-patient trust.<sup>203</sup> Respect for the integrity of the medical profession in this sense provides the strongest argument for the legal recognition of futility.

Second, treatment can violate the physician's personal ethics. The President's Commission suggested a limited ability of physicians to refuse to provide treatment because the provision of such treatment would offend the physician's conscience.<sup>204</sup> Virginia and Maryland respect the integrity of the medical profession in this regard through the recent amendments to their health care decisions acts, which allow a physician to transfer a patient when the physician disagrees with the patient's treatment decisions.<sup>205</sup> Statutes addressing a physician's right to refuse to perform abortions provide examples of responses to ethical conflicts outside of the futility context.<sup>206</sup> Respect for physician integrity in this second sense argues most strongly for transfer provisions when physicians and patients conflict over whether to withhold or withdraw life-sustaining treatment.

Third, treatment can be unethical if it is not the best use of society's scarce health care resources. Treatment that is unethical in this sense does not particularly harm the ethical integrity of the medical profession. How-

202. Paris et al., *supra* note 119, at 1013. The authors note that "a physician who merely spreads an array of vendibles in front of the patient [or family] and then says, 'Go ahead and choose, it's your life,' is guilty of shirking his duty, if not of malpractice." *Id.* (quoting Franz J. Ingelfinger, M.D., *Arrogance*, 303 *NEW ENG. J. MED.* 1507, 1509 (1980)).

203. See Brody, *supra* note 170, at 876-77 (describing unethical practice of misleading patients by falsely raising hopes).

204. See PRESIDENT'S COMM'N, *supra* note 66, at 3 (stating that "health care professionals or institutions may decline to provide a particular option because that choice would violate their conscience or professional judgment, though in doing so they may not abandon a patient").

205. See MD. CODE ANN., HEALTH-GEN. § 5-613 (1994 & Supp. 1995) (providing for transfer of patient by health care provider who refuses to comply with patient's treatment decision); VA. CODE ANN. §§ 54.1-2987, -2990 (Michie 1994) (same).

206. See Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. A Physician's Professional Conscience*, 44 *HASTINGS L.J.* 1241, 1274-77 (1993) (discussing legislation in "vast majority of states" and federal law allowing physicians to refuse to participate in abortion and offering analogy to futility). Daar notes that the abortion conscience statutes are generally strong measures: "In no state does the abortion refusal law require or even suggest that an objecting physician transfer the patient to another physician or facility. At most, the statute may require that the physician notify the patient of his or her objection." *Id.* at 1275 n.151.

ever, society's response to this social problem could harm the medical profession's ethical integrity if the response changes the nature of the physician's role in treatment to include more cost containment.<sup>207</sup>

In prior decisions involving the withdrawal of life-sustaining treatment, courts have balanced concerns for the ethical integrity of the medical profession against respect for patient autonomy.<sup>208</sup> One court noted that, when a willing transferee hospital is available, "[a] patient's right to refuse medical treatment does not warrant such an unnecessary intrusion upon the hospital's ethical integrity" as requiring physicians at the transferring hospital to act contrary to the physicians' ethical principles.<sup>209</sup> Thus, the court affirmed the principle that a hospital, and those treating patients there, should not be forced to act contrary to their ethical principles when their principles are accepted within a significant portion of the professional community.<sup>210</sup>

In these cases, physicians generally argued for continued life support against the patients' wishes to withdraw the treatment — that is, physicians did not want to *withdraw* their services — and courts generally held that concerns for physician ethics could not overcome patient autonomy.<sup>211</sup>

207. Unethical treatment in this third sense can create two harms, one more particular and one more general. The particular harm occurs when, for instance, a particular "futile" treatment is continued on a patient and that patient's bed and other resources are thus kept from another patient who could clearly benefit more from the care. The more general harm is to society as a whole resulting from the unjust allocation of the resources other than to their best uses. For example, some would argue that Helga Wanglie's care was unethical because society could better use the \$800,000 spent on her "futile" care. Rie, *supra* note 18, at 27 (discussing costs of autonomy). However, this social harm results from a social dilemma, and society as a whole must resolve the competing interests, rather than particular physicians resolving them through their treatment of particular patients. Assigning physicians the responsibility of resolving the allocation problem would fundamentally change the nature of the physician-patient relationship. See Veatch & Spicer, *supra* note 149, at 29 (arguing that clinicians should not be "society's cost-containment agent").

208. See Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 425 (Mass. 1977) (providing four state interests contrary to patient autonomy, including "maintaining the ethical integrity of the medical profession"); see also Murphy, *supra* note 201, at 475 n.168 (providing cases acknowledging importance of preserving ethical integrity of medical profession).

209. Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626, 639 (Mass. 1986).

210. *Id.*

211. See, e.g., Gray v. Romeo, 697 F. Supp. 580, 591 (D.R.I. 1988) (deciding that if patient cannot be transferred to facility willing to comply with patient's wishes, hospital must comply); *In re Farrell*, 529 A.2d 404 (N.J. 1987) (deciding that competent, terminally ill woman's right to withdraw life-sustaining treatment outweighed state's interest in preserving ethical integrity of medical profession); Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626, 639-40 (Mass. 1986) (ordering hospital to assist transfer of patient to hospital

Further, there were generally willing transferee facilities available to comply with the patients' requests. However, in futility cases, physicians are arguing for ending life support against patients' wishes to continue the treatment — that is, physicians do not want to be forced to *provide* their services — and generally no facilities have been willing to accept the patients or to comply with the patients' requests for continued treatment.<sup>212</sup> Thus, respect for the ethical integrity of the medical profession and its ability to direct when and how its services must be used supports the recognition of futility.

## 2. *Respect for Patient Autonomy Does Not Undermine Futility Because Autonomy Is a Negative Right Instead of a Positive Right*

Commentators have noted a distinction between the negative right to refuse unwanted medical treatment at the end of life, which has been established by court precedent since the mid-1970s,<sup>213</sup> and a positive right to demand specific treatments.<sup>214</sup> Patient autonomy includes a negative right to direct that certain treatments not be performed on a patient — it is a right to refuse treatment and cannot justify a right to demand treatment.<sup>215</sup> The principal cases in which patient autonomy developed concerned patients' attempts to withhold or withdraw certain life-sustaining treatments. Those cases are most properly characterized as concerning the negative right to prevent certain actions — the provision of unwanted medical treatment — rather than a positive right to direct certain actions — withdrawal of

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willing to comply with patient's request to withdraw treatment); Superintendent of Belcher-town State Sch. v. Saikewicz, 370 N.E.2d 417, 435 (Mass. 1976) (holding that principle of patient autonomy prevailed over competing state interests, including maintaining ethical integrity of medical profession).

212. See *supra* notes 89, 103 and accompanying text (noting that no transferee facility could be found in both *Wanglie* and *Baby K*). But see *supra* notes 125-26 and accompanying text (noting that willing transferee was found in case of *Baby L* despite transferee's agreement that care was futile).

213. See *supra* note 45 (listing leading cases discussing circumstances under which patient may refuse life-sustaining treatment).

214. See Veatch & Spicer, *supra* note 149, at 23 (discussing right to refuse life-sustaining treatment and right to demand treatment). The authors note that "[a]t least one obvious difference exists between the cases of Karen Quinlan and Helga Wanglie. Autonomy gives the patient a right to refuse treatment . . . . But that principle cannot imply that autonomy can give the patient or surrogate a right of access to care." *Id.*

215. *Id.* See also PRESIDENT'S COMM'N, *supra* note 66, at 44 (stating that "[a]lthough patients . . . have the legal and ethical authority to forego some or all care, this does not mean that patients may insist on particular treatments").

treatment.<sup>216</sup> Indeed, the informed consent doctrine upon which patient autonomy rests has significance precisely because it allows a patient to decide that certain treatment is not worth the risks to the individual patient. The constitutional right of privacy upon which patient autonomy also rests has significance because it allows individuals to be left alone. Although courts in some cases have required hospitals to act contrary to the ethical judgment of the hospitals' physicians outside of the futility context,<sup>217</sup> those cases are inapposite because the courts forced action only in the course of enforcing patients' negative rights to refuse unwanted treatment.<sup>218</sup> In sum, the right to refuse treatment cannot imply a positive right of access to care.<sup>219</sup>

Even if autonomy implies a right of access to care, it may not provide a legal right to futile care. For example, the American Medical Association has suggested that physicians may have the authority unilaterally to enter Do Not Resuscitate orders when CPR would be futile.<sup>220</sup> In a case establishing

216. See Murphy, *supra* note 201, at 477-79 (discussing precedent for patient autonomy and finding nothing to support order directing physician to provide treatment against medical and ethical judgments).

217. See Gray v. Romeo, 697 F. Supp. 580, 590-91 (D.R.I. 1988) (concluding that if patient cannot be transferred to facility willing to comply with patient's wishes, hospital must comply); *In re Jobs*, 529 A.2d 434, 450 (N.J. 1987) (concluding that nursing home could not refuse to participate in patient's withdrawal of artificial nutrition by continuing to treat patient until patient was transferred); *In re Requena*, 517 A.2d 886, 891-93 (N.J. Ch.) (determining that right of patient to refuse life-sustaining treatment superseded hospital's policy against withholding food and water from patients and denying hospital's request to compel patient to leave), *aff'd*, 517 A.2d 869 (N.J. Super. Ct. Law Div. 1986); see also Bouvia v. Superior Court, 225 Cal. Rptr. 297, 307 (Ct. App. 1986) (Compton, J., concurring) (suggesting that right to die includes positive right to enlist aid of others "in making death as painless and quick as possible").

218. See Murphy, *supra* note 201, at 474 n.164 (distinguishing circumstances involved in Gray, Jobs, and Requena cases from situations involving positive right to demand treatment).

219. See Veatch & Spicer, *supra* note 149, at 23 (discussing autonomy and right of access to treatment); see also Murphy, *supra* note 201, at 477-79 (discussing autonomy as negative right). Murphy concludes:

Autonomy is limited by the reach of the legal roots that established it: the constitutional right to privacy; the common law doctrine of informed consent; and the common law right to be free from unwanted or nonconsensual bodily invasion. Each is a negative right, from which no entitlement to medical care properly can be inferred.

*Id.* at 479.

220. See generally Council on Ethical & Judicial Affairs, Am. Medical Ass'n, *Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders*, 265 JAMA 1868 (1991) (presenting guidelines). The Council stated that "[a] physician is not ethically obligated to make a specific diagnosis or therapeutic procedure available to a patient, even on specific request, if the use of such a procedure would be futile." *Id.* at 1870. CPR is futile if it "cannot be expected either

that a physician's intentional withdrawal of life-sustaining treatment pursuant to a family request will not create criminal liability, the California Supreme Court noted in dicta that a physician has no duty to continue providing ineffective treatment.<sup>221</sup> The court characterized ineffective treatment as treatment that "cannot and does not improve the prognosis for recovery."<sup>222</sup> A therapeutic privilege to withhold information from a patient that sound medical judgment suggests would potentially harm a patient diminishes the patient's right to refuse treatment by limiting disclosure to the patient under informed consent principles.<sup>223</sup> Because courts limit disclosure requirements under the doctrine of informed consent, they should also limit the derivative right to refuse treatment.

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to restore cardiac or respiratory function to the patient or to achieve the expressed goals of the informed patient." *Id.* at 1871. *But see* N.Y. PUB. HEALTH LAW §§ 2960-2978 (McKinney 1993 & Supp. 1996) (establishing presumption of consent to CPR, establishing procedures for issuing DNR orders, and requiring consent for issuance of DNR order).

221. *See Barber v. Superior Court*, 195 Cal. Rptr. 484, 493 (Ct. App. 1983) (finding that doctor's cessation of life-sustaining treatment upon family's request, though intentional and with knowledge that patient would die, was not unlawful failure to perform legal duty). The court noted in dicta:

A physician has no duty to continue treatment, once it has proved to be ineffective. Although there may be a duty to provide life-sustaining machinery in the *immediate* aftermath of a cardio-respiratory arrest, there is no duty to continue its use once it has become futile in the opinion of qualified medical personnel.

"A physician is authorized under the standards of medical practice to discontinue a form of therapy which in his medical judgment is useless . . . . If the treating physicians have determined that continued use of a respirator is useless, then they may decide to discontinue it without fear of civil or criminal liability. By useless is meant that the continued use of the therapy cannot and does not improve the prognosis for recovery."

*Id.* at 491 (emphasis in original) (quoting Dennis Horan, *Euthanasia and Brain Death: Ethical and Legal Considerations*, 315 ANNALS N.Y. ACAD. SCI. 363, 367 (1978)).

222. *Id.* (quoting Dennis Horan, *Euthanasia and Brain Death: Ethical and Legal Considerations*, 315 ANNALS N.Y. ACAD. SCI. 363, 367 (1978)). However, the court finally concluded that the patient should be the ultimate decisionmaker:

Given the general standards for determining when there is a duty to provide medical treatment of debatable value, the question still remains as to who should make these vital decisions. Clearly, the medical diagnoses and prognoses must be determined by the treating and consulting physicians under the generally accepted standards of medical practice in the community and, whenever possible, the patient himself should then be the ultimate decision-maker.

*Id.* at 492.

223. *See Canterbury v. Spence*, 464 F.2d 772, 788-89 (D.C. Cir.) (recognizing limited therapeutic privilege of physician), *cert. denied*, 409 U.S. 1064 (1972).

### 3. *Potential Limits to Physician Authority to Declare Treatment Futile*

Despite the argument that patient autonomy does not undermine a physician's authority to declare treatment futile as a matter of fact, patient autonomy is obviously the primary limit to potential physician authority to declare treatment futile.<sup>224</sup> Over the last twenty years, courts have firmly established the right of self-determination as a fundamental principle in the context of end-of-life decisionmaking.<sup>225</sup> More recently, legislatures have protected that right through the passage of living will and surrogate decisionmaking statutes.<sup>226</sup>

The state interest in the preservation of life is the primary factor underlying end-of-life cases.<sup>227</sup> The presumption in favor of life limits a physician's authority to declare that certain life-sustaining treatment is futile. In support of this presumption, the Supreme Court has noted the irreversibility of an erroneous decision to terminate life.<sup>228</sup> The presumption should carry even more weight when a patient's preference for continued treatment aligns with the presumption in favor of life.

Several federal statutes may also limit a physician's authority to declare treatment futile. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination by programs receiving federal funds against "otherwise qualified" handicapped individuals, based solely upon the individual's handicap.<sup>229</sup> At least one federal court has concluded that withholding allegedly futile treatment would violate the Rehabilitation Act.<sup>230</sup> The same federal court also considered whether withholding allegedly futile treatment would violate the public accommodations provision of the Americans with Disabilities Act.<sup>231</sup> The court noted that because the claim of futility in *Baby K* rested on the infant's condition of anencephaly, the provider was denying the

224. See *supra* notes 44-63 and accompanying text (discussing patient autonomy).

225. See *supra* note 45 (listing leading cases that discuss patient refusal of life-sustaining treatment).

226. See Mordarski, *supra* note 11, at 778 (noting that every state and District of Columbia have legislation concerning an individual's right to accept or reject life-sustaining treatments and establishing procedures for surrogate decisionmakers); *id.* at 778 n.197 (compiling list of relevant state statutes).

227. See *supra* notes 38-43 and accompanying text (discussing respect for life as important factor in end-of-life cases).

228. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 283 (1990).

229. 29 U.S.C. § 794 (1988 & Supp. V 1993).

230. *In re Baby K*, 832 F. Supp. 1022, 1027-28 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

231. 42 U.S.C. §§ 12102(2), 12182 (1994).

infant life-sustaining treatment based upon the infant's disability.<sup>232</sup> Thus, withholding the allegedly futile treatment would violate the Americans with Disabilities Act.<sup>233</sup> Also, as the Fourth Circuit held in *Baby K*, the Emergency Medical Treatment and Active Labor Act (EMTALA) may preempt statutory authority allowing for a determination of futility.<sup>234</sup> Although the application of EMTALA is unclear and preemption will depend upon the facts of a given case, any situation in which a physician deems treatment to be futile could, as a practical matter, fit within the statute's broad definition of "emergency condition" and trigger treatment obligations.<sup>235</sup>

Finally, the California Court of Appeal has presented the possibility of a collective responsibility among health care providers to share the burden of difficult cases.<sup>236</sup> One commentator has suggested that the medical community may have a similar obligation, stemming from physicians' monopoly privilege to practice medicine, to provide allegedly futile treatment that a patient nonetheless thinks provides a benefit and that this obligation will continue to exist at least until a social consensus about futile treatment develops.<sup>237</sup> Such an obligation would seriously undermine physicians' authority to declare a legal right not to provide "futile" treatment because the profession as a whole would be required to provide any treatment for which a patient perceived a benefit.

#### D. Policy Considerations

Policy considerations that support a physician's right to declare certain treatment futile begin with an examination of the physician's role. Physi-

232. *Baby K*, 832 F. Supp. at 1029.

233. *Id.*

234. See *In re Baby K*, 16 F.3d 590, 597 (4th Cir.), cert. denied, 115 S. Ct. 91 (1994) (determining that EMTALA preempts VA. CODE ANN. § 54.1-2990 (Michie 1994) and requires hospital to treat anencephalic infant); see also *supra* note 108 (discussing Fourth Circuit's opinion in *Baby K*).

235. Withdrawing life-sustaining treatment, by definition of the treatment being "life-sustaining," creates a condition "manifesting itself by acute symptoms of sufficient severity . . . such that the absence of immediate medical attention could reasonably be expected to result in — (i) placing the health of the individual . . . in serious jeopardy, (ii) serious impairment to bodily functions, or (iii) serious dysfunction of any bodily organ or part . . ." 42 U.S.C. § 1395dd(e)(1)(A) (1994).

236. See *Payton v. Weaver*, 182 Cal. Rptr. 225, 230 (Ct. App. 1982) (discussing possibility of collective responsibility among health care providers to share burden of difficult patients, but finding record inadequate to support relief on that ground as matter of law).

237. See Veatch & Spicer, *supra* note 149, at 26-28 (arguing that professional duty requires treatment as condition of monopoly privilege).



cians are specially trained to recognize and react to medical phenomena. Society and individuals entrust physicians with judgments about appropriate treatments based upon the physicians' special knowledge and training. Both because physicians are better informed than lay people regarding the medical facts of a given case and because physicians have a personal ethical stake in how their skills are used, physicians arguably should have at least limited authority to declare that certain treatments at the extremes of life are not within the scope of their obligations and to refuse to provide those treatments. A patient's right to autonomous self-determination does not necessarily conflict with the physician's authority. The patient's right is a negative right to decline particular treatments. If a physician's professional integrity has any meaning, a patient cannot possess a positive right to direct the use of the professional's skills toward any and all ends chosen by the patient.<sup>238</sup> Further, cost limitations and the equitable distribution of scarce health care resources require additional limitations on patient autonomy.<sup>239</sup>

Policy considerations that undermine the recognition of a physician's authority to declare certain treatments futile begin with the patient. Over the last twenty years, courts have recognized the right of a patient to determine when to withdraw life-sustaining treatment, even when doing so means that the patient will die.<sup>240</sup> Recognizing futility as a legal concept would seriously undermine patients' rights. Futility, in effect, would grant physicians the authority to declare that certain individuals should die and would represent a serious devaluation of life through the removal of the presumption in

238. See Brody, *supra* note 170, at 877 (stating that "professional integrity is of little consequence" if all patients desire is "advice from some scientifically informed person about which manipulations will or will not produce certain biological results").

239. See *Cruzan v. Harmon*, 760 S.W.2d 408, 429 (Mo. 1988) (Blackmar, J., dissenting) (raising economic issue in decisions regarding use of life-sustaining treatment), *aff'd sub nom. Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990). Judge Blackmar stated:

The absolutist position is also infirm because the state does not stand prepared to finance the preservation of life, without regard to the cost, in very many cases. In this particular case the state has Nancy in its possession, and is litigating its right to keep her. Yet, several years ago, a respected judge needed extraordinary treatment which the hospital in which he was a patient was not willing to furnish without a huge advance deposit, and the state apparently had no desire to help out. Many people die because of the unavailability of heroic medical treatment. It simply cannot be said that the state's interest in preserving and prolonging life is absolute.

*Id.* (citations omitted).

240. See *supra* notes 44-63 and accompanying text (discussing patient autonomy and right to direct use or nonuse of life-prolonging treatment).

favor of life that has limited patients' authority to remove life-sustaining treatment.<sup>241</sup> Moreover, although the cost of life-sustaining treatment relative to the benefit that such treatment generates is an important consideration, society should weigh the costs and benefits, and should not entrust that analysis to physicians. The law should be particularly concerned about granting physicians such authority given the growing use of managed care systems that provide economic incentives to limit care, which can affect an already-complicated judgment about the appropriate use of life-sustaining treatments at the edges of life.<sup>242</sup>

### V. Recommendations for How the Legal System Should Respond

The legal system should reject a general recognition of qualitative futility that would allow physicians unilaterally to decide the benefits of treatments, to declare that certain treatments are futile, and to refuse to provide certain treatments despite the expressed contrary wishes of a patient or surrogate. Case law does not support a broad qualitative futility concept.

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241. For example, the *Cruzan* Court concluded that a state could require a clear and convincing standard of proof that a now-incompetent patient would have wanted life-sustaining treatment withdrawn before a surrogate's instructions to withdraw the treatment must be honored. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 280-84 (1990). Thus, the presumption in favor of life limits a patient's authority to withdraw life-sustaining treatment.

242. See Lantos, *supra* note 17, at 869 (noting increasing susceptibility of doctors in managed care networks to financial conflicts of interest among patient loyalty, social responsibility, and organizational loyalty). Under managed care systems and capitated fee schedules, providers are paid "up front" to provide health services to subscribers. Providers under these systems do not receive additional money for additional services when a patient becomes sick, as under the traditional fee-for-service arrangement. Thus, there exists an economic incentive to limit care for patients whose care is very expensive, particularly for cases in which the perceived benefits of the care are low. By definition, the benefits of treatment are low or nonexistent for cases in which physicians determine that care is futile. Physicians working for managed care providers "find themselves between a rock and a hard place." Kolata, *supra* note 15, at B8 (quoting Father John J. Paris, ethicist at Boston College and Jesuit priest). That is, managed care physicians' expenses on behalf of patients are monitored, and the physicians must either deny futile care and risk suit by the patient's family or provide the futile care and risk being dismissed for providing needless and expensive treatment. *Id.* For further discussion of this issue, see Ellen Fox & Carol Stocking, *Ethics Consultants' Recommendations for Life-Prolonging Treatment of Patients in a Persistent Vegetative State*, 270 JAMA 2578, 2581 (1993) (finding concern for appropriate resource allocation "evidently influenced" respondent ethical consultant's choices as to recommendations for intensity of treatment for hypothetical patients in persistent vegetative state) and Pelligrino, *supra* note 25, at 203 (discussing importance of futility debate in era of changing fiduciary relationship).

Broad qualitative futility poses potential problems to the gains in patient autonomy that courts have developed in the past several years. Broad qualitative futility may also conflict with several federal statutes — the Rehabilitation Act of 1973, the Americans with Disabilities Act, and EMTALA — through which Congress has sought to protect particular populations that are acutely susceptible to having their medical treatments labeled futile. Further, even if certain treatments are truly futile for the patient, they may offer value to the patient's family if continued for a reasonable period of time.<sup>243</sup> Assuming that most patients would appreciate an opportunity to help their families, continuing futile treatment under such circumstances does not conflict with a patient's best interests and imposes only a marginal burden on a physician's ethics and integrity. As discussed previously, the noncontroversial concept of quantitative futility adds little toward the resolution of the true futility debate concerning the benefits resulting from certain treatments.<sup>244</sup>

Rather than focusing entirely on futility — a concept that establishes physicians and patients as adversaries — the law should instead promote discussion between patients and families and among patients, their families, and physicians.<sup>245</sup> Some evidence suggests that surrogates do not accurately predict patients' wishes in given scenarios unless the patient and surrogate have discussed the particular situation.<sup>246</sup> The evidence also suggests that patients and surrogates do not request allegedly futile treatments when physicians frankly and honestly present all of the facts surrounding the patient's prognosis.<sup>247</sup> Rather, communication generally produces agreement.<sup>248</sup> Further,

243. See Loewy & Carlson, *supra* note 16, at 429-30 (noting that treatment may be futile for patient but have social value for family and approving of extending treatment for reasonable time to allow family and others concerned to come to terms with situation, provided treatment causes patient no suffering).

244. See *supra* notes 165-68 and accompanying text (discussing quantitative futility concept's lack of usefulness).

245. See Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388, 1388-115, 1388-204 (codified at 42 U.S.C. §§ 1395cc(f), 1396a(w)) (1994) (requiring health providers to provide written information to patients regarding their rights under state law to accept or reject medical care and to make advance directives and informing patients of facility's policies regarding use of life-sustaining treatment) (commonly known as the Patient Self-Determination Act). The Patient Self-Determination Act is one such legislative response that promotes conversation.

246. See Suhl et al., *supra* note 5, at 93-95 (finding disagreement between patients' responses to questionnaire for preferences for life support treatment in four scenarios and substituted judgment of patients' surrogates).

247. See Teno et al., *supra* note 5, at 1205-06 (suggesting that physicians and surrogates already acknowledge futility of some treatments). *But see* SUPPORT, *supra* note 64, at 1596

many futile conditions develop over time,<sup>249</sup> which allows for discussion between physicians and surrogates in those cases.

If communication cannot produce agreement, the law should respect the professional judgment and ethical rights of physicians who disagree with patients' requests for continued treatment and should allow such physicians to withdraw treatment after arranging for transfer of their patients.<sup>250</sup> The Virginia and Maryland health care decisions acts respond to this concern by providing for transfer of the patient when physicians determine that requested treatment is inappropriate.<sup>251</sup> The MD-HCDA addresses the transfer option more comprehensively by explicitly stating a duty to comply with treatment requests pending transfer when failure to do so would likely result in the patient's death.<sup>252</sup>

However, transferring a patient is not always an available option. As a practical matter, many facilities will refuse to accept these complicated

(finding that enhanced opportunities for physician-patient communication did not change established physician practice patterns that included major shortcomings in care of seriously ill, hospitalized patients).

248. See Schneiderman, *supra* note 9, at 886 (suggesting that physicians' fear of legal liability may underlie "unreasonable" concerns about treatment that are currently fueling futility debate). Schneiderman also states that "[p]atients and families who demand that 'everything be done' may well be expressing a subtext: 'Do not abandon me.'" *Id.* Thus, improved communication and an "ethic of care" may provide the best solution. See generally Schneiderman et al., *supra* note 164 (arguing for ethic of care). However, such an "ethic of care" may do little to produce agreement that treatment is futile for patients who request extended treatment on religious grounds because conversations between physicians, patients, and families are not likely to change religious convictions. To the extent that such convictions play a part in patients' requests for allegedly futile treatments, they may result in a futility impasse such as in the Baby K and Baby Rena cases. See Tousignant & Miller, *supra* note 96, at A9 (reporting mother's religious convictions and belief that Baby K will one day be normal despite anencephalic condition); Weiser, *supra* note 127, pt. 2, at A6 (describing foster father's discussion of religious views with Baby Rena's physicians).

249. See Paris, et al, *supra* note 180 (presenting case in which parents changed treatment goals for their ill son — from restoring pulmonary function to "simply keeping their son alive" — which raised questions regarding futility and obligations to continue treatment "beyond its intended function").

250. See Daar, *supra* note 206, at 1280-88 (advocating adaptation of ABA Model Rules of Professional Conduct standards for lawyer withdrawal from representing certain clients to medical futility question and establishment of in-hospital Treatment Evaluation Boards to hear and resolve disputes and to arrange for transfer in cases of impasse); Murphy, *supra* note 201, at 483-84 (advocating transfer of patients to resolve futility impasses); Paris et al., *supra* note 119, at 1013-14 (describing transfer that resolved futility debate in case of Baby L).

251. MD. CODE ANN., HEALTH-GEN. § 5-613 (1994 & Supp. 1995); VA CODE ANN. §§ 54.1-2987, -2990 (Michie 1994).

252. MD. CODE ANN., HEALTH-GEN. § 5-613(a)(3) (1994 & Supp. 1995).

cases.<sup>253</sup> Thus, the transfer option, by itself, is an incomplete solution to the problem of medical futility. The Virginia and Maryland health care decision acts are similarly incomplete, as neither addresses the situation in which no willing transferee facility is available.

The refusal of all available medical providers to consider providing allegedly futile treatment may signal a medical consensus that such treatment truly is futile.<sup>254</sup> Perhaps the law should allow courts, on a case-by-case basis, to uphold physicians' determinations of futility to override patients' requests for treatment in limited instances, such as when an impasse occurs and no transferee facility is available. The medical facts of given cases are too important and too varied to allow for a more general determination. Before such a determination is upheld, however, the law should require physicians to show, by at least clear and convincing evidence<sup>255</sup> that (1) the burdens of the treatment substantially outweigh the benefits to the patient<sup>256</sup> or that the treatment constitutes abuse and neglect,<sup>257</sup> and (2) the provision of the requested treatment under the circumstances lies substantially outside of any standard of care, including any respectable minority view. Requiring such a showing protects patient autonomy and patients' interests in determining the

253. For example, the *Wanglie* and *Baby K* cases both involved unsuccessful transfer attempts prior to the ultimate judicial resolutions. See *supra* notes 77-92, 98-108 and accompanying text (discussing these cases).

254. See *Murphy*, *supra* note 201, at 484 (noting that unavailability of transferee demonstrates consensus that confirms original determination of futility) (quoting MARGOT L. WHITE, VIRGINIA'S HEALTH CARE DECISIONS ACT OF 1992, at 3 (1992) (on file at *The Journal of Contemporary Health Law and Policy*)).

255. The *Cruzan* Court noted that many courts require a clear and convincing evidence standard in cases determining whether to withdraw artificial nutrition and hydration from persons in persistent vegetative states. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 284 (1990) (noting other courts' use of clear and convincing standard in substituted judgment situations).

256. See *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985) (describing pure-objective test). The *Conroy* court noted:

In the absence of trustworthy evidence . . . that the patient would have declined the treatment, life-sustaining treatment may still be withheld or withdrawn . . . [if] the net burdens of the patient's life with the treatment . . . clearly and markedly outweigh the benefits that the patient derives from life. Further, the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane.

*Id.*

257. See *In re Baby K*, 832 F. Supp. 1022, 1031 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994) (providing that "[a]t the very least, the Hospital must establish by clear and convincing evidence that Ms. H's treatment decision should not be respected because it would constitute abuse or neglect of Baby K").

benefits of treatments for themselves, rather than having physicians determine those benefits for their patients. This would represent the recognition of a limited qualitative concept of futility.<sup>258</sup>

The refusal of all practically available alternative treatment providers to provide requested treatment could serve as evidence that the requested treatment lies far outside of any standard of care. Courts should closely scrutinize this "consensus," expressed through the absence of a willing transferee facility, that treatment is futile because such absence could result from economic concerns or other concerns unrelated to the medical futility of the requested treatment. However, the Rehabilitation Act, the Americans with Disabilities Act, and EMTALA may still prevent a court from upholding a physician's determination of futility. Thus, to allow for the strictly limited authority to declare life-sustaining treatment futile under these circumstances, Congress should amend the conflicting federal statutes to allow for the futility determination.

Finally, society must confront the social problems surrounding the futility debate. Physicians, patients, and policymakers must discuss the goals and purposes of medicine in our society, or managed care plans will make these important decisions unilaterally.<sup>259</sup> Members of society will necessarily confront questions concerning the meaning that we attach to life, particularly "profoundly diminished life."<sup>260</sup> Society must also discuss the economic questions that futility presents concerning payment for costly treatments at the extremes of life, the equitable allocation of scarce health care resources, and the benefits to society of providing and paying for such treatments.<sup>261</sup>

## VI. Conclusion

The time has come for the law to address the question of medical futility and whether a physician can refuse to provide life-sustaining treatment that the physician deems medically inappropriate or futile despite the patient's request that the treatment continue. Respect for the ethical integrity of the medical profession requires some recognition of futility. A recognition that patient

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258. See *supra* notes 169-87 (discussing qualitative futility).

259. See Michael Lasalandra, *Experts Predict Future Docs Will Have Final Say on Dying*, BOSTON HERALD, Apr. 4, 1995, at 17 (commenting on Gilgunn case, described *supra* note 15, and reporting opinion of medical ethics experts that society will not discuss limits of health care, leaving individual managed care plans to develop protocols and to make decisions concerning treatment at end of life).

260. The term is borrowed from Morreim, *supra* note 8.

261. See generally Callahan, *supra* note 26 (noting that economic scarcity requires setting some limits on patient's ability to define care given).

autonomy creates a negative right to refuse treatment instead of a positive right to demand treatment allows some room for physicians to determine that certain care is futile. Yet patient autonomy, a respect for life, and a concern for "erring on the side of life" require limits to a physician's authority to declare treatment futile. Allowing for a transfer option when patients and physicians disagree about the utility or futility of treatment is an important first step in respecting both patient autonomy and physician ethical integrity. The next step is for courts to recognize, on a case-by-case basis, a physician's authority to declare treatment futile when clear evidence supports the consensus determination of all available physicians that the treatment is futile, and for society to begin discussing the broader effects of the futility debate.

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