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## Medical Disputes and Conflicting Values: Is There a “Right to Die” Later?

Janet L. Dolgin

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# Medical Disputes and Conflicting Values: Is There a “Right to Die” Later?

*Janet L. Dolgin\**

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## INTRODUCTION

Some medical disputes are less amenable to resolution than others. Sometimes efforts to resolve certain types of health care conflicts reflect confusion or disagreement within society, medicine, and law about underlying values. And sometimes, two or more values at stake in a medical dispute conflict with each other. In that situation, validating one set of values may preclude validating another. Medical disputes about so-called "futile" care reflect this pattern. The phrase "futility disputes" is used in this Article to refer to disputes in which clinicians identify care being provided to a patient as "futile"<sup>1</sup> and, accordingly, seek the termination of life-sustaining care even though the patient or his or her surrogate decision maker seeks the continuation of that care. These cases present a conflict between respect for autonomous individuality and concern to shape the process of dying so that it is not unduly burdensome for patients and their clinicians. The first value—respect for autonomous individuality—is foundational in contemporary bioethics.<sup>2</sup> The second, an aspect of physician beneficence, has become increasingly important in the last several decades, even sometimes at the expense of patient autonomy.<sup>3</sup>

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1. Sometimes other terms are used in place of "futile." Clinicians may, for instance, refer to "inappropriate," "unwarranted," or "ineffective" care. See *infra* note 9 and accompanying text.

2. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 101-49 (7th ed. 2013).

3. Debbie Moore-Black, *Go Quiet into the Night*, KEVINMD (Jan. 2, 2019), <https://www.kevinmd.com/blog/2019/01/go-quiet-into-the-night.html>. It is reflected in public fora in efforts to legalize physician-assisted suicide. The U.S. Supreme Court declined to identify a constitutional right to physician-assisted suicide. *Washington v. Glucksberg*, 521 U.S. 702, 720-25, 728 (1997). However, a number of states, including California, Colorado, Oregon, Vermont, Washington, and the District of Columbia, have authorized physician-assisted suicide by statutory law. Paola V. Jaime Saenz, *Morris v. Brandenburg: Departing from Federal Precedent to Declare Physician Assisted Suicide a Fundamental Right Under New Mexico's Constitution*, 48 N.M. L. REV. 233, 234 (2018).

Moral disputes about the continuation of care that a patient's clinicians have deemed futile resemble certain aspects of conflicts at issue in a set of well-known cases, decided in the last decades of the twentieth century, in which patients or their surrogates asked to have life-sustaining care withheld or withdrawn while clinicians sought to continue providing care.<sup>4</sup> Each sort of dispute—those in which patients (or surrogates) have requested the withdrawal of life-sustaining care and those in which clinicians have made that request—has involved questions about end-of-life decision-making. Both sets of disputes have challenged stakeholders' responses to life, death, medicine, and personhood.

However, futility disputes,<sup>5</sup> unlike disputes in which patients or their surrogates have asked to withhold or withdraw life-sustaining care, involve clinicians and hospitals seeking to override the preferences of patients and their surrogate decision makers who favor the continuation of life-sustaining care. In short, medical-futility disputes differ from disputes in which patients have sought a so-called "right to die" insofar as futility disputes preclude privileging both patient autonomy and the avoidance of lingering deaths viewed as burdensome to patients and morally distressing to other stakeholders. The right-to-die<sup>6</sup> cases of the late twentieth century recognized a patient's right to make his or her own medical decisions even if those decisions would result in death.<sup>7</sup> In contrast, medical-futility disputes threaten to undermine respect for patient autonomy—a principle essential to contemporary medical bioethics. As a result, futility disputes often cannot be resolved through reliance on models developed in legal cases that provided

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4. See, e.g., *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261 (1990) (upholding Missouri's clear and convincing evidence standard for surrogates attempting to show that vegetative patient would have wanted care withheld); *In re Quinlan*, 355 A.2d 647 (N.J. 1976) (allowing father of patient in persistent vegetative state to authorize withholding of respiratory support).

5. This Article uses the term "futility dispute" to refer to a situation in which clinicians seek to end life-sustaining treatment against the wishes of the patient (or surrogate).

6. See *Cruzan*, 497 U.S. at 277 ("This is the first case in which we have been squarely presented with the issue as to whether the United States Constitution grants what is in common parlance referred to as a 'right to die.'").

7. *Id.* at 279 ("[W]e assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition.").

for patients (or surrogates) to authorize the withdrawal or withholding of care.<sup>8</sup>

The conflict that sits at the center of medical-futility disputes has rendered those disputes significantly more resistant to successful resolution than disputes in which patients, but not clinicians, seek the termination of life-sustaining treatment. This Article explores legal, moral, and social conundrums at the center of so-called “medical futility disputes.”<sup>9</sup> This Article shows how challenging it has proven for each of three sets of institutional arbiters—legislatures, courts, and hospital ethics consultants—to help with resolving such disputes. That challenge notwithstanding, this Article concludes that everything else being equal, ethics consultations respond to futility disputes more successfully than do statutory rules or court review. That said, there may be a call for court review should an ethics consultation fail to result in agreement and compromise among the stakeholders.

This Article compares the benefits and disadvantages that each institutional approach—that of statutory law, courts, and hospital ethics consultants—brings to medical-futility disputes. This comparison involves cases of the most challenging sort in that each case has been shaped by a basic, intransigent ideological conflict. As a result, that conflict cannot easily be mediated.

Part I of this Article summarizes social and legal responses to conflicts about dying, comparing medical futility disputes with right-to-die cases. Part II describes two conflicting values that are central to contemporary medical ethics. One is the value of autonomous patient choice. The second is the value of beneficent clinical care that places patient welfare at its center. This value is closely linked with the notion of medical integrity.

Part III then describes statutory responses to futility disputes—the first of three institutional responses to such disputes that are reviewed in this Article. Part IV considers judicial responses to futility disputes, suggesting some of the limitations of court review as well as some of the advantages. Part V then reviews the work of a hospital ethics consultation service in resolving futility disputes,

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8. See also *In re Quinlan*, 355 A.2d at 647.

9. Although somewhat difficult to define, the terms “futile” or “futility” most frequently refer to disputes about “inappropriate care” (or other similar phrases). Unless noted expressly, this Article uses the same definition of the word “futile” and its derivative forms.

contending that, at their best, these services balance the interests of diverse stakeholders more adequately than other approaches. At least as an initial response to futility disputes, ethics consultations offer the approach most likely to resolve futility conflicts successfully, without a wake of long-lasting acrimony.

#### I. "NEGOTIATING DEATH"<sup>10</sup>: CONFLICTS ABOUT HOW TO DIE

This Part considers similarities and differences between right-to-die cases and futility cases. In right-to-die cases, courts have invoked the principle of patient autonomy in order to limit the burdens imposed by life-sustaining treatment that was deemed futile.<sup>11</sup> In medical-futility cases, in contrast, clinicians authorize the withholding or withdrawal of life-sustaining treatment. This approach often conflicts with patient autonomy.<sup>12</sup> A clear divide separates these two sets of cases insofar as the centrality of the principle of autonomy in medical ethics in the contemporary United States is not paramount in the resolution of futility cases. Thus, it is not surprising that cases involving patients or families refusing to concur with clinician preferences for terminating treatment deemed futile have often proved less amenable to successful resolution<sup>13</sup> than have right-to-die cases.

The challenge presented by futility cases follows from the effort—almost certain to fail—to serve two sets of values that conflict in medical-futility cases. In these cases, it is often necessary to sacrifice respect for patient autonomy or to quash the conclusion of a patient's physicians that a patient's life-sustaining care should be discontinued for the sake of the patient and that of his or her clinicians (who may undergo moral distress<sup>14</sup> by continuing to provide care deemed futile).

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10. Nancy Dubler, *Limiting Technology in the Process of Negotiating Death*, 1 YALE J. HEALTH POL'Y, L. & ETHICS 297 (2001).

11. See *infra* Section I.A.

12. See *infra* Section I.B.

13. See *infra* Section I.B.

14. Moral distress among clinicians, including frustration and anxiety, can lead to burnout. See, e.g., Subha Perni, *Moral Distress: A Call to Action*, AMA J. ETHICS (June 2017), <https://journalofethics.ama-assn.org/article/moral-distress-call-action/2017-06>.

*A. Patients or Their Surrogates Ask to Terminate Life-Sustaining Care:  
A Right to Die*

During the last decades of the twentieth century, a model emerged for responding to cases in which patients or their surrogates have sought to terminate life-sustaining care. That model has attained widespread, if not unanimous, approval. In 1976, Joseph Quinlan, the father of a young woman in a persistent vegetative state asked New Jersey's highest court for the right to authorize removal of his daughter's respiratory support.<sup>15</sup> Quinlan contended that his daughter, Karen, had a constitutional right to die, a right that could only be exercised by proxy since Karen no longer enjoyed capacity.<sup>16</sup> The trial court denied Quinlan the authority he sought. Justice Hughes, writing for the New Jersey Supreme Court, overturned that decision, even as he noted that each of Karen's doctors and other medical experts who testified in court opposed withdrawing ventilatory support from Karen, viewing that act as a violation of medical standards.<sup>17</sup> Concluding that were Karen capable, she would have asked to have life-sustaining care terminated, Justice Hughes grounded his decision to authorize Karen's father to make that choice for Karen on Karen's privacy right to refuse medical care.<sup>18</sup> The case offered a new perspective on end-of-life decisions for patients without decision-making capacity. Soon, that perspective was being widely followed by courts in New Jersey and elsewhere.<sup>19</sup>

Fourteen years after *Quinlan*, the U.S. Supreme Court assumed the right of a competent patient to refuse medical care, even if that refusal was likely to lead to serious consequences for the patient—even including death.<sup>20</sup> The case involved Nancy Cruzan, a young woman from Missouri, who, like Karen Quinlan, had entered into

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15. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

16. *In re Quinlan*, 348 A.2d 801, 814 (N.J. Super. Ct. Ch. Div. 1975).

17. *In re Quinlan*, 355 A.2d at 655. A more complete description of this case can be found at Janet L. Dolgin, *Dying Discourse: Contextualizing Advance Care Planning*, 34 QUINNIPIAC L. REV. 235, 254–59 (2016).

18. *In re Quinlan*, 355 A.2d at 664, 671.

19. See, e.g., *In re Conroy*, 457 A.2d 1232, 1237 (N.J. Super. Ct. Ch. Div. 1983) (permitting guardian of patient to "cause the removal of the nasogastric tube"); *In re Christopher I.*, 131 Cal. Rptr. 2d 122, 139 (Ct. App. 2003) (citing *In re Quinlan*, 355 A.2d at 665–66 for position that a court may order withdrawal of life-sustaining care to patient); *Newmark v. Williams/DCPS*, 588 A.2d 1108, 1117–18 (Del. 1990).

20. *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261, 279 (1990).

a vegetative state. Nancy's condition resulted from an automobile accident.<sup>21</sup> Her parents requested that their daughter's clinicians withdraw life-sustaining treatment. The case confirmed the proposition that the right of a patient to decision-making autonomy extended to decisions that were likely to end the patient's life.<sup>22</sup> *Cruzan* suggests significant respect for patient autonomy even though the Court sided with the state of Missouri, which had imposed a "clear and convincing" evidence standard on surrogate decision makers seeking to have life-sustaining care withdrawn.<sup>23</sup>

The Uniform Health Care Decisions Act (UHCDA), adopted a few years after the Supreme Court's decision in *Cruzan* by the National Conference of Commissioners on Uniform State Law, offers a flexible approach to end-of-life decision-making by patients' surrogates.<sup>24</sup> Professor Lois Shepherd, a legal scholar and medical ethicist, described the UHCDA as a model for flexibility in surrogate decision-making.<sup>25</sup> The Act gives surrogates broad authority to make health care decisions for patients. By the start of the present century, every state had promulgated laws providing for advance care planning.<sup>26</sup> These laws vary from state to state. In general, they provide for appointment of a surrogate decision maker, should the principal lose capacity, and for pre-incompetency delineation of preferences for medical care.<sup>27</sup> These laws are predicated on a presumed right of competent people to make their own health care decisions and to enjoy that right through proxy should they become incompetent and need medical care.

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21. *Id.* at 266.

22. *See id.* at 279 (assuming right of patient to refuse food and water).

23. *Id.* at 265. The decision allows, but does not require, a high evidentiary standard in such cases. After the Court's decision, new evidence brought to court in Missouri about Nancy's pre-incompetency preferences regarding end-of-life care convinced a Missouri court that the "clear and convincing evidence" standard had been met. Nancy Cruzan died in 1990 following withdrawal of her feeding tube. Tamar Lewin, *Nancy Cruzan Dies, Outlived by a Debate Over the Right to Die*, N.Y. TIMES (Dec. 27, 1990), <http://www.nytimes.com/1990/12/27/us/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html>.

24. UNIF. HEALTH CARE DECISIONS ACT, 9 U.L.A. 83 (1993) [hereinafter UHCDA]. The Act is discussed in greater detail *infra* Section III.A.

25. Lois Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1694, 1723 (2014).

26. *See* Normal Cantor, *Twenty-five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J.L. MED. & ETHICS 182, 189 (2001).

27. *See id.*



*B. When Clinicians' Recommendations to Terminate Life-Sustaining Care Conflict with Patients' or Surrogates' Preferences: Development of the Notion of Medical Futility*

The second set of cases of concern to this Article—those in which clinicians seek to terminate medical care while patients or their surrogates seek to have the care in question continued—conflict with the presumption that patients have the right to make health care decisions for themselves. This set of cases is grounded on the notion that clinicians' recommendations to discontinue care deemed inappropriate should trump patient autonomy. The issue at stake in these cases—sometimes referred to as futility disputes<sup>28</sup>—resembles that at stake in the cases considered in Section A. However, the decision maker seeking withdrawal of care is now the clinician, not the patient. Even more, these cases confront clinicians recommending the withdrawal (or withholding) of care with the contrary choices of patients or their surrogates to continue life-sustaining care.<sup>29</sup> This Section reviews the history of the notion of “brain death” and suggests its relevance to medical-futility disputes.

In the mid-1970s, the trial court judge in *Quinlan* reported that the experts who testified against assenting to Joseph Quinlan's request to withdraw ventilatory support from his daughter, Karen, saw termination of such support as “homicide and an act

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28. Thaddeus Pope has attributed “three distinctive features” to medical futility disputes. Thaddeus Mason Pope, *Procedural Due Process and Intramural Hospital Dispute Resolution Mechanisms: The Texas Advance Directives Act*, 10 ST. LOUIS J. HEALTH L. & POL'Y 93, 102 (2016) [hereinafter Pope, *Procedural Due Process*]. First, these disputes focus on the continuation or withdrawal of life-sustaining care (care without which a patient is likely to die). *Id.* at 97-98. Examples of such care may include assisted nutrition and hydration, ventilatory assistance, hemodialysis, and pressor support. *Id.* at 98. Second, the patient in these cases generally does not have the capacity to make his or her own medical decisions. *Id.* And third, typically, the primary disputing parties are the patient's attending physician and his or her surrogate decision maker. *Id.* Use of the term “futility” to describe the justification for discontinuing treatment has increasingly been replaced with alternative terms such as “non-beneficent care” or “inappropriate care.” *Id.* For ease of reference, this Article mostly continues to refer to “futility” disputes.

29. Patients at the center of futility disputes are generally not able to make their own medical decisions. Pope, *Procedural Due Process*, *supra* note 28, at 102. Thus, this Article will almost always refer both to patients and their surrogates rather than to patients alone. That usefully assumes (pursuant to contemporary law and ethics) that a surrogate's medical decisions for a patient reflect the patient's autonomy.

of euthanasia."<sup>30</sup> The court reported that virtually all of Karen's clinicians and those who testified at trial agreed that withdrawing respiratory support from Karen would conflict with "medical practices, standards, and traditions."<sup>31</sup> Yet, rapidly, in the decades immediately following the New Jersey court's decision in *Quinlan*, medical opinion shifted dramatically.<sup>32</sup>

The roots of that change began to grow in the decade before the *Quinlan* decision. At that time, Harvard Medical School created an ad hoc committee to "examine the definition of death."<sup>33</sup>

The committee's report defined "irreversible coma as a new criterion for death" for patients with "no discernible central nervous system activity."<sup>34</sup> The committee was responding to the development of life-sustaining treatments that could sustain heartbeat and oxygenation in patients with "irreversibly damaged" brains. It expressly hoped that its report would facilitate more easily obtaining oxygenated organs for transplantation.<sup>35</sup>

This new definition of death encouraged elaboration of the notion of medical futility. If a patient is dead, then it is hard to argue with the claim that continuing care is futile.<sup>36</sup> Setting the stage for

30. *In re Quinlan*, 348 A.2d 801, 814 (N.J. Super. Ct. Ch. Div. 1975).

31. *In re Quinlan*, 355 A.2d 647, 655 (N.J. 1976); see also Dolgin, *supra* note 17, at 257.

32. The notion of medical futility began to appear with some frequency in medical literature in the mid-1980s. Paul R. Helft, Mark Siegler & John Lantos, *Sounding Board: The Rise and Fall of the Futility Movement*, 343 NEW ENG. J. MED. 293, 293 (2000).

33. *A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 J. AM. MED. ASS'N 337 (1968) [hereinafter *Report of the Ad Hoc Committee*].

34. *Id.* at 337 (italics omitted).

35. *Id.*

36. In New York and New Jersey, the notion of brain death described here is optional in the case of patients who would have had religious objections to defining death on the basis of neurological criteria alone. See JANET L. DOLGIN & LOIS SHEPHERD, *BIOETHICS AND THE LAW* 516-17 (3d ed. 2013). Most states have adopted the formulation in the Uniform Determination of Death Act. It 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." UNIF. DETERMINATION OF DEATH ACT § 1 (UNIF. LAW COMM'N 1980). New York law allows clinicians to determine death if an "individual . . . 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." N.Y. COMP. CODES R. & REGS. tit. 10, § 400.16 (2018). New York's law further provides that New York state hospitals should create a "written policy," which, among other things, describes "a procedure for the reasonable accommodation of the

claims of medical futility seems to have been an unintentional, though not surprising, consequence of the Harvard committee's report on brain death.<sup>37</sup> This should not be read to suggest that the notion of medical futility is isomorphic with that of brain death. It is not. However, both notions suggest that in relevant—presumptively hopeless—cases, continuing treatment is inappropriate (“futile”). As with the movement within medicine to define brain death as legal death, so advocates of the movement within medicine to define continuing care as futile proposed early in the movement's development that physicians should be granted authority to withhold or withdraw treatment deemed futile, even over the objection of patients or their surrogates.<sup>38</sup> That is to say, patients were to be given little or no room to decide such matters for themselves. This followed the model of the Harvard brain death committee's Ad Hoc Report, which had allocated the task of declaring brain death to the “physician-in-charge” on the ground that “[i]t is unsound and undesirable to force the family to make the decision.”<sup>39</sup> This power, though largely granted to physicians in the context of brain death determinations, has been met with more resistance in the context of treatments deemed futile,<sup>40</sup> though state laws, mostly promulgated in the 1990s, have confronted that resistance with significant success.<sup>41</sup>

While it has been thought that brain death can be adequately defined and identified on the basis of medical criteria,<sup>42</sup> the same cannot be said for futility determinations. Even characterizations of

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individual's religious or moral objection to the determination as expressed by the individual, or by the next of kin or other person closest to the individual.” *Id.* at (e)(3).

37. The Report referred to and quoted an address offered by Pope Pius XII nine years earlier in which he had declared that doctors should use “reasonable, ordinary means” to restore “vital functions and consciousness” to patients but that “a time comes when resuscitative efforts should be withdrawn, and death unopposed.” *Report of the Ad Hoc Committee*, *supra* note 33, at 340 (paraphrasing Pope Pius XII in *The Prolongation of Life*, 4 POPE SPEAKS 393 (1958)). Although this assertion was not about brain death, as a general matter, it suggests flexibility with regard to end-of-life treatment.

38. Helft et al., *supra* note 32, at 293.

39. *Report of the Ad Hoc Committee*, *supra* note 33, at 338.

40. Helft et al., *supra* note 32, at 293 (noting that “[f]utile care in hospitals is still very much an issue”).

41. *See infra* Part III.

42. *See, e.g.*, G. Bryan Young, *Diagnosis of Brain Death*, UPTODATE, <https://www.uptodate.com/contents/diagnosis-of-brain-death/print> (last updated Mar. 8, 2018) (“Brain death implies the permanent absence of cerebral and brainstem functions.”).

treatment as medically "futile" can usually be debated. Identifying life-sustaining treatment as "futile" does not generally mean that the treatment is not, in fact, sustaining the patient's life or goals for care but that the patient is terminally ill or permanently vegetative and is very unlikely to improve. Such characterizations of life-sustaining care as futile in particular cases have not always been grounded on an accompanying presumption that the care in question is not serving to sustain life. Care deemed inappropriate may or may not be necessary to the support of continued cardio-respiratory functions.

A further parallel between the 1968 delineation of brain death and the notion of futility treatment lurks in the Harvard committee's transparency about its definition of death resulting in a wider supply of organs for patients whose lives depend on organ transplantation.<sup>43</sup> A rationing goal has also informed some discussion of futility determinations, though generally that goal has remained tacit. Robert Truog, writing of the case of a desperately ill toddler on life support, acknowledged that health care resources are limited, and doctors may carry an "obligation to ensure that it is distributed fairly."<sup>44</sup> Yet, Truog concluded that futility cases were not a good "target for cost cutting" because too few cases actually meet the criteria for medical futility to result in noteworthy societal savings, and most patients whose care might be deemed futile die quickly even if provided with treatment, generally precluding huge expenditures on treatment for them.<sup>45</sup>

Finally, those declared brain dead and most, though not all, patients whose treatments are identified as futile are without capacity to make their own medical decisions. Thus, decision-making in these cases generally falls to surrogates, appointed by the patients while they were competent or appointed pursuant to state law if the patient, while competent, did not nominate a surrogate or the surrogate appointed is not available or not willing to serve. In cases with surrogate decision makers, the patient's autonomy is putatively preserved through resort to a surrogate whose decisions, most felicitously, reflect those that the patient would make if she or her were competent. Moreover, patients for

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43. *Report of the Ad Hoc Committee, supra* note 33, at 337.

44. Robert D. Truog, *Tackling Medical Futility in Texas*, 357 *NEW ENG. J. MED.* 1, 2 (2007).

45. *Id.*

whom continuing care is deemed futile are sometimes capable. In practice, clinicians' contravening the patient's own preferences may seem less acceptable because it is more openly dismissive of patient autonomy than clinicians' contravening the wishes of a surrogate.

### C. Physician-Assisted Suicide

The shift in clinician responses to end-of-life care in the decades following *In re Quinlan*<sup>46</sup> reflects a more widespread social pattern. Increasingly, society and law accepted – and often applauded – the notion that death is preferable to life for terminal patients facing indignities and pain. That acceptance is reflected in the passage of state laws that facilitate physician-assisted suicide. Physician-assisted suicide (or “physician aid-in-dying,” a phrase that some prefer) is now legal in nine states (California, Colorado, Hawaii, Maine, Montana, New Jersey, Oregon, Vermont, and Washington) and in the District of Columbia.<sup>47</sup>

The increasing acceptance of withdrawing end-of-life care reflects the broader pattern that has resulted as well in states' providing for physician-assisted suicide (aid-in-dying).<sup>48</sup> There is, however, an important distinction between futility determinations that defy patient preferences and physician assistance with requests by terminally ill patients to have increased control over their own deaths, including even to end their lives. The statutes that delineate terms for receiving lethal medication from a physician require the patient, himself or herself, to ingest the medication that will result in death. That is to say, these laws allow physician-assisted suicide only for patients capable of autonomous decision-making both at the time that the medication is requested and at the time that it is ingested.

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46. *In re Quinlan*, 355 A.2d 647 (N.J. 1976); see also *supra* notes 22–31 and accompanying text.

47. *States with Legal Physician-Assisted Suicide*, PROCON.ORG, <https://euthanasia.procon.org/view.resource.php?resourceID=000132> (last updated July 25, 2019); *Death with Dignity: Maine*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/states/maine/> (last visited Feb. 7, 2020); *Death with Dignity: New Jersey*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/states/new-jersey/> (last visited Feb. 7, 2020).

48. PROCON.ORG, *supra* note 47.

The Oregon statute, the first of its kind, provided a model for other states.<sup>49</sup> Only a capable adult “who has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life.”<sup>50</sup> The statute specifically precludes use of a “lethal injection, mercy killing or active euthanasia” by a physician or anyone else to end a patient’s life.<sup>51</sup> Only the patient is permitted to initiate the request for medication that, if ingested, will result in his or her death and actually to ingest that medication.

In short, state laws providing for physician-assisted suicide harmonize with the perspective that prolonging life is not necessarily the best or most moral avenue for some patients. However, these laws, following the model constructed in Oregon, do not undermine patient autonomy. In that regard, cases involving physician-assisted suicide in the jurisdictions in which it has been legalized differ from medical-futility cases—cases in which clinicians seek to terminate life-sustaining treatment in the face of conflicting patient or surrogate preferences. Unlike the withdrawal of care from a patient who has refused to consent to that withdrawal, physician-assisted suicide responds to patients’ requests for help dying and does not undermine respect for autonomy.

## II. THE VALUES AT STAKE

Respect for patient autonomy has become a foundational value in contemporary medical ethics.<sup>52</sup> However, that value may conflict with a second foundational value—the clinician’s ethical obligation to provide beneficent care.<sup>53</sup> This conflict has become a virtual leitmotiv of futility disputes.

Moreover, in practice, patients—especially those reaching the end of life—are not always capable of making their own medical

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49. Oregon Death with Dignity Act, OR. REV. STAT. § 127.800 (2018).

50. *Id.* § 127.805(2.01)(1). Section 2.01(2) precludes anyone to qualify “under the provisions of [the act] solely because of age or disability.” *Id.*

51. *Id.* § 127.880(3.14).

52. See BEAUCHAMP & CHILDRESS, *supra* note 2, at 101–49.

53. *Id.* at 202–48.

decisions. In response to this, law and medical ethics presume that surrogates (often family members) substitute for patients, and that their decisions are equivalent to the autonomous decisions the patient would have made had the patient been capable. That presumption substitutes a fragile subjunctive—e.g., “the decision that the patient *would* have made”—for patient autonomy.

Clinicians’ efforts to withhold or withdraw care from patients in cases in which the patient or his or her surrogate prefers that care be continued undermine respect for patient autonomy. The advent and development of “respect for autonomy” as a foundational principle in American bioethics reflects a more widespread social transformation within health care that brought individualist values into the realm of medical care and the physician-patient relationship in the last half of the twentieth century. In 1979, Tom Beauchamp and James Childress’s first edition of *Principles of Biomedical Ethics* delineated four basic principles in medical ethics.<sup>54</sup> Autonomy was the first on the list. The authors expressly presumed that “the everyday choices of generally competent persons are autonomous.”<sup>55</sup> They understood autonomous action as predicated on intention, understanding, and a context of non-compulsion.<sup>56</sup>

The Belmont Report, drafted as a response to unethical human subject research, describes informed consent as the primary method of implementing autonomy (categorized as part of a necessary “respect for persons”) in human subject research.<sup>57</sup> Within health care settings, respect for autonomy is primarily implemented through a patient’s granting informed consent to the provision of medical care before care is provided. Indeed, patient consent, grounded on the communication of information necessary for the patient to make a reasonable medical choice, has become one of the central tenets of medical ethics in the clinical setting. The Christian theologian, Paul Ramsey, credited as the parent of

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54. *Id.* at 13 (referring to “four clusters of moral principles: (1) respect for autonomy . . . , (2) nonmaleficence . . . , (3) beneficence . . . , and (4) justice.”)

55. *Id.* at 104.

56. Tom Beauchamp and James Childress defined “non-compulsion” (which they refer to as “noncontrol”) in terms of an individual being “free of controls exerted either by external sources or by internal states that rob the person of self-directedness.” *Id.*

57. U.S. NAT’L COMM’N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (Apr. 18, 1979), <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>.

American bioethics, placed informed consent "at the heart of medical care as a joint adventure between a patient and a doctor."<sup>58</sup> Ramsey, in contrast with many contemporary medical ethicists, focused on consent, not autonomy.

In the context of clinical medicine, the principle asserting the importance of respect for patient autonomy privileges the choices of capable patients (or the surrogates of patients without capacity) above other choices. The principle, as it operates in health care, does not presume that choices that are operationalized because they are the choices of autonomous patients are substantively more moral than choices foregone by patients. Respect for individual autonomy is paramount, not the content of the individual's choices. The significance paid to individual autonomy has been consonant with the increasingly individualistic focus of American society, a focus that has supported widespread commitment to safeguarding untrammelled choice.

A surrogate's decisions are generally accepted, in theory, if not always in fact, as if they are presented as reflections of the patient's pre-incompetency choices.<sup>59</sup> Yet, the need for surrogate decision makers with authority to make medical decisions for patients who no longer enjoy the capacity to make their own decisions complicates the presumption that medical choices reflect a patient's autonomous preferences. Among the standards proposed for surrogates, two—"pure autonomy" and "substituted judgement"—reflect the presumption that the surrogate stands in for the incompetent patient, making decisions that the patient would make were he or she competent.<sup>60</sup>

Under a "pure autonomy" standard, the surrogate relies on oral or written statements made by the patients before he or she became incompetent. Advance directives were designed with the expectation that they would ensure that patients'

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58. Toni C. Saad, *The History of Autonomy in Medicine from Antiquity to Principlism*, 21 *MED. HEALTH CARE & PHIL.* 125, 132-33 (2018), <https://link.springer.com/article/10.1007%2Fs11019-017-9781-2>.

59. State laws may impose some limitations on the right of a surrogate to authorize care or the withholding or withdrawal of life-sustaining care. See *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261 (1990).

60. BEAUCHAMP & CHILDRESS, *supra* note 2, at 226 (suggesting that "substituted judgement" may be "presented as an autonomy-based standard"). The other standard is "the patient's best interests;" it can be applied in situations in which it is virtually impossible to discern what the patient would have wanted. *Id.* at 227.



pre-incompetency preferences would be implemented.<sup>61</sup> The expectation that the laws providing for advance directives would protect autonomy even for patients without capacity has not been widely actualized, mostly because the majority of healthy, non-elderly adults do not complete advance directives.<sup>62</sup>

In contrast, the “substituted judgement” standard, less clearly reflective of patient autonomy, can be invoked whether or not the patient signed an advance directive. It asks the surrogate “to make the decision the incompetent person would have made if competent.”<sup>63</sup> By equating autonomy in its “pure” form with autonomy in its more diluted form (“substituted judgement”), surrogates are presumed to safeguard the autonomy of patients whose incompetency precludes their making their own medical decisions and who had not previously delineated their preferences regarding various sorts of medical care or the absence of such care.

Society and the law have more easily developed paradigms and guidelines for resolving disputes about end-of-life care when the request to terminate care comes from patients than when it comes from clinicians. Society, at least in the United States, deems it less discomfiting to sanction the withdrawal or withholding of life-sustaining care in cases in which patients or their surrogates seek those ends than in cases in which patients or their surrogates choose to continue life-sustaining care despite the patients’ clinicians suggesting that care be withheld or withdrawn.

Beneficent clinicians are expected to serve their patients, effecting their best interests and protecting their welfare.<sup>64</sup> Often the principle is understood in the context of competing institutional concerns, including, for instance, the costs of medical care.<sup>65</sup> However, clinician beneficence—the clinician’s sense of a patient’s best interests—may conflict with patient autonomy—the patient’s divergent sense of his or her own best interests. This conflict sits

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61. Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211, 218 (2010).

62. *Id.* at 221.

63. BEAUCHAMP & CHILDRESS, *supra* note 2, at 227.

64. Josué A. Zapata & Christopher Moriates, Case and Commentary, *The High-Value Care Considerations of Inpatient Versus Outpatient Testing*, 11 AM. MED. ASS’N J. ETHICS 1022, 1023 (2015), <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/ecas1-1511.pdf>.

65. *Id.*

behind many ethical disputes between patients, their family members, and clinicians.

Clinicians, unable to implement what they view to be beneficent care, may experience a challenge to their medical integrity and may experience moral distress. This reflects the clinicians' conclusion that they are being prevented from providing the best care for patients. The importance of protecting clinician integrity has been linked directly to futility disputes. The Council on Ethical and Judicial Affairs of the American Medical Association, as well as other medical groups in the United States and abroad, has favored the right of clinicians unilaterally to withdraw or withhold life-sustaining treatment deemed ineffective (sometimes referred to as inappropriate or futile).<sup>66</sup> Until the middle of the twentieth-century, medicine in the United States was proudly paternalistic. It was assumed that "doctor knows best."<sup>67</sup> While that perspective has largely dissipated, the notion of professional "integrity" has preserved some elements of nineteenth- and early twentieth-century medical paternalism.<sup>68</sup> Law professor Thaddeus Pope has suggested that "[t]he 'integrity of the medical profession' is an important societal interest that must be balanced against patient autonomy."<sup>69</sup> Physicians rely on that notion to justify attempts to implement the withholding or

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66. AM. MED. ASS'N, COUNCIL ON ETHICAL & JUDICIAL AFFAIRS, CODE OF MEDICAL ETHICS § 2.035 ("Futile Care") (1994) (providing that "[p]hysicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them"); *id.* § 2.037 ("Medical Futility in End-of-Life Care") (providing that "[w]hen further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure"); *see also* Am. Thoracic Soc., *Withholding and Withdrawing Life-Sustaining Therapy*, 144 AM. REV. RESPIRATORY DISEASE 726, 728 (1991); *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy*, NHS SCOT., [http://www.sad.scot.nhs.uk/media/16026/409019\\_dnacpr-p5.pdf](http://www.sad.scot.nhs.uk/media/16026/409019_dnacpr-p5.pdf) (precluding capable patient from "[d]emand[ing] CPR [cardio-pulmonary resuscitation] if it is clinically judged that it would not be medially successful in achieving sustainable life for that patient") (last visited Feb. 20, 2020).

67. A.M. Stiggelbout, A.C. Molewijk, W. Otten, D.R.M. Timmermans, J.H. van Bockel & J. Kievit, *Ideals of Patient Autonomy in Clinical Decision Making*, 30 J. MED. ETHICS 268, 271 (2004), <https://jme.bmj.com/content/30/3/268>, (referring to the "'doctor knows best' factor").

68. Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 15 (2007) [hereinafter Pope, *No Safe Harbor*].

69. *Id.*

withdrawal of life-sustaining treatment (in light of a conclusion that such treatment can be “bad medicine” in relevant cases) even though the patient or the patient’s surrogate has refused to consent to the termination of treatment.<sup>70</sup>

The importance of safeguarding both clinician integrity and patient autonomy suggests a difficult challenge—to identify an appropriate balance between each set of concerns and interests. That can be difficult, and in practice, achieving a satisfactory balance is likely to depend on the context surrounding, and interests at stake in, particular cases. In undertaking this task, hospital ethicists must attend to the nuances of each approach in constructing a response to divergent concerns and interests underlying disputes between patients and clinicians.

### III. STATUTORY RESPONSES TO MEDICAL-FUTILITY DISPUTES

Beginning in the early 1990s,<sup>71</sup> states widely promulgated laws aimed at responding to futility disputes. Physicians supported this development. However, the results have proven generally wanting. Many of the resulting laws have been “vague and imprecise”<sup>72</sup> and have not defined clear safe harbors for clinicians. Doctors have thus often declined to rely on state-crafted medical-futility laws for fear of suit should they authorize the termination of life-sustaining care for patients whose surrogates ask that the care in question be continued.<sup>73</sup> In contrast with the majority of state laws, one state law promulgated in Texas offers wide protection to physicians who unilaterally discontinue life-sustaining treatment even in cases in which the patient or the patient’s surrogate seeks the continuation of treatment. The price, particularly for patients and their families, for the protection that the Texas law offers to clinicians, however, is steep. The law can be

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70. *Id.* at 16. Pope suggests three additional explanations of physicians’ support for unilateral decisions to withhold or withdraw life-sustaining care. Providers may conclude that continuing care is burdensome to a patient and should thus be ended. *Id.* at 17. They may view the continuation of treatment for patients deemed terminal as an assertion of false hope. *Id.* And, finally, physicians may equate the continuation of care deemed futile with the inappropriate use of scarce resources. *Id.* at 18. Pope notes that “[p]roviders want to be good ‘steward[s]’ of both ‘hard’ resources like ICU beds and ‘soft’ resources like health care dollars.” *Id.* (internal citations omitted).

71. *Id.* at 3.

72. *Id.* at 1.

73. *Id.*

viewed as an outgrowth of the virtually irreconcilable conflict between respect for patient autonomy and clinician beneficence.<sup>74</sup> The Texas law represents an extreme response to futility disputes. It poses patient autonomy against clinicians’ concerns about the continuation of life-sustaining care deemed burdensome and inappropriate and largely displaces the value of patient autonomy with that of clinician beneficence.

Section A of this Part briefly reviews the impetus to provide by law for doctors unilaterally to withhold or withdraw life-sustaining treatment. It also describes the majority of state laws that grant physicians this control. Section B then analyzes the implications and consequences of the medical-futility law promulgated in Texas.

#### *A. The Development of Laws Providing for Implementation of Physicians’ Medical-Futility Determinations*

In 1993, the National Conference of Commissioners on Uniform State Laws approved the Uniform Health-Care Decisions Act (UHCDA).<sup>75</sup> The Act provides a model statute for states defining and regulating medical decision-making for patients, including incompetent patients. Some states have relied on the UHCDA as a model for state legislation.<sup>76</sup> The UHCDA delineates rules that provide for the creation and revocation of advance directives as well as rules regarding the selection and obligations of surrogate decision makers for patients without capacity, including those who

74. At the start of the twenty-first century, Nancy Dubler characterized death in the contemporary United States as a “negotiated event.” Dubler, *supra* note 10, at 297. For the majority of people, death occurs when those with control decide to discontinue life-sustaining care. *Id.*

75. UHCDA, *supra* note 24; see *supra* notes 23–26 and accompanying text.

76. See UHCDA, *supra* note 24; see also Megan S. Wright, *End of Life and Autonomy: The Case for Relational Nudges in End-of-life Decision-Making Law and Policy*, 77 MD. L. REV. 1062, 1074 (2018); David M. English, *The Uniform Health-Care Decisions Acts and Its Progress in the States*, 15 PROB. & PROP. 19, 20 (2001) (noting that the UHCDA had been followed in a number of states including, among other states: California, CAL. PROB. CODE §§ 4600–4805 (West 2000); Delaware, DEL. CODE ANN. tit. 16, §§ 2501–17 (2016); Hawaii, HAW. REV. STAT. §§ 327E-1 to -16 (2019); Maine, ME. REV. STAT. ANN. tit. 18-A, §§ 5-801 to -817 (repealed 2019); Mississippi, MISS. CODE ANN. §§ 41-41-201 to -229 (1999); and New Mexico, N.M. STAT. ANN. §§ 24-7A-1 to -18 (2015)). No state has promulgated a statute identical to the model law. Stephen R. Baldassarri, Ike Lee, Stephen R. Latham & Gail D’Onofri, *An Inter-Disciplinary Examination: Debating Medical Utility, Not Futility, Ethical Dilemmas in Treating Critically Ill People Who Use Injection Drugs*, 46 J.L. MED. & ETHICS 241, 244 (2018).

did not finalize an advance directive.<sup>77</sup> The primary goal of the UHCDA has been to support a patient's right to choose to receive or to refuse recommended care.<sup>78</sup> The construction of rules for resolving disputes about futile care has been secondary.

The Act acknowledges the right of a competent individual to decide all aspects of his or her own health care in all circumstances, including the right to decline health care or to direct that health care be discontinued, even if death ensues. An individual's instructions may extend to any and all health-care decisions that might arise and, unless limited by the principal, an agent has authority to make all health-care decisions which the individual could have made. The Act recognizes and validates an individual's authority to define the scope of an instruction or agency as broadly or as narrowly as the individual chooses.<sup>79</sup> Yet, despite the significance the Act gives to patient autonomy, the UHCDA grants clinicians and health care institutions the right to refuse to provide medical care that a patient's clinicians deem "ineffective."<sup>80</sup>

The Act carves out two exceptions to its broad grant of autonomy to patients, either directly or through surrogate decision makers.<sup>81</sup> Both can be found in Section 7 of the UHCDA. Curiously, it might seem, the Section reaffirms its commitment to patient autonomy just before it delineates exceptions to that commitment. It confirms that

[A] health-care provider or institution providing care to a patient shall:

Comply with an individual instruction of the patient and with a reasonable interpretation of that instruction made by a person then authorized to make health-care decisions for the patient; and

Comply with a health-care decision for the patient made by a person then authorized to make health-care decisions for the patient to the same extent as if the decision had been made by the patient while having capacity.<sup>82</sup>

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77. See UHCDA, *supra* note 24.

78. See, e.g., *Uniform Health-Care Decisions Act*, USLEGAL.COM, <https://definitions.uslegal.com/u/uniform-health-care-decisions-act/> (last visited Feb. 20, 2020).

79. See UHCDA, *supra* note 24.

80. *Id.* § 7(f).

81. *Id.* § 7(e)-(f).

82. *Id.* § 7(d)(1)-(2).

Placement of this reaffirmation of the centrality of patient autonomy in the Act's text—just before delineation of two exceptions—may not have been coincidental. By emphasizing the significance of respect for autonomy in most, though not all, situations, the text of the model law suggests that the need for some exceptions is compelling and also that exceptions delineated in the Act should be framed so that, in practice, they will be implemented in a context of responsible, careful deliberation.

The first exception involves "health-care provider[s . . . offering] reasons of conscience" for not complying with a patient's preference.<sup>83</sup> The second—directly relevant to medical-futility disputes—pertains to health care deemed "medically ineffective" or "contrary to generally accepted health-care standards applicable to the health-care provider or institution."<sup>84</sup> The Act does not define "medically ineffective."<sup>85</sup> Defining the phrase could have created additional confusion and encouraged open disagreement.<sup>86</sup> The significance of the inclusion of the phrase "medically ineffective" is unclear.<sup>87</sup> Perhaps it was intended to encourage reasoned physician conclusions not (or not yet) incorporated in the profession's "standard of care."

The UHCDA further provides that if a clinician or institution refuses to comply with a patient or surrogate's preference, that clinician or institution must notify the patient or surrogate, offer care to the patient until he or she can be transferred to another facility, and assist in trying to arrange the patient's transfer to a clinician or institution ready to comply with the patient or surrogate's preferences.<sup>88</sup> The Act provides for the continuation of

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83. *Id.* § 7(e).

84. *Id.* § 7(f). A number of states that permit health care clinicians or institutions to refuse to comply with patients' or patients' surrogates' request for continuing life-sustaining care follow the post-refusal obligations set forth in the UHCDA. *See, e.g.,* MISS. CODE ANN. § 41-41-215(7)(a)-(c) (West 1999).

85. UHCDA, *supra* note 24, § 7(f).

86. Charles P. Sabatino, *The New Uniform Health Care Decisions Act: Paving a Health Care Decisions Superhighway?*, 53 MD. L. REV. 1238, 1251-52 (1994) ("'[M]edically ineffective' . . . is subject to differing and volatile views that trigger debate over larger issues of rationing, resource allocation, and definitions of futile treatment.").

87. *Id.* at 1251.

88. UHCDA, *supra* note 24, § 7(g)(1)-(3). The patient or patient's surrogate has the right, pursuant to the terms of the UHCDA, to "refuse[] assistance" with the patient's transfer. *Id.*

care for the patient until transfer.<sup>89</sup> This suggests that care cannot be terminated if a transfer cannot be arranged.<sup>90</sup> Yet, as Charles Sabatino, a law professor and Director of the ABA Commission on Law and Aging, has noted, a patient may be “vulnerable to noncomplying providers in locales in which transfer to another provider is difficult or impossible.”<sup>91</sup>

Most states now provide for health care professionals and institutions to refuse to comply with health care choices of patients or surrogates if those choices are deemed ineffective, futile, or inappropriate.<sup>92</sup> Few states use the term “futile” in their advance directive laws, instead using terms such as “ineffective or inappropriate care.”<sup>93</sup> About ten states use the term “medically ineffective,” but only four of those states have defined the phrase.<sup>94</sup>

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89. *Id.* § 7(g)(2).

90. See Ashley Bassel, Note, *Order at the End of Life: Establishing a Clear and Fair Mechanism for the Resolution of Futility Disputes*, 63 VAND. L. REV. 491, 504 (2010) (noting apparent conflict in rule requiring continuing care until transfer and rule noting use of “all reasonable effort” to arrange transfer as appropriate response to futility dispute).

91. Sabatino, *supra* note 86, at 1252.

92. See Charles Sabatino, Dir., Am. Bar Ass’n Comm’n on L. & Aging, Address at the University of Maryland: Overview of State “Futility” Laws (Nov. 30, 2010).

93. See N.J. STAT. ANN. § 26:2H-67 (West 2013) (giving patient right to seek withholding or withdrawal of life-sustaining care if a clinician deems it “likely to be ineffective or futile in prolonging life” or to only lengthen “an imminent dying process”); see also IDAHO CODE ANN. § 39-4514(6) (West 2017).

94. For example, Alaska permits health care providers, institutions, and facilities to refuse to provide “medically ineffective” health care. ALASKA STAT. ANN. § 13.52.060(f) (West 2008). The state defines the phrase to mean “care that according to reasonable medical judgment cannot cure the patient’s illness, cannot diminish its progressive course, and cannot effectively alleviate severe discomfort and distress.” *Id.* Additionally, both Delaware and Maryland define “medically ineffective treatment” as “a medical procedure” that will not “prevent or reduce the deterioration of the health of an individual; or prevent the impending death of an individual.” DEL. CODE ANN. tit. 16 § 2501(m) (West 2016); MD. CODE ANN., HEALTH-GEN. § 5-601(o). New Mexico’s law also defines “medically ineffective health care” as “treatment that would not offer the patient any significant benefit, as determined by a health-care practitioner.” N.M. STAT. ANN. § 24-7A-7(F) (West 2015). Virginia relies on the phrase “medically or ethically inappropriate” care. VA. CODE ANN. § 54.1-2990(B) (West 2018). The Virginia law provides that invoking the notion of inappropriate care in determining that a patient’s care should be withdrawn, even in the face of the patient’s contrary preference “shall be based solely on the patient’s medical condition and not on the patient’s age or other demographic status, disability, or diagnosis of persistent vegetative state.” *Id.* Virginia’s law further provides that the article should not “be construed to condone, authorize, or approve mercy killing or euthanasia or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying.” *Id.* § 54.1-2990(D). Such statutory provisions play a role in resolving debate about life-sustaining

Some states' medical-futility laws carve out broad exceptions to the right of patients to have their decisions implemented.<sup>95</sup> Other states allow clinicians to refuse to comply with patient preferences on the grounds of "conscience"<sup>96</sup> or more generally, for moral, ethical, religious or professional reasons.<sup>97</sup> Still other state laws expressly carve out "futile" care as an exception to the requirement that medical care is predicated on patient consent. Such laws permit clinicians to refuse to provide care considered "medically inappropriate or futile" even in cases in which that decision contravenes a patient or surrogate's stated preference.<sup>98</sup>

Yet, in fact, clinicians have generally not relied on these laws unilaterally to terminate life-sustaining care in opposition to the wishes of a patient or surrogate decision maker.<sup>99</sup> That may reflect the absence of clear safe harbors for clinicians anxious to terminate care deemed futile despite the contrary preferences of the patient or surrogate. Although these laws may encourage physicians to initiate conversations with patients and surrogates that may result in compromise (e.g., waiting for a specified period to see if the patient improves), the vast majority of state futility statutes have not provided physicians with a *modus vivendi* for routinely resolving disputes about the continuation of care deemed futile.

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treatment in states that rely on a substantive, rather than a process-based, approach to futility disputes. See Andrew M. Courtwright & Emily Rubin, *Healthcare Provider Limitation of Life-Sustaining Treatment Without Patient or Surrogate Consent*, 45 J.L. MED. & ETHICS 442, 442-51 (2017).

95. Pope, *No Safe Harbor*, *supra* note 68, at 62.

96. CAL. PROB. CODE § 4734 (West 2000).

97. See, e.g., MASS. GEN. LAWS ANN. ch. 201D, § 14 (West 2018); NEB. REV. STAT. § 30-3428 (2019).

98. IDAHO CODE § 39-4514(6). Idaho defines futile care as "a course of treatment," not "comfort care"; it also states further:

- (a) For a patient with a terminal condition for whom, in reasonable medical judgment, death is imminent within hours or at most a few days whether or not the medical treatment is provided and that, in reasonable medical judgment, will not improve the patient's condition; or
- (b) The denial of which in reasonable medical judgment will not result in or hasten the patient's death.

*Id.*

99. Pope, *No Safe Harbor*, *supra* note 68, at 68.



*B. The Texas Advance Directive Act*<sup>100</sup>

The Texas Advance Directive Act (TADA)<sup>101</sup> differs from other states' futility laws. In Texas, lawmakers promulgated rules about responding to futile care that effectively abandon the principle of autonomy. The Texas law permits clinicians<sup>102</sup> to withhold or withdraw care despite a patient or surrogate's explicit refusal to consent to the termination of medical care.

The Texas law provides that an ethics committee should review a physician's decision not to "honor a patient's advance directive or a health care or treatment decision made by or on behalf of a patient."<sup>103</sup> The protections offered to the patient, detailed in TADA section 166.046(b), may appear to mimic due process protections. However, these protections apply at the level of the hospital's review committee and effectively preclude court review of an ethics committee affirmation of a physician's decision to withhold or withdraw life-sustaining treatment in opposition to the preferences of a patient or that patient's surrogate decision maker.<sup>104</sup>

If the ethics committee reaches a decision in conflict with the preferences of the patient or the patient's surrogate, the patient may be transferred if an alternative facility that will accept the patient can be identified.<sup>105</sup> The patient is responsible for the costs of transfer.<sup>106</sup>

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100. Texas Advance Directive Act (TADA), TEX. HEALTH & SAFETY CODE §§ 166.001-166.209 (West 1999).

101. *Id.*

102. TADA can be invoked by patients as well as clinicians. However, it is usually invoked by clinicians. Pope, *Procedural Due Process*, *supra* note 28, at 115.

103. TADA § 166.046(a).

104. *Id.* § 166.046(b). The patient or surrogate "may" be given a description in writing of the committee's process, policies and procedures, *id.* § 166.046(b)(1); they "shall" be told that the review committee will meet "not less than 48 hours before the meeting," *id.* § 166.046(b)(2); and "shall" be offered a copy of various documents related, among other things, to their potential interest in having the patient transferred, *id.* § 166.046(b)(3)(A)-(B). The patient or surrogate is permitted to "attend the meeting" and "receive a written explanation" of the committee's decision, a copy of the patient's medical record and "reasonably available diagnostic results and reports." *Id.* §§ 166.046(b)(4)(C)-(D). The primary stakeholders – including the patient, his or her surrogate, and his or her clinicians – may attempt to transfer the patient. *Id.* § 166.046(e).

105. *Id.* § 166.046(d).

106. *Id.* § 166.046(e).

The section of TADA that provides for transfer limits the period during which life-sustaining treatment is maintained:

The attending physician, any other physician responsible for the care of the patient, and the health care facility are not obligated to provide life-sustaining treatment after the 10th day after both the written decision [of the ethics committee] and the patient’s medical record . . . are provided to the patient or the person responsible for the health care decisions of the patient . . . .<sup>107</sup>

The patient or surrogate can apply to “the appropriate district or county court” to extend the ten-day period before failure to transfer results in cessation of life-sustaining treatment.<sup>108</sup> An extension may be granted if the court finds “that there is a reasonable expectation that a physician or health care facility that will honor the patient’s directive will be found.”<sup>109</sup>

The primary benefit of TADA—at least from the perspective of those interested in precluding the continuation of care deemed futile—is the clear safeguard it offers to clinicians who seek to withhold or withdraw life-sustaining treatment against the wishes of the patient or the patient’s surrogate.<sup>110</sup> It thereby offers relief to clinicians experiencing moral distress at being asked to continue caring for patients whose care they deem inappropriate and ineffective.<sup>111</sup> TADA also limits the time during which intractable disputes about life-sustaining patient care can fester. Once a hospital ethics committee determines that care can be withheld or withdrawn, dissenters have ten days within which to arrange a transfer of the patient or obtain an extension of the time limit in court.<sup>112</sup>

Yet, the law as a whole is concerning.<sup>113</sup> It negates important goals central to contemporary health care and to the legal order, including autonomy and informed consent. It displaces the possibility of hospital ethics consultants resolving such disputes by

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107. *Id.*

108. *Id.* § 166.046(g).

109. *Id.*

110. Pope, *Procedural Due Process*, *supra* note 28, at 106.

111. *Id.*

112. *See supra* note 108–112 and accompanying text.

113. TADA’s significant deficiencies are further discussed in Janet Dolgin, *Re-Making the “Right to Die”: Give Me Liberty but Do Not Give Me Death*, 73 SMU L. REV. 47 (2020).

granting ethics committee decisions the force of law. Even more, with limited exception, the review of a hospital's ethics committee is not appealable in court.<sup>114</sup> That renders the ethical committee decision far more consequential than a comparable lower court decision would be because a court decision can be appealed.

Law Professor Nora O'Callaghan has described TADA's dangers. Among them, TADA protects even "negligent, reckless, and . . . intentionally malicious decisions to withhold LST [life-sustaining treatment]."<sup>115</sup> There is no requirement that a patient subject to TADA's withdrawal-of-care provisions be terminally ill.<sup>116</sup> The transfer option is largely illusory since there is very little chance that an alternative facility will accept a patient once "the treatment team and the ethics committee" have decided that "further treatment is futile."<sup>117</sup> Finally and most disturbing, TADA would seem to "deprive the patient of any other recourse to the courts beyond [the] limited time-extension procedure."<sup>118</sup>

Remarkably, TADA proceeds as if the informed consent doctrine had not been cemented in American law during the previous several decades<sup>119</sup> and as if respect for patient autonomy were not central to medical ethics. Ironically, the larger statute is deferential to the principle of autonomy. The statute handles provisions about futile medical care differently<sup>120</sup> than it handles decisions about other sorts of medical care.<sup>121</sup> In a comprehensive critique of TADA's conflicts and limitations, Nora O'Callaghan suggests that the Texas law "jettisons many fundamental principles

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114. Nora O'Callaghan, *Dying for Due Process: The Unconstitutional Medical Futility Provision of the Texas Advance Directives Act*, 60 BAYLOR L. REV. 527, 545 (2008). A patient or his or her decision maker may seek an extension of the ten-day waiting period. TADA § 166.046(e).

115. O'Callaghan, *supra* note 114, at 539. Section 166.045(d) of the Texas Health and Safety Code offers strikingly broad immunity protection: "A physician, health professional acting under the direction of a physician, or health care facility is not civilly or criminally liable or subject to review or disciplinary action by the person's appropriate licensing board if the person has complied with the procedures outlined in Section 166.046." TADA § 166.045(d).

116. O'Callaghan, *supra* note 114, at 529; see TADA § 166.044.

117. O'Callaghan, *supra* note 114, at 544 (citing Robert L. Fine & Thomas Wm. Mayo, *Letter to the Editor*, 343 NEW ENG. J. MED. 1575 (2000)).

118. *Id.* at 545.

119. See *supra* notes 61–69 and accompanying text.

120. O'Callaghan, *supra* note 114, at 578; see also *supra* notes 59–60.

121. O'Callaghan, *supra* note 114, at 579.

of American due process and medical law and ethics without explanation or justification."<sup>122</sup>

Texas's legislators responded to a difficult – if not intractable – moral conflict by promulgating a law that, in practice, can deprive seriously ill patients (or their surrogates) of virtually all control over their medical care should their physicians, supported by the hospital's ethics committee, deem that care inappropriate. The law, as O'Callaghan asserted, eviscerates "fundamental principles of American due process and medical law and ethics."<sup>123</sup>

TADA has offered broad protection to hospitals and to clinicians who determine that continuing care is futile and who seek to discontinue the care in question. But the cost to patients and their families is high. The potential consequences of TADA's rule for patients and their surrogates are harsh.<sup>124</sup> TADA should be viewed as an experiment that has failed. As the following two Parts show, the responses, respectively, of courts and hospital ethics consultants to futility disputes, though often imperfect, are preferable to a statutory response that eviscerates some of the central values of contemporary medical ethics.

#### IV. RESOLUTION OF FUTILITY CASES BY COURTS

This Part considers judicial responses to futility disputes. Section A considers two futility cases occasioned by disputes between a patient's family members and the patient's clinicians. Section B then considers a futility case that involved intrafamilial disagreements. Each of these court cases matches an ethics case entertained by ethics consultants (analyzed in Part V of this Article). As a result, read in combination with their matching ethics cases, the court cases reviewed in this Part provide a useful framework for comparing court review with that of a hospital's

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122. *Id.* at 582. O'Callaghan further asserts: "Hence, it is not surprising that the .046 provision is fraught with a cascade of policy problems, all related ultimately to the basic denial of the importance of human dignity, accountability, and autonomy." *Id.* at 582-83.

123. *Id.* at 582.

124. See Truog, *supra* note 44, at 1 (noting that TADA gives hospital ethics committees the role of "a surrogate judge and jury, with the statutory power to authorize clinicians to take actions against the wishes of a patient and family").

ethics consultation service.<sup>125</sup> The comparison facilitates assessing the comparative benefits and limitations of each mode of review.

*A. Court Resolution of Futility Disputes Between Patients or Their Surrogates and Clinicians*

The two cases considered in this Section reflect contrasting perspectives about who should bear ultimate responsibility for decisions about continuing care in futility cases. In the first case considered here, a Minnesota court held for a patient's spouse who refused to authorize the withdrawal of life-sustaining care. In the second case, a California court authorized the withdrawal of life-sustaining care, contravening the patient's advance directive as well as her surrogate's medical decision for the patient after she lost capacity. Neither case asked for explicit review of a "futility" determination. Yet, in different ways, each decision speaks to that matter.

The first case, *In re Wanglie*, decided in 1991, was brought by a clinician during the patient's life.<sup>126</sup> The case posed clinicians' best judgements about medical care against family members' preferences. Helga Wanglie's pre-incompetency choices were murky, but her husband and children opposed the withdrawal of life-sustaining care. Helga's husband claimed that Helga would have agreed with him and his children about this. Even though Helga was in a severely compromised physical and mental state, her family did not view life-sustaining care as futile. That care accomplished what they hoped it would accomplish: it kept Helga alive. Helga's physicians, however, saw continuing care as inappropriate, even harmful to their patient, and thus as a violation of their integrity as doctors.<sup>127</sup>

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125. Futility disputes handled by a hospital ethics consultation service are described in Section B of this Part.

126. *In re Wanglie*, No. PX-91-283 (Minn. Prob. Ct. Hennepin Cnty. June 28, 1991), reprinted in 7 ISSUES L. & MED. 369 (1991).

127. See Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. A Physician's Professional Conscience*, 44 HASTINGS L.J. 1241, 1244-45 (1993) (describing *In re Wanglie* as a case of "patient paternalism").

Helga suffered from a number of serious medical conditions.<sup>128</sup> She entered into an unconscious state in May 1990.<sup>129</sup> She was placed on a respirator and could not be weaned.<sup>130</sup> Several months later, Helga's clinicians recommended withdrawal of life-sustaining care. When her husband and two adult children refused to consent, Dr. Steven Miles petitioned a Minnesota court to remove Oliver Wanglie as conservator for his wife and to appoint a substitute conservator.<sup>131</sup> In an article published in the *New England Journal of Medicine* in the same year, Miles contended that physicians should not be obliged to provide inappropriate, injurious, or extraneous care.<sup>132</sup> Further, Dr. Miles suggested that lawmakers are "ill suited to define medical appropriateness."<sup>133</sup> Accordingly, he did not ask the court to order termination of Wanglie's life-sustaining care but to deprive Helga's husband of authority to make medical decisions for Helga.<sup>134</sup>

Thus, on its face, the *In re Wanglie* case was about how best to select a surrogate decision maker for a patient without capacity. To that question, the court responded by declaring that Oliver Wanglie was better-suited to make medical decisions for his wife "of fifty-three years . . . [than was] a stranger."<sup>135</sup> Helga died less than a week after the Minnesota court concluded that her husband should

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128. A Minnesota probate court noted that Helga Wanglie suffered from six serious medical conditions. *In re Wanglie*, 7 ISSUES L. & MED. at 375. These included:

a. Aortic insufficiency murmur; b. Congestive heart failure; c. Chronic recurrent pneumonias secondary to underlying lung disease, unconsciousness, and recumbency; d. Bilateral Atelectasis and calcified lung disease; e. Chronic respiratory insufficiency with dependence on mechanical ventilation, which her physicians have concluded is irreversible; f. Persistent vegetative state with no change in one year, i.e., unconsciousness since her cardiorespiratory arrest on May 23, 1990, which her physicians have concluded is irreversible.

*Id.*

129. Helga fractured a hip. While in transport from a nursing home to the Hennepin County Medical Center, she suffered an episode of respiratory arrest. *Id.* at 374.

130. *Id.*

131. *Id.* at 371.

132. See Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512, 513 (1991).

133. *Id.* at 514.

134. *Id.*

135. *In re Wanglie*, 7 ISSUES L. & MED. at 376.

be permitted to continue to make medical decisions for her.<sup>136</sup> In effect, the court in *In re Wanglie* supported a vision of family autonomy. Family autonomy differs from the nomination of surrogate decision makers in that family autonomy does not privilege the views of one family member above those of others while a surrogate is understood as standing in for an incompetent patient.<sup>137</sup>

In the wake of *In re Wanglie*, commentators have addressed an underlying, though often unaddressed, issue in futility cases – the wisdom of expending significant sums of money on the type of care that Helga Wanglie received.<sup>138</sup> As a practical matter, funding for Helga Wanglie’s care was not at issue in the case because insurers reimbursed the hospital for that care.<sup>139</sup> Had Dr. Miles invoked the cost of Helga’s care, whatever sympathy the court or the public felt for Miles’s position at the time might have dimmed significantly.<sup>140</sup>

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136. See, e.g., D. John Doyle, *Exploring the Medical Futility Debate: The Tragic Case of Helga Wanglie*, [http://danieljohndoyle.com/uploads/3/4/3/7/34375475/futility\\_essay\\_2012.pdf](http://danieljohndoyle.com/uploads/3/4/3/7/34375475/futility_essay_2012.pdf) (April 2012) (noting that Helga Wanglie died on July 4, 1991 “of multisystem organ failure”).

137. This difference is likely to be more important as a matter of theory than as a matter of practice. But it does alter the framework within which society envisions medical decision-making for patients without capacity.

138. See, e.g., Doyle, *supra* note 136; Cathleen A. Roach, *Paradox and Pandora’s Box: The Tragedy of Current Right-to-Die Jurisprudence*, 25 U. MICH. J.L. REFORM 133, 147 (1991) (estimating total costs to have been between \$800,000 and \$1,000,000); see also *supra* note 70 and accompanying text (considering values that compete with the value of autonomy). Doyle reports a somewhat lower figure for the cost of Wanglie’s care (in 1991) – about \$750,000. Doyle, *supra* note 136. Doyle noted that the Ethics Committee of The Society of Critical Care Medicine prepared a Society policy (1997) on futility: “Treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile.” *Id.* (citing Ethics Comm. of the Soc’y of Critical Care Med., *Consensus Statement of the Society of Critical Care Medicine’s Ethics Committee Regarding Futile and Other Possible Inadvisable Treatments*, 25 CRIT. CARE MED. 887 (1997)). Dr. Marcia Angell expressed dismay about the “resources [that] are spent sustaining the lives of patients who will never be sentient” but concluded that “permitting ourselves to withdraw life support from a patient simply because it would save money” presented a worrisome slippery slope. Marcia Angell, *The Case of Helga Wanglie – A New Kind of “Right to Die” Case*, 325 NEW ENG. J. MED. 511, 512 (1991).

139. See Daar, *supra* note 127, at 1270; Roach, *supra* note 138, at 147 (noting that all of Helga Wanglie’s hospital costs were paid by Medicare or by private insurance companies).

140. Sandra M. Terra & Suzanne K. Powell, *Editorial: Is a Determination of Medical Futility Ethical?*, 17 PROF’L CASE MGMT. 103 (2012), [https://www.nursingcenter.com/journalarticle?Article\\_ID=1330164&Journal\\_ID=54025&Issue\\_ID=1330163#P37](https://www.nursingcenter.com/journalarticle?Article_ID=1330164&Journal_ID=54025&Issue_ID=1330163#P37) (noting that in clinical care, it is “at best, socially unacceptable” to make medical decisions on the basis of “cost, consideration of socioeconomic status, age, gender, or other nonclinical factors as primary determinants”).

Yet, questions about the high cost of the care that Wanglie received pointed to one of the surviving “elephants” in the medical-futility room – the cost of end-of-life care.<sup>141</sup>

In *Alexander v. Scripps Memorial Hospital La Jolla*,<sup>142</sup> decided fourteen years after *In re Wanglie*, a California court sided with the patient’s clinicians. This case resembled *In re Wanglie* in posing a patient’s clinicians, who sought withdrawal of life-sustaining care, against the patient’s family.<sup>143</sup> But it differed from *In re Wanglie* on a number of dimensions. First, the case was brought by the patient’s family, after the patient’s death—a death that resulted from the withdrawal of life-sustaining care authorized by the patients’ clinicians.<sup>144</sup> Most court cases involving disputes about non-beneficial care resemble *Alexander* in that they were initiated after the patient’s death.<sup>145</sup> Second, the patient, Elizabeth Alexander (age seventy), who suffered from aggressive pancreatic cancer, had made her pre-incompetency preferences for continuing care clear through an advance directive and had appointed one of her children, a son named Christopher, as her health care decision maker.<sup>146</sup>

The legal case was initiated by Elizabeth’s children after their mother’s death. The suit was against Scripps Memorial Hospital La Jolla (“Scripps Memorial”), where Elizabeth had been treated,

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141. Peter Ubel remarks that the terms such as “parsimony,” “value,” and “CER” are now employed in place of the term “rationing.” Peter A. Ubel, *Why It’s Not Time for Health Care Rationing*, 45 HASTINGS CTR. REP. 15, 16 (2015). Some have suggested that CER—“comparative effectiveness research,” a term introduced with the Patient Protection and Affordable Care Act (PPACA)—aims to compare modes of care but can also be used to justify what is, in effect, rationed care. See, e.g., Kathryn Nix, *Comparative Effectiveness Research Under Obamacare: A Slippery Slope to Health Care Rationing*, HERITAGE FOUND. (Apr. 12, 2012), <https://www.heritage.org/health-care-reform/report/comparative-effectiveness-research-under-obamacare-slippery-slope-health>. Further consideration of responses to the costs of end-of-life care is beyond the scope of this article.

142. *Alexander v. Scripps Mem’l Hosp. La Jolla*, 232 Cal. Rptr. 3d 733, 740 (Ct. App. 2018).

143. *Id.* Alexander was treated at the Scripps Memorial Hospital La Jolla.

144. *Id.*

145. Thaddeus Mason Pope has collected and posted online “key cases” involving disputes raising issues about medical futility and “non-beneficial ICU treatment.” Thaddeus Mason Pope, *Medical Futility & Non-Beneficial Treatment Cases*, <https://www.thaddeuspope.com/futilitycases.html> (last visited Feb. 24, 2020) [hereinafter Pope, *Medical Futility*]. Pope has posted about sixty U.S. cases relating to these issues that were decided between 1980 and 2016; four or five of them preceded *In re Wanglie*. *Id.*

146. *Alexander*, 232 Cal. Rptr. 3d at 740.



and against clinicians at the hospital.<sup>147</sup> The plaintiffs alleged that the defendants, by failing to provide cardio-pulmonary resuscitation when Elizabeth experienced cardiac failure, had violated the standards of good medical care and had contravened Elizabeth's advance directive.<sup>148</sup> Thus, in contrast with *In re Wangle, Alexander* was brought after a decision to terminate care had been implemented and after the patient's death.<sup>149</sup>

A California appellate court affirmed a trial court decision in favor of the defendants.<sup>150</sup> The court concluded that "a patient's right to control his or her own health care" is not without limits.<sup>151</sup> That the patient expressed (or through an advance directive, had expressed) a contrary position did not alter the presumption that clinicians have room to limit patients' control over their health care decision-making.<sup>152</sup> In short, the court concluded that the treatment preferences expressed in Elizabeth Alexander's advance directive and by her surrogate decision maker after she lost capacity were trumped by the clinicians' conclusion that the care requested was inappropriate.

From the perspective of the informed consent doctrine, and the principle of respect for patient autonomy on which that doctrine is grounded, this is a surprising conclusion. It suggests that the ethical obligation to respect patient autonomy (either directly or through a surrogate)<sup>153</sup> can be outweighed and elided by clinicians' conclusions about the appropriateness of care. The notion is not unique to *Alexander*. It has also been inscribed in statutory law as described in Part III.<sup>154</sup>

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147. *Id.*

148. *Id.*

149. *Id.* at 742-43. When Elizabeth suffered cardiopulmonary arrest, CPR was not initiated. *Id.* at 743.

150. *Id.* at 740.

151. *Id.* at 756.

152. *Id.* Explaining this point, the *Alexander* court quotes the state's Probate Code, Section 4735: "A health care provider or health care institution may decline to comply with an individual health care instruction or health care decision that requires medically ineffective health care or health care contrary to generally accepted health care standards applicable to the health care provider or institution." CAL. PROB. CODE § 4735 (West 2000).

153. See BEAUCHAMP & CHILDRESS, *supra* note 2, at 13 (noting "respect for autonomy[,] a norm of respecting supporting autonomous decisions" to be one of the "pivotal moral principles" in contemporary bioethics).

154. See *infra* Part III (considering statutory responses among the states to care deemed inappropriate).

*B. Court Resolution of Family Disagreement About Continuing  
Life-Sustaining Care*

The case considered in this Section differs from *In re Wanglie* and *Alexander* in that the underlying dispute about end-of-life care developed among the patient's family members rather than between family members and clinicians.<sup>155</sup> Indeed, *Bernstein v. Superior Court*<sup>156</sup> reflects the terribly dismal consequences that an intrafamilial dispute about a parent and spouse's end-of-life care can spawn.<sup>157</sup> The case illustrates the dire impact on family members and potentially on patient care of a surrogate decision maker (one of the patient's three sons in the *Bernstein* case) displacing the patient's preferences as well as those of other family members with his own preferences. *Bernstein* suggests a perversion of autonomous control by a presumptive surrogate.

Karl Bernstein had been diagnosed with Alzheimer disease. He also suffered from a number of comorbidities. He was unable to communicate, "eat or swallow, and . . . unable to undertake any volitional act."<sup>158</sup> Karl's clinicians, his wife, and two younger sons believed that continuing care had "no medical or therapeutic value for Karl."<sup>159</sup> Karl had not completed an advance directive.

Scot, Karl's oldest son by a previous wife, insisted on serving as his father's surrogate decision maker.<sup>160</sup> Initially, Karl's wife, Olga, had acceded to Scott's control.<sup>161</sup> From 1999 until 2008, Scott demanded that Karl be treated aggressively.<sup>162</sup> Karl entered a persistent vegetative state in 2003 and was moved to a nursing home in 2005. At the time, he was connected to "tracheostomy, jejunostomy, and gastrostomy tubes."<sup>163</sup> Olga, Karl's wife, along with Ilya and Nicholas (sons of Olga and Karl and Scott's

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155. See *infra* Section IV.B for consideration of similar cases handled by ethics consultation service.

156. *Bernstein v. Superior Ct.*, No. B212067, 2009 WL 224942 (Cal. Ct. App. Feb. 2, 2009).

157. *Id.* at \*1. In addition to Alzheimer disease, Karl suffered from Parkinson's hypertension and aspiration pneumonia. *Id.*

158. *Id.* at \*2.

159. *Id.*

160. Catherine Saillant, *Family Is Split Over Man's Fate*, L.A. TIMES (Aug. 26, 2006), <http://articles.latimes.com/2006/aug/26/local/me-righttodie26>.

161. *Id.*

162. *Bernstein*, 2009 WL 224942, at \*2.

163. *Id.*

half-brothers) sought to have these tubes withdrawn. But Scott's position remained unchanged, despite increasingly raw conflicts with his stepmother and half-brothers. Finally, in 2008, Ilya and Nicholas sought court assistance.<sup>164</sup> They hoped to limit Scott's control over their father's care or, alternatively, to have Scott replaced as Karl's conservator.<sup>165</sup>

The trial court heard testimony from sixteen people over five days.<sup>166</sup> The court then removed Scott as Karl's conservator, replacing him with Ilya. Scott appealed. The appellate court affirmed, even as it suggested that, whenever possible, "judicial intervention . . . should be minimal" in such cases.<sup>167</sup> In affirming Scott's replacement with Ilya, the appellate court pointed to Ilya's readiness to consider the issues carefully in order to serve Karl's best interests.<sup>168</sup> Presumably, once Ilya became his father's conservator, the life-sustaining treatment at issue was withdrawn.<sup>169</sup>

The relationships in *Bernstein* between Scott and his half-siblings and stepmother are notable for their dysfunctionality. Intrafamilial disputes about the continuation—or not—of life-sustaining care for a loved one rarely involve the level of suffering and animosity that characterized relationships within the Bernstein family.<sup>170</sup> That state of affairs reflects surrogate decision-making gone amok.

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164. *Id.* at \*3. Ilya and Nicholas delineated "medically futile" treatments to include "intramuscular antibiotic injections, . . . feeding methods that are painful and futile, and . . . the tracheostomy tube." *Id.*

165. *Id.* Ilya and Nicholas wanted their father to be offered the level of care that his clinicians deemed appropriate, including the provision of pain medication and the termination of "medically futile" treatment. *Id.*

166. *Id.* at \*5. Initially, the trial court did not find adequate evidence to provide the relief requested. However, the court appointed a Deputy Public Defender to serve as counsel for Karl. Mary Shea, Karl's appointed counsel, prepared a report ("Confidential Status Report Assessing Conservatee's Health and Best Interests"). *Id.* at \*3. Shea's report supported each of Ilya and Nicholas's claims. *Id.* at \*10.

167. *Id.* at \*14.

168. *Id.*

169. No subsequent court materials or journalist accounts of this case have been found. Such documents might have described events after Ilya's appointment.

170. See Saillant, *supra* note 160. Saillant described Olga to have been "fuming." She noted that disagreements within the family about Karl's care related to almost every aspect of that care, and she described the "enmity" among the Bernsteins as "so great" that Scott responded to Olga's having posted photos of herself, Ilya and Nicholas in Karl's room with "much larger photographs of himself and his father." *Id.*

Perhaps involvement of an ethics consultation service would not have rendered the dispute among the Bernsteins less painful for all of the stakeholders. However, a similar sort of dispute was resolved more successfully for all of the stakeholders by an ethics consultation service at "Brookside" Hospital. That ethics consultation case,<sup>171</sup> as well as others resembling both *In re Wanglie* and *Alexander*, are considered in Part V.<sup>172</sup>

#### V. RESPONSES OF HOSPITAL ETHICS CONSULTATION SERVICE TO FUTILITY DISPUTES

The scenario and structure of the dispute described with regard to the first case presented in this Part resemble the situation underlying *In re Wanglie* and *Alexander*. The scenario and structure of the dispute in the second ethics case described here resemble *Bernstein*.<sup>173</sup> Before examining these cases, some background about the aims and scope of hospital ethics committees and ethics consultation services is needed. That is provided in Section A of this Part. Then Section B reviews the two ethics cases.

##### A. Ethics Committees and Ethics Consultation Services

"Brookside" Hospital created an Ethics Consultation Service<sup>174</sup> in 2012. The Hospital is part of a large hospital system in the Northeast. Brookside's ethics consultation service has grown significantly since its creation. Since 2012, Brookside's service has responded to scores of cases occasioned by disputes about whether to withdraw or withhold life-sustaining care from a patient.<sup>175</sup> The Brookside cases considered in this Part involve a subset of patients who faced challenges about end-of-life choices regarding medical care and who refused, directly or through a surrogate, to consent to terminating life-sustaining care that the patients' clinicians deemed medically inappropriate.

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171. See *infra* Section V.B.

172. See *infra* Section V.A.

173. The ethics cases resembling *In re Wanglie* and *Alexander* are considered in Section A of this Part; the case resembling *Bernstein* is considered in Section B.

174. "Brookside" is a pseudonym for the hospital. See Janet L. Dolgin, *Resolving Health Care Conflicts: A Comparative Study of Judicial and Hospital Responses*, 9 WAKE FOREST J.L. & POL'Y 495, 500-05 (2019).

175. All of the ethics consultation cases reviewed in this Article were decided between 2012 and 2017.

For hospital ethicists, as for judges, disputes pertaining to end-of-life care often raise troubling choices.<sup>176</sup> Within this set of cases, a smaller subset has raised questions about futile care.<sup>177</sup> On the whole, in these cases, the notion of futile care, whether identified by that term or not, is understood to occasion questions about care deemed non-beneficial and that, in the view of the patient's clinicians, could entail further suffering for the patient. Clinicians at Brookside generally understand futile care as care that lacks any benefit for the patient beyond the prolongation of physiological life.<sup>178</sup> However, insofar as the care being provided in these cases sustains physiological processes, that care can be termed futile only in a limited sense, one heavily dependent on perspective.

The ethics cases that this Article compares with the matching legal cases reviewed in Part IV were both entertained by the ethics consultation service at Brookside. The service functions independently of the hospital's ethics committee. Ethics committees are now found in virtually all U.S. hospitals<sup>179</sup> and consider issues similar to those considered by consultation services, but their work is distinct.<sup>180</sup> Often, the work of hospital ethics

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176. As a general matter, many of Brookside's ethics consultation cases have involved elderly patients facing end-of-life choices. That is not surprising insofar as older people are more likely than are younger people to be hospitalized. AGENCY FOR HEALTHCARE RSCH. & QUALITY, HCUP FACTS AND FIGURES: STATISTICS ON HOSPITAL-BASED CARE IN THE UNITED STATES, 2009 (2011), <https://www.ncbi.nlm.nih.gov/books/NBK91986/> (noting that "older people had a greater chance of hospitalization" in 1997 and in 2009).

177. Sometimes the term "futile" is used in the relevant ethics consultation case reports. Sometimes other terms, such as "medically inappropriate," are used instead.

178. Clinicians more commonly refer to "ineffective" or "inappropriate" care than to "futile" care.

179. Mark P. Aulisio, *Why Did Hospital Ethics Committees Emerge in the U.S.?*, 18 AMA J. ETHICS 546 (2016), <http://journalofethics.ama-assn.org/2016/05/mhst1-1605.html>. In the early 1990s, the non-profit accrediting group, the Joint Commission, mandated that hospitals host ethics committees or similar bodies able to respond to medical ethics disputes within the hospital. Thaddeus Mason Pope, *Legal Briefing: Healthcare Ethics Committees*, 22 J. CLINICAL ETHICS 74, 76 (2011) [hereinafter Pope, *Legal Briefing*] (citing JOINT COMM'N, 2011 COMPREHENSIVE ACCREDITATION MANUAL FOR HOSPITALS (CAMH): THE OFFICIAL HANDBOOK § LD.04.02.03 (2011)). It also tests "foundational knowledge." See AM. SOC'Y FOR BIOETHICS & HUMANS., *Healthcare Ethics Certification Examination Content Outline and Item Development*, <https://asbh.org/certification/content-outline> (last visited Feb. 22, 2020).

180. Some hospital ethics committees designate members of a subcommittee to serve as consultants. These committee members respond to and assist in resolving medical disputes and conflicts within the hospital. Robert A. Pearlman, *Ethics Committees and Consultation*, U. WASH. SCH. MED., <https://depts.washington.edu/bhdept/ethics-medicine/>

committees overlaps with that of ethics consultation services, and, in some hospitals, differences between ethics committees and ethics consultation services may be difficult to delineate; the functions of each group and its position within a hospital's institutional structure differ from hospital to hospital. Sometimes ethics consultants are members of a hospital's ethics committee and sometimes they are independent.<sup>181</sup> In short, the distinction between ethics committee members and ethics consultants can be murky.

Some differences are fairly routine. Ethics committees within hospitals are composed of unpaid volunteers. They usually include hospital physicians, nurses, social workers, psychologists, clergy and one or more members drawn from the lay public. Judith Henricks, a solicitor and lecturer in law in Britain, noted that ethics "committees," despite variation, generally have three primary functions within hospitals: "education, policy development and case review."<sup>182</sup>

Ethics consultants, usually themselves clinicians, respond to specific disputes as ethicists. They are increasingly likely to have undergone specialized training in clinical bioethics.<sup>183</sup> Working as individuals or as members of a team, ethics consultants respond to "the ethical issues involved in a specific, active clinical case."<sup>184</sup> In the face of a dispute about patient care, clinicians, patients, and

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bioethics-topics/detail/64 (last visited Feb. 22, 2020). The work of an ethics consultation service is often reviewed by the hospital's ethics committee, and some ethics consultants attend ethics committee meetings as members of the larger group.

181. See Andrew M. Courtwright, Joshua Abrams & Ellen M. Robinson, *The Role of a Hospital Ethics Consultation Service in Decision-Making for Unrepresented Patients*, 14 J. BIOETHICAL INQUIRY 241, 242 (2017) (reporting that at Massachusetts General Hospital in Boston, a senior member of the ethics committee, often accompanied by a more junior member, carries out individual consultations which are then reviewed by the larger hospital ethics committee).

182. Judith Hendrick, *Legal Aspects of Clinical Ethics Committees*, 27 J. MED. ETHICS (SUPPL. I) i50, i51 (2001).

183. The American Society for Bioethics and Humanities (ASBH) has created and recommends a certifying examination that tests several areas of skills capability: "assessment, analysis, process, evaluation, and quality improvement." Pope, *Legal Briefing*, *supra* note 179. At Brookside, most ethics consultants have been medical clinicians, but a few have been attorneys or social workers.

184. Salla Saxén, *Untangling Uncertainty: A Study of the Discourses Shaping Clinical Ethics Consultation as a Professional Practice*, 27 J. CLINICAL ETHICS 99, 99 (2016) (quoting J.A. Tulskey & E. Fox, *Evaluating Ethics Consultation: Framing the Questions*, 7 J. CLINICAL ETHICS 109, 112 (1996)).

sometimes others can call for an ethics consultation. The work of hospital ethics consultants is typically labor intensive. Once asked to help resolve a dispute, ethicists may devote many hours to conversation with those involved in the dispute—sometimes individually and sometimes together.

The American Society for Bioethics and Humanities (ASBH) has defined an ethics consultation as follows:

[A] set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care. . . .

. . . .

An ethics consultation is appropriate when there is uncertainty or conflict about values and a question arises about which decisions are appropriate or which actions should be taken. An ethics consultation may be requested to help an individual resolve uncertainty or conflict or to help resolve uncertainty or conflict between and among multiple parties.<sup>185</sup>

The ASBH “Core Competencies” handbook has recommended that ethics consultants engage in “ethics facilitation.”<sup>186</sup> The handbook characterized the approach as helping to “elucidate issues, aid effective communication, and integrate the perspectives of the relevant stakeholders.”<sup>187</sup> The handbook identified the central parameters of the approach to involve “(1) identifying and analyzing the nature of the value uncertainty, and (2) facilitating the building of a principled ethical resolution.”<sup>188</sup>

There is variety among facilities, but as a general matter, ethics consultants focus on resolving specific disputes among stakeholders (e.g., patients, family members, clinicians). Some ethics committees review ethics consultations after the fact. They

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185. AM. SOC’Y FOR BIOETHICS & HUMANS., CORE COMPETENCIES FOR HEALTHCARE ETHICS CONSULTATION 2, 4 (2d ed. 2011). Some critics bemoaned the definition’s vagueness. See, e.g., Giles R. Scofield, *What Is Medical Ethics Consultation?*, 36 J.L. MED. & ETHICS 95, 97 (2008).

186. AM. SOC’Y FOR BIOETHICS & HUMANS., *supra* note 185, at 6.

187. *Id.* at 7.

188. *Id.* The work of the Brookside ethics consultation service reflects those capacities.

also may assist in developing policies for the hospital (or other health care facility) that they serve.

*B. Resolution by Ethics Consultation Service of Futility Disputes  
Between Patients or Their Surrogates and Clinicians*

This Part presents two ethics consultation cases. The facts of the first, the case of "Eddie B.," resemble *In re Wanglie* and *Alexander*. The facts of the second, the case of "Tom F.," resemble *Bernstein*.<sup>189</sup> These ethics cases provide a useful framework for comparing the resolution of futility cases in courts with the resolution of similar cases by hospital ethics consultation services.

1. "Eddie"<sup>190</sup>

The case of "Eddie" involved a 68-year-old with multiple comorbidities, including significant cardiac and renal insufficiency.<sup>191</sup> Eddie was conscious and had some, though perhaps not full, capacity to make medical decisions. He had not completed an advance directive. In the absence of a health care proxy form, state law prescribed that Eddie's wife, Rachel, would serve as Eddie's decision maker should Eddie become incapable of making his own decisions. He had been receiving hemodialysis but suggested, at least from time to time, that he did not want hemodialysis treatment to be continued. Alternately, Eddie asserted that he wanted his wife, Rachel, to make medical decisions for him. That led to some confusion insofar as Rachel preferred that Eddie continue with hemodialysis treatment. Under state law,

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189. *In re Wanglie*, *Alexander*, and *Bernstein* are described *supra* Part IV.

190. Brookside Ethics Consultation Report (identified here as EC20151). The deidentified report about Eddie B.'s case is in the possession of the Author and has been made available to the *Brigham Young University Law Review's* Editors. The name "Eddie B." was chosen at random. Moreover, facts about this hospital patient (and other hospital patients whose cases are discussed in this Article) have been altered to further protect the patients' identities. The names of other people mentioned in connection with Eddie B.'s case (e.g., Eddie's clinicians and family members) have similarly been altered. That is true of any ethics consultation case considered in this Article. These changes were necessary in order to ensure the absence of any identifying information about any of the participants in the hospital ethics consultations discussed in this Article.

191. Information about Eddie's care relevant to this analysis can be found in EC20151. See *supra* note 190. That citation is not continually reiterated in footnote references. The Author has made the deidentified report about Eddie's case available to the Editors of the *Brigham Young University Law Review*.



Rachel would serve as Eddie's medical decision maker should Eddie be deemed to lack medical decision-making capacity. At the time of the ethics consultation, there were some questions about whether Eddie enjoyed an adequate level of capacity to engage in medical decision making for himself. It was clear, however, that should Eddie be deemed incapable, Rachel would be asked to make decisions for Eddie.

Eddie's clinicians had concluded that Eddie was not likely to live for very long with or without life-sustaining care. They further stated that the continuation of hemodialysis would cause unnecessary suffering for Eddie. In fact, one of Eddie's nephrologists had expressed the opinion that Eddie was a poor candidate for hemodialysis.

Eddie's wife, Rachel, did not deny that her husband was nearing the end of life. However, she believed that agreeing to the cessation of life-sustaining treatment was "playing God"—not something in which she wanted to participate. Rachel refused hospice care for Eddie after she learned that he would not receive hemodialysis if placed on hospice care. Similarly, she was unwilling to allow Eddie to be discharged to their home unless he would continue to receive hemodialysis treatments.

Eddie's end-of-life story resembles those of Helga Wanglie and Elizabeth Alexander in that all three involved a difference of opinion about the continuation of life-sustaining care between the patients' clinicians and their family members. However, Eddie, unlike Helga Wanglie and Elizabeth Alexander, was at least sometimes capable of participating in medical decision-making, and Eddie's case seemed to involve intermittent disagreement between the patient and his wife. Yet Eddie's case resembled *In re Wanglie* and *Alexander* in that, in all three cases, family members sought continuation of treatment that the patients' clinicians deemed medically inappropriate.

Dr. S., an attending physician at Brookside who was involved in Eddie's care, sought an ethics consultation. He asked the hospital ethics consultants to help resolve the conflict between Eddie's wife and Eddie's clinicians about whether to continue Eddie's hemodialysis and to review a possible conflict between Eddie and his wife about Eddie's care. The ethics consultation service envisioned its role to include responding as positively and as helpfully as possible in light of the challenges facing Eddie and

those caring for him. In comparison with the court cases considered in Section A of Part IV,<sup>192</sup> the ethics consultants enjoyed more flexibility than did the judges who were, in the nature of their institutional setting, constrained by the shape and posture of particular legal disputes. This flexibility allowed the hospital ethicists to approach questions about care with concern for Eddie's autonomous choices and for the burden facing Rachel, Eddie's wife and surrogate decision maker.

The ethics consultants sought appropriate services for Eddie and Rachel, including help for Rachel, who was already grieving, with the process of bereavement; even though Eddie was alive, he seemed clearly to be dying. The ethics consultants further considered options for Eddie and Rachel that had not been entertained in the original narratives presented to them by the stakeholders. For instance, the ethics consultants conferred with the hospital's social services department to discern whether it might be possible to find a placement for Eddie in a subacute care facility and, if so, whether Rachel would accept that option. Further, the ethics consultants continued to convene meetings that included Eddie, Rachel, other relatives, Eddie's clinicians, and members of the ethics consultation service. The service used these meetings to facilitate appreciation for Eddie's autonomy, however diminished his capacity had become, as well as for the preferences and needs of Eddie's relatives and the burden on his clinicians who were being asked to provide care that they did not deem helpful. Finally, the service recommended—absent compelling shifts in Eddie's situation—that all parties try to refrain from suggesting new preferences regarding Eddie's care, especially if those shifts would have significantly reshaped the terms of care. The consultants grounded this suggestion in their perception that continuity and stability in Eddie's care were important for all of the stakeholders.

These options were available to the hospital ethicists because the ethics consultation service that entertained Eddie's case functioned within a very different framework than that which defined and structured the court proceedings in *In re Wanglie* and *Alexander*.<sup>193</sup> Thus, the consultation service exercised greater

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192. See *supra* Section IV.A.

193. *In re Wanglie*, No. PX-91-283 (Minn. Prob. Ct. Hennepin Cnty. June 28, 1991), reprinted in 7 ISSUES L. & MED. 369 (1991); *Alexander v. Scripps Mem'l Hosp.* La Jolla, 232 Cal. Rptr. 3d 733, 740 (Ct. App. 2018).

flexibility in the sort of help it could offer and the process through which it identified that help than did (or could) either of the courts. Brookside's ethics consultation service saw itself as responsible for the welfare of Eddie, for that of his wife, who suffered under the burden of making decisions for her dying husband, and for the welfare of the clinicians responsible for Eddie's care in the hospital. Unlike the courts, the ethicists—while acknowledging the significant challenges inherent in futility cases—could avoid choosing among decision makers and opining about the appropriateness of the treatment at issue for Eddie. The ethics consultants were able to focus directly on the needs and concerns of each of the stakeholders.

While cases such as Eddie's, *In re Wanglie*, and *Alexander* raise significant challenges for hospital ethics consultants and for courts, the approach of the Brookside ethics consultation service, as compared with that of the courts, encouraged deliberation and reevaluation. Neither court attempted—and in the nature of the judicial enterprise, neither court could easily have attempted—to redefine the community for which it was responsible and to craft a response in light of “care” owed not only to the patient but also to the patient's family and, even, to the patient's clinicians.

In contrast, the ethicists involved in Eddie's case seemed to agree with Eddie's clinicians that continuing care held little medical benefit for Eddie. But that did not settle the matter for them. For the ethics consultants who responded to Eddie's case, concern about the continuation of futile treatment was qualified by concern about the needs and anxieties of Eddie, his wife, and his clinicians. Were Eddie the only party for whose welfare the ethics service accepted responsibility in this case, it might have encouraged the initiation of hospice care (and thus the termination of life-sustaining care) for Eddie. Instead, the service included Rachel among those for whom it felt responsible. The ethics consultation service acknowledged Rachel's “caregiver burden” and her pain as she watched a beloved spouse die. In this regard, the ethicists' approach resembled that of the court in *In re Wanglie* in seeking a framework within which to attend to the patient's family as well as to the patient. In both Eddie's case and that of Helga Wanglie, a vision of communal

(family) autonomy replaced the more usual presumption in the United States that has favored individual autonomy.<sup>194</sup>

Further, the hospital ethicists considered the wisdom of relying on "the tincture of time" before making additional determinate decisions about Eddie's care. That position has particular merit in a case that poses one important value—patient or family autonomy—against another set of values—the "right" of patients' clinicians to limit life-sustaining care for those for whom medical recovery seems virtually impossible. Again, this is an option that, in the nature of their responsibilities and governing rules, was not available to the courts.

The ethics consultation service's broad view of its mission in Eddie's case encouraged the ethicists to seek a far-reaching accommodation that might serve all of the stakeholders. First, they defined an essential conflict at issue in Eddie's medical care: that conflict occurred at the place in which the "technically possible" diverged from the "medically beneficial." That divergence serves well to contextualize claims about futile care. A medical procedure or treatment may be possible; it may accomplish technology's goals (e.g., to sustain physiological function) but may still be considered to violate the bioethical principle of clinician beneficence (sometimes understood as nonmaleficence).<sup>195</sup>

Continued life-sustaining treatments were available for Eddie but were not considered beneficial by his clinicians (nor, it seemed, by Eddie, though his competence was compromised and his conclusions about what he wanted done changed over time). That concern might suggest that life-sustaining care, no longer beneficial to the patient, should be terminated. But the ethics consultation service recognized a second, equally powerful concern—to protect and support those who loved Eddie as he moved through the process of dying. In the face of that concern, claims about the futility of continuing care, however well-founded, were not determinative. In effect, in Eddie's case, family autonomy trumped concerns about futile care.

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194. See *supra* notes 137–138 and accompanying text.

195. "Nonmaleficence" has become a central principle in medical ethics. See BEAUCHAMP & CHILDRESS, *supra* note 2, at 150–54. Beauchamp and Childress explain that nonmaleficence "has been treated as effectively identical to the celebrated maxim *Primum non nocere*: 'Above all [or first] do no harm.'" *Id.* at 150.

In short, all of these cases developed around several competing values. First, the importance of patient autonomy was deeply inscribed in medical ethics by the end of the twentieth century. Second, society and the law have increasingly recognized the disadvantages of sustaining life at all costs, especially for patients without consciousness and without a reasonable hope for recovery. Third, the ethics consultation service at Brookside shaped a perspective that prized autonomy but that broadened that value's reach to groups that encompass individual patients but also extend beyond them to include their family members and other loved ones.

2. "Tom F."<sup>196</sup>

The facts of Tom F.'s case resemble those of *Bernstein*, decided by a California court in 2018, in that the dispute at the center of each case was intrafamilial.<sup>197</sup> Tom's ethics case commenced in 2013 when a physician at Brookside involved with Tom's care requested help from the hospital's ethics consultation service. Concern revolved around how best to respond in light of an intrafamilial conflict about whether to provide life-sustaining care for Tom. At the time, Tom was seventy-nine years old. He had been diagnosed with dementia, Parkinson's disease, hypertension, and renal failure.<sup>198</sup> Tom was not capable of making medical decisions. Moreover, he had not completed an advance directive. His immediate family all reported that Tom had never talked about death or dying. None of them knew what Tom would have wanted done.

Before he was hospitalized, Tom had been living with his daughter, Rosalie. For that reason, other family members agreed initially that Rosalie would serve as her father's primary surrogate decision maker. Pursuant to state law,<sup>199</sup> Rosalie and Hiram,

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196. Brookside Ethics Consultation Report (identified here as EC20131). As with the case of "Eddie B.," the name of the patient in this case as well as those of others involved in the case have been altered to protect the privacy of those involved. In addition, some of the facts of the patient's story have been altered in order to protect the privacy of all of those involved.

197. See *supra* Section IV.B.

198. EC20131, *supra* note 196. As noted in introducing the case of Eddie B., the deidentified report about this patient's case is in the possession of the Author and the *Law Review*. The name "Tom F." was chosen at random.

199. Family Health Care Decisions Act, N.Y. PUB. HEALTH LAW § 2994-d (2010).

Tom's son, had equal status as potential surrogates for their father unless, together, they agreed that one of them would take primary responsibility.

Soon, it became clear that Rosalie's preferences for her father's care conflicted with those of Hiram, and those of Tom's sister, Grace. Rosalie favored hemodialysis for her father, hoping that with hemodialysis, he would be able to return to her home. Grace and Hiram, reflecting the view of Tom's clinicians, opposed hemodialysis. Rosalie explained that her father's quality of life depended on his receiving hemodialysis. But Tom's doctors did not think hemodialysis made sense at that time given Tom's seriously compromised health status.

The ethics consultants informed themselves about Tom's medical situation. That allowed them to establish a frame within which to communicate with all of the stakeholders. A review of medical literature suggested that initiating hemodialysis augured a poor prognosis for Tom, given his age and comorbidities. For the ethicists, this information suggested that a decision to withhold hemodialysis made medical sense and could, thus, be justified ethically but that a decision to initiate hemodialysis could also be justified ethically.

The ethicists shared their perspective on Tom's medical situation with his family. They facilitated sustained conversation among Rosalie, Hiram, and Grace—sometimes also including Tom's clinicians. The ethics consultants further arranged for Rosalie to meet with members of the hospital's palliative care service. Rosalie's conversation with the palliative care team encouraged her to reconsider her original position and brought her preferences more in line with those of her sibling and aunt. Ultimately, Rosalie agreed with other family members and with her father's clinicians that Tom's best interests would be served by his foregoing hemodialysis.

In short, the labor-intensive work of the ethicists in Tom's case resulted in the development of intrafamilial harmony about Tom's care. It was decided that, once stabilized, Tom would return to Rosalie's home where he had been living. There he would receive "conservative management" rather than hemodialysis. Achievement of intrafamilial agreement clearly distinguishes

Tom's case from that of Karl Bernstein.<sup>200</sup> There, conflict among family members became more and more acrimonious until two of Karl's children went to court to deprive their half-brother of any control over medical decision-making for their father, Karl.<sup>201</sup>

In their medical report, the ethicists noted that Tom's children and his sister all agreed to preserve the option of initiating hemodialysis in the future. This was an important component of Rosalie's joining her relatives in the decision to forego hemodialysis for her father, at least temporarily. The ethicists ensured that the family's current agreement about Tom's care did not close the door to hemodialysis should Tom's situation change, making that choice more reasonable. It was hoped that, with a diet shaped for Tom's needs, he could soon be discharged to return home with Rosalie.

Brookside's ethics consultants presumed that Tom's relatives and clinicians were well-intentioned and that each group aimed to identify a course of treatment for Tom that would benefit him. In this, the service focused on the patient's moral agency, a concern that can easily be considered during an ethics consultation but that is not likely to be of explicit concern in court proceedings. In some part, the ethicists' conversations with each of the stakeholders, sometimes individually and sometimes together, proceeded positively because they presumed the goodwill of everyone involved. Further, that perspective facilitated the ethics consultants' displacing discrepant individual choices with a communal choice. Even more, the ethics consultants safeguarded the autonomous choices of Tom's family and identified a reasonable set of options for Tom's end-of-life care that could be accepted by each of the stakeholders. The case shows the benefits of an approach to futility disputes that takes the concerns and needs of all of the stakeholders into account, shows respect for each, and encourages open discussion among those stakeholders, guided by the hospital's ethics consultants.

The *Bernstein* court focused on resolving the dispute among members of the patient's family. In contrast, the Brookside ethics consultation service that attended to Tom F.'s situation reviewed medical literature as well as case law in order to establish a frame

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200. *Bernstein v. Superior Ct.*, No. B212067, 2009 WL 224942 (Cal. Ct. App. Feb. 2, 2009); *see supra* Section IV.B.

201. *See supra* Section IV.B.

within which to mediate among the parties.<sup>202</sup> Further, the ethics consultation service focused on the concerns and needs of all of the stakeholders – the patient, family members, and clinicians – and engaged in serious conversations with each. It must, however, be acknowledged, that even the most proficient and wise ethics consultants cannot always resolve disputes to the satisfaction of each of the stakeholders. In such cases, court review can provide an enforceable resolution to an apparently intractable dispute. That resolution may not be the best for all of the stakeholders, but it does settle a dispute about patient care with a finality (at least after the exhaustion of appeals) that eludes the authority of ethics consultation services. That said, resolution of such disputes within hospitals in a process guided by trained ethics consultants is almost always preferable to the initiation of court proceedings.<sup>203</sup>

### CONCLUSION

The challenges faced by legislators, judges, and hospital ethics consultants in responding to futility disputes reflect the difficult

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202. Perhaps no ethics consultation service could have rendered the dispute among the Bernsteins less ferocious and painful. The history of Karl Bernstein's case may show that not all bioethics interventions can ease disputes among family members. In fact, a hospital bioethics committee (though not an ethics consultation service) reviewed Karl's case fairly early on in the course of Karl's care and then, again, several years later. *Bernstein*, 2009 WL 224942, at \*4. The committee was not acting as an ethics consultation service but as an advisory body, offering guidance on what it saw as appropriate responses concerning Karl Bernstein's end-of-life care. Such guidance from hospital bioethics committees may be desired by clinicians for whom it may provide some protection should a malpractice suit arise. The hospital's bioethics committee reviewed Karl's situation and documented what, in its view, was the right course of action. *Id.* There are several explanations for the committee's failure to ease the conflict. None can be confirmed. The hospital ethics committee assumed an advisory role and did not engage in the labor-intensive work usually undertaken by trained hospital ethics consultants. *Id.* The committee did not respond and did not seem to see its job to include responding to the needs and values of the stakeholders as individuals or as a group. In this regard, the committee's work and its view of that work differed significantly from the work of the Brookside ethics consultation service. It is possible that members of the hospital ethics committee would have told this story differently. The account here relies on the text of the court's decision. *Id.* It does seem clear, however, that the committee, for whatever reason, was unable to negotiate or forge a consensus between Scott and other members of the patient's family. In some part, the ethics committee's response reflects the limitations inherent in the structure of most ethics committees as compared with that of ethics consultation services (hospital insiders who respond to ethics disputes as clinicians). See *supra* Section V.A (describing scope of ethics committees and ethics consultation services).

203. See generally O'Callaghan, *supra* note 114 for a searing critique of one statutory response to futility disputes.



challenges inherent in most disputes about patient care among patients, family members, or clinicians. Even more than in other sorts of medical disputes, those involving clinicians' claims of medical futility occasion conflicting values that can be extremely difficult to reconcile. Often patient autonomy is sacrificed for clinician beneficence and medical integrity or beneficence and integrity are sacrificed for autonomy.

It is possible that medicine and society's increasing interest in providing for ease in dying will result in fewer patients or surrogates asking to have life-sustaining care continued in the sorts of situations considered in this Article. Should that happen, medical futility will be less and less likely to spark disputes between patients (or their surrogates) and clinicians and thus disputes between patients or their surrogates and clinicians seeking the termination of care deemed futile will arise less frequently.

Yet, at present, the many concerns faced by patients and surrogates at the end of a patient's life suggest that futility disputes are not likely soon to disappear. The concerns at issue may be grounded in the initiation of the grieving process for patients' family members, in the belief that "something" should be done for the patient, in the moral burden carried by clinicians asked to provide care they deem inappropriate, and in fear of death itself. Each of the institutional responses to futility disputes examined in this Article entails at least some shortcoming. That is almost inevitable in the face of the challenging moral dilemmas inherent in futility disputes. That said, ethics consultants, far more than judges or legislators, are able to respond flexibly and to heed the needs and concerns of, and show respect for, all of the stakeholders in attempting to direct those involved in a futility dispute toward a mutually acceptable set of responses.

As a general matter, the least felicitous set of approaches to futility disputes has been crafted in state legislatures. Among the statutes promulgated in the states, most are vague and fail to offer adequate guidance or protection to the stakeholders.<sup>204</sup> One state law that avoids those limitations, that promulgated in Texas, imposes a draconian process for resolving futility disputes—one

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204. Pope, *No Safe Harbor*, *supra* note 68, at 68.

that eviscerates due process.<sup>205</sup> Court review, in its turn, brings the benefits of enforceability. But courts are limited by the terms of their task. In that regard, hospital ethics consultants are more likely to exercise flexibility and to be free to attend to each of the stakeholders and to all of them, as a group. That can carry great significance in cases almost always identified with human emotion and that occasion ultimate questions about life and death. Hospital ethicists are equipped to encourage the development of relationships and to guide those involved in futility disputes to listen carefully to each other. In that light, hospitals should be encouraged to support ethics services and to ensure that ethics consultants are wisely trained.

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205. *See supra* Section III.B and accompanying text (reviewing the Texas Advance Directive Law).