



2020

Remaking the “Right to Die”: Give Me Liberty but Do Not Give Me Death

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Recommended Citation

Janet L. Dolgin, *Remaking the “Right to Die”: Give Me Liberty but Do Not Give Me Death*, 73 SMU L. REV. 47 (2020)

<https://scholar.smu.edu/smulr/vol73/iss1/5>

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REMAKING THE “RIGHT TO DIE”: GIVE ME LIBERTY BUT DO NOT GIVE ME DEATH

Janet L. Dolgin*

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I. INTRODUCTION

VISIONS of death and dying have shifted as society’s moral framework—including its understanding of personhood and community—has shifted. As early as the nineteenth century, in the West,

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the vision of death and dying changed as medical events displaced understandings grounded on religious presumptions. The medicalization of death and dying has spawned disputes about the terms of death and the details of dying among patients, medical clinicians, patients' family members and loved ones, and lawmakers.

By the last several decades of the twentieth century, U.S. law granted competent patients, and then more hesitantly the surrogate decision makers of patients without capacity, the right to withhold or withdraw life-sustaining care. The most well-known cases confirming the right of capable patients to make their own end-of-life decisions—*In re Quinlan*¹ and *Cruzan v. Director, Missouri Department of Health*²—involved young women in persistent vegetative states whose family members sought to withdraw ventilatory assistance or assisted nutrition and hydration while the patient's physicians and/or the facility in which the patient was receiving care preferred that life-sustaining care be continued. In a third—*In re Schiavo*³—also involving a young woman in a persistent vegetative state, a dispute about the withdrawal of life-sustaining care split the patient's family. The right at issue in all of these cases—sometimes labeled the “right to die”⁴—gained widespread support by the end of the twentieth century.

Soon, other types of disputes about death and dying replaced those about a patient's (or patient's surrogate's) right to withhold or withdraw life-sustaining care. This article focuses on disputes about dying that contrast with those involved in *Cruzan*, *Quinlan*, and *Schiavo*. In the disputes considered in this article, the patient or the patient's surrogate requests the continuation of life-sustaining care while the patient's clinicians, believing further care to be without purpose and potentially a cause of suffering for the patient, seek to terminate care. These disputes are proving more challenging than those in which patients or surrogates have sought to terminate care.

Medicine and law have developed—and continue to develop—responses to these cases, but none has proven widely acceptable. Even more, the deep discomfort that these cases provoke is troubling for all participants. Yet, attempted solutions that mandate the termination (or continuation) of care have been problematic. This article criticizes both responses that facilitate the prolongation of dispute and those that displace flexibility and uncertainty with rigid rules. The Texas Advance Directive Act (TADA) illustrates the second type of response.⁵

1. 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976).

2. 497 U.S. 261 (1990).

3. No. 990-2908GD-003, 2000 WL 34546715 (Fla. Cir. Ct. Feb. 11, 2000) (original trial court order to allow removal of feeding tube).

4. *Right to Die*, LEGAL DICTIONARY (Oct. 14, 2016), <https://legaldictionary.net/right-to-die/> [<https://perma.cc/E68W-HX4R>].

5. See Texas Advance Directive Act (TADA), TEX. HEALTH & SAFETY CODE ANN. §§ 166.001–.093 (West 2019).

Part II of this article is offered by way of background to consideration of the challenges presented by medical futility disputes. It summarizes social and legal responses in the last decades of the twentieth century to patients and patients’ surrogates who sought to withhold or withdraw life-sustaining care in the face of resistance by clinicians and hospitals, as well as responses to the notion of brain death and to physician-aid-in-dying (PAD) and euthanasia. Then, Part III considers disputes about care deemed “futile”⁶ by a patient’s clinicians but not by the patient (or the patient’s surrogate decision makers). These disputes have proved disconcerting to almost all of those involved in them. Part III analyzes the challenges at the center of “futility” disputes and aims to explain the failures of society, the law, and medicine to craft successful responses. Part IV considers the response to futility disputes promulgated by the Texas legislature. Part V then suggests an alternative approach to such cases, one that avoids the shortfalls of the Texas law.

II. CHANGING VISIONS OF DYING AND DEATH

This part reviews responses to death and dying in the West, and especially in the United States, since the medicalization of death in the nineteenth century. First, it considers the development of a legal right to die. It then reviews the notions of brain death and PAD. The concerns addressed in this part provide background for the continuing challenges about death and dying that are reviewed in Part III.

A. THE MEDICALIZATION OF DYING AND DEATH

Beginning in the nineteenth century, Western society began to medicalize dying and death. With this shift, scientific authority replaced religious authority. By the end of the nineteenth century, the physician had replaced the priest as the expert who attended to the dying patient.⁷ And the process of dying became increasingly opaque to those involved. These shifts were supported by the development of life-sustaining treatment, including effective ventilatory support⁸ and feeding tubes.⁹ Those developments reshaped the process of dying during the last half-century.

6. Increasingly, clinicians refrain from using the word “futile” to describe care they believe has no useful purpose. Alternatives to the term “futile” include “inappropriate,” “ineffective,” and “not medically indicated.” See, e.g., Cheryl J. Misak et al., *Medically Inappropriate or Futile Treatment: Deliberation and Justification*, 41 J. MED. & PHIL. 90, 90–91 (2016); *Medically Ineffective Interventions*, AM. MED. ASS’N, <https://www.ama-assn.org/delivering-care/ethics/medically-ineffective-interventions> [<https://perma.cc/LTZ4-NCHV>] (last visited Sept. 10, 2019).

7. See PHILLIPE ARIÈS, *THE HOUR OF OUR DEATH* 562–63 (Helen Weaver trans., 1987).

8. See John J. Marini, *Mechanical Ventilation: Past Lessons and the Near Future*, 17 CRITICAL CARE, Supp. 1, 2013, at 1, <http://www.ccforum.com/content/17/S1/S1> [<https://perma.cc/WY8J-PMHD>].

9. See Sylvia Kuo et al., *Natural History of Feeding Tube Use in Nursing Home Residents with Advanced Dementia*, 10 J. AM. MED. DIRECTORS ASS’N 264, 265 (May 2009).

The opacity that accompanied dying began with the medicalization of death. It has been deepened by the illusion that death could be endlessly postponed by the prolongation of dying. That illusion encouraged a culture of lies that was appropriated by clinicians, patients, and family members.¹⁰ Phillippe Ariès wrote of the response of a French priest, Father de Dainville, to his own dying in a New York hospital in 1973. Speaking to a fellow member of the Catholic clergy from the hospital's intensive care unit, "with tubes all over his body," Father de Dainville exclaimed: "They are cheating me out of my own death!"¹¹ Ariès compares de Dainville's lament with Tolstoy's description of Ivan Ilyich's dying in the late nineteenth century.¹² The commitment of all of those involved in Ilyich's dying to lie about that reality "degraded the formidable and solemn act of his death."¹³

The development of effective methods for providing respiratory support¹⁴ and enteral feeding¹⁵ has allowed patients unable to breath or to receive hydration and nourishment by mouth to continue living for significant periods of time. These developments create challenges and often significant distress for patients and, as often, for their family members. In the years just after these developments appeared, physicians assumed a duty to provide life-sustaining treatment for as long as a patient continued to breathe.¹⁶ Yet, within a few decades after Father de Dainville re-pined medicine's redesign for dying, U.S. society and the law began to question the presumption that a patient's death should be denied and that the dying process should always be prolonged. By the late 1970s, patients and their family members openly challenged the legitimacy of that assumption. The next section reviews legal responses to those challenges.

B. A "RIGHT TO DIE"?

Three cases decided in the last decades of the twentieth century and the first decade of the twenty-first century, all involving young women in persistent vegetative states, garnered significant public attention and ushered in a new set of legal and social assumptions about the prolonga-

10. See ARIÈS, *supra* note 7, at 565–67.

11. *Id.* at 567.

12. See generally LEO TOLSTOY, *THE DEATH OF IVAN ILYICH* (1886) (Richard Pevear & Larissa Volokhonsky trans., 2012).

13. ARIÈS, *supra* note 7, at 567.

14. See Marini, *supra* note 8, at 2.

15. See Kuo, *supra* note 9, at 265. Percutaneous gastrostomy tubes, developed in 1979, have allowed for assisted feeding without surgery. See generally *Percutaneous Endoscopic Gastrostomy, 1971*, CASE W. RES. U.: DITTRICK MED. HIST. CTR., <http://artsci.case.edu/dittrick/online-exhibits/explore-the-artifacts/percutaneous-endoscopic-gastrostomy-1979> [<https://perma.cc/HJ5H-MF3X>] (last visited Sept. 10, 2019).

16. See, e.g., *In re Quinlan*, 348 A.2d 801, 818 (N.J. Super. Ct. Ch. Div. 1975) ("A patient is placed, or places himself, in the case of a physician with the expectation that he will do everything in his power, everything that is known to modern medicine, to protect the patient's life. He will do all within his human power to favor life over death.").

tion of life-sustaining care.¹⁷ The first of these cases, *In re Quinlan*, crafted a significantly novel understanding of the right of patients or their surrogate decision makers to seek to withhold or withdraw life-sustaining care even as the patient’s physicians sought the continuation of that care.¹⁸ Justice Hughes, who authored the decision in *Quinlan* for New Jersey’s highest court, acknowledged that physicians were almost unanimously opposed to withdrawing life-sustaining care.¹⁹ Yet, concluding that, were the patient—Karen Quinlan—competent, she would have chosen to have had ventilatory support discontinued,²⁰ Justice Hughes transferred the right to authorize the withdrawal of care to Karen’s father.²¹

The second case, *Cruzan v. Director, Missouri Department of Health*,²² is less far-reaching than *Quinlan* but was important when it was decided because it provided an occasion for the U.S. Supreme Court to assert its assumption that a competent adult has the right to have life-sustaining care withheld or withdrawn.²³ The third of these cases, *In re Schiavo*,²⁴ did not establish new law. The case, occasioned by a dispute between Terri Schiavo’s husband, who wanted Terri’s life-sustaining care withdrawn, and Terri’s parents, who wanted care continued,²⁵ was significant because it attracted public attention for several years, bringing squarely into the public arena the implications of a surrogate’s efforts to withdraw a patient’s life-sustaining care.²⁶

By the last decades of the twentieth century, states widely promulgated laws that facilitated advance care planning (ACP) and enabled appointment of a surrogate decision maker authorized to make medical decisions for the principal should he or she need medical care but no longer enjoy capacity to make his or her own medical decisions.²⁷ Further, in 1993 the

17. See generally *id.*; *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261 (1990); *In re Schiavo*, No. 990-2908GD-003, 2000 WL 34546715 (Fla. Cir. Ct. Feb. 11, 2000) (original trial court order to allow removal of feeding tube).

18. See *Quinlan*, 355 A.2d at 671.

19. All of Karen Quinlan’s physicians, the hospital in which she was receiving care, and the state of New Jersey opposed the request of Karen’s father, Joseph Quinlan, to withdraw ventilatory support from Karen. See *id.* at 653.

20. *Id.* at 663.

21. *Id.* at 671.

22. 497 U.S. 261.

23. In *Cruzan*, the Supreme Court refused to identify a constitutional right for a patient’s surrogate decision maker to authorize the withholding or withdrawing of care. The decision did not preclude states from offering that right but did not require them to do so. *Id.* at 285–87.

24. *In re Schiavo*, No. 990-2908GD-003, 2000 WL 34546715 (Fla. Cir. Ct. Feb. 11, 2000) (original trial court order to allow removal of feeding tube).

25. *Id.* at *2.

26. See, e.g., E. Racine et al., *Media Coverage of the Persistent Vegetative State and End-of-Life Decision-Making*, 71 *NEUROLOGY* 1027, 1027–28 (2008). By the time Terri Schiavo’s case was brought to court (at the start of the twenty-first century), people widely relied on the internet to further discourse about matters of public interest. See, e.g., ERIC C. NEWBURGER, U.S. CENSUS BUREAU, HOME COMPUTERS AND INTERNET USE IN THE UNITED STATES: AUGUST 2000, at 8 (Sept. 2001), <https://www.census.gov/prod/2001pubs/p23-207.pdf> [<https://perma.cc/7CZJ-LBW2>].

27. See, e.g., N.Y. PUB. HEALTH LAW § 2981(1)(b) (McKinney 2019). In 1990, Congress passed the Patient Self-Determination Act, Pub. L. No. 101-508 § 4206, 104 Stat. 1388

Uniform Law Commission, through the Uniform Health-Care Decisions Act (UHCDA), identified surrogate decision makers in order of priority for patients without capacity who had left no guidance while competent.²⁸ By that time, most states had already promulgated ACP laws.²⁹ As a result, only a few states appropriated the model supplied by the UHCDA.³⁰ However, most state laws did facilitate surrogate decision-making for patients without capacity, whether or not a particular patient completed ACP documentation.³¹ These laws have institutionalized the right of the autonomous individual to make medical decisions, even if those decisions are likely to result in death, and the right to exercise one's autonomy vicariously through a surrogate decision maker.

As important, in 2015, the Centers for Medicaid and Medicare Services (CMS) finalized two payment codes that covered the cost of clinicians' conversations with patients about their medical preferences should they become seriously ill but no longer enjoy decision-making capacity.³² The codes are intended to pay clinicians for conversations with patients about ACP documentation, including discussion of the patient's preferences for medical care should he or she lose decision-making capacity.³³

The payment is moderate.³⁴ However, an indirect, but very important, consequence of CMS's having included these billing codes is that the codes categorize ACP conversations as a legitimate component of good health care. In short, by the start of the twenty-first century, the right sought in *Quinlan* and *Cruzan*—the right to die—had been accepted by law and society in the United States.

(1990) (codified as amended in scattered sections of 42 U.S.C.). That law mandates that hospitals receiving federal money (e.g., through Medicare) respect patients' advance directives and inform patients about the opportunity to complete ACP documentation. By the start of the twenty-first century, all states had passed laws that facilitated ACP. See Janet L. Dolgin, *Dying Discourse: Contextualizing Advance Care Planning*, 34 QUINNIPIAC L. REV. 235, 267 (2016).

28. Unif. Health-Care Decisions Act § 5(b)–(c), 9 U.L.A. 93 (1993).

29. See David M. English, *The Uniform Health-Care Decisions Act and Its Progress in the States*, 15 PROB. & PROP. 19, 19–20 (2001).

30. See *id.* at 20.

31. See *id.* at 19–20.

32. Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 70, 955–56 (Nov. 16, 2015). See generally *Advance Care Planning*, CTRS. FOR MEDICARE & MEDICAID SERVS.: THE MEDICARE LEARNING NETWORK (Aug. 2019), <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf> [<https://perma.cc/Q8MT-CPH9>]; *FAQs: Advance Care Planning Under Medicare*, COAL. FOR COMPASSIONATE CARE CAL. (Nov. 2017), <http://polst.org/wp-content/uploads/2018/01/2017.11-Advance-Care-Planning-Under-Medicare-CMS-ACP-Codes-FAQs-CCCC.pdf> [<https://perma.cc/5KYB-4BEH>].

33. See *Advance Care Planning*, *supra* note 32.

34. Medicare paid up to \$86 for a half hour ACP conversation in 2016. Nancy K. Zeitoun, *New Medicare Rule Will Reimburse Physicians for Advance Care Planning*, HOSPITALIST (Nov. 2015), <https://www.the-hospitalist.org/hospitalist/article/122030/health-policy/new-medicare-rule-will-reimburse-physicians-advance-care> [<https://perma.cc/4TBN-AAXM>].

C. BRAIN DEATH AND PHYSICIAN-AID-IN-DYING (PAD)

This section summarizes additional developments in understandings of death and dying in the last years of the twentieth century and the first years of this century. These include identification of the notion of “brain death” in 1968 and the trend toward legalization of PAD. First, this section reviews the notion of brain death. It is of significance to this article insofar as the notion has proved consequential to continuing debate about futile care, considered in Part III. In addition, this section reviews the law’s response to the aid-in-dying movement in the present century.

The notion of brain death was proposed by an ad hoc committee at Harvard Medical School in the 1960s. Less than a decade before Justice Hughes, for the New Jersey Supreme Court, rendered the decision in *Quinlan*, the committee issued its report approving of the notion of brain death as adequate evidence of death and, thus, as an alternative to cardiopulmonary evidence of death.³⁵ In short, the committee expressly identified brain death as an alternative to the cessation of breathing and heart activity for establishing death.³⁶ Initially, Karen’s father Joseph Quinlan seeking appointment as his daughter’s guardian, contended in his petition to the New Jersey courts that Karen was, in fact, dead according to brain death criteria.³⁷ That was not the case, a matter that Joseph later acknowledged.³⁸ However, the initial claim brought the notion of brain death squarely into the arena of discussions about withdrawing life-sustaining treatment. Further, the notion suggests a paradigmatic illustration of futile treatment. There is continuing debate about the implications of brain-dead determinations.³⁹ However, for those who are clearly determined to be dead, continuing medical treatment lacks justification.⁴⁰

Since the early 1970s, society has become more familiar with the notion of brain death. Every state in the United States now recognizes the neurological indicia associated with the notion of brain death as a means of establishing legal death.⁴¹ This notwithstanding, there remains doubt among certain neuroscientists about the implications of determining

35. See Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 JAMA 337, 337 (1968).

36. Establishing brain death depended on the cessation of breathing without assistance, reflexes, and movement, as well as a flat electroencephalogram. *Id.* at 338–39.

37. *In re Quinlan*, 348 A.2d 801, 806 (N.J. Super. Ct. Ch. Div. 1975).

38. *Id.*

39. See, e.g., Radhika Viswanathan, *There’s a Surprisingly Rich Debate About How to Define Death*, VOX (Aug. 5, 2018), <https://www.vox.com/2018/8/6/17635098/jahi-mcmath-2018-brain-death-definition> [<https://perma.cc/8SRL-M9T4>].

40. Even if a determination of death would seem definitive with regard to the usefulness of continuing care, the case of Jahi McMath, who was pronounced brain dead in 2017 and dead by cardiopulmonary standards in 2018, raised new questions about the notion of brain death. See, e.g., *id.*

41. Nikolas T. Niokas et al., *Determination of Death and the Dead Donor Rule: A Survey of the Current Law on Brain Death*, 41 J. MED. PHIL. 237, 242 (2016). In both New Jersey and New York, if hospitals know of a patient’s religious (or in New York, religious or moral) objection to the notion of brain death, the hospitals must look to cardiopulmonary factors in order to pronounce a patient dead. *Id.* at 245.

death through reference to neurological criteria.⁴² As noted, the notion of brain death and the continuing uncertainty about its implications become important to the cases involving medical futility that are considered in Part III of this article.

The movement to provide for PAD, sometimes referred to as physician-assisted suicide (PAS), represents an additional strand in developing understandings of death and dying. Oregon passed the first law allowing a physician to respond positively to a patient's request for medical assistance that will result in the patient's death.⁴³ By mid-2019, eight states and Washington, D.C., provided for PAD.⁴⁴ These laws authorize physicians to comply with the request of a terminally ill patient to receive a prescription for lethal medication.⁴⁵ Generally, there is a mandatory waiting period between the patient's initial request for PAD and the provision of a prescription,⁴⁶ and patients must self-administer the medication.⁴⁷ Between passage of the Oregon Death with Dignity Act in 1997 and mid-2019, 2,217 people in Oregon received prescriptions for lethal medication, and 1,459 people died from administration of the medication.⁴⁸ Many patients have sought lethal medication to preserve a choice but then die without administering the medication.⁴⁹

The movement to accept PAD as a dignified mode of death for terminally ill patients has gained significant acceptance in the United States and even greater acceptance in Europe.⁵⁰ A full review of PAD is beyond the scope of this article. Yet, the movement and its growing acceptance within the states are important to the article insofar as they reflect a significant transformation in social understandings of dying and death in the

42. See Joseph L. Verheijde et al., *Neuroscience and Brain Death Controversies: The Elephant in the Room*, 57 J. RELIGION & HEALTH 1745, 1750 (2018).

43. Oregon Death with Dignity Act, OR. REV. STAT. ANN. §§ 127.800–897 (West 2018). Three years earlier, state voters passed a ballot initiative providing for PAD. That law did not become effective. See *Chronology of Assisted Dying in the U.S.*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/assisted-dying-chronology/> [https://perma.cc/6DG2-QSHB] (last visited Sept. 10, 2019).

44. *Chronology of Assisted Dying in the U.S.*, supra note 43. The states included California, Colorado, Hawaii, Maine, New Jersey, Oregon, Vermont, and Washington. *Death with Dignity Acts*, DEATH WITH DIGNITY, www.deathwithdignity.org/learn/death-with-dignity-acts [https://perma.cc/46EQ-7FKL] (last visited Oct. 30, 2019). In addition to these states and the District of Columbia, Montana's Supreme Court offered protection to physicians who help patients die. However, the court's decision did not offer a framework within which to regulate PAD. *Baxter v. Montana*, 224 P.3d 1211, 1218, 1220–21 (Mont. 2009).

45. See, e.g., Oregon Death with Dignity Act §§ 127.800–897.

46. *Id.* at §§ 127.815(1)(h), 127.855.

47. *Id.* at § 127.815(1)(C)(g) (guiding patients to have “another person present” when the medication is taken).

48. OR. HEALTH AUTH., OREGON DEATH WITH DIGNITY ACT: 2018 DATA SUMMARY 5 (Feb. 15, 2019), <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/Documents/year21.pdf> [https://perma.cc/3ZB9-BAQH].

49. *Id.*

50. Euthanasia, not legal anywhere in the United States, differs from PAD in that it can be carried out for patients unable to administer lethal medication to themselves. Yvette Brazier, *What Are Euthanasia and Assisted Suicide?*, MED. NEWS TODAY, <https://www.medicalnewstoday.com/articles/182951.php> [https://perma.cc/RML7-NHVU] (last updated Dec. 17, 2018).

last half-century. The scope of the transformation can be discerned by noting the summary of society’s vision of the physician’s role for dying or seriously ill patients, offered by Judge Muir for a New Jersey trial court in 1975 in *Quinlan*:

There is a higher standard, a higher duty, that encompasses the uniqueness of human life, the integrity of the medical profession and the attitude of society toward the physician, and therefore the morals of society. A patient is placed, or places himself, in the care of a physician with the expectation that he (the physician) will do everything in his power, everything that is known to modern medicine, to protect the patient’s life. He will do all within his human power to favor life against death.⁵¹

That view is now a historic vestige.

III. “FUTILE” CARE?

Indeed, within a decade of the 1975 summary offered by the trial court in *Quinlan*, society, lawmakers, and physicians questioned the sentiment described; one that was widely assumed when the *Quinlan* case was brought to court in the mid-1970s. That change is clearly indicated by the appearance of the notion of futile care, raised primarily in hospital settings with regard to patients deemed terminally ill. This part considers the difficult bioethical challenges occasioned by situations in which clinicians seek the termination of life-sustaining care, even as patients or, more likely, their surrogate decision makers, ask that care be continued.

Section A of this part reviews factors that encouraged clinicians to abandon the perspective ascribed to them by Judge Muir in 1975—that doctors “will do all within human power to favor life against death.”⁵² It then suggests challenges occasioned by attempts even to define futile treatment. Today, medical clinicians do not always favor “life against death,”⁵³ as that phrase was understood in 1975. In a sharp reversal from the days of *Quinlan*, physicians now justify the recommendation that care deemed futile be discontinued with reference to the obligation of physician beneficence. Thus, for clinicians, definitions of futile care (often now referred to through alternative phrases) harmonize with understandings of clinician beneficence.

Section B summarizes the respective roles of hospital ethics consultants and courts in responding to futility disputes. Section C focuses on two court cases occasioned by disagreements about the presumptive futility of a patient’s care. Then, Part IV examines one legislative response to futility disputes—that of Texas.⁵⁴

51. *In re Quinlan*, 348 A.2d 801, 818 (N.J. Super. Ct. Ch. Div. 1975) (footnote omitted).

52. *Id.*

53. *Id.*

54. *See generally* Texas Advance Directive Act (TADA), TEX. HEALTH & SAFETY CODE ANN. §§ 166.001–.209 (West 2019).

A. DEFINITIONS OF AND JUSTIFICATIONS FOR DEEMING CARE
“FUTILE”

Howard Brody summarized the challenge presented by futile care with two questions:

1. Are there medical interventions in a specific patient with a particular disease that we can label *futile* or *useless* because we are sufficiently confident that they will not be beneficial?
2. If so, are physicians entitled, or indeed obligated, to refuse to provide those interventions to the patient in question even if the treatment is requested or demanded by the patient or appropriate surrogate?⁵⁵

Brody's first question suggests the difficulty faced by anyone attempting to define futile care. The question, as phrased, subsumes additional questions about the meaning of “sufficiently confident” and of “beneficial.” Brody's second question implicates lines of decision-making authority for dying patients among the patient (whose view may be delineated in an advance directive), the patient's surrogate decision maker, and the patient's clinicians. Both questions have resisted easy, satisfying answers. This section reviews the technological and ideological factors behind construction of the notion of futile care. It then focuses on the definitional issues that continue to shape understandings of medical futility. Sections B and C of this part, as well as the next part of this article, focus on efforts to respond to Brody's second question.

1. *Factors that Facilitated Development of the Notion of Medical Futility*

The transformations in hospital care for dying and very ill patients during the last several decades of the twentieth century, including the availability of respiratory support and assisted nutrition and hydration,⁵⁶ as well as the increasing readiness of law and society to grant surrogate decision makers the decisional authority that would belong to the patient were he or she capable, occasioned increasingly complex dilemmas about when to forego life-sustaining care.⁵⁷

These disputes generally arise when a patient, or more likely his or her surrogate, hopes to continue care that the patient's physicians consider futile (often characterized not as futile, but as ineffective or inappropriate). For patients or their surrogates, futility disputes reflect confusion about their presumptive right to make medical decisions, even if those

55. Howard Brody, *Medical Futility: A Useful Concept?*, in *MEDICAL FUTILITY AND THE EVALUATION OF LIFE-SUSTAINING INTERVENTIONS 1* (Marjorie B. Zucker & Howard D. Zucker eds., 1997).

56. See generally Marini, *supra* note 8; *Percutaneous Endoscopic Gastronomy, 1979*, *supra* note 15.

57. Alexander Morgan Capron, *Foreword*, in *MEDICAL FUTILITY AND THE EVALUATION OF LIFE-SUSTAINING INTERVENTIONS*, *supra* note 55, at ix-x.

decisions are not the ones that the patients’ clinicians recommend.⁵⁸ That confusion can engender patient and surrogate distrust of those providing clinical care.

In the right-to-die cases entertained in the last few decades of the twentieth century, courts assumed a patient’s right to request the withholding or withdrawal of life-sustaining care.⁵⁹ More broadly, those cases reflected a process in which patient autonomy increasingly displaced physician paternalism.⁶⁰ Yet, futility disputes challenge that model in that they involve clinicians seeking unilateral decision-making authority to withdraw life-sustaining care in cases in which they deem that care futile. In effect, futility disputes have facilitated physicians’ successfully challenging the increasing ubiquity of patient autonomy.⁶¹

A perceived need to ration medical care has provided another factor associated with futility determinations.⁶² At least in theory, however, decisions about futile care and the need to ration care are distinct. The first concerns decisions about medical care for particular patients. The second, a matter of social justice, focuses on considerations of cost and the distribution of scarce resources.⁶³ Yet, concerns about overuse of scarce resources can be the elephant in the room of futility determinations.⁶⁴

2. Definitions of “Futile” Treatment

Construction of the concept of futile care has spawned definitional conundrums that reflect the underlying challenge occasioned by the concept itself. A fairly straightforward scenario suggests the extent to which definitions of futility depend on perspective. In this scenario, physicians deem life-sustaining care futile because the condition of a particular patient, reliant on ventilatory support and on a feeding tube, seems exceedingly unlikely to improve. Everyone involved in medical decision-making for this patient may accept that assessment but still not agree that care is

58. Steven R. Leuthner, *Futility: Interpretation and Usefulness in Clinical Practice*, 18 HEALTH MATRIX 245, 254 (2008) (“[T]he futility cases that stimulate moral distress are really end-of-life cases; if treatment is stopped the patient will die.”).

59. See, e.g., *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 279 (1990) (assuming, “for purposes of this case,” that the Constitution “would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition”).

60. See MARSHA GARRISON & CARL E. SCHNEIDER, *THE LAW OF BIOETHICS: INDIVIDUAL AUTONOMY AND SOCIAL REGULATION* 41 (2003).

61. See Capron, *supra* note 57, at x–xi. Other contexts in which the clinician’s right to challenge patient choices has gained momentum include reproductive care and PAD. See Nadia N. Sawicki, *Mandating Disclosure of Conscience-Based Limitations on Medical Practice*, 42 AM. J.L. & MED. 85, 88–89 (2016).

62. See Capron, *supra* note 57, at xi.

63. Bryan Rowland, Comment, *Communicating Past the Conflict: Solving the Medical Futility Controversy with Process-Based Approaches*, 14 MIAMI INT’L & COMP. L. REV. 271, 279–80 (2006). In Britain, the National Health System is authorized “to ration care based on clinical guidelines that blend efficacy of outcomes, quality of life judgments, and economics.” *Id.* at 275.

64. Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 GA. ST. U. L. REV. 893, 903 (2017) (noting that, in the United States, medical care is rarely rationed overtly).

futile. For the patient, if competent, and for the patient's family members and dear friends, the fact that the care at issue is necessary to sustain the patient's life may be enough to render that care useful. The care is doing what they want it to do.

Dr. Bernard Lo, who characterized the term "futility" as "fraught with confusion, inconsistency, and controversy,"⁶⁵ has distinguished situations in which it may be reasonable to deem care futile and situations in which that characterization can more easily be challenged. In the first category of situations, Dr. Lo included cases in which the care involved does not have a rationale grounded in an understanding of pathophysiology;⁶⁶ cases in which the patient has not responded positively to the care at issue;⁶⁷ and cases in which the care requested has been tried but the patient has not responded to it.⁶⁸ Dr. Lo concluded that doctors are not obliged to provide interventions in such situations and may even "have an ethical obligation not to provide them."⁶⁹

Dr. Lo delineated a second category of situations in which care may be deemed futile but in which the assessment involves "contested value judgments."⁷⁰ These situations are viewed as more likely to occasion legitimate controversy about the ascription "futile" than those in the first category that Dr. Lo delineated. This second category of situations includes cases in which the likelihood that the proposed intervention will help the patient is "extremely small" but more than zero; cases in which the quality of the patient's life is considered so poor that treatment is not viewed as warranted; and cases in which the benefit promised seems too small to justify the resources required to achieve that benefit.⁷¹

65. BERNARD LO, RESOLVING ETHICAL DILEMMAS: A GUIDE FOR CLINICIANS 71–76 (5th ed. 2013) (providing the example of a family asking for an antibiotic to which the organism making the patient sick is known to be resistant).

66. *Id.* Dr. Lo illustrates the category of cases without a pathophysiological rationale with the case of a seventy-four-year-old female suffering from septic shock. Her family requests that a particular antibiotic be administered to the patient. The organism from which the patient is suffering is resistant to the antibiotic that the family wants administered. Dr. Lo comments: "No clinical or physiologic benefit can be expected." *Id.* at 71. A second illustration presents the same patient, now comatose, needing dialysis and a ventilator. She is suffering from progressive multiorgan failure. *Id.* The patient's doctors do not believe that cardiopulmonary resuscitation (CPR) would restore this patient's circulation effectively. *Id.* at 72. A third illustration describes a patient for whom CPR was attempted for thirty minutes. This did not result in a "spontaneous cardiac rhythm or circulation." *Id.* The patient's family members asked that CPR be continued. Dr. Lo comments that "it is pointless to continue or repeat interventions that have already failed." *Id.*

67. *Id.* (providing the example of a patient whose circulation cannot be supported "despite all appropriate therapy" but whose family asks that CPR be provided if the patient experiences cardiopulmonary arrest).

68. *See id.* (providing the example of a patient suffering cardiac arrest for whom "adequate" CPR is provided for thirty minutes without a response; continuing CPR would be futile); *see also* Brody, *supra* note 55, at 2 (citing Lo, *supra* note 65, at 71–75).

69. Lo, *supra* note 65, at 72.

70. *Id.*

71. *Id.* at 73 (noting that some may see a one-percent chance that an intervention will be helpful as worth attempting); *see also* Brody, *supra* note 55, at 1–2.

A finding of futility in each of the situations included in the second category of futility cases identified by Dr. Lo depends on the assessor’s perspective. It is, in that regard alone, open to challenge. Dr. Lo reported that unilateral decisions by physicians to terminate care “commonly antagonize patients and surrogates.”⁷²

Dr. Lo explained that physicians sometimes confuse futile care with care that they do not believe serves the patient’s best interests.⁷³ That confusion suggests a serious flaw at the center of futility determinations. The “best interest” rule is inevitably subjective. Conflating it with decisions about the futility or usefulness of medical care reveals the underlying challenge presented by the second category of futility cases that Dr. Lo delineated.

In light of this, Dr. Lo concluded that the implications and scope of the notion of futility may be so speculative that the notion should be abandoned or extensively modified.⁷⁴ Alternative terms have been proposed.⁷⁵ Alternatives have included “medically or ethically inappropriate” care,⁷⁶ “medically ineffective treatment,”⁷⁷ and care that is “not medically indicated.”⁷⁸ Such terms may suggest a broader category of cases than does the term “futility.” However, they are often treated as synonyms for futility. Although alternative terms do not significantly alter the underlying conundrums raised by the notion of futile care, they may soften the implications of the debate and reshape arguments about futility determinations. Use of the terms “inappropriate” and “ineffective” care instead of “futile” care may, for instance, mitigate any suggestion, potentially intuited by the patient or his or her loved ones in the context of futility disputes, that the patient (rather than the patient’s condition) has been deemed to lack continuing worth (i.e., that the patient’s life and personhood have become futile). Yet, alternative language, precisely because it is less jarring, may prematurely sway the shape of discourse surrounding particular cases.

B. CLINICAL AND LEGAL RESPONSES TO FUTILITY DISPUTES

Futility disputes are especially challenging because they are clouded by several levels of uncertainty. A decision to withhold or withdraw care is

72. LO, *supra* note 65, at 74.

73. *Id.*

74. *Id.*

75. This article continues to use the terms “futile” and “futility” for the sake of consistency and to frame the most challenging issues at stake in these cases.

76. *See, e.g.*, VA. CODE ANN. § 54.1-2990 (West 2019) (medically unnecessary health care is not required; leaving term undefined).

77. *See, e.g.*, MD. CODE ANN., HEALTH-GEN. § 5-611(b)(2)(1) (West 2017) (defining “medically ineffective treatment” as treatment “that, to a reasonable degree of certainty . . . will not (1) Prevent or reduce the deterioration of the health of an individual; or (2) Prevent the impending death of an individual”). *Id.* § 5-601(o).

78. LO, *supra* note 65, at 72.

likely to result in the patient's death, but not always,⁷⁹ and there is often uncertainty about the patient's prognosis if care is continued. Compounding these forms of uncertainty, it is not always clear who has the ultimate authority to make medical decisions in these cases. Each level of uncertainty can exacerbate moral distress and tension among all stakeholders.

Well-trained hospital ethics consultants respond with significant success to futility disputes.⁸⁰ They focus on the nuances of stakeholders' needs and concerns and often mediate disputes about patient care so that the parties reach agreement. The ethicist's work is almost always labor-intensive and can thus be expensive.⁸¹ When successful, it is well worth the cost.⁸² Sometimes, however, ethicists are not easily accessible or are unable to help the parties locate a position on which they can agree. In those situations, most states provide dissatisfied parties the right to seek court review.⁸³

Judges, responsible for court review of futility disputes, do not generally understand the nuances of patient care and the stakeholders' varied needs as thoroughly as hospital ethicists do. However, the right to court review is essential. It offers stakeholders an opportunity to be heard before a presumptively neutral decisionmaker, and it provides closure to disputes about patient care but only after the parties' concerns have been entertained by ethicists and then by one or more judges.

Further, some state legislatures have promulgated statutory responses that, on the whole, have received physician support, even though the laws have generally not provided secure safe-harbors for physicians.⁸⁴ This article focuses on one state law—the law promulgated in Texas. The Texas law delineates a process that promises to resolve futility disputes without protracted litigation. This article contends that the price of the process outlined in the Texas law is unacceptably high.

79. After Karen Quinlan's father gained the right to authorize withdrawal of ventilatory support from his daughter, she was weaned from the respirator that was thought to have been sustaining her life. Yet, she lived for almost a decade after that. Jill Lepore, *The Politics of Death*, *NEW YORKER* (Nov. 30, 2009), <http://www.newyorker.com/magazine/2009/11/30/the-politics-of-death> [<https://perma.cc/3DDS-VWHF>].

80. See Janet L. Dolgin, *Resolving Health Care Conflicts: A Comparative Study of Judicial and Hospital Responses*, 9 *WAKE FOREST J.L. & POL'Y* 495, 568–74 (2019) [hereinafter Dolgin, *Resolving Health Care Conflicts*].

81. See Janet L. Dolgin, *Medical Disputes and Conflicting Values: Is There a "Right to Die" Later?*, *BYU L. REV.* (forthcoming 2020) [hereinafter Dolgin, *Medical Disputes and Conflicting Values*]. Hospital ethics consultants are generally paid by the hospitals in which they work. Ethics committee members are almost always volunteers.

82. Successful ethics consultations may save money by precluding litigation and limiting time devoted to dispute resolution by clinicians. See Dolgin, *Resolving Health Care Conflicts*, *supra* note 80, at 571.

83. The Texas law considered in Part IV of this article is an exception. See, e.g., Texas Advance Directive Act (TADA), *TEX. HEALTH & SAFETY CODE ANN.* §§ 166.001–.093 (West 2019). TADA offers court review only for very limited purposes. See *infra* Part IV.

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

The next section of this part examines judicial approaches to futility disputes. Two cases serve to illustrate resolution of these disputes in courts. Part IV then considers the Texas Advance Directive Act (TADA). TADA’s approach to futility disputes depends on process rather than on substantive definitions of futility. The approach is fairly straightforward and lays out a path along which futility disputes can be decided definitively. But the flaws built into the Texas law outweigh the law’s benefits. TADA undermines due process protection and can eviscerate patient autonomy, effectively denying patients and surrogates the right to court review.⁸⁵

C. MEDICAL FUTILITY IN COURT

This section considers two futility disputes about patient care that were brought to court. The first case was initiated by a hospital physician during the patient’s life.⁸⁶ The second case, in contrast, decided seventeen years after the first, was brought by the patient’s family after her death.⁸⁷ In the first case, a Minnesota court sided with the patient’s family members.⁸⁸ In the second case, a court in California sided with the patient’s clinicians and the hospital in which the patient received care.⁸⁹

Dr. Steven Miles initiated court proceedings in *In re Conservatorship of Wanglie*.⁹⁰ A physician and member of the ethics committee at Hennepin County Medical Center where Helga Wanglie was a patient, Dr. Miles sought a court order to replace Helga’s husband, Oliver Wanglie, as Helga’s conservator.⁹¹ Dr. Miles grounded that request on Oliver’s refusal to “accept the advice and counsel of the physicians treating Helga Wanglie and refus[ing] to consent to remove the ventilator” that was keeping Helga alive.⁹² Helga and Oliver’s children supported Oliver’s choices regarding continued health care for their mother.⁹³

85. The statute provides for very limited appeal to a court to extend the time provided for identifying an alternative placement for a patient whose care has been deemed futile. Texas Advance Directive Act § 166.046(g).

86. *In re Conservatorship of Wanglie*, No. PX-91-283 (Minn. Dist. Ct. June 28, 1991), reprinted in 7 ISSUES L. & MED. 369, 370–72 (1991).

87. *Alexander v. Scripps Mem’l Hosp.*, La Jolla, 232 Cal. Rptr. 3d 733, 738 (Cal. Ct. App. 2018). Read together, these cases—though each is significantly different from the other—suggest the potential importance of family autonomy to the resolution of futility disputes. The notion offers an alternative to the presumption that autonomous decision-making belongs only to individuals and that someone must be nominated as the final decision maker. Hospital ethics consultants are generally aware of the significance of family autonomy and its role in the deliberations that surround an ethics consultation. See, e.g., Sheryl Mitnick et al., *Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships*, 25 J. GEN. INTERNAL MED. 255, 255–58 (2010). Family autonomy can offer an option to decision-making by individuals (a patient, a surrogate, or a clinician). Consideration of the implications of that suggestion is beyond this article’s reach.

88. See *Wanglie*, reprinted in 7 ISSUES L. & MED. at 372.

89. *Alexander*, 232 Cal. Rptr. 3d at 738.

90. See *Wanglie*, reprinted in 7 ISSUES L. & MED. at 369.

91. *Id.* at 371.

92. *Id.*

93. *Id.* at 372.

At the time, Helga, eighty-seven years old, had suffered cardiorespiratory arrest and severe anoxic encephalopathy.⁹⁴ She entered into a persistent vegetative state and was not expected to recover.⁹⁵ She was dependent on ventilatory support.⁹⁶ Helga's clinicians viewed the care she was receiving as inappropriate insofar as her prognosis was "dismal."⁹⁷ Helga's family viewed her care differently. For them, the care that Helga was receiving served useful ends: it kept Helga alive.⁹⁸

Judge Belois, writing for the probate court division of the Minnesota District Court, revealed her response to the case in the first sentence of her memorandum of law: "The Court is asked whether it is in the best interest of an elderly woman who is comatose, gravely ill, and ventilator-dependent to have decisions about her medical care made by her husband of fifty-three years or by a stranger."⁹⁹

Dr. Miles had not asked the court to discern the most appropriate medical care for Helga. He asked only that her husband be replaced as her decisionmaker.¹⁰⁰ In light of that request, Judge Belois confirmed Oliver's capacity to serve as his wife's conservator.¹⁰¹ Helga, still connected to the ventilator, died soon after the court issued its decision.¹⁰²

Judge Belois privileged Helga's family—Oliver and their adult children—as decision makers for their wife and mother, respectively, over a court-appointed conservator.¹⁰³ In doing so, she suggested that, in the context of disagreements about end-of-life care, medical decisions for incompetent patients are better left to the patient's loved ones than to the patient's clinicians.¹⁰⁴ Increasingly, however, courts and legislators have recognized the right of clinicians to refuse to provide care they deem inappropriate.¹⁰⁵

Alexander v. Scripps Memorial Hospital suggests that right.¹⁰⁶ The case resembles *Wanglie* as it involves the family members of a patient who joined in seeking continued care for their loved one despite the preference of the patient's clinicians to terminate care. In fact, Elizabeth Alexander, a seventy-year-old, died from pancreatic cancer several days after her transfer from a nursing facility to Scripps Memorial Hospital La Jolla,¹⁰⁷ but her family claimed that she had inappropriately been denied

94. *Id.* at 374.

95. *Id.* at 374–76.

96. John Doyle, *Medical Futility and the Tragic Case of Helga Wanglie* (Apr. 2004), www.medicalfutility.homestead.com [https://perma.cc/V6GQ-LL49].

97. *Id.*

98. *Id.*

99. *See Wanglie*, reprinted in 7 ISSUES L. & MED. at 376.

100. *Id.* at 372.

101. *Id.*

102. Doyle, *supra* note 96.

103. *Wanglie*, reprinted in 7 ISSUES L. & MED. at 372.

104. *Id.* at 377–78.

105. *See, e.g., Alexander v. Scripps Mem'l Hosp. La Jolla*, 232 Cal. Rptr. 3d 733, 760–61 (Cal. Ct. App. 2018).

106. *Id.*

107. *Id.* at 737.

life-sustaining care while at Scripps Memorial.

Significantly, Elizabeth, unlike Helga Wanglie, had completed an advance directive asserting that she wanted all measures taken that could sustain her life and appointing one of her children as her medical surrogate.¹⁰⁸ Yet, clinicians at the hospital declined to provide certain life-sustaining care to Elizabeth, asserting that that care would cause additional suffering for her and would be medically ineffective.¹⁰⁹

After Elizabeth’s death, her children sued the hospital. The litigation was prolonged.¹¹⁰ The plaintiffs brought a number of claims, including professional negligence and wrongful death.¹¹¹ The California appellate court that entertained the appeal of Elizabeth’s children affirmed a trial court decision for the defendants.¹¹²

The court noted that the hospital had informed Elizabeth’s son, Christopher, her appointed surrogate decision maker, that

physicians could not provide Elizabeth with care they determined was futile because doing so would be outside the bounds of their ethical duties as physicians. Defendants’ decisions to withhold the treatment requested in Elizabeth’s advance health care directive was consistent not only with their ethical duties, but also with the [state] Health Care Decisions Law. A physician may decline to comply with a patient’s health care instruction that requires medically ineffective health care, which is treatment that would not offer the patient any significant benefit.¹¹³

The court held for the defendants, in effect trumping Elizabeth’s own preference articulated in her advance directive that she be provided with “all measures” that might sustain her life.¹¹⁴ The court justified its decision, which seems to contravene the autonomy granted to patients in making health care decisions for themselves, by noting that physicians who act in good faith and in accordance “with the standard of care” gain protection from liability.¹¹⁵

Had hospital ethicists been able successfully to mediate among Elizabeth’s clinicians and her children before Elizabeth died—taking note of

108. *Id.* at 737–38.

109. *Id.* It is difficult to assess the sincerity of such claims. Robert Truog comments: In such situations [e.g., disputes about futile care], clinicians often justify their efforts to override the requests of family members by claiming that the continued use of life support is causing the patient unwarranted suffering or is contributing to an undignified death. Though sometimes valid, these arguments are difficult to sustain in cases like that of Emilio [the eighteen-month-old child discussed in Truog’s article] . . . [P]atients who require mechanical ventilation can always be made comfortable with sufficient doses of sedatives and analgesics

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

110. The process of discovery took three years. *Alexander*, 232 Cal. Rptr. 3d at 739.

111. *Id.* at 738.

112. *Id.* at 739–40.

113. *Id.* at 757–58.

114. *Id.* at 737.

115. *Id.* at 757.

the preferences of all parties—her children might have been left less frustrated and angry. The litigation initiated by Elizabeth’s children took many years¹¹⁶ and was presumably expensive. Yet, even as the California courts held against Elizabeth’s children, the children were privileged to be able to seek and obtain judicial review of their objection to the medical care that their mother received.

IV. TEXAS ADVANCE DIRECTIVE ACT (TADA)

That privilege is not afforded to patients or their surrogates by TADA.¹¹⁷ The law can be understood as a response to the moral distress occasioned for clinicians asked to provide care they find inappropriate, to claims about safeguarding physician integrity,¹¹⁸ and to the high financial cost of providing such care.¹¹⁹ Each of these concerns is pressing. However, difficult bioethical challenges can rarely be satisfactorily met with responses that ignore the nuances inherent in the situations that have led to the disputes at issue. TADA is such a response. Section A of this part summarizes that response. Then Section B suggests some of the factors that can result in exaggerated—and potentially harmful—statutory responses, such as TADA.

A. TADA’S PROVISIONS

TADA is worrisome. The most troubling provisions involve the statute’s attempt to provide for due process. That effort largely precludes court review of futility disputes, relying instead on hospital ethics committees to review decisions about withholding or withdrawing care from patients for whom the care in question is deemed futile.¹²⁰ For a patient or surrogate who continues to seek care despite the patient’s physician and the hospital ethics committee having “conclude[d] that life-sustaining treatment is medically inappropriate,” the only recourse is transfer of the patient to a health care facility willing to provide the care that the patient or surrogate is requesting.¹²¹ The patient or surrogate has ten days within

116. *See id.* at 739 (reporting that discovery in the case extended over more than three years).

117. *See* Texas Advance Directive Act (TADA), TEX. HEALTH & SAFETY CODE ANN. § 166.046 (West 2019).

118. *See* Truog, *supra* note 109, at 2.

119. *See* William Prip & Anna Morett, *Medical Futility: A Legal Perspective*, in MEDICAL FUTILITY AND THE EVALUATION OF LIFE-SUSTAINING INTERVENTIONS, *supra* note 55, at 136, 153. *But see* Truog, *supra* note 109, at 2 (noting that cost of care provided in cases physicians deem futile is usually “trivial” because “such cases are relatively rare” and “the patients usually die within a short period, even when requested life support is continued”).

120. Texas Advance Directive Act §§ 166.046, .052. One survey found that the great majority (about seventy percent) of ethics committee decisions in futility cases supported the physicians requesting to terminate care. Nora O’Callaghan, *Dying for Due Process: The Unconstitutional Medical Futility Provision of the Texas Advance Directives Act*, 60 BAYLOR L. REV. 527, 548–49 (2008).

121. Texas Advance Directive Act § 166.052(a). The patient is responsible for the cost of a transfer. *Id.* During the period given to the patient or surrogate to try to find an

which to identify such a facility.¹²² The only recourse to court assistance is for the purpose of seeking an extension of that ten-day period.¹²³ At the end of the ten days (or of any court-ordered extension of that ten-day period), “life-sustaining treatment may be withdrawn.”¹²⁴ In effect, TADA presumes that the hospital ethics committee offers an adequate due process substitute for judge and jury.¹²⁵

TADA presents additional concerns, some very worrisome.¹²⁶ Nora O’Callaghan has carefully and comprehensively described and analyzed those concerns.¹²⁷ Among them are the following. Initiating ethics committee review of a physician decision to terminate care need not be predicated on the patient’s being terminally ill or having an irreversible condition.¹²⁸ The patient or surrogate’s only option to termination of care is to find another facility willing to accept and treat the patient. However, that possibility is undermined by the very fact that the patient’s clinicians and the hospital’s ethics committee have opted to discontinue care since an alternative facility, reviewing the patient’s case, is likely to place significant weight on the determinations of the patient’s clinicians and hospital.¹²⁹ Physicians who comply with the rules that direct them to refer futility decisions to the hospital’s ethics committee enjoy absolute immunity from liability.¹³⁰ This last dimension of TADA compounds, as it reinforces, the statute’s preclusion of judicial review of physicians’ futility decisions.

As O’Callaghan notes:

The breadth and depth of the immunity conferred in [subsection] .045(d) [of TADA] from all criminal, civil and administrative review of the decisions reached pursuant to the procedures of .046 is virtually unheard of in Texas or American law and confirms its radical departure from traditional concepts of the rule of law. Texas has conferred a form of immunity to doctors and hospitals acting pursuant to

alternative health care facility, the hospital must continue to provide life-sustaining care. *Id.* § 166.046(e).

122. *Id.* § 166.052(a).

123. *Id.* The success of requests to extend the time limit depend on being able to show “that there is a reasonable expectation that you may find a physician or health care facility willing to provide life-sustaining treatment if the extension is granted.” *Id.* § 166.052(a)(6).

124. *Id.* § 166.052(a)(5).

125. *See* Truog, *supra* note 109, at 2.

126. *See* Lo, *supra* note 65, at 75 (“The Texas experience also raises concerns about unfairness because a disproportionately high percentage of cases involved ethnic minorities.”).

127. *See generally* O’Callaghan, *supra* note 120.

128. *Id.* at 541–42.

129. *Id.* at 544. Families or a patient seeking alternative care are required to provide the patient’s medical records. O’Callaghan notes that “these records may be biased in reflecting the doctor’s judgment that continued [life-sustaining care] is medically inappropriate.” *Id.* at 569.

130. Texas Advance Directive Act (TADA), TEX. HEALTH & SAFETY CODE ANN. § 166.045(d) (West 2019) (offering immunity to “a physician, health professional acting under the direction of a physician, or health care facility . . . if the person has complied with the procedures outlined in section 166.046”).

.046 that exceeds even the broad immunity conferred on judges and public prosecutors.¹³¹

B. WHY TADA?

TADA comprises a deeply troubling response to the practical and emotional difficulties that have faced those involved in futility disputes. These disputes have proved particularly resistant to resolution. In part, that resistance reflects continuing social discomfort about a decision to withhold or withdraw life-sustaining care. In the right-to-die cases, that discomfort was balanced, at least in part, by the privilege accorded to patient autonomy. In futility cases, in contrast, clinicians seek to limit or withhold care, knowing that the result will very likely be the patient's death and that the medical responses that they are recommending contravene the patient's (or surrogate's) preferences.¹³²

O'Callaghan reports that TADA followed the failure of scholarly efforts to craft an acceptable resolution to futility disputes.¹³³ That failure is not surprising given the thorny conflicts at the center of futility disputes. TADA comprises an extreme response, one committed to resolving disputes expeditiously but without significant concern for the price the law's process exacts.

Another response, or more accurately, non-response, to the concerns that prompted promulgation of TADA is the failure to craft more effective methods for resolving futility disputes. Without that, futility disputes can fester, sometimes for years, resulting in generalized frustration and distress.¹³⁴ Yet, for patients and surrogates, TADA may be even more discomforting than the prolongation of dispute. The process initiated through TADA provides certainty at the expense of the preferences of the patient, the ongoing grief of the patient's family and loved ones, and the physician-patient relationship. In the wake of TADA's imposition, patients and their families are likely to feel abandoned by their clinicians, as well as by society and the law. TADA facilitates that abandonment by offering absolute immunity to physicians and by precluding court review of ethics committee determinations in futility cases.¹³⁵

Other states have promulgated statutes that support the right of clinicians to withdraw treatments they deem futile, but none precludes court

131. O'Callaghan, *supra* note 120, at 571.

132. Sometimes the patient may be capable of expressing his or her preferences. In other cases, the patient may have detailed preferences in an advance directive. And sometimes, a surrogate is expected to discern what a patient's preferences would be in light of the patient's values and beliefs.

133. See O'Callaghan, *supra* note 120, at 535.

134. See generally, e.g., Bernstein v. Superior Court, No. B212067, 2009 WL 224924 (Cal. Ct. App. Feb. 2, 2009) (involving an intra-familial dispute about end-of-life care for a patient with Alzheimer's disease and several co-morbidities). This case and the dispute among Karl Bernstein's family members are analyzed in Dolgin, *Medical Disputes and Conflicting Values*, *supra* note 81.

135. Texas Advance Directive Act § 166.046.

review.¹³⁶ Some states grant clinicians the right to refuse to provide futile care as an instance of respect for clinicians’ conscientious objection to providing the care requested, and others simply allow clinicians to refuse to provide care they deem inappropriate.¹³⁷ However, these laws do not preclude court review and do not provide absolute immunity to physicians. That is of great significance and may even explain the infrequency with which physicians invoke such laws unilaterally to withhold or withdraw patient care.¹³⁸

V. WHERE NEXT?

TADA reflects an extreme response to a form of medical dispute that has challenged patients, surrogates, and clinicians and that has often seemed virtually intractable. In Texas, the quest for more certainty in responding to these cases has resulted in an approach that has abandoned due process in any meaningful sense and has provided absolute immunity for clinicians who effect the withdrawal or withholding of medical care.¹³⁹ The process delineated by TADA for responding to futility disputes is likely to comfort clinicians and hospitals, but it has come at great expense to patient care and to individual patients and their loved ones.

There is an alternative. It requires a commitment in time and in money.¹⁴⁰ But it safeguards the clinician-patient relationship and respects patients’ personhood, as well as that of the patient’s loved ones. Further, it does not undermine patients’ constitutional rights.¹⁴¹ It aims to guide the parties involved in a futility dispute to a set of compromises that all of the stakeholders can accept.

This approach involves the active participation of hospital ethics consultants¹⁴² who are trained to focus on the needs and values of each party

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

137. See, e.g., CAL. PROB. CODE § 4734 (West 2019) (offering “conscience” as ground for refusal); IDAHO CODE ANN. § 39–4514(5) (West 2019) (allowing physicians to refuse to provide care deemed futile).

138. See Pope, *supra* note 84, at 68.

139. See O’Callaghan, *supra* note 120, at 537.

140. See *infra* note 142 (acknowledging, as well, expenses that may be mitigated through ethics consultations).

141. O’Callaghan suggests that TADA violates the Due Process Clause of the Fourteenth Amendment on three grounds. O’Callaghan, *supra* note 120, at 530. She contends that the law is unconstitutionally vague, that it precludes review of futility cases by an “unbiased forum,” and that it contravenes the “balancing test” of *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976), by failing to place the patient’s “interest in access” to procedural protections above the state’s interest in “granting . . . carte blanche” to hospital ethics committees in futility cases. *Id.* at 530–31.

142. Ethics consultants may be members of hospital ethics committees. The work of ethics consultants and ethics committee members generally overlaps. Ethics committees now exist in the vast majority of U.S. hospitals. See Thaddeus Mason Pope, *Legal Briefing: Healthcare Ethics Committees*, 22 J. CLINICAL ETHICS 74, 76 (2011) (noting that the Joint Commission required hospitals to have ethics committees or other groups doing comparable work). Ethics committees are composed of volunteers, many of whom work at the hospital as clinicians or in some other capacity. They focus on “education, policy development and care review.” Judith Hendrick, *Legal Aspects of Clinical Ethics Committees*, 27 J.

involved in hospital disputes, to encourage discourse among all of the stakeholders, and to explain the needs and values of each participant to the others. Ethics consultants, who may work in teams or as individuals, are not simply members of hospitals' ethics committees. The American Society for Bioethics and Humanities (ASBH) now recommends that ethics consultants receive certification in a process that requires a certification examination.¹⁴³ ASBH expects ethics consultants to "address uncertainty or conflict" among "patients, families, surrogates, health care providers, or other involved parties."¹⁴⁴

The ASBH further recommends that ethics consultants help "elucidate issues, aid effective communication, and integrate the perspectives of the relevant stakeholders."¹⁴⁵ This approach is compelling insofar as it recognizes the essential personhood and respects the perspective of each stakeholder. This work is done best when contingencies afford the luxury of time for attention to detail and nuance.¹⁴⁶ Even though that is not always the case, ethics consultations—when successful—shift goals, broaden perspectives, and encourage disputants to listen to one another and shape compromises to which all can agree.

Since ethics consultations are not always successful, the right to obtain court review must be available to the stakeholders. Judicial review is expensive, time-consuming, and often emotionally difficult. But it affords stakeholders the right to have their voices heard by assessors who are presumptively more objective than members of hospital ethics committees—the committees whose review substitutes for court review pursuant to TADA.¹⁴⁷ Further, ethics committee deliberations are not necessarily guided by rules of fair process. At least in theory, court proceedings are. Further, court decisions can be appealed, offering disputants another layer of protection—another opportunity to be heard.¹⁴⁸

When ethics consultants resolve disputes successfully, the stakeholders avoid the expense and tension of court proceedings. But when compromise cannot be reached, it is essential that parties have the right to court review. The process delineated in TADA will generally provide a practi-

MED. ETHICS i50, i51 (2001). Ethics consultants have generally received focused training in hospital ethics work. They work in clinical settings to resolve specific disputes. Salla Saxen, *Untangling Uncertainty: A Study of the Discourses Shaping Clinical Ethics Consultation as a Professional Practice*, 27 J. CLINICAL ETHICS 99, 99 (2016).

143. See *Healthcare Ethics Certification Examination Content Outline and Item Development*, AM. SOC'Y FOR BIOETHICS & HUMAN., <http://asbh.org/certification/content-outline> [<https://perma.cc/7PC4-DQPA>] (last visited Sept. 10, 2019).

144. AM. SOC'Y FOR BIOETHICS & HUMAN., *CORE COMPETENCIES FOR HEALTHCARE ETHICS CONSULTATION 2-3* (2d ed. 2011).

145. *Id.* at 7.

146. Among other things, this depends on the state of the patient's medical condition and the consequent need (or not) to make decisions as quickly as possible.

147. See Harold L. Hirsch & Richard E. Donovan, *The Right to Die: Medico-Legal Implications of In Re Quinlan*, 30 RUTGERS L. REV. 267, 282-83 (1977) (discussing the composition and potential biases of ethics committees).

148. Legal intervention has disadvantages. One is the tendency to transform moral disputes into legalisms. See Hendrick, *supra* note 142, at i51.

cal resolution to a futility dispute more quickly than the process of attentive ethics consultation, followed, if unsuccessful, by judicial review. But the costs are onerous to patients whose preferences are not respected, to family members who feel abandoned, and even to clinicians who are absolved from engaging with the moral dimensions of medical decision-making.

VI. CONCLUSION

Bioethical disputes often occasion difficult questions. Both *Quinlan* and *Cruzan* raised difficult questions. When those cases were decided, few would have foreseen a future, not long off, in which clinicians sought the discontinuation of life-sustaining care and patients or surrogates sought the continuation of care. Disputes about medical care deemed futile (“inappropriate,” “ineffective,” “not medically indicated”)¹⁴⁹ by a patient’s clinicians are especially challenging.

Futility disputes directly implicate choices about life and death. They are hedged by uncertainty about the identification of those with the authority to make decisions; about the moral dimensions each dispute presents; and, often, about the patient’s prognosis should life-sustaining care be continued (or discontinued). Disagreement among the stakeholders—often including the patient or the patient’s surrogate, family members, or dear friends; the patient’s clinicians; and perhaps even the hospital in which the patient is receiving care—can be intense and profoundly discomforting. At the same time, those who love the patient may experience grief, even as the patient lies dying but is not yet dead. Thus, lawmakers, medical professionals, and others have struggled to delineate guidelines for resolving futility disputes.

There is no single “solution” to these disputes. The processes through which they are resolved are often as important as the conclusions reached. Yet, the pressure to find a solution should not trump the significance of safeguarding constitutional protections and respect for all of the stakeholders.

The pressures and underlying uncertainties that often attend futility disputes may facilitate construction of responses that do not serve the stakeholders as individuals and as a group. At one extreme, responses that fail to encourage and guide discourse among the stakeholders too often result in the prolongation of disputes about the care provided to dying, unconscious patients hooked to tubes and unable to participate in life in a meaningful manner. That scenario can occasion anguish for all of the stakeholders. The other extreme—an approach crafted around rigid guidelines that impose certainty at the expense of discourse among the stakeholders and at the expense of the dignity of patients and of other stakeholders—also results in dissatisfaction and anguish. TADA represents this second type of response.

149. See *supra* notes 75–78 and accompanying text.

Both extremes—those that facilitate prolongation of the status quo because accommodations cannot be reached and those that impose significant limitations on stakeholders' rights—ultimately fail to serve those involved in futility disputes. The responses are very different. Yet, each reflects the obstacles that make futility disputes especially difficult to resolve. Responding to futility disputes wisely requires the capacity to mediate moral differences, attention to nuance, and tolerance for ambiguity. Well-trained ethics consultants generally understand and value those traits. Even so, the right of court review for stakeholders left unsatisfied is essential. This broad approach to futility disputes—as well, of course, as to many other bioethical disputes—is time-consuming and potentially expensive. But in the context of life and death decisions that will affect the care of patients and the continuing emotional responses of patients' loved ones and clinicians, nothing less can be justified.