



Winter 1-1-1997

Better Off Dead than Disabled?: Should Courts Recognize a "Wrongful Living" Cause of Action When Doctors Fail to Honor Patients' Advance Directives?

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Better Off Dead than Disabled?: Should Courts Recognize a "Wrongful Living" Cause of Action When Doctors Fail to Honor Patients' Advance Directives?

Adam A. Milani*

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Introduction

In 1976, Americans celebrated the bicentennial of the Declaration of Independence, which proclaims that all people are endowed with "certain unalienable rights,"¹ including those of "Life, Liberty and the pursuit of Happiness."² That same year also marked the recognition in both case law and statutory law of a new right: the right to die.³ In the following two

1. THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776).

2. *Id.*

3. See *In re Quinlan*, 355 A.2d 647, 662-64 (N.J.), cert. denied sub nom. Garger v.

decades, almost every state has affirmed this right in its statutory law or case law,⁴ and the United States Supreme Court has found that competent persons have a "constitutionally protected liberty interest in refusing unwanted medical treatment."⁵ More recently, a federal appellate court held that recognition of the right to die necessarily includes a right to physician-assisted suicide.⁶

These cases and statutes have arisen because advances in medical technology have drastically changed the way physicians treat patients⁷ and how and where Americans die. In 1939, barely one-third (thirty-seven percent) of Americans died in hospitals or nursing homes.⁸ Less than five decades later, however, between eighty percent and eighty-five percent of Americans died in hospitals or nursing homes.⁹ Furthermore, seventy percent of these individuals did so after a decision to forgo life-sustaining treatment.¹⁰

Many of these people died after enduring treatments that were unheard of fifty years ago. Cardiopulmonary resuscitation (CPR) was not effectively developed until 1960 when it was introduced as an emergency means of restoring circulation in cardiac arrest victims.¹¹ Soon, however, CPR

New Jersey, 429 U.S. 922 (1976); *see also* CAL. HEALTH & SAFETY CODE §§ 7185-7194.5 (West Supp. 1996).

4. *See infra* notes 35-50 and accompanying text.

5. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 278 (1990).

6. *Compassion in Dying v. Washington*, 79 F.3d 790, 838 (9th Cir.) (en banc), *cert. granted sub nom. Washington v. Glucksberg*, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 96-110). Another federal appellate court declined to hold that the right to die necessarily includes the right to physician-assisted suicide, but still struck down New York statutes barring it on equal protection grounds. *Quill v. Vacco*, 80 F.3d 716, 724-25, 731 (2d Cir.), *cert. granted*, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 95-1858). These cases are discussed more fully below. *See infra* notes 51-68 and accompanying text.

7. According to one historian, "[n]inety percent of the medicine being practiced today did not exist in 1950." John Steele Gordon, *How America's Health Care Fell Ill*, AM. HERITAGE, May/June 1992, at 49, 49, *quoted in* John Carroll Byrnes, *The Health Care Decisions Act of 1993*, 23 U. BALT. L. REV. 1, 6 n.18 (1993).

8. *Compassion in Dying*, 79 F.3d at 812 n.61 (citing Cathaleen A. Roach, *Paradox and Pandora's Box: The Tragedy of Current Right-to-Die Jurisprudence*, 25 U. MICH. J.L. REFORM 133, 156 (1991)).

9. Roach, *supra* note 8, at 156 (citing PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* 17-18 (1983)).

10. *Cruzan*, 497 U.S. at 303 (Brennan, J., dissenting) (citing Helene Levens Lipton, *Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications, and Outcomes*, 256 JAMA 1164, 1168 (1986)).

11. Kathleen M. Boozang, *Death Wish: Resuscitating Self-Determination for the Criti-*

became standard procedure in hospitals, and many hospitals established a requirement that it be performed in all cases except when a do-not-resuscitate order had been executed.¹²

Iron lungs for polio patients were introduced in the 1950s, and respirators, or positive pressure ventilators, came into use in the 1960s.¹³ These ventilators require either an endotracheal or tracheostomy tube.¹⁴ Like CPR, intubation of patients in respiratory arrest became standard practice in hospitals unless the patient had previously executed a do-not-resuscitate order.

Widespread use of intravenous nutrition for patients that could neither eat nor tolerate gastrostomy tubes also began in the 1960s.¹⁵ Although not an emergency procedure giving rise to presumed consent, health care providers have often resisted removal of a feeding tube once it has been inserted, and patients and families have responded by suing to have their wishes honored.¹⁶ These suits have sought equitable relief in the form of orders requiring health care providers to discontinue treatment and let patients die.

The widespread recognition of the right to die has also spawned another type of lawsuit: suits for damages alleging that patients who received

cally Ill, 35 ARIZ. L. REV 23, 24 n.2 (1993) (citing Council on Ethical and Jud. Aff., American Med. Ass'n, *Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders*, 265 JAMA 1868, 1868 (1991)). CPR "is the term used to refer to a constellation of procedures administered to patients 'to restore cardiac function or to support ventilation in the event of a cardiac or respiratory arrest' and hence to oxygenate the blood supply, especially vital for brain functioning." 1 ALAN MEISEL, *THE RIGHT TO DIE* § 9.4, at 543 (2d ed. 1995) (citation omitted). Additionally:

Many of these procedures are highly intrusive, and some are violent in nature. The defibrillator, for example, causes violent (and painful) muscle contractions which, in a patient suffering from osteoporosis, may cause fracture of vertebrae or other bones. Such fractures, in turn, cause pain, which may be extreme.

In re Dinnerstein, 380 N.E.2d 134, 135-36 (Mass. App. Ct. 1978) (citing 3 MARSHALL HOUTS & IRWIN H. HAUT, *COURTROOM MEDICINE SERIES: DEATH* § 1.01(3)(d) (1976)).

12. See Boozang, *supra* note 11, at 24-25; Alvin H. Moss, *Informing the Patient About Cardiopulmonary Resuscitation: When the Risks Outweigh the Benefits*, J. GEN. INTERNAL MED., July-Aug. 1989, at 349, 353; see also MEISEL, *supra* note 11, at 544-45.

13. Gordon L. Snider, *Thirty Years of Mechanical Ventilation: Changing Implications*, 143 ARCHIVES INTERNAL MED. 745, 745-46 (1983), cited in Byrnes, *supra* note 7, at 6 n.18.

14. *Id.* at 746.

15. MAURICE E. SHILS & VERNON R. YOUNG, *MODERN NUTRITION IN HEALTH AND DISEASE* 1024-25 (7th ed. 1988), cited in Byrnes, *supra* note 7, at 6 n.18.

16. See, e.g., *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 265 (1990); *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 298 (Ct. App. 1986); *Elbaum v. Grace Plaza of Great Neck, Inc.*, 544 N.Y.S.2d 840, 843 (App. Div. 1989). For a comprehensive list of cases concerning the removal of artificial nutrition and hydration, see MEISEL, *supra* note 11, at 607-08.

unwanted life-sustaining treatment suffered a compensable injury when their right to die was violated. The majority of the suits seeking damages for the unauthorized provision of life-sustaining treatment have relied on traditional common-law torts, such as battery and infliction of emotional distress, or on a constitutional tort under 42 U.S.C. § 1983.¹⁷ There has also been a call, however, for the recognition of a new tort: wrongful living.¹⁸ Plaintiffs bringing wrongful living actions essentially claim that their diminished quality of life after or while receiving treatment makes their life not worth living, and thus, that they would be better off dead.¹⁹ To date, few courts have ruled on the viability of such a cause of action.

Given the increasing use of living wills, durable powers of attorney, and other instruments memorializing patients' wishes to refuse treatment, however, the number of wrongful living cases is likely to increase dramatically. These cases will force courts to attempt to answer the question of whether a plaintiff's life is worth living. Their response may potentially have a profound impact on persons with disabilities that have historically been viewed as indeed having lives not worth living.

This Article argues that courts should reject a wrongful living tort because "life is not a compensable harm."²⁰ In making this argument, this Article first examines the rise of case law and statutory law covering an individual's right to die.²¹ Part II then discusses the medical profession's consistent failure to honor patients' wishes to refuse life-sustaining treatment despite the existing law concerning the right to die.²²

Part III of the Article reviews extant case law on wrongful living and the more abundant case law on "wrongful life" actions brought in the name

17. See M. Rose Gasner, *Financial Penalties for Failing to Honor Patient Wishes to Refuse Treatment*, 11 ST. LOUIS U. PUB. L. REV. 499, 504-12 (1992) (discussing theories advanced in cases seeking damages for failure to honor patients' refusal of treatment); Steven I. Addlestone, Note, *Liability for Improper Maintenance of Life Support: Balancing Patient and Physician Autonomy*, 46 VAND. L. REV. 1255, 1267-73 (1993) (same).

18. See generally William C. Knapp & Fred Hamilton, "Wrongful Living": *Resuscitation as Tortious Interference with a Patient's Right to Give Informed Refusal*, 19 N. KY. L. REV. 253 (1992); A. Samuel Oddi, *The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action*, 75 GEO. L.J. 625 (1986); Tricia Jones Hackelman, Comment, *Violation of an Individual's Right to Die: The Need for a Wrongful Living Cause of Action*, 64 U. CIN. L. REV. 1355 (1996).

19. See, e.g., *McGuinness v. Barnes*, No. A-3457-94T5, slip op. at 8-9 (N.J. Super. Ct. App. Div. Aug. 6, 1996); *Anderson v. St. Francis-St. George Hosp.*, 614 N.E.2d 841, 846 (Ohio Ct. App. 1992), *appeal after remand*, 1995 WL 109128 (Ohio Ct. App. Mar. 15, 1995), *rev'd*, 671 N.E.2d 225 (Ohio 1996).

20. *Anderson*, 614 N.E.2d at 846.

21. See *infra* notes 35-68 and accompanying text.

22. See *infra* notes 69-107 and accompanying text.

of children with disabilities alleging that it would be better if they had not been born.²³ Courts have been reluctant to recognize either action because of a conceptual unwillingness to say that "life, even with severe disabilities, constitutes an actionable injury"²⁴ and because of the impossibility of calculating damages based on a comparison between life with a disability and no life at all.

Not all courts have agreed, however, that life with a disability is better than no life at all. Part IV of the Article discusses how the debate on the right to die, assisted suicide, and wrongful life reflects societal prejudice towards persons with disabilities.²⁵ The Article examines the historical view that life with a disability is not worth living as reflected in both popular culture²⁶ and right-to-die case law.²⁷ This view still predominates, but courts have recently recognized the impact of this prejudice and the lack of support services for persons with disabilities in deciding right-to-die and assisted suicide cases.²⁸

Part V argues that courts should be "attuned to the worth of an individual irrespective of physical or mental handicap,"²⁹ and that therefore they should reject a wrongful living cause of action.³⁰ Courts should reject wrongful life claims because: (1) "legal recognition that a disabled life is an injury would harm the interests of those most directly concerned, the handicapped;"³¹ (2) the question of whether one would be better off dead is one that courts are not equipped to handle and is antithetical to "the very nearly uniform high value which the law and mankind has placed on human life, rather than its absence;"³² (3) it is impossible to calculate compensatory damages based on the comparison between life with a disability and death; and (4) there are adequate remedies available under traditional tort principles for patients whose refusal of treatment has not been honored.

23. See *infra* notes 108-240 and accompanying text.

24. See *Flanagan v Williams*, 623 N.E.2d 185, 191 (Ohio Ct. App. 1993).

25. See *infra* notes 241-324 and accompanying text.

26. See *infra* notes 242-47 and accompanying text.

27. See *infra* notes 248-324 and accompanying text.

28. See *infra* notes 315-24 and accompanying text.

29. *McKay v Bergstedt*, 801 P.2d 617, 628 (Nev 1990).

30. See *infra* notes 325-56 and accompanying text.

31. *Smith v Cote*, 513 A.2d 341, 353 (N.H. 1986) (quoting Geoffrey Disston Menott & Vincent Phillip Zunzolo, Comment, *Wrongful Life: A Misconceived Tort*, 15 U.C. DAVIS L. REV 447, 459 (1981)).

32. *Greco v United States*, 893 P.2d 345, 348 (Nev 1995) (quoting *Becker v Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978)).

*I. Recognition of the Right to Die:
From Quinlan to Cruzan to Assisted Suicide*

Advances in medical technology have made it possible for people to live longer than ever before.³³ It is now possible for patients to continue living for years even when much of their physical and mental capacity has been irrevocably lost. Some have questioned the "quality" of those lives, however, and beginning in the 1970s, patients and their families began "asserting a right to die a natural death without undue dependence on medical technology or unnecessarily protracted agony — in short, a right to 'die with dignity'"³⁴ Courts have recognized this right based on two grounds: (1) the constitutional right to be free from an invasion of one's bodily integrity, including unwanted medical treatment, and (2) a common-law right to refuse medical treatment.

A. The Recognition of the Right to Die

The first courts to recognize a right to die based their rulings on the constitutional right to privacy. In *In re Quinlan*,³⁵ the New Jersey Supreme Court concluded:

Although the Constitution does not explicitly mention a right of privacy, Supreme Court decisions have recognized that a right of personal privacy exists and that certain areas of privacy are guaranteed under the Constitution.

Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances³⁶

A number of courts followed *Quinlan* and found that the right to die was within the right to privacy under the United States Constitution or the individual state's constitution.³⁷ After *Quinlan*, however, most courts have

33. The median life expectancy is now 79 for women and 72 for men. UNITED STATES BUREAU OF THE CENSUS, STATISTICAL ABSTRACT OF THE UNITED STATES: 1995, at 86 (115th ed. 1995).

34. *In re Conroy*, 486 A.2d 1209, 1220 (N.J. 1985).

35. 355 A.2d 647 (N.J. 1976).

36. *In re Quinlan*, 355 A.2d 647, 663 (N.J.), cert. denied sub nom. Garger v New Jersey, 429 U.S. 922 (1976).

37. See, e.g., *Rasmussen v. Fleming*, 741 P.2d 674, 681-82 (Ariz. 1987) (en banc); *Bouvia v Superior Court*, 225 Cal. Rptr. 297, 301 (Ct. App. 1986); *Bartling v Superior Court*, 209 Cal. Rptr. 220, 225 (Ct. App. 1984); *In re Severns*, 425 A.2d 156, 158-59 (Del. Ch. 1980); *In re A.C.*, 573 A.2d 1235, 1244-45 (D.C. 1990) (en banc); *In re Guardianship of Browning*, 543 So. 2d 258, 267 (Fla. Dist. Ct. App. 1989), aff'd, 568 So. 2d 4, 9-12 (Fla. 1990); *Superintendent of Belchertown State Sch. v Saikewicz*, 370 N.E.2d 417, 424

found a right to die based either solely on informed consent principles or on both the right to informed consent and a constitutional privacy right.³⁸

In *Cruzan*, the Supreme Court noted that it had previously decided that "[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law"³⁹ The Court stated that one of the primary means of protecting this notion of bodily integrity is the informed consent doctrine.⁴⁰ Justice (then Judge) Cardozo's famous expression of this doctrine states: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."⁴¹ The *Cruzan* Court decided that a "logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment."⁴²

The Supreme Court in *Cruzan*, however, did not rely solely on the common law in recognizing a right to die. The Court noted that "[t]he

(Mass. 1977); *Leach v. Akron Gen. Med. Ctr.*, 426 N.E.2d 809, 814 (Ohio Ct. C.P. 1980); *In re Welfare of Colyer*, 660 P.2d 738, 742 (Wash. 1983) (en banc); see also ALAN D. LIEBERSON, *ADVANCE MEDICAL DIRECTIVES* §§ 2.4-.5 (1992 & Supp. 1996); MEISEL, *supra* note 11, § 2.8, at 61-66; John D. Hodson, Annotation, *Judicial Power to Order Discontinuance of Life-Sustaining Treatment*, 48 A.L.R. 4TH 67, § 6[a], at 81-83 (1986 & Supp. 1996).

38. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 271 (1990) (citing LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* § 15-11, at 1365 (2d ed. 1988)).

39. *Id.* (quoting *Union Pac. Ry. v. Botsford*, 141 U.S. 250, 251 (1891) (refusing to compel personal injury plaintiff to undergo pretrial medical examination)).

40. *Id.*

41. *Schloendorff v. Society of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914), quoted in *Cruzan*, 497 U.S. at 269.

42. *Cruzan*, 497 U.S. at 270. Several courts have found no need to opine beyond such a common-law analysis in recognizing the right to die. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 489 (Ct. App. 1983); *In re Estate of Longeway*, 549 N.E.2d 292, 297 (Ill. 1989); *In re Gardner*, 534 A.2d 947, 951 (Me. 1987); *In re Peter*, 529 A.2d 419, 422-23 (N.J. 1987); *In re Storar*, 420 N.E.2d 64, 70 (N.Y. 1981). See generally LIEBERSON, *supra* note 37, § 2.3; MEISEL, *supra* note 11, § 2.7 Meisel includes a complete listing of right-to-die cases without regard to the rationale used in Section 1.7 of his treatise. *Id.* at 19-31. For a discussion of the evolution of the common law in the United States, England, and other countries regarding the consent to and refusal of medical treatment, see Danuta Mendelson, *Historical Evolution and Modern Implications of Concepts of Consent to, and Refusal of, Medical Treatment in the Law of Trespass*, 17 J. LEGAL MED. 1 (1996).

principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."⁴³ All nine Justices agreed on the existence of this liberty interest, disagreeing only on how it should be balanced with the State's expressed interests.⁴⁴

43. *Cruzan*, 497 U.S. at 278. Among the prior decisions discussed in the majority opinion were several holding that patients have an interest in refusing to submit to specific medical procedures. See *Washington v Harper*, 494 U.S. 210, 229 (1990) (holding that Washington's procedures for administering antipsychotic medication to prisoners were sufficient to satisfy due process concerns, but stating that "[t]he forcible injection of medication into a non-consenting person's body represents a substantial interference with that person's liberty"); *Jacobson v Massachusetts*, 197 U.S. 11, 27-33 (1905) (balancing individual's interest in declining unwanted smallpox vaccine against state's interest in preventing disease).

44. The state's asserted interests in *Cruzan* were "the protection and preservation of human life," *Cruzan*, 497 U.S. at 280, and the safeguarding of personal choice on the decision to refuse life support. *Id.* at 280-81. The interests most commonly asserted by states in right-to-die cases are: (1) preservation of life, (2) prevention of suicide, (3) protection of the interests of innocent third parties, and (4) maintenance of the ethical integrity of the medical profession. See MEISEL, *supra* note 11, §§ 8.15-18, at 510-29; Hodson, *supra* note 37, § 7, at 85-91.

The question before the Court in *Cruzan* was whether the Constitution forbids the state from advancing these interests through the establishment of a "clear and convincing" standard of proof when an incompetent patient's surrogate seeks the removal of life-sustaining treatment. *Cruzan*, 497 U.S. at 280. The Court held that the Constitution does not and that the state can establish such a standard. *Id.* at 281-84.

The evidence to which the "clear and convincing" standard is to be applied has been the source of some confusion after *Cruzan*. One court has held that life-sustaining treatment can be withdrawn from an incompetent patient only if there is "[n]othing less than unequivocal proof" of the patient's prior express wishes regarding the decision to terminate life support. *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 612 (N.Y. 1988). This is defined as "proof sufficient to persuade the trier of fact that the patient held a firm and settled commitment to the termination of life supports under the circumstances like those presented." *Id.* at 613; see also *Cruzan v Harmon*, 760 S.W.2d 408, 424 (Mo. 1988) (en banc), *aff'd*, *Cruzan v Director, Mo. Dep't of Health*, 497 U.S. 261 (1990). When defined this way, only a "minority of states requires that there be 'clear and convincing' evidence of the patient's intent to withdraw life support." *In re Fiori*, 673 A.2d 905, 911 (Pa. 1996).

The term "clear and convincing evidence" is more commonly used to describe a burden of proof that focuses on the person's life as a whole and not just their prior statements — or lack thereof — on life-sustaining treatment. This standard requires "the proponent of withholding or withdrawing life support to bear the burden of proving by clear and convincing evidence that the ward's decision *would have* been to forego life support." *Mack v Mack*, 618 A.2d 744, 754 (Md. 1993) (emphasis added). When viewed in this way, "the overwhelming majority of cases" utilize the clear and convincing standard. *Id.* For purposes of this Article, it will be assumed that a patient who receives life-sustaining treatment against his wishes has made them known in a way that satisfies the clear and

In her concurrence, Justice O'Connor stated:

I agree that a protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions and that the refusal of artificially delivered food and water is encompassed within that liberty interest.

Requiring a competent adult to endure [procedures for artificial hydration and nutrition] against her will burdens the patient's liberty, dignity, and freedom to determine the course of her own treatment. Accordingly, the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water.⁴⁵

The right to die has also become firmly entrenched in state statutory law. California became the first state with a "living will" statute when it enacted the Natural Death Act in 1976.⁴⁶ In the findings and declarations portion of the statute, the California legislature stated:

- (a) an adult person has the fundamental right to control the decisions relating to the relevancy of his or her own medical care, including the decision to have life-sustaining treatment withheld or withdrawn in instances of a terminal condition or permanent unconscious condition.
- (b) modern medical technology has made possible the artificial prolongation of human life beyond natural limits.
- (c) in the interest of protecting individual autonomy, such prolongation of the process of dying for a person with a terminal condition may violate patient dignity and cause unnecessary pain and suffering, while providing nothing medically necessary or beneficial to the person.
- (d) In recognition of the dignity and privacy that a person has a right to expect, the Legislature hereby declares that the laws of the State of California shall recognize the right of an adult person to make a written

convincing evidence requirement, no matter how articulated.

45. *Cruzan*, 497 U.S. at 287, 289 (O'Connor, J., concurring) (citations omitted). Justice Brennan, in a dissent joined by Justices Marshall and Blackmun, rejected the clear and convincing evidence standard as unduly burdensome on patients and their families. *Id.* at 302 (Brennan, J., dissenting). He stated that *Cruzan* had "a fundamental right to be free of unwanted artificial nutrition and hydration." *Id.* Justice Stevens made a similar statement in his dissent. *Id.* at 343 (Stevens, J., dissenting). Justice Scalia joined the majority, but stated that while he agreed with its analysis he "would have preferred that we announce, clearly and promptly, that the federal courts have no business in this field." *Id.* at 293 (Scalia, J., concurring). Scalia also asserted that a person has no liberty interest in rejecting artificial nutrition and hydration because doing so is tantamount to committing suicide. *Id.* at 293-95.

46. CAL. HEALTH & SAFETY CODE §§ 7185-7194.5 (West Supp. 1996).

declaration instructing his or her physician to withhold or withdraw life-sustaining treatment in the event of a terminal condition or permanent unconscious condition, in the event that the person is unable to make those decisions for himself or herself.⁴⁷

Almost every state has now adopted a living will statute that permits competent adults to execute advance directives stating that they do not wish to be kept alive by medical treatment in the latter stages of a terminal illness or if they become permanently and irreversibly unconscious.⁴⁸ In addition, many states allow patients to delegate decisionmaking power to a surrogate through a durable power of attorney, health care proxy, or similar device, or permit courts to appoint surrogate decisionmakers.⁴⁹ Federal

47 *Id.* § 7185.5.

48. The following list is updated from the one in 2 MEISEL, *supra* note 11, § 11.22: ALA. CODE §§ 22-8A-1 to -10 (1990 & Supp. 1996); ALASKA STAT. §§ 18.12.010-.100 (Michie 1994); ARK. CODE ANN. §§ 20-17-201 to -218 (Michie 1991 & Supp. 1995); CAL. HEALTH & SAFETY CODE §§ 7185-7194.5 (West Supp. 1996); COLO. REV. STAT. §§ 15-18-101 to -113 (Supp. 1986); CONN. GEN. STAT. ANN. §§ 19a-570 to -580c (West Supp. 1996); DEL. CODE ANN. tit. 16, §§ 2501-2508 (1995); D.C. CODE ANN. §§ 6-2421 to -2430 (1995); FLA. STAT. ANN. §§ 765.101-401 (West Supp. 1996); GA. CODE ANN. §§ 31-32-1 to -12 (1996); HAW. REV. STAT. ANN. §§ 327D-1 to -27 (Michie Supp. 1992); 755 ILL. COMP. STAT. ANN. §§ 35/1-10 (West 1992 & Supp. 1996); IND. CODE ANN. §§ 16-36-4-1 to -21 (Michie 1993 & Supp. 1996); IOWA CODE ANN. §§ 144A.1-.12 (West 1989 & Supp. 1996); KAN. STAT. ANN. §§ 65-28, 101-109 (1992 & Supp. 1995); KY. REV. STAT. ANN. §§ 311.621-.643 (Michie 1995); LA. REV. STAT. ANN. §§ 40:1299.58.1-.10 (West 1992 & Supp. 1996); ME. REV. STAT. ANN. tit. 18-A, §§ 5-801 to -817 (West Supp. 1995); MD. CODE ANN. HEALTH-GEN. I. §§ 5-601 to -618 (1994 & Supp. 1996); MINN. STAT. ANN. §§ 145B.01-.17 (West Supp. 1996); MISS. CODE ANN. §§ 41-41-101 to -121 (1993); MO. ANN. STAT. §§ 459.010-.055 (West 1992 & Supp. 1996); MONT. CODE ANN. §§ 50-9-101 to -206 (1995); NEB. REV. STAT. §§ 20-401 to -416 (Supp. 1994); NEV. REV. STAT. §§ 449.535-.690 (1995); N.H. REV. STAT. ANN. §§ 137-H:1 to 16 (1996); N.J. STAT. §§ 26:2H-53 to -78 (West 1996); N.M. STAT. ANN. §§ 24-7-1 to -11 (Michie 1994 & Supp. 1995); N.D. CENT. CODE §§ 23-06.4-01 to -14 (1991 & Supp. 1995); OHIO REV. CODE ANN. §§ 2133.01-.15 (Banks-Baldwin 1994 & Supp. 1995); OKLA. STAT. ANN. tit. 63, §§ 3101.1-.16 (West Supp. 1996); OR. REV. STAT. §§ 127.505-.660 (1993); 20 PA. CONS. STAT. ANN. §§ 5401-5416 (West Supp. 1996); R.I. GEN. LAWS §§ 23-4.11-1 to -14 (Supp. 1995); S.C. CODE ANN. §§ 44-77-10 to -160 (Law. Co-op. Supp. 1995); TENN. CODE ANN. §§ 32-11-101 to -112 (Supp. 1996); TEX. HEALTH & SAFETY CODE ANN. §§ 672.001-.021 (West 1992 & Supp. 1996); UTAH CODE ANN. §§ 75-2-1101 to -1119 (1993 & Supp. 1996); VT. STAT. ANN. tit. 18, §§ 5251-5262 (1987); VA. CODE ANN. §§ 54.1-2981 to -2993 (Michie 1994); WASH. REV. CODE ANN. §§ 70.122.010-.920 (West 1992 & Supp. 1996); W. VA. CODE §§ 16-30-1 to -13 (1995); WIS. STAT. ANN. §§ 154.01-.15 (West 1989 & Supp. 1995); WYO. STAT. ANN. §§ 35-22-101 to -208 (Michie 1994).

49. A complete list of state proxy provisions can be found in 2 MEISEL, *supra* note 11, § 12.52. See generally Colleen M. O'Connor, *Statutory Surrogate Consent Provisions: An Overview and Analysis*, 20 MENTAL & PHYSICAL DISABILITY L. REP. 128 (1996).

statutory law also favors permitting adult patients to refuse life-sustaining treatment by advance directive, which requires hospitals receiving federal financial support to notify adult patients of their right to execute such instruments upon admission.⁵⁰

B. *Beyond the Right to Die? Assisted Suicide*

Two federal appellate courts have recently pointed to *Cruzan* and the federal and state statutory law and held that recognition of the right to die by courts and legislatures precludes the banning of physician-assisted suicide.⁵¹ The two courts disagreed, however, on whether the right to die necessarily includes a right to physician-assisted suicide.

In *Compassion in Dying v Washington*,⁵² the United States Court of Appeals for the Ninth Circuit found a right to physician-assisted suicide in the liberty interest of the Fourteenth Amendment Due Process Clause.⁵³ The court reviewed the various opinions in *Cruzan* and concluded:

50. The Patient Self-Determination Act requires health care providers participating in Medicaid or Medicare programs to inform competent adult patients, no matter what their reason for admission, about state laws on advance directives and to record any advance directives the patient might have. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, §§ 4206, 4751, 104 Stat. 1388, 1388-115, 1388-204 (codified at 42 U.S.C. §§ 1395cc(f) (Medicare), 1396a(w) (Medicaid) (1994)).

51. *Quill v Vacco*, 80 F.3d 716, 727-31 (2d Cir.), cert. granted, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 95-1858); *Compassion in Dying v. Washington*, 79 F.3d 790, 815-16 (9th Cir.) (en banc), cert. granted sub nom. *Washington v Glucksberg*, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 96-110).

52. 79 F.3d 790 (9th Cir. 1996).

53. *Compassion in Dying*, 79 F.3d at 838. The *Compassion in Dying* court noted that, in upholding the right to abortion in *Planned Parenthood v. Casey*, the Supreme Court had surveyed its prior decisions and found a liberty interest sufficient to warrant constitutional protection for "personal decisions relating to marriage, procreation, contraception, family relationships, child rearing, and education." *Planned Parenthood v Casey*, 505 U.S. 833, 851 (1992), quoted in *Compassion in Dying*, 79 F.3d at 813. The *Casey* Court stated that:

These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.

Casey, 505 U.S. at 851, quoted in *Compassion in Dying*, 79 F.3d at 813 (citations omitted). The *Compassion in Dying* court found:

Like the decision of whether or not to have an abortion, the decision how and when to die is one of "the most intimate and personal choices a person may make in a lifetime," a choice "central to personal dignity and autonomy." A competent terminally

Cruzan stands for the proposition that there is a due process liberty interest in rejecting unwanted medical treatment, including the provision of food and water by artificial means. Moreover, the Court majority clearly recognized that granting the request to remove the tubes through which Cruzan received artificial nutrition and hydration would lead inexorably to her death. Accordingly, we conclude that *Cruzan* by recognizing a liberty interest that includes the refusal of artificial provision of life-sustaining food and water, necessarily recognizes a liberty interest in hastening one's own death.⁵⁴

While acknowledging "that in some respects a recognition of the legitimacy of physician-assisted suicide would constitute an additional step beyond what the courts have previously approved,"⁵⁵ the court stated that "we see no ethical or constitutionally cognizable difference between a doctor's pulling the plug on a respirator and his prescribing drugs which will permit a terminally ill patient to end his own life."⁵⁶ Accordingly, the appellate court struck down Washington's statute banning assisted suicide as unconstitutional as applied to competent, terminally ill patients who wish to hasten their deaths with physician-prescribed medication.⁵⁷

Less than a month later, the United States Court of Appeals for the Second Circuit, in *Quill v. Vacco*,⁵⁸ struck down New York's ban on assisted suicide.⁵⁹ The *Quill* court, however, rejected the claim that there was a constitutional right to assisted suicide.⁶⁰ Instead, it found that the New York laws prohibiting assisted suicide violated the Equal Protection Clause.⁶¹

The *Quill* court noted that the Supreme Court has actually or impliedly recognized only a few fundamental liberty interests and has been reluctant to expand this list.⁶² The *Quill* court concluded:

ill adult, having lived nearly the full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, incontinent.

Compassion in Dying, 79 F.3d at 813-14 (citations omitted).

54. *Compassion in Dying*, 79 F.3d at 815-16 (citations omitted).

55. *Id.* at 823-24.

56. *Id.* at 824.

57. *Id.* at 838.

58. 80 F.3d 716 (2d Cir. 1996).

59. *Quill v. Vacco*, 80 F.3d 716, 731 (2d Cir.), cert. granted, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 95-1858).

60. *Id.* at 724-25.

61. *Id.* at 727.

62. *Id.* at 724 (citing 2 RONALD D. ROTUNDA & JOHN E. NOWAK, TREATISE ON CONSTITUTIONAL LAW § 15.7, at 434-37 (2d ed. 1992 & Supp. 1996)). Instead of relying on *Cruzan* and *Casey*, the *Quill* court relied on *Bowers v. Hardwick*, 478 U.S. 186 (1986) — in which the Supreme Court held that there is no fundamental right to engage in consensual

The right to assisted suicide finds no cognizable basis in the Constitution's language or design, even in the very limited cases of those competent persons who, in the final stages of terminal illness, seek the right to hasten death. We therefore decline the plaintiffs' invitation to identify a new fundamental right, in the absence of a clear direction from the Court whose precedents we are bound to follow.⁶³

The Second Circuit, nonetheless, found that New York's laws against assisted suicide were unconstitutional on equal protection grounds.⁶⁴ The court noted that New York case law and statutory law recognized the right of competent, terminally ill patients to hasten death through withdrawal of life-sustaining treatment upon the proper proof of the desire to do so.⁶⁵ Given this, the court stated that:

[I]t seems clear that New York does not treat similarly circumstanced persons alike: those in the final stages of terminal illness who are on life-support systems are allowed to hasten their deaths by directing the removal of such systems; but those who are similarly situated, except for the previous attachment of life-sustaining equipment, are not allowed to hasten death by self-administering prescribed drugs.⁶⁶

homosexual sodomy — to support its conclusion that there is no fundamental right to physician-assisted suicide. The *Quill* court stated:

As in *Bowers*, the statutes plaintiffs seek to declare unconstitutional here cannot be said to infringe upon any fundamental right or liberty. As in *Bowers*, the right contended for here cannot be considered so implicit in our understanding of ordered liberty that neither justice nor liberty would exist if it were sacrificed. Nor can it be said that the right to assisted suicide claimed by plaintiffs is deeply rooted in the nation's traditions and history.

Quill, 80 F.3d at 724.

63. *Id.* at 724-25.

64. *Id.* at 727.

65. *Id.* at 727-28 (citing N.Y. PUB. HEALTH LAW §§ 2960-2994 (McKinney 1993 & Supp. 1996); *Rivers v. Katz*, 495 N.E.2d 337, 341 (N.Y. 1986); *In re Eichner*, 420 N.E.2d 64, 70-71 (N.Y. 1981)).

66. *Id.* at 729. Other courts that have ruled on physician-assisted suicide are split on whether it can be banned. The Supreme Court of Michigan rejected a due process challenge to that state's assisted suicide statute. *People v. Kevorkian*, 527 N.W.2d 714, 724 (Mich. 1994). The court there stated:

We do not discern in *Cruzan* and its historic roots an indication that the federal constitution protects a right more expansive than the right to refuse to begin or to continue life-sustaining medical treatment. Neither do we find in *Casey* or in the precedent from which it evolved an intent to expand the liberty interests identified by the Court in such a manner.

Id. at 725; see also *Donaldson v. Van de Kamp*, 4 Cal. Rptr. 2d 59, 64 (Ct. App. 1992) (finding that patient suffering from growing brain tumor did not have constitutional right to assisted death that would result from premortem cryogenic treatment undertaken to preserve

The constitutionality of states' prohibition of assisted suicide will ultimately be decided by the Supreme Court, which heard arguments in *Quill* and *Compassion in Dying* on January 8, 1997.⁶⁷ No matter what the Court decides, however, the mere fact that the effort to extend the right to die has reached the Court only two decades after its initial recognition reflects the widespread public acceptance of the right.⁶⁸ Whether based on the right of privacy, the common-law right of informed consent, or on state statutory law, there can be no question that patients today have the ability to refuse life-sustaining treatment. As the next Part discusses, however, health care professionals often misunderstand or resist such refusals.

II. Patient Wishes and Health Care Provider Actions: Patients' Refusal of Life-Sustaining Treatment Is Often Misunderstood or Ignored

The increase of assisted suicide cases and the sheer number of right-to-die cases⁶⁹ and statutes is not surprising given the fact that both public

body until such future time as treatment for condition might be available).

In an interesting twist on the equal protection argument, the court in *Lee v. Oregon* held that the Oregon Death with Dignity Act — a ballot initiative permitting doctors to prescribe medications to allow terminally ill patients to end their lives — violated the Equal Protection Clause because it treated the terminally ill differently than the nonterminally ill. *Lee v. Oregon*, 891 F. Supp. 1429, 1438 (D. Or. 1995). The court there found that the Death with Dignity Act deprived terminally ill persons of a benefit afforded the nonterminally ill: the Oregon statutory prohibition making it a crime for anyone, including doctors, to assist a person in ending their lives. *Id.* at 1433-34 n.4 and accompanying text. The court found that no rational basis existed for a state's allowing the terminally ill to receive medical assistance that would enable them to hasten their deaths while preventing the young and healthy from receiving similar medical assistance. *Id.* at 1438.

The *Compassion in Dying* court stated that the *Lee* decision was a clear error and was directly contrary to its holding. *Compassion in Dying v. Washington*, 79 F.3d 790, 838 (9th Cir.) (en banc), cert. granted sub nom. *Washington v. Glucksberg*, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 96-110). These statements were criticized in a dissent from the Ninth Circuit's decision not to have the court rehear the case en banc. *Compassion in Dying v. Washington*, 85 F.3d 1440, 1442 (9th Cir. 1996) (O'Scannlam, J., dissenting) (denying en banc rehearing by Ninth Circuit). Judge O'Scannlam quoted from an unpublished order by the Oregon district court in which "the state defendants agree[d] with plaintiffs that the Ninth Circuit's comments about *Lee* in the *Compassion in Dying* decision were dicta 'and could be considered gratuitous and inappropriate.'" *Id.*

67 See Lyle Deniston, *Justices Reluctant to Create a "Right" to Assisted Suicide; Complexity of Issue Seen Best Addressed by State Legislatures*, BALTIMORE SUN, Jan. 9, 1997, at 1A.

68. The public acceptance of the right to die is discussed more fully below. See *infra* at notes 71-74 and accompanying text.

69. There were at least 84 appellate decisions addressing the right to die issued prior

opinion polls and scientific studies show that many people prefer not to be placed on life-support systems.⁷⁰ This desire is often misunderstood by health care providers, however, and even if it is understood — and is also memorialized in an advance directive — this desire is often ignored.

A. Patients Prefer to Avoid Life-Sustaining Treatment

A 1993 law review article surveying national opinion polls on end-of-life decisions found that a majority of people did not want to be kept alive if they were on life-support systems or in a coma.⁷¹ The percentage of those saying that they would refuse treatment varied greatly, however, depending on the description of the medical condition described in the poll questions. When the condition was described as one that entailed "no hope of recovering," "a coma with no brain activity," "terminally ill or in irreversible coma," or "a coma with no hope of recovery," between seventy-three percent and eighty-five percent of respondents indicated that they would want treatment stopped or withheld.⁷² A significantly smaller number, fifty-one percent, indicated that they would want treatment stopped if it made them "totally dependent on a family member or other person for all of [their] care."⁷³ Only forty-four percent of the respondents desired continued treatment if they "had a disease with no hope of improvement that made it hard for you to function in your day-to-day activities."⁷⁴

to the Supreme Court's decision in *Cruzan*. George J. Annas, *The "Right to Die" in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 DUQ. L. REV. 875, 882 (1996); see also *Cruzan v. Harmon*, 760 S.W.2d 408, 412 n.4 (Mo. 1988) (en banc) (collecting 54 reported decisions from 1976-88), *aff'd*, 497 U.S. 261 (1990).

70. James Lindgren, *Death by Default*, L. & CONTEMP PROBS., Summer 1993, at 185, 197-99. Lindgren reviews over 200 questions from public opinion polls conducted between 1973 and 1991.

71. *Id.*

72. *Id.*

73. *Id.* at 198.

74. *Id.* at 198-99. Based on the preferences shown in these polls, Lindgren argues for a change in what he referred to as the "default rule" in end-of-life situations. According to Lindgren, the current default rule calls for physicians "to assume that the patient wants all available treatments to preserve life, unless it can be clearly documented otherwise." *Id.* at 187 (quoting Jack C. Siebe, *The Patient's Choice of Care: Suggested Hospital Policies*, in *MEDICAL ETHICS: A GUIDE FOR HEALTH PROFESSIONALS* 417, 418 (John F. Monagle & David C. Thomasma eds., 1988)).

Lindgren argues that this default rule should be changed and that it "ought to be death for at least some important classes of end-of-life situations." *Id.* at 196. He bases this conclusion on his application of the principles of "[t]he two leading camps in default-rule analysis — the philosophical school that seeks the intent of the parties, and the law and

Unfortunately, very few people complete formal advance directives memorializing their wishes. A United States General Accounting Office report notes that estimates as to the number of individuals completing formal advance directives varies between ten and twenty-five percent (with some estimates as low as five percent) of the adult population.⁷⁵ A 1993

economics school that seeks sound social policy in the form of wealth or utility maximization." *Id.* at 196, 197-223.

Lindgren concedes that it is difficult to draw the line when the default rule in medical situations — life — shifts to the default rule of death for end-of-life situations, but he suggests that it can be drawn based on patient preferences as expressed in opinion polls. *Id.* at 228. Specifically, he identifies eight overlapping situations in which the default rule should be death:

- (1) patients on life support who have no hope of recovery;
- (2) patients in a coma with no brain activity being kept alive by a feeding tube;
- (3) patients who are terminally ill or in irreversible coma, supported by life-support systems, including food and water;
- (4) patients with an illness that makes them totally dependent on a family member or other person for all of their care (a situation in which they would not want their doctors "to do everything possible to save" life);
- (5) patients with a disease with no hope of improvement suffering a great deal of physical pain;
- (6) patients in a coma with no hope of recovery but no pain;
- (7) hopelessly ill or comatose patients on life support if their families request the withdrawal of support; and
- (8) permanently unconscious patients receiving food and water.

Id.

Lindgren's conclusion is criticized in an accompanying article by the Co-Reporter for the Uniform Healthcare Decisions Act and Chair of the Committee on Healthcare Decisions, ABA Section of Real Property, Probate and Trust Law. David M. English, *Comment: Defining the Right to Die*, L. & CONTEMP. PROBS., Summer 1993, at 255. English notes that although poll data may suggest that terminally ill but conscious patients would want treatment terminated, "[f]here is no agreement on what is meant by a 'terminal illness.'" *Id.* at 258. He also observes that the average time between the onset of a final illness and death is 29 months, and asks:

Is Lindgren suggesting that all treatment be stopped upon the first diagnosis? Perhaps what he intends is that treatment should be terminated if the patient has a "terminal illness" as defined in most living will statutes, which require either that death be "imminent," or that death will occur within a "relatively short time." Both questions raise interpretive questions, however, and would not provide the certainty that Lindgren seeks.

Id. at 258-59 (citations omitted). English concludes, "Lindgren's proposal is attractive because it gives the appearance of being a simple solution. But in this area of the law, there can be no simple solutions." *Id.* at 259.

75. UNITED STATES GEN. ACCT. OFF., PUB. GAO/HEHS-95-135, PATIENT SELF-DETERMINATION ACT: PROVIDERS OFFER INFORMATION ON ADVANCE DIRECTIVES BUT EFFECTIVENESS UNCERTAIN 8 (1995) [hereinafter USGAO].

study by the Office of the Inspector General of the Department of Health and Human Services found that only eighteen percent of hospital patients had advance directives, although fifty percent of patients in nursing facilities did.⁷⁶ That same study reported that only nine percent of patients under age thirty had an advance directive, but thirty-five percent of those over age seventy-five had one.⁷⁷

A recent \$28 million study (SUPPORT study) aimed at "improv[ing] end-of-life decisionmaking and reduc[ing] the frequency of a mechanically supported, painful, and prolonged process of dying"⁷⁸ confirmed patients' desire to avoid artificial life-sustaining treatment.⁷⁹ The study also found, however, that this desire was often either not recognized or not honored. The evidence demonstrated that "nearly half of the 960 phase I patients who indicated a desire for CPR to be withheld did not have a DNR [do-not-resuscitate] order written."⁸⁰ Phase I patients who died spent a median of eight days either in an intensive care unit (ICU), receiving mechanical ventilation, or in a comatose state. Additionally, "more than one-third (38%) spent at least 10 days in ICU, and 46% received mechanical ventilation within 3 days of death."⁸¹ After a phase I patient's death, interviews with "surrogates indicated that 50% of all the conscious phase I patients who died in the hospital experienced moderate or severe pain at least half the time during their last three days of life."⁸²

76. *Id.* at 9; see also Martha Terry & Steven Zweig, *Prevalence of Advance Directives and Do-Not-Resuscitate Orders in Community Nursing Facilities*, 3 ARCHIVES FAM. MED. 141, 141 (1994) (reporting that study of eight rural community nursing facilities found that less than one-third of patients had advance directives).

77. USGAO, *supra* note 75, at 9.

78. SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591, 1591 (1995).

79. *Id.* at 1594. The SUPPORT investigation was divided into two phases. Phase I was a perspective observation study that "documented shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death." *Id.* at 1591. Phase II was a cluster randomized, controlled clinical trial aimed at improving communication between physicians, patients, and families. *Id.* at 1592. The study covered patients who "were in the advanced stages of one or more of nine illnesses: acute respiratory failure, multiple organ system failure with sepsis, multiple organ system failure with malignancy, coma, chronic obstructive lung disease, congestive heart failure, cirrhosis, metastatic colon cancer, and non-small cell lung cancer." *Id.*

80. *Id.* at 1594.

81. *Id.*

82. *Id.*

B. Physician Resistance to Advance Directives

The results of this study may be due in part to physician resistance to advance directives.⁸³ A study of physicians in California and Vermont⁸⁴ identified three reasons for physician failure to honor patients' advance directives regarding the withholding of treatment: "(1) fear of liability; (2) the perception that directives interpose an unnecessary additional control over, and interfere with, the physicians' professional actions; and (3) the

83. An editorial on the SUPPORT project noted that:

Reports of patient preferences from the SUPPORT intervention nurses had little effect on attending physicians. Physicians acknowledged receiving these reports in only 34% of cases. We can only speculate why the intervention failed to improve physicians' appreciation of patients' preferences. Did physicians regard patients' preferences as unimportant? Did physicians believe that they already knew what patients wanted, even though studies show that physicians cannot accurately predict patients' wishes? Did physicians place little value on information communicated by the intervention nurses, compared with information they obtained firsthand?

Bernard Lo, Editorial, *Improving Care Near the End of Life: Why Is It So Hard?*, 274 JAMA 1634, 1635 (1995) (citation omitted).

While the editorial offered no answers to these questions, earlier studies show that both physicians and nurses often inaccurately predict the patient's preference regarding resuscitation. For example, one study shows that eight of twenty-five patients who had been resuscitated had not wanted CPR and did not want it in the future. Only one of the sixteen doctors caring for these patients, however, believed that they did not wish to be resuscitated. Susanna E. Bedell & Thomas L. Delbanco, *Choices about CardioPulmonary Resuscitation in the Hospital*, 310 NEW ENG. J. MED. 1089, 1091 (1984). The study concluded that "physicians are more likely to recognize the preferences of patients who desire resuscitation than preferences of those who do not." *Id.* at 1092; see also Richard F Uhlmann et al., *Understanding of Elderly Patients' Resuscitation Preferences by Physicians and Nurses*, 150 W J. MED. 705, 705 (1989) (reporting that agreement between what patients actually wanted and what health care professionals thought patients wanted for variety of life-sustaining treatments ranged from 59% to 84% for physicians and from 53% to 78% for nurses).

Lo's editorial also noted a more troubling problem:

[E]ven when physicians knew a patient's preferences, the physicians may have disregarded them as uninformed or not in the patient's best interests. No data are reported on another important issue, the preferences of the patients who died after prolonged periods in the ICU or receiving mechanical ventilation. Did these patients (or their surrogates) understand their prognosis, and did they really want these aggressive interventions started or continued so long?

Lo, *supra*, at 1635.

84. Joel M. Zinberg, *Decisions for the Dying: An Empirical Study of Physicians Responses to Advance Directives*, 13 VT. L. REV 445, 452 (1989). The author, a physician/attorney, interviewed 18 physicians in Vermont and 39 physicians in and around Los Angeles concerning their experiences with and understanding of advance directives. *Id.*

perception that directives implicitly question the physicians' judgment of the patients' best interest."⁸⁵

Another recent article reviewing trends in health care decisionmaking shows that physician ambivalence towards advance directives still exists:

The evidence suggests that physicians generally still consider it their responsibility to make treatment decisions that they believe are in the patient's best interest and that patient preferences should be ignored if they are inconsistent with the physician's view of the patient's best interests. In other words, it appears that end-of-life decisions are frequently driven by the physician's values rather than the patient's values.⁸⁶

85. *Id.* at 482. Other studies have also found that fear of liability affects physicians' willingness to follow advance directives which ask that life-sustaining treatment be withheld. See Renee M. Goetzler & Mark A. Moskowitz, *Changes in Physician Attitudes Toward Limiting Care of Critically Ill Patients*, 151 ARCHIVES INTERNAL MED. 1537, 1538 (1991) (finding that physicians were concerned about malpractice liability in deciding how to treat critically ill patients). This fear exists even though major medical journals have informed doctors that "[n]o person has ever been found liable for withdrawing life-sustaining treatment without court permission." David Orentlicher, *The Right to Die After Cruzan*, 264 JAMA 2444, 2446 (1990); see also Alan Meisel, *Legal Myths About Terminating Life Support*, 151 ARCHIVES INTERNAL MED. 1497, 1497-98 (1991); Robert F. Weir & Larry Gostin, *Decisions to Abate Life-Sustaining Treatment for Nonautonomous Patients*, 264 JAMA 1846, 1852 (1990) ("Every court of final decision in every jurisdiction that has addressed the question of physician liability has found physicians participating in the cases to be free from civil or criminal sanctions."). In addition, all state living will and health care proxy statutes confer some sort of immunity from civil or criminal liability or both on health care providers who in good faith comply with a properly executed living will or the instructions of a proxy acting in accordance with the patient's wishes or in the patient's best interest. See, e.g., CAL. HEALTH & SAFETY CODE § 7190.5(b) (West Supp. 1996) (discussing living will); CAL. PROB. CODE § 4750 (West Supp. 1996) (discussing proxy). See generally 2 MEISEL, *supra* note 11, §§ 11.17, 12.40, at 111-12, 196-97 (citing living will and proxy statutes).

Fear of liability, though, is but one reason for physicians to ignore patients' wishes. Zinberg also reports:

One interviewee volunteered that a substantial number of his colleagues dislike directives because they believe directives would curtail doctors' control of treatment. This observation is partially confirmed by the fact that many interviewees strongly opposed the interposition of formal ethics committees. Only three interviewees in each state agreed that other physicians or an ethics committee should be consulted.

Zinberg, *supra* note 84, at 482-83 (citations omitted).

86. David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV 1255, 1281 (1994) (citation omitted) [hereinafter Orentlicher, *The Limitations of Legislation*]. Orentlicher cited several studies in support of his thesis. *Id.* at 1281-87. For example, one study concluded that physicians often overrode living wills when they disagreed with the patients'

C. Financial Incentives to Treat?

It is not surprising then that a newspaper article on the SUPPORT study stated that the study "calls into question a central tenet of the 25-year-old right-to-die movement: that if patients express their wishes about end-of-life care in advance through such documents as living wills, doctors will abide by them."⁸⁷ The article quoted Joanne Lynn, the director of the

choices, including providing undesired treatment when they felt that the treatment was appropriate. *Id.* at 1281-82; see Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882, 886-87 (1991); see also DANIEL CALLAHAN, SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY 175 (1987) ("A continuing problem with 'living wills' has been the unwillingness of many physicians to honor them"); Panagiota V. Caralis & Jeffrey S. Hammond, *Attitudes of Medical Students, Housestaff and Faculty Physicians Toward Euthanasia and Termination of Life-Sustaining Treatment*, 20 CRITICAL CARE MED. 683, 686-89 (1992); David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101, 2101-04 (1992).

The existence of physician resistance to living wills has also been a source of concern for the nurses who work with them. Two nursing journals have discussed nurses' responsibilities when physicians fail to honor patient wishes. Barbara Springer Edwards, *When a Living Will Is Ignored*, AM. J. NURSING, July 1994, at 64; Cindy Hylton Rushton, *What Can a Nurse Do When the Patient Has an Advance Directive and the Physician Disregards It?*, CRITICAL CARE NURSE, Feb. 1993, at 61.

Other studies have found that advance directives are often ignored because they never make it into the patient's hospital charts. One study investigating the accessibility of previously executed advance directives by 114 geriatric patients found that out of a total of 180 hospital admissions over a three-year period, documentation of the advance directive appeared in only 47 (26%) of the charts. R. Sean Morrison et al., *The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings*, 274 JAMA 478, 479-80 (1995). Only 29 of those charts contained an actual copy of the advance directive. *Id.* at 480.

The study also found that in 39 of 53 (74%) admissions in which patients did not have decisional capacity, the advance directive was not recognized nor was there written documentation of any attempt to discern if such a directive had been previously executed. *Id.*, see also USGAO, *supra* note 75, at 13 (noting that 1992 survey found that only 60% of patients with advance directives had copies with their medical charts and another study found that while advance directives were with nursing home charts for 74% of patients transferred to hospital, "the document was successfully delivered to the hospital and incorporated into the hospital record for only about one-third of the cases"); Cynthia J. Stolman et al., *Evaluation of Patient, Physician, Nurse, and Family Attitudes Toward Do Not Resuscitate Orders*, 150 ARCHIVES INTERNAL MED. 653, 655 (1990) (reporting that in study of competent patients with DNR orders, existence of living will was recorded in patients' records in only 6 of 24 patients and only 10 physicians were aware of patients' living wills).

87 Don Colburn, *The Grace of a "Good Death" Escapes Many; Despite Living Wills and Other Innovations, Doctors Often Ignore or Don't Know Patients Wishes*, WASH. POST, Dec. 5, 1995, at Z7. Dr. William Knaus, one of the researchers who directed the study, made a similar statement to the *New York Times*: "People think advance directives are solving the problem. We have very good information that they aren't, that nothing has

Center to Improve Care of the Dying at George Washington University Medical Center and a coleader of the SUPPORT study Lynn stated that one of the problems with the current system is that "it does not hold itself accountable for badly handled deaths. 'If I, as a doctor, do it badly, nothing comes down on me. I get paid well. The family is left behind in grief and goes away The patient's suffering counts for nothing.'"⁸⁸

The existence of financial incentives to continue treatment for a patient on life-support systems was addressed by both the majority and the dissent in *Grace Plaza of Great Neck, Inc. v Elbaum*.⁸⁹ Grace Plaza, a long-term care facility, admitted Jean Elbaum on September 19, 1986 following hospital treatment for a stroke.⁹⁰ When Grace Plaza admitted Elbaum, she received nutrition through a gastrostomy tube and was in a persistent vegetative state.⁹¹ In October 1987, Elbaum's husband sent a letter to Grace Plaza stating that "it was his wife's wish that she be allowed to die naturally

changed — the amount of pain at the end of life, the number of people dying alone attached to machines." Susan Gilbert, *Study Finds Doctors Refuse Patients' Requests on Death*, N.Y. TIMES, Nov 22, 1995, at A1.

88. Colburn, *supra* note 87, at Z7 Dr. Bernard Lo, Director of the Program of Medical Ethics at the University of California at San Francisco, also noted that "doctors had strong financial incentives to put patients in intensive care rather than to sit down and talk with them about alternatives, like dying with pain relief at home." Gilbert, *supra* note 87, at A1. Lo stated: "Invasive procedures are reimbursed at a higher rate than sitting down and talking to patients." *Id.*

Legal commentators have also remarked on the potential problems caused by the current system, which favors treatment over nontreatment. See, e.g., Orentlicher, *The Limitations of Legislation*, *supra* note 86, at 1275-76. Orentlicher stated:

Physicians are not inherently unwilling to take the time needed for sufficient discussion [of end-of-life decisions]. However, under current [insurance] policies, they do not receive any compensation for the time spent. Health insurance policies consider such discussions either nonreimbursable, or reimbursable at very low rates. Unless physicians are compensated for their time discussing end-of-life decisions, they will continue to allocate their time to activities that generate higher compensation.

Id., see Addlestone, *supra* note 17, at 1263. Addlestone states:

The potential moral hazard facing health care providers if they are not held accountable for failing to comply with patient wishes should affect the balance between physician and patient autonomy If not subject to liability, hospitals or other providers may prolong patient care, consciously or unconsciously, to generate increased revenues.

Id.

89. 588 N.Y.S.2d 853 (App. Div. 1992).

90. *Grace Plaza of Great Neck, Inc. v Elbaum*, 588 N.Y.S.2d 853, 853 (App. Div. 1992), *aff'd*, 623 N.E.2d 513 (N.Y. 1993).

91. *Grace Plaza of Great Neck, Inc. v Elbaum*, 623 N.E.2d 513, 514 (N.Y. 1993).

should she fall into an 'irreversible vegetative state'⁹² and instructed Grace Plaza to remove Mrs. Elbaum's feeding tube.⁹³

Grace Plaza responded to Mr. Elbaum by noting the absence of a clear indication of Mrs. Elbaum's wishes regarding removal of her feeding tube.⁹⁴ Grace Plaza also stated that "its own ethical standards would prohibit it from withdrawing life-saving medical treatment from one of its patients"⁹⁵ and encouraged Mr. Elbaum to transfer his wife to another nursing home if he wanted her feeding tube removed.⁹⁶

Mr. Elbaum refused to pay for any further treatment, and Grace Plaza sued to recover payments for services rendered to his wife after October 1987.⁹⁷ Mr. Elbaum then sued Grace Plaza to remove Mrs. Elbaum's feeding tube.⁹⁸ The trial court initially held that there was insufficient evidence that Mrs. Elbaum wanted the feeding tube removed,⁹⁹ but an appellate court

92. *Id.*

93. *Id.*

94. *Elbaum*, 588 N.Y.S.2d at 855.

95. *Id.*

96. *Id.* In a letter to Mr. Elbaum dated February 16, 1988, Grace Plaza's administrator wrote:

At this time, we have not been provided with clear indication of the patient's wishes at a time when she was competent. However, please be aware that *even if irrefutable evidence of the patient's wishes were forthcoming, Grace Plaza is not willing to undertake removal of the gastrostomy tube, and we believe that we have the right under New York State law to refuse to do so.* The goal of this facility is to preserve life, and we will not willingly take actions inconsistent with this position.

[W]e have attempted to find another facility which would accommodate you, but we have been unsuccessful. However, we remain willing to assist you with Mrs. Elbaum's transfer to any facility you name, or to your home where Mrs. Elbaum's needs can be met by appropriate home care.

In the interim, and for the duration of her stay here, we expect payment as per the admissions contract. At this point, you are in arrears for the months of November, 1987 through February, 1988. If payment in the amount of \$18,576 is not received within 10 days of receipt of this letter, we will be forced to initiate actions for recovery of these funds, and delivery of the patient to your care. You may be aware that New York State regulation sanctions the discharge of a patient for non-payment.

Id. at 863 (Rosenblatt, J., dissenting).

97. *Id.* at 855. The record did not reveal any effort on Mr. Elbaum's part to locate an alternative nursing home, and Grace Plaza's efforts were unsuccessful because other facilities "would not admit the patient for the purpose of removing the tube." *Id.*

98. *Elbaum v. Grace Plaza of Great Neck, Inc.*, 544 N.Y.S.2d 840, 843 (App. Div 1989), *aff'd*, 623 N.E.2d 513 (N.Y. 1993).

99. *Id.* at 845.

reversed and ordered Grace Plaza either to transfer Mrs. Elbaum to a nursing home that would enforce her wishes or to enforce them itself.¹⁰⁰ Following this decision, Mrs. Elbaum was discharged from Grace Plaza and died shortly thereafter.¹⁰¹

Grace Plaza's payment action continued after her death, and Mr. Elbaum argued that he rightfully refused to pay because the nursing home should have stopped the treatment as soon as he told them that his wife would not have wanted artificial nutrition and hydration.¹⁰² He further argued that continuing to furnish the nutrition and hydration constituted a battery against his wife.¹⁰³ The appellate division disagreed:

The rule which prevents physicians from recovering payment for medical services which are not desired should not be applied in a case where, because the patient is comatose, her desires cannot be known, but can only be deduced, with a greater or lesser degree of certainty, from evidence of her past conduct and past statements.¹⁰⁴

More specifically, the court held that:

[U]nder the law as it stood at the time this case arose, [Grace Plaza] committed no legal wrong, incurred no legal liability, and forfeited no legal right, when, in the absence of judicial guidance, it continued to provide life-saving medical treatment to a comatose patient over the objections of the patient's conservator.¹⁰⁵

Prior to reaching this holding, the court addressed the moral hazard argument:

It is asserted that, in light of our decision today, all health care providers in charge of competent patients will have an additional financial incentive to prolong the lives of such patients over the objections of the patients' families. This may be true, and the potential evil which we see is that some beleaguered families may, regrettably, be forced to litigation. What is not noted is that, if Mr. Elbaum's conduct in this case were condoned, health care providers would have an additional financial incentive to obey, without question, the orders of those conservators who might prematurely despair of their conservatees' recovery, or the orders of those conservators whose judgment might be tainted by motives less altruistic than Mr. Elbaum's. The potential evil we see

100. *Id.* at 848.

101. *Elbaum*, 623 N.E.2d at 514 n.*

102. *Elbaum*, 588 N.Y.S.2d at 856.

103. *Id.*

104. *Id.* (citations omitted).

105. *Id.* at 860.

resulting from this, i.e., the possible death of one patient whose life might have been saved, is infinitely greater, in our view ¹⁰⁶

Judge Rosenblatt, in dissent, strongly disagreed with this statement. He stated that the court's ruling "allow[ed] a nursing home to profit financially, while ignoring a patient's wishes, as it imposes its own ethical standards upon her."¹⁰⁷

106. *Id.*

107 *Id.* at 861 (Rosenblatt, J., dissenting). Judge Rosenblatt further noted that the court had previously held that Grace Plaza had "ignored Mr. Elbaum's demands while simultaneously insisting upon payment for their undesired services." *Id.* at 862 (Rosenblatt, J., dissenting) (quoting *Elbaum v. Grace Plaza of Great Neck, Inc.*, 544 N.Y.S.2d 840, 847 (App. Div 1989)).

New York's high court avoided directly addressing the moral hazard question in affirming the appellate division. It noted that it had previously required the families of patients unable to express their wishes concerning continuing care to establish by clear and convincing evidence that the patient had previously expressed a clear and settled wish that care not be continued. See *Elbaum*, 623 N.E.2d at 515 (citing *In re Westchester County Med. Ctr.* (O'Connor), 531 N.E.2d 607, 613 (N.Y. 1988)). The court stated: "If a provider harbors some uncertainty on the matter, it acts within the dictates of *O'Connor* if it refuses to discontinue treatment until the issue is legally determined. By doing so, it does not breach a contract of care nor impair its right to be paid for services rendered." *Id.* (citations omitted). The court concluded:

If the provider refuses to act, we find nothing unfair in placing the burden of instituting legal proceedings on those seeking to discontinue treatment. Though the provider has a legal duty to adhere to the known wishes of a patient, a desire to terminate life support does not stand on the same legal footing as a patient's request for a routine change in treatment.

O'Connor instructs decision-makers to "err on the side of life" and makes clear that the burden of establishing an incompetent patient's desire to die rests squarely with those who are asserting that desire.

Id. at 515-16 (citing *In re Westchester County Med. Ctr.* (O'Connor), 531 N.E.2d 607, 613 (N.Y. 1988)).

Two other appellate courts have also allowed nursing homes to recover for unwanted treatment, at least during the time it takes to obtain judicial permission to terminate life-sustaining treatment. See *First Healthcare Corp. v Rettinger*, 467 S.E.2d 243, 244 (N.C. 1996) (per curiam), *rev'g* 456 S.E.2d 347 (N.C. App. 1995); *Leach v Shapiro*, 469 N.E.2d 1047, 1053-55 (Ohio Ct. App. 1984).

One commentator writing after the appellate division's ruling in *Elbaum* was critical of this approach. See Gasner, *supra* note 17, at 514. Gasner noted:

Permitting payment for unwanted treatment provides a serious disincentive to honor patient choice. Families are often reluctant to initiate court cases because of the emotional and financial burden. If the provider is allowed to treat now, and decide later whether it was appropriate, and get paid in the interim, there is little incentive to expedite the court proceedings. There is every incentive to delay taking the requests of the family seriously because stalling financially benefits the provider.

*III. Wrongful Living, Wrongful Life: Can Plaintiffs
with Disabilities Recover Damages When They Argue That
They Would Be Better Off Dead?*

The lack of accountability for failure to honor advance directives has led some commentators to call for the imposition of civil liability when a health care provider violates a patient's wish either to end or never to begin life-sustaining treatment.¹⁰⁸ One writer suggested that a "successful suit of this type might be more effective than legislation in encouraging physicians to take 'living wills' seriously"¹⁰⁹

Id. at 514 (citations omitted).

Gasner further argued:

As a matter of law, it makes sense that once the family withholds consent to treatment, the provider must go to court to receive permission to continue that treatment. In a judicial hearing, the court can determine whether there is legally sufficient evidence that the patient would not consent to the treatment. If the evidence supports the surrogate decisionmaker's directions, then the treatment never gets started. The patient dies according to her wishes and there is no problem of nonpayment. In contrast, if the evidence is insufficient, the facility will get legal permission to treat, and payment will be required thereafter.

Such a system guarantees that the provider will only go to court for those cases in which there is serious reason to question the sufficiency of the evidence. Few families will want to be hauled into court if they cannot prove that they are acting consistently with the patient's wishes. Most families will consent to the treatment before subjecting themselves to a court hearing and incurring legal fees.

Id. at 513-14 (citations omitted).

108. See generally Gasner, *supra* note 17; Knapp & Hamilton, *supra* note 18; David H. Miller, *Right-to-Die Damage Actions: Developments in the Law*, 65 DENV U. L. REV 181 (1988); Willard H. Pedrick, *Arizona Tort Law and Dignified Death*, 22 ARIZ. ST. L.J. 63 (1990) [hereinafter Pedrick, *Arizona Tort Law*]; Willard H. Pedrick, *Dignified Death and the Law of Torts*, 28 SAN DIEGO L. REV 387 (1991); Addlestone, *supra* note 17; Richard P. Dooling, Comment, *Damage Actions for Nonconsensual Life-Sustaining Medical Treatment*, 30 ST. LOUIS U. L.J. 895 (1986); Hackelman, *supra* note 18; see also Gregory G. Sarno, Annotation, *Tortious Maintenance or Removal of Life Supports*, 58 A.L.R. 4TH 222 (1987 & Supp. 1995).

109. George J. Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, 4 AM. J. L. & MED. 367, 386 n.48 (1979), quoted in Dooling, *supra* note 108, at 898. A few living will statutes do expressly provide the basis for a civil cause of action, but either limit the damages available or require that the health care provider's refusal to follow the advance directive be in bad faith. See ALASKA STAT. § 18.12.070(a) (Michie 1994) (allowing "civil penalty not to exceed \$1,000 plus the actual costs associated with the failure to comply with the order or declaration, and this shall be the exclusive remedy at law"); NEB. REV. STAT. ANN. § 20-402(1) (Michie 1995) ("Unjustifiable violation of a patient's direction shall be a civil cause of action maintainable by the patient or the patient's next of kin. Remedy in law and equity may be granted by a court of competent jurisdiction."); TENN. CODE ANN. § 32-11-108(a) (Supp. 1996) ("Any health care provider who fails to make good faith reasonable efforts to comply with the preceding procedure as prescribed by the

To date, in the majority of suits seeking damages for the unauthorized provision of life-sustaining treatment, plaintiffs have relied on traditional common-law torts such as battery and infliction of emotional distress or on a constitutional tort under 42 U.S.C. § 1983.¹¹⁰ There has also been a call, however, for the recognition of a new tort: wrongful living.

A. Wrongful Living: Interference with the Right to Die

1. Wrongful Living Defined

A wrongful living cause of action was first proposed in a law review article published a decade after the recognition of the right to die in *Quinnlan* and in California's Natural Death Act.¹¹¹ Oddi argued that:

attending physician shall be civilly liable and subject to professional disciplinary action. "). Section 10 of the Uniform Health-Care Decisions Act (UHCDA) includes a provision on "statutory damages." UNIF HEALTH-CARE DECISIONS ACT § 10, 9 U.L.A. 242 (West Supp. 1996). Damages are available only for an intentional violation of the act and can range from \$500 to "actual damages resulting from the violation, whichever is greater, plus reasonable attorney's fees." *Id.* A comment to the section indicates that the drafters chose civil damages rather than criminal penalties "out of a recognition that prosecutions are unlikely to occur." *Id.* They also indicate that the statutory damages "do not supersede but are in addition to remedies available under other law." *Id.* at 243. This section of the UHCDA has been adopted by Maine and New Mexico. ME. REV STAT. ANN. tit. 18-A, § 5-810 (West Supp. 1995); N.M. STAT. ANN. § 24-7A-10 (Michie Supp. 1996).

Two commentators have suggested that the Patient Self-Determination Act (PSDA) might give rise to a cause of action when a hospital fails to inform a patient of his rights under state law or of its policy regarding the removal of life support. *See* Gasner, *supra* note 17, at 518; Addlestone, *supra* note 17, at 1278-79. The only case to date on the issue, however, held that the PSDA does not include a private right of action. *See* Anselin v. Shawnee Mission Med. Ctr., 894 F Supp. 1479, 1485 (D. Kan. 1995).

Some states provide a criminal penalty for health care providers who refuse to comply with an advance directive and fail to transfer a patient to a facility where treatment will be withdrawn, but such a failure must be willful or in bad faith. *See* ARK. CODE ANN. § 20-17-209(a) (Michie 1991) (stating action as misdemeanor); CAL. HEALTH & SAFETY CODE § 7191(a) (West Supp. 1996) (same); MONT. CODE ANN. § 50-9-206(1) (1995) (same); NEB. REV STAT. ANN. § 20-411(1) (Michie 1995) (stating action as class I misdemeanor); NEV. REV STAT. ANN. § 449.660(1) (Michie 1995) (stating action as gross misdemeanor). Other states classify the failure to comply with a directive as unprofessional conduct allowing state licensing authorities to penalize a health care provider. *See* D.C. CODE ANN. § 6-2427(b) (1995); HAW. REV STAT. § 327D-11(c) (Supp. 1992); MO. ANN. STAT. § 459.045(1) (West 1992); N.J. STAT. ANN. § 26:2H-78 (West 1996); OKLA. STAT. ANN. tit. 63, § 3101.11 (West Supp. 1995); R.I. GEN. LAWS § 23-4.11-9(a) (Supp. 1995); S.C. CODE ANN. § 44-77-100 (Law. Co-op. Supp. 1995); TENN. CODE ANN. § 32-11-108(a) (Supp. 1996); UTAH CODE ANN. § 75-2-1112(3) (1993); WIS. STAT. ANN. § 154.07(1)(a)(3) (West Supp. 1995).

110. *See* Gasner, *supra* note 17, at 504-12 (discussing theories advanced in cases seeking damages for failure to honor patients' refusal of treatment); Addlestone, *supra* note 17, at 1267-72 (same).

111. Oddi, *supra* note 18, at 637

Once it has been established that a person has the right to die, medical personnel who might otherwise be under a duty to act on behalf of that person are not only relieved of that duty but also restrained by a diametrically opposite duty not to interfere with that person's right to die. Either intentional or negligent interference with the right to die would constitute a breach of that duty¹¹²

Oddi first discussed possible actions based on such a breach under traditional tort concepts:

If the treatment was intentional and with knowledge that the person asserting the right to die had withheld consent, the tort of battery would obviously lie. Absent an intent to override the patient's wishes, there is also the possibility that one could negligently breach a duty not to treat where the party providing the treatment should have known of the patient's refusal to be treated.¹¹³

Oddi continued, however, to identify a new tort:

Whether the interfering treatment is conducted with or without due care is irrelevant, except insofar as such treatment prolongs the life of the individual contrary to the right to die. If the interfering treatment is made and the patient lives, then interference with the right to die involves *compensation for living*. This is a "wrongful living" cause of action.¹¹⁴

112. *Id.*, see also *Anderson v. St. Francis-St. George Hosp.*, 671 N.E.2d 225, 227 (Ohio 1996) ("[I]n a 'wrongful living' action, the plaintiff is asserting a liberty interest in refusing unwanted medical treatment. It is the denial of this liberty interest, when the medical professional either negligently or intentionally disregards the express wishes of a patient, that gives rise to the wrongful living cause of action.")

113. Oddi, *supra* note 18, at 636.

114. *Id.* at 641 (emphasis added) (citations omitted). Oddi argued that this tort is a personal one and may be redressed by the person whose right to die is interfered with or, if they die, by their representative on a survival basis. *Id.* at 642. He later stated:

In a personal or survival action, the loss to the patient asserting the right to die is *the prolongation of life*. Expressed in terms of causation, the question becomes: But for the interference with the right to die, that is, the rendering of treatment, was the life of the patient prolonged? Whether the treatment was rendered in a negligent or skillful manner is irrelevant, except with regard to how that reflects on the damages issue. Thus, the measure of damages should be reflected in how long the life was prolonged after the time when death would be expected to occur had no treatment been rendered.

Id. at 661 (emphasis added); see also *Anderson*, 671 N.E.2d at 227. The *Anderson* court noted:

For purposes of a "wrongful living" cause of action, the event or loss for which the plaintiff seeks damages is neither death nor life but the *prolongation of life*. Thus, once it is established that but for the conduct of the medical professional, death would have resulted, the causation element for a "wrongful living" claim is satisfied.

Id. (emphasis added).

In his article, Oddi declared that *Estate of Leach v Shapiro*¹¹⁵ could be categorized as an action for wrongful living.¹¹⁶ On July 27, 1980, Akron General Medical Center admitted Edna Marie Leach, who was suffering from respiratory distress.¹¹⁷ She later went into cardio-pulmonary arrest, and the medical center resuscitated her.¹¹⁸ Leach was in a chronic vegetative state following her resuscitation, and on August 1, 1980, the medical center placed Leach on life-support systems.¹¹⁹ On October 21, 1980, Leach's husband, as her guardian, filed a petition asking to terminate the life support.¹²⁰ The order to terminate life-support was issued on December 18, 1980.¹²¹ On January 6, 1981, the medical center disconnected the respirator, and Leach died.¹²²

On July 9, 1982, Leach's estate and members of her family filed an action seeking damages for the time Leach was on life-support systems.¹²³ The plaintiffs alleged that the defendants had acted wrongfully in placing her on life support and continuing treatment contrary to the express wishes of Leach and her family.¹²⁴ The plaintiffs claimed that Leach was in a chronic vegetative state when the medical center first placed her on life support on August 1, 1980, that Leach had expressly advised the defendants that she did not wish to be kept alive by machines, and that the medical center performed this treatment without her consent or that of her family.¹²⁵

Citing *Lacey v Laird*,¹²⁶ the *Leach* court concluded that "a physician who treats a patient without consent commits a battery, even though the procedure is harmless or beneficial."¹²⁷ The court then went on to state:

While the patient's right to refuse treatment is qualified because it may be overborn[e] by competing state interests, we believe that, absent legislation to the contrary, the patient's right to refuse treatment is absolute until the quality of the competing interests is weighed in a court proceeding. We

115. 469 N.E.2d 1047 (Ohio Ct. App. 1984).

116. Oddi, *supra* note 18, at 648.

117. *Estate of Leach v. Shapiro*, 469 N.E.2d 1047, 1051 (Ohio Ct. App. 1984).

118. *Id.* at 1052.

119. *Id.*

120. *Id.* at 1051.

121. *Leach v. Akron Gen. Med. Ctr.*, 426 N.E.2d 809, 809 (Ohio Ct. C.P. 1980).

122. *Estate of Leach*, 469 N.E.2d at 1051.

123. *Id.* at 1051.

124. *Id.* at 1051-52.

125. *Id.* at 1052.

126. 139 N.E.2d 25 (Ohio 1956).

127. *Estate of Leach*, 469 N.E.2d at 1051 (citing *Lacey v. Laird*, 139 N.E.2d 25, 28 (Ohio 1956)).

perceive this right as the logical extension of the consent requirement and conclude that *a patient may recover for battery if his refusal is ignored*.¹²⁸

The court recognized that "doctors must be free to exercise their best medical judgment in treating a life-threatening emergency,"¹²⁹ but stated that "[c]arried to its extreme the doctrine of implied consent could effectively nullify those privacy rights recognized in *In re Quinlan*, *Eichner*; *Saikewicz*; and *Leach* since a physician could circumvent the express wishes of a terminal patient by waiting to act until the patient was comatose and critical."¹³⁰ The court decided that the merits of the plaintiffs' claims depended upon facts to be developed in the case, including the existence and nature of any consent or refusal of treatment; the nature of the treatments before August 1, 1980; Leach's condition on that date; and the nature of the treatment on and after August 1, 1980.¹³¹ Given these factual questions, the court ruled that the trial court had erred in dismissing the battery complaint.¹³² The court also ruled that there were factual questions regarding the plaintiffs' efforts to recover for pain, suffering, and mental anguish for Leach and for themselves.¹³³ The court found the plaintiffs' claims valid to the extent that they could prove that the failure to remove Leach from life support caused pain and suffering beyond that which Leach normally would have suffered from her condition.¹³⁴

Oddi argued that *Leach* could be categorized as an action for wrongful living because:

[B]ut for the unauthorized treatment of Mrs. Leach on the life-support system, she would have died naturally. *The unauthorized treatment resulted in the prolongation of the life of a patient who had the right to die naturally without unauthorized treatment. Damages are thus appropriate on a survival basis for the time period that the patient survived due to the interfering treatment.*¹³⁵

128. *Id.* at 1051-52 (emphasis added).

129. *Id.* at 1053 (citations omitted).

130. *Id.* (citations omitted).

131. *Id.*

132. *Id.* at 1054.

133. *Id.* at 1055.

134. *Id.*

135. Oddi, *supra* note 18, at 648 (emphasis added). Oddi also cited the case of *Holmes v. Silver Cross Hospital*, 340 F Supp. 125 (N.D. Ill. 1972), as being representative of a wrongful living case. Oddi, *supra* note 18, at 645-47. The action before the *Holmes* court, however, did not seek compensation for living following unauthorized life-sustaining treatment. Indeed, the patient died despite the unauthorized treatment. *Holmes v. Silver Cross Hosp.*, 340 F Supp. 125, 128 (N.D. Ill. 1972). Instead, the question was whether doctors and a

2. Wrongful Living Cases

a. Anderson v St. Francis-St. George Hospital

An Ohio appellate court citing *Leach* and *Oddi*, however, has twice rejected the wrongful living cause of action, in decisions subsequently ap-

hospital had violated a patient's First Amendment right to free exercise of religion by forcing him to undergo blood transfusions even though they knew it was against his religious principles. *Id.*

In *Holmes*, a 20-year-old man was admitted to a hospital following an accident. *Id.* at 128. While still fully conscious and competent, he told the doctors that his religious beliefs precluded him from receiving blood transfusions. *Id.* The doctors then unsuccessfully attempted to persuade other members of his family that a transfusion was medically necessary. *Id.* All of his relatives also refused to authorize the transfusions on religious grounds, and both *Holmes* and his wife signed a form releasing the hospital and doctors from liability if they were to perform surgery without any transfusions. *Id.*

When *Holmes* lost consciousness, however, the hospital petitioned a court to declare him incompetent as a minor and to appoint a conservator who would consent to the transfusions. *Id.* The court granted this request, and the conservator authorized the transfusions. *Id.* *Holmes* died despite the transfusions; there was no claim that his death was in any way caused by them, however. *Id.*

Holmes's widow brought an action against the doctors and the hospital under the Civil Rights Act of 1871, 42 U.S.C. § 1983, charging that the defendants violated *Holmes's* civil rights by treating him in a manner inconsistent with his religious beliefs while acting under color of state law. *Id.* at 127-28. The court noted that this issue had not been definitely settled by the Supreme Court or the Seventh Circuit and reviewed decisions from other courts on the issue, as well as the Supreme Court's decisions relating to the Free Exercise Clause. *Id.* It concluded that "a state-appointed conservator's ordering of medical treatment for a person in violation of his religious beliefs, no matter how well intentioned the conservator may be, violates the First Amendment's freedom of exercise clause in the absence of some substantial state interests." *Id.* at 130. Given the lack of evidence on such a state interest in the case before it, the court denied the defendants' motion to dismiss. *Id.*

The *Holmes* court also denied the defendants' motion to dismiss based on a lack of state action. *Id.* Noting that the hospital was subject to pervasive state regulations concerning its operations, the court found that its actions were under color of state law for purposes of § 1983. *Id.* at 132-33. It further found that a factual question remained concerning whether the doctors were acting as agents of the hospital and could, therefore, also be held liable under § 1983. *Id.* at 134-35.

At least one court, however, has rejected a § 1983 claim for disregarding a patient's refusal of treatment based on a lack of state action. See *Ross v. Hilltop Rehabilitation Hosp.*, 676 F. Supp. 1528, 1530 (D. Colo. 1987). The *Ross* decision is in line with the majority of case law on whether a private hospital can be deemed a state actor. One commentator noted that "courts have consistently held that the actions of a private hospital do not constitute state action unless the state is significantly involved with specific hospital activity that is the subject of the plaintiff's complaint." Sidney Summers, Note, *Medical Staff Credentialing: Physician Challenges to Board Certification Criteria*, 18 AM. J. TRIAL ADVOC. 673, 686 (1995). Summers provides a brief listing of case law in the area. See *id.* at 886-87. For a more comprehensive look at case law on whether a hospital can be held a state actor, see Annotation, *Action of Private Hospital as State Action Under 42 U.S.C. § 1983 or Fourteenth Amendment*, 42 A.L.R. FED. 463 (1979 & Supp. 1995).

proved by the Ohio Supreme Court.¹³⁶ In *Anderson*, the administrator of Edward H. Winter's estate sued St. Francis-St. George Hospital (SFSG), claiming that SFSG was liable for resuscitating Winter despite the presence of a do-not-resuscitate order.¹³⁷

On May 25, 1988, SFSG admitted Winter, who complained of chest pains and fainted after losing consciousness at a senior citizens' center.¹³⁸ Winter, eighty-two years old, had suffered two previous heart attacks and endured chronic heart disease and other health problems.¹³⁹ While in the hospital, Winter discussed the type of treatment he was to receive with his family doctor, George Russo. Winter was competent and alert during this conversation, and Dr. Russo understood Winter to mean that "he wanted no extraordinary life-saving measures in the event of further illness."¹⁴⁰ In addition, Winter's daughter told Dr. Russo of a conversation with her father concerning life-saving measures that had been performed on Winter's wife and resulted in "great misery and suffering for the remainder of her life."¹⁴¹ During Mrs. Winter's hospital stay, her heart was shocked and her chest beaten while in intensive care, and Winter's daughter told Dr. Russo that Winter was very upset about these actions. Winter subsequently told his daughter "never to let anybody do that to him."¹⁴² As a result of this discussion, Dr. Russo entered an instruction in the hospital record: "No Code Blue."¹⁴³

On May 28, 1988, Winter suffered a ventricular fibrillation, a type of irregular heartbeat that may be quickly fatal.¹⁴⁴ A nurse, apparently unaware of the no-code-blue order, resuscitated Winter using defibrilla-

136. *Anderson v. St. Francis-St. George Hosp.*, 614 N.E.2d 841, 843 (Ohio Ct. App. 1992), *appeal after remand*, No. C-930819, 1995 WL 109128 (Ohio Ct. App. Mar. 15, 1995), *rev'd*, 671 N.E.2d 225 (Ohio 1996).

137. *Id.*

138. *Id.*

139. *Anderson*, 1995 WL 109128, at *1.

140. *Id.*

141. *Id.*

142. *Id.* at *5 n.1.

143. *Anderson*, 614 N.E.2d at 843. Dr. Russo defined a "no code blue" order in his deposition testimony:

Well, in my mind, a no code blue order is an organized process of resuscitating a patient and anything that would initiate that or any procedure that would be, that would occur during that process would be a resuscitative procedure, whether you whap them on the chest or whether you give medicine or whether you give an IV

Anderson, 1995 WL 109128, at *1.

144. *Anderson*, 614 N.E.2d at 843.

tion — electrically shocking the heart with paddles.¹⁴⁵ Winter thanked the nurse for saving his life when he regained consciousness.¹⁴⁶ Dr. Russo ordered lidocaine to be readministered to treat Winter and to prevent further attacks.¹⁴⁷ Another episode two hours later ended spontaneously due to the lidocaine.¹⁴⁸ On May 29, Dr. Russo discontinued the lidocaine and the heart monitor.¹⁴⁹ The following day, Winter had a stroke which left him paralyzed on the right side.¹⁵⁰ On June 16, 1988, SFSG transferred Winter to a rehabilitation hospital. At that time, Winter "was unable to walk, was incontinent of urine, had difficulty speaking, and needed assistance in bathing and dressing."¹⁵¹ After a four-week stay in a rehabilitation hospital, Winter returned to his home where, for a two-month period, a nurse cared for him during the day and one of his daughters cared for him in the evening.¹⁵² He later moved into one of his daughter's homes so that she could care for him.¹⁵³ On April 19, 1989, he moved into a nursing home where he enjoyed numerous visits and outings with his family before he died on April 14, 1990.¹⁵⁴

Winter's estate brought an action against SFSG alleging that the nurse's resuscitation was a battery to Winter, that the nurse was negligent by resuscitating Winter contrary to Dr. Russo's orders, and that SFSG was liable for Winter's wrongful living.¹⁵⁵ The trial court granted SFSG's motion for summary judgment on all counts.¹⁵⁶

The appellate court reversed on the battery claim, finding that there were disputed questions of fact regarding whether Winter's instructions had specifically precluded defibrillation.¹⁵⁷ The court found that if the instructions did preclude defibrillation then SFSG's treatment constituted a battery.¹⁵⁸ Moreover, if SFSG committed a battery, then there was a genuine

145. *Id.*

146. *Anderson*, 671 N.E.2d at 226.

147. *Id.*

148. *Id.*

149. *Id.*

150. *Anderson*, 1995 WL 109128, at *1.

151. *Id.*

152. *Id.*

153. *Id.*

154. *Anderson*, 671 N.E.2d at 276.

155. *Anderson*, 614 N.E.2d at 843.

156. *Id.*

157. *Id.* at 844.

158. *Id.*

issue of material fact regarding whether Winter's alleged damages after the defibrillation — including a paralyzing stroke as well as pain, suffering, emotional distress and disability, and medical expenses — were proximately caused by the original wrongful act.¹⁵⁹

The appellate court, however, affirmed the trial court's summary judgment on the wrongful living claim.¹⁶⁰ Winter's estate had argued that when SFSG prolonged his life by the defibrillation, his life "was for him, not worth living."¹⁶¹ The court relied on *Leach* and two cases allowing wrongful pregnancy actions to support the wrongful living claim.¹⁶² The appellate court found these cases unpersuasive and stated that in the wrongful pregnancy cases the Ohio Supreme Court had "noted with disapproval the wrongful life cause of action for children of negligently sterilized mothers, which measures 'damages on the relative merits of being versus non-being.'"¹⁶³ The Ohio Supreme Court had also "referred to the joy of life as an 'intangible benefit' that [could] not be valued monetarily."¹⁶⁴ The *Anderson* court decided that: "Damages are not those things that add to life, but those that subtract from it."¹⁶⁵

The court also rejected the estate's analogy to *Leach*. Noting that although *Leach* held that the plaintiff had a cause of action for the nonconsensual medical treatment, the court stated that "[t]here was no need to coin a cause of action for the wrongful act. The court held that a 'physi-

159. *Id.* at 845.

160. *Id.* at 847

161. *Id.*

162. *Id.* at 846; see *Johnson v. University*, 540 N.E.2d 1370, 1378 (Ohio 1989); *Bowman v. Davis*, 356 N.E.2d 496, 499 (Ohio 1976). A wrongful pregnancy claim (also known as wrongful conception) is brought by parents alleging negligent performance of a sterilization procedure or abortion and the subsequent birth of a child. BLACK'S LAW DICTIONARY 1612 (6th ed. 1990). In *Bowman* and *Johnson*, doctors had attempted to sterilize women and eliminate future pregnancies. *Johnson*, 540 N.E.2d at 1370-71; *Bowman*, 356 N.E.2d at 497. In both cases, the physicians negligently performed the operations, and the patients became pregnant. *Anderson*, 614 N.E.2d at 846.

163. *Anderson*, 614 N.E.2d at 845 (quoting *Bowman*, 356 N.E.2d at 499). A wrongful life claim is a "type of medical malpractice claim brought on behalf of a child born with birth defects, alleging the child would not have been born but for negligent advice to, or treatment of the parents." BLACK'S LAW DICTIONARY 1613 (6th ed. 1990). For a more complete discussion of how wrongful life claims relate to ones for wrongful pregnancy and the damages allowable therein, see *infra* notes 234-40 and accompanying text.

164. *Anderson*, 614 N.E.2d at 845 (quoting *Johnson*, 540 N.E.2d at 1375). The Ohio Court of Appeals ultimately issued a definitive rejection of wrongful life claims in *Flanagan v. Williams*, 623 N.E.2d 185, 191 (Ohio Ct. App. 1993).

165. *Anderson*, 614 N.E.2d at 846. The court listed as examples of compensable damages wrongful death, unlawful shortening of a person's life, general physical injuries, loss of use of a limb, and emotional harm caused by another's negligence. *Id.*

cian who treats a patient without consent commits a battery.' Under *Leach*, therefore, there is no wrongful-living cause of action."¹⁶⁶ The *Anderson* court concluded: "[The estate's] attempt to create a wrongful-living cause of action fails because life is not a compensable harm."¹⁶⁷ On appeal after remand, the appellate court clarified what it meant in holding that wrongful living is not a compensable harm: "By that we mean that he cannot recover general damages just for finding himself still alive after unwanted resuscitative measures."¹⁶⁸

The Ohio Supreme Court agreed with this conclusion.¹⁶⁹ It stated: "In its simplest form, the question [presented by a wrongful living claim] becomes: Is 'continued living' a compensable injury?"¹⁷⁰ The court concluded that it is not; even if the plaintiff could show a breach of a duty and the resulting prolongation of life.¹⁷¹

The court's decision focused on the difficulty of determining damages for the harm of prolongation of life, stating that "[t]here is perhaps no issue that better demonstrates the outer bounds of liability in the American civil justice system than this issue."¹⁷² It noted that it had previously recognized

166. *Id.* (citations omitted).

167. *Id.* (emphasis added).

168. *Anderson*, 1995 WL 109128, at *3. The court made clear, however, that this did not mean that Winter was precluded from all damages. The court noted that it had previously held that Winter's estate stated a claim for battery and negligence:

To be more precise, Edward Winter gave express directives for his medical care which were ignored, either negligently or intentionally. His right to refuse treatment was expressly violated. [Winter's estate's] claim for damages must be examined in light of the increasingly important public policy issues involved here, namely the right to refuse treatment, either by speaking for oneself or through someone else, if unable to do so. We thus hold that the issue in this case is what compensable damages arise from the violation of a competent adult patient's right to refuse treatment.

Id. The court then specified the allowable damages:

If the jury determines that adverse consequences to Winter's health occurred in a natural and continuous sequence following the unwanted resuscitative effort, then Winter's estate may recover all damages related thereto, including all of Winter's medical expenses after May 28, 1988, until his death, the costs of the nursing home, and any extraordinary expenses related to Winter's care; and his pain, suffering and emotional distress related to having a stroke. On the other hand, if the jury concludes that there is no causal relationship between the unwanted resuscitative efforts and Winter's adverse health consequences, there will be no recoverable damages for Winter's estate.

Id. at *5.

169. *Anderson*, 671 N.E.2d at 228-29

170. *Id.* at 227

171. *Id.* at 228-29.

172. *Id.* at 228.

the "‘impossibility of a jury placing a price’ on the benefit of life"¹⁷³ and concluded: "There are some mistakes, indeed even breaches of duty or technical assaults, that people make in this life that affect the lives of others for which there simply should be no monetary compensation."¹⁷⁴

b. McGuinness v Barnes

A per curiam appellate decision, *McGuinness v Barnes*,¹⁷⁵ also rejected a wrongful living claim, although in dicta it left open the possibility of future recognition of the action.¹⁷⁶ Richard McGuinness is a former Newark, New Jersey detective who suffered brain damage during surgery to remove a brain

173. *Id.* (citation omitted).

174. *Id.* (citing *Heiner v. Moretuzzo*, 652 N.E.2d 664, 670 (Ohio 1995) (*Heiner* affirmed "that 'not every wrong is deserving of a legal remedy.'")). The court did allow Winter's estate to proceed with the negligence and battery claims. *Id.* at 228-29. However, it reversed the appellate court's decision to allow recovery for all foreseeable consequences of the treatment, including pain, suffering, and emotional distress beyond that which Winter would have suffered had he not been resuscitated. *Id.* It stated that the appellate court's "theory of recovery seems to be identical to the theory of recovery underlying a claim of 'wrongful living.' Both the law of the case and our holding here make this theory untenable, and damages, if any, must be based strictly on the theory of negligence or battery." *Id.* at 228. The court then noted, however, that a plaintiff is entitled to only nominal damages when a battery was physically harmless. *Id.* at 229 (citing *Lacey v Laird*, 139 N.E.2d 25, 25 (Ohio 1956)). The court found that Winter suffered no harm due to defibrillation, "i.e., no tissue burns or broken bones." *Id.* Winter's estate conceded that it was not seeking nominal damages. *Id.* Accordingly, the court concluded that there was no issue for the trial court to decide upon remand and entered judgment for SFSG. *Id.*

A concurring opinion suggested that the type of case before the court "should be denominated 'furthering life' rather than 'wrongful living.'" *Id.* at 229 (Douglas, J., concurring). That opinion then asked:

Applying the positive connotation to an act which continues life, where death would have occurred without intervention, what damage could possibly ensue?

Assuming, for purposes of argument only, that the action of the hospital through its staff was negligence, and assuming further that "damages" should be assessed as a result of the negligence, how could they be computed? Can the preservation of life (furthering life) even be amenable to the "damages" concept. I think not!

Id. (Douglas, J., concurring). Three justices dissented and stated:

Contrary to the assertion of the majority opinion, the plaintiff was not seeking to recover because Winter's life was prolonged. He was seeking to recover because the hospital staff failed to follow the instructions Winter had given them. He claimed that this negligence increased the likelihood that Winter would suffer a stroke. Not only did Winter suffer a stroke, he was incapacitated from that day until the day of his death.

Id. at 230 (Pfeifer, J., dissenting).

175. No. A-3457-94T5, slip op. (N.J. Super. Ct. App. Div. Aug. 6, 1996).

176. *McGuinness v. Barnes*, No. A-3457-94T5, slip op. at 8-9 (N.J. Super. Ct. App. Div. Aug. 6, 1996).

tumor.¹⁷⁷ In early 1986, McGuinness noticed that he began stubbing his toe and that once when his brother asked him a question he could not answer it.¹⁷⁸ McGuinness, then fifty-seven years old, went to see a New Jersey neurologist in July 1986; the neurologist diagnosed McGuinness with a probable brain tumor.¹⁷⁹ McGuinness was referred to a doctor practicing at Mt. Sinai Medical Center in New York City.¹⁸⁰ In August 1986, McGuinness underwent an angiogram and a frontal parietal craniotomy with a total removal of a tumor.¹⁸¹ After the surgery, McGuinness was unable to move his legs, and his right arm was weakened.¹⁸² Since then, his condition has improved slightly, but he is unable to care for himself and now lives in a nursing home.¹⁸³

After his injury, McGuinness retained attorney Timothy Barnes to file a lawsuit on his behalf.¹⁸⁴ Barnes failed to do so, and McGuinness brought a legal malpractice action against Barnes.¹⁸⁵ McGuinness claimed that Barnes wrongly advised him that he could not file a lawsuit on McGuinness's behalf in the state in which the operation took place (New York).¹⁸⁶ McGuinness also accused Barnes of abandoning McGuinness's interests shortly before the statute of limitations on filing a medical malpractice suit expired.¹⁸⁷

Among the underlying medical malpractice claims included in the legal malpractice suit against Barnes, McGuinness alleged that if he had been informed of the risks of the procedure he underwent to remove the tumor, he would have rejected the surgery.¹⁸⁸ McGuinness claimed that his doctor told him the operation was routine and did not advise him of the possible serious repercussions.¹⁸⁹ McGuinness later learned that he would have died within six months to a year without the surgery and asserted that he would have preferred this early death to his current disabled condition.¹⁹⁰

177 *Id.* at 3.

178. Plaintiff-Appellant Richard McGuinness' Brief in Support of His Appeal at 5-6, *McGuinness* (No. A-3457-94T5).

179. *McGuinness* (No. A-3457-94T5), slip op. at 2.

180. *Id.* at 3.

181. *Id.*

182. *Id.*

183. *Id.*

184. Plaintiff-Appellant Richard McGuinness' Brief at 7, *McGuinness* (No. A-3457-94T5).

185. *McGuinness* (No. A-3457-94T5), slip op. at 3.

186. Plaintiff-Appellant Richard McGuinness' Brief at 7-8, *McGuinness* (No. A-3457-94T5).

187. *Id.*

188. *Id.* at 6.

189. *Id.*

190. *Id.* at 16.

In his response to Barnes's motion to dismiss, McGuinness stated that "just because [he] is alive today and conventional medical opinion suggests that he would have died without the surgery does not necessarily mean that he benefitted by the operation."¹⁹¹ McGuinness argued that:

His first and only love of his life was being a police officer. When he suffered a heart attack, had cataract surgery, blood disorders and other illnesses, he stayed on the job. While others would have retired, gone out on disability long before, Richard McGuinness remained as a police officer dedicated to law enforcement. He changed job duties but still remained on the job. He wanted to continue as a police officer until he died. Both the United States Constitution and the New Jersey Constitution as well as the common law guarantee his right to self-determination even if he had only six months or a year to live. *Richard McGuinness had the right to live the remainder of his life protecting the rights of others instead of requiring around the clock care in a life of partial paralysis.*¹⁹²

McGuinness further argued that to hold that he had

no legally cognizable claim for damages, would in effect, license the medical profession to disregard the rights of those who have life-threatening illnesses. To rule in favor of the Defendants would send a message to the medical community that it may disregard the rights of those who are terminally ill because they would die eventually. These rights are basic to all of us.¹⁹³

However, in an unpublished oral ruling, the trial court rejected this argument.¹⁹⁴ In a decision based mainly on traditional informed consent principles, the judge found that the doctors had no duty to inform McGuinness of the option of nontreatment because a reasonable person would

191. Brief in Opposition to Motion *In Limine* to Bar Doctor Schneck's Report and/or Dismiss Plaintiff's Case at 19, *McGuinness v. Barnes* (No. UNN-L-171-93) (N.J. Super. Ct. Law Div.). Substantially identical language appears in McGuinness's appellate brief. Plaintiff-Appellant Richard McGuinness' Brief at 15, *McGuinness* (No. A-3457-94T5).

192. Brief in Opposition to Motion *In Limine* to Bar Doctor Schneck's Report and/or Dismiss Plaintiff's Case at 20, *McGuinness* (No. UNN-L-171-93). Substantially identical language appears in McGuinness's appellate brief. Plaintiff-Appellant Richard McGuinness' Brief at 16, *McGuinness* (No. A-3457-94T5).

193. Brief in Opposition to Motion *In Limine* to Bar Doctor Schneck's Report and/or Dismiss Plaintiff's Case at 20-21, *McGuinness* (No. UNN-L-171-93). Substantially identical language appears in McGuinness's appellate brief. Plaintiff-Appellant Richard McGuinness' Brief at 16, *McGuinness* (No. A-3457-94T5).

194. Transcript of Proceedings at 63, *McGuinness* (No. L-1710-93).

have gone ahead with the surgery¹⁹⁵ The court also noted that the record was unclear whether McGuinness's doctor knew before the surgery that nontreatment would result in certain death and whether McGuinness would have withheld consent if he knew all the risks.¹⁹⁶ It concluded: "Given that [McGuinness] had successfully undergone treatment which saved his life, this Court finds that [McGuinness] has no cause of action for wrongful life."¹⁹⁷

The appellate court also based its decision on informed consent principles.¹⁹⁸ It noted that McGuinness's own expert testified that a reasonable and prudent patient given all the appropriate information would have chosen surgery instead of death.¹⁹⁹ Thus, McGuinness's case failed under the causation requirement of the informed consent doctrine, which requires a showing that "the prudent person in the patient's position would have decided differently if adequately informed."²⁰⁰

The court decided that McGuinness's failure to show causation also barred his wrongful living claim.²⁰¹ In doing so, however, it suggested in dicta that such a claim could constitute a viable cause of action in the proper circumstances:

We recognize that a competent person has the right to refuse medical treatment even at the risk of death. *Arguably, if any of the physicians involved in the case intentionally or willfully deprived [McGuinness] of that right of self-determination, that might give rise to an independent cause of action.* Not so in this case. If [McGuinness] was

195. *Id.* The court analogized to *Iafelice v. Zafaru, id.* at 62, in which the court concluded that physicians were not liable under an informed consent theory when they performed an operation that saved an infant's life, but failed to inform her parents that she would likely require permanent institutional care. *Iafelice v. Zafaru*, 534 A.2d 417, 418 (N.J. Super. Ct. App. Div. 1987). The *Iafelice* court stated:

The mistaken premise of this appeal is that allowing the child to die untreated was a legally viable alternative. [W]e find no support for the belief that a newborn child may be put to death through benign neglect on the mere expectation that she will, in some unquantified way, be a defective person.

Id.

196. Transcript of Proceedings at 63, *McGuinness* (No. L-1710-93).

197. *Id.* The parties and the court erroneously referred to McGuinness's action as one for "wrongful life," but it is clear from the facts that the actual cause of action was for wrongful living.

198. *McGuinness*, slip op. at 8-9.

199. *Id.* at 6.

200. *Id.* at 7 (quoting *Largey v. Rothman*, 540 A.2d 504, 510 (N.J. 1988)).

201. *Id.* at 9.

deprived of his right to make a meaningful choice as to whether he wished to live or die, that was because he was deprived of [f] the opportunity to give informed consent to the surgical procedure or procedures. We have already decided that there is no basis for [a] medical malpractice action based on the lack of informed consent.²⁰²

c. *Benoy v Simons and
Bartling v Glendale Adventist Medical Center*

Other appellate courts, although not directly faced with a wrongful living cause of action, have also been reluctant to allow damages for commencing or continuing life-sustaining treatment. For example, in *Benoy v Simons*²⁰³ the court upheld the dismissal of a claim for "wrongful prolongation of life."²⁰⁴ Dustin Reed Benoy was born on March 11, 1985 at Kadlec Medical Center (Kadlec) in Richland, Washington.²⁰⁵ Dustin was born prematurely, weighing less than two kilograms and suffering from severe respiratory distress.²⁰⁶ Kadlec placed Dustin in intensive care, and he subsequently developed a pneumothorax and intracranial hemorrhage with an intracerebral hemorrhage, which required surgical intervention.²⁰⁷ During Dustin's hospitalization at Kadlec, his mother, father, and grandparents had frequent discussions with the hospital staff and doctors concerning the legal, medical, and financial issues surrounding Dustin's care.²⁰⁸ Neither his mother nor his grandparents were willing to permit the appointment of a guardian, and his grandparents refused to be appointed.²⁰⁹ Dustin remained on a ventilator while hospitalized at Kadlec²¹⁰ and was later transferred to a hospital in Seattle. On April 27, 1985, Dustin was removed from the ventilator, and he died.²¹¹

After his death, Dustin's mother and grandparents brought an action against a physician and Kadlec and requested damages for, among other things, wrongful prolongation of life. The plaintiffs argued that the

202. *Id.* at 8-9 (emphasis added) (citation omitted).

203. 831 P.2d 167 (Wash. Ct. App. 1992).

204. *Benoy v Simons*, 831 P.2d 167, 169 (Wash. Ct. App. 1992).

205. *Id.*

206. *Id.*

207. *Id.*

208. *Id.*

209. *Id.*

210. *Id.*

211. *Id.*

rationale of *Harbeson v Parke-Davis, Inc.*,²¹² which allowed "a wrongful birth action by the parents of a [handicapped] child should by analogy allow a wrongful prolongation of life action as well."²¹³ The court disagreed. It found the analogy to *Harbeson* "unsound."²¹⁴ The court stated that *Harbeson* was "based on the recognition that parents have a right to prevent the birth of a handicapped child and health care providers have a duty to the parents correlative to that right."²¹⁵ Thus, wrongful birth actions were based on a doctor's breach of duty to the *parents* of a handicapped child as his patients. This was inapplicable to the case before the court because Dustin was the patient.²¹⁶

In *Bartling v Glendale Adventist Medical Center*,²¹⁷ the court recognized that a patient had a right to refuse treatment, but found that this right was not sufficiently established at the time to support a damages action for its violation.²¹⁸ William Bartling entered Glendale Adventist on April 8, 1984 for treatment of severe chronic depression.²¹⁹ He was also suffering from pulmonary emphysema, atherosclerotic cardiovascular disease, coronary arteriosclerosis, an abdominal aneurysm, and lung cancer.²²⁰ On April 14, 1984, Bartling's left lung collapsed during a needle biopsy.²²¹ After attempts to re-inflate his lung failed, a mechanical ventilator was attached by way of a tracheotomy.²²²

On May 30, 1984, Bartling signed a living will stating that he did not want to be kept alive by "artificial means or heroic measures."²²³ Bartling also executed a "Durable Power of Attorney for Health Care," appointing his wife as attorney-in-fact. Additionally, he, his wife, and daughter executed documents that released Glendale Adventist and its physicians from any claim of civil liability should they honor his wishes.²²⁴

212. 656 P.2d 483 (Wash. 1983).

213. *Benoy*, 831 P.2d at 170.

214. *Id.*

215. *Id.*

216. *Id.*

217. 229 Cal. Rptr. 360 (Ct. App. 1986).

218. *Bartling v Glendale Adventist Med. Ctr. (Bartling II)*, 229 Cal. Rptr. 360, 361 (Ct. App. 1986).

219. *Id.*

220. *Id.*

221. *Id.*

222. *Id.*

223. *Id.*

224. *Id.* He also signed a declaration that stated, in part:

Between June and August of 1984, doctors attempted to wean Bartling from his ventilator. They resuscitated him each time because his "breathing and/or heart action failed during the weaning process."²²⁵ They also tried to transfer him to another hospital, but no other facility was willing to take him. Bartling died while still at Glendale Adventist on November 6, 1984.²²⁶ He remained on the ventilator until his death and had, at one time, been restrained by cloth cuffs around his wrists to prevent him from removing the tubes.²²⁷

A month and a half after Bartling's death, the California Court of Appeals held that a competent nonterminally ill adult patient has a constitutionally based right to reject or terminate medical treatment.²²⁸ Shortly after this decision, Bartling's family filed an amended complaint alleging "battery, violation of constitutional and federal civil rights, breach of fiduciary duty, and intentional infliction of emotional distress and conspiracy"²²⁹

The trial court dismissed this complaint, and the court of appeals affirmed.²³⁰ The court of appeals stated that:

It cannot be said that a common or comprehensive legal standard was in place to guide the medical community at the time of Bartling's hospitalization — one which clearly should have compelled Glendale Adventist to

While I have no wish to die, I find intolerable the living condition forced upon me by my deteriorating lungs, heart and blood vessel systems and find intolerable my being continuously connected to this ventilator, which sustains my every breath and my life for the past 6 and one-half (6 ½) weeks. Therefore, I wish this Court to recognize, honor and protect my constitutional right to liberty, privacy, self-dignity and the control of my own body. I wish this Court to order that the sustaining of my respiration by this mechanical device violates my constitutional right, is contrary to my every wish, and constitutes a battery upon my person.

Id. Bartling's declaration continued:

I fully understand that [this] request which I have frequently made to my wife and to my doctors, will very likely cause respiratory failure and ultimately lead to my death. I am willing to accept that risk rather than to continue the burden of this artificial existence which I find unbearable, degrading and dehumanizing. I also suffer a great deal of pain and discomfort because of being confined to bed, being on this ventilator, and from the other problems which are occurring.

Id. at 362.

225. *Id.* at 361.

226. *Id.* at 362.

227. *Id.*

228. *Bartling v Superior Court (Bartling I)*, 209 Cal. Rptr. 220 (Ct. App. 1984).

229. *Bartling v Glendale Adventist Med. Ctr. (Bartling II)*, 229 Cal. Rptr. at 361.

230. *Id.* at 362.

"pull the plug" on Mr. Bartling's ventilator. The determination of the patient's right to die under extant law was a judgment call. It was only after *Bartling I* that California's physicians had legal precedent for freely acting according to a competent adult patient's instructions to terminate life-support systems without fear of civil liability and without advance court approval.

While we found in *Bartling I* that [the hospital's] refusal to withdraw treatment intruded upon Mr. Bartling's right to privacy, we cannot agree that the Bartlings' rights were so well-defined at the time of Mr. Bartling's hospitalization that Glendale Adventist deliberately acted with "conscious disregard" of their patient's constitutional rights.²³¹

231. *Id.* at 363 (citations omitted). The court dismissed the plaintiffs' emotional distress claim and other claims for the same reason. *Id.* at 364-65.

Other families asserting emotional distress claims caused by witnessing the prolongation of a loved one's life have been similarly unsuccessful. For example, in *Strachan v. John F Kennedy Memorial Hospital*, the appellate court reversed a \$140,000 judgment in favor of the parents of a suicide victim in an action alleging that a hospital had breached a duty to provide consent forms for the pronouncement of death or the disconnection of a respirator, or to have a procedure for turning off a respirator. *Strachan v. John F Kennedy Mem'l Hosp.*, 507 A.2d 718, 723-27 (N.J. Super. Ct. App. Div. 1986).

Jeffrey Strachan arrived at the defendant hospital at approximately 5:00 P.M. on Friday, April 25, 1980, after shooting himself in the head with a .38 caliber bullet. *Id.* at 720. The emergency room physician intubated Strachan and placed him on a respirator at 5:25 P.M. *Id.* He was declared brain dead later that night, and the following morning, Saturday, April 26, 1980, his parents requested that he be removed from the respirator. *Id.* The hospital refused, at first stating that a respirator could not be disconnected without a court order. *Id.* The court order later became unnecessary, however, when a physician agreed to remove Strachan from life-support systems and sign a death certificate if the parents signed a release. *Id.* at 722. The release was signed on Monday, April 28, 1980. *Id.* At that time, Strachan had no spontaneous respiration and was pronounced dead. *Id.*

Strachan's parents brought suit against the hospital alleging, among other things, negligent infliction of emotional distress. *Id.* They were successful in the trial court, but the appellate court reversed. *Id.* at 723. The court found that the "principles distilled from existing law persuade us to conclude that the hospital had no duty to provide consent forms or to have a procedure for turning off the respirator." *Id.* at 726. "Additionally, we discern no defined public policy which imposes a duty on the hospital or its administrator to have procedures and consent forms available for the withdrawal of life-support systems." *Id.* at 727; see also *Westhart v Mule*, 261 Cal. Rptr. 640, 640-42 (Ct. App. 1989) (concluding that widow did not state cause of action for intentional infliction of emotional distress arising from doctor's insertion of feeding tube into her husband, contrary to her wishes that no heroic measures be taken to prolong his life, when there was no evidence that she later made any efforts to have tube removed); *Bartling v. Glendale Adventist Med. Ctr. (Bartling II)*, 229 Cal. Rptr. 360, 365 (Ct. App. 1986) (finding no cause of action for "outrage" or intentional infliction of emotional distress when medical professionals "acted in reliance on what they believed to be prevailing community medical and legal standards and did not use their superior position to intentionally harass or intimidate the Bartlings"); *Benoy v Simons*, 831 P.2d 167, 169 (Wash. Ct. App. 1992) (same).

The court also rejected an emotional distress claim in *McVey v. Englewood Hospital Association*. In *McVey*, the court held that a hospital and physicians could not be held liable for failing to comply with a comatose patient's undocumented oral request, as expressed by family members, to terminate life support. *McVey v Englewood Hosp. Ass'n*, 524 A.2d 450, 452 (N.J. Super. Ct. App. Div. 1987). The estate and surviving daughters of Elizabeth Palermo, sought damages for substantial medical costs and emotional suffering alleged to have arisen from the failure to honor Palermo's wishes, as communicated by her daughters, to be removed from life support. *Id.*

Palermo had been admitted to the hospital on March 17, 1985, "[i]n a deep coma and suffering from respiratory failure," and was connected to a respirator. *Id.* at 451. A physician told Palermo's daughters that same night "that her brain stem activity was minimal and that death would likely ensue" if the respirator were removed. *Id.* Palermo's daughters asked that the respirator be terminated, stating that their mother had said she did not wish to be artificially maintained in such a situation. *Id.* The hospital and doctors refused, however, until Palermo's daughters followed New Jersey procedure to become her guardians, and then authorized discontinuation of treatment on April 22, 1985. *Id.* at 451-52. Palermo died four days later. *Id.* at 452.

The daughters brought suit seeking damages for the defendants' failure to honor their mother's wishes as communicated by them in March. *Id.* The trial court granted the defendants' motion for summary judgment, and the appellate court affirmed. *Id.* at 451. The court held that hospitals and medical professionals do not have the duty or the expertise to explore the extent of conflicting interests, views, and purposes when an incompetent patient's relatives ask that life sustaining efforts be discontinued because of the patient's orally expressed wishes. *Id.* at 452.

The court distinguished cases holding that physicians are free from civil or criminal liability when they acquiesce to an immediate family member's expression of an incompetent patient's presumed or actual wish regarding the removal of life support. *Id.* (citing *Barber v Superior Court*, 195 Cal. Rptr. 484 (Ct. App. 1983); *John F Kennedy Mem'l Hosp. v Bludworth*, 452 So. 2d 921 (Fla. 1984)). The court noted:

Barber and *Bludworth* hold that physicians are free from civil or criminal liability [when acquiescing to family wishes for the removal of life support]. It is a very different thing, however, to assert that failure to comply with such undocumented requests, and absent the appointment of a guardian, constitutes an actionable breach of a duty owed to the patient and family. That time has not come in New Jersey

Id.

One commentator reviewing these decisions suggested that they reflected courts' hesitancy to question physicians' medical judgment: "The judiciary's reaction to those few cases in which patients or their families have sued for damages for nonconsensual [life-sustaining] treatment represents another instance of the legal system's uncritical endorsement of the medical profession's activist approach." Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV L. REV 375, 430 (1988).

One area in which plaintiffs advocating the right to die have achieved monetary success is the recovery of attorneys fees. *See Gray v Romeo*, 709 F Supp. 325, 327 (D.R.I. 1989) (awarding attorneys fees to patient who successfully sought declaration under 42 U.S.C. § 1983 that refusal to withdraw feeding tube violated her constitutional rights); *Bouvia v. County of Los Angeles*, 241 Cal. Rptr. 239, 243-47 (Ct. App. 1987) (awarding attorneys fees to patient who succeeded in obtaining court order allowing removal of feeding

*B. Wrongful Life: A Disabled Child's Assertion That
He Should Never Have Been Born*

Rejection of the wrongful living cause of action in *Anderson* and *McGuinness* and the hesitancy to award damages for life as opposed to death in *Benoy* and *Barling* is consistent with the vast majority of case law on wrongful life claims. In a wrongful life claim:

The child does not allege that the physician's negligence caused the child's deformity. Rather, the claim is that the physician's negligence — his failure to adequately inform the parents of the risk [that the child would be born with a disability] — has caused the birth of the deformed child. The child argues that but for the inadequate advice, it would not have been born to experience the pain and suffering attributable to the deformity.²³²

tube under California's "private attorney general" statute but denying attorneys fees under 42 U.S.C. § 1988 because there was "no evidence of a governmental policy or custom in connection with decision by county hospital physicians and other personnel to withdraw her from morphine"). *But see Foster v. Tourtellotte*, 704 F.2d 1109, 1112 (9th Cir. 1983) (finding that Veterans Administration patient was not entitled to attorneys fees under Equal Access to Justice Act even though he prevailed on claim that failure to remove him from respirator violated his right to privacy; government's position that it needed court guidance in resolving issue in absence of any precedent was "substantially justified").

232. *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 494 (Wash. 1983) (en banc) (quoting Thomas Keasler Foutz, Comment, "Wrongful Life"· *The Right Not to Be Born*, 54 TUL. L. REV. 480, 485 (1980)); *see also Berman v. Allan*, 404 A.2d 8, 11 (N.J. 1979) ("[T]he infant plaintiff [asserts] not that [she] should not have been born without defects but [rather] that [she] should not have born at all In essence, Sharon claims that her very life is 'wrongful.'").

A wrongful life claim is closely related to a wrongful birth action, which includes the same allegations, but is brought by the parents of the handicapped child. BLACK'S LAW DICTIONARY 1612 (6th ed. 1990). Wrongful life and wrongful birth actions differ from wrongful conception or pregnancy cases in which the claim is brought by parents "for damages arising from the negligent performance of a sterilization procedure or abortion, and the subsequent birth of a child." *Id.*, *see also Cowe v. Forum Group, Inc.*, 575 N.E.2d 630, 633 (Ind. 1991) (citations omitted). The *Cowe* court stated:

An action for wrongful conception or pregnancy refers to a claim for damages sustained by the parents of an unexpected child alleging that the conception of the child resulted from negligent sterilization procedures or a defective contraceptive product. The phrase 'wrongful birth' applies to claims brought by the parents of a child born with birth defects alleging that due to negligent medical advice or testing they were precluded from an informed decision about whether to conceive a potentially handicapped child or, in the event of a pregnancy, to terminate it. When such action seeks damages on behalf of the child rather than the parents, the phrase 'wrongful life' instead of 'wrongful birth' is employed.

Id.

With few exceptions, courts faced with the issue have refused to recognize wrongful life claims.²³³ In addition, a number of states have enacted

Several writers have drawn an analogy between wrongful life and wrongful living actions. See, e.g., Allen J. Belsky, *Injury As a Matter of Law: Is This the Answer to the Wrongful Life Dilemma?*, 22 U. BALT. L. REV 185, 223-34 (1993); Dooling, *supra* note 108, at 916-17. Oddi, however, stated that a wrongful living cause of action should be distinguished from wrongful life claims. See Oddi, *supra* note 18, at 641 n.75. Oddi states that "[t]he difficulty with the 'wrongful life' cases is the damages element, because a comparison must be made between nonlife and life in an impaired condition." *Id.* As discussed below, see *infra* notes 344-47 and accompanying text, this same problem arises in wrongful living cases.

Knapp and Hamilton also attempted to distinguish wrongful living and wrongful life cases:

In contrast to the "wrongful life" concept, the "wrongful living" plaintiff does not assert a right to make a retrospective decision about whether to be born, that is, to speculate about what decision the plaintiff would have made had the future been known to the plaintiff prior to conception or in utero. The "wrongful living" plaintiff weighs the effects of his medical therapy and his prognosis with and without the therapy, against the desirability of remaining alive.

Knapp & Hamilton, *supra* note 18, at 258 (citations omitted). I suggest below, see *infra* notes 340-45 and accompanying text, that this is a distinction without a difference and that it ignores the fundamental similarity between the two causes of action: the plaintiffs in both argue that they would be better off dead and that they are entitled to damages due to the quality of their life.

233. The cases in which state courts have denied wrongful life claims include: *Elliott v Brown*, 361 So. 2d 546, 548 (Ala. 1978); *Walker v Mart*, 790 P.2d 735, 741 (Ariz. 1990); *Lmmnger v. Eisenbaum*, 764 P.2d 1202, 1210 (Colo. 1988); *Garrison v Medical Ctr. of Del. Inc.*, 581 A.2d 288, 289 (Del. 1989); *Kush v Lloyd*, 616 So. 2d 415, 423 (Fla. 1992); *Blake v Cruz*, 698 P.2d 315, 322 (Idaho 1984); *Siemeniec v Lutheran Gen. Hosp.*, 512 N.E.2d 691, 701 (Ill. 1987); *Cowe v Forum Group, Inc.*, 575 N.E.2d 630, 635 (Ind. 1991); *Bruggeman v Schimke*, 718 P.2d 635, 642 (Kan. 1986); *Pitre v Opelousas Gen. Hosp.*, 517 So. 2d 1019, 1025 (La. Ct. App. 1987), *aff'd in part, rev'd in part on other grounds*, 530 So. 2d 1151 (La. 1988); *Viccaro v Milunsky*, 551 N.E.2d 8, 12 (Mass. 1990); *Strohmaier v. Associates in Obstetrics & Gynecology, P.C.*, 332 N.W.2d 432, 434 (Mich. Ct. App. 1982); *Wilson v Kuenzi*, 751 S.W.2d 741, 743 (Mo. 1988); *Greco v United States*, 893 P.2d 345, 348 (Nev. 1995); *Smith v Cote*, 513 A.2d 341, 355 (N.H. 1986); *Becker v. Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978); *Azzolino v Dingfelder*, 337 S.E.2d 528, 532 (N.C. 1985); *Flanagan v Williams*, 623 N.E.2d 185, 191 (Ohio Ct. App. 1993); *Ellis v Sherman*, 515 A.2d 1327, 1329-30 (Pa. 1986); *Nelson v Krusen*, 678 S.W.2d 918, 925 (Tex. 1984); *James G. v Caserta*, 332 S.E.2d 872, 881 (W. Va. 1985); *Dumer v. St. Michael's Hosp.*, 233 N.W.2d 372, 376 (Wis. 1975); *Beardsley v Wierdsma*, 650 P.2d 288, 289 (Wyo. 1982).

Three jurisdictions have recognized the wrongful life cause of action. See *Turpin v Sortini*, 643 P.2d 954, 966 (Cal. 1982); *Procanik v Cillo*, 478 A.2d 755, 762 (N.J. 1984); *Harbeson v Parke-Davis, Inc.*, 656 P.2d 483, 495 (Wash. 1983).

In contrast, many courts have recognized the wrongful birth cause of action. See, e.g., *Robak v. United States*, 658 F.2d 471, 476 (7th Cir. 1981); *Gallagher v. Duke Univ.*,

statutory bans on wrongful life, wrongful birth, or wrongful pregnancy claims, or all three.²³⁴

638 F Supp. 979, 982 (M.D.N.C. 1986), *aff'd in part, vacated in part*, 852 F.2d 773 (4th Cir. 1988); Phillips v. United States, 508 F Supp. 544, 551 (D.S.C. 1981); Andalon v Superior Court, 208 Cal. Rptr. 899, 901 (Ct. App. 1984); Haymon v Wilkerson, 535 A.2d 880, 882 (D.C. 1987); Moores v. Lucas, 405 So. 2d 1022, 1026 (Fla. Dist. Ct. App. 1981); Siemieniec v Lutheran Gen. Hosp., 512 N.E.2d 691, 706 (Ill. 1987); Arche v. United States, Dep't of Army, 798 P.2d 477, 480 (Kan. 1990); Pitre v Opelousas Gen. Hosp., 517 So. 2d 1019, 1025 (La. Ct. App. 1987); Thiibeault v Larson, 666 A.2d 112, 115 (Me. 1995); Proffitt v Bartolo, 412 N.W.2d 232, 238 (Mich. Ct. App. 1987); Smith v Cote, 513 A.2d 341, 348 (N.H. 1986); Procanik v. Cillo, 478 A.2d 755, 762 (N.J. 1984); Becker v. Schwartz, 386 N.E.2d 807, 813 (N.Y. 1978); Speck v Finegold, 439 A.2d 110, 113-14 (Pa. 1981); Jacobs v. Theimer, 519 S.W.2d 846, 850 (Tex. 1975); Naccash v Burger, 290 S.E.2d 825, 830 (Va. 1982); Harbeson v Parke-Davis, Inc., 656 P.2d 483, 488 (Wash. 1983); James G. v. Caserta, 332 S.E.2d 872, 882 (W Va. 1985); Dumer v St. Michael's Hosp., 233 N.W.2d 372, 377 (Wis. 1975).

A majority of jurisdictions recognize wrongful pregnancy or conception claims. See Boone v. Mullendore, 416 So. 2d 718, 723 (Ala. 1982); University of Ariz. Health Sciences Ctr. v. Superior Court, 667 P.2d 1294, 1299 (Ariz. 1983) (en banc); Wilbur v Kerr, 628 S.W.2d 568, 571 (Ark. 1982); Turpin v. Sortini, 643 P.2d 954, 957-58 (Cal. 1982) (en banc); Ochs v. Borrelli, 445 A.2d 883, 884 (Conn. 1982); Fassoulas v Ramey, 450 So. 2d 822, 823 (Fla. 1984); Fulton-DeKalb Hosp. Auth. v Graves, 314 S.E.2d 653, 654 (Ga. 1984); Blake v. Cruz, 698 P.2d 315, 317-18 (Idaho 1984); Byrd v Wesley Med. Ctr., 699 P.2d 459, 461 (Kan. 1985); Schork v. Huber, 648 S.W.2d 861, 862 (Ky 1983); Jones v Malinowski, 473 A.2d 429, 432 (Md. 1984); Troppi v. Scarf, 187 N.W.2d 511, 516 (Mich. Ct. App. 1971); Sherlock v. Stillwater Clinic, 260 N.W.2d 169, 170 (Minn. 1977); Miller v Duhart, 637 S.W.2d 183, 188 (Mo. Ct. App. 1982); Kingsbury v Smith, 442 A.2d 1003, 1005 (N.H. 1982); Schroeder v Perkel, 432 A.2d 834, 838 (N.J. 1981); Lovelace Med. Ctr. v. Mendez, 805 P.2d 603, 609 (N.M. 1991); Bowman v Davis, 356 N.E.2d 496, 499 (Ohio 1976); Speck v Finegold, 439 A.2d 110, 113 (Pa. 1981); Jacobs v Theimer, 519 S.W.2d 846, 848 (Tex. 1975); Naccash v. Burger, 290 S.E.2d 825, 830 (Va. 1982); McKernan v. Aasheim, 687 P.2d 850, 856 (Wash. 1984) (en banc); Dumer v St. Michael's Hosp., 233 N.W.2d 372, 377 (Wis. 1975); Beardsley v Wierdsma, 650 P.2d 288, 292 (Wyo. 1982).

234. See IDAHO CODE § 5-334 (1990) (barring both wrongful life and wrongful birth claims); IND. CODE ANN. § 34-1-1-11 (West 1992) (barring wrongful life claims); MINN. STAT. § 145.424(1)- 424(2) (1989) (barring wrongful life and wrongful birth claims); MO. REV STAT. § 188.130 (1996) (same); N.D. CENT. CODE § 32-03-43 (1996) (barring wrongful life claims); 42 PA. CONS. STAT. ANN. § 8305 (West Supp. 1997) (barring wrongful life and wrongful birth claims); S.D. CODIFIED LAWS §§ 21-55-1, 21-55-2 (Michie 1987) (barring wrongful life, wrongful birth, and wrongful conception claims); UTAH CODE ANN. § 78-11-24 (1996) (barring wrongful life and wrongful birth claims).

The wrongful life cause of action has been the subject of numerous law review articles including several in the past few years. See generally, e.g. John F Hernandez, *Perinatal Transmission of HIV: Cause for the Resurrection of Wrongful Life*, 27 J. MARSHALL L. REV 393 (1994); Anthony Jackson, *Action for Wrongful Life, Wrongful Pregnancy, and Wrongful Birth in the United States and England*, 17 LOY. L.A. INT'L & COMP. L.J. 535 (1995); Michael B. Laudor, *In Defense of Wrongful Life: Bringing Political Theory to the Defense*

Courts give two general reasons for not recognizing wrongful life claims. The first is "a general conceptual unwillingness to recognize any cognizable damages for a child born with a genetic impairment as opposed to not being born at all."²³⁵ As one court noted:

Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians. Surely the law can assert no competence to resolve the issue, particularly in view of the very nearly uniform high value which the law and mankind has placed on human life, rather than its absence.²³⁶

Accordingly, those courts have held that "life, even life with severe defects, cannot be an injury in the legal sense."²³⁷

The second basis for rejecting wrongful life claims "is the impossibility of calculating compensatory damages to restore a birth defective child to the position he would have occupied were it not for the defendant's negligence."²³⁸ As one judge explained:

When a jury considers the claim of a once-healthy plaintiff that a defendant's negligence harmed him — for example, by breaking his arm — the jury's ability to say that the plaintiff has been "injured" is manifest, for the value of a healthy existence over an impaired existence is within the experience of imagination of most people. The value of non-existence — its very nature — however, is not.²³⁹

of a Tort, 62 FORDHAM L. REV 1675 (1994); Phillip G. Peters, Jr., *Rethinking Wrongful Life: Bridging the Boundary Between Tort and Family Law*, 67 TUL. L. REV 397 (1992); Tara A. Barrett, Development, *Hummel v Reiss: The New Jersey Supreme Court Takes a Step Backward in Its Recognition of Wrongful Life*, 46 RUTGERS L. REV 535 (1993); Julie F Kowitz, Note, *Not Your Garden Variety Tort Reform: Statutes Barring Claims for Wrongful Life and Wrongful Birth Are Unconstitutional Under the Purpose Prong of Planned Parenthood v Casey*, 61 BROOK. L. REV 235 (1995).

235. *Cowe v Forum Group, Inc.*, 575 N.E.2d 630, 634 (Ind. 1991); *see also Siemieniec v Lutheran Gen. Hosp.*, 512 N.E.2d 691, 697 (Ill. 1987).

236. *Becker v. Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978), *quoted in Greco v United States*, 893 P.2d 345, 348 (Nev 1995).

237. *Azzolino v. Dingfelder*, 337 S.E.2d 528, 532 (N.C. 1985), *quoted in Cowe*, 575 N.E.2d at 635; *see also Flanagan v Williams*, 623 N.E.2d 185, 191 (Ohio Ct. App. 1993) ("[W]e are not prepared to say that life, even with severe disabilities, constitutes an actionable injury").

238. *Cowe*, 575 N.E.2d at 634; *see also Siemieniec*, 512 N.E.2d at 697

239. *Speck v. Finegold*, 408 A.2d 496, 512 (Pa. Super. Ct. 1979) (Spaeth, J., concurring and dissenting), *aff'd by an equally divided court*, 439 A.2d 110 (Pa. 1981).

Put another way: "The wrongful life action involves 'a calculation of damages dependent upon the relative benefits of an impaired life as opposed to no life at all.' This is a 'comparison the law is not equipped to make.'"²⁴⁰

240. *Cowe*, 575 N.E.2d at 634 (quoting *Siemenec*, 512 N.E.2d at 697; *Becker*, 386 N.E.2d at 812). Even those few courts that have recognized the cause of action for wrongful life have been careful to hold that an injured child does not have a claim for general damages, but may only recover special damages resulting from extraordinary expenses for medical care or specialized teaching. For example, in *Turpin v. Sortini*, the court decided:

[W]ith respect to the child's claim for pain and suffering or other general damages recovery should be denied because (1) it is simply impossible to determine in any rational or reasoned fashion whether the [child] has in fact suffered an injury in being born impaired rather than not being born, and (2) even if it were possible to overcome the first hurdle, it would be impossible to assess general damages in any fair, non-speculative manner.

Turpin v. Sortini, 643 P.2d 954, 963 (Cal. 1982). Moreover, a "monetary award of general damages — as opposed to the claim for medical expenses — cannot in any meaningful sense compensate the [child] for the loss of opportunity not to be born." *Id.* at 964. Similar reasoning is found in *Procanik v. Cillo*:

Sound reasons exist not to recognize a claim for general damages.

The crux of the problem is that there is no rational way to measure non-existence or to compare non-existence with the pain and suffering of [the child's] existence. Whatever theoretical appeal one might find in recognizing a claim for pain and suffering is outweighed by the essentially irrational and unpredictable nature of that claim. Although damages in a personal injury action need not be calculated with mathematical precision, they require at their base some modicum of rationality.

[I]t is simply too speculative to permit an infant plaintiff to recover for emotional distress attendant on birth defects when that plaintiff claims he would be better off if he had not been born. Such a claim would stir the passions of jurors about the nature and value of life, the fear of non-existence, and about abortion. That mix is more than the judicial system can digest. We believe that the interests of fairness and justice are better served through more predictably measured damages — the cost of extraordinary medical expenses necessitated by the infant plaintiff's handicaps. Damages so measured are not subject to the same wild swings as a claim for pain and suffering and will carry a sufficient sting to deter future acts of medical malpractice.

Procanik v. Cillo, 478 A.2d 755, 763 (N.J. 1984); see also *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 496-97 (Wash. 1983) (en banc) (noting that general damages were "beyond computation" in wrongful life action, but that extraordinary expenses for medical care and special training were calculable and could thus be recovered).

Courts have reached similar decisions in wrongful birth cases, holding that while ordinary child-rearing costs are not recoverable, parents may recover for extraordinary medical and educational expenses attributable to a child's birth defect. See *Flanagan*, 623 N.E.2d at 188. See generally Melissa K. Smith-Groff, Note, *Wrongful Conception: When an Unplanned Child Has a Birth Defect, Who Should Pay the Cost?*, 61 MO. L. REV. 135,

IV Societal Prejudice Against Disability and the Right to Die: Better Off Dead than Disabled?

Despite the frequent statements in wrongful life cases that it is impossible to compare life with a disability to nonlife, one concern raised regarding these cases — as well as the right-to-die cases and especially the assisted suicide cases — is that they reflect a societal prejudice that devalues the worth of disabled persons' lives.²⁴¹ Specifically, both courts and commentators find that the recognition of each of these rights is based upon a societal prejudice that life with a disability is not worth living. The wrongful living cause of action reflects the same view, and it is vital for courts addressing it to understand the roots of this prejudice and the danger that recognition of this tort poses for persons with disabilities.

A. The View of Disability in Everyday Life and in the Media: A Double Standard Between the Value of Life with a Disability and Without It

The view that life with a disability is not worth living can be seen in everyday interactions among the disabled and the able-bodied, and in artistic depictions of people with disabilities.²⁴² People with disabilities

140-43 & nn.47-67 (1996). At least two courts, however, have denied the recovery of even extraordinary expenses in wrongful conception actions, holding that a doctor's negligent performance of a sterilization procedure does not increase the probability that the child will be born with a defect and is, therefore, too far removed to be considered the proximate cause of a birth defect. *See* LaPoint v Shirley, 409 F Supp. 118, 121 (W.D. Tex. 1976) (labeling action incorrectly as wrongful birth when child resulted from unsuccessful tubal ligation, which is wrongful conception action); Williams v Van Biber, 886 S.W.2d 10, 13-14 (Mo. Ct. App. 1994). Maine has a statutory bar to wrongful birth and wrongful life claims when a child is born healthy and limits damages under both claims to extraordinary expenses when the child is born with a disability. *See* ME. REV STAT. ANN. tit. 24, § 2931 (West 1990).

241. *See generally* Martha A. Field, *Killing "The Handicapped" — Before and After Birth*, 16 HARV WOMEN'S L.J. 79 (1993); Carol J. Gill, *Suicide Intervention for People with Disabilities: A Lesson in Inequality*, 8 ISSUES L. & MED. 37 (1992); Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 ISSUES L. & MED. 141 (1987); Paul Steven Miller, *The Impact of Assisted Suicide on Persons with Disabilities — Is It a Right Without Freedom?*, 9 ISSUES L. & MED. 47 (1993); Lois Shepherd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. ILL. L. REV 761, Teresa Harvey Paredes, Comment, *The Killing Words? How the New Quality-of-Life Ethic Affects People with Severe Disabilities*, 46 SMU L. REV 805 (1992).

242. Both Congress and the Supreme Court have recognized the existence of societal prejudice against persons with disabilities. In the findings and purposes listed in the first section of the Americans with Disabilities Act, Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improve-

report that complete strangers come up to them and talk about suicide.²⁴³

ments, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2) (1994). Further, the Act notes that "studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally." *Id.* § 12101(6). The Act also states:

[I]ndividuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society

Id. § 12101(7). Congress then stated that the purpose of the ADA was "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" and "to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities." *Id.* § 12101(2).

The Supreme Court has not yet ruled on an ADA case, but has recognized the existence of prejudice and discrimination against persons with disabilities in several of its rulings. For example, in *Alexander v. Choate*, the Court quoted sponsors of the ADA's precursor, Section 504 of the Rehabilitation Act of 1973, which forbids federal funds recipients from discriminating on the basis of disability. *Alexander v. Choate*, 469 U.S. 287, 296 (1985). The Court described the treatment of the handicapped as one of the country's "shameful oversights" that caused the handicapped to live among society "shunted aside, hidden, and ignored." *Id.* (quoting 117 CONG. REC. 45974 (1971) (statement of Rep. Vanik describing origins of Section 504)). Similarly, Senator Humphrey asserted that "we can no longer tolerate the invisibility of the handicapped in America." *Id.* (quoting 118 CONG. REC. 525-26 (1972)); see also *Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 454 (1985) (Stevens, J., concurring) (stating that "through ignorance and prejudice, the mentally retarded 'have been subjected to a history of unfair and often grotesque mistreatment'" (quoting *Cleburne Living Ctr., Inc. v. Cleburne*, 726 F.2d 191, 197 (1984))).

For an extensive discussion on disability discrimination in American society and its legal system, see generally WILLIE V. BRYAN, *IN SEARCH OF FREEDOM: HOW PERSONS WITH DISABILITIES HAVE BEEN DISENFRANCHISED FROM THE MAINSTREAM OF AMERICAN SOCIETY* (1996); MARTHA MINOW, *MAKING ALL THE DIFFERENCE, INCLUSION, EXCLUSION, AND AMERICAN LAW* (1990); JOSEPH P. SHAPIRO, *NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT* (1993); RICHARD BRYANT TREANOR, *WE OVERCAME: THE STORY OF CIVIL RIGHTS FOR DISABLED PEOPLE* (1993); and *DISABLED PEOPLE AS SECOND CLASS CITIZENS* (Myron G. Eisenberg et al. eds., 1982). See also Marcia P. Burgdorf & Robert Burgdorf Jr., *A History of Unequal Treatment: The Qualifications of Handicapped Persons as a "Suspect Class" Under the Equal Protection Clause*, 15 SANTA CLARA L. REV. 855 (1975); Jonathan C. Drimmer, Comment, *Cripples, Overcomers, and Civil Rights: Tracing the Evolution of Federal Legislation and Social Policy for People with Disabilities*, 40 UCLA L. REV. 1341 (1993).

243. See JOHN HOCKENBERRY, *MOVING VIOLATIONS: WAR ZONES, WHEELCHAIRS, AND DECLARATIONS OF INDEPENDENCE* 97 (1995). Hockenberry, a paraplegic broadcast journalist, relates his encounter with a flight attendant watching him move from his wheelchair to a plane seat. She first complimented him on his agility in making the move and

Others simply imagine that life with a disability must be worse than without it. For example, in *Annie Hall*, Woody Allen's character says:

I feel that life is divided up into the horrible and the miserable. Those are the two categories. The horrible would be like, I don't know, terminal cases, you know, and blind people, cripples. I don't know how they get through life. It's amazing to me. You know The miserable is everyone else. So when you go through life, you should be thankful that you're miserable.²⁴⁴

then said: "I guess you are the first handicapped person I have ever seen up close. Have you ever thought of killing yourself?" *Id.*, SHAPIRO, *supra* note 242, at 38. Shapiro discussed the experience of Paul Longmore, an historian who walks slowly due to childhood polio. A stranger approached Longmore on the street and said: "If I were you, I'd kill myself." *Id.* The connection of disability with suicide in the popular media was dramatically shown in the fall of 1995 when actor Christopher Reeve gave his first interview after being paralyzed in a fall from a horse. Though Reeve made only one passing remark in the hour long interview about considering suicide briefly after his accident, that sound bite appeared in almost every commercial advertising the interview, in the introductory piece preceding it, in the lead of the Associated Press piece about it, and in several headlines reporting it. See, e.g., Abraham Levy, *Reeve Pondered Suicide After Paralyzing Fall*, AUSTIN AM.-STATESMAN, Sept. 29, 1995, at B10; *Paralyzed Actor Reeve Says He Rejected Suicide*, CHI. TRIB., Sept. 29, 1995, at 6. Perhaps most ominously, Geoffrey Fieger, the attorney for "suicide doctor" Jack Kevorkian, cited Reeve as the kind of patient Kevorkian would help commit suicide. John Larabee, *Fieger, Examiner Square Off*, DETROIT NEWS, Nov 10, 1995, at D1.

Longmore's and Hockenberry's encounters and the reaction to Reeve's statement reflect a society in which:

People with disabilities perceive their situations in much the same way as anyone else with a crisis would [it] may be difficult for the majority of able-bodied people to accept. Adjusting to a physical disability is typically seen as the hardest adjustment a person would ever be called on to make. People have been known to say, "I would rather die than be blind, or paralyzed, or grossly disfigured." People do not usually say, "I would rather die than be poor, or lonely, or depressed."

Nancy Weinberg, *Another Perspective: Attitudes of People with Disabilities*, in ATTITUDES TOWARD PERSONS WITH DISABILITIES 152 (Harold E. Yuker ed., 1988).

244. ANNIE HALL (United Artists 1977), *quoted in* Longmore, *supra* note 241, at 152. Unfortunately, this viewpoint is not limited to a single movie. The author of an encyclopedic review of the depiction of persons with disabilities on television and in the movies noted:

A characteristic overused in disability portrayals is one termed as "devaluation." People with disabilities are illustrated as hating themselves and their limitations. They use poor language to further hammer home the point that they are, in their own eyes, less than human. "Freak" is a word of popular usage among screen characters. "Look at me!" is another term they employ, suggesting their appearance is inherently disgusting. It also serves the unspoken purpose of frightening a non-disabled audience as they see a nervous non-disabled character fighting back tears as they view the sight. This cancels out the possibility that disabled

This statement reflects what Paul Steven Miller, now a commissioner with the Equal Employment Opportunity Commission (EEOC), says is "a double standard between the value of the life of a person whose is able-bodied and that of a person with a disability"²⁴⁵ According to Miller:

people assimilate their own physicality and actually like themselves without the aid of an omniscient non-disabled person to help them acquire understanding.

LAURI E. KLOBAS, *DISABILITY DRAMA IN TELEVISION AND FILM* at xiv (1988). For a more academic look at the depiction of people with disabilities on film, see generally MARTIN F. NORDEN, *THE CINEMA OF ISOLATION: A HISTORY OF PHYSICAL DISABILITY IN THE MOVIES* (1994).

The view that life with a disability is not worth living is most obviously reflected in plays and movies dramatizing the assisted suicide issue. Brian Clark's play *Whose Life Is It Anyway?* (1978) and the movie of the same name (Metro-Goldwyn-Mayer 1982); the TV movie *An Act of Love* (NBC television broadcast, Sept. 24, 1980), based on PAIGE MITCHELL, *AN ACT OF LOVE: THE KILLING OF GEORGE ZYGMANIK* (1976); and Steve Carter's play *Nevis Mountain Dew* (1979) all tell the stories of disabled men who seek help in committing suicide. Similarly, the movie *THE ELEPHANT MAN* (Paramount Pictures 1980), which shows prejudice as a major obstacle for a disabled man, ends with the title character committing suicide. Longmore states that "[w]hether they focus on prejudice or paralysis, all of these stories tell us that disability causes social death, which in turn makes physical death preferable. Thus the point being made is better dead than disabled." Longmore, *supra* note 241, at 152.

Not all plays and movies featuring persons with disabilities end in suicide, of course, but even critically acclaimed ones which have "happy" endings often feature disabled characters who discuss or attempt suicide as a major part of the plot. See, e.g., *FORREST GUMP* (Paramount 1994) (involving amputee); *SCENT OF A WOMAN* (Universal 1993) (involving blinded former Army colonel).

245. Miller, *supra* note 241, at 48; see also Field, *supra* note 241, at 87-88. Field stated:

There is a societal cut of "normalcy" that leads to the devaluation of persons with retardation and other handicaps or unusual conditions, especially by people who have little experience with the populations they devalue. Such persons may truly believe that a child with a serious disability is "better off dead," because it seems to them so terrible to have a handicap.

Id. This double standard was most visibly demonstrated in the Social Darwinism and eugenics movements of the late 19th and early 20th centuries. The ultimate culmination of these movements was Germany's forced killing of over 200,000 persons with disabilities. An exhaustive study of the German "euthanasia" program and an excellent overview of eugenics in the United States and Europe can be found in HUGH GREGORY GALLAGHER, *BY TRUST BETRAYED: PATIENTS, PHYSICIANS, AND THE LICENSE TO KILL IN THE THIRD REICH* (2d ed. 1995).

In the United States, the eugenics movement's most visible manifestation was the mandatory sterilization of persons with disabilities. Sterilization laws were on the books in 28 states by 1937, and 17 states still had them in the late 1950s. See Burgdorf & Burgdorf, *supra* note 242, at 861. Nearly 64,000 sterilization procedures had been performed by 1964. See Drummer, *supra* note 242, at 1368-69 n.121. These laws survived a constitutional challenge in *Buck v. Bell*, in which Justice Holmes upheld Virginia's sterilization of

This double standard exists based upon society's prejudice against persons with disabilities.

Many able-bodied persons are tremendously fearful about becoming disabled. This fear is based upon the notion that a disabled person's life is inferior to, and less precious than, an able-bodied person's life.²⁴⁶

Miller states that this fear is at the root of prejudice against persons with disabilities. He states that of the many sources of such prejudice,

[f]oremost is that of fear: fear of the loss of autonomy and the "there but for the grace of God go I" realization that disability can "afflict" any person. Such fears are, of course, based on a prejudicial assumption about life with a disability that society itself creates. Able-bodied people see "confinement" to a wheelchair, or reliance upon attendant care, or a lack of hearing or vision, as losses of independence, which, in this society, is often regarded as worse than death itself.²⁴⁷

a "feeble-minded" woman with his infamous statement: "Three generations of imbeciles are enough." *Buck v Bell*, 274 U.S. 200, 274 (1927). The factual and procedural flaws in *Buck* are discussed in Robert L. Burgdorf, Jr. & Marcia P. Burgdorf, *The Wicked Witch Is Almost Dead: Buck v Bell and the Sterilization of Handicapped Persons*, 50 TEMP L.Q. 995 (1977); Charles P. Kindregan, *Sixty Years of Compulsory Eugenic Sterilization: "Three Generations of Imbeciles" and the Constitution of the United States*, 43 CHI.-KENT L. REV 123 (1966); and Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v Bell*, 60 N.Y.U. L. REV 30 (1985).

The view that persons with disabilities hurt society was still evident in a 1991 Louis Harris and Associates poll on public attitudes toward people with disabilities. Sixteen percent of respondents said that they felt anger "because disabled people are an inconvenience," and nine percent said that they felt resentment at the "special privileges disabled people receive." SHAPIRO, *supra* note 242, at 328-29.

246. Miller, *supra* note 241, at 48-49.

247. *Id.* at 53. The fear of becoming disabled is reflected in the 1991 Louis Harris and Associates poll on public attitudes toward people with disabilities. Conducted for the National Organization on Disability, the poll found that 92% of respondents said that they usually felt admiration when they met people with severe disabilities, 74% said that they felt pity, and 47% said that they reacted with fear "because what happened to the disabled person might happen to them." SHAPIRO, *supra* note 242, at 328.

One commentator recognized a number of possible bases for the fear of disability:

1. Persons with disabilities *represent a threat to the body image* of the nondisabled.
2. The observation of a person with a disability *reawakens the castration anxiety*. This is particularly true when seeing a person with a missing part of the body
3. Encountering a person with a disability brings to the forefront the *fear of losing one's physical integrity*. Almost everyone is cognizant that there is a very thin line between having a disability and being nondisabled. An accident or disease may at any time change our status from nondisabled to disabled, and

*B. The Depiction of Disability in Right-to-Die Case Law
Lives Not Worth Living*

The societal prejudice against disability can be seen in the few right-to-die cases brought by fully cognizant persons with disabilities who wanted judicial approval for the removal of respirators or feeding tubes. In these cases, courts focus entirely on the plaintiff's physical limitations, ignoring stresses in other areas of their lives, and conclude that life with these limitations is not worth living. In short, "[w]hen the nondisabled say they want to die, they are labeled as suicidal; if they are disabled, it is treated as 'natural' or 'reasonable.'"²⁴⁸

it is this uncertainty and more importantly the lack of control one may have in his status change which creates this fear.

4. Association with persons who have disabilities may create the *fear of contamination or inheritance* of the disability. Although most conditions that create limitations cannot be contracted, especially when proper medical treatment has been applied, the idea of contamination does exist. For some it is subconscious and for others it is a real conscious belief.

5. Persons with disabilities rekindle *separation anxieties*. All children experience this anxiety as it relates to being separated from parents and as we grow older these anxieties are repressed. As adults we experience them occasionally as fears of being separated from children, spouse and other loved ones. In encountering a person with a disability, similar fears emerge with regard to loss of limbs or other body parts similar to the fears of losing one's physical integrity.

BRYAN, *supra* note 242, at 110 (citing Hanoch Livneh, *On the Origins of Negative Attitudes Towards People with Disabilities*, in *THE PSYCHOLOGICAL AND SOCIAL IMPACT OF PHYSICAL DISABILITY* 167-84 (Robert P. Marinelli & Arthur E. Dell Orto eds., 1984)).

Whatever the source of the fear of disability, it is reflected in the terminology often used to describe persons with disabilities, and one commentator has noted:

Disabled people need to get nervous when professionals and the media use phrases like "imprisoned by her body," "helpless," "suffering needlessly," and "quality versus quantity of life." These phrases purport to be humanistic and compassionate, but they really express very primitive human fears of severe disability and a very misguided condemnation, "I could never live like that." Disabled people need to get very nervous because society is translating these primitive emotions into a supposedly rational social policy of assisted suicide, i.e., euthanasia.

Diane Coleman, *Growing Support of the Right to Die a Worrisome Trend*, NASHVILLE BANNER, May 10, 1990, at A19, *quoted in* Stanley S. Herr et al., *No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons with Physical Disabilities*, 8 *ISSUES L. & MED.* 3, 32 (1992).

248. *Compassion in Dying v. Washington*, 79 F.3d 790, 838 (9th Cir.) (en banc) (citing Gill, *supra* note 241, at 38-39), *cert. granted sub nom.* *Washington v. Glucksberg*, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 96-110)

I. Bouvia v Superior Court

The first case to address the propriety of withdrawing treatment from a competent person with a physical disability was *Bouvia v Superior Court*.²⁴⁹ Elizabeth Bouvia was born with cerebral palsy and was a quadriplegic.²⁵⁰ Her parents divorced when she was five years old, and her mother was given custody.²⁵¹ Her mother remarried when Bouvia was ten, and she was put in an institution for handicapped children.²⁵² Bouvia was moved from facility to facility during the next eight years, during which time her mother rarely visited her.²⁵³ At eighteen, she moved out into the community, and for eight years she lived independently, assisted by aides she paid through a California governmental program called In-Home Supportive Services.²⁵⁴ She earned an associate's degree at a community college and then received her bachelor of arts and began graduate work at San Diego State University.²⁵⁵ She married Richard Bouvia.²⁵⁶

Her personal life soon took on additional stresses. The local hospital where she was initially placed for field work in her social work graduate program refused to make accommodations for her disability, and she received no assistance from San Diego State.²⁵⁷ In fact, one of her professors reportedly told her she was unemployable and that if the school had known how disabled she was, she would never have been admitted to the master's program.²⁵⁸

Bouvia became pregnant, but suffered a miscarriage.²⁵⁹ Her brother drowned,²⁶⁰ and she and her husband separated and later filed for divorce.²⁶¹ Severely depressed, Bouvia checked herself into the psychiatric unit of Riverside County Hospital, stated that she wished to end her life, and asked the hospital to assist her.²⁶² The hospital refused, and a court in that county

249. 225 Cal. Rptr. 297 (Ct. App. 1986).

250. *Bouvia v Superior Court*, 225 Cal. Rptr. 297, 299 (Ct. App. 1986).

251. Longmore, *supra* note 241, at 153.

252. *Id.*

253. *Id.*

254. *Id.*

255. *Id.* at 154.

256. *Id.* at 156.

257. *Id.* at 154.

258. *Id.*

259. *Id.* at 156.

260. *Id.*

261. *Id.*

262. *Id.*

demed her petition to "starve herself to death."²⁶³ Bouvia's friends took her to several different facilities, both public and private, in an effort to find a hospital that would allow her to accomplish her goal.²⁶⁴ She ultimately ended up in a public hospital in Los Angeles County and there resumed litigation seeking the right to terminate her life.²⁶⁵ Specifically, she sought the removal of a nasogastric tube that she said was "inserted and maintained against her will and without her consent"²⁶⁶ for the purpose of keeping her alive through involuntary forced-feeding.²⁶⁷

In its opinion granting Bouvia's request, the California Court of Appeals did not see fit even to mention the severe emotional stress arising from Bouvia's miscarriage, separation, and problems in school. Instead, it focused solely on her disability:

[Bouvia's] physical handicaps of palsy and quadriplegia have progressed to the point where she is completely bedridden. Except for a few fingers of one hand and some slight head and facial movements, she is immobile. She is physically helpless and wholly unable to care for herself. She is totally dependent upon others for all of her needs. These include feeding, washing, cleaning, toileting, turning, and helping her with elimination and other bodily functions. She cannot stand or sit upright in bed or in a wheelchair. She lies flat in bed and must do so the rest of her life. She suffers also from degenerative and severely crippling arthritis. She is in continual pain. Another tube permanently attached to her chest automatically injects her with periodic doses of morphine which relieves some, but not all of her physical pain and discomfort.²⁶⁸

The court concluded that this life was indeed not worth living:²⁶⁹

[Bouvia] would have to be fed, cleaned, turned, bedded, toileted, by others for 15 to 20 years! Although alert, bright, sensitive, perhaps even brave and feisty, she must lie immobile, unable to exist except through physical acts of others. Her mind and spirit may be free to take great flights but she herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness. We do not believe it is

263. *Bouvia*, 225 Cal. Rptr. at 300.

264. *Id.*

265. *Id.*

266. *Id.* at 298.

267. *Id.*

268. *Id.* at 300.

269. *Id.* at 300-05.

the policy of this State that all and every life must be preserved against the will of the sufferer. It is incongruous, if not monstrous, for medical petitioners to assert the right to preserve a life that someone else must live, or more accurately, endure for 15 to 20 years. We cannot conceive it to be the policy of this State to inflict such an ordeal upon anyone.²⁷⁰

2. State v McAfee

Similar language is found in a decision involving a quadriplegic's request to be removed from a ventilator.²⁷¹ Larry McAfee was a quadriplegic as a result of a motorcycle accident.²⁷² At the time of his accident, McAfee worked full-time at an engineering firm in Atlanta while completing his engineering degree at Georgia Tech.²⁷³ Within seventeen months of his injury, the cost of his hospitalization, rehabilitation, and home health care had consumed all of his \$1 million insurance coverage, and McAfee became dependent on state Medicaid funding.²⁷⁴ McAfee's parents could not take him into their home and pay for his care, and Georgia's Medicaid program would not pay for home health care.²⁷⁵ Georgia Medicaid would pay a skilled nursing home one hundred dollars per day for McAfee's care, but no nursing home in the state would accept him because this payment was too low for the care of clients who used respirators.²⁷⁶ Other states

270. *Id.* at 305. The California Supreme Court later followed *Bouvia* and held that a quadriplegic prison inmate who refused to eat had a constitutional right to refuse medical treatment and could not be force fed through the insertion of a feeding tube. *Thor v Superior Court*, 855 P.2d 375, 383 (Cal. 1993) (en banc). Other courts are split on the issue of whether prisoners have a right to refuse life-sustaining medical treatment including force-feeding when they seek to starve themselves. *See Singletary v Costello*, 665 So. 2d 1099, 1104 (Fla. Dist. Ct. App. 1996) (holding that inmate who had gone on hunger strike to protest actions of Department of Corrections had right under state constitution to refuse life-saving medical procedures; inmate's constitutional right to refuse nonconsensual medical treatment was not vitiated by fact that he was incarcerated); *State ex rel. Schuetzle v Vogel*, 537 N.W.2d 358, 361 (N.D. 1995) (holding that because prison requirement that prisoner with diabetes take his medication was related to legitimate penological interests, prison officials could require prisoner to submit to diabetes monitoring and, if ordered by physician, provision of food, insulin, and other medications); *Laurie v Senecal*, 666 A.2d 806, 807 (R.I. 1995) (holding that prisoner who did not have terminal illness did not have constitutional right to commit suicide by refusing to eat and could be force fed).

271. *See State v McAfee*, 385 S.E.2d 651, 652 (Ga. 1989).

272. *Id.* at 651.

273. *See SHAPIRO, supra* note 242, at 262.

274. *Id.* at 265.

275. *Id.*

276. *Id.* at 265-66.

paid nursing homes more, and McAfee was moved to a nursing home near Cleveland because Ohio paid nearly three hundred dollars per day to care for clients on respirators.²⁷⁷ After McAfee filed complaints with Ohio officials about his poor care there, the nursing home transferred McAfee by ambulance plane to Grady Memorial Hospital in Atlanta.²⁷⁸ Georgia Medicaid had granted the Ohio nursing home permission to transfer McAfee, but did not inform Grady Hospital of the transfer until his arrival, knowing that the hospital would not have accepted a patient in stable condition and not in need of hospital care.²⁷⁹ Grady Hospital, however, could not discharge McAfee unless it found another place for him, and again, no Georgia nursing home would take a client on a respirator.²⁸⁰

After three months in the noisy and stressful ICU where he had no privacy and only rarely did nurses have time to get him out of bed, McAfee called a lawyer and said that he wanted to die.²⁸¹ The state did not oppose McAfee's petition,²⁸² and the court granted it.²⁸³

In doing so, the court did not mention McAfee's forced moves to the Ohio nursing home and then to the Atlanta hospital. Nor did it mention his experiences in the hospital. Like the *Bouvia* court, it focused only on the plaintiff's physical condition. The court described McAfee as being "incapable of spontaneous respiration, and dependent upon a ventilator to breathe. According to the record, there is no hope that Mr. McAfee's condition will improve with time, nor is there any known medical treatment which can improve his condition."²⁸⁴

3. *Bouvia and McAfee Choose to Live*

Given only the courts' descriptions of *Bouvia's* and McAfee's lives, one would think that the petitioners quickly embraced death after being granted the right to die. In fact, *Bouvia* is still alive today, thirteen years

277 *Id.* at 266.

278. *Id.* at 266-67

279. *Id.* at 267

280. *Id.*

281. *Id.* at 258, 267

282. See *McAfee*, 385 S.E.2d at 652 (indicating that state conceded that its interest in preserving life did not outweigh McAfee's right to refuse medical treatment and stated in its brief that "there is simply no basis in this case upon which the State may intervene and oppose the exercise of Mr. McAfee's right to refuse treatment").

283. *Id.* at 652-53.

284. *Id.* at 651.

after filing her suit,²⁸⁵ and McAfee died of pneumonia six years after the Georgia court gave him the choice of turning off his ventilator.²⁸⁶

McAfee was transferred to an Alabama nursing home with a special wing for clients who used respirators only two days after the trial court's hearing on his petition.²⁸⁷ While in the nursing home, McAfee met Russ Fine, the director of an injury prevention research center at the University of Alabama.²⁸⁸ Fine made it clear to McAfee that he supported his right to end his life, but presented him with other options as well.²⁸⁹ An engineer installed an environmental control system in McAfee's nursing home room that allowed him to operate the telephone and television.²⁹⁰ A computer specialist who saw television news reports on McAfee flew to Alabama and set up a voice-activated computer programmed to recognize McAfee's voice.²⁹¹ With special software, McAfee was able to make architectural renderings of buildings and apartment layouts using a sonar beam directed from a band strapped to his head to draw on the computer screen.²⁹² After considerable pressure, including pressure from President Bush who asked the Department of Health and Human Services to look into the matter, Georgia Medicaid agreed to move McAfee to a new group home in Augusta.²⁹³ McAfee found this setting to be much better and eventually obtained a job in computer mapping.²⁹⁴

285. See Nat Hentoff, *Elizabeth Bouvia and the ACLU: "I Used to Go to the ACLU for Help. Now They're Killing Us,"* VILLAGE VOICE, July 30, 1996, at 10.

286. See *Right-to-Die Litigant Who Chose to Live*, CHI. TRIB., Oct. 4, 1995, at 11 (reporting McAfee's death).

287. SHAPIRO, *supra* note 242, at 281.

288. *Id.* at 281-82.

289. The story of the relationship between Fine and McAfee was told in the 1993 television movie *The Switch*. *The Switch* (CBS television broadcast, Jan. 15, 1993); Ray Richmond, *CBS' "The Switch" Worth Turning On*, S.F. CHRON., Jan. 15, 1993, at C3; *Obituaries*, WASH. POST, Oct. 9, 1995, at B4 (providing obituary of McAfee). At least one person with a disability was critical of the movie, however, as being "just another buddy saga, where the non-disabled person saves the cripple from himself, helps the cripple see the light and choose not to die." Marta Russell, *Hollywood Needs New View of Disabled*, L.A. TIMES, Jan. 25, 1993, at F3.

290. SHAPIRO, *supra* note 242, at 283.

291. *Id.* at 284.

292. *Id.* at 284-85.

293. *Id.* at 287-88.

294. Jan Gehorsam, *State Seeks Funds for Patients' Home Care*, ATLANTA J. & CONST., Mar. 17, 1992, at D12; Sandra McIntosh, *News Update; People and Events That Made Headlines: Life's "Terrific" for McAfee at Special Nursing Home*, ATLANTA J. & CONST., Dec. 29, 1991, at C2.

Elizabeth Bouvia also chose not to take her life. She chose not to have the feeding tube removed at the time the appellate court decision came down because she was receiving morphine for her pain, and "because of the treatment, it (starvation) just became more difficult to do."²⁹⁵ Bouvia stated in 1993 that she still "feel[s] the same way; I wish I could die peacefully, but I don't know at this point that starvation is the way to do it."²⁹⁶

She also reported, however, that she spent her days at the Los Angeles County-USC Medical Center, where she had lived since 1986, reading, listening to music, and watching television and movies.²⁹⁷ She used a telephone by tapping on a lever taped to a bedrail.²⁹⁸ Her family visited occasionally, and she had friends who came to see her on a weekly basis.²⁹⁹ She also received mail, although she had difficulty keeping up with the correspondence because she needed someone to write for her.³⁰⁰

Bouvia worked for some time on getting out of the hospital and said that "I hope eventually that will come to pass."³⁰¹ Specifically, she hoped for "an apartment situation. That way I would have a bit more privacy."³⁰² Bouvia eventually got that wish. She now lives in an apartment with full-time aides and goes out shopping in her wheelchair.³⁰³

4. McKay v Bergstedt

Kenneth Bergstedt never got an opportunity to think about living independently like McAfee and Bouvia, but after his death, the Nevada Supreme Court held that he should have and noted that this might have impacted his decision on whether his life was worth living.³⁰⁴ The court's

295. Jay Horning, *Bedridden Bouvia Still Strong-Willed*, ST. PETERSBURG TIMES, Apr. 25, 1993, at 10A, see Jeff Wilson, *Quadruplegic Carries On After Losing Controversial Right-to-Die Case in '83; Woman Says She Has Learned to "Accept" Her Condition, But Is Bitter About Ruling*, FRESNO BEE, Dec. 26, 1993, at D22.

296. Horning, *supra* note 295, at 10A. Bouvia said: "If I was going to starve to death today it would be more difficult. The situation changed with the morphine. I've learned to accept it." Wilson, *supra* note 295, at D22. At the time of the interview, she was eating well, and her weight was up considerably from the time she filed her suit. *Id.*

297. Horning, *supra* note 295, at 10A.

298. *Id.*

299. *Id.*

300. *Id.*

301. *Id.*

302. *Id.*

303. Hentoff, *supra* note 285, at 10.

304. See McKay v Bergstedt, 801 P.2d 617, 624-25 (Nev. 1990).

initial description of Bergstedt was similar to those found in *Bouvia* and *McAfee*:

At the tender age of 10, Kenneth suffered the fate of a quadriplegic as a result of a swimming accident. Twenty-one years later, faced with what appeared to be the imminent death of his ill father, Kenneth decided that he wanted to be released from a life of paralysis held intact by the life-sustaining properties of a respirator.³⁰⁵

Bergstedt's father filed a petition on Kenneth's behalf requesting a court order permitting the father to turn off the ventilator without liability for murder or wrongful death and asking the court to determine that Kenneth's request was not suicidal. The lower court granted the application, but ordered the Nevada attorney general to appeal the ruling.³⁰⁶ Bergstedt's father, however, disconnected the ventilator days after the trial court's ruling, and Bergstedt died before the Nevada Supreme Court could issue its ruling.³⁰⁷ Despite this, the court issued its opinion and noted that it had

revised certain aspects to reflect changes necessitated by what we consider to be the tragic and untimely demise of a young man who had managed to create a modicum of quality in a life devastated by quadriplegia and total dependence on artificial respiration and the care of others.³⁰⁸

In its opinion, the court focused almost exclusively on the quality of Bergstedt's life, but noted that his concerns over that quality hinged more on a lack of adequate support services than on his physical condition. The court noted:

It appeared that Kenneth's suffering resulted more from his fear of the unknown than any source of physical pain. After more than two decades of life as a quadriplegic under the loving care of his parents, Kenneth understandably feared for the quality of his life after the death of his father, who was his only surviving parent. Although Kenneth completed elementary and high school through private tutoring, study and telephone communication with his teachers, and wrote poetry and otherwise lived a useful and productive life, his physical condition was dire. His quadriplegia left him not only ventilator-dependent, but entirely reliant on others

305. *Id.* at 620.

306. *Bergstedt v. McKay*, No. A281607, slip op. at 5-6 (Nev. Dist. Ct. June 22, 1990), cited in Diane Coleman, *Withdrawing Life-Sustaining Treatment from People with Severe Disabilities Who Request It: Equal Protection Considerations*, 8 ISSUES L. & MED. 55, 58 (1992).

307. See Coleman, *supra* note 306, at 58. Bergstedt's father died a few days after his son. *Bergstedt*, 801 P.2d at 619 n.1.

308. *Bergstedt*, 801 P.2d at 619.

for his bodily functions and needs. His limited sources of entertainment, including reading, watching television, and writing poetry through the oral operation of a computer, also required the attentive accommodations of others. Since the death of his mother in 1978, all these services were provided by his father and attending nurses occasionally called to the home.

It thus appears, and the record so reflects, that Kenneth was preoccupied with fear over the quality of his life after the death of his father. He feared that some mishap would occur to his ventilator without anyone being present to correct it, and that he would suffer an agonizing death as a result. In contemplating his future under the care of strangers, Kenneth stated that he had no encouraging expectations from life, did not enjoy life, and was tired of suffering. Fear of the unknown is a common travail even among those of us who are not imprisoned by paralysis and a total dependency upon others. There is no doubt that Kenneth was plagued by a sense of foreboding concerning the quality of his life without his father.³⁰⁹

Though the state had essentially agreed with Bergstedt's petition and had taken only a "token adversarial stance" on appeal,³¹⁰ the court balanced Bergstedt's interests in avoiding the fear of the unknown against the state's interests in preserving life and preventing suicide. It concluded that:

As medical science continues to develop methods of prolonging life, it is not inconceivable that a person could be faced with any number of alternatives that would delay death and consign him or her to a living hell in which there is hopelessness, total dependence, a complete lack of dignity, and an ongoing cost that would impoverish loved ones. The State's interests in preserving life and preventing what some may erroneously refer to as suicide does not extend so far.³¹¹

Several disability groups attempted to help Bergstedt avoid this "living hell" after learning of his petition requesting removal of his ventilator. Bergstedt's father, however, stated that his son could not come to the phone. According to a reporter from the *Disability Rag*, a disability rights publication, Bergstedt's father said that his son did not like the way he sounded using the ventilator and, because of this, would not speak on the

309. *Id.* at 624.

310. *Id.* at 619.

311. *Id.* at 627 One commentator remarked that:

The judicial reaction to both [Bergstedt] and Bouvia because of their disabilities demonstrates how the new quality-of-life ethic devalues and excludes people with physical disabilities by concurring with them that death is better than life with severe disabilities, rather than by seeking to alleviate the pressures which make lif[e] with such disabilities so difficult.

Paredes, *supra* note 241, at 827

phone.³¹² A California disability group that had begun to arrange a shared living situation and personal attendant for Bergstedt was never permitted to talk with him about these plans.³¹³ Whether Bergstedt ever learned of these efforts cannot be known as his father disconnected his ventilator shortly after the trial court's ruling.³¹⁴

*C. Judicial Recognition of the Influence of Prejudice
Against and Lack of Support Services for People with Disabilities
in Right-to-Die Cases*

The disability groups' efforts on Bergstedt's behalf were nonetheless important because they were implicitly acknowledged in the Nevada Supreme Court's opinion when it identified a state interest in "encouraging

312. See Coleman, *supra* note 306, at 58 (citing *Unanswered Questions*, DISABILITY RAG, Sept./Oct. 1990, at 22).

313. See *id.*

314. *Id.* Many people with disabilities also tried to reach out to David Rivlin, a 38-year-old quadriplegic from Michigan, when he sought to have his ventilator disconnected in 1989. See Herr et al., *supra* note 247, at 14. No defendant was named in Rivlin's action, and no one appeared to either contest it or file amicus briefs. *Id.* Rivlin told a reporter: "The vent [his respirator] takes away all choice in your life. I don't want to live an empty life lying helplessly in a nursing home for another thirty years. Death means to me that I can just rest in peace." SHAPIRO, *supra* note 242, at 275. Rivlin, who had lived in a nursing home in a Detroit suburb for three years told another reporter: "I don't want to live the rest of my life in an institution. I've tried to figure out other ways but there [are] none." Herr et al., *supra* note 247, at 14 (quoting *Accident Victim: Life More Than Surviving*, DAILY REP (Coldwater, Mich.), May 20, 1989, at E8).

Rivlin declined contact with people with disabilities who wrote and called to tell him of ways to live outside of an institution, having apparently given up by the time of his court proceeding. See *id.* Also, before Rivlin's death, a reporter covering his story learned that Michigan had changed its social welfare rules since the last time Rivlin had tried to live independently, and that by calling the social services office Rivlin could receive \$333 a month for personal care. *Id.* at 15. This amount could be doubled if Rivlin was able to get an exception, and a senior clinical social worker told the reporter that he "knew how to work the system" and could get Rivlin even more money for a "decent system of home care." *Id.* Unfortunately, Rivlin's ventilator was shut off before the reporter could tell him of these new possibilities. *Id.*

Rivlin's pleas for a doctor's help in ending his life inspired Dr. Jack Kevorkian, Michigan's now infamous suicide doctor, to build his first suicide machine. See SHAPIRO, *supra* note 242, at 275-76. Kevorkian met Rivlin when he sought a doctor's help in dying. *Id.* at 276. See generally JACK KEVORKIAN, PRESCRIPTION — MEDICINE: THE GOODNESS OF PLANNED DEATH (1991). Kevorkian first used his suicide machine a few months later. Of the forty people Kevorkian "assisted" between June 4, 1990 and September 7, 1996, twenty-eight had diseases that were not life-threatening, and autopsies revealed that they were not terminally ill. Thomas Maier, *Waiting at Death's Door*, NEWSDAY, Sept. 8, 1996, at 4-5. Nine people had multiple sclerosis. *Id.*

the charitable and humane care of afflicted persons."³¹⁵ In making this acknowledgment, the *Bergstedt* court became one of the first to address the problems that lead to suicide among persons with disabilities: the existence of societal prejudice and the lack of adequate support services.

The *Bergstedt* court noted that there is a "clear national and State public policy to encourage charitable contributions for the humane care and treatment of citizens stricken with various maladies and disabilities,"³¹⁶ and that "national and State efforts to improve the circumstances of disabled citizens are indicative of the highest social character — a society attuned to the worth of an individual irrespective of physical or mental handicap."³¹⁷ Noting that *Bergstedt* was not "without a meaningful life"³¹⁸ and that his main fear was life in the care of strangers after his father's death, the court stated that:

It appeared to us that Kenneth needed some type of assurance that society would not cast him adrift in a sea of indifference after his father's passing. Perhaps available governmental, private and charitable support systems would not have been adequate to provide Kenneth the assurance he needed to alleviate his fears. We nevertheless conclude that absent Kenneth's intervening death, it would have been necessary to fully inform him of the care alternatives that would have been available to him after his father's death or incapacity.³¹⁹

315. See *McKay v Bergstedt*, 801 P.2d 617, 628 (Nev 1990).

316. *Id.*

317. *Id.*

318. *Id.*

319. *Id.* The *Bergstedt* court's observation that it is the lack of support services, rather than the disability itself, which often leads to a disabled person's request to die is in line with commentary on the issue. One commentator has noted:

Many are wondering why society is so quick to assist a disabled person who wants to end life when the same desire to die in an able-bodied person is viewed as a genuine cry for help. It is the fear of no support to live independent lives, not their disabilities, that drives people with disabilities to end their lives.

Paredes, supra note 241, at 838 (quoting National Legal Ctr. Staff, *Medical Treatment for Older Persons and Persons with Disabilities: 1990 Developments*, 6 ISSUES L. & MED. 341, 349 (1991)).

Paredes further stated:

[R]ather than assuming that life [with a disability] lacks quality due to disability, decision-makers should question "whether the apparent misery is the result of a lack of adequate support services for the person. If, as is more likely, the issue is one of inadequate support services, the answer is clearly to demand that those services be provided."

Id. (quoting Christopher Newell, *Lives of Inestimable Value: Life Worthy of Life*, 7 ISSUES L. & MED. 245, 251 (1991)).

The court made this informational disclosure a requirement of the procedure for withdrawal of medical treatment from competent adults in the future. Two nonattending physicians must examine the adult and determine, among other things:

If the patient is non-terminal, i.e., has an estimated life expectancy of six months or more either with or without artificial life-support systems, that he or she was apprised of the care options available to the patient through governmental, charitable and private sources with due regard for the value of life, and [then] certify in writing without liability except for fraud, that the aforesaid explanation of care alternatives was given and the patient's response thereto.³²⁰

Unfortunately, the *Bergstedt* court is one of the few courts to identify a concern for persons with disabilities as a state interest in right-to-die cases. Additionally, the other opinions containing these concerns have either been overturned or are dissenting opinions. For example, in the Ninth Circuit's initial ruling in *Compassion in Dying*, the court identified one of the state interests in barring assisted suicide as "protecting all of the handicapped from societal indifference and antipathy"³²¹ The court there noted that it had received an amicus curiae brief on behalf of numerous residents of nursing homes and long-term care facilities³²² and stated:

The vulnerability of such persons to physician-assisted suicide is foreshadowed in the discriminatory way that a seriously disabled person's expression of a desire to die is interpreted. When the nondisabled say they want to die, they are labeled as suicidal; if they are disabled, it is treated as "natural" or "reasonable."³²³

The court found that "an insidious bias against the handicapped — again coupled with a cost-saving mentality — makes them especially in need of Washington's statutory protection."³²⁴

320. *Bergstadt*, 801 P.2d at 630.

321. *Compassion in Dying v. Washington*, 49 F.3d 586, 592 (9th Cir.), *aff'd*, 79 F.3d 790, 838 (9th Cir. 1995) (en banc), *cert. granted sub nom.* *Washington v. Glucksberg*, 65 U.S.L.W. 3218 (U.S. Oct. 1, 1996) (No. 96-110).

322. *Id.*

323. *Id.* at 593 (citing Gill, *supra* note 241, at 38-39).

324. *Id.* Similar concern is voiced in a dissenting opinion in *In re Guardianship of Grant*, 747 P.2d 445, 459 (Wash. 1987) (en banc) (Anderson, J., concurring in part and dissenting in part), *opinion amended*, 757 P.2d 534 (Wash. 1988). Justice Anderson noted that:

[W]e have witnessed too much history to disregard how easily a society may devalue the lives of the "unproductive." The "angel of mercy" can become the fanatic, bringing the "comfort" of death to some who do not clearly want it, then to others who "would really be better off dead," and finally, to classes of "undesirable persons," which might include the terminally ill, the permanently unconscious, the severely senile, the pleasantly senile, the retarded, the incurably or chronically ill, and perhaps, the aged. In the current environment, it may well prove convenient — and all too easy — to move from recognition of an individual's "right to die" to a climate enforcing a "duty to die."

Id. at 459 (quoting Mark Siegler & Alan J. Weisbard, *Against the Emerging Stream: Should Fluids and Nutritional Support Be Discontinued?*, 145 ARCHIVES INTERNAL MED. 129, 130-31 (1985)). The state court in *Cruzan* did touch briefly on the danger of making quality of life a factor in the right-to-die decisions: "Were quality of life at issue, persons with all manner of handicaps might find the state seeking to terminate their lives." *Cruzan v. Harmon*, 760 S.W.2d 408, 420 (Mo. 1988) (en banc), *aff'd*, 497 U.S. 261 (1990).

The concern about the right to die becoming a "duty to die" has also been expressed in articles discussing requests by persons with disabilities to have life-sustaining treatment removed:

In a society where people with disabilities are still intensely stigmatized and largely segregated and in a society that still refuses to acknowledge the reality of that social oppression, the right to die will inevitably become a duty to die. People with major disabilities will be pressured into "choosing" to end their lives.

Longmore, *supra* note 241, at 158-59.

The duty to die sentiment has in fact garnered popular support. In 1984, then Colorado governor Richard Lamm was quoted as saying that the elderly have "a duty to die" to make way for future generations. *Lamm Moves Closer to Thurd-Party Bid*, BOSTON GLOBE, June 8, 1996, at 8. Another time, he stated that tax dollars spent on care of the mentally retarded may be wasted when, after years of care, all they could do is "roll over." *Id.* Though the "duty to die" statement apparently was a misquotation, the governor's press secretary reported that of more than 2000 cards and letters received, 648 writers opposed Lamm's published "position" while 1399 backed it. See Charles Roos, *Many Memorable Phrases Weren't Actually Spoken*, ROCKY MOUNTAIN NEWS, Feb. 24, 1995, at 46A.

The danger of these stereotypes was perhaps most prominently recognized when the Secretary of Health and Human Services denied Oregon's request for a Medicaid waiver to implement its plan for rationing medical services to the state's Medicaid recipients. See Letter from Louis W. Sullivan, United States Secretary of Health and Human Services, to Barbara Roberts, Governor of Oregon (Aug. 3, 1992) (with accompanying three page "Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration"), reprinted in Timothy B. Flanagan, *ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES L. & MED. 397, 409 (1994). The Secretary's denial was based on concerns stemming from the prioritization process. The process had included a telephone survey of the general public asking participants to assign values to different health states based on descriptions in terms of functional impairments and symptoms associated with a given condition. The Secretary stated that Oregon's reliance on the telephone survey

V *Wrongful Living: The Wrong Answer to a Difficult Problem*

Like the *Bergstedt* court and the *Compassion in Dying* panel, courts faced with wrongful living cases must be "attuned to the worth of an individual irrespective of physical or mental handicap,"³²⁵ and to the existence of historical prejudices and lack of adequate support services for persons with disabilities, which lead some to say that life is not worth living. These courts should then follow the wrongful life cases and reject the wrongful living cause of action for four compelling policy reasons: (1) the legal recognition that "a disabled life is an injury would harm the interest of those most directly concerned, the handicapped;"³²⁶ (2) the question of whether one would be better off dead is one which courts are not equipped to handle and is antithetical to "the very nearly uniform high value which the law and mankind has placed on human life, rather than its absence;"³²⁷ (3) the impossibility of calculating compensatory damages based on the comparison between life with a disability and death; and (4) the adequate remedies available under traditional tort principles for those whose refusal of treatment is not honored.

may have "quantified stereotypic assumptions about persons with disabilities." *Id.* at 410. In addition, in ranking the 709 condition-treatment pairs and making its final hand adjustments, the Oregon Health Services Commission partially relied on "certain community values, including 'quality of life' and 'ability to function.'" *Id.* at 411. In these facets of the prioritization process, the Secretary found "considerable evidence that [the list] was based in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability. This is a premise that is inconsistent with the ADA." *Id.* at 410. He concluded that "any methodology that would intentionally ration health care resources by associating quality of life considerations with disabilities does not comport with the mandate of the ADA." *Id.* at 411. For commentary on health care rationing and persons with disabilities, see generally Mary Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV 179 (1995); David Orentlicher, *Deconstructing Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV C.R.-C.L. L. REV 49 (1996); Giles R. Scofield, *Medical Futility Judgments: Discriminating or Discriminatory?*, 25 SETON HALL L. REV. 927 (1995); James V. Garvey, Note, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?*, 68 NOTRE DAME L. REV 581 (1993); Greg P. Roggin, Note, *The "Oregon Plan" and the ADA: Toward Reconciliation*, 45 WASH. U.J. URB. & CONTEMP. L. 219 (1994); Nancy K. Stade, Note, *The Use of Quality-of-Life Measures to Ration Health Care: Reviving a Rejected Proposal*, 93 COLUM. L. REV 1985 (1993); and Note, *The Oregon Health Care Proposal and the Americans with Disabilities Act*, 106 HARV L. REV 1296 (1993).

325. *McKay v. Bergstedt*, 801 P.2d 617, 628 (Nev. 1990).

326. *Smith v. Cote*, 513 A.2d 341, 352-53 (N.H. 1986).

327. *Greco v. United States*, 893 P.2d 345, 347-48 (Nev. 1995) (quoting *Becker v. Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978)).

A. Recognition of a Wrongful Living Cause of Action Would Harm Persons with Disabilities

As Elizabeth Bouvia, Larry McAfee, and countless others illustrate, even life with severe physical handicaps can have a certain quality if people with disabilities are given the support services they need.³²⁸ Unfortunately, a person reading the *Bouvia* and *McAfee* decisions is not likely to know the nonphysical stresses in their lives before they made their requests to die or their subsequent decisions to live. Instead, the reader will work only from the courts' descriptions of their lives. As one commentator has pointed out, the *Bouvia* court's "characterization of the life of a quadriplegic promotes a social attitude likely to at least indirectly influence the choices of disabled persons in the future."³²⁹ A finding that a life with a disability is not worth

328. Indeed, Franklin D. Roosevelt, arguably our greatest president, guided the United States through the Great Depression and World War II though paralyzed by polio. America's — and FDR's own — difficulty in accepting that disability are chronicled in HUGH GREGORY GALLAGHER, *FDR'S SPLENDID DECEPTION* (1985). The importance of FDR's disability continues to be an issue to this day, as evidenced by the debate over whether he should be depicted in a wheelchair in the memorial currently being built in Washington. People with disabilities argue that the failure to show FDR in a wheelchair is a historical distortion, and it deprives people with disabilities today and in the future of a valuable role model. See *FDR Memorial Keeps Wheelchair Hidden*, PHOENIX GAZETTE, May 17, 1996, at A35. Others argue that Roosevelt purposefully chose to keep his disability hidden for personal as well as political reasons, and that the goals of advancing disability perception do not justify violating his self-image. See Charles Krauthammer, *Defining the Image of FDR*, CHI. TRIB., June 17, 1996, at 15.

329. Donald L. Beschle, *The Role of Courts in the Debate on Assisted Suicide: A Communitarian Approach*, 9 NOTRE DAME J.L. ETHICS & PUB. POL'Y 367, 377 (1995). Beschle later states that he finds what he terms the "libertarian" approach to assisted suicide disturbing because of

its tendency to absolve us, as individuals or as a society, from a sense of responsibility to others. *Do we provide enough support for the handicapped? Does medicine devote attention to the relief of pain? Does the absence of universal health care insurance make people choose an earlier death in order not to financially burden their relatives? Do social attitudes emphasizing the importance of physical perfection send disturbing messages about what type of life is not worth living?* If suicide is merely an act of autonomy, we need not address these questions.

Id. at 380 (emphasis added) (citation omitted).

Disability advocates asked to provide testimony to Congress on the assisted suicide issue used more forceful language in discussing their concerns about the view toward disability seen in the right-to-die cases. Diane Coleman, a lawyer and the executive director of the Progress Center for Independent Living, and Carol Gill, Ph.D., of the Chicago Institute of Disability Research, stated:

living could have a similar impact, and this should be a concern of courts faced with wrongful living actions as it has been for those courts ruling on wrongful life actions.

In *Smuth v Cole*, the court listed as among its policy reasons for rejecting a wrongful life action the fact that:

Legal recognition that a disabled life is an injury would harm the interests of those most directly concerned, the handicapped. Disabled persons face obvious physical difficulties in conducting their lives. They also face the subtle yet equally devastating handicaps of the attitudes and behavior of society, the law, and their own families and friends. Furthermore, society often views disabled persons as burdensome misfits. Recent legislation concerning employment, education, and building access reflects the slow change in these attitudes. This change evidences a growing public awareness that the handicapped can be valuable and productive members of society *To characterize the life of a disabled*

No court, or professional whose judgment the courts respected, examined the suicidal feelings of Elizabeth Bouvia, David Rivlin, Larry McAfee or Kenneth Bergstedt. All courts attributed the individuals' desire to die to their physical disabilities per se rather than to events and circumstances in their lives, such as a miscarriage, loss of spouse, and confinement to nursing homes. All courts superficially concluded that the individual's despair was not suicidal, not treatable or deserving of appropriate intervention. These individuals were granted a so-called "right to die" without being offered adequate support for living. These highly publicized cases are the tip of an unexplored iceberg, one that proponents of physician-assisted suicide prefer to ignore. But the legal foundation for applying physician-assisted suicide to non-terminal people with disabilities is already firmly entrenched in our judicial system, and disabled people are beginning to feel that we are riding on the Titanic.

Testimony of Diane Coleman and Carol Gill Before the Constitution Subcommittee of the House Judiciary Committee, Apr. 29, 1996, at *4, *available in* LEXIS, Nexis Library, CNGTST File.

Coleman and others have also taken their concerns to the streets. She is a spokeswoman for "Not Dead Yet," a disability rights group that demonstrated in front of Jack Kevoorkian's house after his recent acquittal on assisted suicide charges. *See Disabled Demonstrate at Kevoorkian's House*, ST. LOUIS POST-DISPATCH, June 22, 1996, at 5A. One woman poured fake blood on the ground and lay down in Kevoorkian's front lawn; another, who used a ventilator to breathe, covered herself in a white sheet and held a sign that said "Kevoorkian Kills Krips." *Id.*, see also Nat Hentoff, *Not Dead Yet*, WASH. POST, June 8, 1996, at A15. Not Dead Yet members also demonstrated outside both the Supreme Court and Kevoorkian's home on the morning of the Supreme Court arguments for the assisted suicide cases. *See Sandy Banisky, Protesters Fear Ruling Could Be Death Sentence; Disabled Urge Ban on Assisted Suicide*, BALTIMORE SUN, Jan. 9, 1997, at 13A, Doug Durfee, *Group Gathers at Kevoorkian's Home*, DET. NEWS, Jan. 9, 1997, at 4A.

*person as an injury would demigrate both this new awareness and the handicapped themselves.*³³⁰

This reasoning is equally applicable to the wrongful living cause of action and is even more relevant today because Congress enacted the most important piece of civil rights legislation for persons with disabilities after the *Smith* court wrote this passage. The Americans with Disabilities Act (ADA),³³¹ signed on July 26, 1990, for the first time extended federal disability rights law into the private sector,³³² prohibiting employment discrimination on the basis of disability³³³ and requiring that public accommodations,³³⁴ governmental services,³³⁵ transportation,³³⁶ and telecommunications³³⁷ be accessible to the disabled. The ADA is

based on the premise that disability is a natural part of the human experience and in no way diminishes the rights of individuals to live independently, pursue meaningful careers and enjoy full inclusion in the economic, political, cultural and educational mainstream of American society³³⁸

Judicial approval of a wrongful living tort, in which a court would declare a person to be better off dead than disabled, would mark a step back from this recognition that persons with disabilities can be valuable and productive members of society. Doing so would demigrate the significant step marked by the ADA, persons with disabilities them-

330. *Smith*, 513 A.2d at 353 (quoting Menott & Zunzolo, *supra* note 31, at 459-60 (emphasis added) (citations omitted)); see *Proffitt v Bartolo*, 412 N.W.2d 232, 240 (Mich. Ct. App. 1987).

331. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101-12213 (1994)).

332. 42 U.S.C. § 12101 (1994). Previous disability rights laws had applied only to the federal government or the recipients of federal funds. See, e.g., Architectural Barriers Act of 1968, Pub. L. No. 90-480, 82 Stat. 718 (codified as amended at 42 U.S.C. §§ 4151-4157 (1994)); Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (codified as amended at 29 U.S.C. § 794 (1994)).

333. 42 U.S.C. § 12112.

334. *Id.* § 12182.

335. *Id.* § 12132.

336. *Id.* §§ 12141-12165, 12184-12186.

337. 47 U.S.C. §§ 225(a)(3), 225(b) (1994).

338. Paul Steven Miller, Letters to the Editor, *ADA Gives Us Our Full Civil Rights*, WALL ST. J., Feb. 14, 1995, at 23. Mr. Miller signed the letter in his capacity as Commissioner of the U.S. Equal Employment Opportunity Commission. *Id.* A discussion of Congress's findings and purposes in enacting the ADA can be found at *supra* note 242.

selves, and what the *Berman v Allan* court characterized as "[o]ne of the most deeply held beliefs of our society is that life — whether experienced with or without a major physical handicap — is more precious than non-life."³³⁹

B. Courts Cannot Answer the Question of Whether Life with a Disability Is Worth Living

Whether this belief is as deeply held as the *Berman* court suggests — and I have argued above that it is not — courts faced with wrongful living claims may still reject them based on an analogy to the reasons commonly given for refusing wrongful life claims. The first reason is a conceptual unwillingness to recognize damages for being born with a disability as opposed to not being born at all.³⁴⁰ This unwillingness should also extend to wrongful living actions in which plaintiffs seek damages for being alive as opposed to being dead.

In *Greco v United States*, the Supreme Court of Nevada noted that:

Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians. Surely the law can assert no competence to resolve the issue, particularly in view of the very nearly uniform high value which the law and mankind has placed on human life, rather than its absence.³⁴¹

The same difficulties in comparing life to nonlife exist in wrongful living cases: the plaintiffs seek compensation for living life in an impaired condition as opposed to being allowed to die. This claim also calls for courts to measure the benefits of life against nonexistence.

Knapp and Hamilton attempt to get around this difficulty by distinguishing wrongful living and wrongful life cases. They state:

In contrast to the "wrongful life" concept, the "wrongful living" plaintiff does not assert a right to make a retrospective decision about whether to be born, that is, to speculate about what decision the plaintiff would have made had the future been known to the plaintiff

339. *Berman v Allan*, 404 A.2d 8, 12 (N.J. 1979) (citations omitted).

340. See *Siemenec v. Lutheran Gen. Hosp.*, 512 N.E.2d 691, 697 (Ill. 1987); *Cowe v Forum Group, Inc.*, 575 N.E.2d 630, 634 (Ind. 1991).

341. *Greco v United States*, 893 P.2d 345, 348 (Nev 1995); see also *Nelson v Krusen*, 678 S.W.2d 918, 925 (Tex. 1984) (stating that perplexities involved in comparing relative benefits of life and nonexistence render it "impossible" to decide question of injury in wrongful life case).

prior to conception or in utero. The "wrongful living" plaintiff weighed the effects of his medical therapy and his prognosis with and without the therapy, against the desirability of remaining alive.³⁴²

This argument ignores the fundamental similarity between the two causes of action: the plaintiffs in both argue that they would be better off dead and that they are entitled to damages due to the quality of their lives. In doing so, the plaintiffs ask the court to make an objective decision about the worth of their lives as opposed to nonexistence. As one court ruling against a wrongful life claim noted, this differs greatly from the typical right-to-die case in which

[t]he court avoids making an objective judgment as to the value of the plaintiff's life; it strives, instead, to protect the individual's subjective will. Even when the plaintiff is incompetent, "the court does not arrogate to itself the individual's choice," but instead allows the plaintiff's guardian or surrogate to make that choice on his behalf.

The same cannot be said of wrongful life cases. At issue is not protection of the [plaintiff's] right to choose non-existence over life, but whether legal injury has occurred as a result of the defendant's conduct. The necessary inquiry is objective, not subjective; the court cannot avoid assessing the "worth" of the [plaintiff's] life. Simply put, the judiciary has an important role to play in protecting the privacy rights of the dying. It has no business declaring that among the living are people who never should have been born.³⁴³

Similarly, the necessary inquiry in a wrongful living case is objective, not subjective, and the court is required to opine on the worth of the plaintiff's life. More specifically, the court must decide if that worth is so minimal that the person would be better off dead and is entitled to compensation for living. This is a decision the judiciary is not equipped to make, and accordingly, it has no business declaring that among the living are people who are better off dead.

*C. Wrongful Living Damages Are Incalculable:
It Is Impossible to Compare and Place a Value on Life
with a Disability vs. Death*

Oddi stated in his article that wrongful living could be distinguished from wrongful life because the "difficulty with the 'wrongful life' cases is

342. Knapp & Hamilton, *supra* note 18, at 258 (citations omitted).

343. Smith v. Cote, 513 A.2d 341, 352-53 (N.H. 1986) (citations omitted).

the damages element, because a comparison must be made between nonlife and life in an impaired condition."³⁴⁴ He then said, however, that the action seeks compensation for living and the possible damages are those "for the time period that the patient survived due to the interfering treatment."³⁴⁵ If this is the case, a wrongful living action, just as a wrongful life action, involves the calculation of damages based on life as opposed to nonlife.

One court discussing the difficulty of making such a calculation stated:

The basic rule of tort compensation is that the plaintiff be put in the position that he would have been in absent the defendant's negligence. The damages recoverable on behalf of a child for wrongful life are limited to those necessary to restore the child to the position he would have occupied were it not for the alleged malpractice of the physician or other health care provider. In a wrongful life case, there is no allegation that but for the defendant's negligence the child would have had a healthy, unimpaired life. Instead, the claim is that without the defendant's negligence, the child never would have been born. Thus the cause of action involves a calculation of damages dependent upon the relative benefits of an impaired life as opposed to no life at all, "[a] comparison the law is not equipped to make."³⁴⁶

The law is also not equipped to make the comparison between life and nonlife in a wrongful living action. There are no damages available that can put the patient in the position in which he would have been if not for the health care provider's failure to honor the advance directive: if the defendant had not acted, the plaintiff would be dead. A computation of damages "would require the trier of fact to measure the difference in value between life in an impaired condition and the 'utter void of nonexistence.' Such an endeavor, however, is literally impossible. [M]an 'who knows nothing of death or nothingness,' simply cannot affix a price tag to non-life."³⁴⁷

344. Oddi, *supra* note 18, at 641 n.75.

345. *Id.* at 648. Oddi later states that "the loss to the patient asserting the right to die is the prolongation of life." *Id.* at 661.

346. *Siemieniec v Lutheran Gen. Hosp.*, 512 N.E.2d 691, 697 (Ill. 1987) (quoting *Becker v Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978)). The court's statement on the purpose of tort law is consistent with that found in the *Restatement*, which provides that "the law of torts attempts primarily to put an injured person in a position as nearly as possible equivalent to his position prior to the tort." *RESTATEMENT (SECOND) OF TORTS* § 901 cmt. a (1965).

347. *Berman v Allan*, 404 A.2d 8, 12 (N.J. 1979) (citations omitted).

*D Adequate Remedies for Failure to Honor Advance Directives
Exist Under Traditional Tort Principles*

Courts need not take on the impossible task of deciding whether a life with a disability is worth living because, as Pedrick notes, the "familiar principles of tort law can be enlisted to better assure that unwanted life-support measures either will not be used, or will be withdrawn when that is the wish of the patient or the patient's agent."³⁴⁸ Pedrick further comments that "when health care givers subject a competent patient to life sustaining procedures against his or her will, the settled law of torts provides a remedy by way of an action for battery, with resultant liability on the part of health care givers for substantial damages, both general and punitive."³⁴⁹

A battery action for unauthorized medical treatment is a matter of hornbook law that the Supreme Court recognized in *Cruzan*.³⁵⁰ Health care providers who act in good faith will have no reason to fear a battery claim because of the protections provided in living will and proxy statutes³⁵¹ and because of the requirement that a battery be intentional.³⁵² A physician who

348. Pedrick, *Arizona Tort Law*, *supra* note 108, at 390. Pedrick's statement follows a discussion of living will statutes. Hence, he is suggesting that the use of tort principles will be more successful in assuring the right to die than the enactment of statutes. The author has borrowed Pedrick's statement to suggest that the use of such familiar principles will also be more valuable in achieving that goal than recognition of the wrongful living cause of action.

349. *Id.* at 396. Pedrick also suggests that Medicare officials and insurance companies should routinely ask whether the health care provider has received instructions declining the use of life-support systems before the patient's death. *Id.* at 399. In such a case, he says these third parties should refuse to pay for medical services rendered after the health care provider knew of the patient's wishes to refuse treatment. *Id.* He states:

Such a policy adopted by Medicare, Medicaid, and the health insurance industry would have a salutary effect in bringing an effective sanction to bear on health care givers, and through fiscal persuasion, should bring them to honor the instructions of patients and surrogate agents on this subject.

Id., see Gasner, *supra* note 17, at 512-15 (arguing that providing financial disincentives to continuing treatment by refusing to reimburse providers for unwanted services is promising enforcement mechanism for individual's right to refuse treatment).

350. See *Cruzan v Director, Mo. Dep't of Health*, 497 U.S. 261, 269 (1990).

351. All state living will and health care proxy statutes confer some sort of immunity from civil or criminal liability or both on health care providers who in good faith comply with a properly executed living will or the instructions of a proxy acting in accordance with the patient's wishes or in the patient's best interest. See 2 MEISEL, *supra* note 11, § 11.17 (citing living will statutes); *id.* § 12.46 (citing proxy statutes).

352. Section 13 of the RESTATEMENT (SECOND) OF TORTS provides:

knowingly ignores a patient's advance directive, however, would be liable for battery and subject to damages. Indeed, the *Anderson* court held that a person who was given life-sustaining treatment against his wishes was entitled to damages resulting from the "natural and continuous sequence following the unwanted resuscitative effort including all medical expenses until death, the costs of [a] nursing home, and any extraordinary expenses related to [the patient's] care."³⁵³

An actor is subject to liability to another for battery if

- (a) he acts intending to cause a harmful or offensive contact with the person of the other or a third person, and
- (b) a harmful contact with the person of the other directly or indirectly results.

RESTATEMENT (SECOND) OF TORTS § 13 (1965). A comment states that:

[A] surgeon who performs an operation upon a patient who has refused to submit to it is not relieved from liability by the fact that he honestly and, indeed, justifiably believes that the operation is necessary to save the patient's life. Indeed, the fact that medical testimony shows that the patient would have died had the operation not been performed and that the operation has effected a complete cure is not enough to relieve the physician from liability

Id. § 13 cmt. c.

353. *Anderson v. St. Francis-St. George Hosp.*, No. C-930819, 1995 WL 109128, at * 5 (Ohio Ct. App. Mar. 15, 1995), *rev'd*, 671 N.E.2d 225 (Ohio 1996). This holding was reversed on appeal because of a failure to show any connection between the defibrillation and Winter's subsequent stroke. *Anderson*, 671 N.E.2d at 228. The Ohio Supreme Court found that:

[T]he record is devoid of any evidence that the administering of the resuscitative measures caused the stroke. Winter suffered the stroke because the nurse enabled him to survive the ventricular tachycardia. Because the nurse prolonged Winter's life, numerous injuries occurring after resuscitation might be foreseeable, but would not be caused by the defibrillation.

Id.

The court decided that the only damages that Winter's estate could recover were those due directly to the battery *Id.* at 229. It then found that Winter suffered "no damages as a result of the defibrillation of his heart, i.e., no tissue burns or broken bones," and thus, his estate could not recover against the hospital. *Id.* The court stated, however, that its decision did not mean unwanted life-saving treatment would go undeterred:

Where a patient clearly delimits the medical measures he or she is willing to undergo, and a health care provider disregards such instructions, the consequences for that breach would include the damages arising from any battery inflicted on the patient, as well as appropriate licensing sanctions against the medical professionals.

Id.

This holding focuses too narrowly on the unwanted treatment itself. The damages resulting from the battery when a patient has specifically asked not to be resuscitated

Such a holding is consistent with the majority of wrongful birth cases, which allow parents to recover for the extraordinary medical and other expenses related to raising a child with a disability, but do not provide compensation for living.³⁵⁴ One commentator noted:

Like the parents of such children, the families of dying patients, must also bear the cost of extensive, long-term, intensive care medicine. If nothing else, hospitals and physicians should at least bear the cost of the unwanted medical care when it is given over the competent, express refusal of the patient.³⁵⁵

necessarily include all future medical expenses: If the patient had not been resuscitated, he would not be alive to incur these expenses. Even if there is no evidence that the resuscitation caused the subsequent medical problems, those problems can be said to have resulted from the health care provider's actions because they would not have occurred otherwise. The Ohio Supreme Court was correct, however, to deny emotional distress damages. The Ohio Court of Appeals stated that Winter's estate could recover for his "pain, suffering and emotional distress related to having a stroke." *Anderson*, 1995 WL 109128, at *5. Such a claim necessarily seeks compensation for living with a disability as opposed to being dead and, as the Ohio Supreme Court stated, involves a "theory of recovery identical to the theory underlying a claim for 'wrongful living.'" *Anderson*, 671 N.E.2d at 228. As such, emotional distress damages should be barred for the same reasons as the wrongful living cause of action.

354. See Smith-Groff, *supra* note 240, at 140-43 & nn.47-67 (discussing case law on issue).

355. Dooling, *supra* note 108, at 917. Pedrick also argues that punitive damages could be available for the failure to honor a patient's advance directive:

The physician who continues to treat the patient and who disregards the patient's instructions forbidding use of life-sustaining procedures is chargeable with a conscious, knowing disregard of the patient's legal right. Such knowing disregard for the patient's legal right, whether for good motives or ill, cannot be tolerated. Punitive damages are appropriate in these cases, regardless of the health care giver's motive in disregarding the patient's instructions.

Pedrick, *Arizona Tort Law*, *supra* note 108, at 82.

Pedrick also states that close relatives who witness a family member's suffering after a physician's intentional refusal to honor an advance directive may bring emotional distress claims. *Id.* at 83. He argues that health care givers are chargeable with knowledge of the family's emotional distress if the patient's wishes are disregarded and draws an analogy to cases in which courts have imposed liability for emotional distress arising out of the merely negligent handling of a dead body. *Id.* (citing W PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 54, at 362 (5th ed. 1984)).

These claims should be barred for the same reason as emotional distress claims brought by the patient: they require the impossible comparison between the stress placed on the family by the patient's survival as opposed to his death. Such a bar is in line with the majority of wrongful birth cases that do not allow the parents of disabled infants to recover for emotional distress arising from their birth. See, e.g., *Becker v. Schwartz*, 386

Health care providers' bearing such costs relieves patients and their families of the burden of paying for unwanted treatment and places them in the same economic position in which they would have been had their wishes been honored. This result satisfies the "basic rule of tort compensation"

N.E.2d 807, 813-14 (N.Y. 1978) (finding that emotional distress damages for parents were too speculative); *Jacobs v. Theimer*, 519 S.W.2d 846, 849-50 (Tex. 1975) (concluding that damages were too speculative as to pluses and minuses of parenting); see also *Goldberg v. Ruskin*, 471 N.E.2d 530, 539-40 (Ill. Ct. App. 1984) (finding that under Illinois law, damages for emotional distress can only be recovered when emotional distress results from physical injury or illness); *Arche v. United States, Dep't of Army*, 798 P.2d 477, 481 (Kan. 1990) (stating that under Kansas law, plaintiff must witness tortious act to recover for emotional distress).

Some courts do allow emotional distress damages as an exception to a jurisdiction's impact rule. See, e.g., *Kush v. Lloyd*, 616 So. 2d 415, 423 (Fla. 1992) ("[T]hese parents went to considerable lengths to avoid the precise injury that they now have suffered. We conclude that public policy requires the impact doctrine not be applied within the context of wrongful birth claims."); *Naccash v. Burger*, 290 S.E.2d 825, 830-31 (Va. 1982) (disallowing emotional distress damages). Other jurisdictions conclude that the parent's emotional distress is a direct harm resulting from the defendant's negligence and is properly included in damages. See, e.g., *Keel v. Banach*, 624 So. 2d 1022, 1029-31 (Ariz. 1993); *Berman v. Allan*, 404 A.2d 8, 14-15 (N.J. 1979).

Even if one accepts the holdings allowing emotional distress damages for parents in wrongful birth actions, however, they are distinguishable from cases brought by persons whose family members receive unwanted treatment. As the court in *Benoy v. Simons* noted, wrongful birth actions are based on a doctor's breach of duty to the parents of a disabled child as his patient. *Benoy v. Simons*, 831 P.2d 167, 170 (Wash. Ct. App. 1992). There is no such relationship between the family of a person receiving unwanted treatment and the doctor.

The *Anderson* court suggests that liability may also arise when the unwanted treatment is not done intentionally, but because a health care provider fails to note the existence of an advance directive in a patient's chart. See *Anderson*, 1995 WL 109128, at *3-*4. As *Oddi* notes, health care providers' failure to examine available medical records may support a negligence claim. See *Oddi, supra* note 18, at 661 n.160. *Oddi* cites several examples: *Larrimore v. Homeopathic Hosp. Ass'n*, 181 A.2d 573, 577 (Del. 1962) (concluding that hospital was liable when nurse failed to read patient's chart before giving injection); *Killebrew v. Johnson*, 404 N.E.2d 1194, 1197-98 (Ind. Ct. App. 1980) (finding jury question on whether physician's failure to examine previously taken x-rays constituted negligence); *Smith v. Courter*, 575 S.W.2d 199, 202-03 (Mo. Ct. App. 1979) (same); and *Edwards v. Means*, 243 S.E.2d 161, 162 (N.C. Ct. App. 1978) (same). A similar failure to examine the patient's chart for an advance directive could support a malpractice claim for the expenses incurred as a result of the unwanted treatment.

A more difficult question arises as to liability for unwanted treatment when the advance directive is never properly filed in the patient's chart. Holding health care providers liable for the expenses resulting from the failure to place an advance directive in a patient's chart, or to include that directive in the information accompanying the patient upon transfer to another facility, may encourage better record-keeping practices.

identified in *Siemieniec v Lutheran General Hospital*,³⁵⁶ without requiring a court to decide whether life with a disability is worth living.

Conclusion

Advances in medical technology have drastically changed the way physicians treat patients and how and where Americans die. Many people die after undergoing invasive life-sustaining treatment unheard of even fifty years ago. In response, courts and legislatures have recognized the right to die, stating that patients have a constitutional or common-law interest in refusing unwanted medical treatment.

Both public opinion polls and scientific studies show that many patients would prefer not to be placed on life-support systems. This desire, however, is often misunderstood by health care providers. Even if the patient's wishes are understood — and are memorialized in a living will or other form of advance directive — they are often ignored. Patients and families have responded in the past by suing to have the treatment stopped. Courts have granted their requests, but in doing so they have often reflected a societal prejudice that life with a disability is not worth living.

Recognition of the right to die has now spawned a different kind of lawsuit: suits for damages alleging that patients who received unwanted life-sustaining treatment have suffered a compensable injury. Most of these suits have been brought under traditional tort principles, but plaintiffs have also sought recognition of a new tort: wrongful living. This tort action seeks compensation for living and is essentially a claim that an individual's diminished quality of life after or while receiving the treatment makes life not worth living and that they would be better off dead.

Courts should reject such actions. Judicial approval of a wrongful living tort, in which a court would declare a person to be better off dead than disabled, would mark a step back from the recent recognition in the ADA that persons with disabilities can be valuable and productive members of society. A wrongful living tort would also force courts to make an inquiry into whether the worth of the plaintiff's life is so minimal that they would be better off dead. This is a decision the judiciary is ill-equipped to make.

Even if the courts could make such a decision, however, there are no damages available which could put the plaintiff in the position in which he

356. *Siemieniec v. Lutheran Gen. Hosp.*, 512 N.E.2d 691, 697 (Ill. 1987). This result also satisfies another purpose of tort law: deterrence. RESTATEMENT (SECOND) OF TORTS § 901 cmt. c (1979). Health care providers who know they will not be compensated for unwanted treatment are far less likely to provide it.

would have been if not for a health care provider's failure to honor his wishes: If the health care provider had not acted, the plaintiff would be dead. Courts are not equipped to make a comparison between the relative benefits of life with a disability and no life at all.

Courts need not take on the task of deciding whether a plaintiff's life is worth living because there are adequate remedies available under familiar tort principles for those whose refusal of life-sustaining treatment has not been honored. Patients who have been treated against their wishes may bring battery actions. These actions will allow them to be compensated for the denial of their autonomy and force health care providers to bear the cost of unwanted medical care. This will place patients and their families in the same economic position in which they would have been had their wishes been honored. This satisfies the basic rule of tort compensation and creates a deterrent to the providing of unwanted treatment without requiring a court to decide whether life with a disability is worth living.