THE RIGHT TO LIVE

Leigh B. Middleditch, Jr. and Joel H. Trotter

As medical technology has developed to enable doctors to keep incompetent patients alive on life-support systems, the legal issue relating to the authority to discontinue medical treatment has grown. In this essay, Messrs. Middleditch and Trotter address the right to live: the issue of whether a doctor should be able to discontinue the medical treatment of an incompetent patient against the wishes of the patient's guardian.

Messrs. Middleditch and Trotter analyze three cases where doctors wanted to disconnect the life support system of an incompetent person against the wishes of the patient's guardian or family members and find that courts differ in their approaches to the problem. The authors hypothesize that the right-to-live issue stems partly from our culture's denial of death's reality, partly from our reverence for patient autonomy, and mostly from economic concerns. Finally, the authors describe several proposals advanced by those in the medical and legal community which aim to clarify and resolve right-to-live issues. These proposals include: that the medical community should deny treatment defined to be futile; that the presumption of treating persons in a persistent vegetative state should be changed to a presumption of not treating such persons; and, that limits on disproportionately expensive treatments should be acknowledged and defined.

A look into the future shows us a society in which more and more people are "kept alive" both with machines replacing vital

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organs and computers checking from time to time to see if some additional physiologic functionings have to be replaced by electronic equipment. Centers may be established in increasing numbers where all the technical data is collected and where a light may flash up when a patient expires in order to stop the equipment automatically.

Elisabeth Kübler-Ross, M.D.¹

This prediction might seem less plausible now than two decades ago, when Dr. Kübler-Ross first ventured her “look into the future.” Back then, the right to die had yet to emerge on the national agenda. Today, after the intervening high-profile legal wrangles that sought to turn off Karen Quinlan’s ventilator,² disconnect Nancy Cruzan’s gastrostomy tube,³ and crank up Jack Kevorkian’s suicide machine,⁴ the future does not readily disclose “increasing numbers” of automated life-support centers. In the present social climate, the mind can more easily imagine burgeoning suicide clinics. By most accounts, the vast majority of Americans would prefer to discontinue medical treatment rather than remain in a persistent vegetative state.⁵ Very few people would choose to live the existence Kübler-Ross described: to have machines and computers keeping them alive.

Some people, however, might choose such a fate. If a physician decides to discontinue the treatment of a terminally ill, incompetent patient while the patient’s guardian insists on continuing the treatment, does the patient have the right to live? Courts have established, of course, that a mentally competent patient can always exercise one form of the so-called right to die—the right to refuse life-sustaining medical treatment—and, for the most part, so can the guardian of a terminally ill, incompetent patient.⁶ Recently, the obverse right—the right to live—has begun to receive attention. This essay discusses the most visible right-to-live cases to date, examines causes that may underlie the recent emergence of the right to live, and identifies potential developments in right-to-live legal doctrine.

⁶ See, e.g., Cruzan, 497 U.S. at 279 (acknowledging “a liberty interest in refusing unwanted medical treatment”).
I. Right-to-Live Case Law

At present, the right to live denotes a certain factual pattern rather than any developed legal doctrine. Although noteworthy authors have theorized about whether the right to live might assume a constitutional dimension,\textsuperscript{7} that development seems especially remote as of yet. The U.S. Supreme Court has already bypassed deciding a constitutional right to die,\textsuperscript{8} and most recently the Court similarly declined to announce a constitutional right to physician-assisted suicide.\textsuperscript{9} The right to live remains undeveloped today, though a mature jurisprudence may emerge in time. So far only three cases have attracted widespread attention for their right-to-live implications.\textsuperscript{10}

A. Gilgunn v. Massachusetts General Hospital

In May 1989, Catherine Gilgunn fell and broke her hip for the fourth time.\textsuperscript{11} The seventy-two-year-old woman from Charlestown, Massachusetts, had suffered from numerous maladies for years.\textsuperscript{12} Diabetes, Parkinson's disease, stroke, heart disease, chronic urinary tract infections, and breast cancer had all taken their toll on her health.\textsuperscript{13} After Mrs. Gilgunn's admission to the Massachusetts General Hospital, she experienced repeated seizures that caused brain damage and rendered her comatose.\textsuperscript{14} Mrs. Gilgunn's husband and children agreed that Joan Gilgunn, Mrs. Gilgunn's daughter and primary


8. Cruzan, 497 U.S. at 279, 284 (assuming “for purposes of this case” that “a competent person [has] a constitutionally protected right to refuse lifesaving hydration and nutrition” to conclude merely that “a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state”).


10. For an account of additional cases, see Judith F. Daar, A Clash at the Bedside: Patient Autonomy v. a Physician's Professional Conscience, 44 HASTINGS L.J. 1241, 1249-52 (1993) (identifying five lesser-known cases implicating the right to live).


13. See id.

14. See id.
caregiver, would become Mrs. Gilgunn’s surrogate decision maker.\textsuperscript{15} Joan Gilgunn informed her mother’s physicians that Mrs. Gilgunn had always wanted aggressive medical interventions; she wanted her doctors to do “everything possible.”\textsuperscript{16}

After several weeks of treatment, Mrs. Gilgunn’s physicians determined that further medical care was futile.\textsuperscript{17} The hospital’s ethics committee and Mrs. Gilgunn’s attending physician issued a do-not-resuscitate order, despite Joan Gilgunn’s objection, because they believed that CPR would be “medically contraindicated, inhumane, and unethical.”\textsuperscript{18} The attending physician then began to reduce Mrs. Gilgunn’s ventilatory support.\textsuperscript{19} Three days later, on August 10, 1989, Mrs. Gilgunn’s breathing stopped, and she died.\textsuperscript{20}

Joan Gilgunn sued the hospital and the physicians for negligently inflicting emotional distress on her by refusing to resuscitate her mother.\textsuperscript{21} The case went to trial in April 1995 before a jury in the Superior Court of Suffolk County, Massachusetts.\textsuperscript{22} The judge asked the jury first to decide whether Mrs. Gilgunn would have wanted resuscitation and, second, to determine whether the doctors correctly refused to resuscitate her.\textsuperscript{23} After a two-week trial, the jury deliberated for two hours before saying “yes” to both questions.\textsuperscript{24} The media called the lawsuit the first case “to test whether doctors must provide treatment that patients have requested, even when the doctors believe that the care would be futile.”\textsuperscript{25}

Others have commented that the case represents a more limited principle. For example, Professor George J. Annas warns of Gilgunn that “many physicians have over-interpreted this case, saying it means they can now do whatever they want, that they can decide when treatment is futile, and it doesn’t matter if patients want to be treated or not, if the doctors say they shouldn’t be treated—you can’t.”\textsuperscript{26} Thus,
he says, the concept of medical futility threatens to “bring us back to medical paternalism which is where we started.”

B. In re Conservatorship of Wanglie

In December 1989, eighty-six-year-old Helga Wanglie slipped on a rug at home and fractured her hip. During her recovery, her breathing failed. Her physicians placed her on a respirator and transferred her to a long-term care facility. There, she had a heart attack in May 1990. Although doctors revived her, she suffered irreversible brain damage from oxygen deprivation. Mrs. Wanglie was returned to the hospital, where her physicians determined that she was in a persistent vegetative state (PVS) without any awareness of her surroundings or hope of recovery. Mechanical devices sustained her breathing and supplied her nutrition.

Mrs. Wanglie’s physicians concluded, in light of her extraordinarily poor prognosis, that her care brought her no medical benefit and should cease. However, Mrs. Wanglie’s husband of fifty-three years and the rest of her family strongly disagreed with the physicians and insisted on continuing all treatments. Mr. Wanglie maintained that “only God can take life and . . . doctors should not play God.” Repeated discussions between hospital personnel and family members failed to resolve the matter.

In February 1991, the hospital filed a petition in the Probate Court Division of the Fourth Judicial District for the County of Hennepin, Minnesota, asking the court to appoint a conservator who would

27. Id.
29. See Cranford, supra note 28, at 23.
30. See id.
31. See id.
32. See id.
33. See id.
34. See id.
35. See id.
36. See id.
37. See id.
38. See id.
recommend a decision in Mrs. Wanglie's "best interest." In July 1991, after a four-day trial, Judge Patricia L. Belois appointed Mr. Wanglie as his wife's guardian because he could best "investigate and act upon Helga Wanglie's conscientious, religious and moral beliefs." Three days after Mr. Wanglie won guardianship, his wife died of multi-system organ failure.

The Wanglie case presents an interesting dichotomy to the Karen Quinlan case. Karen Quinlan's family went to court to remove her ventilator while doctors insisted on continuing ventilation indefinitely. Conversely, Helga Wanglie's doctors sought court approval to discontinue ventilation while her family insisted on keeping her ventilator running, prompting one author to remark that "if Cruzan is properly pegged as a case about the 'right to die,' Wanglie surely stands as a contrasting . . . case about the 'right to live.'" Professor George Annas identified the Wanglie case as "the first time in the United States" that doctors argued in court "that it was wrong to treat someone in a persistent vegetative state once the diagnosis was certain." This "was a very difficult argument to make," Annas explained, because "we know that at least 10,000 people are now being treated that way in the United States." Given that such treatment is now customary, Annas argued that Wanglie demonstrates the need "to change medical custom."

C. In re Baby K

In October 1992, Stephanie Keene, who "will be forever better known as 'Baby K,"' was born at Fairfax Hospital in Fairfax, Virginia. Keene had anencephaly, a congenital defect "in which a major portion of the brain, skull, and scalp are missing." She lacked a cerebrum and remained permanently unconscious, unable to "see, hear, or

40. Id.
41. See Hoepler & Kamoie, supra note 28, at 63.
43. See Capron, supra note 28, at 26.
44. Daar, supra note 10, at 1244.
45. Annas, supra note 5, at 887.
46. Id.
47. Id.
49. In re Baby K, 16 F.3d 590, 592 (4th Cir. 1994).
otherwise interact with her environment." At her mother’s insistence, Keene’s doctors placed her on a respirator whenever she experienced difficulty with unaided breathing.

After Keene stabilized, the hospital transferred her to a nursing home, but respiratory problems forced Keene back to the hospital three times. The hospital filed suit in the U.S. District Court for the Eastern District of Virginia, seeking a declaratory judgment that the hospital had no obligation "to provide emergency medical treatment to Baby K that it deems medically and ethically inappropriate." Keene’s guardian ad litem and her father sided with the hospital, but Keene’s mother, Contrenia Harrell, contested the hospital’s lawsuit. Judge Claude M. Hilton denied the hospital’s request.

On appeal, the U.S. Court of Appeals for the Fourth Circuit upheld Judge Hilton’s decision. The Fourth Circuit found that "a straightforward application" of federal law "obligates the Hospital to provide respiratory support to Baby K when she arrives at the emergency department." Specifically, the Emergency Medical Treatment and Active Labor Act prevents hospitals from "dumping" patients . . . by either refusing to provide emergency medical treatment or transferring patients before their emergency conditions [are] stabilized." Because the hospital had conceded that Keene required respiratory support to stabilize her condition, the court concluded that the hospital should have provided that assistance. The court remarked that "the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants" simply lies "beyond the limits of our judicial function." Despite the court’s ostensible unwillingness to consider the "moral or ethical propriety" of the treatment at issue, morality and

50. Id.
51. See id. at 593.
52. See id.
54. Baby K, 16 F.3d at 593.
55. See Carlton, supra note 48.
56. See Baby K, 16 F.3d at 593.
58. See Baby K, 16 F.3d at 598.
59. Id. at 594.
60. Id. (citing 42 U.S.C. § 1395dd (1994)).
61. Baby K, 16 F.3d at 593 (quoting Brooks v. Maryland Gen. Hosp., Inc., 996 F.2d 708, 710 (4th Cir. 1993)).
62. See id. at 594-95.
63. Id. at 598.
ethics may have influenced the court's "straightforward application" of the statute at hand. Some twenty years before Baby K, Professor John A. Robertson discussed treatment options available to an anencephalic infant and observed that, arguably, "it is necessary to withhold treatment in order to save the infant from the horrible existence that would follow from caring for his many defects." Presciently anticipating Baby K's outcome, Robertson then added: "But lacking precedents for making such a quality-of-life judgment, it is unlikely that a court would be willing to deviate from respecting the value of human life."

II. Recent Emergence of Right-to-Live Litigation

Analysis of these cases has yet to yield consensus on precisely what has changed since Quinlan\(^6\) that would explain the recent emergence of right-to-live litigation. Three possible explanations merit discussion. These explanations include the increasing denial of death, heightened attention to patient autonomy, and changes in economic incentives facing doctors.

A. Society's Increasing Denial of Death

First, our culture's persistent denial of death's reality may have driven patients and their families to an unprecedented level of resisting death. Freud cautioned four decades ago that "in our civilized attitude towards death we are once more living psychologically beyond our means,"\(^6^7\) and Kübler-Ross pointed out the "fantastic degrees of denial that some people require in order to avoid facing death as a reality."\(^6^8\) Advances in medical technology have magnified the problem. Perhaps the Preacher of Ecclesiastes would never have posited a "time to die"\(^6^9\) in our age of mechanical ventilators and gastrostomy tubes. If Shakespeare's Julius Caesar had only seen an intensive care unit, he might have thought twice before saying that death "[w]ill come when it will come."\(^7^0\)

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65. Id. (footnote omitted).
67. SIGMUND FREUD, THOUGHTS FOR THE TIMES ON WAR AND DEATH, IN 4 COLLECTED PAPERS 288, 316 (1959).
68. KÜBLER-ROSS, supra note 1, at 15.
69. ECCLESIASTES 3:2.
70. WILLIAM SHAKESPEARE, JULIUS CAESAR act 2, sc. 2.
Rather than accede to death's inevitability, we vainly engage death in battle. As Sherwin B. Nuland notes, "the prevailing temperament of our times" considers death "a grim adversary to be overcome," and so we deploy "the dramatic armaments of high-tech biomedicine" against that adversary. 71 "Many doctors," he further observes, "especially those who spend much of their time in laboratories, share with statisticians the disbelief in the necessity of death from old age." 72 Despite their disbelief, Nuland counters, "life does have its natural, inherent limits." 73 Finally, when those limits approach, "life, even in the absence of any specific disease or accident, simply sputters out." 74

The right-to-die controversy has shown that many people do accept life's "natural, inherent limits." Those who do accept death can defeat Nuland's "grim adversary" through "conscious acquiescence" to death's power. 75 Acquiescence, Nuland observes, "evokes the serene style for which present usage has invented a term: 'Death with Dignity' is our society's expression of the universal yearning to achieve a graceful triumph over the stark and often repugnant finality of life's last sputterings." 76 The right-to-live debate embodies a clash between these two approaches—"dramatic armaments" on the one hand, and a "graceful triumph" on the other.

B. Heightened Attention to Patient Autonomy

Second, the right-to-die debate has elevated the notion of patient autonomy, 77 which could account for the appearance of right-to-live litigation. Mentally competent patients always have the right to refuse life-sustaining medical treatment, due largely to the paramount value of individual autonomy. 78 On this view, assertions of the right to live resulted in part from changes in the process by which doctors and patients reach treatment decisions. 79

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72. Id. at 70.
73. Id.
74. Id.
75. Id. at 10.
76. Id.
77. See, e.g., Edmund D. Pellegrino, Ethics, 270 JAMA 202 (1993). "What is currently being debated is how far the patient's right of participation extends." Id.
78. See Robertson, supra note 7, at 1140.
79. See, e.g., Pellegrino, supra note 77, at 203 (noting that the futility debate "underscores a growing ethical conflict between the autonomy of the physician and of the patient").
An autonomy-based rationale may present logical difficulties for the right to live because the asserted right arises exclusively with incompetent patients. Such patients no longer possess autonomy, and any effort "to approach the incompetent patient through the lens of autonomy ignores the reality of the incompetent patient as a nonautonomous individual." Consequently, some theorists have argued that a decision by the patient's surrogate ought not piggyback on the patient's supposed autonomy. "A guardian's or family member's judgment," the argument goes, "is not entitled to the special deference arising from the autonomy principle, for it is a judgment that one person makes about another, not a judgment that the patient makes about herself."

C. Economic Incentives Facing Doctors

Finally, assertions of the right to live may have less to do with societal conceptions of death or the legal doctrine of patient autonomy and more to do with money. Robert Taylor and John Lantos identify economic factors as the root cause, explaining that "changes from cost-based reimbursement to prospective payment or managed care put doctors and hospitals at financial risk for providing expensive and marginally beneficial treatment," which has forced health-care providers to "correlate costs with outcomes." For example, hospitals today often lose huge sums when they provide artificial ventilation or nutrition because managed care networks must allocate their scarce resources by producing "clear economic incentives" against those types of "expensive, marginally beneficial therapy." Thus, economic

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80. See Robertson, supra note 7, at 1140.
81. Id. at 1143; cf. id. at 1197 ("When all cognitive and sapient function is irretrievably lost, it is a reasonable judgment that the patient has lost the capacity to have interests at all."); see also Cruzan, 497 U.S. at 275 (citation omitted) (recounting another court's acknowledgment that "to claim that [a patient's] 'right to choose' survives incompetence is a legal fiction at best").
82. See Kamisar, supra note 7, at 1229.
84. Robert M. Taylor & John D. Lantos, The Politics of Medical Futility, 11 Issues L. & Med. 3, 7 (1995); see also Sidney H. Wanzer et al., The Physician's Responsibility Toward Hopelessly Ill Patients, 310 N. Engl. J. Med. 955, 956-57 (1984) ("In the past, cost was rarely an important factor in decision making, but today, as society tries to contain the soaring cost of health care, the physician is subject to insistent demands for restraint, which cannot be ignored.").
85. Taylor & Lantos, supra note 84, at 8.
changes—not “increased emphasis on patient autonomy”—more directly caused the present debate over the right to live.86

III. The Future of Right-to-Live Cases: Recommendations

The outlook for the right to live remains uncertain. Right-to-live cases arise infrequently, and so far the three leading cases have offered little doctrinal guidance for future adjudications of the right. According to one recommendation, the medical community should adopt a universal definition of futile treatment—namely, treatment that “merely preserves permanent unconsciousness or cannot end dependence on intensive medical care”87—and doctors should apply that definition to determine when treatment becomes futile and whether to discontinue the futile treatment.88

Another recommendation urges that we change from presumptively treating patients in a persistent vegetative state to presumptively discontinuing such treatment, because public opinion dramatically rejects continued treatment under the circumstances:89

With persistent vegetative states and other diseases that result in severe brain damage, you’re not dead. Nonetheless, you’re in such bad shape that we know by surveys that 90% of Americans would not want continued medical treatment in a PVS. The presumption in these cases should be changed. It’s wrong to continue the presumption in favor of continued treatment in someone in a persistent vegetative state when we have overwhelming evidence that Americans don’t want to continue to live like that.90

If these polling data are accurate, then the current presumption may well point in exactly the wrong direction, and we should replace it with a presumption in favor of discontinuing aggressive treatment for any patient in a persistent vegetative state.91

86. See id.

87. Dzielak, supra note 28, at 764 (quoting Lawrence J. Schneiderman et al., Medical Futility: Its Meaning and Ethical Implications, 112 ANNALS OF INTERNAL MED. 949, 951 (1990)).

88. See id. at 764-66. The author further argues that “courts must provide physicians with a rebuttable presumption to determine when treatment is futile,” id. at 765, and that the patient’s decision makers could rebut the presumption “by showing that treatment will improve the patient’s condition and correspondingly the patient’s quality of life,” id. at 766.

89. See Annas, supra note 5, at 889.

90. Id.

91. See also Kristi E. Schrode, Life in Limbo: Revising Policies for Permanently Unconscious Patients, 31 Hous. L. Rev. 1609, 1649 (1995) (concluding that “denying treatment to permanently unconscious patients is a reasonable starting point” in setting limits to health care resources).
Ultimately, the "critical question confronting our health care system . . . is whether we can create fair mechanisms to limit the use of expensive but marginally beneficial therapies in order to assure adequate care for all our citizens."\textsuperscript{92} To do so, we should avoid "disguising these decisions as simple futility assessments" and, instead, acknowledge and define limits on "disproportionately expensive" treatments in which the "costs of therapy are high and the expected benefit is low."\textsuperscript{93} Assuredly, this presents a "more ethically complex and politically troublesome task" than merely declaring some treatments futile.\textsuperscript{94} However, this approach would frame the issues in a meaningful way and thus assist lawmakers in directly confronting the right to live.

\textsuperscript{92} Taylor & Lantos, supra note 84, at 11.
\textsuperscript{93} Id. at 12.
\textsuperscript{94} Id.