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Recommended Citation

Kathy L. Cerminara, *Rip Currents: Rough Water for End of Life Decision Making*, 21 J. Health Care L. & Pol'y 59 (2018).
Available at: <https://digitalcommons.law.umaryland.edu/jhclp/vol21/iss1/4>

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RIP CURRENTS: ROUGH WATER FOR END OF LIFE DECISION MAKING

KATHY L. CERMINARA*

Every day brings news of another celebrity's passing. In 2017 alone, comedian Jay Thomas died of cancer and country singer Glen Campbell died after a long struggle with Alzheimer's Disease. South African rugby player Joost Heystek van der Westhuizen and American playwright, actor, and director Sam Shepard both passed away after long struggles with amyotrophic lateral sclerosis.¹ We don't know if these celebrities exerted control over their medical treatment choices during their final days, but we do know that some people suffering through such drawn-out illnesses wish to do so. If they have not and cannot do that themselves, loved ones will do so for them, ideally making the decisions they would have made.

In the early days of end-of-life decision making law, technology such as the ventilator began forcing the law to catch up with evolving medical-ethical principles, to permit death to occur naturally in some cases even though technology existed to technically stave it off. Slightly more than forty years ago, in the first reported appellate end-of-life decision making case, the New Jersey Supreme Court ruled that Karen Ann Quinlan's father, acting as her legal guardian, could authorize withdrawal of her ventilator support.² Fewer than ten years later, in 1985, there were only eleven cases when research began for the first nationwide legal treatise on the law of end-of-life decision making.³

Today, the cases have multiplied several-fold, yet the principles upon which the New Jersey Supreme Court based its decision in *Quinlan* remain surprisingly

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1. Lynn Elber, *Jay Thomas, 'Murphy Brown' and 'Cheers' Actor, Radio Host, Dies at 69*, CHI. TRIB. (Aug. 24, 2017), <http://www.chicagotribune.com/entertainment/tv/ct-jay-thomas-dead-20170824-story.html>; Megan French, *Celebrity Deaths in 2017 Stars We've Lost*, U.S. MAG. (Dec. 28, 2017), <https://www.usmagazine.com/celebrity-news/pictures/celebrity-deaths-in-2017-stars-weve-lost-w485884/june-foray-w494496/>; *South African Rugby Great Joost van der Westhuizen Dies from Motor Neurone Disease*, ABC NEWS (Feb. 06, 2017), <http://www.abc.net.au/news/2017-02-07/springboks-great-joost-van-der-westhuizen-dies-at-45/8246582>.

2. See *In re Quinlan*, 355 A.2d 647, 671 (N.J. 1976).

3. Professor Cerminara began work on *THE RIGHT TO DIE* in the summer of 1985, as the first research assistant working on the book.

unchanged. In end-of-life decision making law, the vast majority of cases in which patients or surrogates acting on their behalf wish to refuse life-sustaining treatment are governed by legal principles honoring patient autonomy. This is true across the states, with individual variations in details in accordance with principles of state sovereignty.

Over the last 25 years the federal government has taken steps to assure that patient autonomy is honored at and near the end of life. First was the Patient Self-Determination Act of 1990, when Congress reacted to the *Cruzan*⁴ decision by attempting to facilitate awareness of state law governing advance directives.⁵ Quite recently, the Centers for Medicare & Medicaid Services (CMS), adopted two billing codes affirmatively authorizing payment for time spent by a physician or other health care professional in advance care planning with patients.⁶

Those events represent not only the current legal bookends of federal government involvement in end-of-life legal issues but also a shift in the law and medical professions away from emphasizing the mere completion of advance directives that accept or refuse particular end-of-life treatments. One example is Gundersen Health System's work in LaCrosse, Wisconsin, in its Respecting Choices program: a series of conversations in which patients, health care professionals, and families discuss the entire continuum of care, addressing both choices of particular treatments *and* the values underlying those choices.⁷ The goals of such programs are both to assist patients themselves in thinking through the issues and to ensure that physicians and surrogate decision makers know what the patient wants to have done – or not done – if the patient loses capacity to make those decisions for himself or herself.

Interestingly, patients and their families who had to fight for recognition of patient autonomy in the form of the ability to refuse life-sustaining treatments at the time of *Quinlan* – sometimes are important sources of pushback against termination of treatment. Eloquent authors such as Atul Gawande remind us that health care professionals are still uncomfortable with the end of life and that they are starved for training in conducting the types of discussions CMS seeks to

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

5. See Patient Self-Determination Act of 1990, H.R. 4449, 101st Cong. (1990), <https://www.congress.gov/bill/101st-congress/house-bill/4449>.

6. *Frequently Asked Questions about Billing the Physician Fee Schedule for Advance Care Planning Services*, CENTERS FOR MEDICAID & MEDICAID SERVS. (July 14, 2016), <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf>.

7. *Respecting Choices*, GUNDERSEN HEALTH SYSTEM, (Dec. 20, 2017) <http://www.gundersenhealth.org/respecting-choices/>; see also Bernard J. Hammes et al., *A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County That Implemented an Advance Care Planning Microsystem*, 58 J. AM. GERIATRICS SOC'Y 1249 (2010) (concluding that “[a] system for [advance care planning] can be managed in a geographic region so that, at the time of death, almost all adults have an advance care plan that is specific and available and treatment is consistent with their plan.”).

encourage.⁸ Yet, in some ways it appears as if some patients and families believe that health care professionals have learned all too well that the technological imperative should be resisted near the end of life.⁹

Specifically, this Essay highlights two trends in the case law that reflect the combination of scientific disagreement and surrogate concerns about “giving up too quickly.” Pushbacks against brain death diagnoses have appeared increasingly in recent years.¹⁰ The field is ripe for the same pushback to develop against persistent vegetative state diagnoses.¹¹ Such pushbacks increasingly toss and turn in rip currents of public discourse about the cost of health care and disability rights.

I. BRAIN DEATH

This Essay begins at the end, so to speak – at least the end of life. For several years, disputes about brain death have featured heavily in annual supplements to *The Right to Die: The Law of End-of-Life Decisionmaking*. Very few of those disputes have resulted in “new law,” because most of them are unreported, and many are trial-level. They have, however, hit the headlines with a vengeance.¹² It seems that newspapers increasingly have written about families protesting brain death diagnoses, usually but not always parents protesting the deaths of their children.

Stunningly, the most recent judicial trend in these cases has been to “side” with the parents, in one way or another. Jahi McMath, a little girl from California who went to the hospital for a tonsillectomy but suffered a terrible outcome,¹³ may be the most famous, but she was only the tip of the iceberg. One case, in Virginia is currently pending regarding whether hospitals must obtain informed consent to administer apnea tests to determine death by neurological criteria.¹⁴

8. ATUL GAWANDE, *BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END* (2015).

9. *Id.* at 6. (“Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it.”)

10. ALAN MEISEL ET AL., *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* (hereinafter *THE RIGHT TO DIE*), at § 6.04 [A][1][a].

11. See Robert E. Cranford, *What Is a Minimally Conscious State?*, 176 *WEST. J. MED.* 129, 129 (discussing how “...many medical and ethical controversies still surround the vegetative state.”)

12. See, e.g., Fr. Mark Hodges, *Girl at Center of ‘Brain Death’ Controversy Dies Before Nevada Hearing*, LIFE SITE NEWS, (Jan. 7, 2016, 12:24 PM), <https://www.lifesitenews.com/news/girl-sparking-brain-death-controversy-dies-before-nevada-hearing>; see also Celeste McGovern, *Top Neurologist: Jahi McMath Is ‘No Longer’ Dead*, NAT’L CATH. REGISTRAR (Nov. 30, 2015), <http://www.ncregister.com/daily-news/top-neurologist-jahi-mcmath-is-no-longer-dead>; Barbara Wallace, *Mom Disputes Kaiser’s ‘Brain Dead’ Diagnosis*, COURTHOUSE NEWS SERV., (Apr. 28, 2016, 10:49 PM), <http://www.courthousenews.com/2016/04/28/mom-disputes-kaisers-brain-dead-diagnosis.htm>.

13. John M. Luce, *The Uncommon Case of Jahi McMath*, 147 *CHEST* 2255, 2256 (2015).

14. See Brief in Opposition-Appellee, *Lawson v. VCU Medical Center*, Record No. 161321., Va. S. Ct. Sept. 19, 2016, available at http://www.thaddeuspope.com/images/Brief_in_Opposition_161321_09-

Another case was decided in September, 2016, in a trial court in Montana.¹⁵ In both cases, the courts thus far have ruled that health care professionals may not perform apnea tests without the patients' surrogates' informed consent. It's autonomy in action, but this autonomy is not being exercised to permit a patient to die. The autonomy sought here would permit a surrogate decision maker to prevent medical tests that would declare someone already dead. It is a way to cut off a true, quantitative, futility argument regarding biological support of a body believed to be dead.¹⁶

In another important brain death case involving 20-year-old Aiden Hailu, the Nevada Supreme Court upheld the law of brain death in that state.¹⁷ Nevada had adopted the whole-brain-death definition contained within the Uniform Determination of Death Act (UDDA).¹⁸ Not unusually, however, its statute also provided that the determination of death must be made in accordance with accepted medical standards.¹⁹ Nearly a month before Ms. Hailu's medical mishap, the hospital in which she was a patient performed three electroencephalogram (EEG) tests.²⁰ They revealed she was not brain dead.²¹ More than a month later, however, the hospital staff performed an apnea test, which she failed.²² The hospital staff notified her father, who was her guardian, that they intended to discontinue her ventilator and other biological support.²³ He objected and sought a temporary restraining order preventing the hospital from removing the technology.²⁴

19-16_.pdf; Findings of Fact and Conclusions of Law, In re A.C., No. DG-16-08, (Sept. 26, 2016), available at http://www.thaddeuspope.com/images/Order_Denying_SVH_Motion_23sept2016.pdf.

15. James B., *Mother Intervenes to Keep 'Brain Dead' Montana Boy Alive*, CROSSMAPS <http://www.crossmap.com/news/mother-intervenes-to-keep-brain-dead-montana-boy-alive-30936> (last visited Nov. 20, 2017); Calixto Machado et al., *Brain Death Diagnosis and Apnea Test Safety*, 12 ANNALS OF INDIAN ACAD. OF NEUROLOGY 197 (2009) (explaining that an apnea test involves taking a patient off ventilator support for ten minutes to see if she can breathe on her own).

16. James L. Bernat, *Medical Futility, Definition, Determination, and Disputes in Critical Care*, 2 NEUROCRITICAL CARE 198 (2005) (describing how in medicine, futility is the notion that further medical treatment or therapy should not be pursued due to a patient's irreversible condition and thus inability to improve).

17. *See In re Guardianship of Hailu*, 361 P.3d 524 (Nev. 2015).

18. NEV. REV. STAT. § 451.007 (LexisNexis 2017). (Nevada requires that the determination of death shall be made "in accordance with accepted medical standards"); *Uniform Determination of Death Act*, UNIFORM L. COMMISSION (1980), <http://www.uniformlaws.org/shared/docs/determination%20of%20death/udda80.pdf>; *see also Determination of Death Act Summary*, UNIFORM L. COMMISSION, <http://www.uniformlaws.org/ActSummary.aspx?title=Determination%20of%20Death%20Act> (last visited Dec. 13, 2016).

19. NEV. REV. STAT. § 451.007 (LexisNexis 2017).

20. *See In re Guardianship of Hailu*, 361 P.3d at 525.

21. *Id.*

22. *Id.*

23. *Id.*

24. *Id.*

The hospital had used American Association of Neurology (AAN) guidelines, which it argued constituted the generally accepted medical standard in determining that Ms. Hailu was brain-dead.²⁵ AAN guidelines, however, could have resulted in a different conclusion from an EEG examination looking for loss of whole-brain activity.²⁶ The trial court ruled in favor of the hospital because generally accepted medical standards (the AAN guidelines) indicated that Ms. Hailu was brain-dead.²⁷ The Nevada Supreme Court reversed, holding that the legislature, in adopting the UDDA, intended to ensure that the brain was not functioning at all before declaration of death.²⁸ It also held that the UDDA sought to achieve uniformity in diagnosis by requiring that determinations of death “be made in accordance with accepted medical standards” and “applied and construed in a manner uniform among the states which enact it.”²⁹

While the trial court had determined that hospital personnel had satisfied the AAN guidelines, and that AAN guidelines constituted an accepted medical standard in Nevada, that court erred by failing to consider whether those guidelines constituted *accepted medical standards applied uniformly throughout UDDA states*. Only then, the Nevada Supreme Court ruled, would AAN guidelines suffice to support a diagnosis of brain death under the UDDA.³⁰ The court noted that the generally accepted medical standard at the time of the promulgation of the UDDA required confirmatory EEG testing, while the AAN guidelines do not. It would not rule that the AAN guidelines had replaced previous generally accepted criteria (the “Harvard criteria”), but it remanded the case to the trial court for additional evidence and reconsideration of whether a

25. *Id.* at 526.

26. *Id.* at 527. A diagnosis of brain death follows the successful completion of a number of prerequisites. They include a clinical evaluation, neurological testing examining the absence of cerebral or brainstem function by testing the patient’s reflexes, as well as imaging tests such as the electroencephalogram (EEG), the apnea test, and other ancillary diagnostic tests. Only after all other diagnostic criteria have been satisfied may the apnea test be performed. The apnea test is required for the diagnosis of brain death and involves disconnecting the patient from the ventilator and supplying oxygen via a nasal cannula. Any spontaneous respiratory efforts are noted and the partial pressure of arterial carbon dioxide (PaCO₂) is measured. Absent visualization of any respiratory efforts and a PaCO₂ over 60 mmHg (or in some cases 20 mmHg over the baseline), the patient meets the criteria for brain death. An EEG is a useful confirmatory test for the diagnosis of brain death and involves connecting electrodes to the scalp and measures electrical activity in the brain by recording summated synaptic potentials. An isoelectric or flat recording for 30 minutes confirms the diagnosis. *See generally Brain Death Determination / Apnea Testing*, THE DEPARTMENT OF SURGICAL EDUCATION, ORLANDO REGIONAL MEDICAL CENTER, (Oct. 10, 2009), http://www.surgicalcriticalcare.net/Guidelines/brain_death_determination_2009.pdf; *see also generally* Zhe Chen et al., *An Empirical EEG Analysis in Brain Death Diagnosis for Adults*, 2 COGNITIVE NEURODYNAMICS, 257 (2008); G Bryan Young, *Diagnosis of Brain Death*, UPTODATE, <http://www.uptodate.com/contents/diagnosis-of-brain-death> (last updated May 27, 2015).

27. *See In re Guardianship of Hailu*, 361 P.3d at 527–28.

28. *Id.* at 532.

29. *Id.* at 531.

30. *Id.*

determination of death using the AAN guidelines would satisfy the state's statutory test.³¹

Ms. Hailu died of cardiopulmonary arrest while the case was pending at the trial court, before the trial court could hold a hearing on the issue to be decided on remand. Her death ended the case on its facts, but the Nevada legislature took up the matter in its next legislative session.³² Now Nevada law provides that physicians determining death must use the AAN guidelines.

Brain death has always been a bit suspect to some, due in part to philosophical³³ and religious objections³⁴ but also due to its utilitarian roots.³⁵ One might believe that death is a matter of fact; Merriam Webster Dictionary defines it as “a permanent cessation of all vital functions: the end of life.”³⁶ One might also think that determining when that cessation occurs is a matter of medical science. After all, vital functions are concerned with or necessary to the maintenance of life” and medical personnel objectively measure respiration and circulation of the blood.³⁷ When it set forth its definition of brain death, the faculty at Harvard Medical School stated that “the law treats [the question of when a patient is dead] essentially as one of fact to be determined by physicians.”³⁸ Yet the law delineating when a physician may declare a patient dead differs from state to state, suggesting that death – as Ben Rich has written - - cannot be determined “by *discovering*, as an objective, scientific fact of the matter, but rather . . . by *deciding*, through a social consensus hopefully supported by the most reliable scientific information.”³⁹

31. *Id.*

32. NEV. REV. STAT. § 451.007 (LexisNexis 2017).

33. D. Alan Shewmon, *Constructing the Death Elephant: A Synthetic Paradigm Shift for the Definition, Criteria, and Tests for Death*, 35 J. MED. PHIL. 256, 274 (2010).

34. *See, e.g.*, 10 N.Y.C.R.R. § 400.16 (requiring policies and procedures for reasonable accommodation of objections to death by neurological criteria); N.J. STAT. § 26:6A-5 (requiring use of respiratory-cardiac death when conscientious objections to death by neurological criteria exist); *see also* CALIF. HEALTH & SAFETY CODE § 1254.4 (providing for a short period of reasonable accommodation in cases of religious and cultural objections); 210 ILL. CONS. STAT. § 85/6.23 (requiring that hospitals take patients' religious beliefs into account when determining time of death); *see generally* L. Syd M. Johnson, *The Case for Reasonable Accommodation of Conscientious Objections to Declarations of Brain Death*, 13 J. BIOETHICAL INQUIRY 105, 109 (2016) (advocating further adoption of statutes like New Jersey's).

35. There is little dispute that the reason the Ad Hoc Committee of Harvard Medical School faculty adopted a brain death standard was the rise of transplantation or organs. Ad Hoc Committee of the Harvard Medical School, *A Definition of Irreversible Coma*, 205 J. AM. MED. ASS'N 85, 85 (1968) [hereinafter Ad Hoc].

36. *Death*, MERRIAM-WEBSTER DICTIONARY, <https://www.merriam-webster.com/dictionary/death> (last visited Apr. 01, 2018).

37. *Vital Function*, MERRIAM-WEBSTER DICTIONARY, <https://www.merriam-webster.com/dictionary/vital> (last visited Apr. 01, 2018).

38. Ad Hoc, *supra* note 35 at 87.

39. *See* THE RIGHT TO DIE, *supra* note 10, at 604 (quoting Ben A. Rich, *Structuring Conversations on the Fact and Fiction of Brain Death*, 14 AM. J. BIOETHICS 31, 31 (2014)); *see also* Don Marquis, *Death as a Legal Fiction*, 14 AM. J. BIOETHICS 28, 28 (2014).

The development of the law governing determination of death illustrates the importance of social consensus while reminding us of its changing nature.⁴⁰ The trend of pushback against brain death diagnoses from families could cause one to wonder where social consensus may take us in the future. Perhaps it means that there are more families unable to accept death now than a few decades ago – even after a period of a few days during which their loved ones’ functions are maintained to permit them time to reach acceptance. Perhaps it is about increased ability to publicize protests due to 24-hour news reporting and the Internet. Maybe it is about an increasing number of families having more “guts” to protest in light of more positive attention being paid to other objectors.

Or it could reflect one of the rip currents mentioned earlier. Increased discussions of the cost of health care surrounding the passage and implementation (and potential demise) of the Affordable Care Act have forced a broader swath of the public to acknowledge resource limits in medicine.⁴¹ All of the cases just mentioned involved relatively sudden deaths, from near-drowning⁴² and choking on popcorn⁴³ to mishaps in surgery.⁴⁴ Couple those shocks to the patients’ families with currently frequent media accounts of high health care costs and scarcities of other types in health care facilities,⁴⁵ and you have a recipe for disbelief.⁴⁶ Couple that natural disbelief with talk about resource shortages and add, in half of these cases, the fact that the families are members of minority populations pre-disposed to distrust the medical establishment in any event, and you have the potential for intransigent

40. THE RIGHT TO DIE, *supra* note 10, at 604.

41. Glenn Llopis, *Population Health Offers Three Critical Lessons For the Future of Our Country*, Part 2, FORBES, (Nov. 25, 2016, 4:30 PM), <http://www.forbes.com/sites/glennllopis/2016/11/25/population-health-offers-three-critical-lessons-for-the-future-of-our-country-part-2/2/#66954936733f>.

42. James L. Bernat, *supra* note 16.

43. Brief in Opposition-Appellee, *Lawson v. VCU Medical Center*, *supra* note 14.

44. See *In re Guardianship of Hailu*, 361 P.3d at 525; VINCENT J. RUSSO & MARVIN RACHLIN, *NEW YORK ELDER LAW AND SPECIAL NEEDS PRACTICE* 314–315 (2016 ed. 2016).

45. Vincent Mor, *Why Now? Concerns About End-Of-Life Health Care Policy*, HEALTH AFF. BLOG, (Dec. 19, 2016), <http://healthaffairs.org/blog/2016/12/19/why-now-concerns-about-end-of-life-health-care-policy/>.

46. This is true even though the actual time between the injury-producing incidents and health care professionals’ desires to call or test for brain death appears benign in these cases. That timing reveals that most of these families had been given at least a few days, and one up to a month, to accept the news. See generally *In re Guardianship of Hailu*, 361 P.3d; James B., *supra* note 16; Brief in Opposition-Appellee, *Lawson v. VCU Medical Center*, *supra* note 14; RUSSO & RACHLIN, *supra* note 44. Jahi McMath had approximately three days. Aden Hailu went in to surgery April 1st and had EEGs two weeks after; an apnea test performed on April 28th and subsequently was determined brain dead. June 2nd was the date physicians decided to take Aden off the respirator. In Montana, on July 22nd, Allen Calloway went 5–15 minute without oxygen when he experienced a near-drowning incident. On July 27th consent to perform an apnea test was obtained and the test was performed the following day on the 28th. By law, a second form of consent should have been obtained on July 29th but was not. In the Virginia case, Miranda Lawson had approximately 9 days (May 11th– May 20th).

disagreement.⁴⁷ Another confounding factor may be economic; the United States Supreme Court has recognized that patients with low incomes may properly be considered a vulnerable group in a system in which obtaining health care depends at least in part on the ability to pay for it.⁴⁸

To be blunt, at least some of the increase in brain-death protests may result from families increasingly believing practitioners are “too quick” to check for and call brain death because of the need for organs, the cost of maintaining the patient, or a need for beds.⁴⁹

None of that suspicion means that the health care professionals involved were indeed acting too quickly, or that they were wrong, or acting improperly or unethically. It does, however, imply that the backlash against brain death diagnoses may continue and even become more common over the next few years. It would be an interesting empirical study to collect, compare, and contrast the facts underlying the highly publicized pushbacks of the past few years, especially their injury-producing incidents, timing, the reasons families voiced protest or disbelief, and patient, family, and facility demographics.

II. PERSISTENT VEGETATIVE STATE

The other trend is currently more apparent in science than in the law, but the past teaches us that the two inevitably will combine in future cases. As neuroscientific research progresses, another diagnosis that has proven troublesome to many is the persistent vegetative state (PVS). End-of-life decision-making law effectively began in *Quinlan* with a patient in a PVS.⁵⁰ Today, that diagnosis has come under increased scrutiny as technology including functional magnetic resonance imaging (fMRI) and the electroencephalogram (EEG) has shed more light on what it means to be “conscious” or “unconscious” and “aware” or “unaware.”⁵¹

47. See generally *In re Guardianship of Hailu*, 361 P.3d; RUSSO & RACHLIN, *supra* note 44. See also Alina M. Perez and Kathy L. Cerminara, *La Caja De Pandora: Improving Access to Hospice Care among Hispanic and African-American Patients*, 10 HOUS. J. HEALTH L. & POL’Y 255, 277 (2010) (discussing some of the cultural barriers and issues that predispose individuals to physician distrust).

48. *Glucksberg v. Washington*, 521 U.S. 702 (1997).

49. Atul Gawande, *Letting Go: What Should Medicine Do When It Can’t Save Your Life?*, NEW YORKER (Aug. 2, 2010), <https://www.newyorker.com/magazine/2010/08/02/letting-go-2>.

50. *In re Quinlan*, *supra* note 2, at 647–48.

51. See THE RIGHT TO DIE, *supra* note 10. Human consciousness can be broken down into two components—arousal (wakefulness) and awareness. A comatose state is characterized by a lack of both arousal and awareness. Although advancements in medicine have allowed for the recovery of most patients from a comatose state within ten days, some will permanently lose all brain functions (i.e. brain death) and others will evolve in to a wakeful yet unaware state. Characterized by an aroused state but a lack of awareness, in a persistent vegetative state (PVS) (also known as unresponsive wakefulness syndrome (UWS)), patients may open and close their eyes but are not exhibiting any kind of responsive or voluntary conduct as they lack awareness of their surroundings. Rather, PVS patients are exhibiting reflexive behavior in response to some external stimuli. In contrast, a minimally conscious state (MCS) is characterized by arousal as well as a minimal amount of awareness that is manifested by inconsistent yet

The vast majority of end-of-life decision-making cases involve patients in PVS.⁵² This is not surprising given that a patient in a PVS, although having been diagnosed as being “wakeful but unaware,” may seem aware to a loving family at the bedside.⁵³ Terri Schiavo’s family is perhaps the most famous contemporary example of this phenomenon; most Americans likely saw the video clips in which Terri seemed to be following a balloon in the air and gazing at her mother.⁵⁴ Many medical professionals may have had doubts at that point;⁵⁵ consider what the emotional impact on a loving family member who wanted Terri to be aware must have been.

The belief that Ms. Schiavo was not in a PVS propelled litigation lasting seven years, and that was before the bulk of the fMRI and EEG research that some believe today could call into question some PVS diagnoses.⁵⁶ While small-scale studies have indicated that some patients with VS diagnoses may be somewhat aware, the research is in its early stages.⁵⁷ Moreover, there is no reason to believe that patients with minimal levels of awareness would wish to continue treatment.⁵⁸ Especially if they have executed written advance directives, they even may have constitutional rights to refuse treatment overwhelming any state interests asserted to require that they be in a PVS – or any other specified condition for that matter – for their advance directives to be given effect.⁵⁹

reproducible behavior. Patients in a MCS show signs of conscious perception of the environment (i.e. patients can react to commands; can respond yes or no verbally or via gesture). *See generally* Andreas Bender et al., *Persistent Vegetative State and Minimally Conscious State: A Systematic Review and Meta-Analysis of Diagnostic Procedures*, 112 DEUTSCHES ARZTEBLATT INT’L 235 (2015); Vanessa Charland & Steven Laureys, *Unresponsive Wakefulness Syndrome and Minimally Conscious State: Towards a Better Understanding of Disorders of Consciousness*, INT’L BRAIN INJ. ASS’N, (Dec. 10, 2012, 4:05 PM), <http://www.internationalbrain.org/articles/unresponsive-wakefulness-syndrome-and-minimally-conscious-state/>; Olivia Gosseries et al., *The Role of Neuroimaging Techniques in Establishing Diagnosis, Prognosis and Therapy in Disorders of Consciousness*, 10 OPEN NEUROIMAGING J. 52 (2016); *see, e.g.*, Steven Laureys et al., *Brain Function in Coma, Vegetative State, and Related Disorders*, 3 LANCET NEUROLOGY 537, 538 (2004).

52. THE RIGHT TO DIE, *supra* note 10 at § 6.04[1].

53. Kathy Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. 147, 152 (2005).

54. *Id.*

55. Charles Babington, *Frist Defends Remarks on Schiavo Case*, WASH. POST, (June 17, 2015), <http://www.washingtonpost.com/wp-dyn/content/article/2005/06/16/AR2005061600501.html> (discussing how Senator Bill Frist, a physician, said at that time that he did not believe she was in a PVS after reviewing the video clips).

56. The litigation lasted from 1998 until 2005, while fMRI and EEG research began around or after 2000. *See* Steven Laureys and Nicholas D. Schiff, *Coma and Consciousness: Paradigms (re)framed by Neuroimaging*, 61 NEUROIMAGE 478, 479 (2011).

57. *See* THE RIGHT TO DIE, *supra* note 10, at 612–15.

58. *Id.* at 614–615.

59. *See* Kathy L. Cerminara & Joseph R. Kadis, *Give Me Liberty to Choose (A Better) Death: Respecting Autonomy More Fully in State Advance Directive Statutes*, 10 ST. LOUIS J. HEALTH L. & POL’Y 67 (2016).

The bottom line at this time is that the law imposes different requirements in cases of minimally conscious patients than in cases of patients in PVS, and it will have to develop somewhat to honor the autonomy of those patients who wish to refuse treatment in minimally conscious states (MCS). Even sooner, however, as in *Schiavo*, a court is likely to once again be asked to prohibit withholding or withdrawing treatment from a patient because of differences in belief regarding whether the patient is in a PVS. This time, there may – with a strong emphasis on “may” – be more scientific evidence on the side of the people saying the patient is not truly in a PVS. And, of course, much depends on the particular facts that reach a court, such as the patient’s condition and its cause.

As we learned at the time of *Schiavo*, the rip current of publicity that can be created by the disability rights movement is powerful. If a patient is aware rather than unaware, then she is a step closer to some people with significant intellectual or developmental disabilities than Ms. Schiavo was. During *Schiavo*, we saw how vulnerable traditional bioethics can be to the disability critique.⁶⁰ Arguments about valuing those who are differently abled have been asserted since at least the *Bouvia* case in California in 1986.⁶¹ Pleas for acknowledgement and conversation came to the forefront during and after *Schiavo*, resulting in authors like Dean Alicia Ouellette seeking to increase cultural competence regarding persons with disabilities among bioethicists.⁶² As the Affordable Care Act increases focus on health equity (assuming its health equity provision is not repealed), such cultural competence should be increasingly valued not only in bioethics near the end of life, but also throughout bioethics, medicine and many other professions.⁶³

Authors such as Dean Ouellette and Professor Lois Shepherd, among others, take pains to note that persons with disabilities should not be robbed of their liberty to refuse treatment, either.⁶⁴ But suspicion remains about PVS, fueled at least in part by the visuals associated with the PVS itself.⁶⁵ Combine a history of social vulnerability and stigma, visuals capable of leading many to believe that patients in PVS are in fact at least minimally conscious, neurological research that supports further exploration of such a possibility in some cases, and

60. *Id.*; see also ALICIA OUELLETTE, *BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS* 4, 280 (2011); LOIS SHEPHERD, *IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO* 30. (Univ. of N.C. Press 2009).

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

62. See OUELLETTE, *supra* note 60.

63. Discrimination Prohibited, 42 C.F.R. § 92.101 (2017) (“Except as provided in Title I of the ACA, an individual shall not, on the basis of race, color, national origin, sex, age, or disability, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any health program or activity to which this part applies.”).

64. SHEPHERD, *supra* note 60; OUELLETTE, *supra* note 60.

65. See Robert M. Walker & Jay Black, *Terri Schiavo and Televised News: Fact or Fiction*, in KENNETH W. GOODMAN, ED., *ETHICS, POLITICS AND DEATH IN THE 21ST CENTURY: THE CASE OF TERRI SCHIAVO* (Oxford University Press 2010).

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the previously mentioned talk about the high cost of health care and scarcity of resources. The result is rather plain to see: future disputes are likely to raise questions about whether patients are actually in PVS more often and more overtly than before. As we proceed into the future, recognition of valid concerns underlying such protests, even if they are not factual, will be increasingly important.

III. CONCLUSION

This Essay has examined two recent trends in the law of end-of-life decision making tossing in rip currents of public concern. Families of patients increasingly have pushed back in spectacularly public ways against two diagnoses in particular: brain death and PVS. Such rough waters are likely to continue due to the social, economic, and cultural realities of medicine, the health care industry, and health care coverage. America's history of inconsistency and sometimes irrationality in access to health care services only helps churn the waves as patients near the ends of their lives.

