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In the movie Inside Out, one of the characters knocks over a bag containing blocks of different sizes, jumbling them all together. "Oh no," she says. "It's facts and opinions, looking so similar." One of her companions replies, "Don't worry about it; it happens all the time."[1]

I. INTRODUCTION

It does indeed happen all the time; facts and opinions are all jumbled together. Facts are portrayed as opinions and opinions are portrayed as facts. Some "facts," it turns out, are opinions, or at least are functions of perspectives and values rather than what a scientist would consider to be "fact." Facts and opinions are confused a great deal among the general public regarding scientific matters, perhaps because truly understanding science requires a degree of expertise many people do not have.[2]

Neuroscience—the science of the brain and the nervous system—is ripe for such confusion: confusion, which can cause great upheaval in medical settings. For example, "the most extraordinary end-of-life case ever" involved a family dispute over what most consider a neuroscientific fact—the diagnosis of a young woman as being in a vegetative state ("VS")—that erupted into a nationwide spectacle.[3] The case of Theresa Marie Schiavo prompted twenty-four-hour-a-day news coverage, public protests, state and federal legislative action, and a

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1. INSIDE OUT (Pixar, Walt Disney Pictures June 19, 2015). Thank you especially for this, Professor Sandra Johnson.

2. Dan M. Kahan & Donald Braham, *Cultural Cognition and Public Policy*, 24 YALE L. & POL'Y REV. 149, 149 (2006).

3. Kenneth W. Goodman, *Terri Schiavo and the Culture Wars: Ethics vs. Politics*, *in* THE CASE OF TERRI SCHIAVO: ETHICS, POLITICS, AND DEATH IN THE 21ST CENTURY 1 (Kenneth W. Goodman ed., Oxford Univ. Press 2010).

papal pronouncement.[4] The resulting "culture war" over whether to withdraw her life-sustaining treatment was a vivid reminder of how differently opposing sides of a dispute can view "facts."

In the decade since Schiavo, neuroscience has developed in leaps and bounds, paving the way to further questions about the "fact" of a VS diagnosis. Neuroscientists have begun reporting success in using brain imagery to capture the structure and function of the brains of patients with disorders of consciousness, such as VS. Tools such as functional magnetic resonance imaging ("fMRI") and electroencephalograms ("EEGs") suggest that the clinical diagnostic criteria used to determine whether a patient is in a VS may be flawed. Such flaws may result in some diagnoses that are arrived at correctly yet are factually inaccurate, indicating that a patient is in a VS when he or she is actually in a minimally conscious state ("MCS").[5] Neurologist Dr. James Bernat has noted, "[t]he public has become both fascinated by states of unconsciousness and skeptical of the ability of clinicians to diagnose them correctly, treat them properly, and issue prognoses accurately."[6]

This skepticism opens up space for discussion into which we must proceed cautiously because of the potential to read these studies as support for opinion in the guise of fact. Ms. Schiavo's brother, Bobby Schindler, for example, has described fMRI techniques as demonstrating that "an 'unscientific, inaccurate' diagnosis of unresponsive patients [in VS] is being used as a 'criterion to kill.' "[7] Yet, neuroscientists themselves caution that their research is not advanced enough to accurately describe such diagnoses as unscientific or inaccurate, even if public opinion or social consensus favored the use of them "to kill." Because of the emotional nature of the life-or-death issues involved, future disputes over VS are inevitable, and they easily

4. *See* Kathy L. Cerminara & Kenneth W. Goodman, *Key Events in the Case of Theresa Marie Schiavo*, U. MIAMI ETHICS PROGRAM (Dec. 23, 2015), http://www.miami.edu/index.php/ethics/projects/schiavo/schiavo_timeline/ [https://perma.cc/8AXB-MHSY].

5. *See infra* Section I.B.1 to 2.

6. James L. Bernat, *Chronic Consciousness Disorder*, 60 ANN. REV. MED. 381, 382 (2009).

7. *'Stop Dehydration Deaths,' says Terri Schiavo's Brother in Response to New Brain Scan*, CATHOLIC NEWS AGENCY (Feb. 4, 2010, 8:32 PM) http://www.catholicnewsagency.com/news/stop_dehydration_deaths_says_terri_schiavos_brother_in_response_to_new_brain_scan/ [https://perma.cc/EK7P-M99L] [hereinafter *Stop Dehydration Deaths*]. The Schindlers had requested functional magnetic resonance imaging ("fMRI") testing of Ms. Schiavo while those cases were ongoing, but she was ineligible because she had had a thalamic stimulator implanted during early attempts to revive her brain activity. *Id.*; *see also* Kathy Cerminara, *Theresa Marie Schiavo's Long Road to Peace*, 30 DEATH STUDIES 101, 102 (2006) (having an implanted neurological stimulator is a contraindication for administering any MRI test); Ronald E. Cranford, *A Common Uniqueness: Medical Facts in the Schiavo Case*, *in* THE CASE OF TERRI SCHIAVO: ETHICS, POLITICS, AND DEATH IN THE 21ST CENTURY 112–13 (Kenneth W. Goodman ed., Oxford Univ. Press 2010).

could become as hotly contested as those that erupted during the final years of Ms. Schiavo's life.

Not only are such disputes emotional and potentially violent, but they also are all too common. Everyone will encounter death at some point in his or her life. Everyone will watch friends and family members die; some rapidly, under emergency circumstances, and some after long, drawn-out dying processes. Tens of thousands of patients lie in VS in facilities across America at this very moment, and emotions easily flare when medical decisions are required in such contexts.[8] Each of those patients' long, drawn-out dying processes, like Ms. Schiavo's, has the potential to involve a struggle between autonomy, liberty, and the awesome capability of medicine—a struggle to respect innovation in the medical sciences without sacrificing important freedoms.

This Article will assist in navigating such struggles. First, Part II will briefly recount Ms. Schiavo's case as a vivid example, before delving into the relevant advances in neuroscience that have occurred since its resolution. Part II will analyze why those advances do not warrant questioning the validity of the current view of VS and MCS. Part III will explain the current sharp demarcation between these two conditions in the law of end-of-life decisionmaking. Finally, in Part IV, this Article will develop a typology of skeptics who question established, long-standing scientific conclusions such as the VS diagnosis. Use of this typology in conjunction with cultural cognition theory will aid in debates over the law relating to end-of-life decisionmaking on behalf of patients in VS.

In short, this Article will demonstrate that knee-jerk, emotional protests against statements like Bobby Schindler's[9] will not be as effective as other approaches to preserving hard-won medical decisionmaking liberties. The line between fact and opinion is still too blurry to accept those protests and change the law regarding refusal of treatment on behalf of those in VS. Nevertheless, we should recognize and engage with those who distrust the received wisdom in this area rather than reject their positions outright.

II. *SCHIAVO* AND NEUROSCIENCE IN THE DECADE SINCE

Now, more than ten years after *In re Guardianship of Schiavo*,[10] seems an appropriate time to reflect on what happened in light of recent

8. Marc Lallanila, *Most End-of-Life Cases Avoid Courtrooms*, ABC NEWS (Mar. 21, 2005), http://abcnews.go.com/Health/LegalCenter/story?id=590373&page=1 [https://perma.cc/84L9-MV84].

9. *See Stop Dehydration Deaths*, *supra* note 7.

10. No. 90-2908-GD-003, 2005 WL 459634, at *1 (Fla. Cir. Ct. Feb. 25, 2005), *aff'd*, 916 So. 2d 814 (Fla. Dist. Ct. App. 2005).

neuroscientific developments. In particular, it seems timely to consider the case's lessons about the proper way to incorporate interim scientific discoveries about VS into the law. Ms. Schiavo was the third of three young women in VS who, so far, have affected American law and the politics of end-of-life decisionmaking in major ways.[11] She followed first, Karen Ann Quinlan,[12] and then Nancy Beth Cruzan,[13] each making legal history roughly fifteen years after the other.[14] Should that consistent trend in timing continue, the nation has only a few more years to prepare for a resurgence of highly publicized debates about the nature of VS—debates like those present in *Schiavo*.[15] Reports of neuroscientific research since that time virtually guarantee that such debates will arise.

A. "The Most Extraordinary End-of-Life Case Ever"[16]

Theresa Marie Schiavo was twenty-six years old when she suffered a cardiac arrest in 1990.[17] As a result of lack of oxygen due to her cardiac arrest, she entered what physicians diagnosed as a persistent VS, a condition in which the brain stem continues functioning but all other regions of the brain do not.[18] For fifteen years, she lay in a VS while her husband and parents first worked together to attempt to cure her and then worked at odds in attempting to carry out two distinctly different versions of what they believed her medical wishes would have been. She passed away in 2005, after courts approved withdrawal of the medically supplied nutrition and hydration that had been keeping her alive since her cardiac arrest.

Ms. Schiavo's death came about only after bitter judicial, legislative, and public-relations battles. Resolution of her case took six

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11. *See* Kathy L. Cerminara, *Three Female Faces: The Law of End-of-Life Decision Making in America*, *in* DECISION MAKING NEAR THE END OF LIFE: ISSUES, DEVELOPMENTS, AND FUTURE DIRECTIONS 95–116 (James L. Werth & Dean Blevins ed., Routledge 2009).

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

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

14. *See In re* Guardianship of Schiavo, No. 90-2908-GD-003, 2005 WL 459634, at *1 (Fla. Cir. Ct. Feb. 25, 2005), *aff'd*, 916 So. 2d 814 (Fla. Dist. Ct. App. 2005). The Quinlan case was in 1976, the Cruzan case was in 1990, and the final Schiavo case was in 2005.

15. Cranford, *supra* note 7, at 112–13 ("[T]he conflicts in the Schiavo case will be faced again and again in the future: A young person is in a PVS secondary to a tragic circumstance; the spouse finally accepts the reality; but the parents or other family members cannot bring themselves to acknowledge the neurological facts and refuse to make any considerations about stopping treatment.").

16. *See* Goodman, *supra* note 3, at 1.

17. Cerminara & Goodman, *supra* note 4.

18. ALAN MEISEL, KATHY L. CERMINARA & THADDEUS M. POPE, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING § 6.04[A][1][a] (3d ed. 2015); Kathy Cerminara, *The Schiavo Maelstrom's Potential Impact on the Law of End-of-Life Decision Making*, *in* THE CASE OF TERI SCHIAVO: ETHICS, POLITICS, AND DEATH IN THE 21ST CENTURY 78 (Kenneth W. Goodman ed., Oxford Univ. Press 2010); *see infra* Part II.A. Medicine differentiates between a "persistent" vegetative state and a "permanent" vegetative state.

years from the date that her husband filed suit, a step he took because of the poor and deteriorating relationship between himself and Ms. Schiavo's parents stemming at least in part from their vehement disagreement about her care.[19] Although the scope of their conflict was unclear at first, they disagreed about two major issues that the initial judge hearing the case identified as key: (1) whether Ms. Schiavo lay in a VS, and (2) whether she would have wished to continue to receive medically supplied nutrition and hydration in that condition.[20] The disagreement was intense; the case that began as a probate court dispute resulted in nineteen federal and state judicial opinions,[21] state regulatory action,[22] one state law,[23] one federal law,[24] and the introduction of several additional state and federal bills.[25]

The case continues to affect America in ways no one could have anticipated at the beginning of the family disagreement. Those involved still suffer from what might be termed "political post-traumatic stress disorder" when thinking about that time. Ms. Schiavo's husband angrily campaigned against former Florida Governor Jeb Bush in the 2016 presidential campaign because of his actions relating to passage of a state law that attempted to legislatively overturn the judicial rulings authorizing withdrawal.[26] In stark contrast, her brother, who is executive director of the Terri Schiavo Life and Hope Network, has spoken approvingly of Governor Bush's actions at that time.[27]

Despite this, the *Schiavo* case left a surprisingly small and ephemeral mark on the law of withholding and withdrawing life-sustaining treatment.[28] Instead, its legacy consists primarily of the collective memories it sparks in all those who lived through the events

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19. Cerminara, *Theresa Marie Schiavo's Long Road to Peace*, *supra* note 7, at 103.

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

21. MEISEL, CERMINARA & POPE, *supra* note 18, § 1.09, at 1-29 to 1-30.

22. Motion for Intervention, Stay of Order of the Probate Court, Appointment of Legal Counsel for Theresa Marie Schiavo and Sealing of Proceedings, *In re* Guardianship of Schiavo, No. 90-2908-GD-003, 2005 WL 34546715 (Fla. Cir. Ct. Feb. 25, 2005); *see also* Kathy Cerminara, *Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo*, 29 W. NEW ENG. L. REV. 279, 288 (2007).

23. H.B. 35-E, 2003 Leg., Spec. Sess. (Fla. 2003).

24. S. 686, 109th Cong., 119 Stat. 15 (2005).

25. *See* Cerminara, *Theresa Marie Schiavo's Long Road to Pea*, *supra* note 7, at 107–08.

26. *See, e.g.*, Michael Schiavo, Letter to the Editor, *Don't Trust Jeb Bush with the Power of the Presidency*, MIAMI HERALD (Feb. 6, 2015), http://www.miamiherald.com/opinion/letters-to-the-editor/article 9637031 [https://perma.cc/74WY-QMGP].

27. TERRI SCHAIVO LIFE AND HOPE NETWORK, *Ten Years Later, Terri Schiavo's Fight to Survive Plays a Vital Role in Shaping Public Policy*, PR NEWSWIRE, (Feb. 4, 2010 08:45 ET), http://www.prnewswire.com/news-releases/ten-years-later-terri-schiavos-fight-to-survive-plays-a-vital-role-in-shaping-public-policy-300030471.html [https://perma.cc/DK6V-9TLJ].

28. Cerminara, *Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo*, *supra* note 22, at 307; LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 6 (2009) (ascribing that view to commentators but noting that, now, "the case of Terri Schiavo is increasingly significant").

of that time—memories of intense, bitter hysteria surrounding the death of a young woman in a VS.[29] Like Karen Ann Quinlan and Nancy Beth Cruzan, Theresa Marie Schiavo reminds us that VS is a puzzling, complex disorder of consciousness, one about which opinions sometimes appear to be facts and facts sometimes appear to be opinions.

B. Neuroscientific Advances Post-Schiavo

In the decade since the *Schiavo* case, there have been exciting advances in scientific research that could (and, one hopes, will) lead to improved diagnostic techniques for identifying and distinguishing among disorders of consciousness. Neuroscience has progressed in profound ways, spawning recognition that "[o]ur understanding of the mind, our private thoughts, and our volition necessitates careful reflection about the scientific, societal, and ethical aspects of neuroscience endeavors."[30] Technology has begun to allow researchers to peer into the human brain using unexpected and promising techniques. Some of this research has prompted suggestions that policymakers consider revising a variety of laws relating to patients near the end of life.[31]

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29. Initially, the Multi-Society Task Force on PVS, in a landmark early definitional study of the condition, used the term "persistent vegetative state" for all stages of the condition, from early diagnosis throughout its existence. THE MULTI-SOCIETY TASK FORCE ON PVS, *Medical Aspects of the Persistent Vegetative State, Part I*, 330 NEW ENG. J. MED. 1499, 1499 (1994). Now, however, there is considered to be a medical difference between a patient lying in a "persistent vegetative state" and one lying in a "permanent vegetative state." *See infra* note 56. The courts in *Quinlan*, *Cruzan*, and *Schiavo* all called the conditions at issue "persistent vegetative states," but actually were referring to "permanent vegetative states" as reflected in their descriptions of the conditions as being permanent. *Compare* Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 302 (1990) (in VS six years before decision) (Brennan, J., dissenting) *and In re* Guardianship of Schiavo, No. 90-2908GD-003, 2000 WL 34546715, at *3 (Fla. Cir. Ct. Feb. 11, 2000) (in VS eight-plus years before lawsuit) *with* Bernat *supra* note 6 (after TBI, a VS lasting 12 months is considered "permanent," and after non-TBI beyond three months constitutes permanence. Statutory language can similarly be confusing. *See, e.g.*, Fla. Stat. § 765.101(12) (2015). Florida's statutory definition of "persistent vegetative state," requires a "permanent and irreversible condition of unconsciousness." *Id.*
To better reflect the true medical facts and avoid the confusion caused by the fact that the abbreviation for both of these terms is "PVS," this Article uses the term "vegetative state" ("VS") to refer to the "vegetative" condition at issue.

30. PRESIDENT'S COMM'N FOR THE STUDY OF BIOETHICAL ISSUES, *Gray Matters, Volume 1: Integrative Approaches for Neuroscience, Ethics, and Society* 2 (2014), http://www.bioethics.gov/sites/default/files/Gray%20Matters%20Vol%201.pdf [https://perma.cc/N2YC-QC8E] (advocating for "early integration of ethics into neuroscience research" in part because of the societal implications of that research).

31. *See, e.g.*, Carol E. Fisher & Paul S. Appelbaum, *Diagnosing Consciousness: Neuroimaging, Law, and the Vegetative State*, 38 J. L. MED. & ETHICS 374, 382 (2010) (suggesting that new legislation should define "the actual functions and behaviors . . . consider[ed] most important to end of life decision-making, instead of referencing 'brain activity' itself or some similarly nonspecific term."); Maxine H. Harrington, *Advances in Neuroimaging and the Vegetative State: Implications for End-of-Life Care*, 36 HAMLINE L. REV. 213, 232 (2013) (noting that "new data on undetected consciousness should alert legislators and courts to . . . question the inviolability of the VS diagnosis."); Stacey A. Tovino, *Functional Neuroimaging Information: A Case for Neuro Exceptionalism?*, 34 FLA. ST. U. L. REV. 415, 488–89 (2007) (proposing legislation to address "gaps in existing confidentiality and antidiscrimination laws that allow employers and insurers to force individuals to authorize disclosures of . . . functional neuroimaging information.").

Disputes over what technology tells us about patients' brains are not new. For example, as noted above, beginning mid-way through the litigation that surrounded Ms. Schiavo's death, her parents contested her VS diagnosis to no avail.[32] Some people believed she had a level of consciousness until the very end.[33] The recent neuroscientific research, which seems on the surface to support those views, has been conducted primarily on research subjects diagnosed as being in VS or the closely related MSC. Controversy also arises, however, regarding diagnoses of death from neurological criteria ("brain death").[34] In fact, brain death and VS are often confused even though they differ greatly. For that reason, it is necessary and valuable to define those conditions here.

1. Brain Death as Distinguished from VS

Interestingly, death itself, not just end-of-life decisionmaking before death, offers a case study in how uncertain a "fact" might be. 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."[35] Surely, determining when that cessation occurs is a matter of medical science, since vital functions are "function[s] of the body (such as respiration or the circulation of blood) on which life is directly dependent,"[36] and medical personnel objectively measure respiration and circulation of the blood by counting breaths, checking blood pressure, or using other medical technology.[37] The faculty at Harvard Medical School have stated that "the law treats [the question of when a patient is dead] essentially as one of fact to be determined by

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32. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, *supra* note 20, at 152–53. Ms. Schiavo's autopsy findings were "consistent with PVS" (or whatever the autopsy), although autopsies can neither confirm nor demonstrate the inaccuracy of a PVS diagnosis. It is a clinical diagnosis. After her death, evidence seemed to indicate that she had indeed been in a VS. *See* AUTOPSY REPORT OF THERESA SCHIAVO (Apr. 1, 2005), https://umshare.miami.edu/web/wda/ethics/documents/schivao/061505-autopsy.pdf [https://perma.cc/3JBV-NPJF].

33. *See* MARY & ROBERT SCHINDLER, ET AL., A LIFE THAT MATTERS: THE LEGACY OF TERRI SCHIAVO-A LESSON FOR US ALL 214 (2006) ("[T]here was no question that Terri was responsive, even at the end."). Declaration of Suzanne Vitadamo at 1, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003).

34. *See generally* Ari R. Joffe, et al., *A Survey of American Neurologists About Brain Death: Understanding the Conceptual Basis and Diagnostic Tests for Brain Death*, 2:4 ANNALS INTENSIVE CARE, Feb. 17, 2012, at 1–8, http://www.annalsofintensivecare.com/content/2/1/4 [https://perma.cc/2KUP-G4BT].

35. *Death*, MERRIAM-WEBSTER DICTIONARY (11th ed. 2015).

36. *Vital Function*, MERRIAM-WEBSTER DICTIONARY (11th ed. 2015).

37. *Cf. Vital Signs*, HEALTH LIBR., JOHN HOPKINS MED, http://www.hopkinsmedicine.org/healthlibrary/conditions/cardiovascular_diseases/vital_signs_body_temperature_pulse_rate_respiration_rate_blood_pressure_85,P00866/ [https://perma.cc/4QV9-4RXY]); *Circulation*, NAT'L HEART, LUNG & BLOOD INST., http://www.nhlbi.nih.gov/health/educational/pad/about/diagnosis.html [https://perma.cc/X2XE-KCB5].

physicians."[38] Yet the law delineating when a physician may declare a patient dead differs from state to state,[39] suggesting that death 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."[40]

The development of the law governing determination of death illustrates the importance of social consensus while reminding us of its changing nature. All states now permit physicians, to varying degrees,[41] to declare patients dead when assessment by neurological criteria determines they are brain dead.[42] Prior to medical-legal recognition of the concept of brain death, however, physicians determined when patients died by watching for the cessation of heartbeat and breathing.[43] By the late 1960s, it had become possible to maintain patients' bodies on ventilators, thus assuring that their hearts could continue to beat and their chests could continue to rise and fall regardless of their physiological states. In other words, some patients lacked all brain function, yet did not satisfy the traditional definition of death because technology kept their hearts beating. Moreover, organ transplantation had become possible, and transplant physicians sought a way to increase organ supply.[44] One way to do that was to increase the number of people considered dead. Thus, an ad hoc committee of Harvard Medical School ("the Ad Hoc Committee") recommended that death be defined by neurological criteria: being unreceptive and unresponsive, having no movement, no breathing, no reflexes, and having a flat electro-encephalogram.[45] Because, as noted earlier, the Ad Hoc Committee considered the determination of death to be a matter of fact, and professional judgment firmly within the realm of physician expertise, it recommended no legal changes to reflect its conclusions.[46]

In reality, however, physician practice likely would not have

38. AD HOC COMM. OF HARVARD MED. SCHOOL TO EXAMINE THE DEFINITION OF BRAIN DEATH, *A Definition of Irreversible Coma*, 205 J. AM. MED. ASS'N. 337, 338 (1968) [hereinafter AD HOC COMM.].

39. Sandra Johnson, *Death, State by State*, 44 HASTINGS CTR. REP. 9, 9 (Jul. 2014).

40. 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).

41. Johnson, *supra* note 39, at 9.

42. AD HOC COMM., *supra* note 38, at 337. That term officially entered the medical-legal lexicon when an Ad Hoc Committee at Harvard Medical School published an influential article in *The Journal of the American Medical Association* in 1968. *See id.*

43. Seema K. Shah & Franklin G. Miller, *Can We Handle the Truth?: Legal Fictions in the Determination of Death*, 36 AM. J. L. & MED. 540, 541 (2010) ("We have long understood death as occurring when a person's heart and circulatory system have permanently and irreversibly ceased to function . . . .").

44. *See* AD HOC COMM., *supra* note 38; Hammond, *supra* note 53, at 838.

45. AD HOC COMM., *supra* note 38, at 337. It confusingly uses the term "irreversible coma" to describe the state it recommended as being a new, redefined "death." *Id.*

46. *Id.*

changed, or would have been much slower to change, without legal recognition of the Ad Hoc Committee's recommended definition of death.[47] A flurry of legal debates eventually led the National Conference of Commissioners on Uniform State Laws to develop a Uniform Determination of Death Act ("UDDA") that was approved by the American Medical Association in 1980, and the American Bar Association in 1981.[48] Today, while not every state has adopted the UDDA, every state's law, whether judicial or legislative, permits a physician to diagnose a patient as being dead *either* when circulation and respiration ceases *or* when the patient's entire brain, including the brain stem, has ceased to function.[49] This "whole-brain" formulation of brain death permits a determination of death based on neurological criteria only when a patient has lost the use of his or her entire brain, including both those portions governing thoughts and perceptions (such as the cerebral cortex) and those portions regulating reflexes and basic biological functioning (such as the brainstem).[50] The brain-death criterion permits a physician to declare a patient dead before withdrawing ventilator support. This in turn permits pre-declaration preparation for immediate post-declaration, pre-transplant procedures.[51]

Although some physicians and ethicists protest that technology has rendered the current understanding of brain death over-inclusive,[52] others argue that it is under-inclusive because some patients whose brains still partially function should be considered dead. Advocates of "partial brain death" criteria would amend existing laws to permit a physician to declare dead a person whose brainstem continues to function but whose cerebral cortex, or higher brain, has ceased functioning.[53] In other words, some would advocate that the law should

47. *Cf.* Kathy L. Cerminara & Seth M. Bogin, *A Paper About a Piece of Paper*, 29 J. LEGAL MED. 479, 500 (2008) ("[I]n many advocates' experiences, it has been important to health care professionals that POLST statutes assure them that they will be immune from liability for acting in good faith based upon the orders contained within a POLST form.").

48. UNIF. DETERMINATION OF DEATH ACT (UNIFORM LAW COMM'N 1980), http://www.uniformlaws.org/shared/docs/determination%20of%20death/udda80.pdf [https://perma.cc/38JD-34U7]; *see also Determination of Death Act*, UNIFORM L. COMMISSION, http://www.uniformlaws.org/Act.aspx?title=Determination%20of%20Death%20Act [https://perma.cc/V5JA-LHT9] (discussing the current status of the UDDA in terms of adoption by the states).

49. *See* MEISEL, CERMINARA, & POPE, *supra* note 18, § 6.04[A]. New Jersey, New York, and California have legislative exceptions and accommodations mandates not at issue for purposes of this article. *See* Thaddeus Mason Pope, *Legal Briefing: Brain Death and Total Brain Failure*, 25 J. CLINICAL ETHICS 245, 247–48 (2014) [hereinafter Pope, *Legal Briefing*].

50. *Id.* at 245–57.

51. Robert D. Truog, *Defining Death: Getting it Wrong for All the Right Reasons*, 93 TEX. L. REV. 1885, 1889 (2015).

52. *See infra* Part IV.A.3.

53. Jeffrey B. Hammond, *The Minimally Conscious Person: A Case Study in Dignity and Personhood and the Standard of Review for Withdrawal of Treatment*, 55 WAYNE L. REV. 821, 826–

permit physicians to declare patients in VS dead.[54]

The law has not followed the suggestions of those advocates. To the contrary, the law uniformly treats patients in VS as being alive, leading to disputes such as those at issue in *Schiavo*. Had Ms. Schiavo been dead as she lay in a VS, there would (or should) have been no dispute; there is no duty under the law to provide any sort of "treatment" to a dead body.[55]

In sum, a patient in a VS is alive, although suffering from a severe "disorder of consciousness."[56] Policymakers have recognized VS as a distinct diagnosis since at least 1983, when the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recognized it in an important report on the ethical, medical, and legal issues surrounding decisions to withhold or withdraw life-sustaining treatment.[57]

2. VS, MCS, and Neuroscientific Research Findings

VS varies depending on whether it resulted from traumatic brain injury ("TBI") or a non-traumatic cause such as cardiorespiratory arrest. In cases resulting from TBI, the connections between the cortex and thalamus are severed; in cases with non-traumatic causes, neurons in the cortex, thalamus, and other portions of the brain are damaged from lack of oxygen (hypoxic-ischemic damage).[58] Generally speaking, a patient with the latter type of VS (the type produced by, for example, a cardiac arrest) has a worse prognosis than a patient with the former (the type produced by TBI).[59] Regardless of cause, however, the longer a patient is in a VS, the less likely he or she is to recover from it.[60] In fact, based on the length of time the patient has been in the condition, the medical field has even distinguished between "permanent" and "persistent" VS.[61]

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27 (2009).

54. *Id.* at 852; Shepherd, *supra* note 28, at 13. Professor Lois Shepherd has argued for a presumption in terms of withholding or withdrawal.

55. Pope, *Legal Briefing supra* note 49, at 246–47.

56. *See* Bernat, *supra* note 6, at 381–82 (using this term to refer to PVS and also coma, minimally conscious state ("MCS"), and others).

57. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 171, 171–192 (1983), https://repository.library.georgetown.edu/bitstream/handle/10822/559344/deciding_to_forego_tx.pdf?sequence=1&isAllowed=y (recognizing that Bryan Jennett, among others, had been advocating the recognition of PVS as a distinct diagnosis since 1972). The term appeared for the first time in a judicial opinion slightly earlier, in 1976, when the New Jersey Supreme Court decided the Quinlan case. *See In re* Quinlan, 355 A.2d 647, 654 (N.J. 1976).

58. Bernat, *supra* note 6, at 386.

59. *Id.* at 386–87.

60. *Id.* at 387.

61. *See supra* note 29. The law remains less clear about the difference. Many laws use the term

Conventional wisdom holds that a patient in a VS is wakeful but unaware. He or she will have sleep-wake cycles or open his or her eyes in response to stimulation.[62] His or her brainstem remains functioning, but damage to his or her cerebral cortex, thalamus, or the connections between the two, has "abolishe[d] awareness of self and environment."[63] Neurologists diagnose VS by observing patients' behavior; it is a clinical, observational diagnosis, not one derived from technology-based testing.

Patients in VS thus differ from patients in comas and those in MCS. Patients in comas are neither wakeful nor aware; their eyes are closed and they appear to be sleeping, in addition to being unaware of their surroundings.[64] In contrast, patients in MCS are both wakeful and aware, displaying "markedly impaired responsiveness that features modest or intermittent evidence of awareness of self and environment."[65] They may gaze at moving objects for a sustained time, reach for or grasp objects, respond to questions through gestures, exhibit appropriate emotional reactions, or even speak a few words.[66] According to Bernat, the boundaries between VS and MCS are, "[t]o some extent, . . . necessarily arbitrary and indistinct."[67]

The term "MCS" appeared in the literature much more recently than the term "VS." MCS was called a "minimally responsive state" prior to 2002, when the condition acquired both its current name and diagnostic criteria.[68] Generally, while prognosis is difficult to determine, the longer the patient remains in MCS, the less chance there is that the patient will recover. As with VS, prognosis is affected by whether the patient entered MCS because of TBI or because of non-traumatic, hypoxic-ischemic damage to neurons. "Patients in MCS from TBI have been studied most frequently. Approximately 40% of these patients regain full consciousness within 12 weeks of injury and 50% regain independent function within a year."[69]

Since the waning days of *Schiavo*, fMRIs and EEGs, among other technologies, have begun to produce increasing amounts of information

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"persistent vegetative state" when they mean "permanent vegetative state." *See. e.g.*, Fla. Stat. § 765.101(2012). After a traumatic brain injury ("TBI"), remaining in a VS for more than one year (twelve months) is permanent. After non-TBI (hypoxic-ischemic injury), three months constitutes permanence. Bernat, *supra* note 6, at 387; THE MULTI-SOCIETY TASK FORCE ON PVS, *supra* note 29, at 1499; *see also* Fisher & Applebaum, *supra* note 31, at 382 (noting broadly that many such statutes "typically contain quasi-operationalized definitions of 'permanent unconsciousness' or VS, which often do not correspond to the current clinical understanding of these diagnoses").

62. Bernat, *supra* note 6, at 383.

63. *Id.* at 382.

64. *Id.*

65. *Id.* at 383; *see also* J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 351 (2002).

66. Bernat, *supra* note 6, at 383.

67. *Id.*

68. *Id.* at 388.

69. *Id.*

about the brain. Even more than five years ago, Bernat noted, "Rare is the week without publication of an fMRI study further elucidating some aspect of brain function."[70] Research has continued since then. Though it is both impossible and unnecessary for present purposes to review all of those studies, the following is a representative sampling.

Much of the pertinent work has consisted of using fMRI and EEG to produce images of the brain to learn whether, when, and where neurons are firing—indicating brain activity—even when clinicians may not have expected it. There are a variety of possible uses for this technology, but to the extent relevant here, it is used to detect whether a patient may actually exist in a VS or may instead be minimally conscious (i.e., whether he or she is unaware, as in VS, or aware, as in MCS).[71] The fMRI, according to Stacey Tovino, "identifies localized changes in blood oxygenation that occur in the brain when an individual performs a mental task."[72] In contrast, EEG measures changes in motor neuron functioning when the patient imagines movements.[73]

Perhaps the most famous fMRI study in this field was conducted by Owen and colleagues in 2005 and reported in *Science* in 2006. There, researchers measured one subject's neural responses to spoken messages and compared them with responses to "acoustically matched noise sequences."[74] Neural activity was speech-specific the same way it was in "healthy volunteers listening to the same stimuli."[75] When the speech contained ambiguous words, there was increased neural activity that, according to the authors, "reflect[ed] the operation of semantic processes that are critical for speech comprehension."[76] After measuring that neural activity, the researchers conducted a second fMRI study, in which they asked the subject to imagine playing tennis and, separately, touring her house beginning at the front door. Different parts of her brain—the appropriate parts—lit up in association with each activity, the same as they did in a healthy control volunteer

70. *Id.* at 385.

71. L. Syd M. Johnson, *Implications of Recent Neuroscientific Findings in Patients With Disorders of Consciousness*, 3 NEUROETHICS 185, 189 (2010). It could also result in better early determination of which patients might have a better chance of recovering. Kathrine Bendtsen, *Communicating with the Minimally Conscious: Ethical Implications in End-of-Life Care*, 4 AM. J. BIOETHICS NEUROSCIENCE, no. 3, 2013 at 46, 50 ("help both families and health care providers understand prognoses, and reduce the confusion and doubt revolving around the possibility that the patient may improve or recover"). Fisher & Appelbaum, *supra* note 31, at 380 (2010). Additionally, some might wish to use it to communicate with patients otherwise incapable of any, or at least any reliable, communication for informed consent or informational purposes. *Id.*

72. Tovino, *supra* note 31, at 416–17.

73. Damian Cruse, et al., *Bedside Detection of Awareness in the Vegetative State: A Cohort Study*, 378 THE LANCET 2088, 2089 (2011).

74. Adrian M. Owen et al., *Detecting Awareness in the Vegetative State*, 313 SCIENCE 1402, 1402 (2006).

75. *Id.*

76. *Id.*

doing the same thing.[77] About a year later, these researchers repeated the process, asking a subject to imagine playing a game of soccer; fMRI detected neural activity in the regions of the brain used when moving or imagining movement of the legs and lower body.[78]

Using a similar method of testing,[79] researchers in Germany began in 2010 to use fMRI to study twenty-two subjects (ten in VS and twelve in MCS) within the first 200 days of their injuries.[80] Three of each category had incurred TBI. Fourteen of the twenty-two, five in VS and nine in MCS, had significant positive brain signal.[81] All five of the patients in a VS became MCS at some point thereafter, and one even progressed beyond MCS.[82]

On a slightly larger scale, between November 2005 and January 2009, Monti et al. asked fifty-four subjects (twenty-three diagnosed as being in VS and thirty-one diagnosed as being in MCS)[83] to perform two imagery tasks: (1) a motor imagery task— "to imagine standing still on a tennis court and to swing an arm to 'hit the ball' back and forth to an imagined instructor," and (2) a spatial imagery task—"to imagine navigating a familiar city or . . . walking from room to room in their home and to visualize all that they would 'see' if they were there."[84] Five of those fifty-four subjects could "willfully modulate their brain activity" as revealed by changing neural firing; supplementary motor areas of the brain, responsible for motor imagery, lit up considerably.[85] In four of the five, the parahippocampal gyrus, responsible for spatial imagery, lit up. The researchers observed the same results in healthy control subjects. The activity was sustained for thirty seconds, and it was associated with the delivery of verbal cues. Four of the five subjects had been diagnosed as being in VS, meaning that one had been diagnosed as being in MCS; the conditions of all five had resulted from TBI.[86]

Monti et al. thereafter asked one of the five VS subjects whose

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77. *Id.*

78. Adrian M. Owen et al., *Using Functional Magnetic Resonance Imaging to Detect Covert Awareness in the Vegetative State*, 64 ARCHIVE NEUROLOGY 1098, 1101 (2007) [hereinafter Owen et al., *Using Functional Magnetic Resonance Imaging*].

79. Dominik Vogel, et al., *Can Mental Imagery functional Magnetic Resonance Imaging Predict Recovery in Patients with Disorders of Consciousness?* 94 ARCHIVES PHYSICAL MED. & REHABILITATION 1891, 1894 (2013).

80. *Id.* at 1891.

81. *Id.* at 1894.

82. *Id.* at 1896.

83. Martin M. Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 NEW ENG. J. MED. 579, 582–83 (2010). Of the VS patients, thirteen had brain damage stemming from TBI and ten did not; of the MCS patients, twenty had brain damage stemming from TBI and eleven did not.

84. *Id.* at 581.

85. *Id.* at 583.

86. *Id.*

brains lit up in the "correct" area to accomplish a communication task, along with sixteen control subjects. Each of those seventeen subjects was asked a "yes or no" question and instructed to respond by using motor imagery for one of the two possible responses and spatial imagery for the other possible response.[87] As with the communication task, in five of six questions, the VS subject's fMRI revealed activity in one area for all the "yes" answers and another area for all the "no" answers.[88] The results of the fMRI regarding the remaining question were inconclusive.[89]

EEG has been used in the same way. In one study conducted in 2010 and 2011, Cruse et al. tested sixteen subjects in VS using right-hand imagery and toe imagery to detect "command-following a universally accepted clinical indicator of awareness."[90] Electrodes on the scalp (electrode caps) were used to take EEGs of the subjects' brain activity to reveal neuron activity levels, which changed when the brain performed each task. Three, or nineteen percent, of the sixteen subjects "were found to be aware and capable of substantially and consistently modulating their EEG responses to command."[91] Although they could not consistently *behaviorally* respond to commands, EEG recordings demonstrated that their *brains* were responding accurately to those commands.[92]

These fMRI and EEG studies join others that have used testing methods as diverse as eyeblinks and positron-emission tomography ("PET") scans. Some reports, for example, indicate that subjects in VS and MCS can learn "to associate [a] sound stimulus with [a] subsequent air puff, as measured by a conditioned eyeblink response to the sound alone."[93] And between 2008 and 2012, Belgian researchers detected brain activity consistent with MCS in thirty-two percent of the VS[94] patients in a study using PET to scan the brains of 126 subjects in that

87. *Id.* at 581.
88. *Id.* at 585.
89. *Id.*
90. Cruse, *supra* note 73, at 2088. The right-hand imagery instructions were "Every time you hear a beep, try to imagine that you are squeezing your right-hand into a fist and then relaxing it . . . . Concentrate on the way your muscles would feel if you were really performing this movement. Try to do this as soon as you hear each beep." *Id.* at 2089. The toe imagery instructions were the same except that the first sentence read: "Every time you hear a beep, try to imagine that you are . . . wiggling all of the toes on both your feet, and then relaxing them." *Id.*
91. *Id.* at 2091.
92. *Id.* at 2093.
93. Johnson, *supra* note 71, at 188.
94. Johan Stender et al., *Diagnostic Precision of PET Imaging and Functional MRI in Disorders of Consciousness: A Clinical Validation Study*, 384 THE LANCET 514, 519 (2014) (referred to in that article as "unresponsive wakefulness syndrome."); *see also* Steven Laureys et al., *Unresponsive Wakefulness Syndrome: A New Name for the Vegetative State or Apallic Syndrome*, 8 BIOMED CENT. MED 68, 68 (2010) (proposing unresponsive wakefulness syndrome as "a new name . . . for an over 35-year-old syndrome with an unintended albeit persistent negative connotation: the vegetative state.").

condition, MCS, and another disorder of consciousness known as locked-in syndrome.[95]

Such research is undeniably important and promising. It could indicate that fMRI should be used along with the current, behavioral method of diagnosing VS. Bernat notes with regard to fMRI that "if these findings can be confirmed in future studies with more . . . patients, fMRI may become clinically useful as an adjunctive test to determine if a VS patient actually has awareness and therefore should be diagnosed as MCS."[96] Owen et al. have opined that the "cooperation" demonstrated by the first patient they studied "confirmed beyond any doubt that she was consciously aware of herself and her surroundings."[97] A year later, they suggested that fMRI "should be more widely used in the assessment of patients with disorders of consciousness and particularly in those for whom existing clinical approaches have left some ambiguity about the diagnosis."[98] Monti et al. concluded: "In patients without a behavioral response, it is clear that [f]MRI complements existing diagnostic tools by providing a method for detecting covert signs of residual cognitive function and awareness."[99]

In addition, perhaps fMRI or another technique eventually will provide a way of communicating with patients with whom we cannot currently communicate. As Monti et al. stated:

> In the future, this approach could be used to address important clinical questions. For example, patients could be asked if they are feeling any pain, and this information could be useful in determining analgesic agents should be administered. With further development, this technique could be used by some patients to express their thoughts, control their environment, and increase their quality of life.[100]

More broadly, some could read the research results to cast doubt on VS diagnoses. Cruse et al. conclude that Owen's and Monti's "findings confirm that a population of patients exists who meet all the behavioural criteria for the vegetative state, but nevertheless retain a level of covert awareness that cannot be detected by thorough behavioural assessment."[101] Cruse et al. describe the results of their own EEG work as being significant because "successful completion of these EEG tasks represents a substantial cognitive feat, not only for patients who were presumed to be vegetative, but also for control

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95. *Id.*
96. Bernat, *supra* note 6, at 388.
97. Owen et al., *Detecting Awareness in the Vegetative State*, *supra* note 74, at 1402; *see also* Monti et al., supra note 83, at 585 (describing that study as showing that "in a minority of cases, patients who meet the behavioral criteria for a vegetative state have residual cognitive function and even conscious awareness").
98. Owen et al., *Using Functional Magnetic Resonance Imaging*, *supra* note 78, at 1101.
99. Monti et al., *supra* note 83, at 588.
100. *Id.* at 588–589.
101. Cruse et al., *supra* note 73, at 2088.

participants."[102] "Taken together," Bentdsen opines, "these . . . studies [both fMRI and EEG] suggest that, despite appearing vegetative and unresponsive, certain patients have preserved some awareness."[103] And Vogel et al. says that their study "confirms the assumption that patients with [disorders of consciousness] who show significant activation have to at least be classified as minimally conscious."[104]

III. MEDICAL, LEGAL, AND BIOETHICAL IMPLICATIONS OF THESE NEUROSCIENTIFIC FINDINGS

Scientists and other experts universally urge caution regarding the results of the studies recounted here. Although no one questions the accuracy of the reports of these studies, many scientists, including the researchers conducting them, point to study limitations to demonstrate that much more work needs to be done before clinicians may rely on them.[105] Legal scholars considering the utility of these findings as evidence in courtrooms or as bases for public policy development also have urged that it is not yet time to accept the findings for those purposes.[106] Bioethics experts, combining this data with philosophical notions of consciousness, remind us that even if these findings are valid and reliable, they may not counsel changes in law or public policy.[107] All in all, while fMRI, EEG, and other studies may be paving the way for exciting developments, they do not provide solid enough evidence for medicine or law to act upon their results at this time.

One problem, for example, is occurrence of false positives, through either mistake or misinterpretation, or both. Neuroscientist Craig Bennett has spectacularly and convincingly demonstrated the risk of false positives by scanning a dead salmon with fMRI.[108] He asked the dead salmon to use mental imagery, by displaying photographs of human beings in social settings and asking it what emotion the person in each photo must have been experiencing.[109] Areas of the salmon's brain

102. *Id.* at 2092.
103. Bendtsen, *supra* note 71, at 48.
104. Vogel et al., *supra* note 79, at 1897.
105. *See supra* Part I.A.2.
106. *See infra* Part III.
107. *See id.*
108. Craig M. Bennett et al., Bennett-Salmon 2009 Poster, *Neural Correlates of Interspecies Perspective Taking in the Post-mortem Atlantic Salmon: An Argument for Multiple Comparisons Correction*, http://prefrontal.org/files/posters/Bennett-Salmon-2009.pdf [https://perma.cc/7QVV-AWGU]; Craig M. Bennett et al., *The Principled Control of False Positives in Neuroimaging*, 4 SCAN 417, 418 (2009) (proposing an approach to limit false positives in neuroimaging).
109. *See* Alex Madrigal, *Scanning Dead Salmon in FMRI Machine Highlights Risk of Red Herring*, WIRED (Sept. 18, 2009 5:37 PM), http://www.wired.com/2009/09/fmrisalmon/ [https://perma.cc/LG43-J5L4] (quoting Bennett as saying "And if I were a ridiculous researcher, I'd say, 'A dead salmon perceiving humans can tell their emotional state.' ").

lit up, which could be read as indicating that the salmon was thinking, if a researcher were not careful about checking false positives. Bennett conducted his study and presented a poster about it to demonstrate the need for scientists to appropriately control for false positives when conducting such research.[110] Other researchers have similarly argued that fMRI research should incorporate "a greater focus on replication and meta-analysis rather than emphasizing single studies as the unit of analysis for establishing scientific truth."[111] That was in 2009, but even in 2015, all three of the most widely used software packages for fMRI data analysis have been shown to produce extremely unreliable results.[112]

Second, these were small studies with technological limitations. Cruse studied only sixteen subjects.[113] In Monti's study, the positive results were associated with only four of twenty-three VS subjects.[114] Although concluding that "[b]ased on these preliminary data, [fMRI] shows promise for identifying patients with high potential for recovery from a VS,"[115] Vogel et al. themselves point to their "very small sample size" (ten VS subjects) as a limitation.[116] Owen et al. repeated their study, but each study was on only one patient.[117] To date, large-scale studies that might be more reliable are still missing.[118]

Third, there is misuse of—and confusion surrounding—terminology that may cloud the meaning of these studies when reported in the popular media or otherwise discussed among laypersons. In many, at least some of the subjects were in MCS[119] or, if in VS, subjects were in that state due to TBI rather than hypoxic-ischemic brain injury,[120] even though great differences exist between those two sub-populations of VS patients. Cruse's single patient was in VS due to TBI. All four of the twenty-three patients in the Monti et al. study had TBI, and two of those, upon clinical re-examination, were shown to exhibit some behavioral signs of consciousness.[121] Behavioral signs of

110. *Id.*

111. Matthew D. Lieberman & William A. Cunningham, *Type I and Type II Error Concerns in fMRI Research: Re-Balancing the Scale*, 4 SCAN 423, 423 (2009).

112. Anders Eklund et al., *Empirically Investigating the Statistical Validity of SPM, FSL and AFNI for Single Subject fMRI Analysis*, 2015 INST. OF BIOMEDICAL ENG'G 1376, 1379, https://dl.dropboxusercontent.com/u/4494604/article.pdf, [https://perma.cc/HEU8-YMJ3].

113. *See* Cruse et al., *supra* note 73, at 2088.

114. *See* Monti et al., *supra* note 83, at 583, 585.

115. Vogel, *supra* note 79, at 1897.

116. *Id.* at 1897.

117. *See* Owen et al., *Detecting Awareness in the Vegetative State*, *supra* note 74, at 1099.

118. *Cf.* David et al., *Potential Reporting Bias in fMRI Studies of the Brain*, 8 PLOS ONE e70104, 1 (July 2013) (examining whole-brain fMRI studies).

119. *See, e.g.*, Laureys et al., *supra* note 94, at 68; Stender et al., *supra* note 94, at 514.

120. *See, e.g.*, Cruse et al., *supra* note 73, at 2088; Monti et al., *supra* note 83, at 582; Owen et al., *Detecting Awareness in the Vegetative State*, *supra* note 74, at 1402.

121. Monti et al., *supra* note 83, at 585, 588.

consciousness indicate that those two patients either originally were misdiagnosed, or they had improved to MCS before the study and had not been behaviorally examined since their earlier labeling as being in VS.

Even Owen et al. themselves have explained that their results would not be generalizable to all patients in VS. The patient in their 2005 to 2006 study was in VS due to TBI, and had only been diagnosed as being in VS for five months. As noted above, patients in VS due to TBI have a much better prognosis than do those in VS due to non-traumatic brain injuries.[122] Prognosis deteriorates after twelve months of VS after a TBI; only at that point should a patient be diagnosed as being in a "permanent" vegetative state.[123] In other words, the patient Owen et al. studied was still in the period during which a VS after TBI would not yet be considered permanent.

Nor is the evidence these studies have produced very reliable when examined through legal lenses designed to measure reliability. Carl Fisher and Paul Appelbaum have expressed uncertainty that neuroimaging data could satisfy either of the two alternative tests used to determine admissibility in a courtroom. They have warned that "courts must be mindful of [neuroimaging results'] sometimes unwarranted persuasive power and of the possibility that the colorful results of the fMRI may be introduced more for their emotional impact than for their probative value."[124] Although noting that many neuroscience researchers "caution readers against inappropriate or too eager interpretations and applications," Stacey Tovino has written of the exaggeration accompanying reports about that research in the popular media.[125] That hype provides extra support for the need to counsel patients and families about "the shortcomings of the neuroscience." Yet another legal scholar emphasizes that "[t]he data are preliminary and families need transparency about the limits of diagnosing or prognosticating on the basis of brain scans alone."[126]

Finally, there are the more existential questions of whether a diagnosis of MCS rather than VS matters, and, if it does, to what extent. Perhaps VS does not mean exactly what earlier legislatures and courts thought it did when enacting advance directive statutes and issuing judicial opinions regarding end-of-life decisionmaking. Nevertheless, the prognosis for a patient in either VS or MCS remains poor. In fact,

122. Owen et al., *Using Functional Magnetic Resonance Imaging*, *supra* note 78, at 1101.

123. *Id.* at 1101. The relevant time period for diagnosis of a patient with a non-traumatic brain injury (one caused by anoxia) as being in a permanent vegetative as opposed to persistent vegetative state is six months. See *supra* note 60.

124. Fisher & Appelbaum, *supra* note 31, at 381–82.

125. Tovino, *supra* note 31, at 439.

126. Harrington, *supra* note 31, at 237.

the potential for recovery when a patient is in a permanent VS is "vanishingly small—in general, the longer the duration of the VS, the less likely is any recovery at all."[127] When recovery occurs, the vast majority of VS patients achieve MCS at most.[128] Speaking of the eyeblink study discussed above, Johnson has cautioned:

> It is important not to read too much into findings of higher cortical functioning or possible awareness in a limited number of VS patients. The popular press has seized upon [that study] and proclaimed that vegetative patients are conscious and can learn .... Such proclamations are likely to lead to greater confusion and controversy among caregivers and families of VS patients.[129]

Johnson prefers to view that study as showing that some MCS patients who are "behaviorally ambiguous" have not been adequately diagnosed or may have been in VS and evolved into MCS since earlier diagnoses.[130]

Indeed, fMRI and EEG research certainly do not disprove the conclusion that the patient is still incapacitated.[131]

> Examining ... patients with prudence using new technologies may allow us to infer awareness and response, but we must also accept the current limitations to our knowledge about brain function and brain injury, and refrain from conclusively stating that these patients have cognitive abilities that we are not certain are present.[132]

Such functioning may or may not constitute a tolerable level of "consciousness" for any individual patient.

IV. THE SIGNIFICANT LEGAL LINE BETWEEN VS AND MCS WITH RESPECT TO END-OF-LIFE DECISIONMAKING

While individual patients may have strong feelings that they would not want to exist in MCS any more than they would want to exist in VS, the law treats the former patient (in MCS) much differently than the latter patient (in VS). Both individuals have the right to have others refuse medical treatments or procedures that they do not wish to undergo. The law, however, treats the two categories of individuals very differently when questions arise about *when* others may exercise that right on a patient's behalf.

It is practically axiomatic in end-of-life decisionmaking law that patients who are receiving life-sustaining treatment may refuse that treatment. This is true of patients with decisionmaking capacity in a

127. Johnson, *supra* note 71, at 190.
128. *E.g.*, Vogel, *supra* note 79, at 1896.
129. Johnson, supra note 71, at 189.
130. *Id.*
131. Bendtsen, *supra* note 71, at 48.
132. *Id.* at 50.

wide variety of medical conditions, permitting practically any such patient to refuse any life-sustaining treatment.[133] As the leading treatise on end-of-life decisionmaking law explains, "A small but gradually increasing number of courts are in effect taking the position that the right of a competent patient to refuse medical treatment is virtually absolute."[134] Underlying that ability to refuse treatment are common-law rights of self-determination and autonomy[135] and constitutional liberty interests and privacy rights.[136] Medically supplied nutrition and hydration constitutes life-sustaining medical treatment due to its technological character and the intrusive nature of its provision through either surgical implantation or nasal-gastric threading of tubes into the body.[137]

Because a patient in VS or MCS does not have decisionmaking capacity, he or she cannot refuse treatment him or herself. Others must refuse for that patient, and those others might be either previously designated by the patient to accomplish that task or chosen by operation of law at the time for decision(s).[138] In most states, patients can authorize others to act on their behalf by executing advance directives in one of three forms.[139] A patient may either name his or her chosen decisionmaker but remain silent or nearly silent about his or her wishes, describe his or her wishes in an instruction directive such as a living will, or execute a document that combines those functions.[140] Choice of a decisionmaker by operation of law will occur through either a guardianship proceeding or application of a statute listing, in order, various categories of individuals who can speak on behalf of incapacitated patients.[141]

The ability to refuse life-sustaining medical treatment on behalf of another human being is an awesome power. Because of the importance of being able to make a decision that will end someone else's life, the state has more ability to regulate that decisionmaking process than it has to regulate a patient's own decisionmaking for himself or herself. In the latter case, the state has scant power to interfere with what a patient wishes to do to his or her own body, save acting in furtherance of certain

133. MEISEL, CERMINARA & POPE, *supra* note 18, § 2.04 at 2-13 to 2-16.
134. *Id.* § 2.04 at 2-15.
135. *Id.* § 2.06 at 2-22.
136. *Id.* § 2.06 at 2-27 to 2-34. Those rights emanate from both the federal and state constitutions. *Id.* at 2-31 to 2-33. In *Cruzan,* Supreme Court said it would "assume" the existence of a federal constitutional right to refuse, and then, in *Glucksberg*, it said that the Court in *Cruzan* had "strongly assumed" that right existed (and also assumed it existed). *Compare* Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 279 (1990), *with* Washington v. Glucksberg, 521 U.S. 702, 720 (1997).
137. *Cruzan*, 497 U.S. at 276.
138. MEISEL, CERMINARA & POPE , *supra* note 18, ch.7–8.
139. *Id.* at ch. 7.
140. *Id.*
141. *Id.* at ch. 8.

state interests such as—to name one—the interest in prevention of suicide.[142] In the former case, however, states have taken it upon themselves to ensure, in the name of state interests, that others may refuse life-sustaining treatment only on behalf of certain categories of patients[143] and/or under certain circumstances.[144] Such limitations may or may not be constitutional, but they are myriad.[145]

One of the common limitations in advance directive statutes is that they purportedly apply only once a patient has been diagnosed as being in one or more of certain listed physical conditions, e.g., in a "persistent vegetative state" or a "terminal condition."[146] Strictly construing a statute containing these limitations would result in a conclusion that the designated decisionmaker could not refuse life-sustaining treatment on behalf of a patient in another condition, no matter how dire the prognosis. For example, in 1999, a statewide panel on end-of-life decisionmaking in Florida heard public testimony convincing a majority of the panelists that it should eliminate the state's statutory requirement that a patient have a "terminal condition" before refusal of life-sustaining treatment, for this very reason.[147] After the panel proposed elimination of the requirement, the legislature amended the statue to expand application of advance directives to incapacitated patients in "end-stage conditions" and "persistent vegetative states" in addition to "terminal conditions."[148]

These triggering conditions represent the first way in which end-of-life decisionmaking law about VS patients differs from the legal standards that pertain to MCS patients. Though many, if not all, state advance directive statutes specify some version of VS as a triggering condition,[149] not one lists patients in MCS within the categories of those on whose behalf a proxy or surrogate decisionmaker may refuse life-

142. Washington v. Glucksberg, 521 U.S. 702, 730 (1997).

143. *E.g.*, MEISEL, CERMINARA & POPE, *supra* note 18, § 7.06 at 7-83 to 7-89.

144. *Id.*at § 7.06 at 7-91 to 7-93.

145. *Id.* at § 6.03[G] at 6-82.2 to 6.82.6. On (un)constitutionality, see Lozada Tirado v. Testigos Jehova, 2010 TSPR 9 (P.R. Jan. 27, 2010) (declaring unconstitutional under the Puerto Rican Constitution advance directive statutory triggering conditions of diagnosis of terminal illness or persistent vegetative state).

146. *See, e.g.,* Fla. Stat. § 765.302(1) (2015) (providing for a living will to instruct a person making decisions on behalf of an incapacitated patient "in the event that such person has a terminal condition, has an end-stage condition, or is in a persistent vegetative state.").

147. *See* PANEL FOR THE STUDY OF END-OF-LIFE CARE, FINAL REPORT-AUGUST 1, 1999, A120 (1999) (quoting panel member Ken Rubin as advocating "removing the 'terminal' requirement . . . much of the public testimony that the Panel has heard has pointed out that it is hard to get physicians to agree on a terminal diagnosis; . . . it is an obstacle to people having their wishes met . . . ."); *see also id.* at A121 (quoting panel member Mary Labyak as saying that the terminal illness requirement was "a wall that exists and inhibits care from physicians, health-care groups, etc. . . . the perception that is out there is that you need to be on the brink of death for any help to be given").

148. 1999 Fla. Laws, ch. 99-331, § 25.

149. *See* Fisher & Appelbaum, *supra* note 31, at 377–78.

sustaining treatment.[150] Assuming that such triggering conditions are constitutional,[151] and that clinicians and courts strictly construe those statutes,[152] then advance directives are of no use to those in MCS who executed them. Until those declarants are diagnosed as having one of the triggering conditions set forth in their state statutes, others will be unable to refuse life-sustaining treatment on their behalf based on those statutes.

Moreover, even if someone has the power to refuse life-sustaining treatment on behalf of a patient in MCS, the courts have been more protective of those patients than they have been of patients in VS with respect to deciding what those patients would have wanted. Very few reported cases have involved patients in MCS, but the courts in those cases have imposed more demanding burdens on the surrogate decisionmakers attempting to demonstrate that the patients would have wanted to refuse treatment.[153] Almost all jurisdictions require proof by clear and convincing evidence as a procedural matter,[154] but there are substantial differences in what they substantively require to be proven in VS as opposed to MCS cases. In VS matters, courts generally will permit surrogates to authorize withholding or withdrawal of life-sustaining treatment based on clear and convincing evidence that the patient would have wanted to refuse it; the type of proof that satisfies this burden usually consists of testimony about what the patient said in the past, even very generally, about such matters, as well as the patient's values, attitudes, and belief system.[155] For example, the testimony supporting withdrawal in the *Schiavo* case included statements Ms. Schiavo had made when young supporting withdrawal of ventilator support from Karen Ann Quinlan and statements she made to her husband, his brother, and his brother's wife supporting rejection of life support when "hooked to a machine."[156]

In contrast, in MCS cases, the courts have required more particular evidence about patient wishes; "any decision about . . . life-sustaining treatment must be based on instructions the patient actually gave before

150. MEISEL, CERMINARA & POPE, *supra* note 18, § 7.06[A] at 7-83 to 7-89; *see also* LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 30. (Univ. of N.C. Press 2009).

151. *See supra* note 145 and accompanying text.

152. Strict construction would not be appropriate if there is a question of constitutionality because of the maxim of statutory construction prompting courts to construe statutes in ways that avoid constitutional questions (in other words, to decide constitutional questions only when they absolutely must be decided). *See* Rescue Army v. Mun. Court of City of Los Angeles, 331 U.S. 549, 568–69 (1947); *see also In re* Wendland, 28 P.3d 151, 166 (Cal. 2001), *reh'g denied* (Sep. 26, 2001).

153. *See In re* Martin, 538 N.W.2d 399, 408 (Mich. 1995); *In re* Wendland, 28 P.3d at 175.

154. MEISEL, CERMINARA & POPE, *supra* note 18, § 3.27[A] at 3-126, 3-131.

155. *Id.* § 3.24[C] at 3-97.

156. *In re* Guardianship of Schiavo, No. 90-2908GD-003, 2000 WL 34546715, at *3–4 (Fla. Cir. Ct. Feb. 11, 2000) *aff'd*, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001).

losing decisionmaking capacity."[157] For example, in perhaps the most famous case involving a patient in MCS, *In re Wendland*,[158] the wife, children, and brother of Robert Wendland, who was in MCS after a truck accident, all joined in refusing consent to surgery to replace the tube through which he received nutrients and fluids after he had dislodged it three times.[159] They recounted pre-accident statements he had made when his father-in-law had been near death, such as "I would never want to live like that [on a respirator], and I wouldn't want my children to see me like that . . . ."[160] Speaking about the possibility that his drinking could lead to a "terrible accident" and result in his being "just like a vegetable," Mr. Wendland said, "don't let that happen. Don't let them do that to me."[161] He also said, "Just let me go. Leave me alone."[162] In addition, his daughter recalled him saying "if he could not be a provider for his family, if he could not do all the things that he enjoyed doing, just enjoying the outdoors, just basic things, feeding himself, talking, communicating, if he could not do those things, he would not want to live."[163] Rather than using the testimony to illuminate the character and values of Mr. Wendland, and determining whether he would want to refuse the re-insertion of the tube if he were in an MCS, the court ruled that the testimony was insufficient to support withdrawal because it was not "an exact 'on all-fours' description of [his] present medical condition. More explicit direction . . . is required in order to justify a surrogate decision-maker terminating the life of . . . someone who is not in a PVS."[164] Because he had made those statements in contexts in which the conversation had revolved about living like a "vegetable," they were not precise enough to indicate that he would have refused treatment in an MCS. As illustrated by the facts of *Schiavo* just described, the courts ordinarily do not require such precision when deciding cases involving patients in PVS.[165]

In sum, whether a patient is in VS or MCS matters a great deal—

157. *In re* Wendland, 28 P.3d at 171–172; MEISEL, CERMINARA & POPE, *supra* note 18, § 4.05[A] at 4-28.1 to 4.29 (emphasis omitted).
158. 28 P.3d 151 (Cal. 2001), *reh'g denied* (Sep. 26, 2001).
159. *In re Wendland*, 28 P.3d at 155.
160. *Id.* at 157.
161. *Id.*
162. *Id.*
163. *Id.* at 157; *In re* Wendland, 28 P.3d 151, 157 (Cal. 2001), *reh'g denied* (Sep. 26, 2001).
164. *Id.* at 173 (quoting and agreeing with the trial court).
165. *See* MEISEL, CERMINARA & POPE, *supra* note 18, § 4.08[B] at 4-83 to 4-84.
The *Wendland* court itself emphasized the limits of its holding:
> [O]ur decision today affects only a narrow class of persons: conscious conservatees who have not left formal directions for health care and whose conservators propose to withhold life-sustaining treatment for the purpose of causing their conservatees' deaths. *Our conclusion does not affect permanently unconscious patients, including those who are comatose or in a persistent vegetative state.*

In re Wendland, 28 P.3d at 175 (emphasis added).

perhaps more than it should. Surrogates acting on behalf of patients in VS will have an easier time effectuating those patients' wishes to withhold or withdraw life-sustaining treatment than will surrogates acting on behalf of patients in MCS. Unless and until the relevant legal standards are changed or determined to be unconstitutional,[166] patients must be extremely concrete and specific in leaving advance directive instructions if they wish to exercise their rights to refuse life-sustaining treatment in MCS, and it is exceedingly difficult to be concrete or specific enough.

Underlying this distinction in the law are long-standing beliefs about the "facts" of patients' conditions when in VS. Courts often have focused on VS patients as having no awareness.[167] They have ruled that the best interests decisionmaking standard does not apply to patients in VS because unaware patients have no interests.[168] They have ruled that pain is not at issue in cases involving withholding or withdrawal of life-sustaining treatment from patients because unaware patients do not feel pain.[169] The courts have never had to determine whether withholding or withdrawal of medically supplied nutrition and hydration causes discomfort—physicians disagree on that point—because the evidence they had before them indicated that a VS patient would not be able to feel that discomfort even if it were present.[170] If, however, patients in VS retain some awareness, this reasoning should be re-thought.

Re-thinking these rationales does not mean that the law should require that life-sustaining treatment continue when a patient is in VS, even if neuroscience establishes that patients in VS retain more awareness than courts and legislatures now believe they retain. Indeed, there are good reasons to believe that some patients would reject the idea of continuing to be treated when in MCS so limited that they cannot interact with their families or friends. If VS patients actually are aware to some extent, at some level, they might find their continued

166. Justice O'Connor has indicated that applying a substantive standard for decisionmaking that requires such precision when the patient in question had self-designated his or her surrogate decisionmaker could violate the constitution. *See* Cruzan v. Dir., Mo Dep't of Health, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring) (emphasizing that the Court had not considered such facts, and in that type of case, "a duty [to honor the surrogate's decision to refuse treatment] may well be constitutionally required to protect the patient's liberty interest in refusing medical treatment").

167. *E.g.*, Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 310 n.9 (1990) (Brennan, J., dissenting); *In re* Quinlan, 355 A.2d 647, 654 (N.J. 1976); *In re* Jobes, 529 A.2d 434, 438 (N.J. 1987); SHEPHERD, *supra* note 28, at 20. That indeed was the conclusion of the MultiSociety Task Force and commentators. THE MULTI-SOCIETY TASK FORCE ON PVS, *supra* note 28, at 1500.

168. *See In re* Jobes, 529 A.2d at 451, 457–58; Estate of Longeway v. Community Convalescent Ctr., 549 N.E.2d 292, 299 (Ill. 1989). *See generally* Johnson, *supra* note 71, at 191 (describing VS patients as being "generally considered to lack all occurrent interests, including interests in continued existence, such that it cannot be in their interests to provide life-sustaining treatment").

169. *Estate of Longeway*, 549 N.E.2d at 295; *In re* L.W., 482 N.W.2d 60, 67, 73 n.17 (Wis. 1992); Morrison v. Abramovice, 253 Cal. Rptr. 530, 531 (Ct. App. 1988).

170. *See Estate of Longeway*, 549 N.E.2d at 295.

existence "undignified and inhumane"[171] or "unacceptably burdensome and inconsistent with the values they held prior to injury."[172] Such patients may wish to refuse life-sustaining treatment out of a "desire not to suffer" because "continued suffering without any means to express oneself might be a fate worse than death."[173]

Ultimately, it does not matter whether a patient's diagnosis is VS or another condition. Ultimately, what matters are the values underlying the decision of whether to withhold or withdraw treatment. As fMRI, EEG, and other research findings reveal more about VS, questions will arise about not only the scientific "facts" but also the legal rulings based upon those scientific "facts."

V. THE INTERSECTION, A TYPOLOGY, AND CULTURAL COGNITION

It is clear then that important and controversial legal and policy questions will arise at the point at which recent brain imaging studies take on statistical and bioethical significance. Even before that, given the volatile nature of the subject matter, some people will seize upon these findings to support assertions of their opinions as facts. It is almost inevitable that those scientific findings will trigger vehement protests that a patient diagnosed as being in VS is actually in MCS. If nothing else, consider the simple probability of that occurring when this exciting research is publicized and tens of thousands of patients lie in VS across the country. Disorders of consciousness are complex and difficult to comprehend and accept in the first place. As observed earlier, they often propel intractable disputes, as those who handle futility issues in clinical settings or study the law and ethics governing the provision of futile treatment can attest. Without doubt, indications that the line between VS and MCS is blurrier than the law previously has acknowledged will open the door for emotional disputes.

Not everyone raising questions, whether in individual cases or as a policy matter, will be operating from the same perspective, and not everyone will have the same goal with respect to changes in the law. On one hand, a skeptic may use brain imagery studies to protest an individual instance of withholding or withdrawal of life-sustaining treatment because VS is not what we thought it was. On the other hand, a skeptic may rely on those studies to argue for broad-based changes in law and policy, including revision of advance directive statute triggering

171. NANCY BERLINGER ET. AL., THE HASTINGS CENTER GUIDELINES FOR DECISIONS ON LIFE-SUSTAINING TREATMENT AND CARE NEAR THE END OF LIFE 4 (2d ed. 2013); Johnson, *supra* note 71, at 191.

172. Johnson, *supra* note 71, at 192.

173. Fisher & Applebaum, *supra* note 31, at 383 (emphasis omitted).

conditions or the decisionmaking standards that apply to VS patients. In both instances, until the data is reliable, those skeptics will be relying not on facts but on their perceptions of the risk that a patient diagnosed as being in VS is actually in another, more aware, state.

Knowledge being the first step toward understanding, preparing for the inevitable clash of viewpoints on this matter must commence with recognizing the participants. To that end, this Article will suggest a typology of skeptics who protest well-established, unquestioned scientific or medical matters, classifying them in terms of their positions with respect to the subject matter being discussed. By identifying and acknowledging personal factors that motivate the skeptics, this typology contextualizes their views of opinions (or value judgments) versus facts. Thereafter, on a macro level, this Article advocates adding cultural cognition to the end-of-life decisionmaking equation by illustrating how research based on cultural cognition theory—that is, research based on cultural worldviews rather than on personal connections to subject matter—might advance any such debate.

A. Typology of Skeptics

The following typology characterizes skeptics based on personal connection (or lack thereof) to the facts in any given medical-scientific matter being disputed. Skeptics in the first two of the four categories on the list below—a list meant to be illustrative rather than definitive—are likely to make appearances in personal, bedside disputes, while the latter two likely will operate mainly in the public policy arena.

1. Personal Stakeholder Disbelievers

The first category of skeptics is undoubtedly familiar to health care professionals worldwide. Indeed, skeptics in this category need not rely on groundbreaking research, although knowledge of the scientific advances discussed above almost certainly would fuel their skepticism. Personal feelings prompt their protests against VS diagnoses, just as they have prompted some protests against brain-death diagnoses.

When an eleven-year-old girl in California, Jahi McMath, suffered great blood loss during a tonsillectomy, for example, her family refused to accept multiple diagnoses of brain death. For very personal reasons, Jahi's family did not accept that she was brain dead.[174] Perhaps their inability to believe the diagnosis was due to shock and a subconscious desire that it would be inaccurate; perhaps it was due to ancient memories imbedded in their cultural psyche counseling distrust of the

174. Pope, LEGAL BRIEFING, *supra* note 49, at 250.

medical system; perhaps it was due to any number of factors, including religious faith, that would affect a family learning their child had died as a result of relatively common and not especially complex surgery. Hospitals regularly account for this type of shocked disbelief by waiting for (usually brief) periods of time before disconnecting ventilator support and other equipment maintaining the patient's physiological functions.[175] Such waiting periods are not unlike those that hospitals often also provide to families who are waiting for other family members to reach the bedside from out of town to say good-bye to patients in VS.

Usually, this type of up-close-and-personal disbelief comes to an end relatively quickly as counselors and others work with the family trying to cope with the news. The McMath case, however, was an exception, with the family asserting claims attempting to invalidate the state's brain death statute under federal constitutional and statutory law.[176] After settling that lawsuit, Jahi's family transferred her to a hospital in New Jersey, supported by the Terri Schiavo Life and Hope Network. Litigation continues in a later-filed medical malpractice lawsuit,[177] with Ms. McMath's family continuing to argue that she is alive.[178]

Ms. Schiavo's case provides another example. As the litigation was drawing to a close, her parents filed a motion with affidavits stating that Ms. Schiavo had "attempted to verbalize a sentence."[179] One of those affidavits said: "She managed to articulate the first two vowel sounds, first articulating 'AHHHHH' and then virtually screaming, 'WAAAAAAA.' She became very agitated but could not complete the vocalization attempted."[180] It is theoretically possible that such affidavits were signed in bad faith, as a last-ditch attempt to convince the court to re-insert the tube that would provide Ms. Schiavo with medically supplied nutrition, but that is unlikely. Affiants must be

175. *Id.* at 247.

176. *Id.* at 250.

177. *See* Complaint, Winkfield v. Rosen, No. RG15760730 (Cal. Super. Ct. Mar. 2, 2015).

178. *See* Notice of Demurrer and Demurrer to Complaint by Defendant, Winkfield v. Rosen, No. RG15760730 (Cal. Super. Ct. Jun. 19, 2015); DOLAN LAW FIRM, MCMATH HEARING POSTPONED TO PROVIDE ADDITIONAL MEDICAL EVIDENCE (2014), http://www.thaddeuspope.com/images/Dolan_Oct_8_pres_releasee.pdf [https://perma.cc/7B58-BAWB]; *see also* Craig Klugman, *The Bell Tolls for Death by Neurologic Criteria: Aden Hailu*, BIOETHICS TODAY (Dec. 2015) http://www.bioethics.net/2015/12/the-bell-tolls-for-death-by-neurologic-criteria-aden-hailu/ [https://perma.cc/WV6G-9JUP] (describing another such case in Nevada).

179. Emergency Motion for Injunction and Immediate Relief at 3, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003); Declaration of Barbara J. Weller at 2, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003); Declaration of Suzanne Vitadamo at 1, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003).

180. Emergency Motion for Injunction and Immediate Relief at 3, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003); Declaration of Barbara J. Weller at 2, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003); Declaration of Suzanne Vitadamo at 1, Schindler v. Schiavo, 900 So. 2d 554 (Fla. 2005) (No. 90-2908GD-003).

presumed to be telling the truth when they sign such documents under penalty of perjury, as those were. Rather than acting in bad faith, it is most likely that those present at the bedside could not accept Ms. Schiavo's VS diagnosis and saw a vision of her that supported their preconception.

Ms. Schiavo's medical records assist in shedding light on whether others would view their vision as being factual. A 2002 CT scan of her brain showed spinal fluid flooding her cortical regions,[181] and her autopsy in 2005 revealed "irreversible damage" and "massive loss of neurons." It revealed that her brain was "grossly abnormal," weighing only 615 grams as compared with Ms. Quinlan's brain, which weighed 835 grams after 15 years in a VS.[182] Although autopsies cannot prove or disprove a VS diagnosis, since it is a clinical diagnosis, this autopsy does indicate that it is highly unlikely, if not impossible, that Ms. Schiavo attempted to speak in her final days, as these affiants believed.

Stories like these prompt some people to react with derision, rejecting out of hand the disbelief of those too emotionally immersed in a situation to see facts that others see clearly—instead, seeing their own version of those facts. Hospitals and clinical personnel recognize that derision is not the appropriate response and often tread carefully, allowing family members and friends time to come to grips with the medical condition of a loved one. When disbelief continues beyond a brief period of time, however, disputes of the type with which this Article is concerned—Is she dead or not? Is she in a VS or not?—become incredibly difficult to handle.

2. Skeptics with a Cause

Both *Schiavo* and *Cruzan*, the famous case involving a young woman in a VS that preceded the *Schiavo* dispute, provide examples of skeptics with a cause. In both cases, protesters picketed the patients' medical facilities in the days just before their deaths. In both cases, they had come to the scene because of causes near and dear to them, not because they had personal familial or friendly connections with the patients. Most of the protesters around Ms. Cruzan's facility were motivated by their religious faith and what that faith had taught them about refusal of medically supplied nutrition and hydration.[183] The protesters around Ms. Schiavo's hospice also included others strongly

181. Cerminara & Goodman, *supra* note 4 (follow "CT Scans" hyperlink).
182. *Id.* (follow "Autopsy Report and Supporting Documents" hyperlink).
183. *See* WILLIAM H COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN 368069, 371–75 (1st ed. 2002).

committed to the rights of persons with disabilities.[184]

A newspaper columnist in Florida provided a vivid example in his portrait of a woman with disabilities protesting outside of Ms. Schiavo's hospice in the waning days of her life.[185] That protester was almost entirely immobile due to brain damage resulting from viral encephalitis, but she was moved to protest because she identified with Ms. Schiavo, as her sign revealed: "I am not a cabbage, an onion, now [sic] a cob of corn. I am a child of God, sister of Jesus, with purpose just like Terri. Just like you."[186] Perhaps she had been motivated by information distributed by Not Dead Yet, a disability rights advocacy group involved in *Schiavo*,[187] but perhaps she had been motivated only by her personal identification with the disability rights movement. The same is true of protesters of deep religious faith who also protested in *Schiavo*; they may have appeared to voice their opinions because of the leadership of Randall Terry, the activist head of the Society for Truth and Justice who both protested and lobbied heavily during *Schiavo*,[188] or they simply may have wished to express their views that withdrawing treatment in that case was equivalent to taking a life. Regardless of whether they were joining the protests for personal or big-picture reasons, they were joining because of their support of their causes.

Skeptics of this sort seek publicity for their causes at least as much, if not more, than they want the individual outcome of any one case to comport with their views. It is possible that some individuals in this cohort, especially those who are well-known, have ulterior motives for their actions, such as a desire for publicity, political ambitions and the like.[189] But others are not knowingly portraying fact as opinion or opinion as fact. They are simply acting in good faith, with a vision of the events at hand that differs from the vision most would have. These are the types of skeptics with whom many hospitals and clinicians do not even deal or attempt to deal, leaving them to their publicity efforts while medical personnel go about their professional tasks.

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184. *See* Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities That End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 LOY. U. CHI. L.J. 343, 364 (2006); ALICIA OUELLETTE, BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS 4, 280 (2011).

185. Cerminara, *supra* note 184, at 343.

186. Ralph De La Cruz, Commentary, *A Battle for the Right to Choose*, SUN SENTINEL (Mar. 29, 2005), http://articles.sun-sentinel.com/2005-03-29/lifestyle/0503280216_1_woodside-hospice-terri-schiavo-culture-war [https://perma.cc/8HJ9-MRKP].

187. *See* Cerminara, *supra* note 184, at 371–372.

188. *See id.* at 372–373.

189. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, *supra* note 20, at 294–95.

3. Principled Debaters

Both of the categories of skeptics identified thus far have been propelled by personal inner drives. They may be motivated by a wide variety of beliefs, but they all have some personal connection to the case at hand—either to the people involved or to a cause it represents. In contrast, other people who challenge widely-held, long-standing scientific-medical matters are working on a more principled level, attempting to update and improve medicine and law.

Medical professional standard-setting provides an example. Traditionally, of course, physicians have been held to a standard of care based on the profession's prevailing custom.[190] Yet increasing use of evidence-based medicine has revealed that those customs are not always valid.[191] As research progresses, sometimes researchers suspect that a long-standing treatment protocol—the one physicians customarily use—is actually ineffective in combatting the disease or condition for which it is prescribed. With enough validated research, evidence may show that the customary treatment is indeed ineffective. For example, the customary wisdom in medicine years ago was that patients with certain heart conditions could avoid death by reducing their cholesterol levels.[192] With time, however, researchers discovered that cholesterol is both beneficial and non-beneficial, so that, for example, dietary restrictions aimed at lowering cholesterol levels were misplaced.[193]

Those who advocate for the use of evidence-based medicine over customary practice in setting standards of care—those who believe that physicians should not simply tell people to watch their diets to avoid heart disease—might be thought of as principled debaters, at least at the time the evidence upon which they rely first appears. They focus on the future of medicine and, consequently, the future of the legal standard of care for medical professionals; the first among them may be termed the "early adopters" among the medical profession.

Owen, Monti, and the other neuroscientists discussed above may fall into this category someday. Currently, they caution that their research should not affect diagnoses, prognoses, or any other clinical medical matters.[194] Should future research affirm and refine these

190. *See* Sandra H. Johnson, *Customary Standard of Care: A Challenge for Regulation and Practice*, 43 HASTINGS CTR. REP. 9 (2013).

191. *Id.*

192. *See* Francie Diep, *Cholesterol Conundrum*, 305 SCIENTIFIC AMERICAN 32–33 (Nov. 1, 2011), http://www.scientificamerican.com/article/cholesterol-conundrum/ [https://perma.cc/3QD6-DJSV].

193. *See* Maria Luz Fernandez & Mariana Calle, *Revisiting Dietary Cholesterol Recommendations: Does the Evidence Support a Limit of 300 mg/d?*, 12 CURRENT ATHEROSCLEROSIS REP. 377 (2010).

194. *See generally* Monti et al., *supra* note 83, at 579; Owen et al., *Detecting Awareness in the Vegetative State*, *supra* note 74, at 1098.

results in large-scale studies, it may be that fMRI imagery will be used in addition to clinical, behavioral observation when physicians diagnose a disorder of consciousness. It may be that physicians could use imaging tools in a variety of ways in cases involving disorders of consciousness. For now, however, even these researchers themselves refuse to ascribe universal significance to their work, declining to disturb long-standing beliefs as to what a VS diagnosis means and how VS differs from MCS. They are not (yet) advocates of re-definition; they are advocates of increased knowledge.

Principled debaters are several steps further along the research path than this. Take, for example, the physicians and ethicists mentioned briefly earlier who protest that technology has overtaken the current understanding of brain death, ensconced in medicine and law since 1968.[195] Neurologist Alan Shewmon has described brain death as being "generally regarded as one of the few relatively settled issues of contemporary bioethics."[196] Yet, he argues that the widespread bioethical and medical agreement since 1968 that a person who is brain dead is dead is inaccurate. "Brain death" he says, "began as a utilitarian legislative decree and has remained a conclusion in search of a justification ever since: [A] conclusion clung to at all costs for the sake of the transplantation enterprise that quickly came to depend on it."[197] Indeed, "many individuals who meet diagnostic criteria for 'brain death' can continue to live and maintain integrated functions for varying periods of time, sometimes for months or even years."[198] Jahi McMath's attorney has written that she has begun her menstrual cycle despite her brain death diagnosis and despite having a death certificate in the state of California.[199] As one commentator has written, "the bodies of individuals determined dead by neurological criteria still do many of the things done by living organisms," including "heal[ing] wounds, fight[ing] infections, and mount[ing] a stress response to surgical incisions."[200]

Well-documented, reliable, scientific research findings like these provide a credible argument for questioning the long-established *fact* that a brain-dead person is dead—i.e., that the entire organism has

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195. *See supra* notes 39–40 and accompanying text.

196. D. Alan Shewmon, *The Brain and Somatic Integration: Insights Into the Standard Biological Rationale for Equating "Brain Death" With Death*, 26 J. MED. & PHIL. 457, 471 (2001).

197. D. Alan Shewmon, *Brain Death: Can It Be Resuscitated?*, 39 HASTINGS CTR REP., Mar.–Apr. 2009, at 18, 19.

198. Robert D. Troug & Franklin D. Miller, *Defining Death: The Importance of Scientific Candor and Transparency*, 40 INTENSIVE CARE MED. 885, 886 (2014).

199. *See* DOLAN LAW FIRM, MCMATH HEARING POSTPONED TO PROVIDE ADDITIONAL MEDICAL EVIDENCE 2 (2014), http://www.thaddeuspope.com/images/Dolan_Oct_8_pres_releasee.pdf. [PermaLink]

200. Pope, *Legal Briefing*, *supra* note 49, at 246.

failed, the same as if respiration and circulation had ceased.[201] Some alternatively might contend that the law should revert to authorizing declarations of death only according to cardiac-respiratory criteria, continue to permit declaration of death based upon brain death as a transparent legal fiction, or re-consider the dead-donor rule and permit now-acknowledged living donations from these patients.[202] The former would cause the supply of organs for transplantation to decrease significantly. Either of the latter two would acknowledge that the law's statement of when a physician may declare death is a matter of social consensus (i.e., society-wide opinion), as Ben Rich has suggested.[203] Recalling *Inside Out*, one might wonder whether death is a matter of fact or opinion, anyway.

Principled debaters are likely to be actively engaged in policy debates about whether to change the law regarding end-of-life decisionmaking on behalf of patients in VS or MCS. They are less likely to surface in the personal disputes around patients' bedsides unless they are hired to serve as experts to confer with or challenge treating teams.

4. Skeptics in Bad Faith

A final, rather dismaying use of science to challenge matters long believed to be fact is to use it in bad faith. Earlier, this Article acknowledged that bad faith sometimes could be in play when skeptics seize on recent research to doubt a VS diagnosis because of either personal beliefs or public causes. More shocking, and likely more harmful, is professional bad faith.

Doubt, skepticism, or pushback against matters of scientific fact may, sadly, be insincere and disingenuous. Perhaps the most famous examples have arisen in the tobacco industry. "In 1954, U.S. tobacco companies created the Tobacco Industry Research Committee, which was later renamed the Council for Tobacco Research-U.S.A., Inc. (CTR)."[204] Although CTR's purpose, for public consumption, was "to fund independent scientific research on the health effects of smoking" through peer-reviewed studies, "[s]pecial projects were funded based on the recommendations of tobacco industry lawyers . . . and were not peer-reviewed prior to funding."[205] Special projects were intended to

201. *See* Shewmon, *supra* note 196, at 458.
202. Truog, *supra* note 51, at 1904–1912 (identifying another option: "muddle through").
203. *See supra* note 38 and accompanying text.
204. Deborah E. Barnes & Lisa E. Bero, *Industry-Funded Research and Conflict of Interest: An Analysis of Research Sponsored by the Tobacco Industry through the Center for Indoor Air Research*, 21 J. HEALTH POL., POL'Y & L. 515, 517 (1996), http://senate.ucsf.edu/townhallmeeting/IndustryFundedResearch.pdf [https://perma.cc/J5WD-QQMV].
205. *Id.* at 517–18.

provide scientific data that lawyers could use "to defend tobacco companies against litigation" and develop relationships with scientists who would later testify on the industry's behalf.[206] The special projects often were designed to "divert attention [away] from tobacco as a cause of disease."[207]

Later, the tobacco industry used the same strategy to counteract scientific data produced by important studies in 1981[208] and 1986[209] regarding the health risks to non-smokers exposed to environmental tobacco smoke ("ETS", or "second-hand smoke"). In 1988, three U.S. tobacco companies formed the Center for Indoor Air Research ("CIAR") with the mission of "sponsor[ing] and foster[ing] quality, objective research in indoor air issues including environmental tobacco smoke, and to effectively communicate research findings to the broad scientific community."[210] CIAR purported to fund only peer-reviewed projects, but in fact it also funded some "special-review" projects.[211] CIAR described those special review projects as being "more goal-oriented," and did not require those projects to go through scientific peer-review.[212] Special review projects turned out to be more pro-industry than peer-reviewed projects; thirty-one percent of the special-reviewed projects were pro-industry while only two percent of the peer-reviewed ones were.[213] In addition, the special projects were overwhelmingly published in non-peer-reviewed or symposium journals, rather than peer-reviewed journals, although peer review constitutes a mark of quality in the scientific research world.[214] Researchers who have studied the CIAR, like Deborah A. Barnes and Lisa A. Bero from the University of California, San Francisco, have concluded that the tobacco industry "appears to be funding special-reviewed projects" through CIAR in order "to develop scientific data to" support its position that passive smoking is not a serious public health hazard.[215]

Developing scientific data to support one's own position would, of

206. *Id.* at 518.
207. *Id.*
208. *See generally* Lawrence Garfinkel, *Time Trends in Lung Cancer Mortality Among Nonsmokers and a Note on Passive Smokng*, 66 J. NAT'L CANCER INST. 1061 (1981); Takeshi Hirayama, *Non-Smoking Wives of Heavy Smokers Have a Higher Risk of Lung Cancer: A Study From Japan*, 282 BRIT. MED. J. 183 (1981); Dimitrios Trichopoulos et al., *Lung Cancer and Passive Smoking*, 27 INT'L J. CANCER 1 (1981).
209. *See generally* NAT'L ACAD. PRESS, ENVIRONMENTAL TOBACCO SMOKE, MEASURING EXPOSURES AND ASSESSING HEALTH EFFECTS (1986); U.S. DEP'T OF HEALTH & HUMAN SERVS., THE HEALTH CONSEQUENCES OF INVOLUNTARY SMOKING: A REPORT OF THE SURGEON GENERAL (1986).
210. See, Barnes & Bero, *supra* note 191, at 519.
211. *Id.* at 520.
212. *Id.*
213. *Id.* at 523.
214. *Id.* at 524.
215. *Id.* at 537.

course, be unobjectionable if it were done on a level playing field in a manner believed to produce the most authoritative, trustworthy evidence—peer review at the design and initial approval stage and then peer review again at the publication stage. When, however, the funding process is rigged precisely to fund research reaching certain conclusions, the data produced is neither authoritative nor trustworthy, and the funders' use of that data to oppose contrary studies is in bad faith.

This is more than simply discrediting data with which an actor disagrees. Here, the tobacco industry created data to counter the data it disliked, establishing processes for approval of studies that would confer the appearance of validity but in fact produce results highly likely, if not guaranteed, to benefit the tobacco industry. Because a multi-billion dollar industry was at stake, some may argue that only great monetary incentives would prompt such actions, but other instances of research fraud demonstrate money is not always involved at all.[216]

Fortunately, examples of this sort of bad faith appear to be few and far between. We must presume that the majority of research is conducted in good faith and in adherence to established scientific standards. Therefore, it seems as if most disputes would not involve these sorts of skeptics—or at least that's what society should hope.

B. Cultural Cognition Theory

The preceding typology, nascent though it may be, will assist those preparing to participate in a policy debate or a lawsuit about the import of recent neuroscientific research on long-held views of VS. Separating the participants into the common-sense categories suggested above will permit identification and understanding of some of what motivates these participants. In addition, policymakers and legal problem-solvers should bear in mind that what the disputants believe the facts to be will be a function of their perspectives on the world, just as much as, if not more, than a function of their perspectives on the particular dispute at hand. Cultural cognition theory enables us to examine the latter proposition.

Cultural cognition is "the psychological disposition of persons to

216. *E.g.*, Ivan Oransky, *Data "Were Destroyed Due to Privacy/Confidentiality Requirements" Says Co-Author of Retracted Gay Canvassing Study*, RETRACTION WATCH (May 29, 2015 9:59 P.M.), http://retractionwatch.com/2015/05/29/data-were-destroyed-due-to-privacyconfidentiality-requirements-says-co-author-of-retracted-gay-canvassing-study/ [https://perma.cc/J6ZU-MTY8]; Ivan Oransky, *Author Retracts Study of Changing Minds on Same-Sex Marriage After Colleague Admits Data Were Faked*, RETRACTION WATCH (May 20, 2015 7:09 A.M.), http://retractionwatch.com/2015/05/20/author-retracts-study-of-changing-minds-on-same-sex-marriage-after-colleague-admits-data-were-faked/ [https://perma.cc/AJ2T-3USG]; Alison McCook, *Science Retracts Troubled Gay Canvassing Study Against LaCour's Objections*, RETRACTION WATCH, (May 29, 2015 10:00 P.M.) http://retractionwatch.com/2015/05/28/science-retracts-troubled-gay-canvassing-study-against-lacours-objections/ [https://perma.cc/RL29-LU4R].

conform their factual beliefs about the instrumental efficacy (or perversity) of law to their cultural evaluations of the activities subject to regulation."[217] Studies of this phenomenon reveal that views of the facts—such as whether a patient's brain is or is not functioning, and to what degree if it is—are influenced, if not totally shaped, by the worldviews of those examining and judging the facts.

In their work on cultural cognition, Professors Kahan and Braman have studied "the epistemic origins of political conflict."[218] Noting that factual disagreements about policy choices abound, Kahan and Braman begin by acknowledging that the reason for such disagreement might seem self-evident. After all, even scientists do not agree about the facts of some complex matters such as pollution, firearm deaths, or drug-related public health statistics, and "even when expert consensus seems to emerge, it is based on highly technical forms of proof that most members of the public [cannot] realistically be expected to understand, much less verify for themselves."[219] In other words, it may seem that various portions of the public do not agree on the facts either "because conclusive information . . . [is] nonexistent" (e.g., scientists do not agree) or because it is "inaccessible to them" (e.g., the public cannot understand).[220]

To the contrary, however, Kahan and Braman conclude that "this explanation is as simplistic as it is intuitive."[221] Their work indicates that "cultural commitments are *prior* to factual beliefs on highly charged political issues."[222] This is so true that "what citizens believe about the empirical consequences of . . . policies *derives* from their cultural worldviews."[223]

"[O]ur argument," Kahan and Braman explain, "is that cultural commitments operate as a kind of heuristic in the rational processing of information on public policy matters."[224] Because people are in no position to determine the facts for themselves, "[t]hey have to take the word of those whom they trust . . . . The people they trust, naturally, are the ones who share their values—and who as a result of this same dynamic and others are predisposed to a particular view."[225]

Kahan and Braman have identified three psychological mechanisms making it likely that people will conform their beliefs about

217. Kahan & Braman, *supra* note 2, at 151–52.
218. *Id.* at 149.
219. *Id.*
220. *Id.*
221. *Id.*
222. *Id.* at 150 (emphasis added).
223. *Id.* (emphasis added).
224. *Id.* at 151.
225. *Id.*

activities to their cultural evaluations of those activities.[226] One is cognitive-dissonance avoidance.[227] "Cognitive-dissonance avoidance will steel individuals to resist empirical data that either threatens practices they revere or bolsters ones they despise, particularly when accepting such data would force them to disagree with individuals they respect."[228] Another is affect.[229] "Perceptions of how harmful activities are . . . informed by the visceral reactions those activities trigger. And whether those reactions are positive or negative is determined largely by cultural values."[230] The final one is in-group/out-group dynamics:

> When faced with conflicting claims and data, individuals usually [are not] in a position to determine for themselves how large particular risks—leukemia from contaminated groundwater, domestic attacks by terrorists, transmission of AIDS from casual contact with infected gay men—really are. Instead, they must rely on those whom they *trust* to tell them which risk claims are serious and which are specious. The people they trust, naturally enough, tend to be the ones who share their worldviews—and who for that reason are likely biased toward one conclusion or another by virtue of forces such as cognitive-dissonance avoidance and affect.[231]

Kahan and Braman used a group-grid characterization of worldviews along two anthropological dimensions—hierarchist versus egalitarian and individualist versus communitarian[232]—to survey thousands of people nationwide to determine where they fit along those dimensions and their factual beliefs about a variety of policy issues.[233] Which version of competing facts a person believes will shape his or her perception of the risk associated with the policy choices at hand.

Kahan and Braman's work regarding proposals to mandate the human papilloma virus ("HPV") vaccination of young women provides an effective example.[234] After pre-evaluation to determine where they fell on the group-grid scale, study subjects were divided into three groups.[235] Researchers asked the first, the "no argument" group, to

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226. *Id.* at 153.
227. *Id.* at 153.
228. *Id.* at 165.
229. *Id.* at 153. Biased assimilation, another psychological mechanism closely related to affect, "suggest[s] that people will . . . discount new information if it is inconsistent with their prior views." Paul M. Secunda, *Cultural Cognition at Work*, 38 FLA. ST. U. L. REV. 107, 116 (2010).
230. Kahan & Braman, *supra* note 2, at 155.
231. *Id.* at 155–56.
232. *Id.* at 150–51 (explaining that typology).
233. *Id.* at 156. Professors Kahan and Braman surveyed 1,800 people in 2004. *Id.; see also* Dan Kahan et al., *The Second National Risk and Culture Study: Making Sense—of and Progress—in the American Culture War of Fact*, Executive Summary (Yale Law Sch. Pub. Law & Legal Theory Research Paper Series, Paper No. 154, 2007), http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1017189 [https://perma.cc/F23C-CKK8] (reporting on surveys and experiments conducted on "some 5,000 Americans" between December 2006 and September 2007).
234. *See generally* Dan M. Kahan et al., *Who Fears the HPV Vaccine, Who Doesn't, and Why? An Experimental Study of the Mechanisms of Cultural Cognition*, 34 L. HUM. BEHAV. 501 (2010) [hereinafter *Who Fears the HPV Vaccine*].
235. *Id.* at 504–05.

provide their opinions on a series of questions about their perception of the risks of mandating HPV vaccination without receiving any information about the vaccine at all.[236] The second group, examining unattributed arguments, provided their opinions on that subject after they read two opposing factual paragraphs about the vaccine.[237] One of the paragraphs featured facts that supported mandating the vaccine; examples include the percentage of young women having sexual relations, the protection the vaccine offers, and the federal government's determination that the vaccine was safe.[238] The other paragraph's facts opposed a mandate, including facts such as the relatively low rate of cervical cancer among all cancer cases in the country, the number of types of HPV against which the vaccine did not protect, and a statement that even a vaccine that had been ruled safe could eventually prove to have side effects.[239] The third group read the same opposing factual paragraphs, but each paragraph additionally included a photo of a fictional expert source of the information, plus a list of titles of his or her fictional publications.[240] Researchers designed the titles to espouse beliefs attributable to various positions along the group-grid scale.[241]

The study revealed that being exposed to information raised the perception of risk overall.[242] In other words, the "unattributed argument" group expressed more concern about risks overall than the "no argument" group did. But the amount by which risk perception increased was a function of the positions along the group-grid scale with which the study participants identified.[243] Thus, hierarchical individualists were more concerned than egalitarian communitarians about the risks of mandating HPV vaccination, when all had read the same sets of facts.[244]

In addition, the results were amplified once the arguments were attributed to policy experts of various group-grid identities (or worldviews).[245] Study participants believed the facts that were presented by the "policy experts" matching their own worldviews.[246] The closer a participant's worldview matched that of the expert, the more likely he or she was to believe that expert's information and, thus,

236. *Id.* at 505.
237. *Id.*
238. *Id.* at 506
239. *Id.*
240. *Id.*
241. *Id.* at 505.
242. *Id.* at 508.
243. *Id.* at 510.
244. *Id.* at 511.
245. *Id.* at 507.
246. *Id.* at 508.

have a corresponding perception of the risk involved in a vaccination mandate. Kahan and Braman concluded that "polarization grows where culturally diverse subjects see the argument they are disposed to accept being made by the advocate whose values they share, and the argument they are predisposed to reject being made by the advocate whose values they repudiate."[247]

This research suggests that it would be valuable to use cultural cognition to study the effect of research revealing unexpected activity in the brains of some VS patients on citizens' perceptions of the risk involved in making certain end-of-life decisions. For example, persons protesting the withholding or withdrawal of medically supplied nutrition and hydration from a VS patient long have argued against the practice based upon beliefs that the patient would feel as if he or she were starving and dehydrating.[248] The long-standing view that patients in VS are unaware has rendered that argument unconvincing to virtually all courts[249] and a whole host of people who support withholding or withdrawal when a VS patient would have wanted it.[250] Framing that argument in terms of risk perception in accordance with cultural cognition theory results in the question being whether withholding or withdrawal presents enough of a risk of causing patients to feel as if they are starving or dehydrating to undermine respect for patient autonomy.

The well-established factual view of VS—that a patient in a VS experiences no awareness—would tend to support a conclusion that there is no such risk. Recent research findings may tend to support the opposite conclusion—that there is indeed a risk. Assuming science has reached no definite conclusion by the time of the next great debate about a patient in VS,[251] as is likely, advocates on either side should begin to consider incorporating principles of cultural cognition when arguing their points. Especially useful might be Kahan and Braman's conclusions—detailed above in the HPV vaccine study but consistently present in other work as well[252]—about the value of aligning spokespersons' cultural worldviews with those of their audiences for maximum communication potential.

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247. *Id.* at 511. They also concluded: "In contrast, when subjects see the argument they are disposed to reject being made by the advocate whose values they share, and the argument they are predisposed to accept being made by the advocate whose values they repudiate, polarization shrinks to the point of disappearing." *Id.*

248. MEISEL, CERMINARA & POPE, *supra* note 18, § 6.03[G] at 6-78.

249. *E.g.*, *In re* Tavel, 661 A.2d 1061, 1066 (Del. 1995).

250. MEISEL, CERMINARA & POPE, *supra* note 18, § 6.03[G] at 6–79.

251. *See supra* Part I.

252. *See, e.g.*, Dan M. Kahan et al., *Cultural Cognition and Public Policy: The Case of Outpatient Commitment Laws*, 34 L. HUM. BEHAV. 118 (2010); Donald Braman & Dan M. Kahan, *Overcoming the Fear of Guns, the Fear of Gun Control, and the Fear of Cultural Politics: Constructing a Better Gun Debate*, 55 EMORY L. J. 569 (2006).

Cultural cognition can work in conjunction with identification of skeptics in the varying classes identified previously. For example, both personal stakeholder disbelievers and skeptics with a cause have some connection with the dispute in which they are involved.[253] Whether asserted in the context of an individual case or as a matter of potential statutory and policy change, the opinions of people in both groups will be affected by their stakeholder status—in one case a personal stake, and in the other a stake in a cause. Although Kahan and Braman's work itself studied the general public rather than stakeholders, cultural cognition has been applied to stakeholders in disputes based on risk perceptions dependent on which version of the facts the participants believe.[254]

Moreover, it is likely that principled debaters will be among those serving as spokespeople for the positions asserted by the participants in whatever dispute arises next. Cultural cognition suggests that expert scientists have a great role to play in communicating facts underlying disputes to those who are making decisions about which side to believe. Having a principled debater whose cultural worldview matches that of the audience is an important part of assisting the audience in crediting the version of the facts that a policymaker believes to be true.[255]

VI. CONCLUSION

This Article has explored the complex overlap between science, death, and the law, specifically the intersection of recent neuroscientific research and the law of end-of-life decisionmaking. In this area, as in so

253. *See supra* text accompanying notes 173–188.

254. *See, e.g.*, Christine Overdevest & Lisa Christiansen, *Using Cultural Cognition to Predict Environmental Risk Perceptions in a Florida Water-Supply Planning Process*, 26 SOC'Y & NAT. RES. 987 (2013).

255. The distinct but related end-of-life debate over aid-in-dying provides an example of advocacy incorporating Kahan and Braman's concept of in-out group dynamics. The Supreme Court has acknowledged the power of the state interest in protecting vulnerable populations such as persons with disabilities as a counterweight to patient autonomy when considering the constitutionality of statutes prohibiting aid in dying. *See* Washington v. Glucksberg, 521 U.S. 701, 732 (1997) ("The State's interest here goes beyond protecting the vulnerable from coercion; it extends to protecting disabled and terminally ill people from prejudice, negative and inaccurate stereotypes, and 'societal indifference.' "). Since then, advocacy groups have begun featuring explanations from persons with disabilities about their wishes that the law would support aid in dying. *See, e.g., Doctors for Dignity Speak Out*, COMPASSION & CHOICES, Spring 2016 at 18, https://www.compassionandchoices.org/wp-content/uploads/2016/02/2016_Spring_Magazine_web.pdf [https://perma.cc/HQ3F-9UGN] (quoting a physician with multiple sclerosis as speaking in support of aid in dying); *The End of Life Liberty Project*, DISABILITY RTS. LEGAL CTR., https://disabilityrightslegalcenter.org/end-life-liberty-project [https://perma.cc/W3AZ-NV8G] (describing itself as being "at the forefront of a movement within the disability rights community to protect and expand the rights of mentally competent terminally ill patients"); Hugh Gallagher, *Disabled Rights Activist Advocates for Aid in Dying*, THE BODY (2001) http://www.thebody.com/content/art16723.html [https://perma.cc/4VZP-7N3F] (reprinting excerpt of a speech by a man with a disability advocating for the legalization of aid in dying).

many others, facts and opinions get "all jumbled up."[256] The task for lawmakers and policymakers is to refrain from drawing conclusions hastily based on opinions masquerading as facts. They also should recognize that skeptics will always exist, arguing that current law should change based on exciting new scientific discoveries, especially in such an emotionally charged field. Such skeptics are not to be feared, disparaged, or ignored. Better decisions will result if lawmakers and policymakers recognize the different roles those skeptics play and employ cultural cognition theory to work with the mixture of opinions and facts being debated.

256. *See supra* note 1.