THE MINIMALLY CONSCIOUS PERSON: A CASE STUDY IN DIGNITY AND PERSONHOOD AND THE STANDARD OF REVIEW FOR WITHDRAWAL OF TREATMENT

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I. INTRODUCTION

A. The Resurrection of a Minimally Conscious Patient

The story of George Melendez, broadcast on the CBS news magazine *60 Minutes*, caused a national stir for its poignancy and human interest. Melendez was an otherwise normal young man when one night he drove his car into a pond and almost drowned.[1] Though rescued, George laid in his bed for years, cared for by his mother, Pat Flores.[2] George was practically incommunicado for most of his post-accident life, occasionally moaning at night.[3]

One night, when the moaning was particularly loud, Ms. Flores gave George a shot of Ambien®, hoping that the popular medicine would help George rest.[4] However, instead of leading him into sleep, the pill had a

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[1] 60 MINUTES, *Awakenings: Return to Life*, CBS Television Broadcast (August 25, 2007), *available at* http://www.cbsnews.com/stories/2007/11/21/60minutes/main-3530299.shtml [hereinafter 60 MINUTES, *Awakenings: Return to Life*] (last visited Oct. 27, 2009).

[2] *Id.*

[3] *Id.*

[4] *Id.*

diametrically opposite effect.[5] The Ambien wrought a change that was nothing short of miraculous. Instead of drifting off to sleep, the Ambien brightened George, and he started looking around his bedroom.[6] Noting her success, Ms. Flores gave George another shot of Ambien the next day, and George has been receiving it every day for over five years.[7] While on the Ambien, George could answer simple "yes" or "no" questions about his environment and his pain tolerance.[8] Ms. Flores then consulted with Dr. Nicholas Schiff, a neurologist at Weill Cornell Medical Center in New York City.[9] Dr. Schiff conducted position emission tomography (PET) scans, both before and after Ambien treatment, and the results were incredible.[10] Schiff concluded that the Ambien produced two-fold metabolic change in George's frontal lobes.[11] Schiff concluded, "[h]is brain is turned on with this stuff."[12]

Importantly, subsequent to George's head injury, he was diagnosed as being in the minimally conscious state (MCS).[13] George had some conscious thought, compared to an able-bodied person, although how much will never be known.[14] Minimal consciousness is considered to be

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[5] *Id.*

[6] *Id.*

[7] 60 MINUTES, *Awakenings: Return to Life*, *supra* note 1.

[8] *Id.*

[9] *Id.*

[10] *See id.*

[11] *Id.* Medical scientists who study the brain's frontal lobes credit them for control over a person's speech and language and "executive functions," among other body processes. Jeffrey L. Cummings & Bruce L. Miller, *Conceptual and Clinical Aspects of the Frontal Lobes*, THE HUMAN FRONTAL LOBES: FUNCTIONS AND DISORDERS 12, 13, 15 (Bruce L. Miller & Jeffrey L. Cummings, eds., 2d ed., 2007). Executive functions include:

> [V]olitional response to environmental contingencies, recalling past events and planning current actions in a temporally informed manner, programming motor acts to follow volitional command, implementing programs to achieve the intended goal, monitoring the results of the action to determine the success of the intervention, and adjusting or stopping the action depending on the outcome of the assessment.

Id. at 15 (citing D.R. Royall et al., *Clox: An Executive Clock Drawing Test*, J. NEUROLOGY NEUROSURGERY PSYCHIATRY, 588, 508-94 (1998)).

[12] 60 MINUTES, *Awakenings: Return to Life*, *supra* note 1.

[13] *Id.*

[14] *Id.* Scientists are reticent to quantify the "amount" of consciousness a MCS patient might or might not have. Instead, according to some scientists, it is more appropriate to quantify the amount and types of responses the MCS patient makes to outside stimuli. *See* James L. Bernat, M.D., *Questions Remaining About the Minimally Conscious State*, 58 NEUROLOGY 337, 337-38 (2002). Dr. Bernat frames the measuring problem thusly:

> A second scientific question is the level of confidence clinicians ever can achieve about the precise level of awareness of a severely brain-damaged

a more advanced clinical diagnosis compared to other neurological devastations, coma, locked-in syndrome, the persistent vegetative state, and whole brain death.[15] George made such an outstanding recovery with the Ambien that Dr. Schiff considered him to have progressed from MCS to "severely disabled."[16]

George Melendez's extraordinary recovery heralds a day when patients in the minimally conscious state can have a shot of Ambien administered to them or have electrodes implanted deep in their thalami, and then later revivify, if almost magically, from their hospital or nursing home beds.[17] However, some cures for the minimally conscious state are not yet ready for widespread clinical application.[18]

To write of "cures" and "revivification" for MCS patients is to belie the fundamental ethical and legal issues at stake. Although any person of

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> patient. It is biologically impossible to experience another person's conscious awareness firsthand. Assessing another's awareness is purely inferential and depends on a subjective interpretation of the quality and quantity of their responses to various stimuli. At the bedside, one can only crudely measure evidence of the fullness of human awareness. So how can we be certain that the awareness of patients in MCS is minimal? Given that the criteria for MCS measure impaired responsiveness, perhaps it would be more accurate to use the older term "minimally responsive" to describe them.

Id. at 338.

[15] *See infra* Part II.A.2.

[16] 60 MINUTES, *Awakenings: Return to Life*, *supra* note 1.

[17] The thalamus helps manage sensory stimuli. *See* Erin A. Hazlett, Ph.D, et al., *Three-Dimensional Analysis with MRI and PET of the Size, Shape, and Function of the Thalamus in the Schizophrenia Spectrum*, 156 AM. J. OF PSYCHIATRY 1190, 1190 (1999). *See also infra* Part II.B.2. (discussing possible therapies for MCS, including deep brain stimulation for the thalamus).

[18] Dr. Nicholas Schiff, one of the researchers of the original test of deep brain stimulation, admits that more clinical testing must be conducted before it can be considered a successful therapy for MCS patients. *See* Rob Stein, *Technique May Help Revive Head Injury Victims*, WASH. POST, Oct. 16, 2006, at A9, *available at* http://www.washingtonpost.com/wp-dyn/content/article/2006/10/15/AR2006101500403.html (last visited Nov. 1, 2009); *see also infra* Part II.B.2 (discussing deep brain stimulation). However, Ambien, the popular sleep aid, may be ready for immediate clinical use because the rules for "off-label" use for prescription pharmaceuticals are not very strict. *See, e.g.*, Randall S. Stafford, M.D., Ph.D., *Regulating Off-Label Drug Use – Rethinking the Role of the FDA*, 358 N. ENG. J. MED. 1427 (2009) (noting that "[a]lthough off-label prescribing— the prescription of a medication in a manner different from that approved by the FDA—is legal and common, it is often done in the absence of adequate supporting data"); *but see infra* Part II.B.2 (regarding the mixed record of zolpidem, an active ingredient in Ambien in bringing patients in PVS and MCS to states of functioning or higher order functioning, respectively). *See also* Carl Zimmer, *What if There Is Something Going on In There?*, N.Y. TIMES, Sept. 28, 2003, at § 6 p.52, *available at* http://query.nytimes.com/2003/09/28/magazine/what-if-there-is-something-going-on-in-there.html (last visited Nov. 1, 2009).

goodwill should be ecstatic at George's recovery and the recoveries of other patients like him, the cold fact is that there is anywhere between 100,000 to 300,000 MCS patients languishing in their beds, cabined away from the rest of the world.[19] Amazingly, there is ten to thirty times the number of MCS patients as there are persistently vegetative patients, yet MCS has received far less popular attention than its more popular cousin-diagnosis.[20] To be fair, many devoted families would love to consistently nurture, talk to, and will the near-mute person to sit up and return the thrust and parry of human interaction in order to reawaken the patient and break the spell upon him. But after the initial trauma of their loved one losing consciousness, many of these families return to a semblance of normalcy and restart their lives without their brain damaged loved one.[21] And from these patients, the families receive, in the groans, nods, pointing, eye-tracking, and other behaviors, love, hope, and anticipation that their stuperous beloved will "come to."[22] At the same time, many family members project upon the patient their own desires for a fulsome recovery. That every MCS patient were as lucky as those with family members who retain vestiges of love and concern for their kin. Sadly, many do not have such filial warmth. Many of America's MCS patients quietly exist, day in and day out, primarily confined to nursing home beds, and never have opportunity to interact with the broader society.[23]

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[19] According to one source, the estimate of 100,000 to 300,000 patients with MCS only include those caused by traumatic brain injury and do not include those caused by anoxia (lack of oxygen). *See* Jonathon Weil, *Patient with Severe Traumatic Brain Injury in 'Minimally Conscious State' Shows Functional Improvement After Deep Brain Stimulation*, *available at* http://nyp.org/news/hospital/dbs-brain-injury.html (last visited Oct. 27, 2009). Other sources do not distinguish between hypoxia and traumatic brain injury, but keep the 100,000 to 300,000 estimate. *See* Denise Gellene, *Electrodes Help Man in Coma-like State Speak, Move*, L.A. TIMES, August 2, 2007, at A12, *available at* http://articles.latimes.com/2007/aug/02/science/sci-awake2 (last visited Oct. 27, 2009) (citing *Nature* article from Aug. 2, 2007 edition). Most of these patients languish in nursing home beds. *See id.*

[20] *See* Marc Lallanilla, *Most End-of-Life Cases Avoid Courtrooms*, ABC NEWS, Mar. 21, 2005, *available at* http://abcnews.go.com/Health/LegalCenter/story?id=-590373&page=1 (last visited Oct. 27, 2009) (quoting the late prominent neurologist and clinical bioethicist, Ronald Cranford, "[w]e have an estimated 14,000 to 35,000 adults and kids in a persistent vegetative state every year").

[21] *See e.g.*, 60 MINUTES, *Awakenings: Return to Life*, *supra* note 1 (recounting the story of Don Hebert, who was brought to the family home on birthdays and holidays).

[22] *See infra* Part II.A.2 for a description of MCS and its expressions.

[23] The exact number of MCS patients who live in nursing homes is unclear. However, one prominent article about MCS maintains that most patients in a vegetative condition from a traumatic brain injury end up in nursing homes in short order. *See* Zimmer, *What if There Is Something Going On in There?*, *supra* note 18. Further, another

And so the stark ethical question comes into clearer focus. What should be done with the minimally conscious patient? There are two choices that stake a fork in the road, and the selection of one eliminates the choice of the other. On the one hand, prominent clinical bioethics experts advocate that MCS patients, whose outward vocal and non-verbal manifestations appear random or meaningless, should be discontinued from their artificially provided nutrition and hydration.[24] These experts contend that the quantum of the MCS patient's consciousness (ability to form thoughts) and will to execute meaningful actions, is so profoundly diminished it should therefore be questioned whether the patient has "enough" characteristics of a normal human being to be considered a member of the human community.[25] These experts also argue that a core characteristic of the good human life is the ability to live a dignified existence.[26] Having one's every bodily need attended to by another person puts the patient in a "one down" position as compared to his able-bodied fellows. Simply, the patient is helpless and dependent, and such dependence does not fit with the current autonomy-based culture.[27] For

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writer posits that up to one-third of vegetative patients in nursing homes are actually in the minimally conscious state. *See* Joseph J. Fins, *Brain Injury: The Vegetative and Minimally Conscious States*, *in* MARY CROWLEY, ED., FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS, 15, 18 (Mary Crowley, ed., 2008), *available at* http://www.thehastingscenter.org/uploadedFiles/Publications/Briefing-_Book/brain%20-injury%20chapter.pdf.

[24] *See* Lawrence J. Nelson & Ronald E. Cranford, *Michael Martin and Robert Wendland: Beyond the Vegetative State*, 15 J. CONTEMP. HEALTH L. & POL'Y 427, 447 (1998-1999) ("For all intents and purposes, both states equally obliterate an individual's personal and sapient existence, leaving him profoundly neurologically impaired.").

[25] *See id.*

[26] *See id.* at 451 ("When legitimate questions arise about the propriety of continuing medical treatment, all persons deserve to be treated as subjects and not objects . . . no one deserves to be treated as an object and potentially infused, invaded, and accosted by whatever medical technology is available.").

[27] Autonomy is, of course, among the four pillars of Beauchamp and Childress's famous "Georgetown Mantra." *See* Tom Beauchamp & James F. Childress, PRINCIPLES OF BIOETHICS (Oxford Univ. Press, 4th ed., 1994). For a brief explanation of why the four principles in PRINCIPLES OF BIOETHICS is dubbed the "Georgetown Mantra," see Stephen E. Lammers, *Only a Place to Start: Reflections on a Changing Classic*, 9 SECOND OPINION 55 (2002), *available at* http://www.parkridgecenter.org/Page1936.html. For more discussion of autonomy's centrality to contemporary bioethics, see James F. Childress, *The Place of Autonomy in Bioethics*, 20 HASTINGS CENT. REP. 12, 12-13, claiming:

> It has been a mistake to use the term "autonomy" or even the phrase "principle of autonomy" as a shorthand expression for "the principle of respect for autonomy." It is important to correct this mistake because many critics seem to suppose that proponents of this principle have an ideal of personal autonomy and believe that we ought to be autonomous persons and make autonomous

example, lying in one's waste without the ability to relieve and clean oneself certainly diminishes a patient's dignity interest.

On the other hand, one could contend that if the patient has what some commentators have deemed the minimal indicia of human personhood—the ability to form conscious thoughts—then that person should receive some form of legal protection, and his "lifeline" should not be precipitously yanked.[28] Though the MCS person cannot display all of the actions an able-bodied person can—he cannot walk, jump, laugh at a movie, or hug his children—he can form some thoughts in the cortices of his brain.[29] Because such a human is a "person" deserving of respect and nurture, to the extent that he wants such nurture, his feeding tube must be kept in place, if that is in accord with his own wishes.

To date, most American courts that have considered family members' requests to remove life-sustaining treatment for minimally conscious patients have denied such requests, reasoning that no surrogate has demonstrated by "clear and convincing evidence" that patient would want to be die by removal of his medically supplied nutrition and hydration.[30] The thesis of this Article is that the four courts that have

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> choices. However, the ideal of personal autonomy is neither a presupposition nor an implication of the principle of respect for personal autonomy, which obligates us to respect the autonomous choices and actions of others.

Id. See also Paul Root Wolpe, *The Triumph of Autonomy in American Bioethics: A Sociological View*, BIOETHICS AND SOCIETY: CONSTRUCTING THE ETHICAL ENTERPRISE (Raymond DeVries & Janardan Subedi, eds., 1998); ONORA O'NEILL, AUTONOMY AND TRUST IN BIOETHICS IX (2002).

[28] *See infra* Part II.A.3.

[29] *See* Joseph Giacino, Ph.D & John Whyte, M.D., Ph.D, *The Vegetative and Minimally Conscious States: Current Knowledge and Remaining Questions*, 20 J. HEAD TRAUMA REHABIL. 30, 33, 36 (2005).

[30] *See infra* Part III (deconstructing the following four cases: *In re* Conroy, 426 A.2d 1209 (N.J. 1985), *In re* Edna M.F., 563 N.W.2d 485 (Wisc. 1997), *In re* Martin, 538 N.W.2d 399 (Mich. 1995), and Conservatorship of Wendland, 28 P.3d 151 (Cal. 2001). For further discussion of these four cases, see ALAN MEISEL & KATHY L. CERMINARA, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING § 4.08[B] (3d ed. 2004). It should be noted, however, that Claire Conroy and Edna M.F., the patients in the New Jersey and Wisconsin cases, respectively, were minimally conscious due to late stage Alzheimer's Disease. *See id.* § 6.04[E][2][a] n.460. Many cases discuss removal of artificial nutrition and hydration to late-stage Alzheimer's patients through different standards other than clear and convincing evidence. *See, e.g.*, Files v. State, 826 So.2d 906 (Ala. Crim. App. 2001) (holding that niece's withholding of artificial nutrition and hydration from her aunt with Alzheimer's Disease was a legal cause of the aunt's death, and thus the niece was guilty of criminally negligent homicide); *In re* Gordy, 658 A.2d 613 (Del.Ch. 2004) (holding that that the patient, at the time of the hearing, was competent to decide to forego a feeding tube, but nevertheless concluding that it was in her best interests to appoint a guardian to oversee her healthcare decisions); *In re* Greenspan, 558 N.E.2d 1994 (Ill. 1990) (holding that the "chronic vegetative" state and

considered removal of life-sustaining treatment for MCS patients have heretofore been correctly decided. I argue that when the clear and convincing evidentiary standard is coupled with the "subjective" substantive evidentiary standard—requiring proof that that the patient foresaw himself being beset with MCS and then wanted his feeding tube removed—it will be very hard indeed for a court to allow the patient's tube to be removed.[31]

Simply, I am willing to grant, for purposes of this Article, that MCS patients contain within their own badly deformed bodies the minimum constituents of ethical personhood that should be guarded and protected. The MCS patient is a person who deserves the law's most scrupulous protections, even though he might not currently display all the attributes of a healthy, vibrant, or even "normal" person.[32] The patient's lifeline to the world of the living should only be removed if the removal constituted his *bona fide* wishes under the circumstances in which he presently finds himself.

It is very important to appreciate the scope of this thesis. I do not argue that a MCS patient may or should never have his artificial nutrition and hydration removed. End-of-life jurisprudence since *Quinlan* has taught that it is the patient's prerogative—guarded by the constitutional right to privacy—to discontinue life-sustaining treatment.[33] Further, *Cruzan* provides a very valuable lesson that a state *may but is not required* to have a clear and convincing standard of evidence before allowing removal of artificial nutrition and hydration.[34] Though no state supreme court is bound to follow the clear and convincing standard of the *Cruzan* Court or the four MCS courts, I argue that it is advisable and preferable that they do so, based on the status of the MCS patient before them, who can still think and will, at least to a small extent.

Alzheimer's patient's desire for removal of feeding tube must be actualized through both the substituted judgment and clear and convincing standards); *In re* Christopher, 675 N.Y.S.2d 807, 809 (N.Y.Sup. 1998) (holding that clear and convincing evidence that Alzheimer's patient did not want a permanent feeding tube and that such a tube would be "futile and unnecessary").

[31] *See* MEISEL & CERMINARA, *supra* note 30, § 3.27[B] (characterizing the subjective standard as "evidence of the patient's actual or probable wishes, respectively, about the forgoing of treatment").

[32] Readers will no doubt understand the reference to Paul Ramsey's classic tome on medical ethics. *See* PAUL RAMSEY, THE PATIENT AS PERSON: EXPLORATIONS IN MEDICAL ETHICS (2d ed. 2002).

[33] *See In re* Quinlan, 355 A.2d 647, 663 (N.J. 1976).

[34] *See* Cruzan v. Dir. Missouri Dep't of Health, 497 U.S. 261, 284 (1990); *see also* Pettis v. Smith, 880 So.2d 145, 151 (La. App. 2004) ("*Cruzan* clearly does not require the imposition of such a standard of proof; it merely permits the state to do so.").

Many end-of-life cases following *Quinlan* and *Cruzan* involved patients in the persistent (or permanent) vegetative state, whose condition prevented either thinking or willing.[35] And courts involved in PVS cases have adopted different evidentiary and decision-making standards before allowing the patient's artificial nutrition and hydration to be removed. The courts might view evidence of the patient's desire not to live tethered to a feeding tube through the clear and convincing or "preponderance of the evidence" evidentiary standards and the "substituted judgment," "best interests," or subjective substantive standard.[36] The preponderance evidentiary standard is lower than clear and convincing, which is the highest level of proof in civil cases.[37] The preponderance standard asks the factfinder to determine if it was more likely than not that the patient would want artificial nutrition and hydration removed. Both the substituted judgment and best interests are looser substantive standards than the subjective tests, because both standards do not solely rely on the actual wishes of the patient with respect to his condition and treatment(s) at the time his surrogate petitioned the court for removal of the feeding tube.[38]

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[35] *See, e.g.*, *In re* Fiori, 673 A.2d 905 (Pa. 1996).

> In this condition, all Fiori's cognitive brain functions were inoperative. He felt no pain or pleasure, and he was unable to communicate with others. Since Fiori had no capacity for voluntary muscular movements, his life functions were maintained by the provision of medications, fluids, and nutrition through a gastrostomy tube, a tube which is surgically inserted in the stomach. There was no hope of Fiori ever recovering.

Id.

[36] *See, e.g.*, Woods v. Commonwealth, 142 S.W.3d 24, 44 (Ky. 2004) (construing case law to mean that a "consensus" has formed that both clear and convincing evidence and actual wishes of the patient or the patient's best interests, must be present); Guardianship of Doe, 583 N.E.2d 1263, 1267, 1271 (Mass. 1992) (requiring substituted judgment substantive standard and preponderance evidentiary standard with the judge's findings laid out in "meticulous detail" (quoting Custody of a Minor (No.3), 393 N.E.2d 836, 844))). For overviews of the three substantive standards, see MEISEL & CERMINARA, *supra* note 30, ch.4.

[37] *See, e.g.*, Succession of Gourgis, 1 So.3d 528, 534 (La. Ct. App. 2008) ("Clear and convincing proof has been defined as more proof than a preponderance of the evidence but less stringent than the criminal standard of beyond a reasonable doubt.") (citing *In re* Brantley, 789 So.2d 1, 6 (La. Ct. App. 2000)).

[38] *See generally* MEISEL & CERMINARA, *supra* note 30, §§ 4.02, 4.06, 4.07.

B. A Proposal to Distinguish PVS and MCS

1. Proposal and Personhood Theory

The proposal in this Article calls for a more robust application of a new definition of death. I advocate for this (relatively) new definition for one main purpose—so that patients affected by the disorder of consciousness known as the minimally conscious state may have the most vigorous substantive and procedural protections known to the civil law, yet protections not so high or impregnable as to frustrate a MCS sufferer's actual spoken wish to slough off this mortal coil should he have predetermined that he would not want to live in the minimally conscious state.

In brief, this Article calls for state legislatures to adopt the "neo-cortical" definition of death to complement the whole-brain and cardio-pulmonary definitions of death currently on the books of every state of the Union. The neo-cortical definition realizes that a person in a permanent (and not merely persistent) vegetative state is not in the process of dying, nor is she languishing in a suspended state of animation later hoping to magically reawaken and return to normal human intercourse. Rather, the permanently vegetative person is dead.[39] The higher parts of her brain, the cerebral cortices, are gone forever, and the basic functions of the rest of her body should match the cerebral silence found in her forebrain.

But in order to understand the proposal, one must first understand the main ethical theory that has enervated bioethics for almost two generations. Significantly, this concept must be ultimately rejected; for every human being must not be denied respect, dignity, and basic and humane care befitting their status as a member of the species, only because the human may twitch, moan involuntarily, and be utterly unresponsive, as is the case with the PVS patient. The new definition of death simply says that the human, indeed the special person before the treatment team, is truly dead, and the person's bodily processes should be stilled to match the stillness within her brain.

"Personhood" or "selfhood" theory is the idea, active in modern bioethics for at least the past thirty years, that the more animated and demonstrative the human subject is (usually a patient subject to some form of medical treatment), the more likely he or she may be deemed a

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[39] *See* Robert M. Veatch, *The Impending Collapse of the Whole-Brain Definition of Death*, 23 HASTINGS CENTER REPORT 18 (1993); *see also* Robert M. Veatch, *Whole-Brain, Neocortical, and Higher-Brain Related Concepts*, *in* RICHARD M. ZEINER, ED., DEATH: BEYOND WHOLE-BRAIN CRITERIA (Richard M. Zeiner ed., 1988).

full and complete "person," and therefore deserving of the most robust ethical and legal protections.[40] Conversely, the more placid, irretrievably ill, permanently unconscious, or deficient in the ability to make one's wishes known (such as in the locked-in state, see *infra* Section II.A.4)—in short, the less the subject looks and acts like a "normal" person who can live, work, and take care of himself - the less likely the subject is to be called a person, and by extension the less deserving she is of the full panoply of protections made available at law. The theory's modern iteration can probably be traced to the Episcopal priest and philosopher, Joseph Fletcher, who, in his work as a medical ethicist, adopted a radical heuristic of human value—with the non-cognitive at the low end of the scale, and those with adult, normal cognitive functioning at the top of the scale and thus deserving of the highest protections of life.[41] Thus Fletcher believed that the essence of what it means to be a human person is entirely wrapped up with intelligence, interaction, and cognitive talent *viz* one's peers.

Fletcher's intellectual heir and fellow consequentialist, Australian moral philosopher Peter Singer, fashioned his brand of utilitarianism upon his system of "preferences." In short, Singer believes that if the human subject—whether infant or demented Alzheimer's patient, can no longer give voice to his or her own preferences or interests, then the subject should have a less solid claim to continued physical life than the

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[40] The literature of personhood theory is expansive and it includes certain phenomenological and personality studies within the disciplines of psychology and philosophy. *See* JOHN F. CROSBY, THE SELFHOOD OF THE HUMAN PERSON (1996); JOHN HERON, FEELING AND PERSONHOOD (1992); and ROBERT SOKOLOWSKI, PHENOMENOLOGY OF THE HUMAN PERSON (2008). For some of the more recent applications of personhood concepts to bioethics issues, see Carl Elliot, *Attitudes, souls, and persons: Children with severe neurological impairment*, 9 MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES RESEARCH REVIEWS 16, 17 (2003) (criticizing the use of the concept as a factual construct without the concomitant acknowledgment that it has a moral or "evaluative" aspect to it as well); *see also* JAMES W. WALTERS, WHAT IS A PERSON?: AN ETHICAL EXPLORATION 4 (1997) (claiming that the more of "higher consciousness" a human displays the more sure her claim upon the strong ethical protections due a person); PATRICK LEE AND ROBERT P. GEORGE, BODY-SELF DUALISM IN CONTEMPORARY ETHICS AND POLITICS 81-94 (2008) (rejecting the notion of personhood as applied in contemporary bioethics and claiming that biological function and not the higher orders of conscious thought are vital to the definition of the person).

[41] *See* JOSEPH F. FLETCHER, HUMANHOOD: ESSAYS IN BIOMEDICAL ETHICS 12-16 (1979) (discussing the fifteen minimum indicia of humanhood); *see also* WESLEY J. SMITH, CULTURE OF DEATH 11-14 (2000) (criticizing Fletcher's "secularist, radically utilitarian" agenda and compares it to Paul Ramsey's covenant theology found in, *inter alia*, THE PATIENT AS PERSON (2d ed. 2002)). *See* SMITH, CULTURE OF DEATH, *supra*, at 13, 14.

subject who can express his or her own wishes and can act autonomously.[42]

For both Singer and Fletcher, there are two keys to their hierarchical systems life-preservation and personhood: one is that the subject only becomes (or continues to exist as) a subject, and therefore a person, and not a mere object to be manipulated once the subject expresses the behaviors associated with conscious thought. Consciousness, then, is the gateway through which a human subject enters personhood. Second, the subject exits personhood, and therefore full ethical protection, once he loses consciousness, or if he does not fully lose consciousness—say through advanced dementia—then the break from reality is so profound that family members and physicians may act as if all consciousness, and therefore all personhood, is lost forever.[43]

Though not tagged with the modern appellation, American jurisprudence is no stranger to the blunt force of the theory. In fact, many foundational cases of American constitutional law, such as *Dred Scott v. Sanford*, which sought to define African-Americans as something other than legal persons and *Plessy v. Ferguson*, which sought to further define blacks' participation in civic life as "separate but equal," and in the separateness denied the fundamental dignity and equality of all American citizens, and thus asserted that African-Americans were less than full and complete people.[44] Also in the twentieth century, the Supreme Court took up *Buck v. Bell*, in which Justice Holmes famously placed the scarlet letter "R"—retarded—on Carrie Ann Buck and deemed her unworthy of finding personal fulfillment through child bearing, dismissively declaring that: "[t]hree generations of imbeciles are enough."[45] In *Buck*, the Court saw Carrie fundamentally deficient—lacking in a certain quality, which for her was a sufficient amount of intelligence—that prompted Virginia (and eventually received the Court's sanction) to quite literally cut her

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[42] *See, e.g.*, PETER SINGER, PRACTICAL ETHICS 175-212 (2d ed. 1993); *see also* SMITH, CULTURE OF DEATH, *supra* note 41, at 14, 15.

[43] *See* SINGER, *supra* note 42, at Ch. 7; *see also* Fletcher, *supra* note 42, at 12-16. All of Fletcher's indicia of consciousness in some way relate to the functioning, conscious person and denigrate the incapable, disordered person.

[44] *See* Dred Scott v. Sanford, 60 U.S. 393, 404-05 (1857) (equating "people of the United States" and "citizens" as "synonymous terms," and therefore shutting off African-Americans from constitutional citizenship); and Plessy v. Ferguson, 163 U.S. 537, 544 (1896) (disclaiming any discriminatory intent in the Louisiana statute in question). The phrase "separate but equal" is found in Justice John Marshall Harlan's dissent. *See id.* at 552.

[45] Buck v. Bell, 274 U.S. 200, 207 (1927); *see also* SMITH, CULTURE OF DEATH, *supra* note 41, at 33, 34.

off from full participation in the community (in the form of procreation).[46]

Though it has modern American roots in early twentieth century Supreme Court cases, polemicists such as Wesley Smith, claim that "personhood theory" is the most pernicious development of the contemporary bioethics movement, because the theory's ultimate aim is eugenic in nature—as were the aims of Justices Holmes, writing for the Court in *Buck*. That is, the theory's adherents seek to marginalize, shuffle off, and in some cases affirmatively kill, those patients whose quality of life, defined by another person according to an inchoate set of criteria, does not meet an arbitrary threshold of completeness as befits a "person."[47] The theory seeks to erect a wall between those with a full complement of personal characteristics and outward manifestations (including interaction, attention, and purposeful action) and the mere human, who though robed in human flesh, does not meet the test of human interaction and intercourse that is becoming of a moral person.

Although Smith and other commentators attribute the move towards defining patients in terms of their personal characteristics, and therefore their worthiness of continued life, on a concerted program of radical consequentialism built upon weeding out the leaches of the healthcare system so that the strong may survive, he has yet to prove that there is a coordinated agenda (at least in America) to favor the strong at the expense of the weak. Though there is a real chance that such a strong, centralized program may materialize in America in the near-term future, to date coordinated efforts at parceling healthcare according to quality concerns have been on a state-by-state basis.[48]

In the end-of-life context, defining the human person and therefore his worthiness for continued life has generally fallen to the state courts. Some courts have done this through the application of a quality of life rubric. Courts have weighed criteria, ranging from the effects on the patient's dignity to the pain caused by continued treatment to the

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[46] *See* Buck v. Bell, 274 U.S. at 205 (stating that Carrie Buck is "feeble-minded" and a "defective person").

[47] *See* WESLEY J. SMITH, FORCED EXIT: EUTHANASIA, ASSISTED SUICIDE, AND THE NEW DUTY TO DIE xx-xxi (1997) (tracing the beginnings of euthanasia in America and compares to the author's characterization of an "equality-of-life" ethic"). Though Smith and I agree on many end-of-life bioethics issues, we disagree on the question whether the person in a vegetative state is alive or dead. *See* SMITH, CULTURE OF DEATH, *supra* note 41, at 174-78.

[48] *See* Michael J. Astrue, *Pseudoscience and the Law: The Case of the Oregon Medicaid Rationing Experiment*, 9 ISSUES L. & MED. 375, 381-84 (1994) (describing the surveys based on quality-of-life criteria that were used, in part, to determine the order of the diseases and conditions paid by the famous "Oregon Plan" Medicaid program).

effectiveness of the given treatment; and if the balance of the patient's life is tilted toward continued suffering, he is allowed to die. Contrarily, if on-balance the patient's life is weighted toward vitality without gratuitous pain and too much loss of face, the patient is allowed to live, and the family member's request to withdraw life-sustaining treatment is denied.[49] The jurisprudential problem with a quality-of-life ethic is that it forces an outside agent—in this case a court—to tally up the relative "merits" of the patient's continued existence, and then balance those merits against the relative "demerits" of continued treatment. The patient whose scale tips toward "quality" is deemed worthy to live, while the patient whose scale tips away from "quality" is allowed to die. And therefore, because the choice is made by the competent, standing in the place of the incompetent, the competent chooser is ceded the power to determine whose quality, and therefore whose worthiness, measures high enough for continued life.

In the modern era, the Supreme Court has famously declined to determine whether a fetus gestating in its mother's womb is a person, preferring instead to leave such determinations to the child's mother's conscience.[50] And though the Court has been ambivalent about the personal interests of nascent human life, at least with respect to abortion, it seems more determined to protect the wholeness and viability of personal life in certain end-of-life contexts. For example, in the seminal 1997 cases of *Washington v. Glucksburg* and *Vacco v. Quill*, the Court determined that there was not a constitutional right to assisted suicide, claiming that biological life itself, however deformed or painful, was the foundational value upon which all other constitutional claims must be made and without which no constitutional rights could be asserted.[51] However, upon closer inspection, it appears that in *Glucksburg* and *Vacco* the Court prized *sentient* life as coextensive with personhood, and therefore the lives at stake in those cases could not be affirmatively foreshortened, even though the person was in unremitting pain. Seven years earlier in *Cruzan v. Director* the Court took an unconditional view

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[49] *See generally* MEISEL & CERMINARA, *supra* note 30, § 4.07[E].

[50] The Supreme Court famously drew the line for legal personhood and concomitant protection at viability. *See* Roe v. Wade, 410 U.S. 113, 163 (1973); *see also* Casey v. Planned Parenthood, 505 U.S. 833, 846 (1992) (reaffirming the essential thrust of *Roe* that a woman may terminate her pregnancy prior to viability).

[51] *See* Washington v. Glucksburg, 521 U.S. 702, 728 (1997) (reaffirming the State of Washington's "unqualified interest in the preservation of human life" (quoting *Cruzan*, 497 U.S. at 282)); *see also* Vacco v. Quill, 521 U.S. 793, 808 (1997) (reaffirming the State of New York's interest in "preserving life"). The patients in *Glucksburg* and *Vacco* were competent and sentient at the time they requested assistance with their suicides.

of the person, this time in a permanent vegetative state.[52] The Court concluded that a state can rightly determine the essence of life's value is in its mere existence, and not the ability of the one having it to use it for chosen ends.[53] That is, mere existence, according to the Court, can be something so distinctive that it must be protected up to the point where the patient clearly states that she no longer wants life-sustaining treatment.[54]

Importantly, though it appears that the Court refused to allow assisted suicide in the *Glucksburg* and *Vacco* cases because to do so would be to will the death of a "full" cognizant, aware, persons racked by overwhelming pain, the Court did not write into the law a dividing line between *Cruzan* and the *Glucksburg* and *Vacco* cases upon the nature of the illnesses and conditions that befell the subjects. In both of the assisted suicide cases, the patients at the heart of the controversies were cognitive and fully aware that they were brokering help to affirmatively end their own lives. The Court would not interject itself as an intermediary of voluntary euthanasia for a person who could wholly determine for what he was asking and its effects. The *Vacco* and *Quill* Courts refused to cede the moral high ground to those who, lucid but admittedly in severe pain, intended to take their own lives. Nor can it be debated that the patients' health was devastated—their misery was as genuine as was their will to die. Nevertheless, because these patients had all their faculties, though racked by pain, the Court concluded that their "lives"—their sapient existences—mattered more than their wills to extinguish those lives.[55]

Similarly, in *Cruzan*, the Court gave narrower birth to Nancy Beth Cruzan's desire to die even though she was in permanent vegetative state—a condition of cognitive death—from which she would never recover. Essentially, the *Cruzan* Court refused to filter Nancy's supposed choice to refuse life-sustaining treatment and then allow her body to expire, through the binocular of her condition and the effects her condition made on both herself and her loved ones. The Court concluded that for Nancy Cruzan, a life voiceless, without purposeful movements, or the ability to interact with one's fellows, was not one that was

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[52] *Cruzan*, 497 U.S. at 261.

[53] *Id.* at 282.

[54] *Id.* (stating that "[w]e think a State may properly decline to make judgments about the "quality" of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual"); *see also id.* at 285 (holding that Missouri could require clear and convincing evidence of Nancy Cruzan's wishes to not be maintained by artificial nutrition and hydration upon falling into a vegetative state).

[55] *See Glucksburg*, 521 U.S. at 728-29; *Vacco*, 521 U.S. at 808.

meaningless—even though the only things that were truly hers were her spontaneous breathing and heart beat.[56]

Apart from its modern judicial applications, the question must be asked whether "personhood" is a viable and valuable lens through which issues involving removal of life-sustaining treatment from those suffering with "disorders of consciousness" may be viewed. Ultimately, the answer to the question must be "no," if by personhood we mean the modern construct that finally judges a life's worthiness according to its quality as determined by another person such as a familial caregiver or physician. Indeed, as an antidote to the quality movement, the most logical and easily intellectually defensible position on end-of-life issues, including those involving removal of artificial nutrition and hydration is that of a "pure" sanctity of life ethic—which holds that the necessary (if not sufficient) qualities for a person comes into existence at conception and leaves at natural death. Such a construct leaves no room for vacillation or interpretive error or introduction of outside factors such as quality criteria that could lead to untoward results.[57] The sanctity of life ethic, however, can, but does not have to bludgeon its insistence on continued life without realizing that at some point, the patient should be allowed to die if treatment will no longer provide any benefit to him. Generally, the sanctity ethic views this point to be where the benefit of continued treatment is outweighed by the burden caused by the treatment. To be sure, it could be said that such a principle is merely a stripped-down version of the quality principle—with benefit and burden as the two factors through which the patient's quality of life, and its continued sapient existence, are judged. However, the benefit/burden calculus, unlike the fulsome quality calculus, is based on at least one objective criterion, while the quality construct is based on several subjective criteria. When burdens outweigh the benefits of continued treatment, the patient's continued treatment cannot produce the desired health-producing effect for the patient and may be permissibly withdrawn. Sanctity does not demand blind vitalism. There comes a point where a patient may be allowed to die if the criterion is met. Herein

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[56] *See generally Cruzan*, 497 U.S. 261 (1990).

[57] *See, e.g.*, Craig Patterson, *A Life Not Worth Living?*, 16 STUDIES IN CHRISTIAN ETHICS 1 (2003) (criticizing the quality of life approaches of Dan Brock and Helga Kuhse in which the appropriateness of continued life support is contingent upon whether the patient can maintain his "personal" or "biographical" life, and instead holding up natural law philosopher John Finnis, who argues that human life is a "basic good" no matter its shape or form); *see also* LEON R. KASS, M.D., LIFE, LIBERTY AND THE DEFENSE OF DIGNITY 231-55 (2002) (discussing sanctity of life).

the sanctity adherent realizes the limits of medicine; he does not necessarily give up on the preciousness of the suffering patient.[58]

The jurisprudential benefit of a pure sanctity ethic is that it upholds equality of human life—however misshapen—as a primary principle that precedes all other principles (such as freedom from pain, deformity, or worthiness to participate in the human community, among others). Equality of human life does not mean, of course, that it is the only good or that it should predominate over all other human goods. It does mean, however, that it is the starting point of all analysis about life issues. Though some legal philosophers might quibble with the notion of ordering one human good (equality) above every other good, the question must be asked, without first treating each human being as worthy, and therefore equal, does such an allowance make room for the strong to order goods on behalf of the weak?[59] If, in fact, equality-in-sanctity is not the primary good over against all other goods, those making decisions for the patient could substitute their own convenience for the patient's worth (in not having to take care of the patient anymore), their repulsion at the sight of the patient's broken condition, and their unwillingness to "own" or make present in their lives the patient's suffering and endure it with the patient as a co-sufferer. In sum, if equality-in-sanctity is not the primary good, then those who are capable have an easy case to set aside and "make dead" those who are not capable—for those who are less capable are fundamentally deficient *viz* the whole person—and wholeness for them, not humanity, ultimately counts.[60]

Suffice it to say, those who adhere to a robust sanctity ethic believe that a medical subject's essence is not forever lost even when the subject receives treatment that cannot bring him back to a complete state of wellness. For example, if the patient is attached to a ventilator and can

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[58] For a nuanced description of benefits and burdens in light of a practical determination that a particular treatment is "futile," see Edmund D. Pellegrino, M.D., *Decision at the End of Life: The Use and Abuse of the Concept of Futility*, *in* LIFE AND LEARNING X: PROCEEDINGS OF THE TENTH UNIVERSITY FACULTY FOR LIFE CONFERENCE (Joseph W. Koterski ed., 2000).

[59] The modern, though "classic" treatments of the incommensurability of human goods can be found in both the new natural lawyer John Finnis' *Natural Law and Natural Rights*, and the liberal positivist Joseph Raz's, *The Morality of Freedom*. *See* JOHN FINNIS, NATURAL LAW AND NATURAL RIGHTS 92-95 (1980); JOSEPH RAZ, THE MORALITY OF FREEDOM ch. 13 (1986).

[60] For the "make dead" phrase, see *Vacco*, 521 U.S. at 802 (quoting testimony of Dr. Leon R. Kass: "A doctor who assists a suicide, however, 'must, necessarily and indubitably, intend primarily that the patient be made dead.'" *Assisted Suicide in the United States*: *Hearing Before the Subcommittee on the Constitution of the H. Comm. on the Judiciary*, 104th Cong. 368 (1996) (testimony of Dr. Leon R. Kass)).

never be disengaged, he does not lose his status as a person who is worthy of treatment as he has lost his ability to breathe on his own. At some point, though, with the aid of physicians, chaplains, and others, families make the decision to let their loved one depart. Such a decision is made by the sanctity-adherent with the realization that sometimes diseases overmaster even the most willing fighter. It does not mean that the subject somehow becomes unworthy or unfit as a person if the physician or hospital ethics committee in the end determines that the patient's treatment is no longer medically beneficial—it is only the recognition that despite best efforts, the treatment(s) did not have the desired results.

2. The Integrative Function of the Brain and Re-Conceptualizing Death

One of the perennial debates in modern neuroscience is the extent to which the brain serves as the integrating, or organizing mechanism for the rest of the body. That the brain serves as the rest of the body's "control center" seems intuitive to most Americans—perhaps due to popular medical dramas such as *ER*, or *Grey's Anatomy*, in which the television doctors patiently explain to shocked family members that their loved one's "brain waves" are completely flat, thus showing no electrical activity in the brain and therefore revealing the brain's "silence" and death. This, of course, is confusing to the family because they see their loved one's lungs inflated with oxygen through the agency of a ventilator and they wonder if their loved one can be really dead if the heart and lungs are still working.

Though television might have popularized the concept of whole-brain death, the hard work of changing the law's entire focus from cardio-pulmonary death to whole-brain death started with the pioneering work done by a committee of the Harvard Medical School in 1968. The Harvard Ad Hoc Committee on Brain Death proposed to broaden the definition of death to include the death of the entire brain, including the brain stem.[61] It opened the door to this new definition in order to reify the practices of many physicians, who had already begun to declare patients dead when they could not detect any electrical activity in the brain. Eventually, the work of the Harvard Committee caught on with the policy zeitgeist of the 1970s, and the National Council of Commissioners on Uniform State Laws adopted the Uniform Determination of Death Act

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[61] *See A Definition of Irreversible Coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 J. AM. MED. ASS'N 85 (1968).

in 1980, which defined death as to include either cardio-pulmonary death or whole-brain death. Every state in the Union has some form of brain-death definition on its books.[62]

Before turning to its implications for the consciously-disordered patient, it is first important to ask why the Harvard Committee took up the issue of brain death and why the definition continues to have currency today. The 1968 group decided that the medical field was ripe for a broadening of the definition of death for two reasons. First, the Committee recognized that "obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation."[63] Organs suitable for transplantation needed to be freshly perfused with oxygen. Waiting until cardio-pulmonary death diminishes the viability of otherwise usable organs. While no one doubts the need for transplantable organs both in the late 1960s and today, the Committee's artifice of the brain death definition for that purpose seems grisly and wholly

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[62] *See* The National Conference of Commissioners on Uniform State Laws, Uniform Determination of Death Act, Prefatory Note (1980); *see also* Alexander Morgan Capron & Leon R. Kass, *A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal*, 121 PA. L. REV. 87 (1972), providing the following definition of death:

> A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an irreversible cessation of spontaneous respiratory and circulatory functions. In the event that artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an irreversible cessation of spontaneous brain functions. Death will have occurred at the time when the relevant functions have ceased.

Id. at 111. Although Capron and Kass appear to endorse a phenomenological approach to death ("he has experienced an irreversible cessation of spontaneous brain functions"), they do not endorse a neo-cortical approach to apprising death because,

> [T]he very fact of spontaneous respiration, as well as coordinated movements and reflex activities in the brainstem and spinal cord levels, would exclude these patients from the scope of the statutory standards. The condition of 'neo-cortical death' may well be a proper justification for interrupting all forms of treatment and allowing these patients to die, but this legal and moral problem cannot and should not be settled by 'defining' these people "dead."

Id. at 115. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed NCCUSL's Uniform Determination of Death Act. *See Defining Death: Medical, Legal, and Ethical Issues in the Determination of Death* 2 (July 1981), *available at* http://www.bioethics.gov/reports-/past_commissions/defining_death.pdf (last visited Nov. 1, 2009). Recently, the current President's Council on Bioethics has reexamined whole brain death. *See* its report, entitled *Controversies in the Determination of Death: A White Paper by the President's Council on Bioethics* (Dec. 2008), *available at* http://www.bioethics.gov-/reports/death/index.html (last visited Nov. 1, 2009).

[63] *A Definition of Irreversible Coma*, *supra* note 61, at 85.

instrumental. The shorter the time between expiration and organ harvesting, the more the donor's body appears to be a field that the farmer wants to pick at the peak of ripeness. Second, the Harvard Committee realized that the brain has a coordinating function for the rest of the body. Without devolving into needless reductionism, the Committee correctly realized that without the brain, the rest of the body is lifeless, impotent, and without any use for both the subject and his loved ones.[64]

A relatively clean case may be made for the discontinuance of life-sustaining treatment from a patient whose entire brain is dead. Never again will the patient return to sentience. Never again will the patient rouse himself from his hospital or nursing home bed. The ventilator—a medical treatment—interrupts the patient's certain cardiac and pulmonary collapse—for his brain can no longer give the signals to his body to maintain itself.[65] Thus it is arguable that the non-brain parts of the brain dead patient's body are not even viable, because without the

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[64] *See id.* The Committee saw a need for a definition of death that would cover situations in which,

> these efforts [at life-saving measures] have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by comatose patients.

Id. Though the Committee advocated for a whole-brain conceptualization of death, its rationale arguably applies to the neo-cortically dead patient ("permanent loss of intellect") as well. It is a point of scientific and ethical controversy as to whether the brain serves as the ultimate coordinator or "traffic cop" for the rest of the body. If it does have such an "integrating" function, then brain death in essence causes the death of the rest of the organism. For without the brain to direct the body's critical pathways, the body has no choice but to expire. Contrarily, some thinkers do not see any necessary connection between the brain's actions and some sapient activities of the rest of the body. *See, e.g.*, 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, 464 (2001) (dismissing the notion that respiration, as one example, is wholly integrated by the brain. The "phrenic nerves, diaphragm, and intercostals muscles," lining of the lungs and "mitochondria of every cell of the body" all play roles in respiration so that no one part of the body can be said to have the integrating function). For the integrative view (and beyond), see Robert M. Veatch, *The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists*, 30 J. MED. & PHIL. 353 (2005).

[65] *But see* Veatch, *The Death of Whole-Brain Death*, *supra* note 64, at 356-58 (summarizing recent research into the vestiges of somatic and brain life after the pronouncement of whole-brain death); *see also* Amir Halevy, *Beyond Brain Death?*, 26 J. MED. & PHIL. 493, 494-96 (summarizing research demonstrating latent brain activity after declaration of brain death).

intervening work of the ventilator, the internal organs would certainly fail.

The whole-brain definition of death is ensconced in American medical practice and does not appear to move for the foreseeable future. Is it possible to have a broader picture of brain death that remains true to the intentions of the Harvard Committee's framers without needlessly exposing patients to discontinuance of life-sustaining treatment? In short, the answer is "yes," if American neurology shifts its focus from the irretrievable loss of all brain functions to one that is solely focused upon loss of functions of the higher brain. The "neo-cortical" definition of death has been proffered by important bioethicists such as Robert Veatch, among others, and the simplicity of the theory brings the pith of what it means to be a protectable legal person into precise focus.[66] In this definition of death, the patient is dead once his cortices, or the centers of thought and consciousness in the forebrain, have been eviscerated. In other words, when the patient has entered into the persistent vegetative state, he can be said to be "upper brain dead."

Why, then, is thought and consciousness so vital to the definition of death? Currently, neurologists believe that a subject's will—the choice-making vitality that makes each person unique—interacts with the person's centers of conscious thought to form chosen plans and goals. A person can only make a determination about an object if he can first formulate thoughts about that object.[67] It is as if the subject's consciousness is the gateway into the subject's inner, willing, choosing world. Without consciousness, the power to will and choose would be meaningless, as the will would never have a chance to be known or express itself.

Of course, the loss of consciousness paradigm for death could be extended to absurd extremes and have frightening consequences for patients in a healthcare system already stretched to the breaking point with resource problems. If death were baldly identified with loss of consciousness, then a surgeon could quickly dispose of his mistake if his patient were still under general anesthesia, or a crowded hospital administrator could quietly order the euthanization of an ICU patient in a coma. Ad hoc, resource-driven choices for death are grisly and almost defy comprehension. The dividing line I advocate is based upon science and upon what I believe to be common sense notions of what it means to be fully alive versus actually dead. It is exceedingly important to know

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[66] *See* Veatch, *The Death of Whole-Brain Death*, *supra* note 64; *see also* Veatch, *The Impending Collapse of the Whole-Brain Definition of Death*, *supra* note 41.

[67] *See* David H. Ingvar, *On Volition: a Neurophysiologically Oriented Essay*, *in* 6 J. CONSCIOUSNESS STUD. 2, 3 (Benjamin Libet, et al., eds., 1999).

that I do not call for the new definition of death to be applied to patients in transient or temporary states of consciousness-less.

Conservative bioethics advocates have decried the possibility of precipitous withdrawals of treatment from PVS patients. Some warn that policymakers and courts will slide down a very slippery slope into full-blown involuntary euthanasia should it become easier for courts, and then healthcare workers, to disconnect life-sustaining treatment from the PVS patient. The argument is that if PVS patients can be summarily disconnected from artificial nutrition and hydration, then it will be very easy to do the same to patients in comas, locked-in states, or even to minimally conscious patients.[68] The ethical case for disconnection is that the severe MCS patient symptomatically looks so much like PVS that patients with the respective conditions are practically the same. In effect, those who might make that argument contend that there is no practical difference between consciousness that is happenstance and very low quality and no consciousness at all.

Two responses must be made. The slippery slope argument, aside from being a logical fallacy, is weak support for legal and policy contentions because: (1) the argument can be made to any policy proposal that has possible deleterious effects, whether or not those effects are truly foreseeable, and (2) no one can foresee a pure, unadulterated causation chain from Trigger A to Bad Effect Z. That is, if it is likely, according to a slippery slope adherent, that if A happens, Z will inevitably occur, then the adherent has to at least allow for the possibility that intermediate causes E, F, M, and Y may not occur exactly as he imagines. Therefore, Bad Effect Z might not happen exactly as he imagines.[69] And that is where the substantive and procedural standards for MCS patients enter the stage. The primary aim of this Article's thesis is to arrest the causal chain at neo-cortical death. However maligned, decrepit, and PVS-like the severe MCS patient is, *she is not dead*, because death is a precise scientific state that can be measured and quantified.

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[68] *See* SMITH, FORCED EXIT, *supra* note 47, at 49-50 (describing the American Medical Association's affirmation of best interests and substituted judgment standards for removal of artificial nutrition and hydration for persons who may not be "'beyond doubt' permanently unconscious"). While this article vociferously criticizes application of the best interests and substituted judgment standards upon minimally conscious patients, I do not see such applications as part of an overarching slide into ruin whereby non-disordered patients would be inevitably involuntarily euthanized.

[69] Two of the most prominent analytical deconstructions of the slippery slope argument can be found in Eugene Volokh, *The Mechanism of the Slippery Slope*, 116 HARV. L. REV. 1026 (2008); and Frederick Schauer, *Slippery Slopes*, 99 HARV. L. REV. 361 (1985).

In fact, the diagnosis of persistent vegetative state can be made only after one month of loss of consciousness.[70] Anoxic PVS patients usually do not recover after three months with the disorder; similarly, patients whose condition was engendered by traumatic brain injury usually do not recover after twelve months with the disorder.[71] Lois Shepherd has called for PVS patients to be disconnected from life-sustaining treatment after, at a minimum, a one year waiting period to determine whether the patient will spontaneously revive from the PVS.[72] This seems to be about right, as it is more than enough time for recovery to occur.

Further, in light of the need for certainty when making the PVS diagnosis, I call for mandatory second and third opinions of neurologists trained to make the PVS diagnosis and unanimous affirmation of the PVS diagnosis by the attending and consulting physicians.[73] Of course, because ultimate questions of existence are at stake, this proposal calls for physicians totally disinterested and free of any all conflicts of interest in affirming the diagnosis of PVS. The cost should be borne by whichever party is recalcitrant in removing life-sustaining treatment. I

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[70] The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State—First of Two Parts*, 330 NEW ENG. J. MED. 1499, 1499-1508 (1994) ("We define such a state operationally as a vegetative state present one month after an acute traumatic or nontraumatic brain injury or a vegetative state of at least one month's duration in patients with degenerative or metabolic disorders or developmental malformations.").

[71] *See id.*

[72] *See* Lois Shepherd, *In Respect of People Living in a Permanent Vegetative State and Allowing Them to Die*, 16 HEALTH MATRIX: J. L. MED. 631, 675 n.178, 676 (2006). Professor Shepherd's proposal is slightly more nuanced than headlong removal of feeding tubes after one or two years. She would require disconnection of ANH after one year and three months for the permanent vegetative patient whose condition was occasioned by non-traumatic injury (three months for the diagnosis of permanence and an extra year waiting period) and two years for the permanent vegetative patient whose condition is occasioned by traumatic injury (one year for the diagnosis of permanence and another year-long waiting period). Treatment would be maintained only if the surrogate could show, by clear and convincing evidence, that the patient would want to have treatment maintained. Perhaps she calls for this extra step waiting period because she sees the patient in a permanent vegetative state "as a living person with rights to self-determination, bodily integrity, and medical privacy." *Id.* at 631.

[73] The Multi-Society Task Force on PVS recognizes that physicians can make mistakes with respect to the PVS diagnosis:

> An accurate diagnosis is critical. Errors in diagnosis have occurred because of confusion about the terminology used to describe patients in the condition, the inexperience of the examiner, or an insufficient period of observation. Physicians caring for such patients should be aware of these potential problems and be as precise and careful as possible when applying the suggested clinical criteria.

The Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State—First of Two Parts*, *supra* note 70, at 1499-1508.

also call for PVS patients to be given the full complement of drug therapies that have been tried out, to some success, on PVS and MCS patients, to bring them back to functioning (or higher order functioning for MCS patients). Only if drug therapies do not work should the PVS patient be disconnected from his or her ANH.[74]

3. *Critics of Neo-Cortical Death—Misdiagnosis of PVS*

In the early-1990s, neurologist Nancy Childs and her colleagues published a series of important articles in which their studies indicated that almost forty percent of all patients diagnosed as being in either coma or the persistent or permanent vegetative states were misdiagnosed and actually should have been considered minimally conscious.[75] Childs' studies raise pressing concerns for anyone who advocates a PVS or neo-cortical trigger for declaration of death. What if the physician is wrong in his diagnosis? Does not the neo-cortical standard mean that some people actually alive will now be allowed to die, if not be affirmatively killed?

Admittedly, it can be exceptionally hard for neurologists to differentiate between the "severe" MCS patient and the PVS patient. If the same two patients—one with PVS and the other with MCS—moan randomly, have contracted limbs, and do not make purposeful eye contact with their interlocutors, it would be very difficult to distinguish

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[74] *See infra* Part II.B.2.

[75] *See* Nancy L. Childs et al., *Accuracy of Diagnosis of Persistent Vegetative State*, 43 NEUROLOGY 1465 (1993). *See also* Nancy L. Childs & Walt N. Mercer, Ph.D, *Late Improvement in Consciousness after Post-Traumatic Vegetative State*, 334 NEW ENG. J. MED. 24 (1996) (questioning the data on late recovery found in The Multi-Society Task Force's NEW ENGLAND JOURNAL OF MEDICINE article, claiming that late recovery was exceedingly rare, less than 2% of all patients. Although they admit that data are scattered and incomplete, they argue that, in at least one data set of 22 permanently vegetative patients due to traumatic injury, three recovered, making a recovery rate of 14%); Barbara A. Wilson et al., *Cognitive Recovery From 'Persistent Vegetative State': Psychological and Personal Perspectives*, 15 BRAIN INJURY 1083 (2001) (noting a case study of a woman who began to recover after six months from either vegetative state or MCS). *See also* Steven Laureys et al., *Auditory Processing in the Vegetative State*, 123 BRAIN 1589 (2000) (demonstrating that for some vegetative state patients, certain sound stimuli can activate isolated auditory receptors in the brain, but the stimuli cannot induce higher level auditory processing in the brain); S. Laureys et al., *Cortical Processing of Noxious Somatosensory Stimuli in the Persistent Vegetative State*, 17 NEUROIMAGE 732 (2002) (featuring a study in which the authors made painful stimuli to a group of PVS patients, and the painful stimuli activated neurons certain pain receptive sites in the brain, but the activations were not integrated together to produce pain for the patients); Nicholas Schiff et al., *Words without Mind*, 11 J. OF COGNITIVE NEUROSCIENCE 650 (1999) (discussing the case study of a woman in a permanent vegetative state for twenty years who suddenly began to speak random words).

between the two states. Who is to say that the moan from the PVS patient isn't his guttural, though very real attempt to vocalize his thoughts or preferences about a matter? Childs' study highlights the scientific verity that minimal consciousness may indeed be extraordinarily minimal and yet qualify for the diagnosis. That is, there are patients who look exactly like a PVS patient, yet can meet one or more of the MCS diagnostic criteria, thus showing that the parts of their brains that govern conscious thought and responses function, even if only by the slimmest of margins.

Apart from the visceral prudential questions outlined above, Childs draws attention to the fluid nature of consciousness at work in the PVS and MCS conditions. It is true that patients in a PVS can progress into the MCS. It is not true, however, that such progression necessarily will happen. Patients have revived after being declared dead according to the cardio-pulmonary definition of death.[76] Should states then jettison the cardio-pulmonary standard because very few persons declared dead might walk out of the emergency room? That even the possibility exists for a person to emerge from PVS is why the proposal affirms a waiting period for diagnosis and subsequent withdrawal of life-sustaining treatment that is over-protective to the PVS patient.

To this conundrum, two possible solutions exist. First, the criteria for diagnosis of MCS are more nuanced than are the diagnostic criteria for PVS. There are several chances to trigger the MCS diagnosis, while PVS is a dichotomous diagnosis—is the patient awake but not aware, or is he both awake and aware? Perhaps because consciousness is a multi-focal phenomenon (*i.e.*, verbalization, responsiveness, eye-tracking, etc.) there currently exists many times more MCS patients than PVS patients because any one MCS patient has at least one indicia of consciousness, while the PVS patient has none. Second, the consensus diagnostic criteria can be coupled with imaging studies such as the Positron Emission Tomogrpahy (PET) or the functional Magnetic Resonance Imaging (fMRI) that might show the relative cerebral silence of the brain (and by contrast, the cerebral activity of the MCS brain).[77]

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[76] This is called the "Lazarus Phenomenon," after the story in the Gospel of John chapter 11 of Jesus raising from the dead his friend Lazarus of Bethany after Lazarus had been dead for three days. *See John* 11:43-44 (New International Version); *see also* Vedamurthy Adhiyaman et al., *The Lazarus Phenomenon*, 100 J. ROYAL SOC'Y MED. 552 (2007) (describing thirty-eight cases of ROSC, or return of spontaneous circulation after the cessation of cardiopulmonary resuscitation, on average within seven minutes of stopping CPR).

[77] *See infra* Part II.B.1.

C. Plan of Article

This Article will proceed in four parts. After this Introduction in Part I, Part II will discuss MCS as a clinical diagnosis and will contrast it with its better known sister-diagnosis, the persistent vegetative state (PVS) and other "disorders of consciousness," such as coma.[78] Part II will also flesh out the hopeful treatments that are on the horizon for patients with MCS. Part III will provide an overview of the four reported MCS cases currently on the books. All four courts that dealt with MCS patients recognized that clear and convincing evidence is required before the court can sanction removal of the patient's feeding tube. Part IV will elaborate on the societal and jurisprudential stakes involved in discontinuance of treatment from MCS patients, and Part V will briefly conclude the Article.

II. THE MINIMALLY CONSCIOUS PERSON AND POTENTIAL THERAPIES

Though some MCS patients' outward manifestations make it appear that they are in a persistent vegetative state, clinicians have been able distinguish between PVS and MCS.[79] In sum, a patient in the PVS state makes no purposeful movements and has no conscious thought.[80] In contrast, the MCS patient's inner world is largely unquantifiable, though

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[78] The appellation "disorders of consciousness" is widespread in the scientific literature. *See* James L. Bernat, *Chronic Disorders of Consciousness*, 367 LANCET 1181 (2006).

[79] *See* Quenin Noirhomme et al., *A Twitch of Consciousness: Defining the Boundaries of Vegetative and Minimally Conscious States*, 79 J. NEUROLOGY NEUROSURGERY& PSYCHIATRY 741, 741 (2008) (claiming that the clinical diagnosis of the two conditions is difficult because "[i]t is very challenging to differentiate reflex or automatic motor behaviour from movements indicating signs of consciousness, and hence some minimally conscious patients might be misdiagnosed as being vegetative"). For a more fulsome description of the characteristics of PVS, see *infra* Section II.A.3. For the venerable standard for diagnosis of persistent vegetative state is found in The Multi-Society Task Force on PVS, see *Medical Aspects of the Persistent Vegetative State – First of Two Parts*, *supra* note 70, at 1499-1508. For a summary of the characteristics of the minimally conscious state see *infra* Section II.A.3. For a consensus statement for diagnosis of the minimally conscious state, see J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 351 (2002).

[80] Consciousness, according to the two pioneers of the PVS diagnosis, consists of both wakefulness and awareness. *See* Bernat, *supra* note 15, at 1181. On the PVS patient's lack of consciousness, Dr. Bernat holds, "[b]ut to the fullest extent determinable, they lack awareness of themselves and their environment. They cannot think, perceive, feel, or experience. Their wakefulness misleads others to assume they are sentient, yet the most careful bedside testing detects no reproducible and unequivocal evidence of awareness." *Id.* at 1182.

his responses might be subject to scientific calculation.[81] This Part will focus on the scientific etiology of the main devastating neurological conditions, including MCS (and by extension the PVS condition), the diagnostic criteria used to make the MCS determination, the most common day-to-day environment for the MCS patient, and new treatment options available to him.

A. *Devastating Neurological Conditions*

1. *Coma*

i. *Medical Presentation and Prevailing Legal Standards*

Coma is a serious, but transient, neurological condition in which patient is temporarily unable to form conscious thoughts.[82] Comas can last anywhere from days to weeks, and sometimes longer.[83] It is a clinical diagnosis; however, it can be confirmed through the use of an electroencephalogram, which detects certain electrical patterns corresponding to different etiologies.[84] The "depth" of the coma can be measured through tools such as the Glasgow Coma Scale (GCS).[85] As in whole-brain death, the patient's eyes are closed.[86] Comas often last only

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[81] *See id.* at 1183 ("[The Aspen Neurobeavioral Conference that formulated diagnostic measures for MCS] emphasized the qualitative difference between patients in minimally conscious state and vegetative state: although patients in both conditions are poorly responsive, those in a minimally conscious state retain measureable evidence of awareness whereas those in a vegetative state do not."). However, Dr. Bernat quickly refines his assessment of the minimally conscious state as one of minimal responsiveness rather than minimal consciousness ("[A]lthough patients in a minimally conscious state had markedly impaired responsiveness but demonstrable awareness, it did not necessarily follow that their consciousness was minimal, as implied by the name of the diagnosis. A more accurate term for them is minimally responsive state, as used in earlier reports of these patients."). *Id.*

[82] *See* David E. Bateman, *Neurological Assessment of Coma*, 71 J. OF NEUROLOGY NEUROSURGERY & PSYCHIATRY 113 (2001).

[83] *See* Steven Laureys, Melanie Boy & Pierre Maquet, *Tracking the Recovery of Consciousness from Coma*, 116 J. CLINICAL INVESTIGATION 1823 (2006).

[84] *See* Christopher M. DeGiorgio, M.D. & Mark F. Lew, M.D., *Consciousness, Coma and the Vegetative State: Physical Basis and Definitional Character*, 6 ISSUES L. & MED., 361, 363-67 (1990).

[85] The GCS is the most prominent scale used to determine the depth of coma. *See* Bryan Jennett, *The Glasgow Coma Scale: History and Current Practice*, 4 TRAUMA 91, 93 (2002). For a reproduction of the clinical chart used to record the measurements of the GCS at the institution at which it was invented, Glasgow, Scotland's Institute of Neurological Sciences, see *id.* at 97.

[86] *See* Stephen Laureys, Adrian M. Owen & Nicholas D. Schiff, *Brain Function in Coma, Vegetative, State, and Related Disorders*, 3 LANCET NEUROLOGY 537, 538 (2004).

a few weeks, and "patients can recover completely from a coma or progress from there to the vegetative state."[87]

Coma is occasioned by any of several possible causes, but the three of the main causes are drug overdose, traumatic brain injury, and cardiac arrest.[88] Other leading causes are hepatic (liver) disease, alcoholism, intracerebral hematoma, subdural hematoma, and brain infarct.[89]

Patients have a better chance of recovering from comas caused by metabolic or toxic factors than they do from those brought on by lack of oxygen.[90] Those occasioned by traumatic brain injury fall in between the metabolic and anoxic prognoses.[91] If patients do not exhibit certain reflexes within the first hours of onset, it is unlikely that they will ever recover.[92] Some patients will transition from coma to the persistent vegetative state.[93]

Unsurprisingly, the state courts have evaluated allegedly comatose patients who sought removal of life-sustaining treatment through the agency of their surrogate. Interestingly, though, all of these patients were either in the persistent vegetative state, or the court recognized that at the time of the court's judgment, the patient soon would transition to the persistent vegetative state. Such classifications and semantic divides did little to courts' ultimate outcomes. Uniformly, these courts allowed life-sustaining treatment to be withdrawn from patients on a variety of theories, including that the withdrawal would be in the patient's best interests to the conclusion that the patients, if able to choose for themselves, would choose to withdraw life support and proceed to death.[94]

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[87] Joseph J. Fins, *Neuroethics and Neuroimaging: Moving Toward Transparency*, 8 AM. J. BIOETHICS 46, 47 (2008).

[88] *See* DeGiorgio, M.D. & Lew, *supra* note 84, at 361. *But see* ALLAN H. ROPPER & ROBERT H. BROWN, ADAMS AND VICTOR'S PRINCIPLES OF NEUROLOGY 302 (8th ed. 2005) (claiming that the main textbook on coma attributed only six percent of comas to traumatic brain injury).

[89] *See id.*

[90] *See id.* at 320.

[91] *See id.*

[92] *See id.*

[93] *See id.*

[94] *See, e.g.*, Eichner v. Dillon, 73 A.D.2d 431, 434-469 (N.Y.A.D. 1980) (describing patient to be in a "chronic vegetative coma," or "permanent vegetative coma" and holding that clear and convincing evidence was presented that the patient would want to have life support removed). *See also* Care and Protection of Beth, 587 N.E.2d 1377 (Mass. 1992) (describing child to be in a "persistent vegetative coma" and holding that it was in her best interests to have life-sustaining treatment removed and be allowed to die); *In re* Guardianship of Barry, 445 So.2d 365 (Fla. Dist. Ct. App. 1984) (describing child's state as a coma, while the trial court described child as in a vegetative state).

ii. Discussion

Though it is cliché to restate that all disorders of consciousness are not the same, the scientific differences between the disorders highlight the need for discrimination in the evidentiary standards used by courts in decisions to withdraw life-sustaining treatment. Coma lays bare the difficulty in choosing those evidentiary standards. The two main features of coma are that the patient's eyes are closed and that it is a transient state. But for the patient's spontaneous breathing and heartbeat, the patient appears to be dead according to a workaday vision of death in which the deceased is on his back with his eyes closed. That coma is transient can comfort the family but has the concomitant potential to multiply the consternation among family members. When will the patient wake up and resume the activities of living? Will he ever wake up again?

Though the condition is transient, but of unknown duration, courts would do better to keep stringent evidentiary and substantive standards. If the unifying principle of this Article is that dead people should not have their vegetative functions maintained, while those who are not dead should receive the law's most vigorous protections unless their *bona fide* choice is to die, then coma should be pegged somewhere between PVS and MCS. Coma is like PVS in that the patient makes no meaningful response to stimuli—in fact, she makes no response at all. The patient is completely still and lies flat on his back. Coma is like MCS because patient's capacity for a robust recovery is great. Further, the condition is more like MCS because the centers of cognition in the patient's brain are damaged, but not dead. The patient will wake up someday—whether a week or twenty years from onset, or he will progress to a vegetative state. Therefore, notwithstanding a real and actual choice for withdrawal of life-sustaining treatment by the patient, if care is actually withdrawn it could look more like an active, willful participation in euthanasia because the patient is not actually dead, as he is in the PVS.

But, if courts continue to uphold the autonomy principle as the primary organizing idea of end-of-life decision making, then they should not have too much consternation with enforcing high substantive and procedural decision making standards (like the clear and convincing and subjective standards) for coma diagnoses. The American people have been enculturated to the diagnosis of coma, and furthermore they have the wherewithal to voice their own preferences concerning the diagnosis. It is not outside of pedestrian knowledge for a person to say to his loved ones: "If I am ever in a coma, I do not want to be maintained on life support." The coma diagnosis is not as exotic as is the diagnosis of MCS or the locked-in state. Of course, like any disorder of consciousness, courts must be very circumspect if the patient's wishes entail the desire to not be a burden or drain on their family or friends. Even with such a vague expressed desire, courts should retreat to the clear and convincing and subjective standards. The argument is similar to that of MCS, discussed below, but not quite the same. In MCS, the patient is currently conscious, and sustained consciousness, however diminished, is the fulcrum upon which the definition of life rests. At the same time, the MCS patient has the latent capacity to recover to a normal, though somewhat moderated state of functioning. Contrarily, the coma patient is not conscious, and therefore cannot display any of the clinical indicia of consciousness (*e.g.*, responsiveness to verbal or tactile stimuli, gestures, etc.). But, like the MCS patient, the coma patient has the capacity to "wake up" to not only the diminished level of functioning characteristic of patients coming out of a MCS, but to a fuller level of functioning that is closer to normal.

2. *The Minimally Conscious State*

The minimally conscious state is qualitatively different from both the persistent vegetative state and whole brain death. In MCS, the patient's cognitive center, while damaged, is not entirely destroyed, for the MCS patient can still cogitate—though for some this is on an intermittent level.[95] Further, some patients can express their wills through gestures and movements and can intelligently verbally communicate with an interlocutor.[96]

The diagnosis of MCS is relatively straightforward for the clinician. Consensus was reached on diagnostic standards for MCS during meetings of the Aspen (Colorado) Neurobehavioral Conference Workgroup (Aspen Workgroup) during meetings between 1995 and 2000.[97] The Aspen Workgroup concluded that the MCS patient must

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[95] *See* Joseph Giacino & John Whyte, *The Vegetative and Minimally Conscious States: Current Knowledge and Remaining Questions*, 20 J. HEAD TRAUMA REHABILITATION 30, 33 (2005) (noting that "[t]he diagnosis of MCS is based on demonstrating the presence of specific behavioral manifestations of conscious awareness. These behaviors occur inconsistently but must be differentiated reliably from reflexive and random spontaneous behavior").

[96] *See* J.T. Giacino et al., *The Minimally Conscious State: Definitions and Diagnostic Criteria*, *supra* note 79, at 350-51.

[97] *See id.* at 350. The medical societies contributing to the consensus statements found in the article are: the American Academy of Neurology (which recommended the article to its members as an "educational tool"), the American Academy of Physical Medicine and Rehabilitation, the American Assoication of Neurological Surgeons, the American Congress of Rehabilitation Medicine, the Brain Injury Association, Inc., and the Child Neurology Society. *See id.* at 349.

display at least one of the following characteristics in order to qualify for MCS:

- Following simple commands;
- Gestural or verbal yes/no responses (regardless of accuracy);
- Intelligible verbalization;
- Purposeful behavior, including movements or affective behaviors that occur in contingent relation to relevant environmental stimuli and are not due to reflexive activity. Some examples of qualifying purposeful behavior include:
    - Appropriate smiling or crying in response to the linguistic or visual content of emotional but not to neutral topics or stimuli;
    - Vocalizations or gestures that occur in direct response to the linguistic content of questions;
    - Reaching for objects that demonstrates a clear relationship between object location and direction of reach;
    - Touching or holding objects in a manner that accommodates the size and shape of the object;
    - Pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli.[98]

The threshold for the MCS diagnosis is quite low. The patient, as mentioned above, has to display only one of the aforementioned movements/statements in order to qualify for MCS.[99]

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[98] *Id.* at 351.

> In view of the absence of a gold standard to "prove" the presence or absence of consciousness, the boundaries that have been established to demarcate VS, MCS and emergence from MCS are necessarily arbitrary. Nevertheless, beahaviourally-based operational criteria are required to provide a standard nomenclature for use in routine clinical care and in research.

Id. See also Joseph T. Giacino & Kathleen Kalmar, *Diagnostic and Prognostic Guidelines for the Vegetative and Minimally Conscious States*, 15 NEUROPSYCHOLOGICAL REHABILITATION 166, 169 (2005).

[99] The consensus authors acknowledge that some MCS patients display more than one of the behaviors outlined in the diagnostic tool:

> Although it is not uncommon for individuals in MCS to demonstrate more than one of the above criteria, in some patients the evidence is limited to only one behavior that is indicative of consciousness. Clinical judgments concerning a patient's level of consciousness depend on inferences drawn from observed behavior. Thus, sensory deficits, motor dysfunction, or diminished drive may result in underestimation of cognitive capacity.

Scientists agree that MCS is usually caused, like its cousin diagnosis, PVS, by either anoxia due to cardiac arrest, traumatic brain injury, or injury to the brain's thalamus.[100] Though head trauma can cause the same effects to the brain as anoxia, scientists maintain that the trauma patient has a better chance of completely recovering in a quicker amount of time than does the anoxic patient.[101]

3. *The Persistent Vegetative State*

The characteristics of the persistent vegetative state are very similar to those of the MCS. Unlike MCS, where the patient can at least sporadically form conscious thoughts, the PVS patient cannot cogitate at all. He is utterly unaware of time, his physical surroundings, the interventions made on his behalf to sustain his body (*e.g.*, his feeding tube), or the imprecations and interactions of caregivers and loved ones.[102] Though the PVS patient's eyes are open during his wake cycles and he retains a startled reflex, such outward manifestations are not connected to conscious thought.[103] If, as some commentators maintain, that the ability to form conscious thought is the *sine qua non* of the person, then the PVS patient's "person" is gone, and what is left is the exterior shell (the body) that houses the patient's badly damaged brain.[104] PVS has been called, as discussed above, "neocortical death."[105]

Giacino et al., *supra* note 79, at 351.

[100] ROPPER & BROWN, *supra* note 88, at 304.

[101] Giacino & Kalmar, *supra* note 98, at 172.

[102] According to Wijdicks and Cranford, "[A] PVS can be described as a state of 'wakeful awareness,' 'eyes open unconsciousness,' or 'being awake but unaware.'" Eelco F.M. Wijdicks, M.D. & Ronald E. Cranford, *Clinical Diagnosis of Prolonged States of Impaired Consciousness in Adults*, 80 MAYO CLINIC PROCEEDINGS 1037, 1037 (2005).

[103] *See id.* at 1038.

[104] For purposes of argument in this Article, I set forth the personhood argument proffered by many bioethicists and legal academics. *See, e.g.*, Jonathan Herring, *Entering the Fog: On the Boderlines of Mental Capacity*, 83 IND. L.J. 1619, 1639 (2008) (describing the capacities of persons suffering from dementia).

> [A]s is well known, Derek Parfit, building on the work of John Locke, has argued that central to personhood is consciousness and psychological awareness. Where a person loses capacity this can cause a loss of psychological continuity. Where the person has no recollection of who they were and loses connections with the values which governed their life then they have, in effect, become a different person.

Id. A more recent discussion of consciousness and personhood took place within the September 2008 issue of The *American Journal of Bioethics* in its issue on "Consciousness, Imaging, Ethics, and the Injured Brain." *See* Dominic Wilkinson, Guy Kahane, and Julian Savulescu, *"Neglected Personhood" and Neglected Questions: Remarks on the Moral Significance of Consciousness*, 8 AM. J. BIOETHICS 31 (2008). As discussed in Section I.B.1., *supra*, I reserve judgment, however, on the moral propriety of

Etiologically, the causes of PVS are practically the same to those of MCS. PVS is caused either by anoxia or blunt force head trauma. The difference, of course, between the two diagnoses is the severity of harm to the patient's cognitive centers.[106] With MCS, the patient's neocortex retains some of its cognition-producing properties, while PVS patients have lost all such abilities. Clinicians are willing to wait one month after the onset of conscious deficit before making a diagnosis of *persistent* vegetative state.[107] A diagnosis of permanent vegetative state is made after six months for patients whose vegetative state is brought on by anoxia and other causes and one year for patients whose condition is caused by traumatic brain injury.[108]

4. Locked-In Syndrome

i. Medical Presentation and Prevailing Legal Standards

The 'locked-in' state is very similar to MCS but is not quite the same. Locked-in patients cannot move their extremities, and their only means of communication is to blink their eyes.[109] There are multiple causes for locked-in syndrome, including tumors, hemorrhaging, and brain lesions and abscesses.[110] Nevertheless, the hallmark of the locked-in state is the patient's utter inability to verbally communicate, yet she retains cognitive abilities.[111]

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personhood argument, as the force of this argument comes dangerously close to devaluing human beings *qua* humans. Further, I report it as a philosophical position undergirding others' arguments to demonstrate what I believe to be the strength of the case for robust protections for MCS patients. That is, if it is true, as some claim, that the PVS patient has lost all ability to cogitate, and therefore the essence of what makes them a 'person,' then the MCS patient has not lost the ability to cogitate (though to be fair, in many cases of MCS it is profoundly damaged) and therefore has not lost the essence of what makes them a 'person.' *See infra* Part IV.B.

[105] Wijdicks & Cranford, *supra* note 102, at 1037.

[106] ROPPER & BROWN, *supra* note 88, at 305.

[107] Wijdicks & Cranford, *supra* note 102, at 1038.

[108] *See id.*

[109] *See* Paul Breen & Vincent Hannon, *Locked-In Syndrome: A Catastrophic Complication After Surgery*, 92 BRIT. J. ANESTHESIA 286 (2004). *But see* James R. Patterson, M.D. & Martin Grabois, M.D., *Locked-In Syndrome: A Review of 139 Cases*, 17 STROKE 758, 758 (1986) (delineating between the "[i]ncomplete" type of locked-in syndrome, where patients "have remnants of voluntary motion besides upper eyelid and vertical eye movement," and "[t]he total variety [which] is composed of... patients who are totally immobile, and are unable to communicate").

[110] *See* Breen & Hannon, *supra* note 109, at 287.

[111] *See id.* at 286. Recovery is rare in the locked-in state. *See id* at 287. *But see* Patterson & Grabois, *supra* note 109 (delineating between the "Incomplete" type of

Courts that have taken up end-of-life cases involving patients in the locked-in state have allowed life support devices to be removed so that the patient could die.[112]

ii. Discussion

The locked-in condition, like coma, poses some very thorny issues in courts' quests to fashion a just and compassionate evidentiary standard when the patient has not pre-determined his end-of-life wishes through a living will or other written advanced directive. Because the locked-in patient is fully conscious, just like the person of normal functioning, there is no question that the patient is "alive" according to the neocortical standard of death. However, his outward functioning appears much like that of the late stage patient with amyotrophic lateral sclerosis (ALS or Lou Gehrig's Disease)—a disease that progressively robs the body of all ability to move. The locked-in patient can move nothing but his eyelids to respond to tactile or verbal stimuli. However, unlike the ALS patient, the locked-in patient does not necessarily have an invariably fatal degenerative condition that will certainly claim his life.[113] Rather, he has a disorder that affects his brain and its ability to command the body's extremities and vocal apparatus. Like in PVS and MCS, the locked-in patient's bodily functions may be sustained indefinitely with artificial nutrition and hydration. Unlike PVS, however, the locked-in patient's consciousness is undisturbed. What then does this mean for the prudential, evidentiary protections that govern the withdrawal of life-sustaining treatment?

The simple answer, of course, is that that because the patient's "life switch" is still in the "on" position, she should be afforded the most restrictive protections before she may be disconnected from life-

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locked-in syndrome, where patients "have remnants of voluntary motion besides upper eyelid and vertical eye movement," and "[t]he Total variety [which] is composed of . . . patients who are totally immobile, and are unable to communicate").

[112] *See In re* Howe, No. 03-P-1255, 2004 WL 1446057 (Mass. Prob. & Fam. Ct. 2004) (shifting the proxy's focus from the locked-in patient's actual wishes to her best interests, as required by the state's proxy statute); McKay v. Bergstedt, 801 P.2d 617 (Nev. 1990) (affirming the decision of a man in a locked-in state to have his life support removed). *But cf. In re* Quinlan, 348 A.2d 801 (N.J. Super. Ct. Ch. Div. 1975) (declaring that Karen Ann Quinlan was not in a locked-in state).

[113] For a description of the symptoms associated with Lou Gehrig's Disease, see ALS Association, http://www.alsa.org/als/symptoms.cfm (last visited Nov. 1, 2009). For an example of a patient described as being in the locked-in state due to the degenerative work of ALS, see *In re Howe*, 2004 WL 1446057 (ordering decisions about the patient's care were to be made through the proxy's use of a best interests decision-making standard even though the patient had vociferously requested heroic measures to keep her alive).

sustaining treatment. In order for a more relaxed standard to apply, one must argue, as he would with coma, that the patient's devastated outward physical aptitudes trump his life-essence; his consciousness. Stated differently, the patient's complete inability to use his arms, legs, or neck so clearly eviscerates the *living of his life* that consciousness is of no use to him. Such an argument, however, highlights the consequentialism rife in quality of life arguments, for that is, in essence, the *living the life* argument. It is the personhood argument. If the locked-in patient cannot bring about a good consequence such as vigorous use of his extremities for his own chosen ends, then his life has little or no quality, and thus little or no meaning. Life, in other words, consists in how vigorously a person can use his body for his own chosen goals. Sapient existence does not have value apart from this. It is possible that some, perhaps many, locked-in patients would steer the ships of their lives on that track. However, to presume that all patients would be so abjectly fatalistic misses the good that is in life itself. The able-bodied person cannot either discern or disprove the rich and complicated thought-world that the locked-in patient can create for himself. Granted, the locked-in patient could deem himself a prisoner of his own thoughts. Even in the macabre, weird, and seemingly senseless world of the locked-in patient, should not the starting point, the presumption, be tilted toward maintaining the life, the consciousness that is preserved within the rusting shell of his body? Further, the consciousness argument is not trumped in any way by the patient's complete inability to ever again use his purely physical abilities. The locked-in patient cannot be brought out of the locked-in state. The MCS patient can be brought out of his state (though the argument for heightened protection does not turn on this possibility). If life, as mediated through sustained consciousness, is the pivot point of human existence, then the decision to protect life is dichotomous—it is either given high protections, that cannot be easily, if ever breached—or it is not, and the patient can be transitioned into death upon the slimmest of evidence.

Evidentiary and substantive end-of-life standards correlate to the passive role the patient takes in letting disease overmaster him. The disease or disorder can be fully unleashed upon the patient or it can be held (sometimes indefinitely) at bay. A court filters the oral evidence through the received standards, and *presto!* the patient is allowed to remain alive or is allowed to die. As described above, locked-in patients should receive, at least, the most aggressive civil evidentiary and substantive standards because the locked-in patient is still alive. Could one not say for the locked-in state (and the MCS for that matter), that no substantive or evidentiary standards should ever be applied because to utilize substantive and evidentiary standards is to allow the possibility of withdrawal of treatment? The case is not close with the locked-in patient. He is fully alive, fully conscious. To withdraw nutrition and hydration is to euthanize the patient—voluntarily if chosen by the patient and involuntarily if chosen by someone else. How else could the withdrawal of nutrition and hydration be viewed? The patient has every essential element of human life, namely, sentience. Viewing the prospect of euthanizing the locked-in patient only highlights the personhood/quality of life argument with more alacrity. The patient must not be merely allowed to die if he is in the locked-in condition. His food and water should not be withdrawn for the purpose of causing his death when it otherwise would not occur through the inevitable decline of the disease process. In fact, "artificial nutrition and hydration"—or "life-sustaining treatment"—is stretched to its breaking point when applied to the locked-in (and MCS) patients. The Ensure® and saline water running through the locked-in patient's gastrostomy tube does not sustain an artificial person. They sustain a badly deformed person, but a person nonetheless, who has lost the ability to eat.

5. *Whole Brain Death*

On the continuum of severe brain damage, whole brain death is the direst condition. Brain death means that both the cerebellum and the brain stem have stopped working, thus requiring mechanical help to keep the patient's heart and lungs pumping.[114] Brain death, like a coma, is an "eyes closed" condition, and the patient cannot make any conscious thoughts, and to the chagrin of many families, never has the hope of ever thinking or willing again.[115] Brain death, like cardio-pulmonary death, is recognized as "death" in every state of the Union.[116] If necessary, for

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[114] *See* ROPPER & BROWN, *supra* note 88, at 306.

[115] *See generally* Eelco F.M. Wijdicks, M.D., *The Diagnosis of Brain Death*, 344 NEW ENG. J. MED. 1215, 1216 (2001) (reciting that coma is one of many criteria required for the diagnosis of brain death); Albert R. Jonsen, *Encephaloethics: A History of the Ethics of the Brain*, 8 AM. J. BIOETHICS 37, 37-40 (2008) (providing a brief history of the brain death diagnosis).

[116] *See* MEISEL & CERMINARA, *supra* note 30, § 6.04[A][1][a] (Table 6.4) (providing the citations to adoptions of brain death standards in the several states). The Uniform Determination of Death Act (stating that "[a]n individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem is dead. A determination of death must be made in accordance with accepted medical standards."). Unif. Determination of Death Act §1, 12A U.L.A. 781 (1980). This Act has been adopted by a majority of the states. *See* The National Conference of Commissioners on Uniform State Laws, "A Few Facts About . . . The Uniform Determination of Death Act," *available at*

some reason like perfusion to maintain transplantable organs before excision, the brain dead person's respiration may be maintained through mechanical ventilation.[117]

Like both MCS and PVS, whole brain death is a clinical diagnosis that can be made by a physician's observation of a patient in conjunction with medical tests.[118] The most common test used to confirm a diagnosis of brain death is the electroencephalogram (EEG), which can show "electrical silence" in the brain.[119]

State courts have both adopted the definition of brain death found in the Uniform Determination of Death Act, and they have allowed hospitals to withdraw life-sustaining treatment on the basis of the patient's real and actual death.[120]

B. Looking Into the MCS Patient's Brain and Therapies for the Condition

Of all the serious neurological conditions caused by oxygen deficit or brain injury, MCS offers the best hope of recovery into a semi-normal condition. Academic neurologists have identified several types of imaging studies that can pinpoint the structures in the brains of MCS patients that may survive brain injury or anoxia. Further two potential

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http://www.nccusl.org/Update/uniformact_summaries/uniformacts-s-udoda.asp (last visited Nov. 1, 2009).

[117] *See generally* Robert D. Truog, M.D. & Franklin G. Miller, Ph.D, *The Dead Donor Rule and Organ Transplantation*, 359 NEW ENG. J. MED. 674 (2008).

[118] *See* ROPPER & BROWN, *supra* note 89, at 306.

[119] *See id.* at 306-07.

[120] *See* MEISEL & CERMINARA, *supra* note 30, § 6.04[A][6]; Law v. Camp, 116 F. Supp. 2d 295 (D. Conn. 2000) (holding that standard of care for deciding brain death was not established by state statute for deciding when to remove life-sustaining treatment thus plaintiff could not maintain her negligence *per se* claim); Alvarado v. New York City Health & Hosps. Corp., 547 N.Y.S.2d 190, 198 (N.Y. Sup. Ct. 1989), *vacated* by 550 N.Y.S.2d 353, 354 (N.Y. App. Div. 1990) (holding that procedures for determination of brain death outlined in a New York regulation were properly activated by the hospital, thus the court could not interfere with the hospital's decision to withhold life-sustaining treatment; Dority v. Superior Court, 193 Cal. Rptr 288, 292 (Cal. App. 1983) (holding that judicial sanction is not required to remove life-sustaining treatment "where the health care provider and the party having standing to represent the person allegedly declared to be brain dead are in accord brain death has occurred"); *In re* Haymer, 450 N.E.2d 940, 945 (Ill. App. Ct. 1983) (adopting brain death as a *bona fide* definition of death); *In re* Bowman, 617 P.2d 731 (Wash. 1980) (en banc) (adopting the definition death found in the Uniform Determination of Death Act); Lovato v. District Court, 601 P.2d 1072, 1081 (Colo. 1979) (en banc) (recognizing brain death alongside cardio-pulmonary death as a legitimate definition of death); State v. Fierro, 603 P.2d 74, 77, 78 (Ariz. 1979) (adopting what would become the standard of brain death in the Uniform Determination of Death Act).

therapies—one pharmacological and the other mechanical—show promise in lifting the patient to where he can robustly interact with his environment.

1. *Imaging Studies*[121]

Henning Voss, a radiologist at Weill Medical College of Cornell University in New York City, and his colleagues performed a unique imaging study, magnetic resonance diffusion tensor imaging (DTI) on two MCS patients. DTI is different from most other imaging mechanisms in that it is "capable of characterizing specific white matter pathologies such as atrophy and diffuse axonal injury."[122] Simply, DTI is able to show the extent of atrophy for a certain type of brain tissue and also injuries to the fibrous, web-like nerve tissue, called axons. Voss' team used the DTI modality on Terry Wallis, a man who progressively roused out of his MCS after nineteen years and another man who was in a MCS for six years.[123] With a baseline DTI study and a second DTI eighteen months after the first, Voss and his team were able to conclude that some of Terry Wallis' axons, damaged during the pendency of his profound brain injury, had regrown.[124]

Other imaging studies show the responsiveness and organic work of the brain, even in a minimally conscious state. For example, Nicholas Schiff and his colleagues performed fMRI on two MCS research subjects and reported that, as compared to the study's control subjects, the MCS patients showed similar brain activity with respect to "passive listening and tactile stimulation tasks."[125] There were, however, notable differences between the MCS brains and the control group brains.[126]

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[121] Joseph Fins and colleagues give a truncated list of the neuroimaging studies performed on MCS and vegetative state patients to date. *See* Joseph J. Fins et al., *Neuroimaging and Disorders of Consciousness: Envisioning an Ethical Research Agenda*, 8 AM. J. BIOETHICS 3, 7 (2008). This subsection will describe just a few of the research projects involving imaging studies of MCS patients.

[122] Henning Voss et al., *Possible Axonal Regrowth in Late Recovery from the Minimally Conscious State*, 116 J. CLINICAL INVESTIGATION 2005, 2005 (2006).

[123] Susan Jeffrey, *Neuroimaging of Recovery From Minimally Conscious State Suggests Late Regeneration*, MEDSCAPE MEDICAL NEWS, Jul. 7, 2006, *available at* http://www.medscape.com/viewarticle/540249; *see also* Voss et al., *supra* note 122, at 2006.

[124] *See* Voss et al., *supra* note 122, at 2009.

[125] N.D. Schiff, M.D. et al., *fMRI Reveals Large-Scale Network Activation in Minimally Conscious Patients*, 64 NEUROLOGY 514, 519 (2005). The authors go on to state that "[t]aken together with the inconsistent evidence of receptive and expressive language skills evident in the bedside examinations of these patients, the fMRI findings demonstrate an unexpectedly consistent language-response network." *Id.* at 521. One of

2. *Mechanical Approaches*

Joseph Fins and his colleagues at Cornell's Medical School conducted deep brain stimulation (DBS) upon a thirty-eight year old man in a MCS.[127] The deep brain stimulation procedure consists of placing an electrode deep into the patient's brain until it reaches the thalamus. The results of the therapy were astounding. After the DBS procedure, the patient was able to eat by mouth, his verbal skills improved, and he responded to an old nickname.[128] It is important to note, though, that as of the publication of the *Nature* article, Dr. Fins and his colleagues had performed the DBS procedure on just one patient, and Fins himself noted that "the generalizability of the results is unknown, and expectations raised by this report should be tempered."[129]

Certain drugs have shown some success in bringing students to higher levels of consciousness. The compound zolpidem, found in the sleep-inducing drug, Ambien, has shown a promise in studies in helping patients recover to fuller awareness.[130] In one very small study, the daily application of zolpidem brought patients from significant impairment, as measured by the Glasgow Coma Scale, to significant improvement. Importantly, the drug had to be used every day in order for the patient to receive the intended benefits.[131] However, another, more rigorous double-blinded study, showed that only a small minority of patients were

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the most fascinating imaging studies was performed on vegetative state patients, yet there could be overlap to MCS patients. Adrian Owen and his colleagues performed fMRIs on vegetative patients, and he asked the study participants to think about playing tennis or walking through their house. The results of the scans showed brain activity that was practically indistinguishable from activity of a healthy person. Adrian Owen et al., *Using Functional Magnetic Resonance Imaging to Detect Covert Awareness in the Vegetative State*, 64 ARCHIVES NEUROLOGY 1098, 1099-1100 (2007). *See also* M. Uzan et al., *Thalamic Proton Magnetic Resonance Spectroscopy in Vegetative State Induced by Traumatic Brain Injury*, 74 J. NEUROLOGY NEUROSURGERY & PSYCHIATRY 33, 36-37 (2003) (demonstrating magnetic resonance spectroscopy to be effective in determining brain function for patients in the vegetative state).

[126] *See* N.D. Schiff, M.D. et al., *supra* note 125, at 519-22.

[127] *Minimally Conscious Patient Makes Strides Following Deep Brain Stimulation*, 15 NEUROLOGY REV. (2007), *available at* http://www.neurologyreviews-.com/07sep/dbs.html (discussing the underlying study article in the August 2, 2007 edition of *Nature* by Joseph Fins).

[128] *See id.*

[129] *Id.*

[130] *See, e.g.*, Ralf Clauss & Wally Nel, *Drug Induced Arousal From the Persistent Vegetative State*, 21 NEUROREHABILITATION 23-25 (2006) (claiming that three patients were brought out of the PVS to interact with their environments after administration of zolpidem).

[131] *See id.* at 25.

transitioned from PVS to MCS by using zolpidem.[132] The vast majority of drug recipients did not show any cognitive improvement from using the drug.[133] Additionally, researchers from Japan have experimented with the compound levodopa (L-dopa), and it has had some success in bringing PVS and MCS patients out of their respective states.[134] L-dopa has worked best for patients with Parkinson's Disease-like symptoms.[135]

To date, and to this author's knowledge, neither zolpidem, levodopa, amantadine, or any other potential therapy has gained across-the-board clinical use. Further, zolpidem seems to have mixed results in awakening PVS patients (and bringing MCS patients to fuller manifestations of their consciousness). If, or when, such therapies do become used widely and have consistently positive results in revivifying PVS patients, it will be necessary to reconsider this Article's thesis that patients in a permanent vegetative state are truly dead and their artificial nutrition and hydration should be allowed to be removed. Until that time exists, it remains appropriate to contend that the permanently vegetative person, with no levels of cognition or consciousness whatsoever, is dead, while the minimally conscious person is very much alive, though he displays muted phenomenological responses to outside stimuli. However, a compromise position is to give the permanently vegetative person a

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[132] *See* John Whyte, M.D., Ph.D & Robin Myers, PT, NCS, *Incidence of Clinically Significant Responses to Zolpidem Among Patients with Disorders of Consciousness: a Preliminary Placebo Controlled Trial*, 88 AM. J. PHYSICAL MED. REHABILITATION 410, 417 (2009).

[133] *See id.* at 417; *see also* Rajiv Singh et al., 22 BRAIN INJURY 103, 104 (2008) (describing a forty-four year old minimally conscious male who was not helped, and even hurt, by administration of zolpidem). *But see* Jeffrey L. Shames, M.D. & Haim Ring, M.D., *Transient Reversal of Anoxic Brain Injury—Related Minimally Conscious State After Zolpidem Administration: A Case Report*, 89 ARCHIVED PHYSICAL MED. REHABILITATION 386, 387 (2008) (describing a MCS patient who dramatically improved with the administration of zolpidem). *See also* C. Schnackers et al., *Measuring the Effect of Amantadine in Chronic Anoxic Minimally Conscious State*, 79 J. NEUROLOGY NEUROSURGERY & PSYCHIATRY 225, 226 (2008) (reporting dramatic cognitive improvement in a twenty-eight year old patient given the Parkinson's drug amantadine).

[134] *See generally* Wakoto Matsuda et al., *Levodopa Treatment for Patients in Persistent Vegetative or Minimally Conscious States*, 15 NEUROPSYCHOLOGY REHABILITATION 414 (2005); Wakoto Matsuda et al., *Awakenings from Persistent Vegetative State: Report of Three Cases with Parkinsonism and Brain Stem Lesions on MRI*, 75 J. NEUROLOGY NEUROSURGERY & PSYCHIATRY 1571, 1572 (2003).

[135] *See* Matsuda et al., *Levodopa Treatment for Patients, in Persistent Vegetative or Minimally Conscious States*, *supra* note 134, at 416, 418; *see also* Ben-Zion Krimchansky et al., *Differential Time and Related Appearance of Signs, Indicating Improvement in the State of Consciousness in Vegetative State Traumatic Brain Injury (VS-TBI) Patients After Initiation of Dopamine Treatment*, 18 BRAIN INJURY 1099, 1101 (2004).

course of one or more of the aforementioned drug therapies to see if he or she responds. If the patient responds and raises out of his blanket of unconsciousness, then he should be accorded the respect, care, and nurture due to minimally conscious patients.

III. THE MINIMALLY CONSCIOUS CASE LAW

A. *Generally*

To date, there have been very few cases that deal with the ultimate disposition of a minimally conscious person. The four cases that do exist follow a relatively set pattern: the patient has suffered a severe injury to his brain or has some debilitating brain disease; after a period of waiting, he is diagnosed as being in a profoundly injured or minimally conscious state. The patient's ability to conduct activities of daily living is greatly diminished, but he still retains the ability to form at least some conscious thoughts. His physical life is not pretty—spasms, incontinence, unintelligible communication, and pain that he cannot adequately describe—fill his days.[136]

The reason that the cases involving MCS patients find their ultimate resolution in state supreme courts is that the patient did not adequately predetermine his wishes by executing an advanced directive, like a living will. Such a written document would be viewed as conclusive proof of the patient's final wishes in most every state of the Union.[137] Though none of the patients in the MCS cases wrote living wills or durable powers of attorney for healthcare, many of them did express some oral wishes that they did not want their corporeal existences to be maintained if it would mean that they had to live like a "vegetable" for the rest of their days. Importantly, many of the MCS patients expressed their revulsion after seeing a PVS patient's contorted body or vapid stare. However, the patients' trepidation at never devolving to the PVS level of existence was a generalized disdain and never amounted to a specific repudiation of living in a MCS state. But, because the patients did not solemnize their wishes in a written advanced directive, they opened the door for close relatives' desire to keep their loved ones alive indefinitely.

Furthermore, in all four of the MCS cases, the state supreme courts retrenched and devolved to the most restrictive civil standard of

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[136] *See generally* 60 MINUTES, *Awakenings: Return to Life*, *supra* note 1.

[137] Each state in the United States has a statute authorizing healthcare powers of attorney and forty-seven states have statutes authorizing living wills. Further, "[a] directive that meets the requirements of a state's legislation is valid and enforceable." MEISEL & CERMINARA, *supra* note 30, § 7.02[D].

evidence—the "clear and convincing" standard—which requires a greater quantum of evidence before the factfinder can deem the question before it "proved" and the "subjective" substantive standard.[138] In each of the four MCS cases, the matter before the factfinder (and ultimately the respective state supreme courts) was whether the patient's wishes were clear and articulate enough to warrant discontinuing life sustaining treatment in the form of a medically placed feeding tube, and further, whether the patient left precise instructions, at all, to discontinue life-sustaining treatment.[139]

B. The Cases

1. In re Conroy

Only nine years after taking up Karen Ann Quinlan's case,[140] the New Jersey Supreme Court decided the case of Claire Conroy, an eighty-four year old single woman, who had fallen into an organic brain syndrome "that manifested itself in her exhibiting periodic confusion, [and she] was adjudicated incompetent."[141] Her nephew, also her guardian, shuffled her off to a nursing home, and upon admission, Ms. Conroy could walk, talk, and "follow directions . . . and was in relatively good condition," but her condition then declined precipitously after admission.[142] Subsequent to her nursing home admission, she was twice admitted to the hospital to treat a urinary tract infection, elevated body temperature, dehydration, and gangrene.[143] Ms. Conroy's nephew did not consent to removal of her gangrenous leg because he thought she would not have consented to the surgery.[144] During her second hospitalization, her physicians inserted a nasogastric tube so that Conroy could more efficiently access food and medicines, but her nephew wanted doctors to remove the tube because he thought she never would have relented for it to be put in.[145] Ms. Conroy was afflicted with several serious chronic diseases, and the court described her interactions with her environment thusly:

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[138] *See supra* note 39 (discussing *Succession of Gourgis*).

[139] *See* MEISEL & CERMINARA, *supra* note 30, §§ 4.08[B], 3.27[A]-[B] (discussing the clear and convincing standard and its function in end-of-life cases).

[140] *See Quinlan*, 355 A.2d at 647.

[141] *Conroy*, 486 A.2d at 1216.

[142] *Id*

[143] *Id.*

[144] *See id.*

[145] *See id.*

> [S]he interacted with her environment in some limited ways: she could move her head, neck, hands, and arms to a minor extent; she was able to scratch herself, and had pulled at her bandages, tube, and catheter; she moaned occasionally when moved or fed through the tube, or when her bandages were changed; her eyes sometimes followed individuals in the room; her facial expressions were different when she was awake from when she was asleep; and she smiled on occasion when her hair was combed, or when she was receiving a comforting rub.[146]

The court went on to describe that Ms. Conroy "was not brain dead, comatose, or in a chronic vegetative state." [147] Her doctors described her as "severely demented" and one whose "mental condition probably would never improve."[148] Ms. Conroy did respond to painful manipulations by moaning.[149]

The stark question posed by Ms. Conroy's guardian was whether her nasogastric tube should be removed, which would lead to dehydration and then death.[150] Although one of her doctors disfavored removal, claiming, "'she's a human being and I guess she has a right to live if it's possible,'" another physician who reviewed her care claimed that she was "'hopelessly ill with no possibility of returning to any sort of cognitive function, in the face of possibly [sic] suffering taking place in the moment.'"[151]

The trial court, upon the nephew's application, allowed the hospital to discontinue Ms. Conroy's nasogastric tube feedings and dispensing of medicine, claiming that her "intellectual functioning had been permanently reduced to a very primitive level, [and] that her life had become impossibly and permanently burdensome."[152] But the appellate court reversed the trial court, and balanced New Jersey's basic interest in the maintenance of life over Ms. Conroy's right to privacy (and therefore

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[146] *Id.* at 1217.

[147] *Conroy*, 486 A.2d at 1217.

[148] *See id.*

[149] *See id.*

[150] *See id.* at 1216-17.

[151] *Id.* at 1217-18.

[152] *Id.* at 1218-19 (characterizing the trial court's decision). *See also In re* Conroy, 457 A.2d 1232, 1236 (N.J. Super. Ct. Ch. Div. 1983), *rev'd by* 464 A.2d 303 (N.J. Super. Ct. App. Div. 1983) ("I am firmly convinced by the evidence in this case that Claire Conroy's intellectual functioning has been permanently reduced to an extremely primitive level . . . . Her life has become impossibly and permanently burdensome for her.").

the discontinuation of food, water, and medicine).[153] The appeals court did allow deprivation of food, water, and medicines, but only to those "incurable and terminally ill patients who are brain dead, irreversibly comatose, or vegetative, and who would gain no medical benefit from continued treatment."[154] Furthermore, in an attempt to refine the first basis of its holding, the appeals court ruled that "a guardian's decision may never be used to withhold nourishment, as opposed to the treatment or attempted curing of a disease, from an incompetent patient who is not comatose, brain dead, or vegetative, and whose death is not irreversibly imminent."[155]

After nuanced explications of Ms. Conroy's fundamental right to self-determination, and therefore, her prerogative were she competent to refuse the nasogastric tube, actualized through the informed consent process and the constitutional right of privacy,[156] the New Jersey Supreme Court then turned to the State's bedrock interest in preserving human life. "It may be seen," wrote Justice Schrieber on behalf of the court, "as embracing two separate but related concerns: an interest in preserving the life of the particular patient, and an interest in preserving the sanctity of all life."[157] Notwithstanding that preservation of life is fundamental to the purpose of the State, the court recognized that the bald interest in life must give way to a competent patient's desire to forego medical treatment.[158]

Due to New Jersey's revolutionary turn in end-of-life jurisprudence, it was necessary for the court to carefully distinguish Ms. Conroy's predicament from that of Karen Ann Quinlan's. At bottom, the difference was factual more than anything else. Karen Quinlan was in a persistent vegetative state (which would now be called a permanent vegetative state because of the length of time Quinlan was in the state upon her death), while Claire Conroy was in what is now called a minimally conscious state.[159] The court held to two important facts that might require a different outcome than the *Quinlan* case: the patient's degree of cognition and sapience and the lack of any supervening terminal illness.[160] The court framed its issue thusly:

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[153] *Conroy,* 486 A.2d. at 1219 (characterizing the appellate court's decision) (citing *Conroy,* 464 A.2d. at 310).

[154] *Id.* (citing *Conroy,* 464 A.2d at 310).

[155] *Id.* at 1229 (quoting *Conroy,* 464 A.2d at 312).

[156] *Id.* at 1221-23.

[157] *Id.* at 1223.

[158] *Id.* at 1223.

[159] *See Conroy,* 486 A.2d at 1228-29.

[160] *Id.*

> We are now faced with one such situation: that of elderly, formerly competent nursing home residents who, unlike Karen Quinlan, are awake and conscious and can interact with their environment to a limited extent, but whose mental and physical functioning is severely and permanently impaired and whose life expectancy, even with the treatment, is relatively short. The capacities of such people, while significantly diminished, are not as limited as those of irreversibly comatose persons, and their deaths, while no longer distant, may not be imminent. Large numbers of aged, chronically ill, institutionalized persons fall within this general category.[161]

Even though Claire Conroy could not personally exercise her common law right of self-determination nor her constitutional right of privacy, those rights were still important to the court, and found fulfillment through the agency of her surrogate.[162] Thus, the court held that an incompetent patient could refuse life-sustaining treatment "when it is clear that the particular patient would have refused the treatment under the circumstances involved."[163] This, the court called a "subjective" standard because it attempts to give voice to the patient's "very personal right to control [his] own life. The question is not what a reasonable or average person would have chosen to under the circumstances but what the particular patient would have done if able to choose for himself."[164] The subjective standard is thought to be the hardest standard to meet by surrogates because it forces the surrogate to precisely match up the patient's pre-incompetency statements and actions with the proposed steps to be taken by the surrogate.[165] That is, in order for a court to find the subjective test met, the patient must say something akin to "If my brain is ever damaged, but I can still think (or still have some movements), I want you to go ahead and pull my plug. I wouldn't want to live that way." None of the patients at the centers of the four MCS cases had the foresight to dream that they would ever be in a MCS, much less that they might retain some thought and function after the trauma that relegated them to their states.[166] For that matter, it is unlikely that all but the most focused and prescient Americans would even dream

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[161] *Id.*

[162] *Id.* at 1229.

[163] *Id.*

[164] *Id.*

[165] *See generally* MEISEL & CERMINARA, *supra* note 30, §4.01[C][2].

[166] *See Wendland*, 28 P.3d 151; *Martin*, 538 N.W.2d 399, 402 (Mich. 1995); *Conroy*, 486 A.2d 1209; *Edna M.F.*, 563 N.W. 2d 485.

of so assiduously parsing their end-of-life wishes. A patient could make general, though sometimes impassioned, pleas to not be maintained if they ever become a "vegetable."[167] Such statements have, in some cases, proved to be important evidence in PVS removal-of-life-support cases.[168]

Though the court rightly acknowledged that an incompetent's interests could be retrospectively ascertained through a living will, durable power of attorney for healthcare, or appointment of a proxy, it was more concerned with those patients who do not commit their wishes to writing or who do not appoint someone over their bodily affairs.[169] Further, the court acknowledged that a patient's end-of-life wishes might be determined from his "religious beliefs and the tenets of that religion," and more importantly for this study, the court acknowledged that the patient's wishes may be ascertained from "an oral directive that the patient gave to a family member, friend, or health care provider," or from

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[167] *See, e.g.*, Tom Buckley et al., *Ethics Roundtable Debate: Withdrawal of a Feeding Tube in a Patient With Persistent Vegetative State Where the Patient's Wishes Are Unclear and There is Family Dissension*, 8 CRITICAL CARE 79, 81 (2004), *available at* http://www.biomedcentral.com/content/pdf/cc2451.pdf (last visited Nov. 4, 2009) (discussing a hypothetical case where the patient expressed a general wish to not live like a "vegetable").

[168] *See, e.g.*, Elbaum by Elbaum v. Great Plaza of Great Neck, Inc., 540 N.Y.S.2d. 840, 846 (N.Y. App. Div. 1989) (holding that clear and convincing evidence was shown that patient would not want to live as, *inter alia*, a "vegetable"); *In re* Gardner, 534 A.2d 947, 953 (ME 1987) (finding that the trial court properly found that there was clear and convincing evidence that the patient would not want life-sustaining treatment continued when the patient claimed that he would not want to live in a "vegetable state"); *In re* Severens, 425 A.2d 156, 159 (ruling that "the interest of the State in the preservation of human life is diminished in importance by the concomitant rise in the right of an individual, expressed through a guardian, to decline to be kept alive as a veritable vegetable").

There are many cases in which the patient might not have used the word "vegetable," yet expressed a desire to not live in a vegetative state. *See, e.g.*, *In re* L.M.R., No. 4392-S-MG, 2008 WL 398999 (Del. Ch. 2008) (finding that there was clear and convincing evidence that the patient would not want to continue to live in a PVS, thus substituted judgment was allowed to remove life-sustaining treatment); *In re* Biersack, No. 10-04-03, 2004 WL 2785963 (Ohio Ct. App. 2004) ("[P]atient had expressed an intent never to be 'kept alive by machine or any type of life support.'"); Woods v. Comm'r, 142 S.W.3d. 24, 31 (Ky. 2004) (stating that "withdrawal of artificial life support from a patient is prohibited absent clear and convincing evidence that the patient is permanently unconscious or in a persistent vegetative state and that withdrawing life support is in the patient's best interest"); *In re* Christopher I, 131 Cal.Rptr.2d 122, 135 (Cal. App. 2001) (holding that clear and convincing evidence of the minor's best interests must be found before removal of life support may be made); San Juan-Torregosa v. Garcia, 80 S.W.2d 539, 545 (Tenn. Ct. App. 2002) (finding that evidence was clear and convincing that patient would not want to be maintained on artificial nutrition and hydration).

[169] *See Conroy*, 486 A.2d at 1229.

"reactions the patient voiced regarding medical treatment administered to others."[170] The court implored that "all evidence" must be weighed by proxies or courts, but recognized that the "probative value of such evidence may vary depending on the remoteness, consistency, and thoughtfulness of the prior statements or actions and the maturity of the person at the time of the statements or acts."[171] But the court warned that the more specific the patient's reaction, concerning both the circumstances under which life-sustaining treatment should be removed and the types of treatments he would find odious, would be an important gloss on the patient's "statements of intent."[172]

Having set up the stakes involved in allowing Ms. Conroy's guardian to discontinue her nasogastric tube, the court then shifted and focused on justifying removal of life-sustaining treatment.[173] Drawing on the state's inherent *parens patriae* power, the court concluded that a patient's best interests should prevail when a guardian decides to discontinue or maintain the incompetent patient's life-sustaining treatment.[174] The court articulated two best-interests tests. In the "limited-objective" best-interests test:

> Life-sustaining treatment may be withheld or withdrawn from a patient in Claire Conroy's situation when there is some trustworthy evidence that the patient would have refused the treatment, and the decision-maker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him. By this we mean that the patient is suffering, and will continue to suffer throughout the expected duration of his life, unavoidable pain, and that the net burdens of his prolonged life (the pain and suffering of his life with the treatment less the amount and duration of pain that the patient would likely experience if the treatment were withdrawn) markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life.[175]

The "hook" for the court is subtle, yet very profound. Instead of requiring the guardian to determine whether there is "trustworthy

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[170] *Id.* at 1229-30.

[171] *Id.* at 1230.

[172] *Id.*

[173] *Id.*

[174] *See id.* at 1231.

[175] *See Conroy,* 486 A.2d at 1232.

evidence" to show whether the patient would not want to continue living in the condition in which she finds herself (*e.g.*, profound cognitive disability) no matter the interventions required to maintain that severely disabled life, instead the guardian asks the following question: Does the patient's life, as treated, and when weighed upon the surrogate's own inchoate, unstated scale, produce a net benefit or detriment for the patient?[176]

Further, the court left open the standards by which the guardian is to judge the quality and quantity of the patient's suffering.[177] This is a very key point that seems lost on the New Jersey Supreme Court. Without demarcations of suffering or how such quanta or stages of suffering fit within a particular condition, there exists the very real possibility that the guardian (and the family members who support the guardian and the patient's medical treatment team) will transfer their own dignity interests onto the patient. That is, when hearing the patient's moans and wails, and not having means for interpretation, or seeing the patient's limb contractures and only surmising at the patient's pain, or smelling the admittedly upsetting odor of the patient's soiled adult diaper, the guardian thinks to himself, "I know I would never want to live like this, so if I care anything for Mom/Dad/Grandma, I won't let them live like this either." The court explicitly disavows "quality of life" determinations—"[w]e do not believe that it would be appropriate for a court to designate a person with the authority to determine that someone else's life is not worth living simply because, to that person, the patient's 'quality of life' or value to society seems negligible."[178] However, the

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[176] *Id.*

[177] *See id.*

[178] *Id.* at 1233. Though the court's disclaimer about quality of life technically applies to its "pure objective" test, the criticism of it as a workable evaluative standard applies equally well to the limited-objective standard. Both empower a third party external to the MCS patient to appraise the patient's current living situation and behavioral manifestations and determine whether such situations and manifestations amount to a net good that should be continued (e.g., the feeding tube is maintained) or a net evil that should be eradicated (e.g., the feeding tube is withdrawn and the patient dies). The court put it thusly, "Since the condition of an incompetent patient makes it impossible to ascertain definitively his present desires, a third party acting on the patient's behalf often cannot say with confidence that his treatment decision for the patient will further rather than frustrate the patient's right to control his own body." *Id.* at 1229. In this respect, such an attempt to determine a patient's quality of life is not truly "objective" in the sense of disinterested. It is rather more of a "substituted judgment," that is fraught with the risk of conflating the surrogate's judgment with the patient's. For a fuller explanation and criticism of the substituted judgment standard, see generally MEISEL & CERMINARA, *supra* note 30, §4.02; *see also* Norman L. Cantor, *Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions*, 48 RUTGERS L.J. 1193, 1217 (1996)

guardian must still make an individualized assessment of the patient's "pain and suffering," "emotional enjoyment," and "intellectual satisfaction," in light of what the guardian himself perceives.[179] Because the patient can think, but not verbalize to a great degree, the guardian must guess about the quantity and quality of the pain. Of course, expert analysis comes into play here. Doctors retained by both sides will opine about the pain and overall quality of the patient's diminished life. However, in the case of minimal consciousness, the court grants that discerning the patient's own real-time reaction to his present circumstances is next to impossible: "Medical experts are often unable to determine with any degree of certainty the extent of a nonverbal person's intellectual functioning or the depth of his emotional life."[180]

Notwithstanding the potential for great pathos inherent in the limited-objective test and the pure objective test discussed below, the court does seem to endorse the clear and convincing standard for the "amount" of evidence required to determine the patient's diminished quality of life and thus trigger the choice to remove the patient's feeding tube. The court cautioned that the surrogate must be "manifestly satisfied that one of the three tests we have outlined has been met."[181]

If, according to the New Jersey Supreme Court, there is no "trustworthy evidence" that the patient does not want life-sustaining treatment, then the guardian must use the "pure objective test." The pure-objective test is very similar to the limited-objective test, only the balancing done by the guardian is starker on the burden-pain-treatment discontinuance continuum.[182] According to the court, "the net burdens of

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(describing the possible conflation of the family's values and interests with those of the patient's in a "loose substituted judgment" case, where the patient's family has wide latitude to make decisions on behalf of the patient). For a fuller discussion of the use of quality of life criteria in substituted judgment cases, see Cantor, *supra* note 31, at 1218-20. Additionally, it should be noted that the *Conroy* court, along with many other courts that have faced hard end-of-life cases, vehemently disclaimed that they are passing upon the "personal worth or social utility of another's life, or the value of that life to others." *Conroy,* 486 A.2d. at 1232, 1233. The court went on to say that, "[w]e do not believe that it would be appropriate for a court to designate a person with the authority to determine that someone else's life is not worth living simply because, to that person, the patient's 'quality of life' or value to society seems negligible." *Id.* at 1233. The court should be lauded for such an unequivocal renunciation of quality of life functioning as a proxy for the surrogate's decision that the patient's life is now useless to society. It is possible in any particular case, though far from clear, however, that such a pure surrogate, unbound from greater societal concerns, would not tie the patient's continued existence (as mediated through his quality of life) to concerns such as funding.

[179] *Conroy,* 486 A.2d at 1232.

[180] *Id* at 1233.

[181] *Id.*

[182] *See id.* at 1232.

the patient's life with the treatment should clearly and markedly outweigh the benefits the patient derives from life."[183] Additionally, "the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane."[184] The test is "pure" in that the court requires no subjective evidence of the patient's unwillingness to endure the life-sustaining treatment.[185]

Eventually, the court determined that the evidence was not sufficient to meet the subjective, limited-objective, or pure-objective tests proffered by the court.[186]

2. In re Michael Martin

Michael Martin was seriously injured in an automobile accident on January 16, 1987—both hemispheres of his brain were damaged.[187] He was unable to walk or talk; he was incontinent; and he received his nutrition and hydration through a gastrostomy tube.[188] Although Mr. Martin resided in nursing homes and a rehabilitation center after his accident, an obstructed bowel necessitated a trip to the hospital.[189] It was at the hospital that Mr. Martin's wife, Mary, asked the hospital's bioethics committee whether Mr. Martin's gasostromy tube should be discontinued.[190] The committee concluded that it would be "medically and ethically appropriate" to discontinue Mr. Martin's tube, yet they required the protection of a "court authorization" before proceeding to do so.[191]

The Michigan Supreme Court characterized Mrs. Martin's probate court testimony as his wish that "he would rather die than be dependent on people and machines," and Mrs. Martin claimed in the probate court

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[183] *Id.*

[184] *Id.*

[185] *See Conroy*, 486 A.2d at 1232. It must be noted, though, the life sustaining treatment is retained for any patient who wants it, notwithstanding the pain he or she experiences. *See id.;* see also *supra* Part III.C. for a discussion of relaxing the clear and convincing standard for late-stage Alzheimer's patients who can no longer physically use food and water.

[186] *See Conroy*, 486 A.2d at 1219. Ms. Conroy died during the appellate process. Additionally, it is important to note that the Court mandated that two disinterested physicians "confirm the patient's medical condition and diagnosis" when the patient is a resident in a nursing home. *See id.* at 1237-42.

[187] *Martin*, 538 N.W.2d at 402.

[188] *Id.*

[189] *Id.*

[190] *Id.*

[191] *Id.*

that "Michael would not want to be kept alive in his present condition."[192] Further, two of Mr. Martin's colleagues testified that Mr. Martin would not want to live in a vegetative state.[193] The court contextualized those conversations, however, one was a "casual conversation" during a lunch break and the other concerned someone else who had been injured.[194] Importantly, both of the colleagues admitted that Mr. Martin was not in the condition that the three of them discussed.[195] Furthermore, the court noted that Mr. Martin's sister testified that "Michael once told her that he would not want to be kept alive by a respirator if he were in a coma."[196]

During the trial, competing experts testified about Mr. Martin's ability to think and function.[197] One expert, according to the court's characterization, claimed that Martin had "no voluntary control over any of his limbs, or any ability to function on a voluntary level, and therefore lacks any meaningful interaction with his environment."[198] However, another expert, according to the court, saw Martin as one who could manipulate his hands and communicate both verbally and non-verbally.[199] Further, the court framed neurologist and bioethicist Ronald Cranford's testimony to be that "Michael possesses an ability to understand some simple questions about basic and familiar items, although even then his responses are not always consistent, but that he lacks an understanding of more complex items, including his physical capabilities and medical condition."[200]

According to the court, Mrs. Martin testified that Mr. Martin "on different occasions and in different settings and contexts, all expressing a preference not to be maintained under various described circumstances . . . Michael was adamant and made it very clear that he did not want to be kept alive in the circumstances described."[201] The trial court found by clear and convincing evidence that Michael did not want life-sustaining

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[192] *Id.*

[193] *Martin*, 538 N.W.2d at 402.

[194] *Id.*

[195] *Id.*

[196] *Id.*

[197] *Id.* at 402-03.

[198] *Id.*

[199] *See Martin,* 538 N.W. at 403. According to the court, yet another expert witness testified that Martin's functioning fit somewhere in between that testified to by the first and second witnesses.

[200] *Id.* at 403-04.

[201] *Id.* at 404.

treatment for the conditions in which he found himself.[202] The court of appeals agreed with this assessment.[203]

The Michigan Supreme Court ruled on common law grounds, based in informed consent, that a patient has such a right to refuse life-sustaining treatment.[204] Further, the court agreed that statements made by a person expressing a desire to refuse life-sustaining treatment survive when the person slips into incompetency.[205]

The court then surveyed the substantive decision-making standards available to courts when confronted with end-of-life situations for incompetent patients. The court considered the best interests standard, but ultimately rejected it in favor of the substituted judgment standard, wanting to empower, at least somewhat, the now incompetent patient: "Given that the right the surrogate is seeking to effectuate is the incompetent patient's right to control his own life, '[t]he question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself.'"[206]

This court grounded its decision in the common law right of informed consent, and therefore, it saw the objective standard of "best interests" in irreconcilable conflict with the informed consent.[207] The court noted that "[i]n the cases that have applied a more objective test or suggested that a more objective test would be proper, the patient generally has been comatose or in a persistent vegetative state."[208] Further, the court explicitly stated that "[i]n this case, Michael's life and health are not threatened by infirmities of this nature. Because he was competent and able to express his wishes and desires, we decline to move along the continuum from the subjective standard."[209]

Importantly, the court sided with the *Conroy* court's iteration of its objective tests, and claimed that if the burdens of Michael's treatment, including, "pain and suffering . . . [no] physical pleasure . . . [no]

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[202] *Id.* (citing *In re* Michael Martin, 205 Mich. App. 96, 98-99 (Mich. Ct. App. 1994)). The court described the trial court's proceedings upon remand, because in the trial court's original determination, it was in Mr. Martin's best interests to have his feeding tube removed. However, the trial court could not use the best interests standard because although Mr. Martin was profoundly devastated, he was not terminally ill. *See In re* Martin, 504 N.W.2d 917, 921 (Mich. Ct. App. 1993)).

[203] *See Martin,* 538 N.W.2d. at 404, 405 (citing *In re* Martin, 205 Mich. App. 96, 104 (1994)).

[204] *Id.* at 405.

[205] *See id.* at 406.

[206] *Id.* at 408 (quoting *Conroy*, 486 A.2d at 1229).

[207] *Id.*

[208] *Id.*

[209] *Id.* at 408-09.

emotional enjoyment or [no] intellectual satisfaction" were his lot, then he would have an enhanced case for removal of life-sustaining treatment.[210] However, the court concluded that such a sorry state was not Michael's and was all the more reason to keep nutrition and hydration running through his gastrostomy tube.

The court then considered which standard of proof to apply to Michael's purported desire to have his life-sustaining treatment ended. After considering the highest standard of "beyond a reasonable doubt," the court declined to use it, claiming that it was not usually appropriate for civil cases. It also refused to apply the "preponderance of the evidence" standard because the "interests at stake in the instant proceedings are more substantial, both on an individual and societal level, than those involved in a run-of-the-mine civil dispute."[211] The court found particular solicitude in the *Cruzan* court's use of the clear and convincing evidentiary standard:

> [It is acceptable to] place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment. An erroneous decision not to terminate results in the maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.[212]

While the court acknowledged that, in the end-of-life context, a piece of evidence's clear and convincing nature can most readily be seen in a written advance directive, it conceded that oral statements can rise to the level of clear and convincing if they are "made under the proper circumstances."[213] The court adopted the *Conroy* court's rubric of "remoteness, consistency, specificity, and solemnity" of the prior statements as the grid through which oral statements must be put before

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[210] *See Martin*, 538 N.W.2d at 409 n.16 (quoting *Conroy*, 486 A.2d. at 1232).

[211] *Id.* at 409-10 (citing *Cruzan*, 497 U.S. at 283).

[212] *Id.* at 410 (quoting *Cruzan*, 497 U.S. at 283).

[213] *Id.*

they can be deemed clear and convincing evidence of the patient's desire that life-sustaining treatment be removed.[214]

Importantly, the court flatly said that "[s]tatements made in response to seeing or hearing about another's prolonged death do not fulfill the clear and convincing standard," but instead held that:

> Only when the patient's prior statements clearly illustrate a serious, well thought out, consistent decision to refuse treatment under these exact circumstances, or circumstances highly similar to the current situation, should treatment be refused or withdrawn. In all events, the proofs in such must meet the exacting standard of clear and convincing evidence.[215]

The court then went through Mrs. Martin's affidavits of Mr. Martin's statements about not wanting to be maintained on life-sustaining treatment and concluded that these statements did not rise to the level of clear and convincing evidence.[216]

Though the court refused to deem Michael Martin's statements as clear and convincing evidence of his unwillingness to be maintained by artificial hydration and nutrition, the court gave future litigants little practical guidance about the types of patient pronouncements that would be "serious" and "well thought out" enough to be clear and convincing evidence of the patient's willingness to go without the artificial nutrition and hydration (ANH).[217] If the *Martin* court is to be taken at its word, then the patient would have to anticipate two major future statuses: (1) that he would be in a minimally conscious, over against a persistent vegetative state. Recall that Michael Martin said that he would not want to go on living if he were a "vegetable." Though his state was profoundly diminished *viz a viz* full functioning, at no time did he devolve into a PVS.[218] Therefore, practically Michael would have had to frame the entreaties to his friends and family in "minimally conscious" language: "If my brain is ever disturbed, but I can still somewhat think, then

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214. *Id.* at 411 (quoting *Conroy,* 486 A.2d at 1230).

215. *Id.*

216. *See Martin*, 538 N.W.2d. at 411-13; *see also* Thomas J. Marzen Daniel & Avila, *Will the Real Michael Martin Please Speak Up! Medical Decisionmaking for Questionably Competent Persons*, 72 U. DET. MERCY L. REV. 833, 842 (1994-1995) (arguing that "the majority was unwilling to believe Mr. Martin's preaccident expressions, if truly made, reliably reflected his actual present wishes. This too was reasonable given the additional "specific circumstance" of Mr. Martin's postaccident life-affirming behavior.").

217. *See Martin*, 538 N.W.2d at 411-13.

218. *See id.* at 403.

remove my feeding tube," or "if I can still follow some verbal directions, but not live a complete life, then remove the tube." (2) The patient would have to foreclose even the possibility that he might appreciate mere existence, though radically altered. This is not what happened with Michael. After a period of initial recalcitrance, Mr. Martin started to cooperate with his therapists and doctors and seemed to show a genuine desire to live with his brain injury.[219]

3. In the Matter of the Guardianship and Protective Placement of Edna M.F.

At the time of her death, Edna M.F. was an elderly woman with "dementia of the Alzheimer's type."[220] The court describes her as "bedridden, but her doctors have indicated that she responds to stimulation from voice and movement. She also appears alert at times, with her eyes open, and she responds to mildly noxious stimuli."[221] Edna received nutrition and hydration through a surgically-placed tube.[222] Her sister sought to remove the feeding tube, based in part on statements Edna made in 1966 or 1967 during which she said, "I would rather die of cancer than lose my mind."[223] Her nursing home's ethics committee approved removal of her feeding tube in 1994, assuming no family member disagreed with the decision, but a niece refused to approve the removal of the tube.[224] In 1995, Edna's sister petitioned the local circuit court to reinforce her decision to remove Edna's tube.[225] The court appointed an attorney to function as "respondent designate" to argue for the continuance of the life-sustaining treatment, and then the trial court denied the sister (the guardian's) petition.[226] The case bypassed the court of appeals.[227]

The court noted that most adults are able to choose for themselves whether to dispose of their lives, yet mentally disabled adults deserve special protection from the state, because "free choice is an empty option

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[219] *See id*; *see also id.* at 406 n.10.

[220] *Edna M.F.*, 563 N.W.2d at 487; *see also infra* Part III.C. for further discussion of how decision-making standards may work with Alzheimer's patients.

[221] *Edna M.F.*, 563 N.W.2d at 487.

[222] *Id.*

[223] *See id.*

[224] *Id.*

[225] *Id.*

[226] *Id.*

[227] *Edna M.F.*, 563 N.W.2d at 487.

for those who cannot exercise it."[228] Thus, in the case of *In re Guardianship of L.W.*, the court adopted the "best interest" standard for surrogates who make life and death decisions for their wards.[229] However, the court in *Edna M.F.* was unwilling to extend *Guardianship of L.W.'s* best interests standard to non-PVS patients:

> However, if that person is not in a persistent vegetative state, this court has determined that, as a matter of law, it is not in the best interests of the ward to withdraw life-sustaining treatment, including a feeding tube, unless the ward has executed an advance directive or other statement clearly indicating his or her desires.[230]

One of the main reasons the Wisconsin Supreme Court refused to make such an extension was because the *Guardianship of L.W.* court allowed the withdrawal of nutrition and hydration from PVS patients because their void of consciousness means that they cannot feel pain or discomfort.[231] Thus absent palliation in the form of narcotic pain management, the minimally conscious patient would experience severe pain during the ANH withdrawal process.[232] To be sure, no pro-

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[228] *Id.* at 489 (quoting *In re* Guardianship of Eberhardy, 307 N.W.2d 881, 897 (Wis. 1981).

[229] *In re* Guardianship of L.W., 482 N.W.2d 60, 76 (Wis. 1992).

[230] *Edna M.F.*, 563 N.W.2d at 489-90; *see also Guardianship of L.W.*, 482 N.W.2d at 76.

> We conclude that in some circumstances it may well be in the patient's best interests to have treatment withheld or withdrawn. A dignified and natural death may outweigh the interest of maintaining a physiological life as long as medically possible. Therefore, where it is in the best interests of an incompetent person in a persistent vegetative state to refuse life-sustaining medical treatment, his or her right to refuse must be exercised by a surrogate decisionmaker.

Id.

[231] *Edna M.F.*, 563 N.W.2d at 490 (citing *Guardianship of L.W.*, 482 N.W.2d at 73 n.17).

[232] *See e.g.*, *In re* Gardner, 534 A.2d 947, 949 (Me. 1987) (describing the trial court's characterization of Mr. Gardner's (a PVS patient) desire to die and lack of pain in the face of withdrawal of ANH: "[p]rior to the 1985 accident Gardner had declared his 'intent and desire that he not be maintained on the nasogastric tube'; that he would rather die than be maintained in a persistent vegetative state by artificial means." In the event that Gardner's stated wish is respected, his "death will be without conscious pain or discomfort" and will come within three to fourteen days."). *See also* Mack v. Mack, 329 Md. 188, 218 (Md. Ct. App. 1993) (holding that "[a] best interest test applied to Ronald or to any patient who is in a persistent vegetative state, who is not in pain, and who is not terminally ill, requires this Court to make a quality-of-life judgment under judicially adopted standards, without any legislative guidelines. There are many reasons why it is

withdrawal court seen by this author advocates withholding pain management drugs from MCS patients.[233] This, however, is the wrong approach in attacking the withdrawal of ANH issue for MCS patients. We must first ask whether the MCS patient is someone who could appreciate nutrition and hydration. That is, does the MCS patient have daily, personal interests in receiving food and water? If so, then courts should erect very high barriers to their withdrawal, such as the clear and convincing and subjective standards. If, like PVS patients, who have more attenuated interests in receiving food and water, because their conscious faculties are gone, then courts could have greater leeway in erecting high barriers to withdrawal of the feeding tube.

The court foresaw a slippery slope if it extended the best interests standard of the *Guardianship of L.W.* case to situations in which the ward is not in a persistent vegetative state.[234] The court likened the breach of this boundary to euthanasia:

> While at first euthanasia may be institutionalized only for those in terrible pain, or those who are terminally ill, or those for whom it is otherwise appropriate, the pressure of the allocation of health care resources will inevitably enlarge the class for whom euthanasia is deemed appropriate. Every society has a group who are deemed to be socially unworthy and members of that group—the uneducated, the unemployed, the disabled, for example—will become good candidates for euthanasia.[235]

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not appropriate for this Court to do so."); *In re* Colyer, 660 P.2d 738, 740 (Wash. 1983) ("She required a respirator in order to breathe, and she remained in a comatose state, unresponsive to pain or verbal stimuli. In short, she was unable to breathe on her own and remained in a persistent vegetative state."). *But see In re* Lawrance, 579 N.E.2d 32, 35 (Ind. 1991) (stating that an expert testified in the trial court that the patient could experience pain although he testified that the patient was in a PVS); Gregory v. Carey, 791 P.2d 1329, 1334 (Kan. 1990) (stating that the trial court and at least one expert claimed that patient could feel pain even though she was in a PVS).

[233] *See, e.g.*, *In re* Greenspan, 558 N.E.2d 1194, 1196, 1197 (Ill. 1990), *superseded by* 755 ILCS 40/1, et. seq. (stating that in a PVS case, "[a]nalgesics could be given to relieve any pain associated with withdrawal of the feeding tube, but Mr. Greenspan shows no ability to feel any pain from any source") (holding of case not quote). *See also In re* Estate of Austwick, 656 N.E.2d 773, 776 (Ill. App. Ct. 1995).

[234] *Edna M.F.*, 563 N.W.2d at 490.

[235] *Id.* (quoting BARRY R. FURROW ET AL., BIOETHICS: HEALTH CARE LAW AND ETHICS 325 (1991)). The court noted that Edna did not want to "lose [her] mind," yet she never expressed to her close relatives and friends her wishes concerning removal of ANH. *See Edna M.F.*, 563 N.W.2d at 491.

While commentators acknowledge that withdrawal of ANH is a form of passive euthanasia, or "dysthanasia," the court fails to fully explain why withdrawal of ANH from minimally conscious patients such as Edna M.F. will inevitably lead to euthanizing the "uneducated" or the "unemployed."[236] A good reason for the *Edna M.F.* court to draw the proverbial line in the sand is the respective natures of the PVS and MCS diagnoses. In PVS, two prominent clinical bioethicists argue, much of what gives life and vitality to a person is irretrievably lost, because the person can no longer form conscious thoughts or act upon those thoughts.[237] Contrast, however, the MCS diagnosis. The patient still has (at least) rudimentary, "but clear evidence of awareness of themselves or their environment, on a reproducible or sustained basis."[238] In all MCS cases, in order to have a *bona fide* diagnosis, the patient must fulfill at least the diagnostic criteria set forth by the Aspen Workgroup, and any such response shows that the MCS patient has at least a minimal ability to interact with his environment.[239]

In the end, the court recognized the fundamental verity about Edna: notwithstanding her badly deformed mind, she had a "life" that must be saved absent a high amount of proof that her wishes would be to the contrary.[240] Stated another way, some could claim that the essence of the

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[236] For use of the term "dysthanasia" to refer to passive euthanasia, see Thane Josef Messinger, *A Gentle and Easy Death: From Ancient Greece to Beyond Cruzan – Toward a Reasoned Legal Response to the Societal Dilemma of Euthanasia*, 71 DENV. U. L. REV. 175, 179 n.41 (1993).

[237] *See, e.g.*, LAWRENCE J. SCHNEIDERMAN & NANCY S. JECKER, WRONG MEDICINE: DOCTORS, PATIENTS, AND FUTILE TREATMENT 12-14 (John Hopkins Univ. Press 1995) (claiming that, "[a]ll patients with complete and permanent loss of consciousness, such as permanent vegetative state, lack a necessary feature of being a person. For, regardless of widely different conceptions of personhood almost everyone agrees that personhood requires consciousness and self-awareness."). *Id* at 12. *But see* Joseph Torchia, *Postmodernism and the Persistent Vegetative State*, 2 NAT'L CATH. BIOETHICS Q. 257 (2002), *available at* http://www.lifeissues.net/writers/torc/torc_01postmodernismandpvs1.html (last visited Nov. 4, 2009) (arguing that proponents of withdrawal of life-support force a choice between "biological humanity" and "moral personhood," but that a human loses his moral personhood only upon the death of his body). For my caveat in presenting the personhood argument in this Article, see *supra* note 40. For discussion of when to relax the need for clear and convincing evidence for late-stage Alzheimer's patients who can no longer physiologically use food and water, see *infra* Part III.C.

[238] Laureys, Owen & Schiff, *supra* note 86, at 539 (describing the consensus criteria propounded by the Aspen Working Group).

[239] *See* J.T. Giacino, *supra* note 80, at 351.

[240] *Edna M.F.*, 563 N.W.2d at 491 (relying upon the irreversibility of death and the possibility of future cures for Edna's condition in its requirement for a "clear statement" of her wish to have ANH removed. "Like sterilization, the decision to withdraw life-sustaining medical treatment is also not reversible, because death is not reversible. It is

PVS patient's life has already left him through his "neocortical death."[241] However, though hacked away and greatly reduced, the MCS patient is still "alive" in the sense of having a viable conscious mind. Therefore, to withdraw ANH from a MCS patient is to truly cause his death—from the neocortical, whole brain, and cardio-respiratory perspectives.

The court may have muddied the waters of proof more than it cleared them. For this court required "a guardian to show a clear statement of the ward's desires by a preponderance of the evidence."[242] Thus it appears that for non-PVS patients, Wisconsin's standard for withdrawal of ANH is a substantively subjective ("clear statement" by the patient), but procedurally requires an intermediate amount of evidence (preponderance) to prove the guardian's claim.

Chief Justice Abrahamson challenged the majority's characterization of Edna and, therefore, its commitment to a bright line standard. The chief justice wrote:

> Ms. F. breathes without assistance but in all other respects is dependent on others for her care and continued existence. Ms. F's muscles have deteriorated to the point her limbs are contracted and immobile. She demonstrates no purposeful response, such as withdrawal, to tactile, aural or visual stimuli; she makes non-specific responses to pinching or tapping of the arm or sternum. There is also some testimony suggesting Ms. F. occasionally may track movements in the room with her eyes.[243]

Abrahamson thus compares PVS and severe MCS and finds no practical differences between the conditions. Important for Abrahamson were the physical manifestations of Edna's severe MCS.[244] Outwardly there were no practical differences between the two conditions. And inwardly there might not have been much difference between the Edna of the end stage dementia and the Edna were she in a PVS.[245] But the difference is this: in Edna's severe MCS, she could interact, in however a limited fashion, with her environment, and were she in a PVS she could not.[246] Thus, whether the chief justice acknowledged it, this seems to be the tipping point of the court's holding and the basis of its warning about

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for this reason, then, that we require a guardian to show a clear statement of the ward's desires by a preponderance of the evidence."). *Id.*

[241] *See supra* note 40 for discussion of personhood theory.

[242] *See Edna M.F.*, 563 N.W.2d at 491.

[243] *Id.* at 492 (Abrahamson, J. concurring).

[244] *Id.*

[245] *Id.*

[246] *Id.*

a slippery slope. The court desired to give extra protection to a person who still has the ability to form a thought or make a response to environmental stimuli over against those who cannot.

4. Conservatorship of the Person of Robert Wendland

Robert Wendland crashed his truck while driving drunk.[247] The accident initially left Robert in a coma for many months. Robert's coma eventually lifted, and he began to interact with his environment, although inconsistently.[248] Robert was in a minimally conscious state.[249] Though Robert's wife, Rose, consented on three occasions to surgically repair Robert's feeding tube,[250] she did not consent the fourth time the gasostromy tube came loose.[251] One of Robert's doctors placed a nasogastric tube in Robert's stomach as a stop-gap measure until his hospital's ethics committee could render an opinion about the appropriateness of discontinuing the gasostromy tube.[252]

Though the ethics committee unanimously affirmed Rose's decision, Robert's mother and sister applied for and received a temporary restraining order preventing the permanent removal of the tube.[253] Although Rose's petition to become Robert's conservator was granted, the trial court refused Rose to permanently remove the feeding tube,

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[247] *Wendland*, 28 P.3d at 154.

[248] *Id.* at 154. The court described Robert's progress this way:

> Intensive therapy followed [after the initial signs of post-accident consciousness]. Robert's "cognitive responsiveness was observed to improve over a period of several months such that by late spring of 1995 the family and most of his health care providers agreed that he was inconsistently interacting with his environment. A video recording of [Robert] in July 1995 demonstrated clear, though inconsistent, interaction with his environment in response to simple commands. At his highest level of function between February and July 1995, Robert was able to do such things as throw and catch a ball, operate an electric wheelchair with assistance, turn pages, draw circles, draw an 'R' and perform two-step commands." For example, "[h]e was able to respond appropriately to the command 'close your eyes and open them when I say the number 3.' . . . He could choose a requested color block out of four color blocks. He could set the right peg in a pegboard. Augmented communication was met with inconsistent success. He remained unable to vocalize. Eye blinking was successfully used as a communication mode for a while, however no consistent method of communication was developed."

Id. at 154-155.

[249] *Id* at 156.

[250] *Id.* at 155.

[251] *Id.*

[252] *See Wendland*, 28 P.3d at 155.

[253] *Id.*

preferring instead an initial sixty-day waiting period to determine the efficacy of physical therapy.[254]

Eventually, a trial was held on the question of whether Rose, as Robert's conservator, should be allowed to remove Robert's feeding tube.[255] The trial court determined that Rose could follow-through with such a decision if she satisfied two criteria: (1) the decision was in Robert's best interests, "taking into account any pertinent wishes the conservatee may have expressed before becoming incompetent," and (2) the conservator would have to make such a showing by clear and convincing evidence.[256]

On more than one occasion, Robert expressed strong desires not to live in a severely diminished, dependent state. On the occasion of Rose's father's attachment to a ventilator Robert said, "I would never want to live like that, and I wouldn't want my children to see me like that and look at the hurt you're going through as an adult seeing your father like that."[257] Further, Rose testified that Robert said that he "wouldn't want to live like a vegetable," and "wouldn't want to live in a comatose state."[258] Additionally, once Robert's drinking problem worsened, his brother Michael confronted him about the possibility of suffering a cataclysmic driving accident. Said Robert, "[i]f that ever happened to me, you know what my feelings are. Don't let that happen to me. Just let me go. Leave me alone."[259] Said his brother Michael, "[y]ou're either going to go out and kill yourself or kill someone else, or you're going to end up in the hospital like a vegetable—laying in a bed just like a vegetable."[260] According to Michael, Robert said the following, "Mike, whatever you do[,] don't let that happen. Don't let them do that to me."[261]

Notwithstanding the evidence presented at the trial court, the court held that Robert was not in a persistent vegetative state nor was there clear and convincing evidence that Robert would want his nutrition and hydration disconnected in the circumstances under which he found himself.[262] Rose appealed to the California Court of Appeals, which

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[254] *See id.*

[255] *Id.*

[256] *Id.* at 156.

[257] *Id.* at 157.

[258] *Wendland*, 28 P.3d at 157.

[259] *Id.*

[260] *Id.*

[261] *Id.* (recalling Robert's daughter Katie 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'").

[262] *See id.*

reversed the trial court.[263] The court of appeals rejected the second prong of the trial court's holding.[264] Robert, according to the appeals court, did not have to state that he would want his nutrition and hydration removed if he ever found himself in the exact same circumstances in which he found himself.[265] Rather, the appeals court held that the trial court's sole function was "'merely to satisfy itself that the conservator had considered the conservatee's best interests in good faith.'"[266]

The incompetent patient is a bit of a different story, than the run-of-the-mill case of a competent person refusing life-sustaining treatment.[267] Bolstered by the state's inherent *parens patriae* power, the court based much of its analysis on *In re Drabick*.[268] In *Drabick*, the court held that a conservator may withdraw life-sustaining treatment to a persistently vegetative conservatee if the treatment, "'offers no reasonable possibility of returning the conservatee to cognitive life and if it is not otherwise in the conservatee's best interests, as determined by the conservator in good faith.'"[269] The *Drabick* court focused on whether the life-sustaining treatment—not extraordinary treatment—would bring the patient back to "cognitive life."[270] The *Drabick* court acknowledged that it was navigating between the Scylla and Charybdis of two fundamental rights—the right to life and the right to "terminate unwanted treatment."[271] Nevertheless, the court thought it a greater harm to abrogate the patient's right to refuse treatment.[272] However, this court fashioned the dichotomous choice made by the *Drabick* court from one of 'right to life' over against 'right to choose,' and instead claimed that the fundamental issue before them in the *Wendland* case was whether "incompetent patients retain the right to have appropriate medical decisions made on their behalf. An appropriate medical decision is one that is made in the patient's best interests, as opposed to the interests of the hospital, the physicians, the legal system, or someone else."[273]

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[263] *Wendland*, 28 P.3d at 157.

[264] *Id.*

[265] *See id.* at 158.

[266] *Id.* (citing *In re* Wendland, 93 Cal.Rptr. 2d 550, 567 (Cal. Ct. App. 2000)).

[267] Like all the other cases considering the ultimate disposition of minimally conscious patients, the California Supreme Court briefly recounted the common law informed consent doctrine and the constitutional right of privacy of a competent person to refuse life-sustaining medical treatment. *See id.* at 158-61.

[268] *Id.* at 156-75.

[269] *Id.* at 161 (quoting *In re* Drabick, 245 Cal. Reptr. 840, 861 (Cal. Ct. App. 1988)).

[270] *Wendland*, 28 P.3d at 161 (quoting *Drabick*, 245 Cal. Reptr. at 861).

[271] *Id.* at 162 (quoting *Drabick*, 200 Cal.App.3d at 856).

[272] *Id.*

[273] *Id.* at 162-63 (quoting *Drabick*, 245 Cal.Rptr. at 852).

Key to the *Wendland* case was Section 2355 of the California Probate Code, which gives a conservator the prerogative to order medical treatment for a conservatee, regardless of whether the conservatee consents (indeed whether she can consent at all).[274] The section, as rewritten to take into account the *Drabick* case, gives weight to not only the "conservatee's individual health care instructions, if any," but also to "other wishes to the extent known to the conservator."[275] Importantly, the court interpreted Section 2355 to mean that the best interests standard only comes into play when the conservator does not know the conservatee's health care wishes.[276]

Also key to the court's analysis regarding the standard of proof were comments by the California Law Review Commission on Section 2355, in which the Commission stated that "[t]he general rule applies: the standard is by preponderance of the evidence. Proof is not required by clear and convincing evidence."[277] But without much explanation, the court rejects the preponderance standard, and suggests that the statute might be up to constitutional challenge if the conservator were allowed to use the low preponderance standard of evidence.[278] The court acknowledged that its more conservative position amounts to a "partial rejection of the Law Review Commission's understanding that the preponderance of the evidence standard would apply."[279]

If California is willing to apply the clear and convincing standard for legal proceedings such as: determining whether it was in the best interests to sterilize a mentally disabled person, whether the discipline of a judge was supported by the evidence, whether a person cannot provide for him or herself and thus a guardian should be appointed, and whether a conservatee is incompetent so that he cannot reject electroconvulsive

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[274] *Id.* at 163.

[275] *Wendland*, 28 P.3d at 165 (quoting CAL. PROB. CODE §2355(a) (2000)).

[276] *Id.*

[277] *Id.* at 166 (quoting 30 CAL. L. REV. COMM. REPORTS, App. 6, 264 (2000)).

[278] *Id.*

[279] *Id.* The court, like the *Conroy* and *Martin* courts, granted that a more exacting standard of proof was required because of the nature of the underlying controversy:

> [T]he function of a standard of proof is to instruct the fact finder concerning the degree of confidence our society deems necessary in the correctness of factual conclusions for a particular type of adjudication, to allocate the risk of error between the litigants, and to indicate the relative importance attached to the ultimate decision.

Id. at 169 (citing Weiner v. Fleischman, 54 Cal.3d 476, 487 (1991)). Thus the court concluded, "'the standard of proof may depend upon the 'gravity of the consequences that would result from an erroneous determination of the issue involved.'" *Wendland*, 28 P.3d. at 169 (citing Weiner v. Flesischman, 816 P.2d 892, 898) (in turn quoting People v. Jimenez, 580 P.2d 572, 676 (1978)).

therapy, then it should be willing to require clear and convincing evidence for an action (the withdrawal of ANH) that will be *at least* a cause in fact of the patient's death.[280] Even then, if there is no supervening terminal illness that will eventually claim the patient's life, like there was in *Edna M.F.* (where Edna had Alzheimer's disease).[281] So, withdrawal of ANH would be the *proximate* cause of the patient's death and not merely a cause in fact.[282]

In short, there must be a very high evidentiary standard because the risks of a wrong decision are so great. The court characterized this risk as the tension between the conservator's powers under Section 2355 to act in the conservatee's best interest and the ward's own possible, present, and conscious interest in remaining alive through the intervention of the ANH:

> [T]he ultimate decision is whether a conservatee lives or dies, and the risk is that a conservator, claiming statutory authority to end a conscious conservatee's life...by withdrawing artificial nutrition and hydration, will make a decision with which the conservatee subjectively disagrees and which subjects the conservatee to starvation, dehydration, and death. This would represent the gravest possible affront to a conservatee's state constitutional right to privacy, in the sense of freedom from unwanted bodily intrusions, and to life.[283]

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[280] *See id.* at 169-70 (internal citations omitted). The court was plain as to what it deems "clear and convincing" evidence: the "clear and convincing evidence" test requires a finding of high probability, based on evidence "'so clear as to leave no substantial doubt" and "sufficiently strong to command the unhesitating assent of every reasonable mind." *Id.* at 173 (quoting *In re* Angelia P., 28 Cal. 3d 908, 919 (Cal. 1981)).

[281] *Edna M.F.*, 563 N.W.2d at 485.

[282] This focus of this Article is not to tease out the tort implications of removal of ANH from minimally conscious patients. The discussion of causation is meant to reinforce the idea that minimally conscious patients are not terminally ill. They merely need assistance with their daily nutrition and hydration needs.

[283] *Wendland*, 28 P.3d. at 169 (citing with approval the *Cruzan* court, which presciently discerned the difference between a competent patient making his own decision about the future of his health care and a surrogate making the decision on behalf of the patient).

> The differences between the choice made by a competent person to refuse medical treatment, and the choice made for an incompetent person by someone else to refuse medical treatment, are so obviously different that the State is warranted in establishing rigorous procedures for the latter class of cases which do not apply to the former class.

Id. at 173 (quoting *Cruzan*, 497 U.S. at 287 n.12).

Therefore it was relatively easy for the court to agree with the trial court's description of Robert's conversations with friends and family about not wanting to be maintained on life-sustaining treatment as not "an exact 'on all fours' description of the conservatee's present medical condition."[284] And thus the court required, "more explicit direction than just 'I don't want to live like a vegetable' . . . in order to justify a surrogate decision-maker terminating the life of . . . someone who is not in a PVS [persistent vegetative state]."[285]

The court also considered whether the withdrawal of nutrition and hydration fit within California's 'best interests' standard.[286] Rose argued that Section 2355 gave her (as the conservator) "'the exclusive authority'" to give consent for such medical treatment as she 'in good faith based on medical advice determines to be necessary.'"[287] The trial court found that there was clear and convincing evidence that Rose acted "in good faith" according to Robert's "'best interests, including his likely wishes, based on his previous statements.'"[288] The court, however, disagreed, and introduced the possibility that, without judicial supervision, the conservator can act precipitously and not out of an altruistic sense of the patient's best interests.[289]

In the end, the court held that a surrogate could withhold life support to a patient if the surrogate provided clear and convincing evidence that withdrawal matches with the patient's previously expressed desire, or it

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[284] *Id.* at 173 (quoting *Wendland*, 93 Cal Reptr. 2d at 558).

[285] *Wendland*, 28 P.3d at 173 (noting perhaps the most telling and interesting piece of evidence from the trial court: "While experts dispute the consistency and accuracy of Robert's responses to questions, it is difficult to ignore the fact that he declined to answer the question "Do you want to die?" while giving facially plausible "yes" or "no" answers to a variety of other questions about his wishes").

[286] *See id.* at 173-74.

[287] *Id.* at 173 (quoting CAL. PROB. CODE §2355(a) (2000)).

[288] *Id.* at 174 (quoting *Wendland*, 93 Cal. Reptr. 2d at 559).

[289] *See id.* Lawrence Nelson argues that the court's omission of a robust discussion of best interests is "irresponsible." *See* Lawrence J. Nelson, Ph.D, J.D., *Wendland and Forgoing Life Sustaining Treatment for the Incompetent*, 14 HEALTH LAWYER 12, 15 (2002). Professor Nelson also contends that, as a practical matter, the best interests prong of the decision will have the most impact for the "never competent persons who are conserved, namely the developmentally disabled, [because] conservators have no competent wishes of the conservatee to refer to and thus must rely on a best interest showing if they wish to refuse life-sustaining treatment." *Id.* at 15. *See also* Michelle Mello, case Comment, *Death, Life, and Uncertainty: Allocating the Risk of Error in the Decision to Terminate Life Support*, 109 YALE L.J. 635, 640 (December 1999) (contending that "[a] lower evidentiary standard is necessary in order to enable MCS patients to avoid the burdens of continued life, because, as a practical matter, it is impossible for a patient's previously expressed wishes to satisfy the clear-and-convincing standard if the patient is in MCS").

was clear and convincing that the withdrawal would be in the patient's best interests.[290]

C. *A Note on the Alzheimer's Cases*—In re Edna M.F. *and* In re Conroy

Both of the cases involving late stage Alzheimer's Disease, *Edna M.F.* and *Conroy*, highlight the slippery nature of MCS and also how evidentiary and substantive standards must be managed depending upon the etiology of the MCS. One path that courts could take is to give the same robust protections to late-stage Alzheimer's patients that they do to MCS patients whose condition was caused by traumatic brain injury. This is what happened, more or less, in the *M.F.* and *Conroy* cases (with the caveat of the three different standards in *Conroy*).[291] Both courts required clear and convincing evidence of the patients' actual wishes to be removed from the ANH before the court would actually sanction the withdrawal.[292] Internal consistency should demand that minimal consciousness, no matter how minimal or how it is caused, deserves the law's best protections. The logical extension of this premise is that ANH should be given to the very late-stage Alzheimer's patient even when the disease is working the imminent demise of the patient. Or, the Alzheimer's patient should be given food and water even when she can no longer assimilate them or no longer has a hunger drive.

To take such a position, however, is, at best, belligerent. At worst, the position is cruel because it could interfere with the natural mechanisms of death. If clear and convincing and subjective evidence is required before a late-stage Alzheimer's patient can be disconnected from ANH and allowed to die, then the patient must not only anticipate her diagnosis but also the progression of that diagnosis before the ANH can be removed. "If I am ever severely demented and about to die, just take my food away," or something close to it is what the prospective Alzheimer's patient must say even before she develops the disease. Unlike the first, more unlikely scenario, one could forecast a situation in which the then healthy person said, "If I ever lose my mind, then just let me go."

Herein lies the trouble for the conscientious proxy. Why must the surrogate wait until the Alzheimer's patient is actively dying before removing ANH? Why not refuse to give ANH in the first place and just let the patient starve to death the moment she can no longer take food

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[290] *See Wendland*, 28 P.2d at 175.

[291] *See Conroy*, 426 A.2d at 1244; *Edna M.F.*, 563 N.W.2d at 494.

[292] *Id.*

and drink by mouth? The answer is, I think, found in the imminence of death. When a person is first diagnosed with Alzheimer's or any other neurological disease that will inevitably, but slowly claim their lives, it is rare that the listlessness and surrender of the body follows directly on the heels of the diagnosis. No one, for example, becomes completely incompetent upon first diagnosis of ALS or Parkinson's Disease. Rather, the Alzheimer's patient slowly descends into the Kafkaesque rings of amnesia and childlike behavior that is the disease. Eventually, in the last stretch of the disease, the body gives up, and no longer can accommodate food or water (this is true of cancer patients and many others dying of progressive conditions).[293] If the surrogate were forced to abide by the "high" evidentiary and substantive standards, then theoretically she would be required to maintain the feeding tube until the body thoroughly capitulated and suddenly died. But, such a fastidious application of the high standards is not contemplated in this proposal. Some patients are oppressed with a disease, which like a fierce Roman army, will certainly and inevitably conquer its quarry. The Alzheimer's sufferer is such a patient. Death will certainly outwit her. Ethical praxis does not demand the administration of food and water when the ferocious power of death would make the food and water meaningless to the patient. On the other hand, some patients are not oppressed with a disease whose fate is certain, but rather with a disorder or condition that merely masks the small, yet consistent germ of life within the patient. MCS is such a condition. MCS is not a terminal disease. It is, rather, a disorder of consciousness in which the patient can indefinitely stay if provided sustenance and other basic care.

IV. ARGUMENTS FOR THE CLEAR AND CONVINCING AND SUBJECTIVE STANDARDS

A. Generally

When the next case involving the new Robert Wendland or Michael Martin comes before a state court, that court should take heed of its fellow state supreme court holdings and demand that the surrogate demonstrate by both a clear and convincing evidentiary standard and a subjective substantive standard that the patient would make a choice for death. Bifurcated, yet very high, even aspirational, standards are the only way to insure that the either the patient's true, deeply-felt wishes made before his traumatic injury are respected, while at the same time giving

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[293] *See* Muriel R. Gillick, *Rethinking the Role of Tube Feeding in Patients with Advanced Dementia*, 342 NEW ENG. J. MED. 206 (2000).

the patient enough time to recover to let him voice either a decision for death or one for life.

The clear and convincing evidentiary standard would lead a court to focus on the fundamental ethical and legal issues involved when considering whether to discontinue life-sustaining treatment from a minimally conscious patient. Simply, the clear and convincing standard forces the court to realize that however diminished, vulnerable, and disabled the patient lying in the nursing home or hospital bed is, he is both a human being and a 'person' deserving of humane attention and the time and space necessary to be restored to a better functioning state. That is, because the very life of a *person* (and not a mere human being) is at stake, the court should be bound to navigate a very high hurdle before it sanctions a surrogate to remove the patient's lifeline to the living world.

The subjective standard, then, must be viewed through the prior grid of the clear and convincing standard. If adopted, the surrogate would search for clues about the patient's deepest intentions about his end-of-life care and then try to match up those intentions with the patient's current medical condition. If the statements and the condition matched, then the surrogate could feel safe in discontinuing the ANH because the surrogate would know that withdrawal is what the patient actually wanted. The clear and convincing standard reigns in the surrogate's assessment and demands that she have a very large quantum of evidence of the patient's own wishes, beliefs, feelings, and thoughts on the matter before deeming that the patient's judgment would be to discontinue life-sustaining treatment.

To be sure, there are different mechanisms through which states can accomplish their life-protection charge. Some states, like those that have adopted the Uniform Health Care Decision Act (UHCDA) or other statutory carve-outs, allow surrogates to make decisions on behalf of incompetent patients who have not previously executed an advanced directive.[294] Importantly, the UHCDA, which allows for patients to make health care instructions orally, first asks "agents" to make decisions according to the patient's actual wishes—a subjective standard.[295] Only if

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[294] *See* Unif. Heath-Care Decisions Act, §§ 1-19, 9 U.L.A. 310 (1993) [hereinafter UHCDA] (stating that the UHCDA has been adopted by nine states, including Maine, ME. REV. STAT. ANN. TIT. 18, §§ 5-801 to 5-818 (1995); New Mexico, NEW MEX. STAT. ANN. § 24-7A-1 to 24-7A-18 (West 1995); Delaware, Del. CODE ANN. TIT. 16, §§ 2501-2517 (1996); Alabama, ALA. ADMIN. CODE § 22-8A-1 to 22-8A-13 (1997); Mississippi, MISS. CODE ANN. § 41-41-201 to 41-41-229 (West 1998); California, CAL. PROB. CODE §§ 4670 – 4743 (1999); Hawaii, HAW. REV. STAT. § 327E-1 to 327E-16 (1999); Alaska, ALASKA STAT. § 13.52.010 – 13.52.395 (2004)); For a summary of the UHCDA's provisions, see generally MEISEL & CERMINARA, *supra* note 30, at §7.04[A].

[295] *See* UHCDA, § 2(a), (e), 9 U.L.A. 310 (1993).

the patient's wishes cannot be discerned may the agent then decide for the patient based on his best interests.[296] However, not all states that have adopted the UHCDA would allow surrogates to withdraw or withhold ANH from a minimally conscious patient when the MCS patient has not prewritten his wishes in the form of an advance directive or health care proxy designation. Many of the UHCDA states, and some other states, circumscribe withdrawal to patients who have a "qualifying condition" of either terminal illness or permanent unconsciousness. The minimally conscious state is not a terminal condition and it is not complete and permanent unconsciousness.[297] And some states that have these statutory

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[296] *See id.* at § 2(e).

[297] Alabama defines "qualifying condition" as either terminal illness or "permanent unconsciousness." *See* ALA. ADMIN. CODE § 22-8A-11(a)(2) (1997). If the patient did not make a written advance directive or designate in writing his health care proxy, then the surrogate may terminate life support only if the patient has a qualifying condition. *See id.* Alaska's provisions are substantially the same. *See* ALAS. STAT. § 13.52.390(36) (2004) (defining "qualifying condition" to include terminal illness or permanent unconsciousness) and § 13.52.045 (requiring the presence of a qualifying condition when there is no written advance directive and a determination that the withdrawal is in the patient's best interest and is done in good faith). Delaware allows the surrogate to withdraw or withhold ANH when there is a qualifying condition (defined as permanent unconsciousness or terminal illness "documented in writing with its nature and cause, if known, in the patient's medical record by the attending physician"). *See* DEL. CODE ANN. TIT. 16, §§ 2501(r) and 2507(b)(6) (1996). Maine requires that an oral instruction be given by the patient to the surrogate, but the surrogate can only make a decision to withdraw ANH if the patient is either terminally ill or in a persistent vegetative state. *See* ME. REV. STAT. ANN. TIT. 18, §§ 5-802(a) and 5-805(a) (1995). *See also* KY. REV. STAT. ANN. §§ 311.631(5)-311.629(3) (West 2004) (constituting an example of a non-UHCDA state that circumscribes the allows removal of ANH only for immanent death of the patient, permanent unconsciousness (but only if there is an advanced directive on file), where the ANH cannot be broken down by the patient, and where the benefits of removal outweigh the burdens of continued treatment.) *But see* OKL. ATT'Y. GEN. OPIN. No. 06-7 (2006) (questioning the constitutionality of Oklahoma's provision narrowing the instances in which artificial nutrition and hydration can be removed to only terminal illness or "persistent unconsciousness"). *See also* MEISEL & CERMINARA, *supra* note 30, at §1A-06, 8.08 (giving a fulsome list of state statutes regarding surrogate decision-making). California, on the other hand, seems to have looser standards for withdrawal of ANH. If the patient has made "actual instructions" about his wishes, then the surrogate can execute those instructions. However, if the patient has not made any advance instructions, then the surrogate can make decisions on behalf of the patient based on the patient's best interest. *See* CAL. PROB. CODE § 4714 (1999). The standards are the same for proxies appointed through a power of attorney for healthcare. *See id.* at § 4684. *See also* CAL. HEALTH & SAFETY CODE § 1418.8 (West 2006), a surrogacy statute for patients in long-term care facilities or intermediate care facilities. In Hawaii, the surrogate can remove ANH only when the patient's primary physician and one other physician concur "that the continuation of artificial nutrition and hydration is merely prolonging the act of dying and the patient is highly unlikely to have any neurological response in the future). *See* HAW. REV. STAT. § 327E-5(g) (1999). It would seem then that in a Hawaii MCS case,

allowances mandate that the surrogate have clear and convincing evidence of the patient's prior wishes to go without life-sustaining treatment before the surrogate can remove such treatment. In these states, the legislature has shifted the burden to favor the surrogate to make the correct decision on behalf of the charge in his care. It is this paper's argument that for the states that have not adopted the statutory allowances that would allow surrogates to easily remove life-sustaining treatment, courts should retain a firmer control over the end-of-life decisions involving MCS patients.[298] Courts should look at the 'end prize'—the protection of the patient's life—through the binocular of the clear and convincing evidentiary standard and the subjective substantive standard, and only after the surrogate has met both standards working in tandem, can she work to forfeit the patient's life.

Of course, the state's interest in preserving life is mitigated by the individual's interest in controlling the course of his own life. The overriding heritage from the seminal *Quinlan* case is that the sovereign patient can either commit to live or commit to die, and the state must not

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whether the patient lives or dies depends on whether the two physicians believe that the current responsiveness of a minimally conscious patient and the prospect for greater recovery in the future satisfies the "any neurological response in the future" prong of the statute. *See id.* In Mississippi, the surrogate has wide ranging powers to make healthcare decisions on behalf of patients when the "patient has been determined by the primary physician to lack capacity and no agent or guardian has been appointed or the agent or guardian is not reasonably available." MISS. CODE ANN. § 41-41-211(1). The surrogate must act according to the patient's individual instructions or best interest. *See id.* § 41-41-211(1), (6). In New Mexico, the patient may make oral instructions, but if he does so they must be made to the health care provider him or herself. *See* NEW MEX. STAT. ANN. § 24-7A-1 (West 1995). Additionally, a surrogate is allowed to make health care decisions for a patient according to the patient's individual instructions, and if there are none, then according to the patient's best interest. *See id.* § 24-7A-5.A., 5.F. Similarly, in a guardianship setting, the guardian must comply with any individual instructions made by the ward and is forbidden from annulling the patient's advance directive until (and unless) authorized to do so by a court. *See id.* § 24-7A-6. In Wyoming, the patient may make an oral individual instruction. The agent then must act according to that individual instruction, and for items not covered in the individual instruction the agent must act according to the patient's best interest as determined, in part, by the patient's values. *See* WYO. STAT. ANN. § 35-22-403(a), (f).

[298] *See* MEISEL & CERMINARA, *supra* note 30, § 8.08 for a summary and discussion of the substantive decision-making standards at play in all the states' surrogate statutes, not just those states that have the UHCDA, and the criteria of the conditions that trigger those substantive standards. They argue that there is a decided mix in the states' statutes between the subjective, substituted judgment, the best interests standards, and no standards at all, and when the surrogate may use the respective standards to make his or her decisions. *See id.* The authors note that, for those states that do not have case law on the books regarding substantive decision-making standards, it will be a bona fide issue whether the state will apply the substituted judgment standard, the most common decision-making standard, in a case of first impression. *See id.*

interfere if he does make a decision for death.[299] It is crucial, though, that this reason be viewed in light of the nature of the MCS diagnosis. In MCS, the patient retains some portion of his native ability to reason, cogitate, and then act upon those cogitations.[300] In PVS, however, the patient has irretrievably lost that functionality forever.[301] So, it might be more precise to claim that the MCS courts protected the *germ of thought* housed within the bodies of the MCS patients along with their bodies and their functions. On the other hand, the PVS courts did not protect the patients' bodily lives, though most were functioning only with the aid of artificial nutrition and hydration. Many PVS courts saw the functioning brain as the seat of life, and they made the sharp dichotomy between the rational, which controls the rest of the body, and the merely corporeal, that which is controlled by the rational. For the PVS patient, practically all medical and legal commentators have argued, is "neo-cortically" dead; thus, according to these commentators, it is *merely* and *only* a patient's body that is being "maintained" by the artificially supplied nutrition and hydration—that which is the patient's life, has flown away.[302] Thus, the syllogism would go something like this: if the body is animated by the willful functions and choices of the brain, then when those functions and choices can no longer be made at all by the brain, the body cannot be further animated, and should be allowed to die.

B. The Nature of the MCS Condition

The minimally conscious state is a condition that leaves its sufferers profoundly disabled, yet: (1) still alive; (2) still conscious, though for many, if not most, that consciousness is diminished and intermittent; (3) not in the persistent vegetative state;[303] and (4) with potential or actual personal interests that include an interest in living itself. Let no one try to obfuscate the serious condition that a MCS patient, even an advanced patient, finds himself in. The patient, like Robert Wendland, could at one time grasp objects and answer 'yes' or 'no' questions (though sometimes not all correctly), and requires intense rehabilitation just to maintain the progress he has won through prior rehabilitation or other therapy.[304] Even the most miraculous MCS 'cure' likely will never result in the patient

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[299] *See Quinlan*, 355 A.2d at 664.

[300] *See supra* Part II.A.2.

[301] *See supra* Part II.A.3. *But see supra* Part II.B.2 (for discussion of drug therapies that have been successful for some PVS and MCS patients).

[302] *See, e.g.*, The Multi-Society Task Force on PVS, *supra* note 70.

[303] *See* Giacino et al., *supra* note 79, at 350-51.

[304] *See id.* at 351 (explaining more on emergence from the minimally conscious state).

resuming all the activities of daily living he might have enjoyed prior to his trauma. It will be difficult, if not impossible, for the rehabilitated MCS patient to hold a job and live on his own.

However, when the MCS patient is compared with the PVS patient, the argument for the clear and convincing standard comes into sharper focus. PVS patients, some might say, are alive and viable as human beings, deserving of humane medical care, but can no longer be said to have 'personal' interests. Indeed, the idea of a 'personal' interest makes plain that the human bearing the interest is a 'person' deserving of the most comprehensive legal and ethical protection along with humane attention. The PVS patient's centers of cognition and judgment have been eviscerated. The patient is like a seashell after the snail has slithered away. Though the lower, reptilian part of the brain still directs the patient's heart to beat and lungs to inflate and deflate, the patient is completely unable to marshal a willful response to outside stimuli. Any movements, gestures, or noises made by the patient are a result of his autonomous nervous system, controlled by his brain stem.[305] However, while this is generally the case, one must be cognizant of the pharmaceutical interventions made over the past ten years for the benefit of persistently and permanently vegetative patients and should give these patients use of these therapies before removing their ANH.[306]

Lawrence Nelson and Ronald Cranford contend that Robert Wendland and minimally conscious patients like him should be treated exactly like PVS patients because patients in a MCS are practically the same, physiologically and behaviorally, as PVS patients.[307] They argue that the MCS patient has so little cognition that is so inchoate and intermittent that her condition should not be practically distinguished from PVS.[308] Further, they argue that the quality of the cognition is so low the patient should be allowed to die.[309]

Second, Nelson and Cranford do not allow for the robust recoveries witnessed over the past several years.[310] In fairness, neither Nelson nor Cranford could have anticipated the imaging breakthroughs wrought by fMRI, drug-related therapies like off-label Ambien use, or deep brain stimulation. But, it is debatable that either commentator would have advocated for the time and space necessary for Robert Wendland's

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305. *See supra* Part I.B.1.

306. *See supra* Part II.B.2.

307. Lawrence J. Nelson & Ronald E. Cranford, *Michael Martin and Robert Wendland: Beyond the Vegetative State*, 15 J. CONTEMP. HEALTH L. & POL'Y 427, 429, 441, 446 (1998-1999).

308. *See id.*

309. *See id.* at 447.

310. *See id.*

recovery even if the exciting new therapies were available during the pendency of his life.[311] To these authors, the ultimate ground of concern is that Robert Wendland voiced sentiments in which he strongly preferred death if he were ever attached to life-sustaining machines or in a vegetative state.[312]

Any argument grounded in the possibility for recovery to normal function need not undercut the contention that all human, conscious life, however distant that conscious life may be from normal functioning, is worth valuing and is deserving of unique defense by the courts. The possibility argument looks to the person's potential for return to workaday human communication, and is grounded in the possibility for filial and familial affection and interaction that a normal level of talking and non-verbal gesturing may bring to the patient's family and associates and the patient's own interest in resuming semi-normal life activities. To be sure, the potential argument is grounded in utility and in a very real sense instrumentalizes the patient as someone who can provide love, care, and provide human interaction to fellow persons, instead of respecting the patient as someone as one who deserves the same amount of love, affection, food, water, and other health care items, merely because he is a *homo sapiens*. Nevertheless, the point is that the argument for heightened standards can be grounded in either the utilitarian pro-recovery camp or the deontological pro-existence camp without the argument needlessly suffering.

Further, Nelson and Cranford argue that the MCS patient's life is so depressed and painful that the patient would be better dead than stuck in the quasi-suspended animation that is profound MCS.[313] However, they do not measure or quantify the amount of quality a MCS patient's life must contain before he can be protected by the higher standards.[314]

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[311] However, the authors concede that the main interest that either the PVS or MCS patient may have is to emerge from their respective conditions and "[go] back to a more functional form of human existence, however unlikely this may be." *Id.* at 445-46. How much time Nelson and Cranford would allow the MCS patient to recover is up for debate.

[312] *See, e.g.*, Nelson & Cranford, *supra* note 307, at 447. Jim Stone has framed a very powerful argument in favor of allowing MCS patients to live in his 2007 essay in the journal *Bioethics*. *See* Jim Stone, *Pascal's Wager and the Persistent Vegetative State*, 21 BIOETHICS 84, 89-92 (2007). Stone originally framed his "Pascal's Wager" argument for maintaining ANH for PVS patients. *See* Jim Stone, *Advance Directive, Autonomy, and Unintended Death*, 8 BIOETHICS 223 (1994). Stone's 2007 Bioethics article was written to dialogue with Thomas Mappes' criticism of the Pascal's Wager argument. *See* Thomas Mappes, *Persistent Vegetative State, Prospective Thinking, and Advance Directives*, 13 KENNEDY INST. ETHICS J. 199 (2003).

[313] *See* Nelson & Cranford, *supra* note 307, at 447-49.

[314] Specifically, the authors contend that:

Perhaps another way to look at this issue is: How much consciousness and physical functioning must the patient have before he would not be better off dead (*e.g.*, how 'advanced' does his MCS state have to be?). It behooves Nelson and Cranford to be intentional about the quanta or amount of quality required before a person should be protected by the high standards of clear and convincing evidentiary and subjective substantive standards. This, too, is the flaw of the *Wendland* and *Conroy* courts, which allowed for some form of a best interests substantive standard to be used.[315] Best interests, as a rule of decision, is grounded, in part, in a quality of life calculus. The quality of life standard views the propriety of continued corporeal existence, in part, in light of the current existence's quality.[316] In response to qualitists, one point should be made. Tragically, most MCS patients cannot communicate the quality or lack thereof they experience in their devastated and incompetent states. Therefore, what surrogates judge as a very low quality of life, the surrogate (and other competent concerned people) may actually be the surrogate's own estimation of the patient's diminished dignity based on her medical condition. That is, the surrogate may judge that seeing a patient with contractures or lying in his own waste contributes to a very low quality of life. However, because of the patient's inability to forcefully communicate, he is unable to tell the surrogate if those conditions are indeed contributing to a low life quality. Instead, the surrogate may conflate his own or the patient's dignitary interests ("John would have never wanted to live this way;" or, "I would have never wanted to live this way") with a judgment that the patient's life quality is low.

> [T]he argument for requiring continued treatment of a minimally conscious patient ignores the pain and suffering the patient will have to undergo while his life is being prolonged. Vegetative patients experience nothing with or without life-sustaining treatment. In contrast, continued treatment of minimally conscious patients – precisely because they are conscious – may result in them suffering for years, or ever decades, and probably being wholly unable to express adequately to anyone the depth of their pain, not to mention their elemental sense of frustration or loss.

Id. at 448. The authors also mention the total dependence of MCS patients on others for support activities of daily living, and while the authors did not use the terms "quality" or "quality of life," it seems logical that a person's inability to take care of himself would be a quality of life concern (as well as a dignitary concern). *See id.* at 446.

[315] *See Conroy*, 486 A.2d at 1241; *Wendland*, 28 P.3d at 173.

[316] *See, e.g.*, Barber v. Superior Court, 195 Cal. Rptr. 484, 493 (Cal. Ct. App. 1983) (stating that "[i]f it is not possible to ascertain the choice the patient would have made, the surrogate ought to be guided in his decision by the patient's best interests. Under this standard, such factors as the relief of suffering, the preservation or restoration of functioning and the quality as well as the extent of life sustained may be considered."); *see also* MEISEL & CERMINARA, *supra* note 30, § 4.07[E][3][a][ii].

Indeed it is protection of the patient's quality and dignitary interest that may contribute to surrogates (and commentators) clamoring for a low evidentiary threshold. As explicated in the four MCS cases, surrogates' primary motivation is to actualize the past wishes of their loved ones. They want to, in essence, provide for the incompetent patient a way to forego temporal life in the present because he said that he would not want to live like this current condition sometime in the past. However, the surrogate himself does not precipitously arrive at the judgment to withdraw life-sustaining treatment. Only after the initial shock of the trauma (or oxygen deprivation) that has caused the patient's MCS, and only after living with, at least for a while, the practical effects of MCS, does the surrogate decide to fight for the patient's prior wishes. Since the surrogate does not want to see their loved one waste away under the oppressive weight of machines, relative isolation, and incontinence, the surrogate forcefully argues that whatever the patient said prior to becoming incompetent amounts to a preponderance of the evidence and enough to sanction the surrogate's withdrawal of life-sustaining treatment. The dignitary interest becomes a convenient, but secondary, reason that the surrogate demands that life-sustaining treatment be stopped.

C. The Interest in Judicial Circumspection

All four main MCS courts have placed a premium on deliberation, consideration, and resolving the case before them in a sober manner befitting the life and death subject matter of the case.[317] Each court recognized that if it was going to allow the surrogate to contribute to the patient's death, it would require the surrogate to produce an extraordinary—that is out of the ordinary (or beyond preponderance of the evidence)—amount of proof that the patient did truly make a choice for death.[318]

The tenor struck by the MCS courts seems to be appropriate considering the gravity of the controversies before it. Just as each court recognized that surrogates would have to traverse a high wall of proof before they could 'make dead' their patients, the courts also recognized that the choice of evidentiary and substantive standard would lead to a dichotomous choice—one choice would lead to the status quo *ante*—the patient would be in no worse position than he was before the choice. His feeding tube would be maintained, and he would still have at least the

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[317] *See Wendland*, 28 P.3d 151; *Martin*, 538 N.W.2d 399; *Conroy*, 486 A.2d 1216; *Edna M.F.*, 563 N.W.2d 485.

[318] *See id.*

possibility of returning to more of a normal life than his current disabled state. On the other side of the coin, a precipitous ruling in favor of the surrogate (and her desire to discontinue life-sustaining treatment) under a preponderance standard could result in a decision that did not accord with the patient's actual wishes at the time those wishes were voiced.

Therefore, the interest in judicial circumspection is one that places a check on both the court's and the surrogate's internal predilections and passions. In most of the four MCS cases, courts have found the patients to be pitiable and pitiful characters. These courts agree with the surrogate and expert physician's assessments that the patient is living a vacuous, meaningless, and painful life in which he can never recover to normalcy. Thus, because of his unrelenting pain, it would be, in the court's estimation, in the patient's best interests to be relieved of his suffering and have his feeding tube removed. But notwithstanding the court's merciful impulse, its judicial temperament kicks in, and the court raises the flag of clear and convincing to stop its otherwise headlong dive into passive euthanasia. By invoking clear and convincing, the court volleys the burden of proof onto the surrogate, and he is forced to find a statement the closely matches the patient's actual condition (and not a statement like in *Wendland*, where Robert Wendland said that he did not want to be a vegetable).[319] The court is required to shift its focus from the amount of evidence—the number of statements the patient may have made about his end-of-life wishes—and onto the quality of the evidence—the precision of prior wishes.

D. Objections to Clear and Convincing

1. Social Cost and Euthanasia

The social cost of maintaining MCS patients is staggering. MCS patients (and PVS patients too) need only basic nursing care (*e.g.*, turning of the patient's body to prevent bedsores, cleaning the patient, etc.) and daily provisions of ANH, yet the total annual bill for American MCS patients runs into the billions of dollars.[320] The mere introduction of the fiscal drain on a healthcare system that is itself on life-support

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[319] *See Wendland*, 28 P.3d at 157.

[320] Assume that each and every MCS patient will be taken care in a nursing home, which is not likely because some MCS patients will be tended to in hospitals (which cost substantially more than nursing homes) and some will be taken care of at home. Also assume that each MCS patient's care is reimbursed by the various states' participation in the Medicaid program. If we assume 100,000 MCS patients (low-end) and a $100 day Medicaid room rate (which too is low), the total Medicaid reimbursed costs would be around $3.65 billion per annum. The actual costs would likely be much higher than that.

presents the tantalizing possibility of a consequentialist lens through which to view the MCS patient. Surely, the billions used to maintain the vegetative functions of MCS patients can be better used to help patients who have a more immediate chance of full recovery. Aside from the basic moral assertion that life (defined as consciousness, however diminished) should be given extraordinary protection, why not require a low evidentiary standard and/or objective evidence of a patient's desire for death, with the result that many more MCS patients would be disconnected from their ANH and subsequently die?

Two answers to this thorny question immediately appear. First, notwithstanding the crisis in American healthcare, for which a one-time nominee for the country's top health policymaker has called for European style rationing of expensive treatment and procedures, there is an undercurrent in the American public that would welcome maintaining MCS patients *if* they could be brought back to a fuller sentient existence.[321] This is a "reverse" consequentialist argument. If the patient can not only be saved (sapient life) but also brought back to normal functioning (full sentient life), then it becomes an obligation to maintain and to administer the function-producing treatments.

Second, though there seems to be a gradual loosening of American public opinion toward euthanasia, there is a strong contingent of the public that is skittish toward the deliberate ending of another's life.[322] Though sanctioned through the best interests and substituted judgment standards, the ending of the mentally incompetent patient's life (usually PVS patients) can be correctly deemed as non-voluntary euthanasia. To be sure, removals of treatment made under the more relaxed evidentiary standards are sometimes done with the blessing of the court, but the characterization of the act and the decision to remove rests with the patient's surrogate. Though given protection by the court, or the state statute, it is not a stretch to say that the surrogate wills the end of the patient's physical functions. Were best interests or substituted judgment allowed for MCS patients, no circumlocutions would be necessary. The will of the surrogate would not be to end the patient's physical functions

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[321] *See* SENATOR TOM DASCHLE, CRITICAL: WHAT WE CAN DO ABOUT THE HEALTH CARE CRISIS (Thomas Dunne Books 2008) (lauding the use of "quality of life years" (QALYs) to determine the prospective effectiveness of a treatment for patients treated in the United Kingdom's National Health Service).

[322] *See* Gallup Organization, *Public Continues to Support Right-to-Die for Terminally Ill Patients*, *available at http://*www.gallup.com/poll/23356/Public-Continues-Support-RighttoDie-Terminally-Ill-Patients.aspx (last visited Nov. 8, 2009) (showing the aggregation of Gallup's 2003-2006 polling data showed that 69% of the sample "support[ed] [the] doctor ending [the] patient's life by painless means," and 58% "support[ed] doctor assisting [the] patient to commit suicide").

but his life itself. And so, the choice is dichotomous—either indefinitely maintain the MCS patient's life with the hope of a "cure" (or at least better functioning) as a possibility sometime in the future, or allow the surrogate end the patient's life through the medium of the other decision-making standards.

Could not the same charge of non-voluntary euthanasia be leveled at the court that found a MCS patient to have given clear and convincing, subjective evidence of the patient's desire to die should she ever fall into a MCS? Yes, if such a case were to occur, the court would be responsible for the patient's demise, if the patient's MCS is due to a non-fatal trauma or other disorder that would not inevitably take the patient's life.

The principle of double effect has no currency in a situation where death is not imminently foreseeable. That is, the removal of ANH for the trauma-induced MCS patient cannot be to make the patient comfortable or free from pain with the possibility *but not the intention* that the patient dies. Rather, because the patient only needs food and water and basic nursing care to survive, withdrawal of treatment looks much more like euthanasia of a hybrid kind. It is voluntary in the sense that the patient, according to the court, was plain enough about his wishes that he purposed his own demise. It is non-voluntary in the sense that the patient, once incompetent, has no chance to weigh in on his incompetent state and ratify his prospective decision for death or nullify it.

2. *The Patient's Actual Wishes*

The other, and more troubling, charge that could be leveled against advocates for clear and convincing and subjective evidence is that these standards frustrate the true intention of the person who eventually falls into a MCS. Though it is highly unlikely that any patient who expresses oral sentiments about his end-of-life care would ever mention the minimally conscious state, it is more likely that the patient would express an unwillingness to be maintained if he ever became a "vegetable." Of course, without further elaboration by the speaker about his definition of vegetable, the surrogate will have no idea whether such definition includes the severe MCS patient who looks and acts a PVS patient. In such a case, it is very plausible for a court to allow a proxy, under for example, a substituted judgment theory, to withdraw ANH under the theory that the two disorders—severe MCS and PVS are so similar that to distinguish them is to prize form over substance.

The argument has currency, especially if the MCS is viewed under a best interests decision-making standard. Best interests is, at bottom, a consequentialist heuristic in which the actual decision-maker must order the life-preferences of the patient for him and conclude that the most good for him is accomplished through the extinguishment of all other preferences and thus his life.[323] In the case of the MCS patient, the surrogate must conclude, like Cranford and Nelson, that MCS is a fate worse than death, because the patient may be experiencing pain—whether psychic or physical—and have no way to express it or his desire to be relieved from it. Best interests falls apart, however, because it does not order life—in all of its beauty, tragedy, inanity, and pathos, above all other desires, even the desire to not be trapped in what might be deemed as a meaningless existence.[324] Simply, best interests cannot anticipate what exactly the patient is thinking while lying in the MCS on the nursing home bed. Has he adopted a nihilistic posture and checked out because all for him is meaningless? Does he value the radically diminished life that he now has? That the MCS patient participates with interlocutors, whether family, friends, rehabilitation professionals, or doctors, shows some desire to interact with the land of the living. For one could easily imagine a petulant, purposefully non-responsive MCS patient if he did not want to live in a trapped existence.

V. CONCLUSION

On the continuum of disorders of consciousness, the MCS patient occupies a very high rung. The patient is neither brain dead, nor in a coma or a vegetative state—awake but never aware. Rather, like the patient himself, who is on a continuum of brain disorders, his minimal consciousness is on a continuum of severity—from 'severe' MCS, where the patient might have only brief, sporadic cognitions or might move to specific commands—to a more 'advanced' MCS, where the patient might be able to act and talk more fluidly than the severe state would allow.[325]

The main courts that have taken up MCS cases have staked their claim on the status of the patient's mental states *viz* the PVS patient. In most cases involving ANH withdrawal from a patient in a PVS, the court is quick to concede that the person's essence—the ability to think, experience, feel pain, etc.—is gone, and thus the patient should be let go with reduced evidentiary and procedural constraints. However, in MCS, most of the courts have drawn the proverbial line in the sand upon the

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[323] *See* PETER SINGER, PRACTICAL ETHICS (Princeton Univ. Press 1993).

[324] *See generally* Nelson, *supra* note 289.

[325] *See* Giacino et al., *supra* note 79, at 351 (describing likely consciousness seen from small, rudimentary movements), and *Wendland*, 28 P.3d at 154, 155 (describing Robert Wendland's day to day actions such as manipulating his wheelchair, before he regressed into a more severe MCS).

status of the patient's mind—it still exists and thus must be given the most robust evidentiary and procedural protections possible. It behooves future courts concerned with protecting patients' interests in life and their interests in privacy, to make sure their oral wishes comply with the most scrupulous protections possible, not only because the patient before them is a living, breathing person, but also because he has the chance, small though as it is, of getting up out of his hospital or nursing home bed and living a more normal life.