Death, Life, and Uncertainty: Allocating the Risk of Error in the Decision To Terminate Life Support

In re Conservatorship of Wendland, Prob. Case No. 65669 (Cal. Super. Ct. Jan. 21, 1997 & Mar. 9, 1998), *appeal pend'g*, No. C029439 (Cal. Ct. App. 1998).

On September 29, 1993, forty-two-year-old Robert Wendland flipped his pickup truck on a highway in Stockton, California. The accident left him comatose with severe head injuries. After languishing in a persistent vegetative state (PVS) for sixteen months, Robert began to show signs of cognitive responsiveness. He regained the ability to pick up designated objects with his left hand, to make some voluntary movements, and occasionally to respond to yes-or-no questions. His progress leveled off, however, in mid-1995. He now exists in what physicians refer to as a "minimally conscious state" (MCS)—a condition between sapient consciousness and PVS. Although not comatose, he remains severely brain damaged, partially paralyzed, dependent upon others for all of his needs, unable to communicate, and reliant upon artificial nutrition and hydration.[1]

On at least two occasions prior to his accident, Robert told his wife, Rose, that he would not want to live in a state of incapacitation and total dependence on others. Because of Robert's previously expressed wishes and his poor prognosis, in August 1995 Rose asked his physicians to remove his feeding tube. The physicians and the hospital's bioethics committee agreed, but Robert's estranged mother and sister intervened and obtained a restraining order, arguing that Robert would not have wanted to die. Thus began four years of legal maneuvering holding Robert's life in the balance.

After a lengthy hearing, in March 1998 the court denied Rose's petition to terminate life-sustaining treatment.[2] In the first part of its bifurcated decision, the court ruled that Rose had the burden of proving through "clear and convincing" evidence that the withdrawal of artificial nutrition and

1. *See In re* Conservatorship of Wendland (*Wendland II*), Prob. Case No. 65669, slip op. at 5 (Cal. Super. Ct. Mar. 9, 1998), *appeal pend'g*, No. C029439 (Cal. Ct. App. 1998).

2. *See id.*

hydration would be in Robert's "best interests." The court chose this "tempered best interests" standard for surrogate decisionmaking over the "substituted judgment" and "pure subjective" standards, which would have mandated that the surrogate decide on the primary or sole basis, respectively, of what the patient would have wanted. While noting that Robert's previously expressed wishes "may be included in the decisionmaking process" under the best interests standard, the court made clear that the basis for decision is "what is objectively best for the patient."[3] In its second ruling, the court found that Rose had not established by clear and convincing evidence either that Robert would have wanted to die in this situation or that the termination of life-sustaining treatment was in his best interests.[4] The court appeared troubled by its own ruling, but concluded that "if it must err, it must err on the side of caution."[5]

The *Wendland* court's ruling is deeply troubling, reflecting a misapprehension of the medical realities of the minimally conscious state and the legal interests that follow therefrom. Both *Wendland* and a factually similar Michigan case that predated it, *In re Martin*,[6] involved a judicial decision to err on the side of life. While the court's nearly irrebuttable presumption in favor of life may be reasonable when applied to patients in a persistent vegetative state, who cannot experience pain, suffering, or degradation, it presents a grave risk of harm to patients in a minimally conscious state, who can. Both the substantive decisionmaking standard adopted by the *Wendland* court—the best interests test—and the evidentiary standard—clear and convincing evidence—are unsuitable standards for decisionmaking when the patient is in a minimally conscious state.

I

The *Wendland* case presents a question of first impression in California, but when considered in conjunction with *Martin* and a recent Wisconsin case,[7] suggests "an emerging judicial trend to distinguish" PVS from MCS.[8] *Wendland* has significant implications for this incipient movement, as the court held that stricter standards should apply to petitions seeking to terminate life support for MCS patients than to petitions concerning PVS patients.

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3. *In re* Conservatorship of Wendland (*Wendland I*), Prob. Case No. 65669, slip op. at 11, 17 (Cal. Super. Ct. Jan. 21, 1997), *appeal pend'g*, No. C029439 (Cal. Ct. App. 1998).

4. *See Wendland II*, slip op. at 3.

5. *Id.* at 5.

6. 538 N.W.2d 399 (Mich. 1995).

7. *See* Spahn v. Eisenberg (*In re* Guardianship of Edna M.F.), 563 N.W.2d 485 (Wis. 1997).

8. Lawrence J. Nelson & Ronald E. Cranford, *Michael Martin and Robert Wendland: Beyond the Vegetative State*, 15 J. CONTEMP. HEALTH L. & POL'Y 427, 431 (1999).

The question of how medical decisions for MCS patients ought to be made is likely to recur in the courts with increasing frequency because MCS is emerging as a recognized medical classification.[9] A recent conference of neurological specialists produced a consensus statement identifying MCS as a distinct clinical syndrome, different in many respects from PVS.[10] Their report defines MCS as a condition in which one or more of the following clinical features are clearly observable "on a reproducible or sustained basis": (1) following simple commands; (2) making verbal or nonverbal "yes-no" responses to questions (regardless of accuracy); (3) making intelligible verbalizations; and (4) making movements or displaying behaviors that are clearly responses to environmental stimuli.[11] In contrast, patients in PVS are permanently unconscious; they have no cognitive functioning.[12]

The most ethically significant feature of MCS is that MCS patients, unlike PVS patients, can experience pain and suffering.[13] They may suffer from a number of painful medical complications that commonly arise from prolonged immobilization.[14] Additionally, although MCS patients have varying degrees of self-awareness, some patients appear to be aware of their physical condition and able to experience humiliation and degradation from their uncontrolled bodily functions and their total dependence on others.[15]

Thus, there are several clinical characteristics of MCS that distinguish it from PVS. As this medical consensus grows, so too will the momentum pushing courts to distinguish between the two conditions when articulating legal standards for decisions to terminate life support. Because *Wendland* is

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9. *See, e.g.*, Ronald E. Cranford, *The Vegetative and Minimally Conscious States: Ethical Implications*, GERIATRICS, Sept. 1998, at S70; Nelson & Cranford, *supra* note 8, at 428 (citing Joseph Giacino et al., *Development of Practice Guidelines for Assessment and Management of the Vegetative and Minimally Conscious States*, 12 J. HEAD TRAUMA REHABILITATION 79 (1997)).

10. *See* Nelson & Cranford, *supra* note 8, at 428 (citing ASPEN NEUROBEHAVIORAL CONFERENCE WORK GROUP, ASSESSMENT, PROGNOSIS AND TREATMENT OF THE VEGETATIVE AND MINIMALLY CONSCIOUS STATES: THE ASPEN NEUROBEHAVIORAL CONFERENCE CONSENSUS STATEMENT (forthcoming 1999)).

11. *See id.*

12. *See* Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State* (pt. 1), 330 NEW ENG. J. MED. 1499, 1500 (1994).

13. *See* Cranford, *supra* note 9, at S72; Kristi E. Schrode, Comment, *Life in Limbo: Revising Policies for Permanently Unconscious Patients*, 31 HOUS. L. REV. 1609, 1638 (1995).

14. *See* Cranford, *supra* note 9, at S72. Among the medical conditions an MCS patient may experience are spasticity and contractures, bedsores and other forms of skin breakdown, urinary tract infections, bronchial infections, and dental problems. In addition, the insertion and maintenance of urinary catheters and feeding tubes may be painful and may give rise to other medical problems. *See* Robert J. Sullivan, *Accepting Death Without Artificial Nutrition or Hydration*, 8 J. GEN. INTERNAL MED. 220, 220 (1993); *see also* Amicus Curiae Brief of the California Medical Association in Support of Appellants at 28, *Wendland* (No. C029439) [hereinafter Amicus Curiae Brief] (listing 15 medical complications from feeding tubes).

15. *See* Amicus Curiae Brief, *supra* note 14, at 28 (noting that "[t]he minimally conscious patient may also suffer other torments," including confusion, disorientation, and frustration); Cranford, *supra* note 9, at S72.

the first case to address this distinction in depth, its ruling will have a profound impact on this developing area of jurisprudence—which will determine who will live and who will die.[16]

II

The *Wendland* court adopted standards for terminating life support that not only are ill-suited to the clinical situation of patients in MCS, but that also undervalue those patients' interest in avoiding the burdens of continued treatment. The court failed to recognize that because individuals in MCS are capable of feeling pain and suffering, a presumption in favor of continued treatment exposes MCS patients to harm that cannot be experienced by PVS patients. This consideration militates against imposition of both of the legal standards espoused by the *Wendland* court: the best interests standard and the clear-and-convincing-evidence standard. Each of these standards is considered in turn.

Courts and bioethicists have recognized three possible substantive standards for surrogate decisionmaking concerning end-of-life care: the best interests standard, the pure subjective standard, and the substituted judgment standard. The best interests standard calls for the surrogate to make decisions based on "such factors as the relief of suffering, the preservation or restoration of functioning[,] and the quality as well as the extent of life sustained," as well as the impact of the decision on the patient's loved ones.[17] In contrast, the pure subjective standard calls for the surrogate to draw solely on the prior expressed wishes of the patient. If there is insufficient evidence of the patient's preferences, then the surrogate is not permitted to withdraw life support under any circumstances.

The substituted judgment standard takes a middle course, allowing the surrogate to form her own conclusion about what the patient would have wanted from his prior statements or, if he has not explicitly expressed a preference, from what the surrogate knows about the patient's values,

16. It is possible that the *Wendland* appeal will be decided on a narrow issue of statutory construction: whether § 2355 of the California Probate Code, which provides that conservators have the authority to make medical decisions for conservatees, encompasses the power to terminate life support for a conservatee in MCS. If Rose Wendland succeeds in persuading the appellate court that it does, then she will be required to show only that her decision to withdraw artificial nutrition and hydration was made "in good faith." CAL. PROB. CODE § 2355(a) (West 1999). While *Wendland*'s outcome thus may turn on statutory interpretation, the broader policy issues the case raises have relevance for future litigation in other jurisdictions.

17. Barber v. Superior Court, 195 Cal. Rptr. 484, 493 (Ct. App. 1983). The *Wendland* court invoked this definition from *Barber* but modified it by suggesting that the determination should be "tempered" with "subjective" considerations of what the patient would have wanted. *Wendland I*, slip op. at 16. However, since the court said only that the patient's wishes "*may* be included" along with other factors, *id.* at 17 (emphasis added), its tempered best interest standard is quite different from the substituted judgment standard, which is based *solely* on the surrogate's determination of the patient's own preferences.

beliefs, personality, and prior lifestyle. The substituted judgment standard seeks to preserve the patient's right of self-determination after incompetency by placing the patient's own preferences at center stage, but also recognizes that it is the exceptional case in which the patient has previously articulated his wishes through clear and specific instructions.

The *Wendland* court erred in selecting the best interests standard. The best interests test requires the surrogate to ask questions that, for MCS patients, are unanswerable. Medical science has determined that MCS patients, unlike PVS patients, are able to feel pain (and pleasure); however, because they are so limited in their means of expression, no one can be sure to what extent a particular MCS patient is experiencing pain, suffering, and humiliation (or joy, pleasure, and contentment).[18] These are precisely the factors upon which the best interests test is based. Because of the uncertainty surrounding the experience of patients in MCS, the best interests of those patients are indeterminable. The best interests test encourages surrogates faced with this uncertainty to project their own fears, hopes, and prejudices onto the patient and to make a decision on the basis of speculation about what he *might* be feeling.

III

Wendland's requirement that a surrogate provide clear and convincing evidence is also distressing. The clear-and-convincing standard is extremely stringent, requiring that the evidence be "so clear as to leave no substantial doubt,"[19] or "sufficiently strong to command the unhesitating assent of every reasonable mind."[20] The court's adoption of this standard was grounded in a fear that extending to MCS patients the lesser evidentiary showing adopted by the California courts for PVS patients—a "good faith" decision[21]—would be to start down a slippery slope. It "would certainly provide the opportunity for unethical conservators of non-communicative incompetents to try and end the life of patients based on mere inconvenience, or for personal gain," the trial judge wrote.[22]

This justification is insufficient for two reasons. First, this danger is equally strong for PVS patients. In fact, since many MCS patients are able

18. *Cf.* 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. REV. 1193, 1230-31 (1996) (noting the difficulties of assessing pain even in communicative patients).

19. Sheehan v. Sullivan, 126 Cal. 189, 193 (1899) (citation omitted).

20. Lillian F. v. Superior Court, 160 Cal. App. 3d 314, 320 (Ct. App. 1984) (quoting *Sheehan*, 126 Cal. at 193).

21. *See* Drabick v. Drabick (*In re* Conservatorship of Drabick), 200 Cal. App. 3d 185, 201 (Ct. App. 1988).

22. *Wendland I*, slip op. at 16.

to interact in a limited way with loved ones, family members may maintain stronger emotional attachments to MCS patients than to PVS patients and thus may be *less* likely to want to terminate life support. Second, there are a host of evidentiary standards between "good faith" and "clear and convincing" with sufficient power to detect cases in which the conservator has no ground for terminating life support other than her own personal interests. Selecting the strictest conceivable evidentiary standard is judicial overkill and entails serious costs in the form of erroneous denials of petitions to terminate treatment.

Wendland's clear-and-convincing evidentiary standard also evinces a misunderstanding of MCS. This standard previously has been articulated and defended in cases involving PVS patients.[23] In those cases, the courts held that patients' strong interest in avoiding an erroneous deprivation of life resoundingly trumps their interest in avoiding unwanted treatment. That interest-balancing, however, is predicated on the assumption that the patient is in PVS. MCS patients, because they are capable of suffering, have a far stronger interest in avoiding the burdens of continued treatment. This interest is strong enough to warrant a lower evidentiary standard for withdrawing life-sustaining treatment.

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. The clear-and-convincing standard requires highly context-specific evidence of the patient's prior wishes: Courts typically require that the patient have envisioned the precise medical situation he is now in when he made the statement expressing a preference for nontreatment.[24] This standard is ill-suited to MCS given the wide range of medical situations that fall under that designation. The degree of presence of the four distinguishing features of MCS varies dramatically from patient to patient, and a patient need only display one of these abilities to be classified as MCS.[25] While a person might be able to foresee himself one day being in a persistent vegetative state, it is unlikely that he would be able to predict the exact combination of cognitive and physical abilities and disabilities he might have as an MCS patient. Thus, the clear-and-convincing standard creates a nearly insurmountable barrier when applied to MCS patients. Ironically, this was the very situation that the *Wendland* court sought to avoid.[26]

23. *See, e.g.*, Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 280-87 (1989).

24. *See, e.g.*, *In re* Martin, 538 N.W.2d 399, 411 (Mich. 1995).

25. *See* Nelson & Cranford, *supra* note 8, at 429.

26. *See Wendland I*, slip op. at 15 (rejecting the pure subjective standard adopted in the factually similar Michigan case, *In re Martin*, on the ground that it effectively precluded anyone who had not left written instructions from ever forgoing medical treatment after incompetency).

IV

Because of the uncertainty surrounding MCS, it is not at all obvious that courts confronted with decisionmaking for these patients should choose to err on the side of life. Until medical science has a better understanding of the physical and cognitive experience of MCS patients, there will always be a large risk of error in decisions to terminate life-sustaining treatment for these patients. But in choosing what it called "the cautious approach," the *Wendland* court misallocated this risk. The court placed such a heavy burden on the party seeking to terminate treatment that it ensured that treatment will be continued whenever any degree of uncertainty exists. The presumption in favor of life may make sense for PVS patients, who are not affirmatively harmed by continued treatment. But a nearly insurmountable presumption in favor of life is not appropriate where the patient may be enduring pain, suffering, and degradation.[27]

A better approach would be to allocate the risk of error more evenly between the parties by adopting a "loose substituted judgment" standard.[28] The substantive basis for decisionmaking under this standard is what the surrogate believes the patient would have wanted, as evidenced by the patient's prior statements and by what the surrogate knows about the patient's values, beliefs, attitudes, lifestyle, and life goals. A surrogate applying this standard should not be required to prove the accuracy of the putative preference by clear and convincing evidence; rather, a lower standard, such as a preponderance of the evidence, is appropriate. The best interests test should be applied only as a last resort when there is no way to ascertain the patient's wishes. Even in that case, a clear-and-convincing evidentiary standard should not be applied.

The loose substituted judgment standard has been adopted by a number

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27. It might be argued that because MCS patients are capable of experiencing pleasure as well as pain, the argument for favoring life is *stronger* for MCS patients than for PVS patients. If it could be established that a particular MCS patient was living pain-free and experiencing considerable pleasure, then that patient indeed would have a significant interest in continued life. But in most cases, one cannot reliably conclude that a particular MCS patient is experiencing pleasure. The MCS patient in *Martin*, for example, frequently smiled—but also smiled when told of his daughter's death. *See* Andrew J. Broder & Ronald E. Cranford, *"Mary, Mary, Quite Contrary, How Was I to Know?": Michael Martin, Absolute Prescience, and the Right to Die in Michigan*, 72 U. DET. MERCY L. REV. 787, 820 (1995). Because of the limited cognitive capacity of MCS patients, their extreme physical limitations, and the medical complications of immobilization, it is reasonable to conclude that it is the rare MCS patient for whom the pleasures of life outweigh its burdens. Given (1) the indeterminacy of any one patient's experience, (2) the statistical likelihood that pain and discomfort outweigh pleasure, and (3) the consequence of erroneously choosing life and damning the patient to what the *Wendland* court called a "living hell on earth," *Wendland I*, slip op. at 15, the rational decisionmaker operating under this uncertainty would not adopt a presumption in favor of continued treatment.

28. *See generally* Cantor, *supra* note 18, at 1211 (describing this standard).

of courts.[29] Substituted judgment is not uncontroversial, however.[30] Empirical studies have found that surrogate decisionmakers often are poor judges of what family members' treatment preferences would be in various medical situations,[31] and that negative attitudes about illness and disability expressed by individuals when they are healthy may soften as they age or when they actually become ill or disabled.[32] Thus, critics note, there is a not insignificant risk of error in relying upon a surrogate's educated guess as to what the patient would now want were he competent to make medical decisions. This may be so, but the risk is far less than that of the best interests standard, which involves mere speculation about the patient's quality of life and does not require that the surrogate even attempt to ground the decision in the patient's own autonomous choice. Preferences expressed prior to incompetency may not be infallible indicators of what the patient would now choose, but they should at least establish a rebuttable presumption regarding that choice.

Adoption of the substituted judgment standard would reduce the uncertainty surrounding terminal care decisionmaking. Unlike the quality-of-life considerations upon which the best interests test is based, the subjective considerations that form the basis for substituted judgment are usually ascertainable to at least some extent. If the patient has not executed a written advance directive or orally expressed some preference concerning end-of-life care, the surrogate can at least infer his preferences from knowledge of his values and beliefs. If even that information is not helpful, *then* the surrogate may make an educated guess about the patient's best interests. But why *start* with this guess, rather than using it as a last resort?

The *Wendland* court erred in its allocation of the risk of error between the parties, undervaluing MCS patients' strong interest in avoiding the burdens of continued life. A loose substituted judgment standard would acknowledge, as the *Wendland* court did, that PVS and MCS are different. But it would also recognize what the *Wendland* court failed to see: that MCS patients deserve *more* judicial protection of their liberty interest in refusing unwanted treatment—not less.

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29. *See id.* at 1212 n.68 (citing cases from six states).

30. *See id.* at 1216-17 (summarizing common criticisms).

31. *See, e.g.*, Allison B. Seckler et al., *Substituted Judgment: How Accurate Are Proxy Predictions?*, 115 ANNALS INTERNAL MED. 92, 95 (1991); Jeremiah Suhl et al., *Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support Is Unreliable*, 154 ARCHIVES INTERNAL MED. 90, 94 (1994).

32. *See, e.g.*, Shah Ebrahim et al., *The Valuation of States of Ill-Health: The Impact of Age and Disability*, 20 AGE & AGEING 37 (1991).