

OPEN PEER COMMENTARY

A Review of Terman's "Timely dying in dementia: Use patients' judgments and broaden the concept of suffering"

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On its face, Dr. Terman's piece represents a commendable effort to promote implementation of many people's desire to avoid prolonged immersion in advanced dementia (with its extreme cognitive dysfunction and complete dependence on others in daily living tasks). Dr. Terman seeks to use the legal prerogative of people, while still competent, to shape their post-competence medical fate. He urges advance care planning (ACP; i.e., advance medical directives) to accomplish the objective of abbreviating a lingering, debilitated demise by avoiding unwanted life-extending intervention.

Dr. Terman's major innovation is to lead ACP toward a concept of "irreversible severe suffering" in an apparent effort to encourage cooperation from health-care providers ultimately being asked to allow deeply demented patients to die. He correctly notes the frequent hesitancy of health-care providers to implement advance directives and he sees the language of severe "suffering" as an encouragement of provider cooperation. The suffering Dr. Terman recognizes is not confined to discernible distress. He "expands" the notions of physical and emotional suffering to encompass elements of indignity accompanying a deep cognitive and physical decline and even includes altruistic concern about the attendant burdens on family caregivers. He justifies his expanded vision of "severe enough suffering" by citing the difficulties of assessing the presence and depth of contemporaneous suffering in the context of uncomprehending and uncommunicative patients with advanced dementia.

While the Terman piece's intentions are commendable, I cannot endorse the effort to refocus ACP in terms of redefined "suffering." That suggested focus is deceptive as applied to many patients with advanced dementia. And that focus on suffering terminology is unnecessary because the existing legal and moral frameworks already provide for implementation of advance directives without connection to observable suffering.

I first address the deceptive overbreadth embodied in the concept of "severe enough suffering." True, some demented patients do experience distress (including embarrassment, frustration, or despair) in the course of their steep cognitive decline. But some deeply demented patients are not, as far as determinable, enduring distress from their debilitated circumstances. Their existence may be tranquil even if characterized by complete dependency and inability to relate in a comprehending or meaningful way to their environment. The aversion of some people to being mired in this state, as expressed in an advance directive or other prior instructions, is grounded on prospective distaste for a gravely diminished quality of life (QOL) that sullies their lifetime images, spoils the recollections left with loved ones, and imposes physical, emotional, and financial burdens on caregivers.¹ An attempt to bend these QOL concerns into a vocabulary of suffering seems to me deceptive and unnecessary.

Focus on suffering is unnecessary because the existing legal and ethical framework mandates adherence to clearly expressed advance instructions rejecting life-sustaining medical intervention (LSMI) at the point of decline defined by the now-incompetent demented patient as an intolerable QOL. Initially, the right to reject LSMI was a prerogative of competent patients grounded in bodily integrity and self-determination. Courts have now gone further and widely embraced a principle of precedent autonomy—liberty to control in advance post-competence medical interventions—as a matter of state constitutional law or state common law.² Some rejections of LSMI might be motivated by aversion to suffering, but such choices can also be based on religious principles or on aversion to a deteriorated QOL deemed by the patient to be intolerably undignified. The landmark case of *In re Quinlan*, 355 A.2d 647 (N.J. 1976) showed that precedent autonomy applies not only to avoidance of experienced harm like pain and suffering, but also to avoidance of a QOL deemed repugnant. (The court there assumed

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that a permanently unconscious patient could no longer feel pain, but understood that a permanent inability to interact with an environment might well be deemed so degrading that a person would not want to be medically sustained at that point.) As I summarized elsewhere: “The judicially established ... prerogative is aimed not only at avoidance of experienced harms like pain and suffering in a dying process, but also at avoiding a QOL the person deems repugnant, including a level of cognitive deterioration deemed to be intolerably degrading.”³ Given this existing framework binding health-care providers, Dr. Terman’s effort to tailor ACP to fit a revised conception of “suffering” seems to me a needless complication and distraction.

Another unfortunate aspect of the Terman piece is its position endorsing providers’ non-cooperation with advance instructions seeking rejection of LSMI so long as the demented patient “can still enjoy living.” Dr. Terman deems withholding of LSMI to constitute an unacceptable “premature dying” if the patient is not ostensibly suffering and can still extract some rudimentary satisfaction from sensory inputs (like music or TV) or social interactions. He tells clinicians that cooperation with fatal advance instructions in such a circumstance is legally, ethically, and morally inappropriate.⁴

This input from Dr. Terman gives credence to a movement by some medico-legal commentators to discredit implementation of ACP instructions where the now-demented patient, though gravely debilitated, is not ostensibly suffering and still extracts some element of satisfaction from life.⁵ These commentators see a moral imperative to uphold the immediate well-being of the non-suffering patient who has forgotten a prior determination to avoid prolongation of life at the QOL now at hand.

I have explained at length elsewhere why this movement to put aside clearcut advance instructions and substitute providers’ assessment of an acceptable QOL is misplaced and misguided.⁶ Here I will sketch the basis for my contention that it is both morally acceptable and legally required to implement the now-forgotten instructions defining the non-suffering patient’s current debilitated status as an intolerable QOL.

For some people drafting advance instructions, antipathy toward deep dementia is grounded not on prospective distress or suffering but on personal values such as indignity, degradation, or altruism. A declarant may well be seeking to shape a dying process that respects a vital lifetime image and influences the *post mortem* recollections to be left behind. US Supreme Court Justice Stevens explained the importance of this objective: “[An incompetent patient’s] interest in life ... includes an interest in how she will be thought of after her death by those whose opinions mattered to her. ... How she dies will affect how that life is remembered.”⁷ And some declarants are also seeking to avoid being an emotional, physical, or financial burden on loved ones. Justice Stevens noted that a patient devoted to family normally has an interest in “minimizing the burden that her own illness imposes on others” as well as in filling their memories with thoughts about her past vitality.⁸

As noted earlier in this review, American jurisprudence upholds a right to precedent autonomy to control a person’s post-competence medical fate. And precedents confirm that the competent declarant is

entitled to rely on personal considerations beyond avoidance of physical and emotional distress. Personal values to be respected include distaste for a deteriorated cognitive status deemed to be intolerably undignified, adherence to religious principles, and altruism toward survivors. Contrary to Dr. Terman’s suggestion, providers are legally and ethically required to uphold clear advance instructions about medical intervention even if it is wrenching to allow a non-suffering patient to die who no longer recalls the dignity concerns underlying those instructions. Where a demented patient’s prior expressed preferences are known, “the surrogate must make the medical choice that the patient ... would have made ... and not one the surrogate might think is in the patient’s best interests.”⁹ Dr. Terman’s importuning to act according to the immediate well-being of any deeply demented patient who can still extract some element of satisfaction from continued existence is neither consistent with the prevailing legal framework nor helpful.

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CONFLICT OF INTEREST STATEMENT

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CONSENT STATEMENT

No human subjects were involved in this paper.

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2. In re Browning, 568 So.2d 4, 12-13 (Fla. 1991); In re Conroy, 486 A.2d 1209, 1229 (N.J. 1985); K.L. Cerminara & J.R. Kadis, Give me Liberty to Choose a Better Death, 10 *St. Louis U. J. or Health Law & Policy* 67-92 (2016). A right to determine post-competence medical fate might also be part of the liberty protected by the federal constitution according to dictum in *Cruzan v. Missouri Dept of Health*, 110 S.Ct. 2841 (1990).
3. Cantor NL, “On Avoiding Deep Dementia,” 48:4 *Hastings Center Report* (July 2018), 15-24, at 17.
4. Terman SA, Steinberg KE, Hinerman N, Timely dying in dementia: Use patients’ judgments and broaden the concept of suffering. *Alzheimer’s Dement.* 2024:e12527. [10.1002/dad2.12527](https://doi.org/10.1002/dad2.12527)
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6. Cantor NL, “Dispelling Medico-Legal Misconceptions,” supra n. 1.
7. *Cruzan v. Director, Missouri Dept of Health*, 110 S.Ct. 2841, 2885-86 (1990).

8. Cruzan, 110 S.Ct. at 2892.
9. In re. Browning, 568 So.2d 4, 13 (Fla. 1991); see also In re Conroy, 486 A.2d 1209, 1229 (N.J. 1985).

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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