

OPEN PEER COMMENTARY

Broadening the concept of suffering is a less than adequate strategy for respecting patients in advanced dementia

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Open Peer Commentary on SA. Terman, KE. Steinberg, and N. Hinerman, "Timely dying in dementia: Use patients' judgments and broaden the concept of suffering"

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Terman, Steinberg, and Hinerman¹ argue that at both the planning and implementation stages of advance directives (ADs), the use of a broader than typical concept of suffering can help accomplish the goal of not living into prolonged years of severe dementia. For both practical and fundamental ethical reasons, this strategy cannot live up to its promise.

The authors are to be lauded for working to make ADs for hastening death in dementia more effective. They have many helpful things to say about ADs and suffering, among them: (1) What is "severe enough suffering" is a subjective judgment, to be made by the patient. There is no "objective" clinical test for it. Since there is not, clinicians should use patients' judgment. (2) Advance care planning should then be driven by patients' judgments about what is, to them, severe enough suffering to warrant not extending life. (3) Both the construal of suffering by Cassel to include the eroding of "integrity" in a person's life and Saunders' conception of "total pain" are insightful expansions of how to understand suffering.² (4) Many patients with advanced dementia have difficulty communicating their suffering. (5) ADs need to speak clearly not just to what care should be withheld, but to when it should be. (6) Patient appointment of a health care agent is an important complement to any instructional AD. An agent's leverage in representing the patient is hampered when there is no AD to serve as a guide, and an AD without a patient-chosen agent can languish in the face of inevitable ambiguity and difficulties of interpretation.

Notwithstanding these strengths, the authors' effort has a central flaw: it is not just unacceptable suffering that many patients with pro-

gressive dementia want to avoid, but unacceptable deterioration, only some of which involves suffering. Such situations occur in advanced dementia, when, as cognitive and sensory capacity diminish, patients may be relatively "contented." Further on, they may pass the stage where they can even subjectively experience much suffering. And suffering that is not subjectively experienced is not real suffering.

Even if the deterioration involves little subjective suffering, people can strongly want their lives not to end with years of such deterioration. It is their life, and they want it not to be saturated with characteristics that depart from, if not conflict with, the values and character dearest to their identity. To concentrate only on suffering and whether it is severe enough is to miss a major part of what many people want to avoid.

It will not help to note that before such deterioration occurs, people suffer from the prospect of living into it. Such suffering does not make the deterioration they fear into actual suffering when the deterioration comes. This is partly what creates the "then-self versus now-self" problem noted by Rebecca Dresser, among others: the now-self may be contented, for example, in a condition that the then-self said was not an acceptable one in which to continue to live.³

Broadening the concept of suffering does not solve this problem. For one thing, not all deterioration that is unacceptable to the person whose deterioration it is can be brought under "suffering." The solution to the then-self/now-self problem is to understand that people can strongly and knowledgeably desire not to live into the kind of deterioration that advanced dementia involves. Only respecting them as

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persons who ought to have basic control over their very lives and how their lives end can resolve the then-self/now-self problem in favor of implementing the AD.

Nancy Rhoden's defense of ADs in the face of Rebecca Dresser's attack on them is emblematic of that solution.⁴ The Dresser argument starts with the observation that in severe dementia, the patient who wrote an AD—to cease providing her food and drink, for example—no longer even knows she wrote such a directive, much less what is in it. Caring for her at that point thus requires us to ignore her AD and treat her solely on the basis of her current “best interest.” Rhoden's response to this is powerful: treating the patient in Dresser's proposed, best-interest only way is the same treatment we would give someone who has never had the capacity to write a directive. But when we are caring for a patient with an AD, the patient is not, even now, such a never-competent person. She is a real individual with a whole life out of which her strong and clear AD emerged. She is still Aunt Mary, or he is still brother Charles. The lives at stake are still their lives. If we are to treat them with dignity and respect, we must pay careful attention to their ADs.^{4,5,6} It is not prospective suffering that gives ADs their moral power; it is that people make them in order to retain the dignity of controlling their lives.

That said, the temptation to force everything into the mold of suffering is understandable. For one thing, the duty to relieve suffering is present in ethical codes. Terman, Steinberg, and Hinerman note two statements from the American Medical Association (AMA). “The social commitment of the physician is to sustain life and to relieve suffering” (AMA Code of Ethics Opinion 2.20).⁷ “The practice of medicine... is fundamentally a moral activity that arises from the imperative to care for patients and to alleviate suffering” (AMA Principles of Medical Ethics).⁸ Clinicians' duties do indeed include relief of suffering, but the presence of this duty in the AMA's Code and Principles does not imply that there are no other duties.

For decades, contemporary medical ethics has moved from a medical paternalism in which physicians could define what was for the good for the patient, to a patient-respecting model in which the patient's values ultimately call the tune.⁹ That means not only that suffering needs to be determined from the patient's subjective experience. It also means that patients' strong preferences about matters other than relief of suffering, like advanced cognitive and physical deterioration, must be recognized and respected. Suffering tends to elicit our immediate compassion more than deterioration does, but this psychological fact hardly constitutes an ethical argument for focusing so exclusively on suffering when patients just as badly want to avoid unacceptable deterioration.

If these points are correct, then advance care planning needs to reflect them. In discerning the conditions in which people want manually assisted food and drink to be withheld, for example, they should be asked not only what conditions they regard as constituting “severe enough suffering,” but also the kinds and levels of cognitive and physical deterioration unacceptable for them to live into. Constructing ADs for dementia from a process that focuses almost exclusively on suffering will only make their ADs more vulnerable to the then-self/now-self problem.¹⁰

In defending their focus on suffering, the authors contrast their view with that of Norman Cantor, who focuses more on deterioration.⁶ Cantor directs that his food and drink be withheld when he has declined to the point where he “can no longer read and understand written material such as a newspaper or financial records such as a checkbook,” although he might not then be suffering. Terman, Steinberg, and Hinerman believe that such a directive should not and would not be clinically implemented, whereas one focused on unacceptable suffering should and more likely would be.

Why should we think, though, that Cantor's AD should not be followed? Why is the absence of suffering a reason for not implementing an otherwise clear and cogent directive? After all, where does sufficiently severe suffering get its moral power? The reason is that this is the level of suffering the patient regards as necessary and sufficient to justify hastening death. But then why shouldn't the patient's word about what level of deterioration is necessary and sufficient also be heeded?

Basing the leverage of ADs to withhold manually assisted food and drink predominantly on suffering represents a relatively cramped view of persons. People often have strong reasons beyond suffering for wanting not to live into years of advanced dementia, reasons that can be readily understood even by those who themselves would not share these reasons as adequate for hastening their own deaths.

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CONFLICT OF INTEREST STATEMENT

The author has no conflict of interest to declare.

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SUPPORTING INFORMATION

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