

## REPLY

# Responses to Open Peer Commentaries about “Timely dying in dementia: use patients’ judgments and broaden the concept of suffering” and “Can an effective end-of-life intervention for advanced dementia be viewed as moral?”

Responses to OPCs about “Timely dying in dementia: use patients’ judgments and broaden the concept of suffering” submitted by Jenny T. van der Steen, Trijntje M. Scheeres-Feitsma, Petruschka Schaafsma; Norman L. Cantor; Paul T. Menzel; and Dena S. Davis

By Stanley A. Terman and Karl E. Steinberg

We agree with these comments of van der Steen et al.:<sup>1</sup>

- It is hard to judge if persons with dementia are experiencing unbearable suffering.
- Asking patients to judge how much suffering future conditions would cause helps clarify their end-of-life wishes.
- Attempts to treat suffering with palliative care must occur before ceasing assisted feeding and hydrating. Suffering must be severe and irreversible, meaning that attempts to reduce suffering by non-burdensome treatment failed.
- Asking all concerned—the patient, family members, and providers—honors the complexity of suffering and decision-making.
- Considering loved ones’ suffering as a significant contributor to patients’ suffering is innovative.
- “Bi-directional empathic suffering” (Terman’s new term) is based on personal interactions and targets an important aspect of the complexity of suffering. We agree that providers should be sensitive to decision-makers’ increased feelings of guilt due to focusing on bi-directional empathic suffering. Yet its appreciation could also reduce decision-makers’ emotional burden by justifying suffering as severe enough to allow patients to die of their underlying disease.
- It is unfortunate that US statutes usually neglect the burdens of nonprofessional caregivers.

The protocol we recommend (detailed elsewhere<sup>2</sup>) strives to reduce the complexity of making end-of-life decisions by sharing the process among (A) the patient’s judgments formed during advance care planning (ACP), (B) designated proxies/agents and others who are members of the Patient Decision Committee that the patient established during ACP, and (C) the physician/provider. The committee’s main function is

to decide *when* the patient has reached a condition that justifies a different, more clinically appropriate Physician Orders for Life-Sustaining Treatment (POLST), which the patient completed during a conversation with his/her ACP provider during ACP. End-of-life decisions may cause less emotional toll on members of the Patient Decision Committee because members share the burden of making these difficult existential decisions with other members.

We disagree with the semantic argument that both Cantor<sup>3</sup> and Menzel<sup>4</sup> stated, paraphrased as: unacceptable deterioration may not cause suffering, so concentrating on only suffering misses much of what many people want to avoid in dementia. Yet we are willing to change our position if Cantor or Menzel presented examples of clinical conditions that cause “unacceptable deterioration” but do not cause suffering. Alternatively, they could conduct surveys or focus groups of clinical professionals or lay people that convincingly distinguish between unacceptable deterioration and suffering. We believe Cantor and Menzel have the burden of proof that these terms are *not* subsumed under suffering because our specific patient decision aid<sup>5</sup> uses words and illustrations that generate conditional advance treatment decisions. Example: a man cannot or does not interact with anyone, even at his birthday party. Some observers may not appreciate his suffering; they describe his condition as “just sitting there.” Yet a broadened view of suffering would view his condition as extreme social isolation due to the ravages of advanced dementia that destroyed his brain’s ability to communicate and resulted in the dying of all his relationships, which left him with severe existential suffering.

If data from focus groups and surveys do *not* support subsuming types of deterioration and nonmedical terms under suffering, then Cantor and Menzel may have committed the logical fallacy of false exclusion,<sup>6</sup> where one asserts (X) does not include (Y) when evidence convincingly demonstrates (X) does include (Y).

Menzel asked:<sup>4</sup> why would Cantor’s published living will not be honored?<sup>7</sup> Cantor requests stopping food and fluid if his irreversible mental deterioration causes the loss of ability to read newspapers and balance checkbooks. We judge this condition would cause only

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moderate suffering, which could be reduced to mild suffering, if family/friends shared the news, bookkeepers balanced checks, and Cantor enjoyed written material or other media at a lower literacy level. Even moderate suffering would not justify a provider writing an order to allow Cantor to die since it would violate two principles of medical ethics: it would provide no benefit and cause grave harm. Critics could judge the order as inconsistent with generally accepted medical care, immoral, and illegal—if viewed as euthanasia, which possibility Sulmasy raised based on Cantor's request for sedating medications if fasting causes discomfort.<sup>8</sup>

We contend our Perspective essay's broadened concept of suffering includes what Cantor and Menzel claim does not cause suffering, including "severe physical and cognitive degradation"; "altruism" (wanting to spare loved ones and society burdens of the disease); "intolerable indignity"; "withering"; "dwindling"; and a state that is "repugnant."

Physical deterioration causes suffering: (A) Immobility predisposes patients to developing painful bedsores. (B) Joint contractures due to flexors muscles overtaking extensors can lead to excruciating pain when patients are transferred between wheelchair and bed. (C) Muscle weakness and atrophy can lead to falling that causes pain from bruises and broken bones. (D) Swallowing difficulties can lead to malnutrition and dehydration that can lead to extreme fatigue and weakness and predispose to painful bedsores.

Cognitive deterioration causes suffering: (A) Patients who become disoriented and confused may experience anxiety, fear, bewilderment, and paranoia. (B) Disruption of their life narrative can lead to their inability to function in their previous roles, which causes them to lose the essence of what gave their lives meaning. (C) Becoming increasingly dependent on others for help with activities of daily living (such as dressing, bathing, eating, and toileting), can lead to intense feelings of helplessness, desperation over lack of executive functioning, frustration in not fulfilling certain needs, and depression. (D) Changes in patients' personality and behavior, especially agitation and aggression, may reflect their inner turmoil and loss of ability to communicate effectively. Patients may be dismayed at not being able to control their own behavior, including incontinence, which can cause extreme distress for them, their loved ones, and their caregivers. (E) Patients whose agitation and dangerous behavior are difficult to manage cause their loved ones more suffering that may include paying for more expensive care. The other extreme—withdrawn behavior—can lead to neglect, social isolation, and profound depression.

Cantor asserted "the existing legal system" allows nonsuffering patients to die because courts honor precedent autonomy. But in practice, courts may not rule this way, and Cantor failed to cite any of several legal rulings that began with conflicts among family members, or between proxies/agents and providers or administrators, and which commonly force patients to endure unwanted prolonged suffering and dying.

Cantor also failed to cite relevant statutes that allow physicians to decline to comply with living will requests. Example: California probate code allows providers to legally refuse to comply with patients' requests (A) if their directive requests mercy killing, assisted suicide, or euthanasia (\$4653), (B) if health care would be contrary to generally

accepted health care standards (\$4654), (C) if treatment would be medically ineffective (\$4735), or (D) if the provider claims a conflict with personal conscience (\$4734).

If the above analysis and interpretation of Cantor's argument are correct, then Cantor may have committed the logical fallacy of selective inclusion of evidence (cherry-picking).<sup>9</sup>

Cantor's explanation for having confidence that the judicial system would favor his living will requests relied in part on his quoting statute: "Where a demented patient's prior expressed preferences are known, 'the surrogate must make the medical choice that the patient ... would have made.'" The authority of this statute is undeniable, but it seems irrelevant: surrogates are legally obligated to honor patients' living wills, but judges are not. If this analysis and interpretation are correct, then Cantor may have substituted a strong argument (relevant for surrogates/agents) to support his weak argument (relevant for courts)—thereby committing the logical fallacy of *ad verecundiam* (fallacy of relevance of authority).<sup>10</sup>

Cantor used the term "deceptive" three times in referring to our proposal using severe suffering as the sole criterion for when a person would want to die. We wondered why Cantor repeatedly made such a pejorative allegation. Perhaps because (in his words) he dreads "a moral imperative to uphold the immediate well-being of the non-suffering patient" would prevent him and others from dying when they want. Yet our criterion is consistent with our government's adoption of *parens patriae*, which protects vulnerable individuals from harming themselves. So, despite the clarity of Cantor's living will, his "resolute" agent may fail in his/her attempt to persuade providers to implement Cantor's requests.

We are concerned about Menzel's statement, that patients living with advanced dementia (PLADs) may progress to a stage where they "cannot subjectively experience suffering," which in his opinion "is not real suffering." Such a perspective fails to appreciate how difficult it is to determine if nonverbal, incapacitated patients are suffering. Furthermore, it is dangerous since it could lead to treating providers' complacency and neglect as patients suffer—perhaps for years.

Menzel argued that what gives advance directives their moral power is not prospective suffering but the right to retain the dignity of controlling their lives. We disagree, although dignity is important. Patients who complete advance directives are not just moral agents; they are morally obligated to protect from prolonged suffering, the vulnerable, nonverbal, future incapacitated patient living with dementia, whom they may someday become.

We agree with Dena Davis's opinion: it is legal and makes sense to not administer food and nutrition to avoid prolonging the final stage of dying—even though assisted feeding seems like basic human care. We also agree that for some patients, this strategy will be implemented too late<sup>11</sup>—although stating "all [categories of suffering] come to pass long before the person reaches the stage where hand-feeding is necessary" is likely an incorrect overstatement.

Yet dying can occur earlier if patients are at risk of contracting aspiration pneumonia, which causes more suffering than dying from medical dehydration (especially in nonverbal patients who cannot verbalize complaints). Withholding food and fluid is ethical since every

person has the “claim right” to reduce suffering, which imposes correlative duties on others. We are currently exploring other ways to avoid being “too late.”

Davis has long touted preemptive suicide as the only certain way to avoid prolonged dying in advanced dementia.<sup>12</sup> But her informal surveys fail to prove that most people want to die soon after they receive a diagnosis of dementia. Here are two reasons, based on my attending one of her lectures: Davis’s “subjects” were self-selected attendees at her lectures, and she failed to share adequate information to make an informed decision. Preemptive suicide can sacrifice years of reasonably good living and is a draconian “solution” that may not be necessary if the strategies added to ACP are effective in facilitating patients’ end-of-life goals. If so, the consequences of her recommendation could be tragic.

#### Responses to Open Peer Commentaries for “Can an effective end-of-life intervention for advanced dementia be viewed as moral?”

by Stanley A. Terman

##### Response to William Lawrence Allen’s OPC<sup>13</sup>

I provide two citations<sup>14,15</sup> to support “about 90% of PLADs have eating problems.”

Allen harshly criticized the second, companion order, to this first order, “Cease assisted oral feeding and hydrating.” The purpose of the second order, “Always offer food and fluid by placing them in front of, and within reach of the PLAD,” is, in part, to help convince those in authority to facilitate acceptance of the first order, which may be PLADs’ last resort to avoid prolonged dying with suffering. (See other purposes, below.)

Using the term “ruse” from my Perspectives essay, Allen argued that, if PLADs have already proved they cannot eat or drink independently, then such offering of food and fluid is a *ruse* whose purpose is to attempt to protect those involved from being indicted for euthanasia or elder abuse; and whose real purpose is to obscure the intent to hasten dying, which many consider immoral.

My counterarguments are based on two widely accepted principles. The Principle of Proportionality<sup>16,17</sup> states: if the burden and harms of continuing an intervention are disproportionate to its potential benefits, then, even if the intervention is life-sustaining, it can be morally acceptable to discontinue it. The Principle of Double Effect<sup>18</sup> permits actions such as physician orders whose intent is good (such as to reduce suffering), even if there is a possible, foreseeable, bad side effect (such as death).

Allen argued, “If the vast majority of patients cannot feed themselves ... always placing food and fluids within reach is futile” and “irrelevant and unnecessary.” If my interpretation and analysis are correct, then Allen may have committed the logical fallacy of extrapolation—from “vast majority” to 100%. While appropriate for many decisions, it is morally inappropriate if the life of a human being is at stake. Example: even if only 1 or 2 of 100 PLADs can resume independent eating and drinking, they deserve a revised treatment plan rather than being allowed to die. (This is another purpose of the second order.)

Allen also contended, “Documentation of a dementia patient’s disinterest in eating or drinking should be adequate, without ‘proving’ it by constant placement of food and drink in reach.” But disinter-

est in eating and drinking is not why PLADs want to cease assisted feeding. Their motivation is to avoid prolonged, irreversible, severe suffering.

Allen stated, “Every patient has the ethical and legal right” “to shorten suffering ... by ceasing assisted feeding and drinking.” I agree—provided patients had capacity during ACP, when they voluntarily made a clear and convincing request after their provider shared sufficient information for them to give their informed consent.

Allen states he relies on competent, trained professionals to determine the etiology and reversibility of a PLAD’s not eating—instead of placing food and fluid within the patient’s reach, which he claims is neither effective as a defense against a charge of euthanasia nor a way to determine the etiology of not eating.

Here, Allen may be assuming facts not in evidence. I am not aware of any data that support the ability of “trained, competent professionals” to determine with 100% accuracy, which patients can, and which cannot, regain their ability to independently eat and drink—before beginning medical dehydration. I do *not* share Allen’s confidence in “competent trained professionals” ability to determine the cause(s) of not eating. Most common is dementia-caused brain damage that led either to losing their ability to recognize items as food and fluid (*agnosia*) or to losing their ability to coordinate moving their hands to put food and fluid in her mouth (*dyspraxia*). But Allen failed to acknowledge the Perspective essay’s list of clinical situations that could—albeit with an unknown but likely small percentage of patients—lead to a *reversible* loss of ability to eat and drink. Medical dehydration may (A) increase hunger that overcomes depression, apathy, or voluntarily waiting for caregivers’ assistance with feeding as their last vestige of social interaction; (B) discontinue medications that had been causing nausea or other GI side effects; and (C) shrink a comorbid brain tumor by reducing excess cerebral fluid.

Allen claimed proxies and care providers are “excused from legal liability” if their actions are based on advance directives. I asked health-care law and bioethics professor Thaddeus Pope for his opinion on this point. He wrote: “The consent of the deceased does not excuse what is otherwise a crime” and consent is not always a defense, which is “the very nature of the prohibition on assisted suicide” in every state. Regarding clinician’s “prima facie duty to feed, the patient can waive [this] right,” but “there is some uncertainty whether this is assisting a ‘suicide’ in some states.” Pope therefore opined there is “risk and uncertainty in many jurisdictions.” Most important is this opinion with which we agree: providers are not exempt from legal liability if they follow illegal requests in directives, including euthanasia.

Here are examples of why it is prudent to place food and fluid within the patient’s reach: (A) it minimizes providers’ risk of being accused of euthanasia; (B) it makes it easier for proxies/agents to persuade providers to implement the order, “Cease assisted feeding”; (C) it can serve as an effective defense, if a provider is accused of a crime; and, (D) it may save the lives of a few patients, which makes it moral to “waste” food three or four times a day for the vast majority of patients (until they fall asleep) to give a small minority of patients the opportunity to survive. The last point is based on this fundamental belief: the life of every human being is sacred/precious.

If my interpretation and analysis are correct, Allen may have committed the *petitio principii* fallacy (“begging the question”) that uses the conclusion of the argument in support of itself in the premise. To explain, Allen’s argument can be reduced to: PLADs who have irreversibly lost the ability to self-feed/drink cannot resume this function (the premise); therefore, it is not necessary to prove that they cannot resume this function (the conclusion).

Finally, Allen stated researching healthcare professionals and facilities regarding their willingness to comply with the order, “Cease assisted feeding” is the “best way” for patients to attain their goals. While important, such research cannot overcome flawed directives.<sup>19</sup>

**Response to the OPC of Trijntje M. Scheeres-Feitsma, Petruschka Schaafsma, Jenny T. van der Steen, and Johannes J.M. van Delden<sup>20</sup>**

I agree with these authors’ statement that arguing whether assisted feeding is “basic care” or “medical treatment” adds little to the moral debate.

Their main argument is based on this incorrect assumption: my “core idea is that an advance directive [alone] can solve the future dilemmas regarding assisted feeding.” Instead, my Perspective essay attempts to answer this question: Can a set of moral arguments persuade those who might otherwise oppose the conditional order, “Cease assisted feeding”? My other published and preprint articles<sup>2</sup> recommend adding several strategies to directives, to overcome common challenges, which body of work is based on this premise: by themselves, advance directives “cannot solve very particular and precise end-of-life dilemmas for people with dementia and ensure a peaceful and timely dying” (which are the OPC’s words).

How the word “moral” was used: Society’s cultural morals are the consensus of behaviors that people believe are right and constitute a good life. Religious morals are derived from divine revelation, scripture, or traditional practices, which some religious leaders presume they are empowered to interpret or mandate. Yet both can change and neither has garnered unanimous consensus. Still, both types of morality usually agree on honoring patients’ claim right to be allowed to die if their severe suffering cannot be ameliorated, since this act is compassionate, humane, and respects patients’ dignity.

I agree it is difficult for patients with dementia to imagine their future and care preferences. Since 2009, I have continually revised a patient decision aid that has become an online program that generates a directive for dementia (and other terminal illnesses). It includes illustrated line drawings and words written at the third-grade level of reading comprehension, to help early-stage dementia patients (and others) “imagine their future” for 50 conditions.<sup>5</sup> Its development included using cognitive interviewing to improve content validity.<sup>5</sup>

I agree that people living with dementia can be happy and experience quality of life. The companion Perspectives essay included an illustration in which a patient cannot recognize close relatives but can still enjoy their visits.<sup>21</sup> Directives that request ceasing assisted feeding as soon as the patient cannot recognize relatives are dangerously flawed since following their requests could lead to premature dying.<sup>22</sup>

Regarding the possibilities of coping with [advanced dementia] and a diminishing death wish or a change of heart, patients completing ACP must make a mutually exclusive choice. One is to direct others

to strictly follow their *durable* requests, the price of which is to forgo their ability to change their treatment preferences after they lose capacity. The other is to grant 100% leeway to their proxies/agents by empowering them to make contemporaneous decisions on their behalf. The downside of choosing 100% leeway is a weakened strategy to persuade providers to write controversial orders, and placing their fate in the minds of surrogates whose substituted judgment is notoriously unreliable.<sup>6</sup> The protocol described elsewhere<sup>5</sup> invites input from providers, caregivers, family members, and surrogates—as well as patients’ directives.

“Healthcare providers [who] experience the tension and stress of the moral dilemma of whether to cease feeding at least three times a day” could be relieved by this explanation: PLADs have reached a condition that during ACP that they judged would cause irreversible, severe suffering and they have the right to forego life-sustaining treatment.

Conclusion: I agree with using a wider lens than patients’ autonomy and considering input from others to fulfill patients’ end-of-life goals. For patients in the United States, I recommend using “Future POLSTs” to increase the clarity of orders and reduce conflicts surrounding their interpretation.<sup>23</sup> In Europe, adopting POLSTs is just beginning.<sup>24</sup> The POLST protocol requires having a “POLST Conversation.” Routine conversations between providers and patients during ACP have the potential to reduce ambiguity regarding what treatment the patient wants and thereby prevent such sad stories as the 74-year-old Dutch PLAD whose treating geriatrician endured a four-year legal battle against both civil and criminal charges.<sup>25–27</sup>

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