

## PERSPECTIVE

# Timely dying in dementia: Use patients' judgments and broaden the concept of suffering

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**Abstract**

Patients living with advanced dementia (PLADs) face several challenges to attain the goal of avoiding prolonged dying with severe suffering. One is how to determine when PLADs' current suffering becomes severe enough to cease all life-sustaining treatments, including withdrawing assistance with oral feeding and hydrating, a controversial order. This article broadens the concept of suffering by including suffering that cannot be observed contemporaneously and the suffering of loved ones. Four paradigm shifts operationalize these concepts. During advance care planning, patients can judge which future clinical conditions would cause severe suffering. To decide when to allow patients to die, treating physicians/providers only need to assess if patients have reached patients' previously judged, qualifying conditions. Questions: Will this protocol prevent PLADs' prolonged dying with suffering? Deter early-stage dementia patients from committing preemptive suicide? Sway decision-making surrogates from withholding life-sustaining treatments from patients with middle-stage dementia? Provoke providers' resistance to relinquish their traditional, unilateral authority to determine patients' suffering?

**KEYWORDS**

advanced dementia, advanced instructional health care directives, ceasing oral nutrition and hydration, end-of-life suffering, timing of allowing patients to die, withdrawing life-sustaining interventions, living wills

**ADVANCE DIRECTIVES: THEIR GOAL AND MEANS**

This article proposes a potentially effective but controversial solution to a conundrum that is, or will, affect millions of patients living with advanced dementia (henceforth, PLADs). Capacitated persons who complete advance care planning (planning principals) can decide and inform their future treating physicians/providers (providers) that their sole criterion to be allowed to die is "irreversible severe suffering." Their wishes can be memorialized in a living will/advance health care instructional directive (directive). Direc-

tives are needed because patients who reach advanced dementia will have lost decision-making capacity. Many will have also lost their ability to communicate or complain, even nonverbally. Unfortunately, many dementia-specific directives are flawed.<sup>1</sup> A further challenge is that the order that PLADs need to have a peaceful and timely dying, "Cease oral assisted feeding and hydrating" (cease assisted feeding), is controversial. Opponents from various disciplines have or may criticize this order as being immoral. A companion article presents alternative views, which may, like this article, inspire debate.<sup>2</sup>

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Patients have the right to decide whether their suffering is severe enough to be allowed to die, according to the American Medical Association (AMA)'s Code of Ethics Opinion 2.20:

The social commitment of the physician is to sustain life and to relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail.<sup>3</sup>

According to the federal Patient Self-Determination Act,<sup>4</sup> patients can memorialize their preferences in advance via a directive. Yet, no objective set of clinical criteria has been proven sufficiently reliable to justify making the decision to allow PLADs to die based on determining to PLADs' contemporaneous intensity of suffering. Uncertainty can lead providers to deny or hesitate in honoring what may be PLADs' last resort for a timely dying by ceasing assisted feeding. Such refusals not only can prolong dying and suffering; they can also lead some patients in early-stage dementia to commit preemptive suicide.<sup>5</sup> Some worry, if they wait too long, they will lose the required mental and physical capacity and "get stuck" in advanced dementia. Also, decision makers for incapacitated patients living with middle-stage dementia may deny them minimally invasive and burdensome treatment, such as antibiotics for pneumonia. Surrogates may view an untreated life-threatening illness as an "opportunity" to prevent patients from reaching advanced dementia. Yet, premature dying is tragic. Finally, loving spouses may commit "mercy killing" after decades of devotion merely because they are not aware of other ways to allow them to die. Sadly, surviving spouses can be indicted for murder; live with horrific memories, guilt, and depression; and some commit suicide.

Directives are considered successful if treating providers promptly write orders that honor planning principals' specific requests so patients can attain a peaceful and timely dying. Success depends on adequate answers to this two-part "when/what" question: "When would the patient want to implement what intervention?" This article focuses on the conceptual and practical aspects of "when"; a companion article by Terman focuses on the morality of "what."<sup>2</sup>

To answer the "when" question, future treating providers must agree (1) in general, that planning principals' criteria to die are appropriate and thus acceptable, and (2) specifically, that patients have met their qualifying, memorialized qualifying criteria.

This article has five sections: Section 1 presents background regarding the importance of suffering in end-of-life decision making.

Section 2 explores the difficulty of assessing PLADs' contemporaneous suffering. Then it cites experts and quotes directives that dismiss suffering as relevant to deciding when to allow PLADs to die.

Section 3 broadens the concept of suffering by adding sources of patient suffering that cannot be contemporaneously observed, as well as the suffering of their family members. This broadened definition strives to comprehensively capture what people dread most about prolonged dying in advanced dementia. The criterion "severe-enough suffering" strives to be acceptable and compelling to providers and other authorities.

Section 4 consists of four paradigm shifts designed to operationalize the concepts in Section 3.

Section 5 considers how to resolve a conflict when patient's past and present wishes conflict.

The Discussion considers why providers may resist losing their traditional role as the only agent responsible to determine whether PLADs' contemporaneous suffering is severe, as the article proposes a time shift, shared decision-making protocol for deciding when to allow patients to die. During advance care planning, planning principals would judge which future conditions would cause "severe-enough suffering" based on their personal values and treatment preferences.

## SECTION 1. SUFFERING IN END-OF-LIFE DECISION MAKING

1.1. A general definition of "suffering" is the unwanted, alien, life-disruptive, unpleasant feelings of great discomfort and distress that lack meaning or purpose, which often includes feeling helpless and being victimized. Here, "severe" does not imply intensity as in rating scales where it may lie between moderate and extreme; instead, severe means "enough" suffering to want to be allowed to die.

Below are some views on suffering, but no claim is made that this review is comprehensive.

1.2. Eric Cassel focused on patients' reaction to pain. He required suffering make patients feel "out of control when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is chronic." For Cassel, suffering must be "a threat to patients' continued existence—not merely to their lives, but to their integrity as persons." He stated, "Suffering would not exist if the future were not a major concern."<sup>6</sup>

Comment: Cassel's definition of suffering may not apply to PLADs as dementia can cause the listed symptoms without physical pain. Examples: Diminished mental capacity can lead to confusion that makes patients feel out of control while they cannot appreciate the meaning of their suffering or existence. Impaired memory and changes in their personality not only threaten but cause the loss of "integrity as a person." Also, patients can suffer contemporaneously despite their inability to appreciate and be concerned about their future.

1.3. Dame Cicely Saunders, the renowned founder of the hospice movement, coined the phrase "total pain." She taught that cognitively intact terminal cancer patients may experience suffering that includes physical, emotional, social, and spiritual components; that spiritual pain does not simply arise from fears about the future;<sup>7</sup> and that patients may have "bitter and most understandable anger at the unfairness of what is happening ... and above all a desolating feeling of meaninglessness."<sup>8</sup> The authors believe that broadening the concept of suffering is needed for PLADs.

1.4. The AMA Council on Ethical and Judicial Affairs' position on palliative sedation defined existential suffering as, "The experience of agony and distress that may arise from such issues as death anxiety, isolation, and loss of control."<sup>9</sup> While agony may not be common, social isolation is frequent and can be extreme for PLADs whose dementia

caused the loss of all relationships by impairing brain functioning and communication. Loss of control may cause suffering for patients in middle-stage dementia. Yet patients who cannot appreciate their future may not suffer from death anxiety.

1.5. Members of AMDA—The Society for Post-Acute and Long-Term Care Medicine, include over 5000 providers who treat long-term patients in nursing homes and assisted living communities. AMDA adopted Policy A19 proposed by their ethicists. It recommended: “offering hand feeding as long as the resident is not showing signs of distress and stopping the practice if ... choking, coughing, or respiratory difficulty” develop.<sup>10</sup> This definition of suffering (here, called distress) is narrow. Yet it served as part of the basis for Policy A19’s categorical recommendation until it was retired in 2023 that providers refuse to honor all directives that request ceasing assisted feeding.

1.6. The role of suffering in medical aid in dying (MAiD; physician-assisted dying) depends on where the patient is located. Generally, to qualify for MAiD outside the United States, competent terminally ill patients and their providers must agree there is no alternative to reduce patients’ unbearable suffering. In the United States, the criterion is more arbitrary: “Likely to die within 6 months.” Yet, once US patients qualify to receive a lethal dose of medication, the final decision is theirs to make regarding when (and if) they ingest these medications. Many patients wait months after qualifying, until they feel their suffering has become severe enough. Example: Brittany Maynard received medications in May but did not use them until November 2014.<sup>11</sup> Unfortunately, PLADs lack decision-making capacity so they cannot qualify for MAiD, or let others know contemporaneously when they would prefer to be allowed to die.

1.7. Bioethicist Rev. Kevin O’Rourke broadened the concept of suffering by including “spiritual, psychic, and economic as well as physiological burdens.”<sup>12</sup> A Catholic guide included “excessive expense on oneself, one’s family, or the community.”<sup>13</sup>

## SECTION 2. DIFFICULTY IN ASSESSING PATIENTS’ CONTEMPORANEOUS SUFFERING AND EXAMPLES OF NOT VIEWING SUFFERING AS RELEVANT TO DETERMINE WHEN TO ALLOW DYING TO OCCUR

2.1. The experience of suffering is subjective. Yet, patients may not be able to communicate, complain, or writhe due to cognitive impairment and restricted mobility that advanced dementia has often causes. Such factors challenge providers who want to be certain that their patient’s suffering is severe before they write orders to allow them to die.

2.2. Contemporaneous suffering is difficult to assess in PLADs.

2.2.1. Ladislav Volicer created useful scales for measuring discomfort (Discomfort Scale for Dementia of the Alzheimer’s Type [DS-DAT])<sup>14</sup> and pain (Pain Assessment in Advanced Dementia [PAINAD])<sup>15</sup> in non-verbal dementia patients. Yet in two April 4, 2020, private e-mails, he stated: “It is quite difficult to determine if suffering is severe in advanced dementia patients. Also, physicians may recognize only pain and discomfort. These scales detect only certain types of suf-

fering. They do not assess existential suffering, and they may not detect suffering caused by incontinence that results in loss of dignity.”

2.2.2. Some experts claim the behaviors of advanced dementia overlap with behaviors of experiencing pain and that makes detecting pain challenging.<sup>16</sup> “Pain, although common among older people with dementia, is often underestimated and undertreated. Because cognitive impairment limits the ability of older people with dementia to express their pain, nurses rely on what they observe. However, the behavioral and psychological symptoms of dementia, such as agitation, confusion, aggression, and hallucinations—often obscure the indicators of pain such as repeated calling out, moaning, crying, facial grimacing, restless, distressed pacing, pulling, kicking, or pushing away—which hinders pain assessment.”<sup>17</sup>

Comment: The confusion between dementia behaviors and pain behaviors could be based on the dangerous presumption that patients are not suffering. If patients are suffering, the result could be dire. Providers who do not appreciate that suffering may be widespread among PLADs may not assess or treat PLADs’ chronic suffering.

2.3. Three anecdotes illustrate that pain and suffering may be difficult to observe.

2.3.1. This anecdote is unfortunately common. The staff at a memory unit routinely ignored a patient who, for hours every day, repeatedly called out, “Help me. Help me.” A new visitor asked, “Why does she do that?” A staff person responded, “That’s just the way she is.”

2.3.2. A case where pain was confirmed by follow-up (see Video 1. See link.<sup>18</sup>). A caregiver accidentally spilled hot coffee in a PLAD’s lap. Her resulting second-degree burns were not discovered until 2 days later, during routine incontinence care. By then, welts from second-degree burns had become obvious. Her treatment lasted several weeks, first in the hospital and then in rehabilitation. Yet for 2 days—likely the most painful in her ordeal—she suffered in silence.

2.3.3. Some PLADs manifest agitation because they have no other way to express their pain and suffering. Sedating antipsychotics can make these patients easier to manage but do not relieve pain. This patient-centered approach sometimes works: empirically treat patients with increasing doses of analgesics; if behavior eventually normalizes, then it is likely that they were previously experiencing pain or suffering.

Comments: The inarticulate patient (2.3.1) could not inspire a work-up that might have discovered the source of her pain so it could be treated. The silent patient (2.3.2) likely lost her ability to complain and writhe due to dementia. The agitated patient (2.3.3) may represent a more common than currently appreciated type of patient who contributes to underestimating the prevalence of suffering. Note that dependence on anecdotes is due to the difficulty in designing research protocols whose goal is to survey the prevalence of the unobservable.

2.4. Directives designed for dementia may not use the clinical criterion, severe-enough suffering.

2.4.1. Legal scholar Norman Cantor’s published directive<sup>19</sup> would “reject ... hand feeding ... [when he] can no longer read and understand written material such as a newspaper or financial records such as a checkbook”—even if he “might not be physically or emotionally suffering.” Cantor based this request on his “strong aversion to being

mired in dementia” and “personal visions of intolerable indignity.” He requested others “respect [his] precedent autonomy ... even if surrogates feel that an alternative course would be more consistent with [his] contemporaneous best interests.” In dismissing suffering, Cantor wrote that he expects courts to “understand that advance instructions for post-competence medical issues can be based on personal visions of intolerable indignity—not just on avoidance of suffering.”

Comments: Cantor’s criteria may not be severe-enough to allow him to die, and some may be reversible. A friend could summarize current events. Cantor might enjoy reading material written at a lower grade level of comprehension. A personal assistant could write checks. If so, his suffering could decrease from moderate to mild. If Cantor’s designated “resolute health care agent” did persuade his future provider to honor his requests by writing an order to cease assisted feeding, others could judge this order as clinically inappropriate since it caused premature dying, which is immoral, unethical, and illegal (euthanasia)—especially if the planning principal had asked his future providers to prescribe sedation for discomfort from not eating and drinking.<sup>20</sup>

Providers are not obligated to honor all directives. Consider California’s statute: “A health care provider or health care institution may decline to comply with an individual health care instruction or health care decision that [is] ... contrary to generally accepted health care standards.”<sup>21</sup> Physicians who refuse to allow patients to die because they believe in good faith that their patients can still enjoy living are on solid clinical, legal, ethical, and moral ground.

2.4.2. Compassion & Choices’ “Dementia Values & Priorities Tool”<sup>22</sup> states even one of their fifteen conditions can suffice to refuse assisted feeding. Yet combining the following five conditions may not cause severe suffering: “I cannot dress, bathe, or toilet myself” (1–3) and “I no longer recognize my loved ones, but I still smile and seem happy in my own world” (4) and “I can no longer communicate with my loved ones through words” (5). Regarding (4): patients who smile and seem happy are not suffering. Regarding (5): many patients can communicate adequately non-verbally. Similarly, End of Life Choices New York’s directive<sup>23</sup> lets planning principals use any version of the Functional Assessment of Staging, Stage 6 to stop assisted feeding. Its last two criteria are urinary and fecal incontinence,<sup>24</sup> which for many people would not be enough suffering if combined with Compassion & Choices’ first three criteria, to want to be allowed to die.

2.4.3. End of Life Washington’s instructions for the refusal of assisted feeding<sup>25</sup> states: “I want the instructions in this directive followed even if the person who has the right to make decisions for me and my caregivers judge that my quality of life, in their opinion, is satisfactory and I appear to them to be comfortable.” Comment: this statement clearly dismisses suffering as a criterion to allow patients to die.

2.4.5. A commonly dreaded condition of advanced dementia is: “(As soon as) I no longer can recognize my family members and loved ones (by recalling their names and how we are related).” In one directive, it is the only criterion.<sup>26</sup>

2.4.5.1. Figure 1 has drawings of two patients; both fulfill the criterion in 2.4.5. The patient on the left is likely experiencing severe suffering: loneliness from total social isolation. He sits there, unable to interact. His family members are also suffering because they are

frustrated and sad that they cannot enjoy him. In contrast, the patient on the right is interacting with his family members, and all are experiencing joy. At this moment, neither patient nor family members are suffering.

Comment: Writing the order, “Cease assisted feeding,” may be appropriate for the patient on the left, but not for the patient on the right, for whom this order may cause premature dying. The patient seems to enjoy family visits; if so, he would want these visits to continue. Therefore, it is clinically, legally, ethically, and morally right to continue assisted feeding.

2.4.6. Bioethicist and philosopher Paul Menzel, whose directive used the full, original Functional Assessment Staging and added other dreaded conditions,<sup>27</sup> nevertheless advised, “If avoiding suffering is neither the primary aim nor a necessary condition to attain the goal of a living will [directive], then authors of such living wills should explicitly say so.”<sup>28</sup> He opined, “A life can be harmed ... by its length regardless of suffering,”<sup>29</sup> and, “It’s not misery people are afraid of. They just don’t want years of withering.”<sup>30</sup> Menzel compassionately warned, “Caregivers may resist [honoring] the directive later when they correctly observe that the patient is not suffering.” Menzel’s statements could be consistent with this incorrect belief: it is (always) possible to rule out suffering by current observation, which is not true, especially if the concept of suffering in advanced dementia is broadened. It is this topic to which this article now turns.

### SECTION 3. BROADENING THE CRITERION, “SEVERE-ENOUGH SUFFERING,” AND FOUR PARADIGM SHIFTS DESIGNED TO OPERATIONALIZE THIS CRITERION

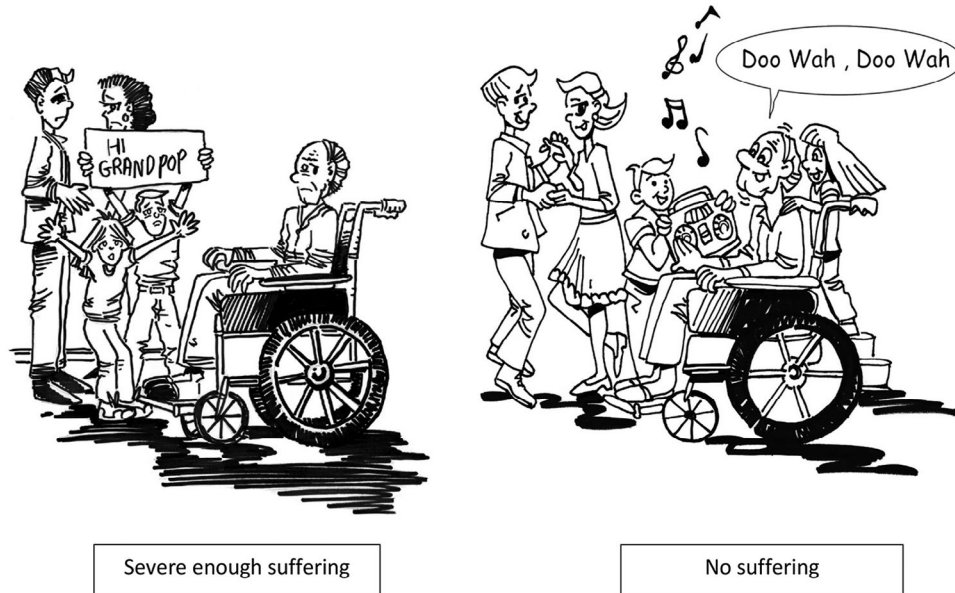
According to the AMA, the social responsibility of physicians “1.1.1” is:

The practice of medicine, and its embodiment in the clinical encounter between a patient and a physician, is fundamentally a moral activity that arises from the imperative to care for patients and to alleviate suffering.<sup>31</sup>

The discussion in Section 2 revealed the disparity between the importance of suffering and its dismissal. This section broadens the concept of suffering as it strives to comprehensively reflect what people dread most about prolonged dying in advanced dementia. This section also presents a protocol to determine when suffering has become severe enough to allow patients to die.

Table 1 summarizes a broadened concept of five types of suffering. Further details are presented in Paradigm Shift #2.

Table 2 presents four paradigm shifts. Paradigm 2 operationalizes this broadened concept of suffering. The other three are: Paradigm Shift #1 presents a protocol whereby treating providers and planning principals share the responsibility of determining if PLADs are experiencing contemporaneous suffering. Paradigm Shift #3 includes loved ones’ suffering. Paradigm Shift #4 presents ways to combine conditions



**FIGURE 1** Reaching a condition may, or may not, cause severe-enough suffering

**TABLE 1** Five types of suffering in advanced dementia, which may not be currently observable in patients (indicated by bold emphasis).

<b>1. Physical: Detectable</b>	Bedsores	Bone fractures	Lethargy	Shortness of breath	Muscle spasms	Decreased appetite
<b>Hard to detect</b>	Constipation	Headache	Extreme fatigue	Subjective suffocation	Arthritic pain	Nausea
<b>2. Psychic/emotional</b>	Confusion	Fear	Paranoia	Delusions	Hallucinations	Anxiety/depression
<b>3. Existential</b>	Patients no longer can: (A) communicate, even nonverbally, or interact with other human beings so these relationships cease to exist and cause feelings of loneliness due to <b>social isolation</b> ; (B) make meaningful contributions to society; (C) positively impact the lives of others; (D) <b>recall their life goals and values</b> ; (E) <b>feel spiritual or relate to a Supreme Being</b> ; and (F) (possibly) <b>feel at peace regarding the mystery of what happens after their life ends</b> .					
<b>4. Disruption of life narrative</b>	Patients no longer can: (A) function as a loving parent, grandparent, or close friend; (B) make contributions in their career, hobbies, or other life pursuits; (C) feel joy by contributing to the joy of family gatherings; (D) independently take care of themselves instead of depending on others for virtually all their personal care; (E) trust caregivers' and loved ones' benevolent intentions instead of fighting those who try to help them; (F) benefit from expensive care that is draining precious family assets; (G) <b>avoid leaving their survivors tarnished, negative, embarrassing memories of themselves</b> ; and (H) <b>avoid living in a state of indignity (in their previous, capacitated opinion)</b> .					
<b>5. Loved Ones' Suffering</b>	Patients cannot spare their loved ones' suffering that includes: (A) <b>physical exhaustion, financial pressures, and disruption of their own life narratives due to the burdens of caregiving responsibilities to caregiving burdens</b> ; (B) <b>missing enjoyable interactions with the patient</b> ; (C) <b>feeling helpless as they watch the patient decline</b> ; (D) <b>prolonged grieving as the patient is confusingly still "here" in body, but "not here" in mind</b> ; and (E) <b>"bi-directional empathic suffering" that causes relatives to worry how long the patient will be forced to endure possibly unrecognized and undertreated suffering, and to appreciate that the patient's suffering would be even worse if she/he were somehow aware of how dementia significantly devastated his/her life that leads to thinking and/or saying, "George/Georgia would be horrified if his/her former self could somehow see himself/herself in his/her current state."</b>					

that planning principals judged would cause only moderate suffering if the sole criterion were met, but could cause severe-enough suffering when combined with other conditions.

**3.1. Paradigm Shift #1.** To determine whether suffering is "severe-enough" to cease all life-sustaining interventions, the process of shared decision making includes a time shift that expands the responsibility to planning principals. They can complete the first part of decision making during advance care planning by answering this question for each future condition: "Do you judge this condition would cause

severe-enough suffering to die of your underlying disease?" Their responses can be memorialized in their directives. After the person becomes a PLAD, providers can complete the process of shared decision making by clinically assessing the PLAD and answering: "Has my patient reached any qualifying condition (that she/he previously judged would cause severe-enough suffering to want to be allowed to die)?"

Proxies/agents can alert treating providers that the patient may have reached a qualifying condition and they can also serve as

**TABLE 2** Four paradigm shifts allow “enough-enough suffering” to serve as the sole criterion to answer the advance directive/living will “when” question.

One	<p><b>During advance care planning, capacitated persons judge each condition. Later, physicians determine whether dementia patients have reached any qualifying clinical condition(s).</b></p> <p>To overcome provider uncertainty if contemporaneous suffering is severe-enough to allow the patient to die, <b>Task one</b> is for planning principals to answer during advance care planning: “Based on your values, do you judge this condition would cause severe-enough suffering to want to be allowed to die?”</p> <p><b>Task two</b> is for providers to determine whether their patient has reached the clinical criteria for any of these pre-judged conditions. If so, it may be time to cease assisted feeding.</p> <p><i>The paradigm shift divides the process of determining “severe-enough suffering” into two tasks performed by two people at two times—to decide when advanced dementia patients would want others to allow them to die of their underlying disease.</i></p>
Two	<p><b>Broaden the concept of patient’s personal severe suffering.</b> Consider physical suffering beyond distress from assisted feeding by including pain that is difficult to detect; emotional and psychic suffering; existential suffering; disruption of life narrative; and suffering from being unable to spare the suffering of loved ones either due to, or caused by, patients’ disease (as Table 1 presents in detail).</p> <p><i>The paradigm shift considers all types of personal and loved ones’ suffering as potentially severe-enough for patients to want others to allow them to die of their underlying disease.</i></p>
Three	<p><b>Broaden the concept of loved ones’ suffering.</b> Loved ones can suffer in two ways. One is direct <b>personal</b> suffering: grief, financial, emotional, physical burdens of caregiving, and disruption of caregivers’ life narratives such as pausing their careers to become caregivers. The other is <b>bi-directional empathic</b> suffering from observing patient’s suffering, worrying when it will end, knowing how upset they would be if they could observe their current condition.</p> <p><i>The paradigm shift considers loved ones’ suffering as potentially severe-enough for patients to want to be allowed to die of their underlying disease.</i></p>
Four	<p><b>“Severe-enough suffering” can comprehensively reflect what people dread most about prolonged dying in advanced dementia.</b></p> <p>Proxies/agents can be authorized to decide if the patient would want assisted feeding to cease based on (A) a combination of several conditions, each of which causes moderate suffering, but they add up to severe-enough personal suffering; or (B) if the disease causes more than one loved one to experience moderate suffering for a long time.</p> <p><i>The paradigm shift would cease assisted feeding if proxy/agents judge suffering severe from a combination of patients’ conditions or if several loved ones will have moderate suffering for a long time.</i></p>

advocates who try to persuade treating providers to write the order, “Cease assisted feeding.”

3.2. **Paradigm Shift #2** broadens the concept of suffering (see Table 1).

3.2.1. Some sources of physical suffering are clinically difficult to detect by currently observing the patient. Listing them in Table 1 may raise providers’ index of suspicion, so patients receive better treatment.

3.2.2. Emotional suffering can lead patients to become withdrawn if they are confused, depressed, paranoid, hallucinating, or if providers over-sedated them to make their disruptive behavior easier to manage. These patients may not complain but their suffering may be severe and under-treated or untreated.

3.2.3. Advanced dementia can cause a relationship-type of existential suffering. Relationships can be viewed as having “lives of their own” that will cease to exist if dementia makes them unable to communicate so they cannot interact meaningfully. The resulting type of suffering is social isolation; for example, the patient on the left in Figure 1.

3.2.4. Disruption of one’s life narrative causes suffering. While anxious middle-stage dementia patients are sometimes calmer if dressed in familiar working uniforms, PLADs are unlikely to benefit from this intervention. Yet, their lives will still have lost meaning because they no longer can function in roles that they previously considered important.

3.2.5. Many patients loathe leaving their survivors tarnished memories of themselves, which could cause them to suffer. Several authorities explained why:

Ronald Dworkin: “We worry about the effect of [our] life’s last stage on the character of [our] life as a whole, as we might worry about the effect of a play’s last scene or a poem’s last stanza on the entire creative work.”<sup>32</sup>

Justice John Paul Stevens: “Each of us has an interest in the kind of memories that will survive after death ... [we prefer] memories ... filled predominantly with thoughts about [our] past vitality rather than [our] current [unconscious or demented] condition.”<sup>33</sup>

Judge Stephen Reinhardt: “A competent terminally ill adult, having lived nearly the full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, [and] incontinent. How a person dies not only determines the nature of the final period of his existence, but in many cases the enduring memories held by those who love him.”<sup>34</sup>

Comment: Society generally honors deceased persons’ wishes—even if they are not currently aware or have no way to learn if others have complied. Capacitated people may honor others’ wishes so their wishes will similarly be honored. “Interest theory” further supports persons’ rights after they lose capacity. Smolensky reviewed laws that protect the rights of the dead that may “contradict the preferences of the living.” She noted, the “forces driving the creation of these legal rules are cultural norms, including dignity and respect for decedents’ wishes.”<sup>35</sup> Logically, whatever actions honor the dead should similarly honor the wishes of incapacitated patients who have lost long-term memory.

3.3. **Paradigm Shift #3** broadens the concept of suffering by considering the suffering of loved ones. While usually moderate, it can be severe. Example: a PLAD's daughter had long suffered from major depressive disorder, recurrent episodes. She blamed herself for not visiting her mother often enough while her mother could still enjoy her visits. When her guilt became overwhelming, she required psychiatric intervention for suicidal ideation.

Paradigm Shift #3 conceptualizes two types of suffering that loved ones can experience.

3.3.1. Suffering can cause loved ones' direct suffering from losses and burdens. Examples: they cannot enjoy being with their relative, or they reel from financial, emotional, and physical burdens caused by their relative's disease.

3.3.2. "Bi-directional suffering" results from loved ones' empathy for the patient as they witness the the patient's suffering.

3.3.3. To distinguish between these two types of suffering, consider asking this: "About what is the loved one complaining?" If the answer is "poor me," then the suffering is traditional (3.3.1). If "poor patient," then the suffering is "bi-directional" (3.3.2). While this term may be new, it characterizes a long-recognized and common cause of suffering. Many well relatives think or say: "The patient would be horrified if her former self could somehow see her in her current state."

3.4. **Paradigm Shift #4** broadens the concept of suffering by including conditions that cause only moderate suffering by themselves. Planning principals can authorize their proxies/agents to judge if a combination of several such contemporaneous conditions add up to severe suffering. Planning principals can memorialize their judgments for these conditions during advance care planning. After patients reach an advanced stage of dementia, treating providers can determine whether the patient has reached any of these qualifying conditions.

Comments: Consideration of conditions that cause moderate suffering is needed only for patients who have not (yet) reached a clinical condition judged to cause severe-enough suffering. Advance care planning is important not only for end-of-life decisions, but also to guide surrogate decision makers and providers regarding when the patient would want selective treatments that, for example, forgo cardiopulmonary resuscitation, hospitalization, and intensive care treatment.

Planning principals can also authorize their proxies/agents to judge if their disease is causing "two or more family members to endure moderate suffering for a long time." A common example: paying for the patient's increasingly expensive care forced the patient's wife to sell the family home and his grandchildren to forgo their dream of attending private colleges.

## SECTION 4. AN EXAMPLE OF AN UNACCEPTABLE REQUEST

Stuart is a married man whose family has a history of dementia. He read about the husband of former Supreme Court Associate Justice Sandra Day O'Connor. Dementia likely caused him to forget he was married, or severely impaired his social judgment. Stuart worried about manifest-

ing similar behaviors. So, his directive explained his values for making his conditional advance request:

If I were to commit an act of infidelity, it would cause my wife and children to suffer a long time. It would also cause me to suffer by leaving tarnished memories. I want to be remembered as a caring, devoted, and faithful husband who never caused my wife suffering. I therefore request my future provider write an order to forgo all life-sustaining interventions, including assisted feeding, to prevent my behavior from manifesting this transgression.

Fourteen years later, Stuart's brother and proxy/agent observed him sitting in bed with a woman who also resided on the memory unit. His brother presented Stuart's directive to his treating provider and requested she write orders to cease assisted feeding, per his brother's request. Her initial response was that she needed a day to think about it.

The next day, the provider gave Stuart's brother five reasons that explained her refusal: "First, Stuart seems to be enjoying his new relationship, so his suffering cannot be severe. Second, his actions result from lack of capacity, which makes him "legally not guilty." Third, even if he were guilty of adultery, it is not a capital offense. Fourth, generally considered immoral for physicians to hasten the death of patients who can still enjoy living. Fifth, state law permits me to "decline to comply with an individual healthcare instruction or health care decision that requires health care contrary to generally accepted health care standards,"<sup>15</sup> which in my opinion, includes Stuart's request and your instructions."

This fictional story illustrates a truth: even if a planning principal uses a broadened concept of suffering and applies the relevant paradigm shifts, his specific request may not be considered clinically, legally, ethically, or morally correct and acceptable. Providers who view living will requests as unacceptable can refuse to comply clinically and legally, and should refuse to comply ethically and morally.

## SECTION 5. A POSSIBLE WAY TO RESOLVE A LONG-DEBATED CONFLICT

This article's recommendations may help resolve a clinical and philosophical debate that has lasted three decades. Rebecca Dresser,<sup>36</sup> among others, argued that planning principals lack moral authority to determine the fate of their future demented selves because, by the time the patient reaches an advanced stage of dementia, his/her life values will have changed so much that they are no longer related to the "new" demented person. But Ronald Dworkin<sup>25</sup> and others, including Cantor (2.4.1), argued why patients' precedent/prospective autonomy should be honored. Providers can thus find themselves wondering which version of their patient's expressed wishes they should honor: the decision made by the past capacitated planning principal who memorialized "cease assisted feeding" in his/her directive or the

### BOX 1 Ethical reasons why providers should honor patients' precedent autonomy for requests to reduce severe suffering

1. Every person has the positive "claim right" to avoid suffering. Claim rights impose a correlative duty on others to act so they fulfill the person's demands.<sup>38</sup>
2. The personal value, to avoid irreversible severe suffering, does not change as dementia progresses. Therefore, planning principals and their future demented selves share this unchanged, universal goal (even if other values arguably change).
3. Planning principals engage in advance care planning to protect their "future demented selves" from being forced to endure prolonged, severe suffering.
4. Planning principals have more than moral agency, they have moral responsibility, to complete effective advance care planning.
5. Planning principals are the best moral agents for themselves, because no one knows their values better than they.
6. Directives that use the criterion to avoid irreversible severe suffering have durable moral authority; therefore, proxies/agents acting as their designated advocates can demand that providers and others honor the planning principals' precedent autonomy—unless the request is contrary to generally accepted health-care standards.

incapacitated PLAD who currently indicates his/her desire "to continue assisted feeding" (even if nonverbal)?

Box 1 presents six points that support honoring patients' precedent autonomy—to specifically avoid severe suffering in an advanced stage of dementia. Comment: By themselves, these ethical points may not succeed in convincing future treating providers to write the controversial order, "Cease assisted feeding." The companion article<sup>2</sup> presents a series of criticisms and "alternative views" regarding opponents' claim that the order to cease assisted feeding is immoral. Debate may help resolve this formidable challenge. Another (forthcoming)<sup>37</sup> article presents an optional set of strategies that includes a bilateral contract that the planning principal and his/her proxies/agents can sign, if planning principals want to empower proxies/agents to make their requests irrevocable. It uses a Ulysses (irrevocable) contract.<sup>37</sup>

## DISCUSSION

This is likely the first article to propose two recommendations, and their combination. First: use a broadened concept of "severe-enough suffering" as the sole criterion to determine when to honor patients'

### BOX 2 Four criteria for the timely writing or implementing an order to cease assisted feeding

The patient must have:

- A. Received the diagnosis of advanced dementia, or another terminal illness that causes severe, irreversible brain damage and loss of decision-making capacity;
- B. Lost the ability to eat and drink independently so their survival depends on a caregiver's hand to assist oral feeding and hydrating; and,
- C. Reached a condition(s) that she/he previously judged, based on her/his personal values, would cause irreversible suffering severe-enough to want all life-sustaining interventions to cease, including assisted oral feeding and hydrating.

The provider must then:

- D. Agree that the planning principal's criteria for severe-enough suffering is generally acceptable and that the patient was clinically assessed and determined to have reached a specific condition(s) that she/he or he previously judged would cause severe suffering.

advance request to forgo assisted feeding so they are allowed to die from their underlying disease. Second: treating providers must relinquish their traditional role of being unilaterally responsible to assess their patients' contemporaneous suffering; instead, they would be responsible only to contemporaneously assess the patient to determine whether she/he reached a condition(s) that, as a planning principal, she/he previously judged would cause severe suffering. The first recommendation is consistent with the social role of physicians that prioritizes reducing suffering—along with preservation of life, if possible.

The second recommendation reflects a patient-centered approach to end-of-life decisions that is consistent with AMA's Opinion 2.20 quoted at the beginning of this article. For this protocol to work, physicians/providers must be willing to relinquish some of their traditional authority. Some may resist, for which strategies may be necessary to overcome.

Box 2 summarizes the four criteria patients must fulfill so providers can be persuaded that it is time for them to write or implement the order to cease assisted feeding.

Upton Sinclair's famous quote, "It is difficult to get a man to understand something, when his salary depends on his not understanding it,"<sup>39</sup> as paraphrased, is relevant here: "It is difficult to get providers or their organizations to understand something, when their preferred way to view their professional role depends on their not understanding it." Providers may "not understand" why a protocol that limits their traditional role, to assess patients' suffering, is necessary for patients to attain their end-of-life goal. If so, what may lie ahead? Until new practice guidelines are adopted, ongoing battles over patients' right



of self-determination may continue to unfold, at bedside, in ethics committee, and in courts.

## AUTHOR CONTRIBUTIONS

ST conceived of using “severe-enough suffering” and the four paradigm shifts; researched the relevant literature in the clinical, ethical, and legal areas; and wrote the initial drafts. KS contributed to the clinical descriptions of dementia patients in long-term care and made suggestions to enhance the clarity of the writing. NH contributed his knowledge about end-of-life suffering.

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## CONFLICT OF INTEREST STATEMENT

Dr. Terman owns the Institute for Strategic Change, a for-profit California corporation that publishes books and forms related to end-of-life challenges and advance care planning. As a health-care provider, he counsels patients about advance care planning in three settings: Institute for Strategic Change; Caring Advocates, a California not-for-profit corporation that he founded and for which serves as its CEO and Chief Medical Officer; and Psychiatric Alternatives and Wellness Center, as an independent contractor. He helps patients receive reimbursement for his services from health insurance companies, but his ability to accept new patients is limited so he trains other health-care providers. He has not accepted fees as a consultant, provided expert testimony in this area, or received royalties. He infrequently receives modest honoraria for presentations. This article does not describe the advance directive or specific strategies that Dr. Terman and his colleagues developed since 2004, although it implies that advance directives should use “severe-enough suffering” as a criterion to determine when to implement interventions that may allow patients to die. Those who read this article are not likely to be surprised to learn that Dr. Terman offers such a directive for dementia because who else but a directive drafter would analyze this area in such depth? Co-author Karl E. Steinberg has no competing interests. Co-author Nathaniel Hinerman has no competing interests.

## DATA AVAILABILITY STATEMENT

The manuscript does not contain any data.

## CONSENT FOR PUBLICATION

The article contains no individual person's data in any form other than already published facts, so no consent is required.

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## SUPPORTING INFORMATION

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

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