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PERSPECTIVE

Can an effective end-of-life intervention for advanced dementia be viewed as moral?

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Abstract

Many people dread prolonged dying with suffering in the terminal illness, advanced dementia. To successfully facilitate a timely dying, advance directives must be effective and acceptable. This article considers whether authorities, including treating physicians, can accept as moral, the effective intervention that ceases caregivers' assistance with oral feeding and hydrating. The article presents eight criticisms and "alternate views" regarding ceasing assisted feeding/hydrating. It draws on perspectives from clinical medicine, law, ethics, and religion. The conflict is between (A) people's core beliefs that reflect cultural norms and religious teachings regarding what is moral versus (B) patients' autonomous right of self-determination and claim right to avoid suffering. The article presents each side as strongly as possible. Accepting the intervention as moral could allow patients a peaceful and timely dying from patients' underlying disease. Confidence in future success can deter patients and their surrogates from considering a hastened dying in earlier stages of dementia.

KEYWORDS

advance instructional directives, advanced dementia, allowing dying versus killing, catholic principle of proportionality, ceasing oral nutrition and hydration, end-of-life interventions, intent to hasten dying, morality of withholding basic care

1 | INTRODUCTION

Most people dread prolonged dying with suffering after becoming persons living with advanced dementia (*PLADs*).[1] Traditional directives are usually not effective in helping patients attain the goal of a peaceful and timely dying. Many PLADs survive for years without high-tech medical interventions if providers write orders for caregivers to continue oral hand-feeding and hydrating (henceforth, *assisted feeding*). More than a dozen recently published or revised dementia-specific directives conditionally request cease assisted feeding in advance.[2] But if physicians and providers (*providers*) and other authorities consider the order immoral, they will refuse to write the order or refuse to let this order stand. The result: patients may not attain their goal of a peaceful and timely dying and may be forced to endure a prolonged dying with suffering. Fearing this can lead to preemptive suicide in early dementia[3] or hastened dying in middle dementia if surrogates decide not to treat pneumonia.

This article presents criticisms and supporting citations and quotations to support the view that ceasing assisted feeding is immoral, followed by "alternate views" that the intervention can be viewed as moral. Disclaimers: while each view is presented strongly, this author favors the view of cease assisted feeding can be moral if appropriately implemented, and no claim is made that the citing of critical authorities or considering eight areas of contention (see Box 1) are comprehensive.

BOX 1 Areas of controversy regarding the order "Cease assisted feeding"

1. Is this order euthanasia?
2. Does the order cease basic care?
3. Is the request Voluntarily Stopping Eating and Drinking in advance?
4. Is the intent of the order to hasten dying?
5. Can fulfilling the Principle of Proportionality make the order moral?
6. Is it a ruse to place food and fluid within the reach of PLADs?
7. Do the sight and smell of food and fluid cause patients harm?
8. Do life-sustaining efforts of human beings defy the will of God?

The goal of this article is to inspire debate about an issue that is, and will, affect millions of patients and their families.

Box 2 presents the meaning of key terms this article uses such as "assisted feeding" versus "comfort feeding."[4] The secular meaning of "moral" is what society agrees is right; the religious meaning is what religions teach is right.

2 | A BRIEF PERSPECTIVE ON TUBE FEEDING

The history of forgoing tube feeding in advanced dementia provides a perspective for forgoing assisted oral feeding. Box 3 summarizes the 2021 findings of Davies et al.[6]

This review validates the Alzheimer's Association's 2015 position and recommendations in "Feeding Issues in Advanced Dementia."[7] It stated, "In comparison with careful hand-feeding, tube feeding by percutaneous endoscopic gastrostomy (PEG) or nasogastric tube offers no advantages and incurs a number of disadvantages," and, "It is ethically permissible to withhold nutrition and hydration artificially administered…in the end stages of the disease."

While the Alzheimer's Association's position statement "encouraged surrogates to discuss the risks and benefits of all feeding alternatives…consistent with the person's values," it did not consider the decision to withdraw "careful hand feeding" among "all alternatives." Yet this may be the last resort for many PLADs who want a peaceful and timely dying. This article focuses on the debate regarding whether this intervention can be considered moral, and therefore acceptable, which is required for those in power to implement it.

In 2019, the controversy regarding ceasing assisted feeding reached national proportions after ethicists at AMDA—The Society for Post-Acute and Long-Term Care Medicine—proposed Policy A19, which was adopted. (AMDA's 5000 member/providers care for residential patients in nursing homes and assisted living facilities.) Policy A19 categorically recommended not honoring any advance directive that conditionally requested ceasing assisted feeding unless providers interpreted patients' behavior as being consistent with refusal or distress.[8,9] The interpretation of non-verbal patients' behavior is fraught with false negatives and false positives, the magnitudes of which are not known.[2]

3 | THE SEESAW: INTERVENTIONS THAT ARE EITHER EFFECTIVE OR ACCEPTABLE, BUT NOT BOTH

3.1 | An acceptable, but not effective intervention

Gaster's "dementia-directive" requests, "I would not want any care that would keep me alive longer,"[10] Yet "any care" is vague, so providers may refuse to write an order to cease assisted feeding that proxies/agents request. Thus, Norah Harris's husband could not fulfill her end-of-life goal.[11] Ineffective directives often force patients to wait until they die from another terminal event that may not occur for years. Worse, patients may be forced to starve to death slowly. A sad example: Margaret Bentley's dying took 5 years and near the end, her emaciated body resembled that of a holocaust victim.[12,13]

3.2 | An effective, but not acceptable intervention

Compassion & Choices' "Dementia Values & Priorities Tool" states, "Keep me comfortable while…withholding food and fluid so that I can die peacefully."[14] Similarly, Menzel and Chandler-Cramer stated, "To withhold food and water by mouth [is] a realistic and morally justified way for people to control living into extended years of dementia."[15] But Rebecca Dresser warned that others could judge withholding food and fluid as euthanasia.[16]

3.3 | Comment

Gaster's noncontroversial intervention is high on acceptability, but low on effectiveness. Compassion & Choices, and Menzel's controversial intervention is high on effectiveness, but low on acceptability. This article proposes an intervention that strives to be both effective and acceptable.

4 | THE PROPOSED INTERVENTION: A SET OF FOUR ORDERS

Box 4 displays the proposed "set of orders," which number four if POLSTs are not used; or two, if POLSTs are used (POLSTs are explained in Box 2).

Comments: Order #1 only withdraws caregivers' assisting feeding. It does not withhold food and fluid. Order #2 always offers food and fluid, which may make Order #1 legal and moral. These orders operationalize this perspective: putting food and fluid into patients' mouths—if not wanted—is unethical since it violates patients' bodily integrity. Orders

BOX 2 Key terms and their meanings (part 1)

Term	Meaning
Assisted oral feeding and oral hydrating (assisted feeding)	Caregivers put food and fluid into the mouths of patients living with advanced dementia (PLADs) who have lost their ability to eat or drink independently
Comfort feeding	Best gentle effort to provide patients food and fluid, which stops if patients seem to refuse or to be distressed
Advanced dementia	A devastating, slowly terminal brain disorder that causes severe impairment of cognitive ability, judgment, and eventually for 90% of PLADs, loss of ability to independently eat and drink, which makes them dependent on caregivers' assisted feeding to sustain their lives
Advance instructional health care directive	Commonly referred to as a "living will," but in this article, "directive" (whether standalone or supplemental)
Effective	The directive's intervention allows patients living with advanced dementia to experience a peaceful and timely dying that ideally is caused by their underlying disease
Peaceful	The directive's intervention allows PLADs to die without adding to their suffering or their loved ones' suffering
Planning principal	The person engaged in completing advance care planning, whose goal is a peaceful and timely dying that anticipates the patient's future loss of decision-making capacity
Timely	The dying process (A) begins based on the planning principal's personal values and treatment preferences—as reflected in their directive's requests; and (B) ends within a reasonable duration—such as 2 weeks
Medical dehydration	A way to die from a total fast of all food and fluid, which nurses' observations rated "good" and "peaceful"[a]
Starvation	A prolonged way to die, often with suffering, from a fast of only food while still drinking fluid

[a] According to nurses' observations of cognitively intact patients who died by refusing food and fluid.[5]

BOX 3 Key terms and their meanings (part 2)

Authorities with power	Physicians/providers and their organizations, bioethicists, health care administrators, judges, religious leaders, relatives, and "well-meaning" third parties—whose views may be either incorrect or misguided, or are not patient-centered
Acceptable	Authorities respect and thus accept planning principals' choice of an intervention as legal, clinically appropriate, ethical, and moral (even if authorities personally disagree)
Treating providers	Health care providers including physicians, nurse practitioners, and physician assistants
Other health care providers	Emergency medical personnel first responders and other supporting clinicians
Successful	Treating providers promptly honor requests that planning principals expressed in their directives and POLSTs—that are consistent with proxies/agents/surrogates' instructions
POLST (and variations on this acronym, such as MOLST) that can contribute to making the intervention effective	Formerly "Physician Orders for Life-Sustaining Treatment," POLST is an immediately actionable set of orders that all health care providers "shall" honor across all treatment settings (unless contrary to acceptable medical practice or in conflict with provider's conscience)
Withholding (the substances of) food and fluid	Not placing the substances food and fluid within PLADs' reach, which may be viewed as euthanasia and thus illegal
Withdrawing (the act of) assisted oral feeding and hydrating	Not putting food and fluid into the mouths of PLADs, but offering these substances within patients' reach—which is ethical and legal for patients who requested this intervention but some authorities consider it immoral
Set of two or four orders	Two orders must be written in POLSTs or in patients' charts; another two orders are standard in POLSTs but must be written in patients' charts if POLSTs are not used
Competence and capacity versus decision-making capacity	Competence is a legal, global term. Capacity is relevant to a specific task—here, the mental ability to make treatment decisions for which the full term is "decision-making capacity," herein referred to as "capacity"

BOX 4 Findings of Davies et al. regarding tube feeding patients with severe dementia

No evidence that tube feeding:

1. Improves survival
2. Improves quality of life
3. Reduces pain
4. Decreases behavioral and psychological symptoms of dementia
5. Leads to better nourishment
6. Improves family or carer outcomes such as depression, anxiety, carer burden, or satisfaction with care

Some evidence that tube feeding causes harm by:

1. A clinically significant risk of pressure ulcers

BOX 5 The proposed set of two, or four, orders

1. Cease assisted oral feeding and hydrating; cease putting food and fluid into the patient's mouth. (Add to POLSTs.)
   Always offer the patient food and fluid by placing them within the patient's reach. (Add to POLSTs.)
   Withdraw and withhold all medical life-sustaining treatment unless needed for comfort care. (Included in POLSTs.)
   Administer all appropriate comfort measures so dying can be as peaceful as possible. (Included in POLSTs.)

#3 and #4 can be written in patients' hospital or nursing home charts, although they are standard Comfort-focused Treatments in widely used POLSTs.[17,18]

Box 5 Lists inclusion and exclusion criteria to implement an order to cease assisted feeding.

5 | EIGHT ARGUMENTS THAT CRITICIZE THE SET OF ORDERS AS IMMORAL, AND "ALTERNATE VIEWS"

5.1 | Criticism I: The intentional cessation of assisted feeding is, according to Catholic teaching, euthanasia by omission

Taylor and Barnet[19] focused on Rev. Kevin McGovern's Internet article (in which he used the term "Natural Dying" for the four orders) and opined that a patient decision aid could "identify the sorts of circumstances in which some treatments [including assisted feeding] might become extraordinary or disproportionate, and therefore may be refused, withheld or withdrawn."[20]

Taylor and Barnet argued, "If hand feeding is not a treatment but rather a necessary act that obligates both family and professional caregivers, [then] even the beneficent motive to free the patient from a miserable life, thereby respecting intrinsic dignity, is unethical." The Catholic Church's *Declaration on Euthanasia* includes any "act or an omission intended to cause death"[21] and the set of orders omits assisted feeding. These may have been influenced by an Allocution of Pope John Paul II, which is discussed below.

Alternate views

Taylor and Barnet's criticism has three flaws: they omitted Order #2; they did not consider inclusion/exclusion criteria; and they did *not* apply the Catholic Principle of Proportionality[22] which could have weighed the suffering of PLADs and their loved ones versus the benefit of continuing assisted feeding.

Pope John Paul II's (controversial) Allocution of March 2004 stated,[23] "The administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act…[and] should be considered, in principle, ordinary and proportionate, and as such morally obligatory."

Tube feeding is more medical than oral feeding, and persistent vegetative state patients (*PPVSs*) are less functional than PLADs. Thus, it may seem logical to consider assisted feeding morally obligatory for PLADs. But these two diseases are clinically different. PPVSs' condition can be stable while PLADs' course is progressively downward; and presumably can not experience pain or suffering (PPVS) cannot experience pain or suffering while PLADs can. Preserving life is generally a benefit, but for PLADs, the harm may be outweighed by their suffering and inability to interact with others.[1]

Pope John Paul II later reversed his position to: "True compassion…helps draw the line when it is clear that no further treatment will serve the purpose" of "the patient's recovery," so "to halt a treatment will be deemed ethically [morally] correct if the treatment is ineffective or obviously disproportionate to the aims of sustaining life or recovering health."[24] He thus applied the Principle of Proportionality.

5.2 | Criticism II: Assisted feeding is "basic care" so any order to cease it is immoral

4.1. Assisted feeding does not require a provider's order or medically skilled personnel, so it is "basic care," not medical treatment.
2. Every human being needs basic care, so it should never be discontinued.
3. Order #1 intentionally discontinues basic care, so it is immoral.

Alternate views

Catholic ethicist Rev. O'Rourke presented a clinical example to support his contention that the term "basic care" is irrelevant. The simple act of frequently turning bedbound patients can prevent painful bed sores and life-threatening infections. But if a patient is not likely to

BOX 6 Inclusion and exclusion criteria for implementing the order "Cease assisted feeding"

Inclusion criteria	Exclusion criteria
Patient has the diagnosis of a terminal illness from which she will most likely die, such as Alzheimer's or a related dementia, which caused the loss of decision-making capacity	The patient is not terminally ill or has capacity to decide how and when s/he wants to die; such as by Voluntarily Stopping Eating and Drinking
The patient's current condition meets the criterion of severe enough suffering based on his/her previous judgments as s/he completed advance care planning as a planning principal who had capacity	The patient's current condition does not meet the criterion of severe suffering, or s/he did not complete an advance instructional directive that memorialized his/her judgments regarding the severity of suffering of future conditions
The brain disease causes the patient to lose his/her ability to eat and drink independently, which loss of function seems irreversible	The physical or brain disease causing the loss of ability to eat and drink independently could be reversible, such as a recent small stroke
Sustaining the patient's life depends on continuing caregivers' assistance with oral hand-feeding and oral hydrating	The patient can actively participate in ingesting nourishment such as drinking through a straw if placed in her mouth—even though, for example, both of her arms are broken and in casts
The order to "cease" assisted feeding can be implemented only if the patient had recently been receiving assisted feeding	The patient's most recent way to ingest nourishment was by self-feeding and self-hydrating, such as before a sudden stroke or fall
The legal and moral basis of "Cease assisted feeding" depend on Order #2: "Always offer the patient food and fluid by placing them within his/her reach"	Clinical practice guidelines often recommend waiting a certain time to see if the functions of self-feeding and self-drinking recover; for example, after a small stroke
If the patient uses the food and fluid placed within his/her reach by resuming self-feeding or self-drinking, then his/her treatment plan must promptly change	If the patient still has the mental and physical capacity to self-feed and self-hydrate but refuses, then s/he will have chosen to hasten his/her dying by Voluntarily Stopping Eating and Drinking

recover and her bones are so fragile that they may fracture if turned and cause excruciating pain, then turning is not morally obligatory.

Similarly, for PLADs what is relevant is whether they have reached a condition that they previously judged would cause irreversible severe suffering—not whether some authorities choose to label assisted feeding "basic care."

5.3 | Criticism III: The set of orders is an advance request to "voluntarily stop eating and drinking" that intentionally hastens dying, so the set of orders is immoral

1. It is never moral to intentionally hasten the dying of a human being.
2. Voluntarily Stopping Eating and Drinking (*VSED*) is a legal alternative to Medical Aid in Dying for capacitated patients who can eat and drink, but intentionally decide not to.
3. The set of orders is essentially VSED requested in advance by a directive.
4. The intent of the set of orders is thus to hasten dying, so it is immoral.

Alternate views

Premise (3) is false. PLADs cannot "voluntarily" make decisions or execute acts in any area for which they have lost capacity. They cannot "stop" a behavior they are not currently doing. They were not "eating" or "drinking"; they were being fed and hydrated by caregiver's hands. Semantically and clinically, "ceasing assisted feeding" is not "voluntarily stop eating/drinking"; therefore, this argument alone, does not prove it is immoral.

5.4 | Criticism IV: The intent of implementing the set of orders is to die, which is immoral

1. Planning principals' future intent is to be allowed to die within 2 weeks.
2. This intent is why their advance directives requested the set of orders.
3. Therefore, the set of orders is immoral.

Three alternate views.

5.4.1 | The intent was instead to attain the most peaceful dying possible

Example: a PLAD aspirated and then recovered from pneumonia. Her provider informed her proxy/agent that her risk of dying from pneumonia was high and that dying from pneumonia can be less peaceful than from medical dehydration.[5] Pneumonia can cause toxicity due to high fever with sweating; low body temperature with shaking chills; extreme fatigue from debilitating coughing; sharp or stabbing chest pain; nausea and vomiting; and worst of all, not only shortness of breath but panic due to air hunger. Furthermore, incapacitated nonverbal patients may be unable to complain and may be undertreated.[1]

5.4.2 | The intent was instead to reduce suffering, which "claim right"[25] imposes a correlative duty on others

Example: since *Bouvier*,[26] capacitated persons can legally refuse tube feeding. They can also stop eating and drinking.[27] Since incapacitated PLADs cannot currently affirm their choice to die, "well-meaning" third parties can argue they changed their mind or have different values.[28] Authorities can impugn proxies/agents' motivation by claiming their instructions are selfish. Yet planning principals can still state their future treatment preferences, request relief from future suffering, and refuse to have their bodily integrity violated. Their advance directives can quote AMA's Code of Ethics' Opinion 2.20:

> The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail.[29]

5.5 | Criticism V: The principle of proportionality cannot make killing moral

1. "By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated."[21]
2. No principle, including the Principle of Proportionality, can justify killing a person.
3. The set of orders is therefore immoral.

In his 1995 encyclical *Evangelium Vitae* (Gospel of Life, #65),[30] Pope John Paul II defined euthanasia as "an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering"—which is precisely what ceasing assisted feeding does.

Alternate views

The Pope also clarified, "To forgo extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death." The Pope thereby acknowledged conditions for which it can be moral to refuse life-prolonging interventions. An early opinion of the U.S. Bishops Pro-Life Committee (regarding tube feeding for PPVSs, which can apply to PLADs) stated[31] "Although the shortening of the patient's life is one foreseeable result of an omission, the real purpose of the omission was to relieve the patient of a particular procedure that is of limited usefulness to the patient or unreasonably burdensome for the patient and the patient's family or caregivers [which] decision should not be equated with a decision to kill."

> Rev. O'Rourke distinguished between being human and the ability to act (for PPVSs)[32] by focusing on the relationship between PPVSs and God. A parallel argument can apply to relationships between PLADs and other human beings. Below are O'Rourke's original statement and a parallel statement where words (in Italic font) apply to human relationships.
>
> O'Rourke: To know, love, and be happy requires cognitive-affective function. If a person does not have the potential for cognitive-affective function, it does not mean that God does not love him or her, or that the person is no longer a friend of God. But it does mean that the person cannot pursue the friendship of God, the purpose of life, through his or her free actions.
>
> *A parallel statement*:
>
> To know, love, and be happy requires cognitive-affective function. If a person does not have the potential for cognitive-affective function, it does not mean that *members of his or her family and close friends no longer love him or her, or do not deeply value their relationships*. But it does mean that the person cannot pursue *these loving relationships, or continue his/her personal life narrative*, through his/her free actions.

Both statements can end with the same conclusion by O'Rourke:

> Therefore, the moral imperative to help the person toward health and existence is no longer present if there is no potential for cognitive-affective function and treatment offers no palliative benefit.

Ceasing assisted feeding to "help the person towards…existence" can be viewed as moral. O'Rourke noted, "the moral mandate to help [PVSSs] prolong their lives is no longer present because they will never again perform human acts, that is, acts proceeding directly from the intellect and will…[so] life support that keeps them alive need not be continued because it does not offer them any hope of benefit." These statements can apply to PLADs.

O'Rourke asserted that removing life support "is simply accepting the fact that human life is not an absolute good," so, "do not ask whether life can be prolonged, but rather, should it be prolonged?"[33] For the devoutly religious, the afterlife has the higher priority.

BOX 7 Possible reasons why patients may infrequently resume assisted feeding

1. The patient enjoyed and wanted the social interaction accompanying assisted feeding to continue so s/he tolerated moderate hunger as s/he waited to be fed. After assistance stopped and hunger increased, however, s/he resumed self-feeding.
2. The patient stopped self-feeding due to dementia-caused apathy, hallucinations, or depressive symptoms. But increased hunger motivated her to resume self-feeding.
3. Prescribed medications decreased her appetite or caused nausea, which side effects resolved after these medications were discontinued.
4. Medical dehydration reduced increased intracranial pressure from a previously undiagnosed, co-morbid brain tumor, which allowed self-feeding to resume.

Comment: this religious view distinguishes between killing patients and allowing them to die.

5.6 | Criticism VI: Order #2, placing food and fluid within the advanced dementia patient's reach, is a ruse since PLADs have already proved they cannot eat or drink independently

1. Order #2 may protect those involved from being indicted for euthanasia or elder abuse.
2. But no one expects these patients to resume independent eating and drinking.
3. The real purpose of Order #2 is to obscure the actual intent: to hasten dying.
4. Therefore, the set of orders is immoral.

Medical and legal alternate views:

5.6.1 | Medical

Implementing the set of orders can be viewed as a way to determine if PLAD's inability to self-feed/drink is reversible. The vast majority of PLADs will leave offered food and fluid untouched and die, proving it was irreversible. Box 6 lists four reasons why patients might resume self-feeding. Admittedly, the clinical prevalences of these reasons are not high enough to include them in the process of differential diagnosis. Yet a prevalence higher than zero is morally and legally relevant. Importantly, if a PLAD does resume self-feeding, the treatment plan must be promptly revised.

5.6.2 | Legal

Implementing the set of orders almost always leads to death whose physiological cause of death is medical dehydration. Question: Did those who requested, directed, or ordered assisted feeding to cease, intend to cause the patient's death? Answer: only if the person committed the "crime." Causation must be established before considering intention. (Example: A hit man intended to use his hidden revolver to kill a diner owner who refused to comply with the mob's demands. Their argument ended when a drunk driver unexpectedly killed the diner owner. The hit man was not indicted for murder since he did not cause the diner owner's death.)

Lou Gehrig's disease (ALS) destroyed a patient's ability to breathe independently

For several months, a mechanical ventilator provided life support. Then, other factors led his proxies/agents and provider to agree it was appropriate to withdraw the ventilator.

The patient died. Did those who withdrew the ventilator cause his death? No. ALS caused the patient's death. His disease destroyed the ability of his lower motor neurons to receive signals from the brain to produce muscle contractions necessary to breathe, even though he had access to an adequate source of oxygen. But for the disease ALS, the patient would have lived.

Advanced dementia seemed to have destroyed a PLAD's ability to eat and drink independently

For several months, assisted feeding provided life support. Then, her proxies/agents and provider agreed it was appropriate to cease assisted feeding. She reached a condition that her directive indicated she had judged would cause severe suffering.

The patient died. Did those who ceased assisted feeding cause her death? No. Dementia caused the patient's death. Dementia destroyed her brain's ability to either recognize the items placed within her reach as food and fluid (*agnosia*) or to coordinate moving her hands to put them in her mouth (*dyspraxia*), even though food and fluid were always offered. But for dementia, the patient would have lived.

5.7 | Criticism VII: Order #2 harms patients by always offering them food and fluid

1. Order #2 is designed to protect providers from adverse legal judgments such as committing elder abuse or euthanasia.
2. But placing food and fluid within patients' reach exposes them to sights and smells that cause frustration by stimulating their senses that makes them desire food and fluid. They are also confused since they cannot understand why assisted feeding has ceased.
3. The combination of hunger, thirst, frustration, and confusion harms patients.
4. Treating providers know Order #2 will harm patients, so their acts are immoral.

BOX 8 Reasons why Order #2 causes relatively less harm than the severe suffering that dementia causes

1. PLADs' diminished mental state may prevent them from appreciating the substances within their reach are food and fluid. If true, Criticism VII does not apply.Below, assume Reason #1 is not true:
2. Any discomfort from frustration and confusion will be less than "severe enough suffering" from reaching a condition of advanced dementia that has met the planning principal's inclusion criterion to be allowed to die (by cease assisted feeding).
3. Ketogenesis naturally reduces patients' experience of hunger.
4. OTC aids can effectively treat thirst and dry skin.
5. Planning principals appreciate the human condition that they cannot predict the future, and they thus have only two choices. One is to make the best decision for themselves while they still have capacity; the other is to let surrogates make life-or-death decisions on their behalf after they reach an advanced stage of dementia. The latter is treacherous given the amount of evidence that supports the recommendation to abandon the practice of asking surrogates for their substituted judgment.[a]

[a]Terman, S. Abandon the Three-Decade U.S. Tradition of Asking Surrogates for Their Substituted Judgment to Honor the End-of-Life Wishes of Incapacitated Patients, Including Patients Living with Advanced Dementia (July 28, 2022). Preprint available at: https://doi.org/10.2139/ssrn.4175688

Alternate views.

Box 7 Lists reasons why the harm from Order #2 is typically less than from severe suffering.

5.8 | Criticism VIII: Implementing the set of orders is against the will of God

5.8.1 | Some Christians believe

"To end the life of a sick person…is to take the place of God in deciding the moment of death."[34] And, "Our lives are in God's hands. He knows the time of our death, and He has even appointed it,"[35] and, "God knows exactly when, where, and how we will die,"[36] and, "God the Creator offers life and its dignity to man as a precious gift to safeguard and nurture, and ultimately to be accountable to Him."[34]

5.8.2 | Some Jews believe

"Our soul belongs to God; it was given to each of us to perform a special purpose in this world. When that mission is complete, the soul will be ready to leave. Just as we cannot choose the moment of birth, it is equally not up to us to determine when it is time for a soul to move on," according to Chabad/Orthodox teaching.[37]

Alternate views.

5.8.3 | Christian

"The renunciation of treatments that would only provide a precarious and painful prolongation of life can also mean respect for the will of the dying person as expressed in advance directives for treatment."[34]

5.8.4 | Jewish

The Talmud relates this story about how Rabbi Yehuda HaNasi died.[38]

> Despite all medical advice to the contrary, the rabbi's devoted students were engaged in constant prayer as they hoped their favorite teacher would not die. They encouraged him to eat and to drink. Yet the rabbi's maid correctly appraised the conflict between the upper realm of God and the lower realm of earth. She concluded that students' prayers were prolonging the rabbi's dying, which in turn were increasing his pain and suffering. Due to his GI illness, he needed to visit the bathroom frequently; and each time, tradition required him to change his religious garments (an act that now caused much suffering).
>
> So, the maid literally took matters into her own hands. She filled a pitcher of water, climbed onto the roof of the home, leaned over, and with all her might threw the pitcher down. It landed on the rocks just outside the window of the rabbi's bedroom. As it crashed, the loud sound distracted those in prayer—just for a moment. But this moment was long enough to allow the patient to die, so the will of God prevailed.

Comments: The lesson derived from this parable depends on the reader's perspective. For religious persons of faith, the story may affirm the supremacy and omniscience of a deity who knows and determines when human beings will die and its "moral" warns it is wrong for human beings to alter God's timing—even to prolong dying. The admonition of Chabad Rabbi Taub is consistent: "Don't…interrupt the natural dying process."[37] The teachings of liberal rabbis are consistent: "Judaism's zealous obsession with life…does not include torturing someone by force-feeding…and Jewish law does permit the removal of factors that are keeping the suffering person alive."[39]

Some readers may note these potential inconsistencies: If God is all powerful and all knowing, and if only God can determine when people die, how can these questions be answered: (A) Did God need the maid to act so that the rabbi could die? (B) Are students' prayers more powerful than God's will? (C) Did students' prayers determine the time of

dying? Such questions may lead some readers to be merely amused by a story that "cannot hold water."

6 | DISCUSSION

This article is likely the first to propose and consider the morality of a set of orders that ceases assisted oral feeding and hydrating after patients reach advanced dementia, which many PLADs need to avoid prolonged dying with suffering.

6.1 | Importance and potential impact of the intervention

Dworkin's secular[40] admonition[41] asserts that life is precious and that end-of-life treatment decisions are complex. His perspective is consistent with recommending health care professionals deliberate to make diligent end-of-life treatment decisions on a case by case, person-centered basis. They should consider patients' values and treatment preferences, and their particular condition, rather than follow a categorical mandate based on the ethical, moral, or religious view of one provider, person, or group.

> *The greatest insult to the sanctity of life is indifference or laziness in the face of its complexity*.
>
> —Ronald Dworkin

6.2 | Limitations

There may be possible selection bias by choosing quotations that support the set of orders. But the author also strived to find quotations that strongly supported the eight criticisms. No claims are made in these eight criticisms, or the cited supporting citations and quotes, are comprehensive.

This article considered only conceptual issues regarding whether the intervention, to cease assisted feeding, is acceptable. Volicer and Stets conducted two small focus groups of close relatives of persons who died with advanced dementia. All participants indicated that stopping assisted feeding was acceptable for at least one presented condition of advanced dementia.[42] Larger surveys and more focus group research are needed whose subjects should include providers and other authorities.

This article did not consider cultural and ethnic differences that may influence patients' trust.[43] Yet the set of orders are implemented only if PLADs meet criteria that planning principals judged for themselves, which they based on their lifelong personal values. Trust is less of a concern if patients are empowered to exercise their autonomy.

Regarding concern for people living with disabilities, Sulmasy posed this feared question:[44] "Since you have been so dependent for so long, when are you going to allow yourself to die?" The inclusion criterion of severe enough suffering may reduce worry about this kind of abuse.

6.3 | Resistance

Some critics may insist that (A) basic care cannot be refused; (B) depending on a machine for air is different from depending on a caregiver's hand for nurturance; (C) it is never be moral to cease assisted feeding patients who open their mouth and swallow what others put in; (D) the Bible teaches, "For I was hungry and you gave me food, I was thirsty and you gave me drink";[45] (E) feeding is an act of love; and (F) if no contemporaneous suffering is observed, then preserving life is the priority. (Regarding the last: the companion article[1] argued that patients may still be suffering.) Critics may essentially dismiss advanced dementia as a cruel and burdensome terminal illness that can cause severe enough unobservable suffering to qualify for being a unique time in patients' lives when it is not in their best interest to continue to receive nurturance.

6.4 | Can attitudes about assisted feeding change?

Over time, the mindset of thought leaders in clinical bioethics may not change, may change slowly, or may revert to a previous set of beliefs.

6.4.1 | No change

Taylor and Barnet[19] accessed the same ethical and religious literature, but interpreted it differently, which may not change.

6.4.2 | Slow change

Major physician organizations accepted "The Choosing Wisely Initiative" that tube feeding is futile for advanced dementia patients in 2013.[46] Yet convincing data had been available for more than 14 years.[47,48] Mitchell et al. documented the slow change in reducing the use of tube feeding for PLADs[49] after evidence was sufficient to change practice guidelines.

6.4.3 | Reverting

The controversial Allocution of Pope John Paul II[23] reverted to a categorical position after 5 centuries of Catholic teaching that had applied the Principle of Proportionality.

6.4.4 | What can bring about change?

Planning principals can empower their proxies/agents to advocate honoring their wishes. Advocates might change the mindset of providers and their organizations, one patient at a time.

Poignant reporting, OP/Eds, letters,[50] and surveys may facilitate change. Law review articles may inspire malpractice insurance companies to summarize lawsuits in their warnings to policy holders, where the message is to honor your patients' directives. News reports of

providers whose licenses were sanctioned by medical boards may also provoke change. Yet success at the bedside is infrequently reported and may have minimal impact.

7 | CONCLUSION

How society deals with millions of advanced dementia patients will become increasingly challenging. Financial pressure from the huge cost of care may not allow the "luxury" of 14 years for major medical organizations to adopt appropriate guidelines for oral feeding (as they did, for tube feeding). If debate surrounding these issues does not lead to reasonably prompt changes in health care policy, society may be unprepared for the "dementia tsunami" that could force politicians to urgently adopt draconian measures that violate individuals' autonomy, threaten individuals' freedom, and undermine individuals' right to self-determination. To find acceptable solutions, clinicians, ethicists, religious leaders, health care attorneys, and politicians must evaluate the options for clinical practice as they consider interventions that are both effective and acceptable. On an individual level, this may reduce the suffering of millions of patients and their family members. On a national level, it may help the healthcare system and the economy avert a dementia-driven "medical" bankruptcy.

AUTHOR CONTRIBUTIONS

Stanley A. Terman, PhD, MD, is a bioethicist and board-certified psychiatrist who sees patients in person, in the San Francisco Bay Area and uses HIPAA-compliant telepsychiatry to help patients wherever they are. He provides end-of-life counseling to patients and trains professionals. In 2000, he founded the not-for-profit organization, Caring Advocates, which he continues to lead. Since 2004, his career has been devoted to reducing how long and how much patients and their families must suffer if they face the many challenges of advanced dementia.

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Karl Steinberg, MD, CMD, is Director, Sone Mountain Medical Associates. He contributed his clinical knowledge regarding PLADs in long-term care, the use of POLSTs, and suggested ways to enhance the clarity and logic of some arguments in this article. **Nathaniel Himerman, PhD,** is Dean, Golden Gate University and Professor University of San Francisco. He suggested relevant citations and provided his perspectives, especially regarding the 2004 debate in Catholic bioethics that began with the Allocution of Pope John Paul II. **Thaddeus Mason Pope, JD, PHD,** is Director of the Health Law Institute at Mitchell Hamline School of Law. He read and commented on some legal citations and arguments, including the legalization of VSED, and the article's argument that one must prove causation before evaluating intention (although he may not completely agree with this article's perspective on this issue). **Guy Micco, MD,** is former Director, University of California Berkeley, Center on Aging. He offered his personal and clinical perspectives on Catholic bioethics, and voiced his opinion that putting food and fluid in front of patients who had required assisted feeding was a ruse. **Rabbi Moshe Levin, DivM,** is Emeritus Rabbi, Ner Tamid, San Francisco, and Beth El, La Jolla synagogues. He helped research sources for the story surrounding the dying of Rabbi HaNasi, and alternate Jewish opinions. **Ladislav Volicer, MD, PhD,** is Professor, University of South Florida, School of Aging Studies. In 2012, he suggested (in person) to place food and fluid in front of patients. This led to Order #2. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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 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 specifically refer either to the advance directive or to specific strategies that Dr. Terman and his colleagues developed since 2004. Those who read this article are not likely to be surprised to learn that Dr. Terman offers a directive for dementia since who else but a drafter of a directive would analyze this area in such depth? Author disclosures are available in the supporting information.

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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