Severe Suffering as the Criterion for “When”

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The goal of most living wills is to allow patients to attain a peaceful and timely dying.

The means of living wills is to answer two questions: The “When Question” (timing), and the “What Question” (treatment/intervention). “Timely” is at best based on patients’ values.
Premature dying: Patients opt for preemptive suicide because they believe there is no other certain way to prevent prolonged dying with possible suffering in advanced dementia.

Timely dying: “When” is determined by patients’ values by making prior judgments regarding which conditions meet their personal criteria of “Severe Enough Suffering.”

Prolonged dying: Patients endure unwanted prolonged dying along with “severe enough suffering” because physicians and others insist “comfort feeding” continue until they interpret patients’ behavior as refusal or distress [AMDA’s Resolution A19; March 2019], or until patients die from other causes such as a serious infection, heart attack, stroke or slow starvation. (As did Margaret Bentley)
Ethical Principles – Autonomy

The physician’s twofold duty 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. [paraphrased]

The principle of patient autonomy requires that physicians respect the decision to forgo life-sustaining treatment of a patient who possesses decision-making capacity.

—AMA: “Opinion 2.20 - Withholding or Withdrawing Life-Sustaining Medical Treatment”
A competent, adult patient may, in advance, formulate and provide a valid **consent to the withholding or withdrawal of life-support systems** in the event that injury or illness renders that individual incompetent to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law. **[Precedent Autonomy]**

[A] surrogate’s decision for the incompetent patient should **almost always be accepted** by the physician ... **[unless]** (4) a health care provider believes that the decision is not a decision that could reasonably be judged to be in the patient’s best interests. **[Nonmaleficence]**

Ethical Principles – Beneficence

“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.”

The Goal of Palliative Care

The goal of palliative care is to **prevent** and **relieve suffering** and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care.


http://www.nationalconsensusproject.org/guidelines.html

A relevant question:

Why isn’t “untreatable, irreversible severe suffering” already the accepted standard answer to the living will “When Question”? 
Why dismiss suffering? Some answers:

1. Dementia patients lack capacity to complain, even nonverbally; interpreting their behavior may be difficult.

2. Physicians lack confidence to determine definitively if their patient’s current suffering is “severe enough” to be allowed to die.
   – Plus, when in doubt, we “err on the side of life”

3. A common myth is “Advanced Dementia patients don’t really suffer; they are just out of it.” Assumptions may increase suffering
Avoid being complacent:

Caring, diligent healthcare providers may simply not be aware that their patient has pain. If they are not aware, they may not provide adequate (or at worst, any) treatment.

Some overworked, uninformed caregivers may develop an attitude that leads to such unfortunate statements as:

“About that old lady in the wheelchair who sits in the hallway all day and repeatedly mumbles, ‘Help me, help me, help me…’?

“Well she’s always been that way. That’s just how she is.”
“Pain, although common among older people with dementia, is often underestimated and undertreated.”

“Cognitive impairment limits the ability of older people with dementia to express their pain [so] 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 (Husebo et al., 2012, Scott et al., 2011).”

Anecdote re: Unrecognized Pain

A caregiver accidentally spilled hot coffee in the lap of an advanced dementia patient. Her second degree burns were not discovered until routine continence care, two days later. By then, welts were apparent.

She needed extensive treatment, first in a hospital, and then in a skilled nursing facility rehabilitation unit.

She thus [presumably] had severe suffering from pain for two days, even though she exhibited neither verbal nor behavioral symptoms of pain.

YouTube video (33 seconds): “Advanced Dementia patient--unable to complain--suffered unrecognized pain from second degree burns” https://youtu.be/-6FkR-9jhQ0
Examples of experts who dismiss suffering to answer the living will “When Question”

Bioethicist and philosopher Paul Menzel wrote, “It’s not misery people are afraid of. They just don’t want years of withering.”

“If avoiding suffering is not the goal of a living will, then the author of that living will should say explicitly that avoiding suffering is neither their primary aim nor a necessary condition.”

“Incorporating ‘possible suffering’ is not relevant, perhaps distracting, and I fear may lead caregivers to resist the directive (living will) later when they correctly observe that the patient is not suffering.”


Examples of experts who dismiss suffering to answer the living will “When Question”

Legal scholar Norman Cantor wrote this disclaimer in his published personal living will:

“I understand...I might not be physically or emotionally suffering,” and,

“Courts understand that advance instructions for post-competence medical issues can be based on personal visions of intolerable indignity—not just on avoidance of suffering.”
Three Other Attempts to Answer the Living Will “When Question” & a Fourth Option:

I. The Principle of Proportionality

II. Patients’ behavior during feeding and hydrating

III. Patient has reached an “Advanced Stage of Dementia”

and if all else fails,

IV. Preemptive Suicide before losing capacity
I. The Principle of Proportionality

“It is moral to withhold or withdraw an intervention if the harm and burdens from providing the intervention are disproportionately greater than the possible benefits.”

(From Catholic medical ethics.)

CA Probate Section 4701: “If the likely risks and burdens of treatment would outweigh the expected benefits” [...]then I do not want this treatment to prolong my life].

—A great guiding principle, but conditions should be described clearly & specifically to avoid conflicts regarding interpretation.
II. Patients’ behavior during feeding and hydrating: Suffering is not relevant

Patient turns head away from feeder, refuses to open mouth, spits out food, or gags or coughs up food (or seems indifferent/uninterested but still opens his/her mouth).

One living will requests stopping food and fluid if the above behavioral criteria are met—even if “my quality of life [seems] satisfactory and I appear to be comfortable”—that is, in the absence of suffering.

Another living will dismisses refusal behaviors as not being relevant. It states: “I do NOT want to be fed by hand—even if I appear to cooperate.”
II. Patients’ behavior during feeding and hydrating: Pitfalls in interpretation

**False positives:**
Patients may appear to refuse food and fluid or seem distressed, but actually “want” to live. A few examples: their behavior may result from nausea, mouth pain, or GI tract obstruction.

⇒ Premature dying is possible, here.

**False negatives:**
Patients may seem to willingly accept comfort feeding but really want to be allowed to die. They may open their mouths by reflex, by habit, or just not be able to manifest refusal behavior due to the devastation of function caused by their progressive dementia. In short, they no longer have the ability to refuse.

⇒ Prolonged dying with unrecognized suffering is possible, here.
III. Patient has reached an “Advanced Stage of Dementia”:

To our knowledge, dementia is the only terminal illness for which authors of living wills/directives suggest using “stage of disease.”

The reason is obvious: When their disease is sufficiently advanced that they would not want to live, patients lack capacity to make the decision.

Patients using “Medical Aid in Dying” cannot use “reaching a stage” as a criterion. Instead, patients balance their ability to enjoy life with their increasing suffering and burdens, and decreasing function. Patients who do not meet their personal criteria (and who retain decisional capacity) do not ingest the prescribed lethal dose of medication.

Problem: Using “stage” for advanced dementia patients does not allow them to change their mind. Yet third parties may appoint themselves as observer, judge, and spokesperson.
Using “Stage” may be Fraught

1) Descriptive criteria may not be specific enough. (Example: a patient may not be able to recognize her relatives, but still enjoys being with them, as they enjoy being with her.)

2) Conditions may not cause enough suffering, especially if dread is replaced by accommodation. (When they reach this condition, it is not as bad as they expected.)

3) At worst, “stage” is an arbitrary standard that may be used to discriminate against dependent, incapacitated, vulnerable human beings in a devastating and tragic way: by needlessly shortening their lives.
Example: a Simple Set of Criteria for “Stage”

“People are no longer able to recognize loved ones and family members.
“People may be awake through the night, disruptive, and yelling.
“Many become angry and agitated and sometimes even violent.
“People need around-the-clock help with all daily activities, including bathing and wiping off their genitals, or needing to wear an adult diaper at all times.”

➔ Ask: (a) “Would any one of these statement—by itself—cause you enough suffering to want to die?”
And, (b) “What if someday all four statements applied to you?”
(c) Is this set of criteria comprehensive enough or does it omit some conditions that could cause you severe enough suffering?
IVa. Preemptive suicide.

**Advantages:** There is only one required criterion: capacity. Suicide is legal. Commonly chosen options are: Voluntarily Stopping Eating and Drinking, and breathing only nitrogen.

**Disadvantage:** Loss of months to years of living that may be enjoyable although challenging—even after loss of capacity.

**Example:** Why was Debra Koosed’s dying premature? Because she killed herself after completing her tax returns, for only one reason: The “helping” organization informed her they could not help, if she lost capacity. If she waited “too long,” she would lose her “window of opportunity.” Debra signed a statement that she had considered all other alternatives, but no one informed her about strategic advance care planning.
IVb. Preemptive Homicide and Suicide—a Double Tragedy.

Janet Goodman was Debra Koosed’s “Exit Guide.”

Janet lost both parents in 2012.

Her mother had significantly declined from advanced dementia.

Her father, a loving and devoted husband of 64 years, first shot his wife, and then shot himself.

What About Using the Criterion, “Quality of Life?” or “Indignity”?

The problem: Where might the “slippery slope” end up?

Suppose we accept “Quality of Life” and/or “Indignity” as criteria for people to judge their own lives, to be used only to inform others “when” they want to die from advanced dementia. The next step could be to grant proxies/agents and physicians, the authority to make this judgment about us, if we had not clarified our criteria and no longer have the ability to do so. The following step could establish a general “best interest” standard based on experience, which could be used for patients who did not state their own criteria and did not designate others whose judgment they trusted, to make this decision.
What about using the criterion, “Quality of Life?” or “Indignity”?

Concern: Where might the “slippery slope” end up?

Given the pressure of high cost of care for millions of advanced dementia patients, which threatens to devastate not just all of our entitlement programs but our entire economy, those in political power may invoke the ethical principle of social justice to strive for equitable access to health care resources. They may authorize one or more professional organizations to establish a set of guidelines so that dying can be allowed to occur if patients meet these new, general criteria.

In other words, politicians may ultimately assume the power to determine when an individual’s life is no longer worth living—that they can “justify” as being based on a consensus of “best interest.”

➤ Frightening parallel to how the infamous Nazi program, T4, began.
Thank You!