DEMENTIA, ADVANCE DIRECTIVES, AND ORAL FEEDING: WHAT DOES RESPECT FOR PATIENTS PERMIT? WHAT DOES IT REQUIRE?

Paul T. Menzel, PhD
Pacific Lutheran University (emeritus)

Chinese University of Hong Kong
Centre for Bioethics
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KEY ELEMENTS

- Demographics
- Limited number of ways to avoid living into advanced dementia – ADs primary
- Flawed ADs, and a stronger one
- Major objections to even the best AD
- Refutation of those objections
- Option of minimal comfort feeding (MCF)
- Is adherence ethically permitted, or required?
- Status of these arguments in China and HK

Prevalence of Progressive Dementia

- Current U.S.: 6m, 1.6%. 2060: 13m (6m >85).

  China: 2022, 15m, 1.1%. 2060, 1.4%.

- Deaths from dementia (not just with dementia):

  U.S. 2021: 300,000, >100,000 from Alzh's

  2060: 500,000

- People living with advanced dementia:

  U.S. 2024: >500,000-700,000

  2060: 1m

Limited Ways to Avoid Living into …

- Legalized aid-in-dying: of no use. Terminal illness & current capacity are typically required.
- Voluntarily stopping eating & drinking(VSED): legal, but in severe dementia, not decisive enough to act. If decisive enough, "pre-emptive" (good time left yet).
- Pre-emptive suicide: risky, legally and in result.
- Stopping eating & drinking (SED) by AD: yes, in principle, but problematic unless done right.

AD for SED: the basic argument

- Same basis for VSED as for refusing lifesaving treatment (RLST): informed consent, "bodily integrity."
- Foundation of ADs: one does not lose one's rights with loss of capacity – have to be exercised for you by someone else.
- Same applies to VSED: as with RLST, one does not lose the right with loss of capacity. Becomes "VSED by AD" or "AD for SED."
- That said, ADs for SED are frequently weak.

Margot Bentley

2011

2016

Margot Bentley

- Died Nov 2016, end-stage dementia, age 85
- 12 yr in dementia, 4 in most severe stage
- A former nurse experienced in dementia care
- Had AD refusing food & water as early as 1993
- Flawed AD: only "no food and fluids," without "… no oral food and fluids."
- Still swallowed food. B.C. courts regarded that as a "choice" and voluntary acceptance.
- Similar case: Nora Harris, 2017, Oregon

Critical Issues an AD for SED Must Address

- What is to be withheld? (oral food & drink)
- When should it be? ("triggering conditions")
- Extent of palliative measures to be used (sedation?)
- What if TC's are met but person seems happy, or agent believes QoL is sufficient?
- What if clinicians or facility refuse to implement the AD?
- What if person expresses desire to eat/drink?

Prominent Publicly Available ADs for SED

Northwest Justice Project. Advance Directive for VSED	https://www.washingtonlawhelp.org/resource/vsed-directive
Advance Directive for Dementia, (developed by Barack Gaster)	https://dementia-directive.org/
Caring Advocates (S Terman), Strategic Adv. Care Planning	https://caringadvocates.org/
Compassion & Choices, Dementia Values and Priorities Tool	https://compassionandchoices.org/dementia-values-tool/
Dartmouth College, Dartmouth Dementia Directive	https://sites.dartmouth.edu/dementiadirective/
End of Life Choices New York, Dementia Advance Directive	https://endoflifechoicesny.org/directives/dementia-directive/
Final Exit Network, Advance Directive Dementia Provision	https://finalexitnetwork.org/advance-directives-for-dementia/
Final Exodus, Advance Health Care Directive	https://finalexodus.org/EndOfLife/advance-directive/
Life Circle, Living Will,	https://www.lifecircle.ch/en/downloads/

Only the first AD addresses all the critical issues.

Specific Strengths of the NJP Directive

- Triggering conditions are not described exclusively in terms of "sufficient suffering," but also by kinds of unacceptable deterioration.
- Provides options for palliative sedation.
- Provides direction if person wants to be fed:
  - continue to withhold all food & drink, or
  - minimal comfort feeding (MCF)
- What to do if facility or clinician refuses to implement.

Major Objections

- "Different person"
  - Insufficient psychological connectedness or similarity.
- "Change of mind"
  - Something short of "revocation," which requires awareness of what one is revoking
- Then-self/now-self problem
  - Current patient wants something at odds with AD. Clinicians and agents feel obligated to satisfy current desires.

Refutations: “Different Person”

- Spurred by Parfit’s philosophical view that there’s no identity of person throughout a life.
- Unacceptable everyday implications:

  We would think Charles at 60 a different person than Charles at 3. We don’t.

  We would hold either (1) two memorials, one for then-Charles, one for demented Charles, or (2) one when Charles got to advanced dementia and another when Charles died. We don’t do either.

Refutations: “Change of Mind”

- Expressions that conflict with the person’s AD are not “revocations” – that would require awareness of the AD.
- They do constitute some sort of “change of mind,” but is it of the relevant sort? Involves nothing like the mental activity in forming the preferences stated in the AD.
- Berghmans: “At the time you would most likely ‘change your mind,’ you don’t have enough of a mind to change.”

Refutations: Then-self vs. now-self

- Dworkin's solution: "critical interests" have priority over "experiential" ones.

  Too simple. More powerful arguments:

- Self-ownership: *one's life is one's own*.

  A *life* has larger aspects – e.g., people make value judgments about how theirs would best end. In treating *the patient as a person,* we pay attention to these values.

- *Even now*, the person before us is the person who wrote the AD.

Nonetheless: "not yet" cases

- No matter how clear and complete the AD, doubts about its implementation may arise.
  - May not have been recently written or reiterated, or patient/agent communication may not have been substantial.
  - Even with triggering conditions met, patient may seem to take an interest in living.
- Clinician and agent may then say "not yet," but still attend to implementing in future.

Minimal Comfort Feeding (MCF)

- Example: Gladys, long-term care, FAST #7a.
  - Incontinent. Says a few words, including "I love you" and "help me." Sleeps 18-20 hours/day. Appetite waning.
  - Brother (her agent) visits weekly. Promised he'd implement her AD, whose TCs are now met.
- Will open mouth and swallow when carefully spoon fed, until not comfortable. Assistants believe it their compassionate duty to feed, not to follow the AD to withhold all food & drink.

Minimal Comfort Feeding (cont'd)

- Would MCF be appropriate for Gladys?

  Comfort feeding only (CFO): *no more than is comfortable* is provided.

  MCF: *only what is necessary to avoid discomfort* is provided. Meals not scheduled, but occur only as patient wants them.

- CFO: can survive for many months, even years.
  MCF: typically only weeks or a few months.

- MCF "goal-concordant" for patients with ADs for SED and those whose agents affirm similar goal.

Minimal Comfort Feeding (cont'd)

- An appropriate option when clinicians or facilities refuse to follow an AD for SED. (Provided for in the new AD.)
- How much less respectful of the patient is MCF than the full withholding requested in the AD?
- How important are caregivers' beliefs that not feeding violates their duty to feed?
- Big moral advantage of MCF: it simply avoids then-self/now-self problem.

Ethically Permitted, or Required?

- "Permitted": would be doing nothing wrong.
  - Implied by previous arguments: same person, no change of mind, ownership of one's life, moderate resolution of then-self/ now-self problem (allowing "not yet" cases).
- "Required": it would be wrong not to implement.
  - In clearest cases, yes.
  - Legitimate options for "not yet" or MCF soften the requirement.
- Conscientious objection exception.
  -

Elements for This Argument in Chinese Law

- Article 32, 2019 Law of PRC on Basic Medical and Health Care and the Promotion of Health:

  Citizens…have the right of informed consent…. Before performing any surgery…or treatment, medical and healthcare professionals shall explain the…risks, alternative therapy…and other conditions…in a timely manner *and obtain their consent*; if…not possible or appropriate…, explain them to close relatives and obtain informed consent thereof….

- Article 25 of the 2021 Medical Practitioners Law adds "…and obtain their *explicit* consent….
- Additional sources include 2009 Tort Law.

Balance of Patient/Family Roles

Actual Medical Practice, China

- Close relatives readily become agents of consent when patients lose capacity. Little use of appointed surrogates.
- 2024 study* of young Chinese doctor decisions for *unconscious* patients, where families often have prerogative of refusing recommended LSTs:
  - 5% of doctors would override family refusal, though 20% of patients, when they had capacity, indicated they would want family refusal to be overridden.

*Pingyue Jin and Xinqing Zhang. “Family Refusal of Emergency Medical Treatment in China: An Investigation from Legal, Empirical, and Ethical Perspectives.” *Bioethics* 34 (2020): 306-317, at 310 and 312. https://doi.org/10.1111/bioe.12728.

Balance of Family/Patient Roles (cont'd)

Actual Medical Practice, China (cont'd)

- Another study* of family roles where patients had capacity found that young Chinese doctors
  - Pay extra attention to informing patient's family, even when they see that not to be in patient's best interest.
  - 70% choose to comply with family requests to withhold information from patient. Many doctors felt distress in doing so, believing that it "not only violates professional ethics but also… relevant laws."

*Hanhui Xu and Mengci Yuan. "Family Roles in Informed Consent from the Perspective of Young Chinese Doctors: A Questionnaire Study." *BMC Medical Ethics* 25:1 (2024), https://dx.doi.org.ezproxy.plu.edu/10.1186/s12910-023-00999-6.

VSED and ADs: China and Hong Kong

- Right of informed consent and refusal implies a right to VSED….
- Advance directives:
  - Family and physicians typically have large role in decisions for patients without capacity. But:
  - Common law foundation for ADs in Hong Kong.
  - 2019 HK Health Authority guidelines for Advance Care Planning (ACP) encourage patients to engage family and physicians in conversations about their end-of-life preferences.

Advance Directives: Hong Kong (cont'd)

- 2019 HK Health Authority guidelines explicitly permit AD to refuse all "life-sustaining treatments *other than basic and palliative care*."
  - Is manually assisted oral food & drink "basic care"?
  - Palliative care exception is no problem.
- HK Law Reform Commission (2020) provides model forms for ADs for three cases: terminal illness, irreversible coma/PVS, *and "other end-stage irreversible life-limiting conditions."*
- Thus, a legal basis in HK for ADs for SED in severe dementia.

Concluding Observations

- Comprehensive ADs for withholding oral food and drink in advanced dementia stand on solid ethical and legal ground.
- Objections based on "different person," change of mind, and the then-self/now-self problem are not persuasive, especially if MCF is noted in the directive as an option.
- In very clear cases, agents and clinicians are morally *obligated* to implement such ADs.
- Such ADs have a basis in Chinese & HK law.

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