INTERESTS, CONSENT, AND THE PROVISION OF FOOD IN DEMENTIA

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Control of Longevity in Dementia

- Some strongly want life not to continue long into dementia
- Limited options:
  - Advance directives to refuse life-sustaining treatment – common, but provide no assurance
  - Pre-emptive suicide or VSED – provides assurance, but involves sacrificing valuable time in life
  - ADs to withhold food & water by mouth – the focus of this paper

Assumptions of this paper

- Death by stopping eating & drinking can be a comfortable death
- VSED is legally permitted
- ADs to withhold medically delivered nutrition and hydration are accepted
- Institutional and legal barriers to implementing a clear directive to withhold food & water by mouth are real but surmountable

Fundamental Challenge to ADs: the Then-self/Now-self Problem

- Person who wrote AD has changed
  - Doesn't remember writing the AD
  - Doesn't care about autonomy
  - Doesn't find her diminished life unbearable
  - Little concern re burden to loved ones
- So what gives the then-self authority over the now-self?

The Dresser-Robertson Position

- Interests of the patient have changed
- Respect for autonomy cannot override best interest
  - No current autonomy left
  - "Precedent" autonomy is a misnomer – it's the person's previous autonomy, no longer relevant
- Only treating the patient to satisfy her current best interest can respect the patient and be good care

Dworkin's Response: Two Kinds of Interests

- Experiential interests derive from "first-order" desires and beliefs
- Critical interests derive from second-order desires, beliefs, and values – desires and beliefs about, and evaluations of, the first-order ones
  - Often highly reflective and considered – convictions, e.g., about "what helps to make my life good on the whole"

Critical Interests

- Not dependent on current experience
  - Can exist even when what satisfies them is no longer being experienced at all (e.g., posthumously – will or reputation)
  - Can exist even when what satisfies them is no longer being experienced as such (e.g., in dementia – not conscious of how long one wishes to live)
- Compete with experiential interests in determining what constitutes a demented patient's best interest

Critical Interests Trump (Dworkin)

- Reinforced at second-order level and thus most important – what ultimately matter to people
- Not following critical interests would be paternalistic – failing to judge a person's well-being as she did when competent
- Following the AD satisfies a patient's best interest – if we don't follow it, we cannot claim to be acting for her sake

Do Critical Interests Trump?

- Why cannot more or strong EI's outweigh fewer or weak CI's?
  - Is happy demented person who still wants to live really better off dead?
- Dworkin's paternalism argument:
  - we'd be saying we know better than patient what's in her best interest
  - NOT CORRECT: we'd only be saying we know better now than the patient knew then what her current best interest is

Better than Dworkin: a Sliding Scale

- How important are the critical interests represented in the AD?

  How much experiential interest in survival does the patient now have?

- Sliding Scale: authority of an AD about life-sustaining measures gains as critical interest in not surviving is strong and capacity to enjoy life and appreciate survival is weak

Experiential Interest in Life

- In dementia, dependent on stage
- Suppose:
  - Little if any suffering
  - Passive kind of minimal happiness
  - Little anticipation or memory – weak psychological continuity within person's own subjective life
- She wants, in a sense, to go on living
- Subjective value of survival low – she cannot expect or see it as her survival

Strong Critical Interest in Not Living

- AD is knowledgeable and clear about dementia (stages, variety) and the point at which life is not to continue
- AD conveys some of the beliefs about person's life that lead to wish not to live long in dementia
- Acknowledges difficulties of interpretation – entrusts to proxy
- Reiterated relatively recently

Why Critical Interests and Previous Wishes Must Count

- Best-interest of the now-self must include more than experiential interest. Otherwise we will have treated the person as if she had never been competent.
- But we must never treat a previously competent person that way – it would ignore most of the elements of her life that have made her the person she is.

Nancy Rhoden, "The Limits of Objectivity," *North Carolina Law Review* 68 (1990): 845-865, at 860.

Extending Life in Dementia

- End-Stage Dementia
  - Not unhappy, but passive/unresponsive
  - No recognition of anyone as an individual

  If critical interests have <u>any weight at all</u>, here they outweigh EI in survival
- Severe Stage Dementia
  - Some eye contact, notices some sounds
  - Intermittent small pleasures
  - Little anticipation or memory

  A clear AD outweighs EI here, too

Extending Life in Dementia (cont'd)

- How much earlier, into less severe dementia, does previous argument and the Rhoden objection apply?
  - At some point, person is engaged enough that experiential interest in survival is clear and significant
  - Even if the AD is clear and critical interest in not surviving strong, we may say "not yet" and still respect the AD

Changing One's Mind

- A basic assumption about ADs: people may change their minds
- Someone in dementia may come to value new activities and find diminished life worth living – why should we hold her to earlier AD?
- Extreme position: ADs never valid, since we cannot now check to find out whether person has changed her mind

Accounting for Change of Mind in Dementia

- No burden of proof that a person has not changed her mind should be so strong that it blocks all ADs
- Reiteration is still important
- In dementia, at some point no longer possible to change one's mind – not enough mind to change
- Revert to interest considerations: following AD does what person wants, even if she no longer remembers wanting it (critical int's)

Summary (so far)

- ADs for dementia should be allowed, enabling people to control the ending of their lives
- Three questions:
  - How strong is the current experiential interest in survival?
  - How strong is the critical interest in not continuing to live?
  - Has the person changed her mind?

Three Cases re Food & Water

1. In severe dementia (per AD), person **desires food** – shows pleasure when fed, grimaces when not
2. In severe dementia (per AD), person is **indifferent to food** – in trial withholding, no distress
3. In moderate dementia (*earlier* than point stated in AD), person **resists food** – not readily persuadable but can be brought to swallow

The Desire Case

- Experiential interest in survival low, but not vanishingly low (desire to eat)
- Experiential interest in not going without food
- Strong critical interest in not now surviving, though it might be stronger if the AD spoke to current situation
- Desire to be fed is not a change of mind about the AD, but it is a conflicting element in patient's volition

The Indifference Case

- Some experiential interest in not continuing to live, but minimal
- Strong critical interest in not continuing to live – especially clear if indifference possibility was addressed in the AD
- Minimal experiential interest in living does not diminish critical interest in not living
- No evidence of change of mind

The (Premature) Resistance Case

- Current experiential interest in living is significant – no suffering, not unhappy, some capacity to anticipate and remember
- Critical interest in not living is ambiguous
  - Reasons for AD's trigger being severe dementia
  - That withholding food & water by mouth is in AD at all shows strong critical interest in not living far into dementia
  - Has a critical interest in surviving in the meantime, but is it all that great for this interval?
- Premature resistance not a change of mind re AD, but it's not surprising or inconsistent

Conclusion

- ADs must be accorded considerable authority – not acceptable to treat the previously competent as never competent
- Strength of experiential and critical interests varies by current state, the AD, and other previous wishes
- Relevant changes of mind are possible in early/moderate dementia
- Desire to eat in severe dementia is likely not a change of mind, but may indicate positive experiential interest in survival

optional supplements

Stopping Eating and Drinking as Comfortable Death

- Proper pacing: food is stopped first (for 1-3 weeks), then fluids.
- Hunger pain subsides after 2-4 days, as stomach shrinks.
- After fluids are stopped, sponge on lips provides comfort.
- In last 12-48 hours, patients often lapse into minimal consciousness; some experience "euphoria" near end.

J.K. Schwarz, "Death by Voluntary Dehydration: Suicide or the Right to Refuse Life-Prolonging Measure?" *Widener LR* 17: 2 (2011): 351-61

Legal Basis of Right to VSED

- A common law right based in battery.

  Rehnquist: "…odd that bodily integrity is violated by sticking a needle in your arm but not a spoon in your mouth."

- Consistent with right to refuse medical life-support, including ANH.

- Not a right to suicide, but a right *not to be forced to do something*.

T.M. Pope & L.E. Anderson, "Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at End of Life," *Widener Law Review* 17 (2011): 2: 363-427

U.S. Medicare and Medicaid

- Withholding food & water can be neglect or abuse that removes Medicare and Medicaid eligibility
- But for "failure to provide adequate nutrition & hydration to support and maintain health" to be an abuse is explicitly conditioned on the absence of an advance directive to withhold food and water

CMS State Operations Manual, App. Q, "Guidelines for Determining Immediate Jeopardy," rev. 1, 5/21/04

Is the Degree of Assistance Needed Relevant to Whether Withholding Is Justified ?

NO:

- All eating requires someone else's assistance. Pureeing for a smoothie is no more assistance than cooking.
- The assistance required by dementia is parallel to that in physical disability.

YES:

- The greater the assistance needed, the more similar F&W by mouth is to ANH

publications that underlie much of this presentation

- Menzel and Steinbock, "Advance Directives, Dementia, and Physician-Assisted Death," *Journal of Law, Medicine, and Ethics* 41: 2 (summer 2013): 484-500
- Menzel and Chandler-Cramer, "Advance Directives, Dementia, and Withholding Food and Water by Mouth," *Hastings Center Report* 44: 3 (May-June 2014): 23-37