Changing One’s Mind: An Issue for Advance Directives

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The Easy Part, the Hard Part

- Basic assumption: by voluntary and competent decision, an advance directive (AD) can always be changed.
- But after a person loses competence, what (if any) changes of mind can alter an AD’s authority?
  - Person is not competent to write new directive
  - Precisely what motivates people to write ADs and brings them into operation – becoming incompetent – may also bring changes in values, attitudes, and desires that throw a directive’s authority into question.
Change of Mind Isn’t Everything

- Concern about change of mind is limited: in implementing a directive, we tolerate the possibility that the person may have had a change of mind.

- Even if person has not changed her mind, we perhaps should still not implement the directive. ADs also confront another problem – the then-self vs. now-self.
The Then-self/Now-self Challenge to ADs

- Person who wrote AD has changed
  - Doesn’t remember writing it
  - Doesn’t care about autonomy
  - Doesn’t find diminished life unbearable
  - Little concern re burden to loved ones

- So what gives the then-self authority over the now-self?
Incompetence and Change of Mind: Three Cases


- **Margo**: 55, moderate/severe Alzheimer’s, does not recognize ind’s but enjoys life. AD says no life-extending care when no longer recognizes.... Contracts pneumonia – treat?

- **Mrs. Bentley**: 84, former nurse, strong AD for no food/water in severe dementia, which she now has. Accepts food. Stop feeding?
What Change of Mind Alters the Validity of an AD?

- Once a person has lost enough competence to be no longer capable of explicitly changing her directive, what kind of change of mind, if any, is still “relevant” – that is, would throw her directive’s moral authority into doubt?

- Would a change in the values, judgments, or desires that were the reasons for the person’s directive constitute a relevant change of mind?
Richard

- Has an “all life-extending care” AD that includes antibiotics. Now has pneumonia.

- Primary reason for AD: thought he would never be “tired of life” or “ready to go” – life too precious, no matter how diminished physically and mentally he might become or how long life would go on.

- Now the judgment that was his primary reason for AD has changed – has expressed “ready to go” numerous times.

- Has he changed his mind about his directive even if he can’t write a new one?
Revised Richard

- Has different reason for same AD – belief that God means for life always to be lived as long as it can be, barring significant pain and suffering (a merciful God).

- Current “ready to die” attitude is not a change in that belief. He’s no longer capable of such change. Validity of AD still stands. Per directive, treat his pneumonia.

- This “no relevant change of mind” conclusion does not settle question whether to extend his life: experiential interest in dying could outweigh critical interest in AD.
Margo


- If reason for her AD was that she thought she would not have such appreciation, then she has had a relevant change of mind, and validity of her directive is thrown into doubt. Her pneumonia should be treated.

- While her change of mind may determine this decision now, in future a relevant change of mind will no longer be possible.
Revised Margo: Same AD, Different Reasons

- Level of “engagement” in years like hers now is not what she lived for and supported others to aspire to all her life.
- Prefers her resources go to other things she cared about much more strongly than continuing in such condition, even if happy.
- Wants loved ones not to have to care for her for years, with likely result that she will not be remembered as well for who she was.
- Her current positive accommodation is not a relevant change of mind, especially if in her directive she said “no … even if I’m happy.”
“Not Enough Mind to Change”

Berghmans: the irony of dementia is that “... at the time you would most likely ‘change your mind’ [about your directive because you have adapted to your situation and are no longer distressed by it], you do not have enough mind left to change.”*

Mrs. Bentley

What does opening mouth constitute?

- Her consent to eat, or only a reflex?
- A change of mind about her directive?
  - No: her reason was not that she thought eating would be uncomfortable, or she would not accept food, or she would not want to eat.
- An expression of desire to live?
  - For her, what is “desire to live”? What is value of survival to her if can’t anticipate surviving or remember having survived?

Other issues in the case: do ADs govern personal care as well as health care? etc.
Summary of the Cases

- Richard
  - His change of mind removes basis of reasons he had for AD. We are permitted not to follow it, and thus to not treat his pneumonia.

- Revised Richard
  - Reasons are too complex for him any longer to change his mind. Directive remains reason to treat pneumonia despite his “ready to go” expressions.

- Margo
  - New appreciation of her diminished life alters basis for her AD. Treat her pneumonia.
Summary of Cases (cont’d)

- Revised Margo
  - Beyond capacity to change her mind. Per directive, we shouldn’t treat her pneumonia.
  - But her positive appreciation of life points toward preserving it – experiential interests of now-self outweigh critical interests in AD being followed.

- Mrs. Bentley
  - Can no longer have change of mind re AD.
  - Combination of low experiential interest in survival + strong AD points toward following her directive and not feeding.
General Conclusions

1. When the judgments and desires involved in the reasons people had for making their directives have changed, then even if they have lost the capacity to rewrite them, change of mind can be sufficient to call a directive’s validity into question.

2. If the reasons for a directive are relatively complex and involve convictions about the shape of whole lives (e.g.), people with significantly diminished cognitive capacity will have passed the point where they can any longer relevantly change their mind.
Conclusions (cont’d)

3. Either situation – when altered judgments constitute a relevant change of mind, or when the nature of the reasons for the directive imply that the person is past the point of being able to have a relevant change of mind – points to the importance of people articulating the reasons for their directives.

• Do that either within the directives themselves or through discussion with future representatives.
Change of Mind: Limited Importance

- Often in incompetence, given the nature of the reasons people had for their ADs, they will no longer be capable of a relevant change of mind (e.g., Revised Richard, Revised Margo).

- Even if there is no change of mind that alters a “don’t treat” AD, question whether to treat may still be open due to then-self/now-self problem (e.g., Margo).

- Whether there’s change of mind is often ambiguous. Decision will have to move to assessment of patient’s best interest.
optional supplementary slides

(if needed, given previous presentations or Q & A)
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.

Dresser-Robertson Position on ADs

- 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
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.

publications that underlie much of this presentation
