– introductory lectures in bioethics –

Advance Directives: Compelling and Problematic

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What Are Advance Directives (ADs)?

- Allow people to make known their wishes for medical treatment when they are no longer competent to participate in medical decision making
- Called "advance directives" because they are made in advance of the situation in which they will be used (situations of incompetence)
- Not "advance**d** directives"

Two Kinds of ADs

- Living will ("advance directive for health care")
  - Written document that sets out what kind of medical interventions a person wants and doesn't want
- Health care proxy ("appointment of durable power of attorney for health care")
  - Individual(s) designated by people to make health care decisions for them

Rationale for ADs

- Promote self-determination and respect for autonomy
- Competent adults have right to refuse medical treatment (RRMT)
  - Treatment without consent is “battery”
- People don’t lose their rights when they become incompetent – their RRMT, e.g., just has to be exercised by others
  - ADs provide a way to instruct others how to exercise those rights
  - ADs help proxies discern “substituted judgment” and “best interest”

Connections in Moral Philosophy

- Utilitarianism
  - J.S. Mill: a person herself is ultimately the best judge of her own good. E.g., whether living another month is worth the suffering involved.
- Kantian fairness and respect for persons
  - One can will the maxim, "to avoid suffering…, I refuse life-extending treatment and accept a natural death," to be universal law.
  - Following ADs respects people as decision-making agents – treats persons as ends-in-themselves.
- Natural Law ethics
  - Refusing extraordinary care is not intentionally destroying life but allowing death to come.

Precedent Case: ...*Quinlan* (U.S., 1976)

- Parents wanted daughter, in PVS, removed from ventilator and allowed to die natural death
- Hospital refused, saying that would be homicide
- NJ Supreme Court ruled for parents
- After ventilator removed, she began breathing on her own and survived another 9 years in PVS
- NJ Supreme Court: removing ventilator is not homicide – is not killing the patient, but allowing death from underlying causes to occur
  - Seems suspect: removal would be homicide if a non-physician disconnected the ventilator
  - More plausible: disconnecting does kill patient but is permissible when done by treating physician in ....

Withholding v. Withdrawing

- Some maintain withholding is permissible but withdrawing once treatment is started is wrong. Withdrawing is action that kills, not merely omission that lets nature ….
- Now largely rejected (and was in *Quinlan)*
  - If we cannot later withdraw treatment, we will have an undue incentive not to start it.
  - Withdrawing is just as much letting nature take its course as withholding is.
  - Neither is active intentional killing.
- ADs may request withdrawal & withholding.

ADs Are a Failure (Fagerlin & Schneider)*

- They are not often used
  - In 2004, only 18% of U.S. adults had them. This increased only to 32% by 2014 (though to 42% if HC proxy included, and 72% for elderly)
- An effective living will will have to speak, in advance, to many possible treatments for many medical situations – impossible
- Preferences change – update how often? – and are hard to state clearly & consistently
- Better alternative: HC proxy and good conversation (at least as supplement)

* "Enough: The Failure...," *Hastings Center Report 34: 2 (2004)*

Basic Philosophical Challenge to ADs: Then-self vs. Now-self

- Person who wrote AD has changed
  - Doesn't remember writing it
  - Doesn't care about autonomy, or often other values that motivated substance of the AD
  - May not find diminished life unbearable
  - Little concern re burden to loved ones
- So what gives the then-self authority over the now-self ??
  - Autonomy cannot be invoked – it represents only the then-self

CASE STUDIES*

- Jehovah's Witness with AD refusing blood transfusion. Now senile, "happy." Give transfusion?
- Redemptive Suffering. AD for aggressive lifesaving; suffering seen as redemptive. Now terrible pain. Sedate patient? Cease life-prolonging care? Both?
- Heart Tx and Financial Legacy. AD requests no Tx; expense would decimate inheritance for children. Now prematurely senile but not suffering. Tx will add 3-5 years, cost $100k (all of estate). Perform?
- Sociology Professor. AD requests no lifesaving treatment once she can no longer read a soc. text. Now stroke, permanently incapable of reading, not in pain, enjoys music. Withhold feeding tube?

* N. Cantor, "Testing the Limits…," in his *Advance Directives…* (1993).

Dresser-Robertson Position on ADs

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

Why Previous Wishes Must Count*

- Best-interest of the now-self must include more than currently experienced interests. 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.
- Such treatment is incompatible with respect for persons.

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

Dworkin's Response to Dresser & Robertson: Two Kinds of Interests

- Experiential interests derive from "first-order" desires and beliefs. E.g., I enjoy life now, so I have an interest in living.
- Critical interests derive from second-order desires, beliefs, and values – 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"
  - Represented by self-constituting narrative identity

* Ronald Dworkin, *Life's Dominion* (1993), pp. 220-232.

Critical Interests

- Not dependent on current experience
  - What satisfies some critical interests can never be experienced. E.g., posthumous interests – the carrying out of one's will, or preservation of one's reputation.
  - What satisfies them can be experienced but does not have to be. E.g., an interest in having done well to one's children.
- Critical interests are still *current* interests of the now-self. They combine with experiential interests in determining what is an incompetent patient's best interest.

Critical Interests Trump (Dworkin)

- Reinforced at second-order level and are 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 does when she's 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 a 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

* Menzel & Steinbock, "ADs, Dementia, and Physician-Assisted Death, *Jr Law Med & Ethics* 41: 2 (summer 2013): 484-500

Experiential Interest in Life in Dementia, e.g.

- 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

A Different Challenge: Change of Mind

- Basic assumption: by voluntary competent decision, an 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 after Incompetence

- When the judgments and desires involved in the reasons people had for making their directives have changed, then even if they have lost capacity to rewrite a directive, change of mind can be sufficient to call its validity into question. E.g., sociology prof.
- On other hand, if reasons for directive are complex – e.g., they involve convictions about the shape of a whole life – persons with significantly diminished cognitive capacity will have passed the point where relevant change of mind is possible.

To Be Effective, a Directive Will …

- State measures that are/are not to be used in specified sorts of conditions. Yes/no on a treatment means little without a sense of the situation to which that request applies.
- State and explain the most important reasons for the directive's substance. Otherwise a proxy gains little guidance from the AD in all those circumstances that are not specifically mentioned in the directive.
- Be accompanied by appointment of a proxy for health care and by discussion with the proxy and others of influence.

Legal Strategy for ADs

- Common law & case law precedent often protect basic idea behind ADs, that incompetence does not lose people their rights.
- Legislative authorization may describe scope of directives that gain explicit state sanction, but this may lead people to see legally authorized ADs as confined to that scope.
  - E.g., if applicable conditions are “terminal illness,” “irreversible coma,” “persistent vegetative state”
  - Common law may not limit ADs to that scope
  - Will legislation then assist ADs or restrict them?

Current *and* Previous Wishes Count

- Then-self/now-self issue must be addressed.
- If only now-self is considered, or if now-self's interests are confined to current experience, we will be treating previously competent person no differently than never-competent persons. That is morally unacceptable.*
  - Would ignore most of the elements that have made someone the person she is
  - Incompatible therefore with respect for persons
  - Cannot pass test of "public reason"

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

Paul Menzel acknowledges his gratitude to Bonnie Steinbock for use of some slides from her previous talks.

Supplementary slides if discussion should make it advisable to review any segments of the earlier lecture on “foundations of bioethics”

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1. Utilitarianism

- Reasonably expected consequences
- Subjective value of the consequences (utility, satisfaction, pain/pleasure)
- The consequences for every person affected – each person counts equally
- Max. aggregate value, NOT "greatest happiness for the greatest number"
- Must look at all options
- Empirical and realistic

2. Kantian Ethics (Immanuel Kant): Fairness and Respect for Persons

- Not *instrumental* goodness of an act
- First imperative: "Act always so you can will the maxim of your action to become a universal law (of nature)"
  - Maxim: a subjective principle of volition
  - E.g., borrow $ with no intention to repay
  - If everyone were to follow the same maxim, would it contradict itself? Could I consent to the resulting situation?

Kant: Respect for Persons

- Second imperative: "Never treat people merely as means, but always as ends-in-themselves"
- As rational decision-making agents, we are ends-in-ourselves
- Case: lying to a patient about her diagnosis in order to reduce her anguish/suffering
- OK to treat people as means to our ends, just not merely as such means

3. Natural Law Ethics

- Theistic and non-theistic versions
- Four natural human goods (objective)
  - Life
  - Procreation and child rearing
  - Knowledge and reason
  - Sociability

  [where is reduction of pain/suffering here?]
- Never intentionally destroy nat. goods
- As long as …, promote and maximize the realization of natural goods

4. "Principlism"

- Four principles *for bioethics*
  - Beneficence – promote patient's good
  - Non-maleficence – "first, do no harm"
  - Autonomy – respect persons in their capacity to make their own judgments
  - Justice – fair, equitable distribution of power and benefit
- Priorities: non-maleficence weightier than beneficence; otherwise, case-by-case comparative consideration