THE NOTION OF ADVANCE DIRECTIVES: HEADWAY OR HAZARD?

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Advance Directives: What Do We Mean?

- Advance – beforehand
- Directives – providing instructions or direction

- ***Hypothesis 1: ADs can be less effective when anchored in individual autonomy motives but more effective when based on community-based reasoning.***

- ***Hypothesis 2: Advance Planning is often more complex than static documents can address, particularly in face of an indeterminate future.***

Background

- The AD movement in USA from before the PSDA (Quinlan, Cruzan, etc), 1991
  - Patient need to write instructions to push against perceived default of “do everything” to preserve life.
- USA written directive types:
  - Living will
  - CPR Directive
  - Agent with MDPOA
  - [POLST-paradigm]

The Spectrum in USA:

Acts and Omissions that Lead to Death

Considered Legal, Ethical, Acceptable

Legal, Ethical, Mostly Acceptable

Illegal or, Not Acceptable or Ethical

Headway/Progress/Expansion of ADs

- Medical advance directives:
  - End-of-life wishes
- Psychiatric advance directives:
  - “Ulysses” contracts
- Dementia, frailty, etc.
  - Protecting against unwanted continuation of biological life when people unable to refuse interventions that are unwanted (currently challenged)
  - Driving in setting of frailty/loss of insight
- Childbirth
  - Respect for mother’s birth plan preferences (consumer-driven)
- Sexual advance directives

Core Assumptions

- There is a need to push back on the perceived "do everything" mentality of the HC system
- There is a power imbalance between "consumers" and providers
- Procedural/treatment decisions can be predicted
- Values/preferences stay stable over time
- "Character" stays constant and not contextual (i.e. there is an "authentic" self)
- Control is desirable and possible

A Case:

- 65 year old woman with end stage COPD
- Presents to the ED with severe respiratory distress
  - pCO2 70, somnolent and lacks decisional capacity
- Written ADs from last admission reviewed: No tubes!
- BUT daughter protests: her granddaughter is getting married in 2 weeks, and she has been eagerly anticipating this for months.
- What to do?

End of Life Advance Directives

PROS

- Protects families from difficult choices
- Counters “do everything” default of healthcare system
- Expresses limits or commitment to EOL interventions

CONS

- Static
- Rarely reflect “intent”
- Context changes
- Pathways are countless
- Previous wishes vs. “best interests”
- We adapt in ways we can’t predict
- Even our “self” may evolve

A Psychiatry Case

- Patient with history of bipolar disorder with periods of dysthymia and frank severe depression punctuated by mania with psychosis.
- Requires hospitalization when manic, and historically refuses all intervention when in this state
- Risks to him?
- Risks to his community?
- What about a “Ulysses” contract?

Psychiatric ADs: “Ulysses Contracts”

PROS

- Recurrent situation with predictable repeats
- Early treatment could prevent family losses, crimes
- Anosognosia – impaired recognition of illness

CONS

- Creative self has benefits
- “Authentic” self changes
- Restriction of freedom, patient voice
- Treatment input from patient absent

Anosognosia:

- "..a deficit of self-awareness, a condition in which a person with some disability seems unaware of its existence."
- Neurological disorder, R hemispheric
- Associations:
  - Some TBIs, strokes
  - Dementia
  - Schizophrenia (50%?) & Bipolar disorder
  - Anorexia nervosa

Another case:

- A patient with mid/late stage dementia.
- As a lawyer before he lost capacity, he has said that he wouldn't want to be kept alive for a pneumonia if he didn't recognize his kids – which he hasn't for the last 4 months.
- Up until now, he is enjoying his memory care unit – food, companionship, staff, Gilligan's Island reruns.

Advance Directives in Dementia

PROS

- We see this in others, gain reflective experience
- Family concerns – resources, caring needs
- People want to hold onto the concept of themselves – with family, legacy
- Suffering may be evident
- Anosognosia

CONS

- Could be “happy” despite prediction of suffering
  - Changing character
- Already know there is a trajectory of adaptation to compromised physical capacities – why not mental?
- Is cognitive self the authority on the non-cognitive self?

Spectrum of Intent for Advance Directives

Personal Freedom

- To support autonomy
- To support personal beliefs about “life worth living”
- To help substitute decision makers uphold personal values
- To control interventions in anticipation of lack of decisional capacity

Communitarian

- To save family from financial devastation
- To avoid family suffering from burden of the uncertainty of substitute decision making
- To protect the public and family (high-risk driving/manic episodes/loss of impulse control)

Challenges in “Personal Freedom” Reasoning

- Patients adapt to more constrained circumstances over time, priorities evolve
- Questions of Authenticity – does the “authentic self” change?
  - Raised by mental health, disabilities communities, “happy demented”
- Is “control” as important while people are dying or turning inward, or should the “mystery” be embraced?

The challenges of communitarian arguments:

- Situations where communitarian arguments for ADs are supportive to families
  - Legacy of “gifting” a pathway to help family make difficult decisions
  - Affirm value of family and protect family financial interests
  - Recognize the burden of caregiving as well as the gift
- Situations where communitarian arguments float like a lead balloon
  - Resource utilization on a societal scale
  - Reduce financial burden on society

Back to Our Hypothesis

- ADs help with shared decision-making and ***patient "control"*** in an era where people's values and wishes vary significantly.
- ADs are most successful within a ***community-based*** framework that recognizes not just the person, but their desires within their community.
- Lessons in EOL:
  - ADs have encouraged anticipation of EOL, but have not "solved" the problem of guiding medical care at the EOL.
  - Future desires can be hard to predict if future situation is hard to predict

Moving Forward:
EOL planning for your incapacitated self

- Assign an agent/surrogate
- Share ”what matters” to you
- Conversations and discussions with your loved ones (not just agent)
- Think about “looking to the future when you will need to rely on others to make your decisions.”
- Recognize need to be humble about our future selves, our ability to predict
  - Renew and review
  - Allow agent flexibility

Moving Forward:

Helping surrogates make decisions at EOL

- It can't just be written ADs
- We need to recognize that patient wishes *in this particular context* are unknowable.
- Robust conversations would involve synthesis of:
  - How lived life
  - Articulated values and preferences
  - Consistency
  - Current joys
  - What most people want "in this context"
  - What family wants (surveys support this)

Moving Forward:
Other Kinds of ADs

- Psychiatric:
  - Rosenbaum: Consider single trial of non-consented interventions, with patient/provider review
  - Affirmation if/when capacity restored.

- Dementia:
  - Understand intent of patient's expressed wishes – self vs. family?
  - Review potential for contentment: what to do?

- Childbirth
  - Consider a matrix for discussion between provider/patient/loved ones
  - Recognize fluidity and context
  - Permit leeway

THOUGHTS?
CRITIQUE?

Thank you!