Advance Care Directives: Do They Help or Do They Harm?

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Disclosures and Thank You

• No Financial Interests to Disclose
• Not Intending to Give Medical or Legal Advice
Outline of Today’s Talk

• Historical Cases
• Federal & State Responses to Cases
• Advance Directive Use Today
• Proposed Harms of ADs and Replies

• I will defend the robust use of ADs against various challenges.
Why This Talk?
Historical Context

• Quinlan Case
• Cruzan Case
Quinlan Case

- April 1975, 21 y.o. found not breathing by friends.
- Admitted to St. Clare’s Hospital in New Jersey, put on a ventilator.
- In a coma; unconscious but her eyes would open and move disconjugately, her body moved randomly.
Quinlan Case cont’d

• After several months, her parents decided she should be disconnected from the ventilator.

• Doctors said no:
  – AMA said withdrawal of treatment = euthanasia
  – Fear of malpractice; deviation from normal standards of medical practice

• Parents filed suit to remove life support.
Quinlan Case cont’d

• Initial lower court decision held:
  – respirator should not be disconnected,
  – Karen’s parents testimony about her wishes were insufficient,
  – a non-family guardian was needed for Karen.
Quinlan Case cont’d

• New Jersey Supreme Court appeal overturned lower court decision based on the Constitutional implied right to privacy (liberty).

• Three main findings:
  – allowed Karen’s father to be her guardian (*Substituted Judgment*),
  – gave Karen’s doctors immunity for discontinuing her treatment,
  – suggested use of an ethics committee to help in future cases.
Quinlan Case Resolution

• Karen was weaned from the ventilator so she was ultimately able to breathe on her own.
• Decubitus ulcers had developed exposing her hip bones in places.
• Karen languished in a nursing home for 10 years until she developed pneumonia and her parents declined the use of antibiotics.
• She died on June 13, 1986.
Cruzan Case

- Jan 1983, 24 y.o. thrown from her car, landed face down in a watery ditch. Anoxic brain injury. In a coma.
- Able to breathe on her own, but required feeding tube.
- After four years in a PVS parents decided to discontinue feeding tube.
Cruzan Case cont’d

• Missouri Supreme Court held:
  – the State has an interest in preserving life,
  – Nancy’s parents had not met the standard of “clear and convincing” evidence in making their argument to discontinue feedings.
Cruzan Case cont’d

• In 1990, U.S. Supreme Court reviewed the Missouri Supreme Court decision. Three main holdings:
  – Competent individuals have a Constitutional liberty right to decline treatment.
  – Withdrawal of feeding tube did not differ in kind from withdrawals of other life sustaining treatment.
  – States could pass a statute requiring “clear and convincing” evidence for determining what formerly competent patients would want done. (*Substituted Judgment*)
Cruzan Case Resolution

• Nancy’s case was reheard in a lower court.
• More friends of Nancy came forward to testify that she would not want the feeding tube.
• Her feeding tube was legally removed on Dec 14, 1990, she died 8 days later.
NANCY BETH CRUZAN
MOST LOVED
DAUGHTER — SISTER — AUNT

BORN JULY 20, 1957
DEPARTED JAN. 11, 1983
AT PEACE DEC. 26, 1990
Patient Self Determination Act (1991)

• The right to facilitate health care decisions
• The right to accept or refuse medical treatment
• The right to make an advance health care directive (*Expressed Wishes and Substituted Judgment*)

• Intended to fulfill the clear and convincing requirement suggested by the Cruzan case finding.
Case Type for PSDA

- Young, previously healthy individual struck by unexpected tragic event which requires individual to be maintained – in a compromised health state – with life support in order to remain alive.
Advance Directive Defined

Broadly construed: *Any measure authored or initiated by an individual that is intended to direct the health care of that individual when he or she is unable to do so.*

Instruction Directive ("living will")
Proxy Directive ("DPOAHC")

Not necessarily focused on limitations or refusals.
Intended Ethical Benefit of ADs

• Respect individual autonomy (*Expressed Wishes and Substituted Judgment*)
  – Decisions made through an AD are intended to have the same ethical standing as contemporaneous decisions.

• Clarify obligations of providers
  – Intended to help providers navigate between a wide range of medical goals.
Goals of Medicine

• Preserve Life
• Restore Function
• Reduce Suffering
• Manage Pain and Symptoms
• Prevent Disease
• Promote Health
• Maintain Health State
• Allow Natural Death
Possible Harms of Not Having an AD

- Unwanted treatment
- Unnecessary treatment
- Conflict over medical futility
- Negative impact on others needing treatment
Uniform Health Care Decisions Act (1993)

• Proposed rules for combining instruction directives with proxy directives into a single document.
“The patient has the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives...”

42 CFR §482.13(b)(3)
Oregon’s Advance Directive (1993)

- Legally codifies an individual’s right to designate a health care representative and give health care instructions.

- Particular content is specified, format may vary.
Oregon Revised Statute 127

- Chapter 127 — Powers of Attorney; Advance Directives for Health Care; Physician Orders for Life-Sustaining Treatment Registry; Declarations for Mental Health Treatment; Death with Dignity

www.leg.state.or.us/ors/127.html
Oregon’s Advance Directive

Two Main Parts:

• **Part B** = Appointment of Health Care Representative (*Substituted Judgment*)

• **Part C** = Health Care Instructions (*Expressed Wishes*)
Part B

• Appoint a primary representative
• Appoint an alternate representative
• Place limits on rep decision-making (if applicable)

• Specifically consider whether to give representative(s) decision-making ability regarding *life support* and *tube feeding*.

• Considered a durable power of attorney for health care.
Part C

• Give health care instructions for *life support* and *tube feeding* in four conditions:
  – Close to Death,
  – Permanently Unconscious,
  – Advanced Progressive Illness,
  – Extraordinary Suffering.

• Three basic choices: Yes, No, Let Physician Decide.

• Room for additional instructions (if desired).

• Considered a living will.
Life Support in Oregon

“...any medical procedure, pharmaceutical, medical device or medical intervention that maintains life by sustaining, restoring, or supplanting a vital function.” (ORS 127.505)
Limitations on Rep’s Decision-making

- Convulsive treatment
- Psychosurgery
- Sterilization
- Abortion
- Withholding / withdrawing life support or tube feeding only if given this decisional ability or the principal is in one of the four conditions from Part C
Oregon’s ANH Presumption

• If *no advance directive*, there is presumed consent for artificially administered nutrition and hydration (ANH) in the event someone is unable to take food orally and cannot/has not made medical decisions regarding ANH.

• Four conditions are exempt:
  – Terminal Condition (Close to Death)
  – Permanently Unconscious
  – Advanced Progressive Illness
  – State of Extraordinary Suffering
Special Considerations in Oregon’s AD

- Designating a health care representative allows an individual to forgo ANH in circumstances beyond the four exempted conditions.

- Writing specific instructions allows an individual to limit (or possibly increase) treatment beyond the four default conditions on the AD.

• Physician Orders for Life Sustaining Treatment
• Focuses on documenting individual wishes for specific medical interventions
• Intended to transfer from one care setting to another
Oregon POLST Form

• Allows a physician (or PA or NP) to write medical orders which follow a patient:
  – Cardiopulmonary Resuscitation
  – Other Medical Interventions (mechanical vent, other airway interventions, IV fluids, antibiotics, etc.)
  – Artificially Administered Nutrition

• Appropriate for patients who are not expected to live longer than a year.
Other Types of Directives?

- A validly executed advance directive from another state “may be given effect in accordance with its provisions, subject to the laws of this state.” (ORS 127.515)
Advance Directive Use Today
Prevalence of Advance Directives

- 88% of hospice patients have an AD
- 65% of nursing home residents have an AD
- 37% of the general public have an AD
  - (other studies range from 18-36%)

Factors Associated with AD Completion

- Older Age
- Greater Disease Burden
- White
- Higher Socioeconomic Status
- Long-standing Relationship with PCP
- Whether PCP has a Directive
- Patients with Cancer

Effectiveness of ADs

• Study involving 3746 individuals over 60 years of age who died between 2000-2006 showed that patients who had completed an AD received care that was strongly associated with their wishes.
  – Reduced hospitalizations
  – Less likely to receive all care possible
  – More likely to receive limited care
  – More likely to receive comfort care

• Median time for directive completion was 19-20 months prior to death.

Effectiveness of POLST

• Study involving 1711 individuals over 65 living in nursing homes in Oregon, Washington, and Virginia showed:
  – Those with a POLST were more likely to have comprehensive life support orders in their chart,
  – Those with a POLST were 50% less likely to receive unwanted life support than those without a POLST.

Hickman et al., A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities, JAGS 58:7 (2010).
POLST Admission Project at SHRB
Patient Protection and Affordable Care Act (2010)

• Originally included ability for physicians to receive Medicare reimbursement for advance care planning discussions with patients every five years.

• Rescinded after fear of “death panels” took root.
Benefits and Harms of ADs
Intended Ethical Benefits of ADs

• Respect individual autonomy (*Expressed Wishes and Substituted Judgment*)
  – Decisions made through an AD are intended to have the same ethical standing as contemporaneous decisions.

• Clarify obligations of providers
  – Intended to help providers navigate between a wide range of medical goals.
Challenges to ADs

1. ADs don’t respect autonomy in practice.
2. ADs can’t respect autonomy in principle.
3. ADs rarely apply.
4. Ignoring ADs produces more benefit.
Challenge #1: ADs Don’t Respect Autonomy in Practice

ADs often fail a basic requirement of informed consent = having sufficient knowledge.

– individuals who fill out ADs lack sufficient knowledge about future disease state in order to make an informed choice. (Opacity Problem)

Hence, ADs often harm individuals because individuals are lulled into a false sense of self control which may or may not exist.
Response to #1

• Seems to misunderstand the nature of deliberation.
  – The difference in knowledge between informed consent for treatment and filling out an AD is a matter of degree as opposed to type.
  – Opacity is a problem of degree for all types of decision-making.
Challenge #2: ADs Can’t Respect Autonomy in Principle

ADs in principle fail a basic requirement of informed consent = voluntary deliberation.

– Individuals who fill out ADs lack the future ability to deliberate over options.

– Tantamount to “indentured servitude” since the future patient is involuntarily bound to a contract.

Hence, ADs harm individuals because individuals are lulled into a false belief that self control can be achieved by an AD.
Responses to #2

• Comparing Proxies to “Masters” seems dis-analogous.
  – Proxies use substituted judgment to deliberate.
  – “Masters” use their own judgment.
  – Third parties are obligated to help preserve this distinction (without being coercive).

• Would implicate many other future looking decisions which depend on others...
Challenge #3: ADs Rarely Apply

Version A: Often irrelevant to the treatment plan since patients are rarely in one of the four conditions.

Version B: New treatments exist since time when AD was completed.

Hence, ADs fail to give provider clear guidance (and patients are subsequently harmed by false sense of self control)
Responses to 3A and 3B

• Don’t put the cart before the horse...define the goal of medicine.
  – ADs need to be identified and integrated at beginning of care plan.

  – *If proxy states patient would never want to live in long term nursing home, how does offering a trach or tube feeding help meet the goals of medicine?*
Responses to 3A and 3B Continued

• POLST can address issues of AD application.
  – Focus on specific interventions as opposed to general medical conditions.

• Reflective, thoughtful conversation with proxy about whether new treatments align with patient goals is appropriate. (Substituted Judgment)
Challenge #4: Ignoring AD Provides Important Benefit

Current treatment provides important benefit for present interests of patient (and forgoing such benefit would be harmful).

– Patient’s current interest in receiving beneficial treatment should outweigh prior interests expressed in an AD.

– Radical variant: Current incapacitated patient is a different person from the one who completed the AD, so AD does not apply!

Typical Case

• Patient with advanced dementia who completed an advance directive a few years ago...should tube feeding commence?

• Prior Wishes vs. Present Welfare Problem
Responses to #4

• Distinguish between critical interests and experiential interests.
  – Critical interests = derived from “self-chosen values and goals that give overarching meaning to people’s lives, regardless of what sorts of experiences result from fulfilling them.”
  – Experiential interests = derived from “carrying out certain activities just for the experience of doing so.”

Possible Benefits of Medical Interventions

- Medical (Physiological)
- Psychological
- Economic
- Spiritual
- Aesthetic
- Legal
- Familial
- Social
- Cultural

Qualitative vs. Quantitative Benefit

• Quantitative Benefit = measurable in terms of labs, physiological processes, numerical data, etc.

• Qualitative Benefit = measurable in terms of patient goals, quality of life, experiential moments, etc.
Patient Wishes vs. Best Interest

- The ethical and legal presumption is that Patient Wishes (as expressed in an AD) take priority over Best Interest.

- Ignoring an AD based on Best Interest is an uphill endeavor...
Best Interest Defined

• Decisions based on Best-Interest must:
  – Maximize long term benefits, minimize short term burdens,
  – Meet a minimum threshold of acceptable care (as understood by reasonable person standard)
  – Align with other moral and legal duties to the individual.

Kopelman L. The Best Interest Standard for Incompetent or Incapacitated Persons of All Ages, JLME 58:7 (2007).
Other Important Considerations

• Consider date of AD completion.

• Following an AD ought not require inhumane treatment.

• Reflect on the meaning of “patient advocacy.”

• Consider thoughts of all available family members and friends.
Difficult Balance of Advance Care Planning

• Plan early enough so that enough distance exists, but not so late that fear of death (and death panels) is overwhelming.
A Patient Perceived Harm of Advance Care Planning

• “Physician/provider is attempting to ration health care to my detriment.”

  – Is the directive being used from framework of *Expressed Wishes/Substituted Judgment* or is it being used from framework of *Best Interest*?
Trust in Advance Care Planning

• Trust is a four-part relation...

• Patient W trusts Person X to do Action Y in Circumstance Z.

• “While seeing the physician in the hospital for the first time (Z), the patient (W) trusts the physician (X) to complete a POLST in a manner that reflects the patient’s sense of benefit and doesn’t attempt to ration health care (Y).”
Thank You
Other References
