Autonomy and Ethical Decision-Making in Elder Care

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It is old age, rather than death, that is to be contrasted with life. Old age is life's parody, whereas death transforms life into a destiny...

Simone de Beauvoir in *The Coming of Age*
Each is the proper guardian of his own health, whether bodily or mental or spiritual.

John Stuart Mill in *On Liberty* published 1859
Historical definitions of personhood emphasize rationality

“since mind more than anything else is man.”

Aristotle in *The Nicomachean Ethics*, 350 BCE
REASONS GIVEN FOR SEEKING ASSISTED SUICIDE UNDER OREGON'S DEATH WITH DIGNITY ACT 1998-2014, N=859

Reason for seeking assisted suicide

- Losing autonomy
- Loss ability to enjoy life
- Loss of dignity
- Loss of bodily functions
- Burden
- Pain control
- Finances

Number of individuals endorsing item*

* Able to choose more than 1 items

Data from the 2014 Annual report on Oregon’s Death with Dignity Act
What is Autonomy?

• Autonomy is a property intrinsic to the concept of personhood

• An autonomous act has these properties*:
  – Intentional
  – With understanding
  – Without coercion

*From: Beauchamp & Childress, 2001
Why Respect Autonomy?

• Agency - A self capable of deliberate (autonomous) action

• Respect for person - Persons have ultimate value

• Moral equality - Each person’s moral worth is synonymous

Equals⇒
• **Liberty** - The right to pursue one's own interests without interference.

• **Which in health care means:**

• **Respect for autonomy** - The duty of clinicians to respect and enhance patients’ autonomy over treatment decisions and health care goals.

• *Note: Respect for Autonomy is active requiring skill and effort by the clinician while liberty is a passive right.*
Autonomy, DMC, informed consent, & responsibility are interrelated concepts

**Autonomy**
Defining human attribute of great moral significance

**DMC**
Mental status needed to be autonomous

**Informed consent**
Technique to ensure that treatment decisions are made autonomously

**Responsibility**
Conferred by autonomous decision-making

Respect for autonomy
1. Extending Autonomy
   – Advanced directives

2. Over-riding Autonomy
   – Hiding meds in food

3. Beyond Autonomy
   – Sex & Dementia
Well, How long do you want to live?
Advanced directives respect patient autonomy by extending it to times when the patient lacks decision-making capacity, i.e. autonomy.
Advanced Directives

• Designed for use in EOL care*
  – But can be used for psychiatric or other condition

• First used in 1970’s
  – Following a series of high profile court case

• Patient Self-Determination Act of 1991
  – Information about AD Must be provided on admission

Advanced Directives are used to:

- Express a patient wishes regarding Life Sustaining Treatments (LST)
  - Such as CPR, tube feeding, or ventilator

- Express the patients overall goals of care
  - Such as pain relief, mental clarity, quality family time

- Name a surrogate decision maker
  - Called Durable Power of Attorney (DPOA)
Advance Directive Process

• Person with Decision-Making Capacity (DMC) completes AD stating:
  – Wishes about treatments at EOL
  – Preferred surrogate decision maker

• AD invoked when patient lacks DMC

• Physician writes orders based on AD and consultation with surrogate
Myths

- DPOA immediately becomes responsible for health care decisions
- DPOA is a guardian
- Decisions can’t be changed
- Choices are absolute
- Care won’t be as good if you choose DNR
Why have an AD

- Better chance of getting preferred treatment
- Avoiding unwanted treatment
- Avoids futile treatment
- Better quality of life in terminal illness
- Comfort to family
- Helps providers
AD’s: Not used & Not clear

• Only 15-25% complete an AD

• AD’s often fail to clarify wishes enough to adequately guide treatment
Typical treatments anticipated in AD

- CPR
- Ventilation
- Dialysis

- Feeding tubes
- Antibiotic
- Hospitalization
The following blue-format slides come from a study testing the effect of a tool to train nurses in Advance care planning conversations on the completion rate of advanced directives and patient satisfaction with the process with Veterans living in rural Alabama. P.I. Ann Mahaney-Price, PhD, RN.


When your breathing or heart stops, or no longer works well enough to meet life needs, death follows. CPR is blowing air into your lungs, and repeatedly pushing on your chest. This way blood with oxygen gets to the brain and other parts of the body.

**Cardiopulmonary Resuscitation** (CPR)

<table>
<thead>
<tr>
<th>PROS (1)</th>
<th>CONS (1)</th>
<th>ALTERNATIVES</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPR can save life.</td>
<td>Death is the most common outcome.</td>
<td>Instead you can choose</td>
</tr>
<tr>
<td>If you are less than 65, your chance of surviving CPR is 25-40%.</td>
<td>CPR can cause broken ribs and lung damage. CPR can cause brain damage and coma.</td>
<td>➢ no CPR</td>
</tr>
<tr>
<td>If you are over 65, your chance of surviving CPR is 1-4%.</td>
<td>You may end up needing a breathing machine for a long time.</td>
<td>➢ a natural death without CPR.</td>
</tr>
<tr>
<td></td>
<td>You will probably die if you already have heart disease or lung disease already.</td>
<td></td>
</tr>
</tbody>
</table>
When you need artificial breathing, you are hooked up to a machine. The machine is connected to a long tube. The tube goes through your nose or mouth and enters your windpipe. If you need a breathing machine for a longer time, it is hooked up to a tube that enters your neck.

<table>
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<th>PROS (1)</th>
<th>CONS (1)</th>
<th>ALTERNATIVES</th>
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| A breathing machine can save your life. It can make your breathing feel better. | Being on a breathing machine may be uncomfortable. You may be  
- unable to talk.  
- confined to bed.  
You may need help for feeding, bathing, dressing, toileting. You will need suctioning of your windpipe to clear mucus. A breathing machine may increase your suffering at end of life. | Instead you can choose  
- no breathing machine  
- a natural death  
- medicine for breathing comfort  
- CPR for 30-60 minutes but no breathing machine.  
- short term breathing machine (e.g. one week) |
Some illnesses cannot be treated outside a hospital.

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS (5)</th>
<th>ALTERNATIVES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital treatment can save your life.</td>
<td>When you are hospitalized for care you could have new problems like</td>
<td>Instead you can choose not to go to the hospital.</td>
</tr>
<tr>
<td>Hospital care can cure some illnesses.</td>
<td>➢  infection after surgery</td>
<td>If you have a terminal illness you might prefer to stay home.</td>
</tr>
<tr>
<td>Hospital care can prevent more serious illness.</td>
<td>➢  infection from a tube into your body</td>
<td></td>
</tr>
<tr>
<td></td>
<td>➢  your incision breaks open</td>
<td></td>
</tr>
<tr>
<td></td>
<td>➢  bad side effects of medicine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>➢  health care mistakes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The US government says that 14% of elder adults have at least one harmful event in the hospital.</td>
<td></td>
</tr>
<tr>
<td>Scenario's</td>
<td>Yes %</td>
<td>No %</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td>If I am unconscious, in a coma, or in a vegetative state and there is little or no chance of recovery.</td>
<td>13</td>
<td>43</td>
</tr>
<tr>
<td>If I have permanent, severe brain damage that makes me unable to recognize my family or friends.</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>If I have a permanent condition where other people must help me with my daily needs (for example, eating, bathing, toileting).</td>
<td>43</td>
<td>23</td>
</tr>
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</table>

**Yes.** I would want life-sustaining treatments.

**No.** I would not want life-sustaining treatments.

**I'm not sure.** It would depend on the circumstances.
### AD DECISION TRENDS

<table>
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<tr>
<th>Scenario's</th>
<th>Yes %</th>
<th>No %</th>
<th>It would depend %</th>
</tr>
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<tbody>
<tr>
<td>If I need to use a breathing machine and be in bed for the rest of my life.</td>
<td>20</td>
<td>60</td>
<td>20</td>
</tr>
<tr>
<td>If I have pain or other severe symptoms that cause suffering and can’t be relieved.</td>
<td>27</td>
<td>47</td>
<td>27</td>
</tr>
<tr>
<td>If I have a condition that will make me die very soon, even with life-sustaining treatments.</td>
<td>13</td>
<td>67</td>
<td>20</td>
</tr>
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</table>

Yes. I would want life-sustaining treatments.
No. I would not want life-sustaining treatments.
I'm not sure. It would depend on the circumstances.
Limitations of AD’s

• Current affective state bias
• Instability
  – 23% misremembered wishes after 1 year
• Surrogates often get it wrong
  – Even after discussion
• Physician bias affects decisions
• Physicians often don’t follow AD’s
Clinician barriers to completing AD

- Discomfort with the topic
- Unfamiliar with alternatives to aggressive tx
- Lack of time
- Belief that patients do not want AD discussions
- Belief that AD discussions are not needed
Barriers to completing AD’s identified by patients (N=143)*

- Irrelevant (84%)
- Personal barriers (53%)
- Relationship concerns (46%)
- Information needs (36%)
- Health encounter time constraints (29%)
- Problems with advance directives (29%)

Overriding Autonomy
Justifications for overriding autonomy

- Lacks DMC
  - Consent is not valid
  - Consent by surrogate

- Dangerous with mental disorder
  - Clinician decision
  - Legal/procedural protections
Justifications for over-riding autonomy

• Emergency
  – Clinician
  – Criteria based

• Public health e.g. mandatory vaccine
  – Large social benefit to personal cost
  – Governing body

• Therapeutic privilege – Not telling diagnosis
  – Least protections
Decision-making capacity
Aside on terminology

• Competence
  – A legal term
  – Adjudicated by a judge
  – Presumption that decision making capacity is lacking

• Decision-making capacity
  – Determined clinically
  – Mental ability needed to make a specific decision
Elements of DMC*

- Understanding
- Appreciation
- Reasoning
- Expressing a choice*

Grisso & Appelbaum, 1998
Assessment of patient’s DMC determines how the rights and protections are applied

**Patients with DMC**
- Have right to refuse even life preserving treatment
- Have broad rights to manage care, choose among options, and request any appropriate treatment
- Are only person who can authorize care

**Patients lacking DMC**
- Are deficient in defining basic human attribute
- Require protection from decisions or actions for which they are not responsible
- Should have a responsible person assigned to monitor and authorize care and speak on the patient’s behalf
Mistakes can be disastrous
Consequences of incorrect assessment of DMC

**Having DMC assessed as lacking**
- Risks abuse of the patient’s rights, unjustified forced treatment, denial of liberty, and assault

**Lacking DMC assessed as having**
- Leaves highly vulnerable patients without essential protections
Decision-making capacity is a continuum

**Lacks capacity**

<table>
<thead>
<tr>
<th>Coma, Florid psychosis</th>
<th>Delusional, Severe Alzheimer's</th>
<th>Moderate Alzheimer's, Severe or psychotic Depression</th>
<th>Early Alzheimer's, Residual phase Schizophrenia</th>
<th>Substance dependant, Severe Personality Disorder</th>
<th>Late adolescent, Impulsive personality</th>
<th>Mature independent adult</th>
<th>Professor of Moral Philosophy</th>
</tr>
</thead>
<tbody>
<tr>
<td>No communication, No decision, or Nonsense</td>
<td>Manifestly poor decisions without giving rationale</td>
<td>Decision articulated but without any reflection</td>
<td>Decision deliberated on socially accepted grounds</td>
<td>High level reflection</td>
<td>Graphic inspired by Chen et al, 2002, categorization by Miller, 1982</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1. DMC is not an absolute
   – It is relative to the risks, benefits, and complexity of each treatment decision

2. DMC depends on mental ability
   – Which is an aggregate of separate related functions each of which influences DMC

3. DMC often fluctuates
   – Cognitive ability fluctuates widely in many conditions

4. DMC must be assessed as fully present or absent
   – Although the mental abilities that determine DMC occur as multi-factorial continua
Aspects of mental functioning that can be disordered and thus influence DMC

- **Thought**
  - Executive function
  - Verbal Fluency
  - Working memory

- **Mood**
  - Depression
  - Mania

- **Self (personality)**
- **Experience**
- **Relational functioning**
- **Behavior**
Percent with decision-making capacity for research informed consent: Alzheimer's patients (N=37) and matched comparison group (N=15)

Decision-making in the context of a caregiving relationship
Hypothetical social network of home care patient

- Wife & CAREGIVER
- Son
- Sister
- Daughter
- Co-worker prior to illness
- Housebound Neighbor
- Visiting Nurse
- Primary Care Physician
- Psychiatrist
- Therapist
Complexities of autonomy in a caregiving relationships

- Dependence on caregiver
- Difficult to see patient’s rights in isolation from caregiver concerns in enmeshed situations
  - But rights structured by view of persons in isolation
- Equating rationality with personhood encourages infantilizing persons with cognitive impairment
“Let’s just put it in her applesauce!”
Is it ethical to hide medication in the food of a patient who refuses?
Ethical analysis

1. Identify values in conflict
2. Identify ethically relevant variables
3. Explicate status of ethically relevant factors in the specific case
4. Make judgment

Social Context & Self-Reflection
Values in conflict

Respect for autonomy
- Patients have right to refuse tx

Beneficence
- Do what will most improve patient's health and improve QOL
Options

• Put the med in the apple sauce without telling the patient
• Give patient option to take or not take medication
Ethically relevant variables
Ethically relevant variables

- Patient’s experience of the situation
- State of patient’s decision making capacity
- Cost benefit ratio of treatment/non-treatment
  - Any factor that affects that ratio
- Clinical Relationship
- Family input / Quality of surrogate
Ethically relevant variables in this case

- Patient’s decision-making capacity
  - Knowledge of patient’s wishes prior to loss of capacity
    - Prior capacity or no prior capacity
- Benefit of taking med
- Harm of not taking med
- Possibility of harm from loss of trust
- Quality of surrogate decision-maker
Algorithm with examples

Overall Decision

- Hide meds
- Respect pt refusal

Patient’s decision-making capacity
- Complete Lack
- High level thinking

Benefit of taking the medication
- Life-saving
- Great increase QOL
- Some increase QOL
- Little benefit

Possible harm of not taking the med
- Fatal
- No harm

Possible harm from loss of trust
- Not likely
- Great harm

Quality of surrogate decision-maker
- Knows pt intimately, has best interests
- Little knowledge of pt, self-interested
Algorithm with examples

Overall Decision

- Hide meds
- Respect pt refusal

Patient’s decision-making capacity

- Complete Lack
- High level thinking

Benefit of taking the medication

- Life-saving
- Great increase QOL
- Some increase QOL
- Little benefit

Possible harm of not taking the med

- Fatal
- No harm

Possible harm from loss of trust

- Not likely
- Great harm

Quality of surrogate decision-maker

- Knows pt intimately, has best interests
- Little knowledge of pt, self-interested
Easy decision: Hide med

Overall Decision

- Patient’s decision-making capacity
- Benefit of taking the medication
- Possible harm of not taking the med
- Possible harm from loss of trust
- Quality of surrogate decision-maker

Hide meds

Respect pt refusal

* indicates lower importance or lesser consideration.
Easy decision: Respect refusal

Overall Decision

- Hide meds
- Respect pt refusal

- Patient’s decision-making capacity
- Benefit of taking the medication
- Possible harm of not taking the med
- Possible harm from loss of trust
- Quality of surrogate decision-maker

* * *
Hard Decision

Overall Decision

- Patient’s decision-taking capacity
- Benefit of taking the medication
- Possible harm of not taking the med
- Possible harm from loss of trust
- Quality of surrogate decision-maker

Respect pt refusal

Hide meds

Distinctions

- Even though an ethically relevant factor occurs on a continuum – for some factors a distinction may be required to justify the correct action.

- Criteria for making the distinction are helpful.
Social Context

• Trust
• Meaning of food

Self-reflection

• Whose benefit?
• Is there a workload issue?
Under what conditions would it be ethical to hide medication in a patient’s food?

- Medically necessary
- Improves QOL
- Little chance of trust being lost
- A surrogate decision maker that agrees
- Med is compatible with delivery
SEX & Dementia
The Case

An 78-year-old retired state legislator and farmer in Iowa was tried for rape. It was alleged that he had sex with his wife, who had severe Alzheimer’s disease, in her shared room in a nursing home.*

Two questions

- When is protection needed and when is it intrusive and harmful or paternalistic?
- What are the mental abilities required to consent to sex?
Two visions of “autonomy/capacity”

From the New York Times:

Mr. Yunek [the defense attorney] asked Dr. Brady [the nursing home MD] if “Donna is happy to see Henry — hugs, smiles, they hold hands, they talk — would that indicate that she is in fact capable at that point of understanding the affection with Henry?”

Dr. Brady said no, calling that a “primal response” not indicative of the ability to make informed decisions.
Ethically relevant variables

- Mental capacity of patient
- Prior relationship
- Advance directive statement or equivalent
- Use of force/coercion
- Prior feelings about sex and/or sexual behavior
- Potential negative consequences
- Contextual considerations
- Self-reflection
Sex with person lacking DMC

Overall Decision

- Treat as Rape
- Treat as loving sex

- Patient’s decision-making capacity
  - Complete Lack
  - Strangers
  - Signs of struggle
  - Negative about sex
  - Possible pregnancy/STDS

- Use of Force
  - No evidence of force/coercion

- Quality/Nature of prior relationship
  - Spousal-loving

- Prior feelings/behavior
  - Advanced statement

- Consequences
  - Beneficial consequences
Sex with person lacking DMC

Overall Decision

Treat as Rape

Complete Lack

Patient’s decision-making capacity

Quality/Nature of prior relationship

Use of Force

Prior feelings/behavior

Consequences

Treat as loving sex

High level thinking

Spousal-loving

No evidence of force/coercion

Advanced statement

Beneficial consequences

The End