Ethical Challenges in Medical Decision Making

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Objectives
1. Define autonomy, beneficence, nonmaleficence, and justice
2. Balance competing medical ethics in making decisions about patient care
3. Define Decision Making Capacity
4. Discuss a process to assess capacity
5. Differentiate Capacity and Competence

Medical Ethics
Medical ethics and principles
1. Autonomy
2. Beneficence
3. Nonmaleficence
4. Justice
5. Veracity
6. Fidelity
The Basic Ethical Principles

Autonomy:
'self-rule'
- promotes patients to act as their own agent
- free will with informed consent

The down side:
Consumerism: commitment to non-involvement in client decision making
Non Caring

The Basic Ethical Principles
 Beneficence:
 Do good (or 'provide benefit')
- the basic principle of "caring"
- act in accordance with a patient's welfare

The down side
Paternalism: health provider makes decision for the patient based on provider's values more than patient's values

The Basic Ethical Principles
 Non maleficence:
 Do no harm
- the calculation of risk in medical decision making and determining risk/benefit ratio
- the balance of benefit and harm = utility

The down side
Non action or unwillingness to offer treatments with questionable benefit
The Basic Ethical Principles

**Justice:**
Be fair (distributive justice > entitlement)
- the appropriate distribution of limited resources;
  non discrimination
- transparency, accountability and consistency

The down side
- Restriction of higher end resources from those who could "afford it"
- Transparency can drive inappropriate practice (data mongering)

Other Ethical Principles

**Truth-telling or Veracity:**
- full, honest disclosure

The down side
- Assaulting patients with "the truth"

Other Ethical Principles

**Fidelity:**
- do as you say you will do +
  respect confidentiality

The down side
- Confidentiality can impede quality and efficiency of care
### Ethical Principle

<table>
<thead>
<tr>
<th>Ethical Principle</th>
<th>Moral Basis</th>
<th>Over Emphasis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>Respect for individual</td>
<td>Consumerism, Lack of caring</td>
</tr>
<tr>
<td>Beneficence</td>
<td>Do good</td>
<td>Paternalism</td>
</tr>
<tr>
<td>Non-maleficence</td>
<td>Do no harm</td>
<td>Lack of action</td>
</tr>
<tr>
<td>Justice</td>
<td>Be fair</td>
<td>Lack of individualization</td>
</tr>
<tr>
<td>Veracity</td>
<td>Be truthful</td>
<td>Truth causing harm</td>
</tr>
<tr>
<td>Fidelity</td>
<td>Maintain confidentiality</td>
<td>Treating patient as an “island”</td>
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### Ethics

“The practice of ethics is NOT the application of rules; but the careful consideration of principles in the complex world of decision making about human action.”

### A Case to Demonstrate

92 yo woman: tear of her quadriceps muscle; wants surgery as she has lost independence.
- Preop: new anemia (Hgb 9) and hyponatremic (Na 127)
- Refuses further workup as angry she has been “put off” so long (orthopedist appropriately tried conservative therapy)
- WANTS SURGERY NOW!
Apply the ethical principles to assist in making a decision about care:
- Autonomy
- Beneficience
- Non maleficence
- Justice
- Veracity and Fidelity

Decision Making Capacity
The ability (of a patient) to be able to make their own decisions about medical care (ethically and legally)

Capacity and Competence

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>Legal</td>
</tr>
<tr>
<td>MD/ARNP assessment</td>
<td>Judge assessment</td>
</tr>
<tr>
<td>Inexpensive</td>
<td>Costly</td>
</tr>
<tr>
<td>Immediate/brief</td>
<td>Time consuming</td>
</tr>
<tr>
<td>Gray/Unclear often</td>
<td>Either/Or</td>
</tr>
<tr>
<td>Can fluctuate and is decision/task specific</td>
<td>Is semi-permanent and global in most cases</td>
</tr>
<tr>
<td>Requires substitute decision maker</td>
<td>Requires permanent guardian</td>
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NEW HAMPSHIRE RSA 137: J

Decision Making Capacity

New Hampshire Legal Definition:
NH RSA 137-J:2(V)

“the ability to understand and appreciate generally the nature and consequences of a health care decision, including the significant benefits and harms of and reasonable alternatives to any proposed health care.”

Clinical Concepts:

“the ability to understand”:
- the medical problem (“generally the nature and consequences of”)
- the options for care (“alternatives”)
- the risks and benefits of each option (“significant benefits and harms”)

www.genjoint.state.nh.us/rsa/html/x/137-j/137-j-mrg.htm
Decision Making Capacity

Definitions:
“the ability to appreciate “:
- ability to reason, attach personal meaning, and justify options and choice
  - element of free choice
    - not controlled by others or a mental health condition
  - reasoning is consistent with known values

To have capacity, a patient must:
1. Understand problem and options
2. Reason between the options
3. Appreciate personal nature of options and choose consistent with values
4. Communicate the choice

... in a manner consistent with intellect, personal environment and culture

Capacity is Presumed
Onus on clinician to prove lack of capacity.
The legal decision tree

1. Presume capacity.
2. If any red flags are apparent; assess capacity.
   - Obligation to assess is a "sliding scale"

Decision Making Capacity

**Red Flags** (When we should not presume):
- Significant mental illness especially thought disorders
- Dementia
- Delerium
- Either end of age spectrum
- Polypharmacy

**Red Flags: When we should not presume**
- Making a choice not consistent with prior values and choices
- Making a choice that has high risk of harm and low risk of benefit
- Refusing a treatment that has high risk of benefit and low risk of harm
Legal Decision Tree

3. If patient does NOT have capacity:
   Find substitute decision maker (SDM)
   ▪ In NH: ONLY legal authority to be a SDM is Durable Power of Attorney for Healthcare (DPOAH) as defined in an Advance Directive.

Surrogate Decision Makers

Hierarchy in most states:
1. Spouse
2. Child or majority of adult children
3. Parent(s)
4. Sibling(s)
5. Nearest living relative

NH law: No hierarchy

The legal decision tree

4. Where a patient lacks capacity, and there is no DPOAH -> only legal authority is a (temporary) court-appointed guardian
Legal Decision Tree

Presume Capacity;
If 'red flags':
Assess capacity

Lacks capacity to make medical decision
Has capacity: Patient makes decision

Legal Decision Tree

Lacks capacity = needs substitute decision maker

Has DPOAH: DPOAH makes decision
No DPOAH

Legal Decision Tree

No DPOAH

Emergency = risk to 'life or limb'; then Proceed
Non emergency: Obtain temporary court appointed guardian
Court Appointed Guardianship

- Expensive depending on complexity
- The NH Bureau of Adult and Elderly Services (BEAS) reluctant to proceed without neuropsychiatric evaluation
- Days to months to obtain
- Court appointed guardians are not trained in palliative/end of life care
- Most efficient if a family member petitions

Capacity

Capacity is:
- A slope not a step
- Can fluctuate over time
- Specific to the medical decision
  - One can have capacity to make a simple but not complex medical decision
    - i.e. assign DPOAH but not make a medical decision

Capacity

- Does not require a psychiatrist; MD/DO or NP
- Best provider: the one with the best knowledge of the patient and the medical decision to be made
- Sometimes cannot be done at one visit
- Requires listening skills, not speaking skills
Situations?/ Cases?

Bill

62 yo previously healthy patient other than major depression develops empyema and acute renal failure.
- states he wants treatment when asked by hospitalist
- transferred DHMC
- refuses decortication and hemodialysis
- transferred back to LRH to assist and control symptoms and die

Thelma

87 yo female presents for 3rd time in last 6 months due to CHF (normal EF)
- Wants to be with her husband who has died
- Losing independence at home and poor self care
- Asks what will happen if she stops her meds
- Told likely would get fluid overload and die
- Asks if symptoms could be controlled and when assured then states she wants to stop all meds and get symptom control to die
Judd

51 year old cachetic (95 lb) male in hospital due to pneumonia not recovering
- 5 year hx metastatic prostate ca multiple mounting complications (c diff, recurrent SVT, hypotension, hypoalbuminemia and edema)
- not eating and resistant to attempts to assist in recovery from pneumonia
- full code and states he wants to treat all conditions and get back to work

Judd

Also states he does not want to linger, only wants comfort care when he is dying, and "if I knew what this past year was going to be like, I would have preferred to die."
- Refuses to eat and angrily reacts to anyone suggesting his recovery would benefit from better nutrition
- Has a different symptom (often different pain source) that comes and goes each day when PT/OT comes by to help him

Gerard

65 yo male malnourished alcoholic
- Admitted for acute sepsis
- No prior medical care until saw surgeon 3 wks previous for non-healing stage IV LE ulcers
- 10 cm hepatocellular carcinoma dx during treatment for ulcers
- Initially alert
Gerard

- Suddenly develops acute renal failure and loses decision making capacity
  - Requires dialysis or will die
- Attending surgeon thinks comfort care; GI consultant pushing hard for dialysis

Gerard

- Only ‘family’ is son of a former girlfriend who he raised (who is on probation)
  - Owns own home where they lived
  - Has no ADs, no financial will
- Ethics consultation requested

Other examples

1. Access to harmful treatment
   - Radiation and chemotherapy at end of life (ECOG IV)
2. Access to treatments that cannot be afforded
   - Targeted vemurafenib and ipilimumab for melanoma with BRAF mutation
     - $50,000 + $120,000 for a course of therapy
Other examples

- Physician assisted suicide

Complicating Factors

NH RSA 137-J:5, IV

"irrespective of the principal's lack of capacity to make health care decisions, treatment may not be given to or withheld from the principal over the principal's objection unless the principal's advance directive includes the following statement initialed by the principal, "Even if I am incapacitated and I object to treatment, treatment may be given to me against my objection.""

Complicating Factors

- NH RSA 137-J:10, II

"...medically administered nutrition and hydration and life-sustaining treatment shall not be withdrawn or withheld under an advance directive unless:
(a) There is a clear expression of such intent in the directive;
(b) The principal objects pursuant to RSA 137-J:5, IV, or
(c) Such treatment would have the unintended consequence of hastening death or causing irreparable harm as certified by an attending physician and a physician knowledgeable about the patient's condition."

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