Ethics draws on:

**Disciplines**
- Philosophy
- Theology
- Medicine
- Nursing
- Clinical Science
- Public health
- All others
- Law
- Humanities

**Sources**
- Scholarly publications
- Professional codes of ethics
- Laws
- Policies
- Treatment standards
- Precedent cases
- Expert opinion
- Popular culture
Uses of the term “Ethics”

1. Wrongdoing
2. Dilemmas
3. Enacting our values
4. Right values

<table>
<thead>
<tr>
<th>Type of problem</th>
<th>Description</th>
<th>Question needing answered</th>
<th>Examples</th>
<th>Style of Resolution</th>
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<tbody>
<tr>
<td>Wrongdoing</td>
<td>Acts that clearly violate moral norms</td>
<td>How do we change the situation?</td>
<td>Excessive use of restraints; Racial disparities in treatment</td>
<td>Eliminate bad actors; Systemic analysis and reform</td>
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<td>Dilemmas</td>
<td>A conflict in legitimate values</td>
<td>What is the right way to proceed?</td>
<td>Should you ever conceal meds in the food of a patient with dementia?</td>
<td>Ethical analysis</td>
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<tr>
<td>Enacting values</td>
<td>Devising better ways to enact values</td>
<td>Can this be done better?</td>
<td>Should palliative care be offered earlier in the cancer trajectory?</td>
<td>Empirical analysis; Clinical innovation</td>
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<td>Right values</td>
<td>Determining what values should guide professional decisions and behavior</td>
<td>What principles should guide clinical action and decisions?</td>
<td>Should sanctity of life override patient choice when a terminal patient asks for assisted suicide?</td>
<td>Academic &amp; philosophical analysis</td>
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Values

“A value is something that is prized or held dear; something that is deeply cared about.”

From: Canadian Nurses Association Code of Ethics, (2002)
Values are what tell you – _This_ is better than _that_.

WE VALUE: 
**Self-Determination**

Respect for autonomy: The duty of clinicians to respect and enhance patients’ autonomy over treatment decisions and health care goals.
John Stuart Mill (1806-1873)

Each is the proper guardian of his own health, whether bodily or mental or spiritual.

*On Liberty.* 1859.

“The limits on respect for autonomy are greater when agents request than when they refuse treatments.”*

Informed Consent – Ensure that patient’s decisions are autonomous

Advanced Directives – Extends a person’s autonomy to times when they lack decision making capacity, i.e. they lack “autonomy”

Techniques for enacting patient self-determination

“That pill they advertise all the time on TV. I’m not sure what it is, but I want it!”
What is informed consent?

• An autonomous authorization by individuals for treatment.
• Adequate informed consent requires three elements*:
  1. Decision-making capacity – An essential precondition to giving a valid informed consent
  2. Information – That relevant information is given to and understood by the patient
  3. Consent – That the patient voluntarily agrees to the treatment

*From: Beauchamp & Childress, 2008

Potential exceptions to informed consent

• Lacks decision-making capacity
• Dangerous with mental disorder
• Emergency
• Public health e.g. mandatory vaccine
• Therapeutic privilege – Not telling dx
Protections are required when overriding consent

- Protections vary by rationale for overriding consent
- Substitute decision maker
- Assent
- Legal oversight
- Legal/clinical criteria
- Clinical oversight

Improper Consents

- Blanket consent
- Implied consent
- Retroactive consent
  - Research
- Gurney consent
Elements of DMC

- Understanding
- Appreciation
- Reasoning
- Expressing a choice

*Grisso & Appelbaum, 1998

Decision-making capacity

© Estate of Alice Neel
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

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
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.

- Early Alzheimer's
- Residual Personality
- Schizophrenia
- Late adolescent, impulsive personality

Lacks Decision-Making Capacity

- Coma
- Delirium
- Severe Alzheimer's
- Depression
- Substance dependent, severe
- Personality Disorder
- Mature independent adult
- Professor of Moral Philosophy
- No communication, no decision, or nonsense
- Manifestly poor decisions without giving rationale
- Decision articulated, but without any reflection
- Decision deliberated on socially accepted grounds
- High level reflection

Graphic inspired by Chen et al, 2002, categorization by Miller, 1982
Assessment of DMC

- Capacity is assessed in relation to the specific treatment decision
- Patients are assessed as either having or lacking capacity
- Tools for assessing capacity are aids to clinical judgment and not determinant
- The MMSE is not an effective test of DMC

Tools for assessing DMC

- The MacArthur Competence Assessment Tool for Treatment (MacCAT-T)
  - Most used with the most evidence
  - Copyright and so costs to use
- The Aid to Capacity Evaluation (ACE)
  - Good evidence
  - Public access
- Both are specific to patient’s situation
Informational Distinctions

Disclosure

Understanding

Appreciation

Consent without coercion
Advance Directives

Well, How long do you want to live?
Advance directives extend patients’ ability to participate in treatment decisions by having their wishes documented for use when they lose the mental capacity to participate directly in treatment decision-making.

**Advance Directive Process**

- Person with Decision-Making Capacity (DMC) completes AD stating:
  - Wishes about treatments anticipated at EOL
  - Preferred surrogate decision maker
- Advanced directive invoked when patient determined to lack DMC
- Physician writes orders based on AD and consultation with surrogate
**Current Problems with ADs**

- Only 15-25% of adults complete an AD
  - Often fail to clarify patients wishes
- Significant racial, ethnic and economic disparities
- Clinician and patient barriers to AD completion

**Clinician barriers**

- Discomfort with the topic
- Unfamiliarity with alternatives to aggressive treatment
- Lack of time
- Belief that patients and families do not want such discussions
- Belief that such 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%)


### Typical treatments anticipated in AD

- CPR
- Ventilation
- Dialysis
- Feeding tubes
- Antibiotic
- Hospitalization

AD’s can also name surrogate decision-maker
What matters is what’s important to you - throughout your life and as end of life nears.

- What are the important aspects of your life that you most wish to preserve?
- Is it important to you to prolong life?
- Is it important to you to have a natural death, without tubes and wires?
- Is it important to you to be at home when you die?
- Is comfort important to you?
- Is it important to you to be able to walk, talk, feed self, dress self, and know your loved ones?
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>
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<tbody>
<tr>
<td>CPR can save life. If you are less than 65, your chance of surviving CPR is 25-40%. If you are over 65, your chance of surviving CPR is 1-4%.</td>
<td>Death is the most common outcome. CPR can cause broken ribs and lung damage. CPR can cause brain damage and coma. You may end up needing a breathing machine for a long time. You will probably die if you already have heart disease or lung disease already.</td>
<td>Instead you can choose  - no CPR  - a natural death without CPR.</td>
</tr>
</tbody>
</table>

Limitations of AD’s

- Current affective state bias
- No experience of treatments to base choices on
- Instability of choice
  - 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
WE VALUE:
Truthfulness

WE VALUE:
Patient Dignity
WE VALUE: Patient Well-Being
Beneficence: One should act for the benefit of others, both maximizing positive good and minimizing or preventing harm. From Beauchamp & Childress, 2008.
Values can be conflicted within an individual or between individuals.
Situations susceptible to value conflict

1. Unhealthy behaviors, lifestyles, and choices
2. Preference sensitive conditions
3. Marginal certainty

Ethical analysis

1. Identify values in conflict
2. Get the facts
3. Identify options
4. Identify ethically relevant variables
5. Are there critical distinctions?
6. Explicate status of ethically relevant variables & distinctions
7. Make judgment
8. Develop policy recommendations
Distinctions

Ethical situations often require distinguishing between subjective judgments – for example between beneficial and futile treatment.

Develop Policy Recommendations: Guiding questions

• Under what conditions is it ethical to …?
• What are ethically justifiable options?

• How can professional values be best expressed in this situation?
• What action will bring about the most good?
Resources mentioned in the presentation

- douglas.olsen@hc.msu.edu
- Ethical considerations that arise when a home care patient on long term oxygen therapy continues to smoke – http://www.ethics.va.gov/docs/necrpts/NEC_Report_20100301_Smoking_while_on_LTOT.pdf