Ethics At the End of Life
• Dr. Firn has no conflicts of interest to disclose.
Objectives

• Review the ethical principles that underlie clinical care for seriously ill and dying patients, illustrated by clinical cases

• Four key issues are reviewed that have direct applicability to daily patient care
Principles

• The discipline of medical ethics has helped develop a framework for decision making that applies to care near the end-of-life.

• Four principles: Autonomy, Beneficence, Non-Maleficence, and Justice
A Warning

• Applied ethics may mask underlying philosophical assumptions

• Pluralistic society – same words but different meanings
Autonomy

• **Respect for Persons**: Individuals should be treated as autonomous agents able to write their own story.
  • Persons with diminished autonomy are entitled to protection.

• Autonomy = self-determination
  • Cultural differences?
  • Limits?
  • Common mistakes?
  • Informed consent and informed refusal
Beneficence/Non-maleficence

- **First do no harm**: Protecting people from harm.
- **Do better than no harm, help**: make efforts to secure well-being.
- Who identifies and defines harm and/or benefit?
- How should suffering be viewed?
Justice

• Who ought to receive the benefits of x and/or bear its burdens?
  – “fairness in distribution” or “what is deserved.”

• Patient in front of you vs. system as a whole
  – Allocation of resources based on cost? Effectiveness? Combination of both?

• The return to the individual, not the return to the society, is the standard against effectiveness of an intervention is measured.

• Respect for persons not their productive capacity
Goal: To determine the best, morally acceptable, practically realizable decision for this patient.

I. What is/are the ethical issues, concerns, or conflicts?
II. What are the facts of the case?
   a) Health issues, history, prognosis, options for treatment, context, legal issues, resources, financial concerns, family dynamics
   b) What is the best course of action from a medical perspective
   c) What is the best course of action overall (taking into account the patient’s preferences and values, context of that person)

III. State the ethical arguments for and against each option.
IV. Can the ethically preferable option(s) be implemented?
V. If conflicts, can they be resolved? Is it possible to compromise without loss of moral integrity?
VI. What is your final decision, how will you act?

Ethics Work-Up
Case-Based Approach to Ethical Decision-Making

MEDICAL INDICATIONS
The Principles of Beneficence and Non-maleficence
2. What are the goals of treatment?
3. In what circumstances are medical treatments not indicated?
4. What are the probabilities of success of various treatment options?
5. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

QUALITY OF LIFE
The Principles of Beneficence, Non-maleficence, and Respect for Autonomy
1. What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds?
2. On what grounds can anyone judge that some quality of life would be undesirable for a patient who cannot make or express such a judgment?
3. Are there biases that might prejudice the provider’s evaluation of the patient’s quality of life?
4. What ethical issues arise concerning improving or enhancing a patient’s quality of life?
5. Do quality-of-life assessments raise any questions regarding changes in treatment plans, such as forgoing life-sustaining treatment?
6. What are plans and rationale to forgo life-sustaining treatment?
7. What is the legal and ethical status of suicide?

PATIENT PREFERENCES
The Principle of Respect for Autonomy
1. Has the patient been informed of benefits and risks, understood this information, and given consent?
2. Is the patient mentally capable and legally competent, and is there evidence of incapacity?
3. If mentally capable, what preferences about treatment is the patient stating?
4. If incapacitated, has the patient expressed prior preferences?
5. Who is the appropriate surrogate to make decisions for the incapacitated patient?
6. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

CONTEXTUAL FEATURES
The Principles of Justice and Fairness
1. Are there professional, inter-professional, or business interests that might create conflicts of interest in the clinical treatment of patients?
2. Are there parties other than clinicians and patients, such as family members, who have an interest in clinical decisions?
3. What are the limits imposed on patient confidentiality by the legitimate interests of third parties?
4. Are there financial factors that create conflicts of interest in clinical decisions?
5. Are there problems of allocation of scarce health resources that might affect clinical decisions?
6. Are there religious issues that might affect clinical decisions?
7. What are the legal issues that might affect clinical decisions?
8. Are there considerations of clinical research and education that might affect clinical decisions?
9. Are there issues of public health and safety that affect clinical decisions?
10. Are there conflicts of interest within institutions or organizations (e.g. hospitals) that may affect clinical decisions and patient welfare?
Box 1


MEDICAL INDICATIONS

*The Principles of Beneficence and Non-maleficence*


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3. In what circumstances are medical treatments not indicated?

4. What are the probabilities of success of various treatment options?

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2. Is the patient mentally capable and legally competent, or is there evidence of incapacity?

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Key Ethical Issues

1. Decision Making Capacity
2. Withdrawal/Withholding of Life Sustaining Treatments
3. Futility
4. Doctrine of Double Effect
Ethics Case #1

- 67 year old man with widely metastatic lung cancer including brain involvement, which has progressed despite aggressive chemo/radiation therapy, referred to hospice by his oncologist.
  - Life-long bachelor, no close friends, estranged from family
  - Closest relationship is with his medical case manager, whom he has listed as his emergency contact.
  - Enrolled on hospice at home on Tuesday
    - No advance directive
    - Expressed a desire to be comfortable at the end of life
    - No recorded discussion of code status
Two days later, a nurse arrived to review patients symptoms, and the patient is found in bed, confused and unable to ambulate

- Patient is transferred to an inpatient hospice unit for management, where he continues to decline and shows clinical evidence of stroke, and appears to be close to death
  - Patient remains FULL CODE by default
  - No time to obtain an emergency guardian
- Patient’s clinical case manager, oncologist and primary care provider are contacted
  - No family is known
  - No surrogate defined
Medical Decision Making Capacity

• **Capacity** is a medical term:
  – Implies the capacity to provide *informed consent or refusal to treatment*
  – Determined by a physician
  – Decision dependent
  – May fluctuate

• To say a patient has Decision Making Capacity, the patient must be able to:
  – **Understand** the information (e.g. be able to relate what they have been told and what it means)
  – **Evaluate** the information and make a choice based on personal values
  – **Communicate** a choice (implies ability to communicate)
Who should participate in shared decision making when a patient is incapacitated?

- Durable Power of Attorney for Health Care, preferred document to legally authorize an agent
  - Agents legally empowered to make medical decisions
  - Agents should be familiar with patient, her values and wishes, and willing to act as a strong patient advocate

- A surrogate decision-maker, as defined by state surrogacy statutes
  - Many states have surrogacy laws that define by statute the order by which family members have legal decision making capacity

- A court appointed legal guardian
**If there is no Legal Surrogate**

- Decisions should be made according to the *patient’s previously expressed wishes*, if known.

- If the patient’s wishes are unknown, decisions should be made in the *patient’s best interest*.

- Physicians should include family members, and/or close friends who know patient’s wishes in the decision making discussion.
Application of “Best Interest”

- People who had but are no longer capable of expressing values or preferences or individuals who never had opportunity to form values or preferences.

- Give preference to the patient’s voice if possible.
  - If wishes are not known or never articulated, then inferred wishes.
  - If no inferred wishes, then best interest

- Objective assessment of burdens/benefits of available treatment options.
• Oncologist, PCP and clinical nurse manager all describe patient’s previously expressed goal of focusing on his comfort at the end of life

• Based on prior expressed wishes, a clinical decision is made that a FULL CODE status in the setting of a terminal condition is not consistent with patient’s stated goals of focusing on comfort at the end of life.
  – Efforts are made to provide patient with comfort measures as he approaches death
  – Patient expires within three hours of arrival to the in-patient hospice facility without regaining consciousness
Ethics Case #2

• 58 year old man with severe non-ischemic cardiomyopathy eventually leading to placement of a left-ventricular assist device (LVAD)
  – Clinically doing very well; minimal symptoms, improved functional status, few reported complications or side effects
  – Able to work and participate in the care of his 7-year old daughter

• Four years after his device was placed, he presents to his cardiologist’s office and requests that his LVAD support be discontinued
  – Expresses a belief that he no longer requires the LVAD support because of a religious vision he had in which God told him he was healed
Ethics consult is placed
  - Review of chart and discussion with patient reveals that shortly after his LVAD was placed, patient was “born again” and became an active member of a Pentecostal Church
    - Religious tradition includes a belief in divine healing
    - Patient expresses a belief that by continuing to have the LVAD in place, he is demonstrating a lack of faith that will risk his eternal salvation
  - Cardiologist’s office cites all available evidence suggests that patient will most likely die within minutes of discontinuation of his LVAD
    - Weaned LVAD support in the clinic which caused patient to syncopize
      - “You do not walk into God’s arms, you jump”
Time Out: Definitions

- **Euthanasia** defines a situation where a patient or surrogate decision maker requests a clinician to perform an action with the intent of ending that patient's life.

- **Physician Assisted Death** defines a situation where a physician prescribes a lethal dose of medication which the patient can then take for the express purpose of ending his/her life.
Withholding/Withdrawing Life-Sustaining Treatments (LSTs)

• Many types: hemodialysis, ventilators, etc.

• Ethics principle: respect for autonomy
  – Rights to refuse, or request the withdrawal of, unwanted interventions even if doing so results in death; should not impose treatments
  – No ethical or legal differences between withholding and withdrawing
  – Informed refusal
## W/W LSTs

**Legal permissibility**

<table>
<thead>
<tr>
<th>Case</th>
<th>Year</th>
<th>Type</th>
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<tr>
<td>Quinlan</td>
<td>1975</td>
<td>WD ventilator</td>
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<tr>
<td>Saikewicz</td>
<td>1977</td>
<td>WH chemotherapy</td>
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<tr>
<td>Dinnerstein</td>
<td>1978</td>
<td>WH CPR</td>
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<td>Spring</td>
<td>1980</td>
<td>WD hemodialysis</td>
</tr>
<tr>
<td>Barber</td>
<td>1983</td>
<td>WD IV fluids</td>
</tr>
<tr>
<td>Bouvia</td>
<td>1985</td>
<td>WH/WD feeding tube</td>
</tr>
<tr>
<td>Cruzan</td>
<td>1990</td>
<td>WD feeding tube</td>
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<tr>
<td>Schiavo</td>
<td>2005</td>
<td>WD feeding tube</td>
</tr>
</tbody>
</table>

WD=withdrawal, WH=withhold
Karen Quinlan
70 N.J. 10 (1976), Supreme Court of New Jersey

• Found unresponsive; PVS
• The family wanted to withhold LST; the institution did not

• Court decision:
  – Patients have the right to refuse treatment
  – Surrogates may exercise the patient’s right
  – Such decisions are best made by families, not courts
  – The state’s interest in preserving life can be overridden by the patient’s right to refuse treatment
Elizabeth Bouvia
179 Cal App 3d 1127, 225 Cal Rptr 297, 1986

- Born with cerebral palsy
- Quadriplegic and in constant pain
- At 28, she announced her intent to no longer eat or drink
- She was competent and understood risks
- Received a feeding tube against her will
- Court ordered tube removed; barred replacement without consent
- The right to refuse treatment is not limited to terminally-ill patients
Nancy Cruzan

- 1983: in a motor vehicle accident; never regained consciousness (PVS)
- 1988: parents sought removal of feeding tube
- Hospital refused without court order
- Trial court ordered removal of tube
Nancy Cruzan
Missouri Supreme Court

- Must have clear and convincing evidence of a patient’s wishes (e.g., an advance directive) before removing a feeding tube
- The state’s interests in preserving life outweigh the patient’s interests
- Artificially administered hydration and nutrition are not medical treatments
• Competent adults have a constitutional right to refuse unwanted treatments
  – 14th Amendment “liberty interest”
• This right extends to incompetent persons through their surrogates
• Artificially administered hydration and nutrition are medical treatments
Precedence of Landmark Cases

Not a right to die, but a right to be left alone

- A competent patient has the right to refuse or request the withdrawal of LSTs
- The incompetent patient has the same right (exercised through a surrogate)
- No difference between withholding and withdrawing LSTs
- Artificial fluid and nutrition are medical treatments
- No physician liability for granting such requests
• Ethics:
  – Recommended spiritual care consult
  • Clarified patient’s goals: “I’d rather die a saved man than live a life of damnation”
  • Consulted with leaders of the Pentecostal faith, who discussed with the patient and supported his decision
    – Supported the patient’s decision to withdraw life-sustaining treatments if it does not support his goal of care (religious salvation)
• With hospice present at the home, LVAD support was withdrawn while patient was surrounded by his friends and family
  – Died shortly thereafter
Ethics Case #3

• 58 year old female with widely metastatic breast cancer, is brought to the emergency room by her family after being told by an outside hospital that no further chemotherapy or radiation therapy options existed for her
  – In addition to breast cancer, patient also has a small bowel obstruction, worsening kidney function, and is diagnosed with peritonitis

• Over the next several days, despite aggressive measures to stabilize patient’s medical state, patient continues to worsen
Ethics Case #3 (cont.)

• Family demands that additional chemotherapy be provided
  – Cite their cultural values which, per family, demand that the patient be allowed “to fight” the cancer until her last day
  – This belief was supported by the patient, when she was able to speak

• Medical team states that further chemotherapy would shorten patient’s dying process and likely worsen her symptoms (pain, nausea, etc.).
  – Ethical question: Are they obligated to provide the care requested?
Futility

• An intervention is considered futile when it cannot accomplish the intended physiologic goal.

• The concept of how to define futility and when to invoke it is controversial.
  – Judgments are often mistaken or problematic
  – Futility applies to few patients
  – Unilateral decisions polarize parties
  – Value judgments may be masked as scientific expertise

http://eduserv.hscer.washington.edu/bioethics/topics/futil.html
Potentially Inappropriate and/or Non-Beneficial Treatments

• **Non-Beneficial Treatment** - Treatments that the health care team believes have no reasonable medical chance of achieving the outcome sought beyond minor physiologic changes are outweighed by the danger to the patient, and/or would not achieve a medically appropriate goal are considered to be non-beneficial treatments.
  
  – Under this definition, futile interventions may be considered a type of non-beneficial treatment.

• **Potentially Inappropriate Treatment** - Treatments that, while they may achieve a certain goal, are outside the standard of care.
  
  – Use of broad-spectrum antibiotics to treat a simple bacterial infection or use of high-dose narcotics to treat chronic, non-terminal pain.

Withdrawal and Withholding of Medical Treatments (Non-Beneficial Treatment/Intervention) Policy

When a medical intervention is futile, the attending physician is under no obligation to initiate, or to continue such treatment, even though it may have been requested by the patient, or the patient's family or representative(s).

An intervention may be considered futile when it satisfies all of the following conditions:

1. The attending physician has determined that the patient's condition is terminal and incurable;
2. The attending physician has determined that the intervention in question is not required for relieving the patient's discomfort; and
3. The attending physician has determined that the intervention in question offers no reasonable medical benefit to the patient, and that such intervention could serve only to postpone the moment of death.

Note: The issue of futility has not been considered under Michigan law so this section of the Policy sets forth the Hospital's ethical position.
Futility-Resolution

• Many cases of invoking futility involve significant barriers or breakdown in trust and communication, between the patient/surrogate and the health care team.

• Resolution can be best achieved by mediation with staff trained in conflict mediation (palliative care, patient relations etc.)

• Due process approach to cases involving ongoing conflicts about continued ‘futile’ treatment
  • Negotiate disagreements
  • 2nd opinion by consultant if appropriate
  • Ethics consultation
  • Seek transfer of care
  • MD has no obligation to provide futile treatment

AMA Code of Ethics § 2.037
Ethics Case #3 (cont.)

- Ethics Consult
  - Supports physicians in not providing care they deem to be inappropriate or futile
  - Recommended a good-faith effort be made to seek second opinion from other clinicians and other institutions
  - Recommend reframing the role of chemotherapy
    - In this case, further chemotherapy would limit the patient's natural ability to “fight” the cancer
  - Recommended Palliative Care Consult

- After much discussion and psychosocial support to the family, they expressed understanding and acceptance of the decision to not provide further chemotherapy
  - Patient expired 36 hours after ethics consult was placed
Ethics Case #4

- 87 year old man with end-stage COPD, admitted to the hospital after a fall results in a broken hip; not deemed a surgical candidate because of his compromised pulmonary status, and during his hospitalization develops severe multi-focal pneumonia
  - DNAR status is clearly stated in his advance directive and this is supported by family
- Over 48 hours, he worsens despite aggressive care and appears to be approaching the end of his life.
  - After much discussion, the decision is made to transition to a comfort-focused plan of care
    - Includes morphine for pain and dyspnea
Ethics Case #4

• Overnight, patient appears to be in great distress related to his known hip fracture

• Overnight nurse refuses to administer morphine given his respiratory status
  – Family very distressed by patient’s apparent suffering as he approaches the end-of-life
Doctrine of Double Effect

- States that clinicians can institute a therapy that may cause a bad effect if the intention is to provide a good effect
  - The bad effect can be foreseen, tolerated and permitted but it must not be intended
  - The good effect must outweigh the bad effect
  - The bad effect must not be a means to the good effect (i.e. I intend to kill this patient so he/she no longer feels pain). If the good effect were the direct causal result of the bad effect, the agent would intend the bad effect in pursuit of the good effect.

- Often cited in end-of-life care, when aggressive symptom control risks shortening a life

- At its heart the idea that intentions matter
Conclusion

• End of life care is an emotional time for all involved, and can be fraught with conflict, ethical or otherwise

• The general concepts of medical ethics (autonomy, beneficence, non-maleficence, justice) apply

• Other ethical concepts can guide appropriate care for those at the end of life
References

- EPEC curriculum; www.Epec.net