

Ethics in Palliative Care



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Acknowledgement



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Disclaimer



While this program provides educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some of the information cites the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling.

Accordingly, the official prescribing information should be consulted before any such product is used.

Objectives



- List and discuss the ethical principles that underlie clinical care for seriously ill and dying patients:
 - Advance care planning
 - Decision making capacity
 - Informed consent
 - Withdrawal of life-sustaining treatments
 - Futility

Case Question



- An 83 year old female in the early stages of dementia is diagnosed with colon cancer during a routine work-up for anemia. The cancer is potentially curable with surgery. The nurses tell you that the patient refuses surgery but that she hasn't been oriented. Her son, who is the patient's POA for healthcare, wants curative surgery for the patient. The patient's daughter says that her mother was devastated to learn of her dementia and made statements that she does not want life to be prolonged.
- Who should make the decision about surgery in this situation?

Principles



- The discipline of medical ethics has helped develop a framework for decision making that applies to care near the end-of-life.
- Five key issues will be reviewed that have direct applicability to daily patient care.

Key Issues in Patient Care



1. Advance Care Planning
2. Decision Making Capacity
3. Informed Consent
4. Withdrawal/withholding of life sustaining treatments
5. Futility

Advance Care Planning (ACP)



- ACP is a process of planning for future medical care
 - Values and goals are explored and documented
 - Determine a proxy (surrogate) decision maker
- Implies open communication between patient, health care proxy and health care provider
- The documents created as a result of ACP are called ***Advance Directives***

Regional Documents



- The POLST form is an example of a regional or state system to document and track patient wishes for life-sustaining treatments. Such documents may include:
 - DNR status
 - Antibiotics
 - Artificial nutrition and hydration
 - Level of medical intervention

See www.polst.org for more information

Advance Directive (AD) Planning



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

Advance Directive Planning *should be:*



- Part of routine outpatient care for all patients
- Reviewed and revised with changes in medical condition
- Immediately accessible by the physician, patient and agent

Variation Across States



- States have different statutes that impact key aspects of advance care planning, such as:
 - How documents are constructed
 - Legal requirements for witnessing signatures
 - Activation of agents as decision makers
 - Order of legal authority for surrogates to make medical decisions if no document exists.
 - Withdrawal/withholding of artificial nutrition and hydration

5 Steps for Advance Care Planning *



1. Introduce the topic
2. Engage in structured discussions
3. Document patient preferences
4. Review/update with change in condition
5. Apply directives when need arises

* EPEC Curriculum; www.epec.net

Decision Making Capacity



- **Decision making capacity** is a medical term, determined by clinicians, usually physicians or psychologists:
 - Implies the capacity to provide *informed consent to treatment*
 - Depending on state law, may require more than one physician, or a physician and psychologist, to invoke a state Power of Attorney for Health Care document, so that a designated *Health Care Agent* becomes the legal decision maker.

Decision Making Capacity



- **Competence** is not a medical term
 - can only be adjudicated by a court
 - may or may not be correlated with decision making capacity

Decision Making Capacity



- 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)
 - Ability to make a rational **Evaluation** of the burdens, risks, benefits, and alternatives to the proposed health care
 - **Communicate** a choice (implies ability to communicate)
- A patient who is not fully oriented may still be decisional if s/he can provide the above

Order of decision making



- Patient; if non-decisional ...
- A court appointed legal guardian; if none ...
- The *Agent* (surrogate) designated on a Power of Attorney for Health Care; if none ...
- 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; check with your hospital attorney or ethics committee
 - In states without surrogacy laws, decisions should be arrived through a consensus process of interested parties.

If there is no legal surrogate..



- Decisions should be made according to the patient's previously expressed wishes, if known.
- If the patients 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.

Informed Consent



- Informed consent is a process of shared-decision making between physician and patient or surrogate
- The doctrine of Informed Consent applies to
 - Medical Procedures
 - Medical Treatments
 - Biomedical Research

Elements of Informed Consent



- **Decision Making Capacity**
 - Patient must possess decision-making capacity
- **Information**
 - Sufficient information must be provided that a reasonable patient would need to make a decision
- **Voluntariness**
 - Any treatment decision must be entirely voluntary, without coercion

What Must Be Discussed?



- Nature of procedure
- Risks, including side effects and complications
- Alternative treatments, including no treatment

Note: The clinician should make a recommendation rather than present this information as a “menu” for the patient’s choice

Emergency Privilege



- Physicians may act without obtaining informed consent when all of the following are present:
 - Patient lacks decisional capacity and
 - No one legally authorized to act for the patient is available and
 - Time is of the essence and
 - Serious risk of bodily injury or death exists and
 - A reasonable person would consent

Common Myths



#1 Signed consent forms are required by law for invasive procedures ...

- Signed consent forms are not required by law **except** in special instances (e.g. HIV, genetic testing)
- They may be required by The Joint Commission or hospital policy
- Documentation of discussion should be made in medical record

Common Myths



#2 No informed consent is necessary for patients transported by an ambulance or after a 911 call

...

- Not everyone who presents by ambulance or through the emergency department has a medical condition which fulfills the requirements of the emergency privilege.
- If emergency privilege standard is not met, an informed consent process is needed with the patient or the legal surrogate decision maker.

Common Myths



#3 No informed consent is necessary for low-risk or “low tech” treatments...

- There is no legal difference between high vs. low risk or “low tech” treatments – all require informed consent:
 - ✓ Radiological procedures
 - ✓ Antibiotics
 - ✓ Feeding tubes: NG or PEG
 - ✓ Dialysis
 - ✓ Central line
 - ✓ etc.

Common Myths



#4 Physicians should not introduce bias by making a treatment recommendation

- Informed consent legal standards require *information*
- Informed consent professional standards require *recommendation*
 - ✦ “The physician’s obligation is to present information...*and to make recommendations...*in accordance with good medical practice”

AMA Code of Ethics 2008-9 8.08 Informed Consent

Summary - Informed Consent



- Informed consent is a process, not a piece of paper.
- When in doubt, more documentation of discussion is appropriate.
- The need to provide alternatives, including withholding life prolonging treatments, is a professional standard of practice.
- Even low risk or “low tech” life prolonging medical interventions require an informed consent discussion.

Withdrawal/Withholding



- Current legal/ethical standards
 - ✓ A patient may refuse medical treatment
 - ✓ Surrogates may assert incapacitated patient's right to refuse medical treatment
 - ✓ Withholding and withdrawing are ethically and legally equivalent
 - ✓ Withholding and withdrawing are clearly distinguished as distinct from euthanasia (illegal) or assisted suicide

What are life-sustaining treatments?



- Artificial nutrition (PEG tubes, TPN)
- Artificial hydration (IV fluids)
- Kidney Dialysis
- Ventilator support
- Blood products
- Antibiotics
- Pacemakers and other cardiac support devices

Futility



- When no consensus about the goals of care can be reached, especially in very sick ICU patients, the issue of invoking medical futility is often raised.
- The concept of how to define futility and when to invoke it is controversial.
- The following discussion highlights various issues in the futility debate.

Futility



- Medical futility refers to interventions that are unlikely to produce any significant benefit for the patient or meet a goal of care.
 - *Quantitative futility* - where the likelihood that an intervention will benefit the patient is exceedingly poor
 - *Qualitative futility* - where the quality of benefit an intervention will produce is exceedingly poor

Futility – Strict Definitions



- **Intervention has no pathophysiological rationale**
 - (e.g. ineffective antibiotic)
- **Cardiac arrest despite maximal treatment**
 - (e.g. septic shock with pressors, on dialysis)
- **Intervention has already failed**
 - (e.g. CPR ineffective for asystole after 30 minutes)

Lo B. Resolving ethical dilemmas: a guide for clinicians. 3rd ed. Williams and Wilkins. 2005

Futility – Loose Definitions



- No worthwhile goals of care can be achieved
 - (e.g. cardiopulmonary bypass for failed CPR)
- The likelihood of success is very small
 - (e.g. less than 1% success – Schneiderman LJ, Jecker NS, Jonsen AR, 1990.)
- Quality of life is unacceptable
 - (e.g. PVS and renal dialysis - Renal Physicians Association and American Society of Nephrology Clinical Guideline 2, 1999)

Lo B. Resolving ethical dilemmas: a guide for clinicians. 3rd ed. Williams and Wilkins. 2005

Argument in favor of invoking futility



“Even though futility determinations in resuscitation involve value judgments, certain sorts of value judgments must be made unilaterally by physicians as part of reasonable medical practice.”

Tomlinson T, Brody H. Futility and the Ethics of Resuscitation. JAMA 1990; 264:1276-1280.

Argument in favor of invoking futility



“The goal of medicine is to help the sick. There is no obligation to offer treatments that do not benefit the patient. Futile interventions are ill advised because they often increase a patient's pain and discomfort in the final days and weeks of life, and because they can expend finite medical resources.”

<http://depts.washington.edu/bioethx/topics/futil.html>

Argument in favor of invoking futility



“Although the ethical requirement to respect patient autonomy entitles a patient to choose from among medically acceptable treatment options (or to reject all options), it does not entitle patients to receive whatever treatments they ask for. Instead, the obligations of physicians are limited to offering treatments that are consistent with professional standards of care.”

<http://depts.washington.edu/bioethx/topics/futil.html>

Problems with invoking futility



- Judgments are often mistaken or problematic
- Futility applies to few patients
- Unilateral decisions polarize parties
- Value judgments may be masked as scientific expertise
- Physicians don't understand they are not obligated to offer/recommend all interventions

Lo B. Resolving ethical dilemmas: a guide for clinicians. 3rd ed. Williams and Wilkins. 2005

AMA Code of Ethics



- All health care institutions should adopt a policy on medical futility
- Recommends a “Due Process” approach to cases involving ongoing conflicts about continued ‘futile’ care
 - 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 2008-9 2.037 Medical Futility in End-of-Life Care

Futility-Resolution



- Using the term futility with patients or families can lead to mis-understandings and anger
- In most cases where the issue of futility arises, this is a breakdown in trust and communication between the patient/surrogate and the health care team.
- Resolution is best achieved by following principles outlined in the [Running Goal Setting Family Conference](#) module.

Case Question



- An 83 year old female in the early stages of dementia is diagnosed with colon cancer during a routine work-up for anemia. The cancer is potentially curable with surgery. The nurses are telling you that the patient refuses surgery but that she hasn't been oriented. Her son, who is the patient's POA for healthcare wants curative surgery for the patient. The patient's daughter says that her mother was devastated to learn of her dementia and made statements that she does not want life to be prolonged.
- Who should make the decision about surgery in this situation?

Answer



- Patient should first be assessed for decisionality. She may be decisional even though she is not oriented.
- If the patient is not decisional, her HCPOA is the next decision maker. Conversations should be initiated to explore what the patient's wishes would be in this situation, if she were decisional. Although the patient's daughter does not have any legal authority, her statements about what her mother would have wanted may help the HCPOA in making a decision for the patient.

Learning Points



List 3 new things you learned from this presentation.

- 1.
- 2.
- 3.

References



- AMA Code of Ethics <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.shtml>
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