Medical Ethics: Informed Consent
Advanced Directives
and
Patient Advocacy
Common Ethical Issues Encountered by House Officers

- Who decides on a course of treatment?
- What constitutes “informed consent”?
- What happens when a patient refuses treatment?
- Does my patient have decision making capacity?
- When is a treatment futile?
- How do I maintain confidentiality?
- What are the exceptions to confidentiality?
- Must I always tell the truth to patients?
- How shall I deal with my mistakes?
- How can I resolve conflicts with patients, attendings, colleagues, and staff members?
Who decides?

• Patients with decision making capacity have the right to make decisions regarding their own care.
  • This is true even if you don’t agree with their decision.
  • We have a duty to provide patients with adequate information to make an informed decision.

• Patients with decision making capacity have the right to refuse any medical treatment.
  • This is true unless a court order mandates such treatment (e.g. effective chemotherapy for a young child with leukemia, even though the parents refuse.)
Informed Consent 1

- **Informed consent**
  - Is a process involving conversation between the patient (or surrogate) and the physician
  - The purpose of a “consent form” is to document the process
  - The components of informed consent include
    - **Disclosure**
    - **Voluntariness, and**
    - **Capacity**
Informed Consent 2

• **Disclosure – You must disclose**
  • The patient’s clinical status, diagnosis, and prognosis
  • The range of medical interventions
  • The risks of recommended treatment
  • The benefits of recommended treatment
  • The risks and benefits of alternatives
  • And give the patient (or surrogate) an opportunity to ask questions and have them answered
Informed Consent 3

- **Voluntariness**
  - Coercion is prohibited
  - Undue influence or manipulation is prohibited
- **Decision Making Capacity (all 4 required)**
  - Ability to understand medical information
  - Ability to apply personal values to medical options
  - Ability to understand consequences of the decision
  - Ability to communicate a choice
Deciding on a treatment when the patient can’t choose.

- A patient may lack decision making capacity because of
  - age (minors)
  - infirmity (dementia, delirium, coma)
  - mental impairment (developmental defect, psychosis)
- Adults are presumed to have capacity, unless evidence shows otherwise.
- Any physician may evaluate decision-making capacity, and two physicians need to document if a patient lacks capacity.
- If a patient **lacks capacity due to mental illness**, a psychiatrist must evaluate and concur.
Advance Directives

• A document or a statement
  ✓ made by a patient who has decision making capacity
  ✓ about how he/she would like to be treated (or who should make decisions about care)
  ✓ if and when he/she loses decision making capacity.

• Written advance directives
  ✓ Selecting a Health Care Agent (by completing Health Care Proxy form)
  ✓ Living will
  ✓ DNR order

• Oral advance directives
  – Verbal statements made by the patient when they have capacity which may provide evidence of the patient’s preferences
Health Care Agents

- Appointed in accordance with New York’s Health Care Proxy law
- When a patient is no longer capable of making decisions, the patient’s chosen Health Care Agent is fully empowered to make health care decisions as if he or she were the patient, with two exceptions...
Limits on Health Care Agents

1. For withdrawal of artificial nutrition and hydration (ANH), under the 1991 New York Health Care Proxy law, the Agent must act on the patient’s explicitly expressed wishes.
   - These may appear in writing on the proxy form,
   - Or the Agent must report that the patient explicitly told him or her that the patient did not want to be sustained on ANH.

1. This limit to the NY Health Care Proxy Law is somewhat inconsistent with the 2010 Family Health Care Decisions Act, which grants family members the ability to make decisions about declining artificial nutrition and hydration for patients who are terminally ill, permanently unconscious, or have an incurable condition if the family member feels the patient would find hydration and nutrition an “extraordinary burden”
1. You may challenge the Agent’s decision *only* if you have strong reason to believe that he/she is going against the patient’s expressed wishes.

- Challenging an agent leads to an administrative *mediation process* and going to court to contravene an agent’s decisions.
- The mere fact that you believe an Agent will benefit in some way from the patient’s death does not constitute evidence that the Agent is going against the patient’s wishes.
Living Wills

- Living wills are legal in New York State
- The problem with living wills is that many are not very specific, so there are often differences in interpretation, especially between the patient’s surrogate(s) and the health care team.
  - Words like “terminal illness,” “extraordinary,” or “only prolong my dying” are open to broad range of interpretations.
- If the patient has both a living will and a health care agent, the agent’s interpretation of the living will has precedence over the health professional’s interpretation.
2010 New York Family Health Care Decisions Act (FHCDAA) and Surrogate Decision-Makers

• Only 20% of patients have named a Health Care Proxy
• Patients with Mental Retardation or Developmental Disabilities are covered under the NY 2003 Health Care Decisions Act for Persons with Mental Retardation (HCDA), which has a process that Risk Management will help your team navigate – notify them if you have an end-of-life issue or need a surrogate medical decision-maker for such a patient
• The Family Health Care Decisions Act of 2010 covers surrogate medical decisions for all other patients
2010 New York Family Health Care Decisions Act (FHCDA) and Surrogate Decision-Makers 2

- Provides Legal Authority for family members to consent to:
  - “routine medical treatment” decisions (generally those not requiring a written consent)
  - “major medical treatment” decisions (usually those requiring a written consent form)
  - withholding or withdrawing of life-sustaining treatments (CPR, ventilators, dialysis, feeding tubes) for patients who have a terminal condition (<6 months prognosis), are permanently unconscious, or have an irreversible or incurable condition
2010 New York Family Health Care Decisions Act (FHCDA) and Surrogate Decision-Makers

- Under FHCDA, the surrogate decision maker is the highest priority of:
  - Legal guardian
  - Spouse or domestic partner
    - Defined in the law as: 1) formal relationship under law of other states, 2) person recognized as beneficiary or covered person under partner’s health insurance or employment benefits, or 3) person is mutually interdependent on the other person for support as evidenced by the totality of circumstances
  - Son or daughter (age 18 or older)
  - Parent
  - Brother or sister (age 18 or older)
  - Close friend
    - Defined in the law as - a person who has maintained such regular contact with the patient as to be familiar with the patient’s activities, health, and religious or moral beliefs, and who presents a signed statement to that effect to the attending physician
2010 New York Family Health Care Decisions Act (FHCDA) and Surrogate Decision-Makers

- Two Substantive Standards for Decision-Making – in NY substituted judgment is the first standard to for health care agents/proxies and surrogates, best interests second
  - “Substituted judgment” – The surrogate should make the decision that the patient would have made if he/she had capacity, taking into account his/her actual interests and preferences
    - Asks: What would this patient choose if he/she were capable?
  - “Best interests” – if it is impossible to ascertain what the patient’s actual preferences and values are (or if the patient has never been capable of forming preferences or values), the surrogate should decide on the basis of the patient’s well-being and best interests
    - Asks: What option has the best (or least worse) consequences for the patient? (i.e., most favorable ratio of burdens to benefits)
DNR Orders 1

• A “Do Not Resuscitate” (DNR) order means that CPR will not be performed if the patient has a cardiac or pulmonary arrest.
• A DNR order does not refer to, or restrict, any other treatments the patient is currently receiving or might receive.
  ▪ To withdraw or withhold other life-extending treatments requires separate consideration of those treatments.
  ▪ The conversation with the patient should focus on overall goals of therapy.
  ▪ When the goals are established, the specific treatments will follow.
DNR Orders 2

- To write a DNR order, the physician must
  - Have the patient’s permission, or
  - If the patient lacks capacity, the permission of a health care Agent as designated under the New York Health Care Proxy statute – named by the patient when they had capacity, or
  - If the patient lacks capacity and does not have a Health Care Proxy/Agent, the permission of a family Surrogate as designated in the New York Family Health Care Decisions Act – a surrogate can only consent to a DNR if the patient is terminally ill (<6 month prognosis), permanently unconscious, or has an irreversible or incurable condition
  - The patient or surrogate is not required to sign any forms.

- Even without a DNR order, CPR need not be initiated if the attending physician is present at the time of the arrest and believes that CPR would be futile, but
  - A DNR order cannot be written prior to the arrest on this basis, and
  - The determination must be made at the time of the arrest.
Artificial Nutrition/Hydration 1

- Tube feeding (NG, PEG) and TPN are medical treatments and may be refused or withdrawn similar to any other treatment.
- Feeding by hand is basic human care and cannot be withdrawn, except for a strong medical reason.

- Bottom line questions
  - What are the goals of treatment?
  - Is a PEG likely to achieve these goals?
Artificial Nutrition/Hydration 2

- Common myths
  - PEG as a “bridge” to better swallowing (this only happens in a small percentage of cases)
  - Need a PEG to get into a nursing home (this is not true if patient is placed on a hospice program in the nursing home)
  - It is illegal not to feed the patient with a PEG (see “Advance Directives”)
  - PEG will prolong life (this is usually not true for patients with dementia, cancer, or severe neurological deficits)
  - PEG will prevent aspiration (this is simply not true – patients may aspirate oral secretions, we make up to 1 liter per day of saliva and nasopharyngeal mucous, or regurgitated tube feeds)
  - PEG will make the patient more comfortable (PEG causes more discomfort than it alleviates)
Three confusing but important concepts

- Futility
- Comfort care
- Brain death
What is “Medical Futility”? 

- **Futility means**
  - The specific treatment (e.g. CPR) will not achieve its physiological goals (e.g. an effective and sustained cardiac rhythm)

- **What to do if you think the situation is futile**
  - Coordinate the message.
  - Select a primary communicator.
  - Increase open-ended contacts with the family.
  - Spend a lot of time listening.
  - Selective referrals—chaplain, etc.
What is “Comfort Care”? 

- Comfort care should not be a euphemism for “withdrawing all diagnostic tests and treatment”.
- Comfort care means
  - Providing whatever it takes to maximize the patient’s comfort and quality of life.
  - This is the most compassionate standard of care when the medical condition cannot be ameliorated or reversed.
- Thus, the specifics of comfort care must be individualized for each patient.
What is “Brain Death”?

- Brain death is a shorthand way of saying, “The neurological criteria for the determination of death apply in this case.”
  - This means the complete absence of both cortical and brainstem activity.
  - Brain death is recognized in all 50 states.
What is “Brain Death”?

• **The brain dead person is dead**
  - Therefore, in theory there is no need to obtain family consent to withdraw “life-support.”
  - However, New York and other states recognize that families may need time to come to grips with the situation, especially since an acute injury or illness is often involved.
  - Consequently, we must allow a reasonable period of time for families to adjust to the death.
Getting help with ethical questions

- Senior residents
- Fellows
- Attendings
- Consultants
- Hospital Ethics Committee
- Other experienced staff, e.g. chaplaincy, risk management, hospital administration
Hospital Ethics Committee

• **Ethics Case Consultation Service**
  - Consultants on-call, 24 hr/day, 7 d/week
  - Respond by phone or in person
  - Formal ethics case consultation involves meeting, including attending, team members, family members, and consultants.

• **Consultation Outcomes**
  - Recommendations
  - Chart note
  - Follow-up
  - Repeat consultation meeting, if needed
  - Evaluation
An Invitation

• We are interested in hearing about your questions and concerns regarding ethical issues in patient care.
• Members of the ethics committee would be happy to conduct informal “ethics rounds” or brief in-service presentations on your unit.
• If you have questions, or wish to initiate a consult, just give us a call
  ✓ Request the ethics consultant on call (ethics beeper)
By clicking the button below, you attest that you have viewed this presentation and have understood all its contents.

After clicking the button, you will be returned to the Orientation website.