Introduction

- Ethical Principles
- Ethics in dementia care
- Ethics is everyday
- Approach to Ethical Dilemmas in the care of patients with dementia

Principles of Medical Ethics

- Autonomy
- Beneficence
- Non-maleficence

Principles: Autonomy

- Right to information and self-determination
- Free and informed consent
- Free will - intentional participation in treatment
- Respect and dignity

Principles: Beneficence

- Do only that which benefits the patient
- Patient's welfare is the first consideration
- Competent providers are expected

Principles: Nonmaleficence

- Try to avoid doing harm
Principles: Justice

- Actions are consistent, accountable and transparent
- No discrimination based on age, sex, religion, race, position or rank
- Greater good of society
- Equity and distribution of burden & benefits

Fidelity

- We should always tell the truth and be truthful but what should be done. But, are things different with a person with dementia?
- Is lying ethical?

Confidentiality

- We should always keep the information we have learned about people we care for safe and private.

Ethical Principles in Dementia Care

- Capacity and Competency
- Quality of life
- Substituted judgment

Principles: Capacity

- **Capacity:** a clinical judgment that addresses whether or not a person is capable of understanding health care options and participating in decision-making about one's own health care.

Principles: Competency

- **Competence:** Legal concept presumes that someone over the age of 18 has the right to make decisions about his/her health care unless a judge has determined otherwise.
**Principles: Quality of Life**

- What does ‘Quality of Life’ mean?

- Problematic since diminished emotional life can be part of dementia

**Principles: Quality of Life**

- Discuss goals of dementia care

- Caregivers can provide whatever forms of pleasure and comfort are possible.

- Caregivers should resist actions that diminish comfort.

**Principles: Quality of Life**

- How can demented individuals continue to derive joy?

- Emotional and relational well-being

- Expression of respect may be through touch.

**Principles: Substituted Judgment**

- If no advance directive, determine whom to approach about critical care decisions.

- Without legal guidance, the most frequent hierarchy is the spouse, then the adult children, and then the parents.

- Encourage the decisions that best support the patient’s values.

**Principles: Substituted Judgment**

- How would the patient, if able to fully understand his or her condition make the decision.

- Requires the decision makers to put themselves in the patient’s shoes, using the patient’s values to make the decision.
Case Study

Range of Decisions

- DNR: yes or no;
- TPOPP (Transportable Physician Orders for Patient Preferences – coming April, 2014 to Wichita/Sedgwick County)

Now, we have a much broader choice of decisions.
- Do-not-hospitalize orders;
- Medically assisted nutrition or hydration
- Initiate or prohibit future interventions: (i.e., antibiotics, surgery, chemo-therapy, etc);

Range of Decisions

- Discontinuing life-sustaining treatments
- Providing sufficient analgesia necessary to control pain

Conflict of Interests

- Between physician and patient
- Between physician and family
- Between family members
- Between physicians and payors
- Between medical ethics and society

Conflicting Principles

- Between autonomy and beneficence
- Between beneficence and substituted judgment
- Etc.

Medical Uncertainty

- Prognosis is difficult
- Risk/benefit analysis may be uncertain
Resolution of Ethical Dilemmas

- Family Meeting
- Ethical committee’s consult

Recommended Steps for Discussing End-of-Life Plans of Care
(from American Academy of Family Practice)

1. If present, advance directive documents should guide the subsequent process as much as possible.

2. If neither DPOA-HC nor any written directive is available, determine who should be approached to make the decisions.

3. Find a quiet meeting place where all are comfortably seated.

4. Sit down, and establish rapport with each person present.

5. Clarify the difference between substituted judgment and decisions in the best interest of the patient.

6. Try to develop a consensus about the patient’s clinical situation, especially prognosis and goals of care.

7. Question whether the patient has ever communicated clear advance directives or a values history.
   a. If so, reinforce the principle of substituted judgment following the patient’s previously stated preferences. Proceed to #9.
   b. If no specific statements or directives had been given, try to recreate a values history at least on the issue of survival versus comfort and dignity.

8. Share your meaning of the patient’s words and behaviors. Use such statements and recommendations to support family’s impressions or to provide a professional observation upon which the family can build. If the physician’s recommendation differs from the family’s, seek clarification of the differences.

9. After such a discussion and negotiation, restate or reframe the value statement that best matches the patient’s expressed or implied values.

10. Discuss procedures and directives, if appropriate.

11. Depending on the family’s substituted judgment, describe what will and will not be done. If not choosing aggressive care, assure the family of the attention to patient comfort and dignity that will occur. Seek confirmation of understanding and agreement.

12. Throughout the interview, respond to feelings and to support family members. Pay attention to the family’s emotional responses.
References


