

# Ethical Issues at the End of Life

Katherine Wasson, PhD, MPH, HEC-C

Professor

Neiswanger Institute for Bioethics

Loyola University Chicago



# Common Issues as Patients Approach the Dying Phase of Life

- How much life sustaining therapy is “enough”?
- What are the “goals of care”?
- What would ----want?
- Is “stopping” ----- ethical?
- Who is making/can make decisions?
- What do “we” (patients, families, healthcare team) do now?
- How much longer?
- How do “we” cope with this loss?

# Case 1: Mrs C

- Mrs. C is 67 y/o non-resectable colon cancer (6 mo)
- Current admission: sepsis from bacteremia via colon
- Edema, skin excoriation, can't move legs
- Pt communicates by nodding
- Pt given antibiotics for infection
- Pt wants to be "Full Code", "Do Everything"
  
- 3 days later – differential of CHF or pulmonary embolism
- Mrs. C confused, brain mets?, intubated and admitted to the ICU

# Case 1: Mrs C

- Patient's daughter is making decisions on behalf of her mother
  - Appropriate surrogate decision maker
  - Mother wants “everything done”
- Daughter, physician and ethics consultant discussing plan of care, in particular potential withdrawal of life-sustaining therapy (LST)

# Futility Case

- Scene 1
- <https://luc.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=50d62169-f5af-46e6-8691-ab0d00fed196>

# Ethical Issues

- What went well or poorly in this discussion?
  - What are the clinical issues?
  - What are the ethical issues?
- 
- Key goal of ethics consultation is to identify and clarify the ethical issues, facilitate conflict resolution

- Scene 2:
- <https://luc.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=19cf501b-7ab1-415e-80ea-ab0d00fed1ea>

How do physicians  
think about ethical decisions?

# Physician Decision-Making Principles

- Non-maleficence
- Beneficence
- Respect for Autonomy
  - Physician, patient, parent
  - What about minors?
- Justice
  
- Additional Issues at End of Life
  - Duty to care
  - Best Interests
  - Quality vs Quantity of Life

# Decision Making for Adults

- Gold Standard = obtaining wishes directly from patient with decision-making capacity
- If not possible, then ethically appropriate decision maker should be identified
  - Power of Attorney for Healthcare (POAHC)
  - Surrogate decision maker

# Decision Making for Adults

- Advance Directives
  - POAHC: patient has appointed a person to make decisions for them when unable to speak for self
    - Legally documented
    - Request documents for chart
  - Living Will: outlines patient's wishes regarding end-of-life decisions
    - Gives instruction or indication of patient's wishes, i.e. "do everything" or "let me go"

# Decision Making for Adults

- Surrogate Decision Makers
  - Guardian, spouse, adult child, parent, adult sibling, adult grandchild, close friend, guardian of estate
- IL Healthcare Surrogate Act: Forgoing Life-Sustaining Treatment

## *Qualifying Conditions*

- Terminal condition
- Permanent unconsciousness
- Incurable or irreversible condition

*If surrogate is named POA in a DPAHC document, qualifying conditions do not matter*

- Other states – unspecified order of surrogates, next of kin, consensus

# Decision Making for Adults

- Substituted Judgment Standard
  - Patient without capacity cannot express own wishes
  - What would the patient want in this circumstance?
  - NOT – What does surrogate want for the patient?
- Best interests Standard
  - Patient without capacity with unknown preferences
  - Surrogate should determine highest net benefit of options given patient's known wishes, values
  - Assess risks/burdens/benefits

Beauchamp and Childress 2013, pp. 226-29

# What are benefits and burdens of interventions?

- Benefits = improvements in the patient's health or in the relevant goals of care
  - Subjective standard—from the patient's perspective
- Burdens = medical or non-medical
- Ethical and Religious Directive, No. 57
  - *“Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.” Burden applies beyond patient to “family or the community”*

# What about Pediatrics?

## Parental Decision Making

- Parents have legal and moral authority to make decisions for their children
  - Assumed to care, know unique needs
  - Assumed to balance competing familial interests
  - They face consequences of these decisions

Diekema, Mercurio, Adam (2011, p 1-2)

# Parental Decision Making

- The Harm Principle: “Does the decision made by the parents *significantly increase the likelihood of serious harm* as compared to other options?” (Diekema 2004, 2011, emphasis added)
  - Recognizes parental authority and tries to define its parameters
  - Minimum threshold below which decisions cannot fall, i.e. imminent harm
  - When should it be overridden by the state, i.e. medical abuse, neglect
  - Based on an ethics of protection not respecting the interests of the child

# Pediatric Decision Making

- Assent = active agreement of a minor to participate in a diagnostic/treatment regime
- Assent is not informed consent
- Focuses on capacity and developmental stage
- Age groups
  - Less than 7 = lack capacity
  - 7-13 = developing capacity (case by case assessment)
  - 14+ = presumed to have capacity unless proven otherwise
  - (Cardwell v Back 1987)

# Adolescent Decision Making

- Presumed to have capacity
- Who should make the decisions about treatment options? What's the rationale?
- Legal vs. Ethical may diverge

“Doctor, Can you speed this up?”

Euthanasia and Physician Assisted  
Death/Suicide

# The Dying Process...

## Ethics of dying

- Euthanasia
- Physician Assisted Dying/Suicide (PAD/PAS)
- Withholding or withdrawing LST is not euthanasia or PAS/PAD – you are not “killing” the patient

# Euthanasia

## (Voluntary Active Euthanasia)

- The physician intentionally
  - ends the patient's life
  - at the patient's request
  - with the patient's fully informed consent
  
- No state in the United States permits euthanasia

# Physician Assisted Dying or Suicide (PAD or PAS)

- At the patient's request, a physician provides
  - a prescription for a lethal dose of medication
  - that the patient can self-administer by ingestion
  - with the explicit intention of ending life
  - Patient meets certain criteria, i.e. terminal, 6 mo, decision-making capacity
  - PAD/PAS: Oregon (1997), California, Colorado, Hawaii, New Jersey, New Mexico, Maine, (Montana), Vermont, Washington, Washington DC

# Withholding/Withdrawing LST

- **AMA Code of Ethics:** “There is no ethical distinction between withdrawing and withholding life-sustaining treatment. A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law.”
- “Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis.”

American Academy of Hospice and Palliative Medicine (AAHPM)  
Statement on Physician Assisted Dying (June 2016)

....Social policy concerns notwithstanding, the Academy recognizes that in particular circumstances some physicians assist patients in ending their lives. Efforts to augment patients' psychosocial and spiritual resources so that they are better able to manage their **suffering**, may make palliative treatments of **physical symptoms** more effective, and may make these circumstances rarer. Nevertheless, some patients will continue to desire PAD...

-Catholic Healthcare does not permit PAD/PAS – Ethical and Religious Directives and Principle of the Sanctity of Life

# Key Points

- Adult and Surrogate Decision Making
- Assent vs Consent for Minor
- Pediatric Decision Making = sliding scale of capacity
- Withholding/Withdrawing LST
- Euthanasia and PAD/PAS

# STEP 2 Questions

- *Source Board Vitals Q Bank*

A 76- year old man with decision making capacity has end stage renal disease from diabetes mellitus. He receives hemodialysis three times weekly. He has decided to stop dialysis treatment understanding that he will die as a result. His wife and children are asking for treatment to be administered emergently.

Which of the following is the most appropriate next step?

- A. Consult a psychiatrist to confirm the patient's decision-making capacity.
- B. Consult ethics.
- C. Dialyze the patient against his will to avoid legal liability.
- D. Obtain a court order to administer dialysis.
- E. Offer to hold a meeting with the patient and his family members to discuss the decision to stop dialysis

A 12-year old male patient is terminally ill with metastatic osteosarcoma. He asks how much longer he will live. His parents have requested that their child not receive information about the severity of his condition. What is the most appropriate next step?

- A. Request the patient's parents discuss the prognosis with their son.
- B. Dismiss the patient's question since a patient must be 18 years or older before participating in this type of conversation.
- C. Provide the patient with an estimate of survival based on a literature review.
- D. Discuss the patient's condition honestly without providing an estimated survival time.