End of Life Ethics and Ethical Myths
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“Issues” that Arise as Patients Approach 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?

Pediatric Case

• Jessica Jones 14 y/o w Acute Myeloid Leukemia for the past 3 years
• 1st stem cell transplant, chemo, and radiation therapy
• Remission – now AML has recurred
• 2nd stem cell transplant begun
• Physician says treatment isn’t working
• Mother wants further treatments including any experimental trials
• Jessica has begun to express a desire to stop aggressive therapy
  -- Christian faith is important to her
• Attending requests ethics consultation for help
Pediatric Case: Scene 1

- https://luc.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=9ace29e1-b8b8-42ee-ba99-a9cf01311210e

Ethical Issues

- Key goal of ethics consultation is to identify and clarify the ethical issues, facilitate conflict resolution
  - What are the ethical issues?
  - What are the clinical issues?
  - What else do you need/want to know to assess the case?

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)
Physician Decision-Making

• Non-maleficence
• Beneficence
• Autonomy
  – Physician, patient, parent
  – What about minors?
• Justice – equality, fairness, equity

Physician Decision-Making

• Additional Issues at End of Life
  – Best Interests
  – Quality vs Quantity of Life

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)

Diekema, Mercurio, Adam (2011, p 2)
Pediatric Case: Scene 3

- https://luc.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=57487e20-9c82-41cd-b6b7-a9cf01334348

Adolescent Decision-Making

- Jessica is 14 y/o
- Presumed to have capacity
- Who should make the decisions about her treatment options? Why?
- What are the specific EOL issues in this case?

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
  – POA for Healthcare
  – Surrogate decision maker
Decision Making for Adults

• Advance Directives
  – Power of Attorney for Healthcare – patient has appointed a person to make decisions for him/her when unable to speak for him/herself
  • Legally documented
  • Request documents for chart
  – Living Will – document which 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”

• Surrogate Decision-Makers
  – Guardian, spouse, adult child, parent, adult sibling, adult grandchild, close friend, guardian of estate

• Surrogate Decisions to Forgo Life-Sustaining Treatments:
  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

• Substituted Judgment Standard
  – Patient without capacity cannot express his/her 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
Withholding/Withdrawal 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.”

Key Points

• Assent vs Consent for Minors
• Legal vs Ethical Considerations
• Pediatric Decision-Making = sliding scale of capacity
• Adult Decision-Making
  – POA, Surrogate
• Withholding/withdrawal

The Dying Process...
Ethics of dying

• Euthanasia
• Physician Assisted Dying
Euthanasia (Voluntary Active Euthanasia)

- The physician intentionally
  - ends the patient’s life
  - at the patient’s request
  - with the patient’s full informed consent
- No state in the United States permits euthanasia
- Euthanasia is legal only in the Netherlands, Belgium, Luxemburg, Colombia, and Canada (as of February 2016)

Physician Assisted Dying (PAD) or Suicide (PAS)

- A physician providing, at the patient’s request
  - a prescription for a lethal dose of medication
  - that the patient can self-administer by ingestion
  - with the explicit intention of ending life
- PAD/PAS has become a legally sanctioned activity, subject to safeguards, first in Oregon in 1997 and, subsequently, in other states - California, Colorado, Hawaii, Vermont, Washington, Washington DC, and by court ruling in Montana

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...