Ethical Issues at the End of Life

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Participants will be able to:

1. Identify ethical issues related to surrogate decision making for dying patients

2. Describe ethical issues related to withholding vs. withdrawing of life sustaining treatment

3. Give examples of how word choice and framing can influence end-of-life decision making

Common cases to consider….

- Mother refuses life sustaining treatment and her daughter insists the patient doesn't have capacity and demands she be a full code
- Staff concerned surrogate decision maker is making treatment decisions which aren't in the patient's best interest
- Some members of the clinical team using the word "futile" when discussing a patient's care and some consultants on the case reporting clinical improvement

She's torturing her mom

- A 74 y/o woman with stage 4 lung cancer is admitted to the hospital with pneumonia. The patient's oncologist recently told her that there is nothing more they can do for her. When the woman entered the hospital she was extremely short of breath and somewhat confused. When the attending discussed code status and treatment options with the patient's daughter /MPOA representative, she said to "do everything." The nurses put in an ethics consult accusing the daughter of asking them to torture her mother.

"almost half (**47.4%) of all patients for whom a consult was requested were in the intensive care unit (ICU)** at the time of the request, and 44.2% died in the hospital."

"**end-of-life was noted as an issue in 73.1% of cases**."

Wasson, K., Anderson, E., Hagstrom, E. et al. HEC Forum (2016) 28: 217.

Withholding

Deciding not to use certain medical means to prolong life in a terminally /chronically ill patient.

This is not killing, but allowing to die of an underlying disease process.

Withdrawing

Deciding to stop using certain medical means to prolong life in a terminally /chronically ill patient.

This is not killing, but allowing to die of an underlying disease process.

The Same

There is not ethical or legal difference between withholding and withdrawing of life sustaining interventions (at end of life).

That is not how it FEELS

- Many patients, surrogates, and providers report struggling more with withdrawing
- And, decisions about different types of LST feel different from others. For example…ventilators and feeding tubes…feeding tubes and hydration….LVADS and pacemakers….

Intention

Withdrawing feels like intending to end life

Autonomous Patients

Know what their own values and preferences are and can make values based judgments about quality of life.

More importantly, they can make them in the moment—so they can change their mind based upon the specific circumstances.

Balancing

Benefits	Burdens
More time with family	Extended inpatient
Relief of discomfort	Expense
	Extends dying process

Unfortunately…

Most patients at the end of life lack the capacity to make their own decisions.

Surrogate Decision Makers

"Surrogate decision makers are authorized to reach decisions for doubtfully autonomous or nonautonomous patients"

(Beauchamp & Childress, 2009)

Standards of Surrogate Decision Making

- The Substituted Judgment Standard—
  - "What would the patient want in this circumstance?"
- The Pure Autonomy Standard
  - Based upon patient's previously expressed wishes or patterns of behavior
- The Best Interest Standard
  - The patient's wishes may not be known and the surrogate decision maker must determine the highest net benefit to the patient from among the available options.

Surrogate Decision Makers

Patient-designated and next-of-kin surrogates incorrectly predict patients' end-of-life treatment preferences in one third of cases.

Arch Intern Med. 2006 Mar 13;166(5):493-7.

Tools to respect patients wishes

- Advance Directives
  - Medical Power of Attorney
  - Living Will
- Advance Medical Orders
  - POST
  - DNR
  - Out of Hospital DNR
- eDirectives Registry

Words Matter

She's torturing her mom

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Reasons for consults…

- Futility
- Torture
- Denial
- The family/doctor is "selfish, difficult, crazy, …
- Providing false options
- Unclear directives
  - Do everything
  - CPR but no intubation
- Careless wording
  - Discontinuation of care
  - Nothing more we can do

Redefining and Reframing

"Definitions are not neutral, they are not just the innocent tools that allow us to describe reality. Rather, they shape our perceptions of reality. They select. They emphasize. They embody a bias. Therefore definitions constantly need redefinition."

Marker, RL, Smith, WJ. The Art of Verbal Engineering. The Duquesne Law Review, 35:81

Reframing

- Death with dignity
- Terminal→Life Limiting Illness
- Terminal Sedation→Palliative Sedation
- Do-Not-Resuscitate→Allow Natural Death
- Futile→Non-Beneficial Medical Treatment
- Physician Assisted Suicide→Physician Assisted Death
- Brain Death→Total Brain Failure
- Palliative Care→Supportive Care

Tractor Accident

A 75 year old man flips over his tractor while mowing the grass and suffers a stroke. The patient was initially intubated, but no longer requires mechanical ventilation. He is minimally responsive and can neither speak nor swallow. His wife reports that the patient would never want to live in his condition and requests the patient be made a DNR. After 10 days, the clinical team approaches the patient's wife about a PEG tube rather than an NG tube. The wife refuses the PEG and requests the NG be removed and the patient not be fed by mouth, despite the fact that both neurology and cardiology report improvement in the patient's condition. She said she's been married to the patient for over 50 years and if they can't guarantee he will be independent again that he would rather be dead.