End of life care

Carol R. Schermer MD

LUMC student case management series

Case

- 75 yo previously healthy man MVC with severe TBI, extensor posturing, rib fractures, pulmonary contusion, leg fxs.
  - HD 3 increasing ventilator support, suspect pneumonia
  - Wife present
  - Oldest son present
  - Advance directives state would not want aggressive care if was terminal

Case

- HD 7 pt become hypotensive, has some ischemic EKG changes, requires aggressive fluid and pressor support
  - Hct=28 , receives 2U prbc
  - Cardiac enzymes markedly elevated
- HD 14 becomes febrile, hypotensive again
  - Suspected sepsis
  - Family decides to lighten up on sedation to “talk to him” but he postures extensively and becomes hypoxic with decreasing sedation

What to do?

- Talk with family
- Honor wishes
- How you go about withdrawing LST

Background

- Of patients dying in hospitals, one-half are cared for in an ICU within 3 days of their death
  - One third spend more than 10 days in ICU
- most deaths in ICUs are due to withdrawal of therapy
- in ICUs most patients cannot communicate regarding death decisions

Background

- Clinicians are oriented to saving lives rather than helping people die
- families rate ICU clinician communication skills as more important than clinical skill
- > 50% of families do not understand the basic information on the patient's prognosis, diagnosis and treatment after a conference

Background

- most people with terminal illnesses die in the hospital
  - aggressive care versus comfort care
    - not clear if patients wishes are valued or used
- hospitals end up providing EOL care
- Physicians, patients, and families may overestimate prognoses

Legal Barriers-1

- "forgoing life-sustaining treatment for patient's without decisional capacity requires evidence of the patient's actual wish"

Legal Barriers-2

- "withholding or withdrawing artificial fluids and nutrition from terminally ill or permanently unconscious patients is illegal"

Legal Barriers-3

- "risk management personnel must be consulted before life-sustaining treatment may be terminated"

Legal Barriers-4

- "advanced directives must comply with specific forms and are not transferable between states"

Legal Barriers-5

- "If a physician prescribes or administers high doses of medication to relieve pain or other discomfort, and the result is death, he or she can be criminally prosecuted"

Legal Barriers-6

- "when a terminally ill patient's suffering is overwhelming despite palliative care, and he/she requests a hastened death, there are no legally permissible options to ease suffering"

Legal Barriers-7

- "The 1997 Supreme Court outlawed physician-assisted suicide"

Legal and Ethical Background

- 1914 Justice Cardoza
  - right of individuals to refuse care
- Dame Cicely Saunders and Elizabeth Kubler Ross
  - 1972 hearings on Death with Dignity
- 1976 Karen Ann Quinlan Case
- 1990 Nancy Cruzan case
- 1990 Danforth amendment-
  - pts must be informed of rights to refuse care
  - right to have advanced directives
- 1991 Patient Self-Determination Act

Legal and Ethical Background

- 1991 Patient Self-Determination Act
  - inform of right to living will or POA
  - patient autonomy
  - informed decision making
  - truth telling
  - control over the dying process
- assumes the individual is the decision maker

Life in the ICU

- Health care is to prolong life, restore health and relieve suffering
- Some patients never regain health or the ability to live independently
- Overall 30-40% of ICU patients will die
  - Increased risk from
    - Advanced age
    - Increased length of stay
    - Organ failure

Life in the ICU

- Artificial life support may deny some patients a peaceful and dignified death
- ICU two goals
  - Save lives by intensive invasive therapy
  - Provide a peaceful and dignified death
- A good death should not be viewed as a failure
  - Death with peace and dignity

Life in the ICU

- Physicians duty to
  - preserve life
  - Ensure and acceptable quality of life
  - When medically futile, ensure comfortable and dignified death.

Palliative Care

- What it is:
  - active total care of patients whose disease is not responsive to curative treatment
    - effective management of pain, emotional, social, psychological, and spiritual support
- What it is not:
  - physician assisted suicide
  - euthanasia
  - homicide

Palliative Care

- Affirms life and regards death as a normal process
- neither hastens or postpones death
- provides pain and symptom relief
- integrates psychological and spiritual aspects of care
- offers a support system for living actively until death
- offers family support to cope with illness and bereavement

Quality End of Life

- Good death: “One free from avoidable distress and suffering for patients, family, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards”

Quality Assessment for the Dying

- Adequate pain management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden
- Strengthening relationships with loved ones

Discussions

- Introductions
- Identification of relevant decision makers
- agenda setting
- Information exchange
- the future: prognosis, uncertainty, and hope
- decisions to be made by clinicians and families
- explicit discussions of dying and death

Discussions

- Information exchange
  - patient's baseline status, values
  - clarification of terms, significance of facts
- Prognosis
  - survival
  - quality of life
  - uncertainty

Discussions

- Decision making
  - surrogates
  - advanced directives
  - options and choices indicated, recommended, selected
  - resuscitation and emergency care
  - transition from curative to palliative care
  - burdens and benefits
  - withdrawal of life-sustaining treatment

Discussions

- Death and Dying
  - what will it look like
  - symptoms, process of care, location, spiritual support
  - directly raise possibility and likelihood of death
  - Closing
    - give family control over timing, time for private conversations, implementation
    - assure patient comfort
    - discuss continuity, further discussions

Communication Style

- Be direct about information in general and dying specifically
- elicit questions/solicit information
- confirm understanding
- summarize
- allow discussion among family members
- express concern/value
- acknowledge caring/complexity/difficulty
- ask about spiritual support
- acknowledge team members

Ethical and Legal Concerns

- Patients, families and physicians find themselves considering clinical actions that are ethically and morally appropriate but raise legal concerns
- State laws and hospital protocols vary
- KNOW your state laws

Ethical and Legal Issues

- Patient is key authority
  - Surrogates need to ascertain patients thoughts on quality of life
- Most state courts support withholding and withdrawing life support from patients who will not regain a reasonable quality of life
- When continued intensive care is futile, curative care should be withdrawn
  - Terminal illness, irreversible condition, imminent death

How to do it (one way)

- Find out who wants to be there
- Ensure adequate pain control and anxiolysis
  - MSO4 and Ativan
- Robinul for secretions (if extubate)
- Turn down FiO2
- Turn off pressors and fluids
- Put ventilator on CPAP or to t-piece
- Turn monitors away, silence alarms

Principles on Guiding Care at the End of Life

- Respect dignity of patient and caregivers
- be sensitive and respectful to patient/family's wishes
- use appropriate measures c/w patient's choices or legal surrogate
- ensure alleviation of pain and mgt of physical symptoms
- recognize assess and address
  - psychological, social and spiritual problems
- ensure continuity of care
- provide access to therapies that may improve quality of life
- provide access to appropriate palliative and hospice care
- respect the patient's right to refuse treatment
- recognize the physician's responsibility to forego futile treatment