End of life care
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LUMC student case management series

Case
► 75 yo previously healthy man MVC with severe TBI, extensor posturing, rib fractures, pulmonary contusion, leg fx.
  ▪ 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

► “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

► “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

► 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
  * MS04 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
► respect the patient’s right to refuse treatment