Palliative Care After Injury

Barry K. Bennett, LCSW, ACSW
Adjunct Assistant Professor
Department of Surgery

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

- Medical patients with debilitating illness
  - majority have thought about EOL care
  - less than half have communicated it
  - some patients want to make own decision
    - most want to do it in conjunction with physician
- patients say they prefer to die at home

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

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

Cases

- 80% TBSA flame burn injury to a 45 year old, all full thickness, 24 y/o daughter who pt has not spoken to in seven years is the decision maker, no POA, pt lives with "significant other", how should we handle consent? Should we treat?
- 70% TBSA flame burn injury to a 34 year old female, self inflicted, history of chronic mental illness, survivable injury, should we treat?
- 20% TBSA flame burn, grade III smoke inhalation injury to an 83 year old male with a history of COPD, has a living will, should we treat?

Legal Barriers-1

- “forgoing life-sustaining treatment for patient’s without decisional capacity requires evidence of the patient’s actual wish”
- False
  - if surrogate relates it is the wish
  - patient’s probable wish
  - patient’s “best interest” when wishes not known”
  - “substituted judgement standard”
    - X NY, MO, MI, WI

Legal Barriers-2

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

- False
  - fluids and nutrition are considered medical therapy

Legal Barriers-3

- “risk management personnel must be consulted before life-sustaining treatment may be terminated”
- False
  - risk management personnel are to protect the hospital from legal risk, may not know the law
  - hospitals may have guidelines

Legal Barriers-4

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

- False
  - specific forms may be more helpful
  - even oral directives count
  - an alert patient supersedes an existing AD

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"

- False
  - principle of double effect
  - determined by intent
  - not physician assisted suicide or euthanasia

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”
- False
  - terminal sedation
    - uses principal of double effect and of withdrawal of fluids and nutrition

Legal Barriers-7

- “The 1997 Supreme Court outlawed physician-assisted suicide”

- False
  - decisions are up to the states
    - only Oregon specifically allows PAS
    - some states have outlawed it
    - most have no laws either way

Legal and Ethical Background

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

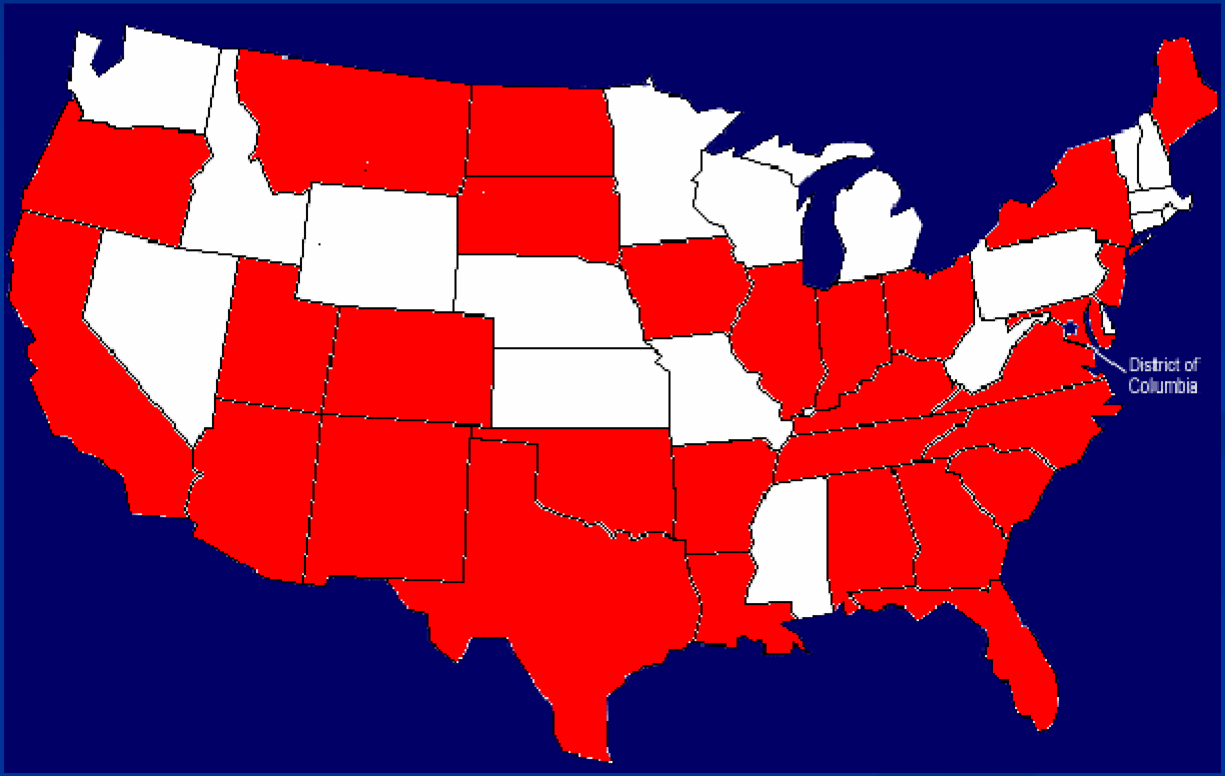
Legal and Ethical Background

- 1991 Patient Self-Determination Act
  - patient autonomy
  - informed decision making
  - truth telling
  - control over the dying process
- assumes the individual is the decision maker

Health Care Decision Making Legislation
(American Bar Association 2004)

- Proxy Statutes – 51 states
- Living Will Statutes – 48 states
- Default Surrogate Consent Statutes – 37 states
- EMS-DNR statutes – 34 states

Has Surrogate Law in Absence of Advanced Directive



Key Differences in State Surrogate Laws

Priority of Surrogates

- Spouse, adult child, parent, sibling (3)
- “nearest” or “other” relative (16)
- Include adult grandchildren (8)
- Include grandparents (5)
- Include close friends (17)
- Include Aunts, Uncles, Nephews, Nieces (2)

Key Differences in State Surrogate Laws

Priority of Surrogates

- In Michigan: "Immediate Family or Next of Kin priority not specified"
- In California, Domestic Partner #2
- In Indiana, A "Religious Superior"
- In Mississippi, A LT Facility Employee
- In Florida, LCSW selected by bioethics committee

Illinois Surrogate Law

Priority of Surrogates

- Spouse
- Adult child
- Parent
- Sibling
- Adult grandchild
- Close friend

Illinois Surrogate Law

Limitations on Types of Decisions

- Mental health
- Must be considered “terminal” or “incurable” to withdraw care

Illinois Surrogate Law

Disagreement Process Among Equal Priority Surrogates

- Majority Rules

Cases

- 80% TBSA flame burn injury to a 45 year old, all full thickness, 24 y/o daughter who pt has not spoken to in seven years is the decision maker, no POA, pt lives with "significant other", how should we handle consent? Should we treat?
- 70% TBSA flame burn injury to a 34 year old female, self inflicted, history of chronic mental illness, survivable injury, should we treat?
- 20% TBSA flame burn, grade III smoke inhalation injury to an 83 year old male with a history of COPD, has a living will, should we treat?

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

- Current studies show quality of communication is poor
- early discussions with families shorten ICU stay prior to death
- giving the right data helps families make the informed decisions
- poor communication is associated with increased malpractice suits

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

Communication

- Dying people know they are dying
- fear abandonment/loneliness
- want to talk to people they know
  - resolve issues
  - families may feel uncomfortable, guilty, embarrassed
  - may want to change subject or withdraw from patient’s situation
- dying patients want to talk to their doctor

Communication

- Perception is selective
- stress may alter what families hear
  - can't discern relevant information
- verbal and nonverbal communication need to be congruent to establish trust
- culture may influence communication patterns
  - be aware of cultural differences but do not avoid interactions

Communication Pitfalls

- Concerns regarding suffering
  - importance of minimizing
  - minimize ongoing bodily injury in those who are dying
    - pursue patient well-being separate from cure
- emotional support and acceptance that patient is dying
- maintain good relationship despite disagreement

Futility

- Persistent vegetative states
- less than 1% chance of success
    - continued dependence on intensive care
- VERY poorly defined
- mostly in non-trauma settings
- does not include QUALITY of life
- best definition: “treatment that will only prolong the final stages of dying”

Demands for Treatment when care is Futile

- Viewed by providers as most important ethical problem
- conflicts are protracted
- stressful for ICU staff and families
- providers concerned about
  - suffering
  - distressed families
  - relationship breakdown

Demands for Treatment when care is Futile

- Does not improve trust or decrease lawsuits
- may need to find another physician
- family may not realize that patient is dying
  - may believe survival is still possible
    - is there provider consensus?

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

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