Ethics Consult Service: A Case Study

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Objectives

• Using a case study
  – explore ethical principles
  – discover how the ECS may help resolve ethical concerns in patient management.
Case Study:

79 year old woman has aged gracefully

• Very independent, lives alone.

• Ten days ago while out shopping
  — experienced a massive stroke
  — required endotracheal intubation by EMS.

• She remains in ICU on a ventilator.
Case Study:
79 year old woman has aged gracefully

• No advance directive.
• Widow with three children
Case Study:
79 year old woman has aged gracefully

• local daughter
  • “don’t keep mom on ventilator”
  • admits no related talks with mother
• daughter from NYC – newly arrived
  • “do everything”
• son from CA - travels frequently
  • not yet notified
Case Study:

79 year old woman has aged gracefully

- MD wants
  - withdraw ventilator
  - tracheostomy and feeding tube
Questions

• What is the difference between ethics committees and ethics consult services?
• How may ECS help resolve ethical concerns in patient care?
ETHICS COMMITTEE

■ MUHA Committee within Center for Clinical Effectiveness and Patient Safety

■ Charter
  ■ Facilitate shared clinical decision-making within ethical framework by patients, family members or surrogate decision makers, and staff.
  ■ Subcommittee structure on education, policy development and review, and clinical ethics consultation
Ethics Consultation Service

• Service branch of the Ethics Committee
• Multiprofessional group
  – Nurses, physicians, chaplains, community representatives, an attorney, other clinicians

• PROVIDING HELP FOR DIFFICULT AND COMPLEX PATIENT CARE DECISIONS
• Providing help with professional conflicts
Ethics Consultation Service

• PROVIDING HELP FOR DIFFICULT AND COMPLEX PATIENT CARE DECISIONS
  – Identify the ethical issues
  – Identify the ethically appropriate treatment options
  – Provide problem-solving and informational expertise
  – Promote efforts to work out the conflict among the participants, if necessary
Ethics Consultation Service

Difficult & Complex Patient Care Decisions

- differences in opinion among caregivers and/or family members about treatment
- end of life decision-making
- surrogate decision-makers and/or patient advance directives
- questions about policies, such as resuscitation or withholding/withdrawing life-sustaining treatment
Questions

- How do Advance Directives differ from Health Care Powers of Attorney?
- Who are health care surrogates and under what standard do surrogates act?
- Who may be patient surrogates under SC Law?
Advance Directives

• Statements by competent decision-makers
  – Interventions to accept or refuse if they lose decision-making capacity
  – Who may act as surrogate
Advance Directives

• Oral Statements
  – To family members or friends
    • Informed? Specific treatment/ situations? Repeated?
  – To physicians

• Written documents
  – Living will
  – Health care proxy / power of attorney
Advance Directives

• Oral Statements
  – Limited by court requirements for evidence
    • “Beyond reasonable doubt”
    • “Clear and convincing”
      – May require mention of specific intervention and clinical situation
    • “Preponderance of evidence”
Advance Directives

• Written documents
  – Living will

• Directs physicians to withdraw or withhold specific life-saving treatments if patient has terminal condition or persistent vegetative state
  – What is “terminal condition”
  – Which treatments “merely prolong dying process”
Advance Directives

- Written documents
  - Health care proxy / power of attorney
    - Decision-making priority over other potential surrogates
    - Applies to all medical situations where decision-making capacity is lost
    - Substituted judgment
      - Patient’s previously expressed choices or best interests
Healthcare Surrogate

• Has authority to make healthcare decisions for patient who has lost decision-making capacity

• Standards
  – Substituted judgment (if patient’s wishes known)
  – Best interest

• ADULT HEALTH CARE CONSENT ACT
  – SC Code of Laws, Title 44 Chapter 66
ADULT HEALTH CARE CONSENT ACT

• Priority of Surrogates
  – Legal guardian, attorney-in-fact appointed by the patient in a durable power of attorney, statutory surrogate given priority
  – Spouse, unless legally separated
  – Parent or adult child of the patient
  – Adult sibling, grandparent, or adult grandchild of the patient
ADULT HEALTH CARE CONSENT ACT

• Priority of Surrogates (2)
  – any other relative by blood or marriage who reasonably is believed by the health care professional to have a close personal relationship with the patient;
  – person given authority to make health care decisions for the patient by another statutory provision.
Case Study:

79 year old woman has aged gracefully

• No consensus obtained on withdrawal of care. Tracheostomy done and PEG-tube inserted.

• Three months pass. NY sister has accused the local sister and physicians of "wanting to murder mother." NY sister camps out in patient's room; local sister visits infrequently; brother has appeared, but has difficulty mediating between sisters.
Case Study:

79 year old woman has aged gracefully

• Patient successfully weaned from ventilator, but no change in mental status. Has spontaneous eye opening, but does not otherwise respond.

• She develops pneumonia and incipient respiratory insufficiency. Nurses express discomfort about continuing "futile" care.
Questions

• What is persistent vegetative state (PVS)?
• How do Quinlan, Cruzan, Schiavo cases affect care of persons in PVS?
Quinlan, Cruzan, Schiavo
Vegetative State

- No cortical function
  - No purposeful activity
  - Can not obey verbal commands
  - Can not experience pain

- Preserved brainstem function
  - Breathing and circulation intact
  - Not comatose (has sleep-wake cycles)
Vegetative State

- Preserved brainstem function (2)
  - Roving eye movements, may track
  - Reflexes intact (not replicable)
    - Suck, chew, swallow
    - Pupillary, oculocephalic, deep tendon reflexes
    - Withdrawal, posturing, startle to noise
Persistant Vegetative State

• Vegetative state lasting over one month
  – Nontraumatic injury waking rare after 3 months
  – Traumatic injury waking rare after 1 year

• Mean survival 2-5 years, some over 15 years
Persistant Vegetative State

- Tube feeding required
  - Unable to swallow or protect airway
- Incontinent, requiring total nursing care
- Common complications
  - Decubitus ulcers
  - Aspiration pneumonia
  - Urosepsis
Persistent Vegetative State

- Other neurologic catastrophes
  - Brain death – no cortical or brainstem function
  - Locked-in syndrome – conscious, minimal motor
  - Severe dementia – conscious, poorly responsive; some motor
Quinlan, Cruzan, Schiavo

• Karen Ann Quinlan case
  – 21 year-old woman in PVS on ventilator (1975)
    • had ingested alcohol and sedatives during party
  – Physician beliefs
    • would never regain consciousness
    • would die off ventilator
Quinlan, Cruzan, Schiavo

- Karen Ann Quinlan case (2)
  - Father
    - supported by chaplain, Catholic priest and Diocese of New Jersey
    - wanted ventilator stopped
    - requested court appointment as guardian with authority to stop ventilator when physicians refused
Quinlan, Cruzan, Schiavo

• Karen Ann Quinlan case (3)
  – New Jersey Supreme Court ruling (1976)
    • SUBSTITUTED JUDGEMENT
    • Right to privacy included right to decline medical treatment – guardian could exercise this right – permitted to render best judgment whether patient would choose to decline treatment
    • Withdraw ventilator if guardian, family, physicians, and ethics committee agree no possible recovery of cognitive state
Quinlan, Cruzan, Schiavo

• Karen Ann Quinlan case (4)
  – First “right to die” case exploring dilemma that life-sustaining interventions inappropriate in some circumstances
  – Decision-making by patients, family, and physicians without routine recourse to courts
  – Hospital ethics committees development supported
    – Survived 10 years PVS post ventilator removal
Quinlan, Cruzan, Schiavo

• Nancy Cruzan case
  – 26 year-old woman in PVS post-MVA (1983)
  – Parents asked feeding gastrostomy be removed (1986)
  – State hospital requested court order
  – Cruzan statement prior to MVA made to housemate “not want to live as vegetable”
    – family supported statement
Quinlan, Cruzan, Schiavo

• **Nancy Cruzan case (2)**
  – Missouri Supreme Court (1986)
  – Restricted decision-making for incompetent patients
    • withhold life-sustaining treatment only if living will or clear statement that specific intervention not wanted in specific situation
  – Unqualified state’s interest in preserving life
Quinlan, Cruzan, Schiavo

• **Nancy Cruzan case (3)**
  – U.S. Supreme Court (1990)
    • Competent patients have “constitutionally protected liberty interest in refusing unwanted medical treatment”
    • Constitution may rely on family decision-making, but not required
Quinlan, Cruzan, Schiavo

- Nancy Cruzan case (4)
  - U.S. Supreme Court (1990)
  - States
    - may establish “procedural safeguards” for medical decisions for incompetent patients
    - may require life-sustaining interventions absent clear evidence incompetent patient would refuse
Quinlan, Cruzan, Schiavo

- **Nancy Cruzan case (5)**
  - U.S. Supreme Court dissents
    - Brennan, Marshall, Blackmun
      - Freedom from unwanted treatments is fundamental right of competent and incompetent patients
      - Decisions for incompetent patients by families or patient-designated surrogates
Quinlan, Cruzan, Schiavo

- **Nancy Cruzan case (6)**
  - U.S. Supreme Court dissents
    - Stevens
      - Constitution requires that patients’ best interest be followed
Quinlan, Cruzan, Schiavo

• **Nancy Cruzan case outcomes (6)**
  – Established “right to die” - tube removed
    • additional witnesses validated Cruzan wishes, physician decided to support feeding stop, Missouri withdrew court proceeding
Quinlan, Cruzan, Schiavo

Nancy Cruzan case outcomes (7)
- Support for legislation on advance directives
  - state laws on health proxies
  - federal Patient Self Determination Act (1991)
    - written advice upon admission about right to advance directive
NANCY BETH CRUZAN
MOST LOVED
DAUGHTER — SISTER — AUNT

BORN JULY 20, 1957
DEPARTED JAN. 11, 1983
AT PEACE DEC. 26, 1990
Quinlan, Cruzan, Schiavo

• Theresa Shiavo case
  – 27 year-old woman in PVS post cardiac arrest due to potassium abnormalities (1990)
  – 1998 – husband requests court to discontinue feedings; parents oppose feeding tube removal
  – Trial court ruled clear evidence patient would want tube removed, decision appealed
Quinlan, Cruzan, Schiavo

- Theresa Shiavo case (2)
  - 2002 – overwhelming evidence patient in PVS with no potential treatment benefit
  - Florida appellate court denies appeals; Florida Supreme Court declines case
  - 2003 Florida legislature passes “Terri’s law”
    - Governor authorized to stay removal of feeding tube challenged by family member
Quinlan, Cruzan, Schiavo

- **Theresa Shiavo case (3)**
  - 2004 *Florida court* declares “Terri’s law” unconstitutional – *Florida Supreme Court* affirms decision
  - 2005 *Congress* passes legislation to move case to federal court – *US Supreme Court* refuses case
Quinlan, Cruzan, Schiavo

- Theresa Shiavo case outcomes(4)
  - Feeding tube removed
  - Written advance directive importance illustrated
  - Family disagreements requiring court intervention highlighted
Quinlan, Cruzan, Schiavo

• **Theresa Shiavo case outcomes**(4)
  - Third party interference in end-of-life decision-making occurred
  - SC act to provide nutrition and hydration to incompetent patient without advanced directive proposed
Questions

• Does withholding/withdrawing care differ?
• What is “futile care” (medically ineffective treatment)?
Withholding/withdrawing Life-sustaining Treatments

- No ethical difference
- Courts consistently rule no difference
- Passive vs active action
  - patient wishes more important
Withholding/withdrawing Life-sustaining Treatments

• Autonomy of competent patient/surrogate
  – Informed consent justifies treatment
  – Informed refusal justifies foregoing or discontinuing treatments

• Decide by weighing benefits and burdens
  – Minimize disability and pain
  – Relieve suffering
  – Avoid harm
Futile treatment

• **Ordinary vs extraordinary treatment**
  – no difference

• **Given patient preferences,**
  examine benefit and burden of treatments

• ****Medically Ineffective Treatment****
  – provides little/no benefit with undue burden
    ****futile****
Questions

• How does “Allow Natural Death” differ from “Do Not Resuscitate”?
• How does “distributive justice” affect treatment?
AND versus DNR

• **Do Not Resuscitate**
  - relays patient/family wish ... no resuscitation attempts (CPR) start if patient dies
  - does not stop treatment...changes goal to comfort care
AND versus DNR

• **Do Not Resuscitate (2)**
  – Negative statement generates confusion
    • ? abandon care and stop all treatment
    • ? permission to terminate patient’s life.
    • ? family guilt about not sufficiently helping patient
    • ? unrealistic expectation
AND versus DNR

- **Allow Natural Death**
  - acknowledges patient is dying
  - comfort measures becomes positive goal
  - reflects language used in SC Declaration of Desire for Natural Death
AND versus DNR

• **Allow Natural Death (2)**
  
  —holds or withdraws painful and burdensome treatments (including ventilator, artificial nutrition/hydration, feeding tube)
AND versus DNR

• Using AND...
  – FULL SUPPORT
  – INTERMEDIATE SUPPORT - ALLOW NATURAL DEATH...medical procedures discontinued (vent, IV's, artificial nutrition/hydration) but if patient arrests no code started
  – COMFORT SUPPORT - ALLOW NATURAL DEATH...all care aimed at comfort.
Distributive Justice

• Allocation of health care resources
  – Fairness – get what deserved
  – People equal ethically, treated equally;
    different ethically, treated differently
  – Ration time and resources according to need,
    probability and degree of benefit

AMA Code of Ethics 2.03 Allocation of Limited Medical Resources
Distributive Justice

- **Adequate health care access**
  - **Democratic decision** after public input during development and approval stages
  - **Monitor variations** in care not medically explained to avoid ethnic/ racial disparity
  - **Adjust level of care** over time assuring public acceptance

- **Equal access to basic care; equal consideration for discretionary care**

  AMA Code of Ethics 2.097 Provision of Adequate Health Care
Distributive Justice

• Barring disaster or prior societal decisions rationing healthcare resources…

physician shall remain focused upon effective treatment of individual patient
Questions

• May physicians withdraw or withhold care without consent of the surrogate?
• What must the physician do for the patient or surrogate if medical staff members ethically feel they can not continue “futile treatment”? 
Withdraw or Withhold Care without Consent of Surrogate

• No ethical obligation to render medically ineffective treatment
• Denial must be justified by ethical principles and acceptable standards of care

AMA Code of Ethics 2.035 Futile Care
Stopping medically ineffective treatment without surrogate consent

• Obligations
  – to shift care toward comfort/closure
  – to not prolong dying without benefit to patient or legitimate interest

• All health institutions need policy with due process
Stopping medically ineffective treatment without surrogate consent

—Medically ineffective treatment policy (1)

• Negotiate what constitutes medically ineffective treatment for patient, and limits for physician, surrogate, and institution

• **Maximize joint decision-making** between patient or proxy and physician
Stopping medically ineffective treatment without surrogate consent

—Medically ineffective treatment policy (2)

• Negotiate disagreements for resolution, involving appropriate consultants

• Involve ethics committee/ECS, if unable to resolve differences
Stopping medically ineffective treatment without surrogate consent

—Medically ineffective treatment policy (3)

- If institutional review supports patient and physician unpersuaded, arrange transfer of care within institution

- If institutional review supports physician and patient/proxy unpersuaded, seek transfer to another institution while medically supporting patient

- If transfer not possible, need not offer treatment

AMA Code of Ethics 2.035 Medical Futility in End-of-Life
Case Study:
79 year old woman has aged gracefully

- Pneumonia successfully treated with brief use of ventilator and antibiotics; however patient develops progressive renal insufficiency.

- A month goes by. Despite skin care patient develops large sacral decubitus. She develops increasing creatinine, edema, and dyspnea.
Case Study:
79 year old woman has aged gracefully

- Granddaughter appears "from off"; she remembers grandmother saying she wanted to "go quickly when her time came, but God would decide."
Questions

• Does euthanasia differ from terminal sedation?
• What is the rule of “double effect”? 
Euthanasia and Palliative Sedation

• Active euthanasia
  – Physician provides means and causes patient’s death
  – Voluntary – patient requests;
    involuntary – patient opposes;
  nonvoluntary – patient lacks decision-making
Euthanasia and Palliative Sedation

• Passive euthanasia or AND
  – Withholding or withdrawing treatment
  – Comparable to informed refusal of life-sustaining treatment by patient or surrogate;
  respects patient autonomy
  – underlying illness causes death
Euthanasia and Palliative Sedation

• Palliative sedation
  – High dose opiate or sedative with object to relieve suffering or dyspnea
  – May hasten death, but death not intended
  – Ensure excellent palliative care;
    decision to use informed and voluntary;
    no depression
Rule of Double Effect

- Distinguishes between intended effect and effects foreseen but unintended
- Applicable to passive euthanasia and palliative sedation
- **Bad effect** (respiratory depression/ death from opiates) *not means of good effect* (relief of suffering); unintended but foreseen bad effect proportional to intended good effect
Questions

■ Are dialysis or medical hydration and nutrition indicated in PVS?
■ What is the physiologic response to withdrawal of hydration?
Medical Hydration and Nutrition or Dialysis in PVS?

• Value judgment…
  – What is a human being?
  – Decisions personal,
    often involve religious beliefs of patient

• Ethically…may withdraw or withhold any intervention in accord with advance directive or surrogate decision
Medical Hydration & Nutrition and Religion

• “Pope declares feeding tube removal immoral.”
  AP News March 20, 2004

• “There should be presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is sufficient benefit to outweigh the burdens involved to the patient.”

  Ethical and Religious Directives for Catholic Health Care Services, 4th ed, 2001
Medical Hydration & Nutrition and The Law

• Nancy Cruzan case (1990)
  – Medical hydration & nutrition: treatment subject to refusal
  – State has right to “clear and convincing evidence” from patient about stopping medical hydration & nutrition
Medical Hydration & Nutrition and The Law

• Helga Wanglie case (1991)
  – Upheld right of husband to continue feeds in PVS though seen as nonbeneficial by health care team
Medical Hydration & Nutrition and SC Law

- **SC Health Care Power of Attorney**
  - If no decision re tube feeding, agent has no legal authority to withhold / withdraw medical hydration and nutrition “necessary for comfort care”

SC CODE SECTION 62-5-504.

Health care power of attorney
Medical Hydration and Nutrition

- Hunger rare at end of life
- Artificial hydration and nutrition can be harmful, increase suffering and prolong dying
- If fluid/food stopped, death from dehydration — not starvation
Physiology of Terminal Dehydration

- Increased endogenous endorphin release
- Azotemia and uremic encephalopahy
- Decreased body fluids
  - Urine output
  - Pulmonary secretions/ edema
  - Gastric fluids, so decreased vomiting
Questions

• How do cultural and religious differences affect the concept of “good death”?  
• How may hospital chaplains contribute to ethics consultation?
“Good Death”

• Some cultural differences
  – Telling person she is dying may not be accepted
  – Surrounded by family
  – Freedom from pain or indignity
  – Life preserved at any cost may have value
“Good Death”

• Some religious differences
  – Rituals required differ as death approaches
  – Faiths weigh ethical principles differently
  – Accepting suffering may have value
“Good Death”

• How does your cultural tradition define a “good death”?
• What is your personal definition of a “good death”?
Chaplains

• Provide insight to clinicians about cultural and religious expectations
• Help patient, families, and surrogates clarify how their religious beliefs, needs, and desires affect treatment decisions
• Offer pastoral and emotional support regardless of faith traditions
Case Study:

79 year old woman has aged gracefully

- Ethics consult service has met several times with the family and medical staff during the patient's hospital stay. ECS each time has offered treatment options.
- After the last ECC visit, the family agreed with the recommendation for no dialysis, stopping tube feedings & hydration, and offering opiate sedation based upon apparent need for comfort.
- The patient died peacefully days later.
Question

- Have you completed a personal Health Care Power of Attorney?
SCHIAVO

THERESA MARIE
BELOVED WIFE

BORN DECEMBER 3, 1963
DEPARTED THIS EARTH
FEBRUARY 25, 1990
AT PEACE MARCH 31, 2005

I KEPT MY PROMISE