The Lady and the Reaper: End-of-Life Ethics in the Intensive Care Unit

Part One: How We Want to Die

- More than 80 percent of patients with chronic diseases say they want to avoid hospitalization and intensive care when they are dying (Dartmouth Atlas of Health Care)
- Only 25 percent of Americans actually die at home (Centers for Disease Control, 2005)
- Nearly 70 percent of Americans die in a hospital, nursing home or long-term-care facility (Centers for Disease Control, 2005)
- ICU stays of longer than a week have been increasing. In 1996, 10 percent of Medicare recipients spent at least a week in an ICU during the last six months of their lives; by 2005, the number was 14.4 percent (Dartmouth Atlas of Health Care)

Costs of End-of-Life Care

- Patients with chronic illness in their last two years of life account for about 32 percent of total Medicare spending (Dartmouth Atlas of Health Care, 2005)
- Medicare pays for one-third of the cost of treating cancer in the final year, and 78 percent of that spending occurs in the last month (HemOnc Today, 2009)
- One large-scale study of cancer patients found that costs were about a third less for patients who had end-of-life discussions than for those who didn't (Archives of Internal Medicine, 2009)
ICU Statistics

- More than 4 million patients are admitted to ICUs each year in the United States.
- Mortality rates in patients admitted to the ICU average 10 to 20 percent in most hospitals.
- Patients in ICUs occupy between 5 and 10 percent of inpatient beds in hospitals, but account for 20 to 35 percent of total hospital costs.
- Respiratory failure is the most common cause of ICU admission.

Joint Commission on Accreditation of Healthcare Organizations, 2004

Advance Directives...do they work?

Advance Directives

- Only 20 to 30 percent of Americans report having an advance directive such as a living will (Associated Press, 2010)
- Even when patients have an advance directive, physicians are often unaware of their patients' preferences. One large-scale study found that only 25% of physicians knew that the patient had an advance directive on file (Critical Care Journal, 2007)
- How do advance directives hold up once the patient is unable to speak for him/herself?
Part Two: Quality of Life

- Film focus: Magazine cover of man on ventilator
  - Headline: Famous Doctor Saves Another Miserable Life
  - Doctor quote: “I feel like a god”
- What defines quality of life?  
- How is success measured?  
- Increase in medical technology has led to increased ethical dilemmas
  - ECMO
  - VADs
  - On the horizon: Liver support
- When is enough enough?

Defining Quality of Life

- The bulk of ethical dilemmas in the ICU surround what seem to be unreasonable expectations from families
- Surrogate decision making
  - We rely on families to teach us what this patient would be willing to endure
  - Families must be challenged to step outside what they wish for and help determine what that patient would really want
  - Do families really understand the burden of an ICU stay?

At first she didn’t want to live if it meant being attached to tubes. But before you knew it, they were getting along just fine.
The Flip Side of Futility

- Most ethical dilemmas stem from families demanding what the team feels is futile care
- What happens when the medical team decides to continue aggressive care despite the protests of the family?
- How does the film exemplify this?
- Examples/discussion

Part Three: “Heroic” Interventions

- What is heroic? Extraordinary?
- The power of language
  - If you don’t choose heroic measures, are you cowardly?
  - What if you are asked if you want everything done for your loved one?
  - How fair is it to ask a family what to do in a crisis situation?
  - “Doing everything”
  - How is autonomy corroded by asking if the patient/family wants an ineffective intervention?

CardioPulmonary Resuscitation

- Does it work?
  - Very low success rate, especially in ICU patient with multiple co-morbidities
  - Success is measured by discharge from hospital
- Media portrayals
- Ethical dilemmas occur when we offer interventions that do not work
  - How does this impact the basic bioethical principle of autonomy?
- Futility laws
Other Interventions

- Continuous renal replacement therapy (CRRT)
- Vasopressors
- ECMO
- VADs
- Ventilators
- Artificial nutrition and hydration

Part Four: An Uncomfortable Romance

- Movie explores the tug and pull between medicine and death
- How often do we long for death to come to our ICU patients?
- How does that affect us personally and professionally?
- Goes against the culture of medicine
- How could this affect medical care?

Part Five: Out of Control

- Movie pace becomes frenetic, just like the ICU
- Rollercoaster effect
  - Common terminology from patients
  - Mixed messages from different teams
  - Focus is on everchanging numbers, peaks and valleys
  - Intermittent hope vs. despair
- Medicine and death become entangled and roll after patient in one big ball
- All come tumbling down
- The Grim Reaper gives up!
  - Prolonged dying
Part Six: Would They Do It If They Could?

- Lady punches doctor in face
  - Leads back to issues of surrogate decision making
  - If the patient was able, would he/she want all this?
  - Euthanasia vs. physician-assisted suicide
  - Withholding and withdrawal of life support are ethically equivalent but emotionally they can be poles apart

- Suicide
  - What is rational suicide?
  - Have you had a terminally patient end his/her own life?
  - How did you feel about that?

Ethical Dilemmas

- Legal next of kin
  - How is this determined?
  - Privacy issues
  - Role of ethics committee

- Informed consent
  - Do patients/families understand?
  - How fully is "doing nothing" explored?
  - For cancer patients, what is expected for 2nd line and 3rd line treatments and clinical trials?

Ethical Dilemmas

- Brain death
  - How is brain death discussed at your institution?
  - Case of Jahi McMath
    - December 2013: 14YO teen declared brain dead after tonsil surgery
    - Death certificate signed
    - Family rejects this, fights to keep her on machines
    - As of 3/15 LA Times story, Jahi is still supported at an undisclosed facility
Ethical dilemmas

- Cultural diversity
  - Are there specific belief systems that influence decision making?
  - How can we address this early in care?
- Religious beliefs
  - God’s will
  - Miracles

Social Work Interventions

- FAMILY MEETINGS, FAMILY MEETINGS, FAMILY MEETINGS!!!!
- Superb model from Medical Center of Central Georgia (Journal of Palliative Care, 2011)
  - Hospital has 600 beds
  - EIGHT Transitions counselors
    - This model uses mainly LMFTs
    - LCSWs are perfect fits
  - Defined goals of meetings

Family Meetings

- Getting ready
  - Gathering medical information
  - Achieving consensus on goals of care among primary and consult teams
  - Negotiating conflict among teams
  - Keeping meeting “on track”
  - Staying with family post meeting to act as translator
Family Meetings

- Assessing situation
  - Allowing family to tell their story, including experiences with healthcare system
  - Focus is on joining with the family and establishing trust
  - Clarifying misconceptions
  - Arranging additional meeting with clinicians

Family Meetings

- Identifying roles
  - Early identification of legal next of kin
  - Family systems theory
    - Hierarchies and subhierarchies within family system
    - Methods of communication
    - Role of patient in family system
    - Family equilibrium
  - Identifying religious/cultural issues

Family Meetings

- Providing information
  - Pros and cons of treatment
  - Likely progression of illness
  - Understanding ways patients/families receive and process information
    - Serving as translator
    - Translation to family about medical information
    - Translation to team about family dynamics
Family Meetings

**Processing essentials**
- Grief inhibits decision making
- Social worker role is to join with family without offering false hope
- Helping team understand how and when to give bad news
- Helping transition to medical palliative consult

**Managing conflict**
- Family vs. family
- Family vs. physician
- Primary physician vs. consulting physician

**Follow through**
- What does the family understand?
- Processing emotions of bad news
- Listening to family values, morals
- Helping understand consequences of decisions
  - Long term disposition options for patients requiring artificial life support
  - Helping families find peace, forgiveness when making end of life decisions
Jonsen’s “Four Topics” Approach

- Medical indications
- Patient preferences
- Quality of life
- Contextual features


Meaning of Life and Death

---

---

---

---

---

---

---

---

---

---

---
THERE IS NO RIGHT ANSWER
So....
Practice Equanimity
mental calmness, composure, and evenness of temper, especially in a difficult situation

References