Advance Directives: Ethical Dilemmas

Learning Objectives
- Appreciate ambiguities of medical futility
- Quote success rates of CPR
- Understand legal statutes governing treatment decisions
- Address patient fears about advance directive decisions
- Incorporate values history into advance planning

HIPAA Disclaimer
- All patient names are changed
- Ages are approximate but not exact
- Stories are real

Lucy Smith
- 80 year old retired typist
- Severe Alzheimer’s dementia, dependent, ambulatory, refused to leave home
- Chest mass detected during evaluation of altered mental status
- Surgeon advised surgery to prevent hemoptysis or metastasis
Lucy Smith
- Admitted for surgery in November
- Palliative care consulted in February
- Pneumonia, chest tube, tracheostomy, ventilator, persistent fever, acute renal failure, MI, MRSA, VRE
- Barely arousable, struggles against ventilator, anasarca
- Gestures to communicate?

Palliative care consulted in February
- Pneumonia, chest tube, tracheostomy, ventilator, persistent fever, acute renal failure, MI, MRSA, VRE
- Barely arousable, struggles against ventilator, anasarca
- Gestures to communicate?

Lucy Smith
- Family desires full code, no dialysis
- Hospital staff feel she is suffering
- 6 children not all in agreement
- Daughter Lucille DPOA hopes for miracle, struggles with isolation and guilt
- DPOA Lucille feels patient not suffering and could cope in ICU indefinitely
- Son insists to keep patient alert

Dilemma
- Conflicting perceptions
- Conflicting values
- Conflicting expectations
- Escalate treatment?
- Treat pain and agitation?
- Discontinue antibiotics?
- Plan for pressors or CPR?

Advent of CPR in 1960
- 14 / 20 patients aged 2 months to 80 years still alive 10 months later
- “This technique…has given an overall permanent survival rate of 70%. Anyone, anywhere, can now initiate cardiac resuscitative procedures. All that is needed are two hands.”

Kouwenhoven WB. JAMA 1960;173;1064-7.
Theodore Geisel, Green Eggs and Ham, 1960.
Anyone, Anywhere in 1960

“All that is needed are two hands.”
- On a boat
- With a goat
- In a box
- With a fox
- In a house
- With a mouse
- Here or there
- Anywhere

Geisel TS, Green Eggs and Ham, 1960.

Efficacy of CPR Overall

- National Registry of Cardiopulmonary Resuscitation
- 1/3 survive immediate event
  - 2/3 who survive die in days-weeks in ICU
  - Other 1/3 risk disability or placement
- 1/6 survive to leave hospital
- Unchanged over 40 years

Peberdy MA. Resuscitation 2003;58:297-308.

Efficacy of CPR Details

- <10% survival to discharge
  - Sepsis
  - Multi-organ failure
  - Renal failure
- Up to 40% survival to discharge
  - Drug reaction
  - Acute coronary syndrome


Efficacy of CPR in Cancer

- Survival to hospital discharge with metastatic cancer
  - 5.6 % in 1966-2005
  - 7.8% in 1990-2005
- Performance status, critical illness, clinical deterioration more important predictors than metastatic cancer per se

Reisfield GM. Resuscitation 2006;71:152-60.
Lucy Smith: What Focus?
- Symptoms
- Family support
- Overall goals
- Code status
- Family doesn’t budge

Is CPR Futile?
- Daughters of Danaus, King of Argos
- Condemned to collect water in leaking buckets
- Futility = easily pours
  

Futility – Many Definitions
- Physiologically impossible to succeed
- Statistically unlikely
  - 0-13% chance (AMA poll)
  - 0 success in last 100 cases
- Outcome not desirable qualitatively
- Unlikely to be beneficial
- Not worth the cost to society

Group Definitions
- American Thoracic Society
  - “highly unlikely to result in meaningful survival”
- Critical Care Society
  - “will not achieve the intended goal”
- American Heart Association
  - “no survivors reported under the circumstances in well designed studies”

Futility Defies Definition

- Relationship among effectiveness, benefit, and burden of the treatment in question
- AMA:
  - "Objectivity is unattainable"
  - Best approach implement “fair process"

Cantor MD. Arch Intern Med 2003;163:2689-94.

Futility Overtones

- Can only be discussed with defined goal
- Offering CPR as hope is “cruel”
- Family view of futility:
  - Paternalism
  - Medical trump card
  - Patient not worthy of care


Lucy Smith – DNR Order

- Two daughters express wish for comfort
- DPOA Lucille did not agree with them
- Family did not attend planned meeting
- Primary attending wrote DNR order, informed DPOA Lucille

Unilateral Futility Orders

- DNR or other orders
- Physicians often unaware of hospital policy
- 1993 Uniform Health Care Decisions Act:
  - NM, Maine, DE, AL, MI, CA 1999, HA, TN, AK, WY
- TX (GWB) & CA enacted statutes in 1999
Texas and California

- Inform patient / proxy of decision
- Obtain concurrence of two physicians
- Offer transfer to another facility
- Continue care
  - TX: 10 days + optional court appeal for more time
  - CA: until "appears transfer cannot be accomplished"
- TX: review at ethics or medical committee
  
  Cantor MD. Arch Intern Med 2003;163:2689-94.

UCSF Policy 6.07.03 (Apr 06)

- CPR not indicated if any one:
  - no reasonable promise for recovery
  - burdens grossly disproportionate to expected benefit
  - would only artificially postpone death
- Unilateral DNR allowed after:
  - Inform patient / surrogate
  - Offer Ethics Committee consult
  - Offer transfer to another provider / hospital

Lucy Smith

- Survived 6 weeks in ICU after DNR
- Transferred to step down on Bipap
- Continue analgesia, skin care, social support
- Died after 4 days on step down unit

Mike Jones

- 90 year old retired construction worker
- Blind, moderate dementia (20/27)
- Severe cachexia, walks with assistance
- Osteomalacia from gastrectomy
- Emaciated since age 70
- Admitted 3 times in 3 months for aspiration
- Daughter / conservator insists full code but no prolonged ventilation
Prior History
- Father raised 26 children with 2 wives
- Patient finished 5th grade
- Snazzy dresser
- Married “almost 7 times”
- Carried his gun on trips to bank
- APS involved repeatedly for self neglect

Aspiration Admissions
- Gasp from admitting intern
- Admitted to ICU, not intubated
- Septic, pressors, antibiotics
- Transferred out of ICU

Third Admission
- Recurrent tachypnea 40 / minute
- Metabolic acidosis
- Acute renal failure
- Patient:
  - Pulled out arterial line
  - Kicked doctor
  - Refused BP or oxymetry check
- Daughter: requests transfer back to ICU

Dilemna
- Conflicting expectations
- Conflicting requests
Families Fear DNR

- Fear that DNR = Do Not Treat (DNT)
  - AMI: less cardiac meds, reperfusion
  - “Don’t treat that patient – they want to die anyway”
- Fear of abandonment

Sulmasy DP. Med Care;37:719-21.

DNR and Staff

- Ethics training of interns ➔
  - more attention to other medical concerns in DNR patients
- Most interventions to educate that DNR doesn’t equal DNT unsuccessful


Survival After DNR Order

- ICU patients <2%
- Other patients 50%
- DNR cause or marker of ICU death?
- Medicalized ritual “last rites”

Clinical Ethics, McGraw-Hill
Sulmasy DP. Med Care;37:719-21.

“Allow Natural Death”

- Introduced 2000 by Rev Chuck Meyers
- Movement ↓ after his death Nov 2000
- DNR evokes threatened feelings
- Negative phrases less clear than positive
- AND specifically mentions death

**AND Vs. DNR**
- Nurses, nursing students, and controls read vignette about loved one near death
- Nurses supported AND or DNR both 85%
- Nursing students and controls
  - favored either AND or DNR less than nurses
  - but more likely to support AND than DNR
- Will time alter perceptions of AND?
  

**Levels of Care Vs. DNR**
- Leuven (Belgium)
- Concern “DNR” limits care for frail elderly
- Pick overall extent of care instead of simple “DNR”
- Each of 4 levels includes everything from prior level
  

**Levels of Care – Goals**
- Terminal: comfort in dying
- Palliative: symptom management
- Usual: restore function
- Intensive: prolong life
  

**Levels of Care – Interventions**
- Terminal: hygiene, analgesia
- Palliative: mobility, oral nutrition
- Usual: IV, enteral treatments
- Intensive: resuscitation, life support
  
  First 3 of 4 would all be “DNR”
  
### Mike Jones – Plan
- Explain prognosis – expect recurrence
- Elicit goals – avoid suffering
- Elicit concerns – dislike of hospital
- Then decide interventions – signed DNR

### Mike Jones – What Happened
- Daughter insisted discharge that day (Fri)
- All 4 hospice agencies booked until Mon
- Home Health nurse took case
- Ordered equipment, morphine, ambulance
- HH RN visited 3 hours later and daily
- Daughter put Thickit in Manischewitz wine
- Died in his own bed 72 hours later

### Lucy Smith and Mike Jones: How These Compare
- Family perceived quality of life still good
- Family avoided hypothetical decisions
- Lucy Smith:
  - Family discord, guilt, distrust of doctors
  - Family unable to face acute decisions
- Mike Jones:
  - Family priority to avoid suffering

### Sally Brown
- 85 year old retired scientist
- Battling bilateral breast cancer metastases to lung, spine, stomach for 2 years
- Mild cognitive impairment
- Still gardens, yoga, music lessons
- Seizures (age 20-40), aphasic TIA (81)
- 911 for acute profound expressive aphasia
- Left frontal hemorrhage
**Dilemma**
- Uncertain etiology of aphasia:
  - Metastasis?
  - Stroke?
- Survival prognosis: unclear, likely poor
- Functional prognosis: unclear, likely poor
- DPOA already assigned, but
- She gave me vague answers when I asked her goals 2 years earlier

**Neurosurgery**
- I was out of town
- Family opted for craniotomy
- Pathology benign
- Suspect congenital AVM
- Postop moderate recovery
- Limited recall, perseverative, disinhibited
- Slowed thoughts, distress from insight

**Life After Neurosurgery**
- Refused home PT or OT
- Barely allowed ST once a week
- Intense dislike of 24 hour attendants
- MMSE sentence “The world is tolerable”
- Unpredictable anger
- Enjoyed family gatherings if cajoled
- Rarely played music but self critical

**Sally Brown – Complications**
- Frequent aphasic TIAs despite Keppra
- Pain, difficulty walking, and poor balance from new pelvic metastasis
- Oncologist strongly recommended MRI and daily XRT
- Patient could voice preferences (fewer interventions, not force to do things, focus on quality time)
- Patient unable to balance risk / benefit
**Dilemma**
- Conflicting recommendations from doctors
- Multiple opinions among family members
- Patient alert but confused by discussions
- Significant burden for daily XRT trip
- Family challenged to question oncologist

**Advance Directive Shortfalls**
- SUPPORT trial in 1995 sick cohort:
  - Physician understands patient DNR wishes <50% of time
  - Physician aware of advance directive <25%
  - Advance directives did not affect decisions
  - Nurse facilitated discussions of goals and prognosis did not affect decisions or communication
- 10 years later still no improvement

**Advance Directive Shortfalls**
- Family prediction of patient wishes only slightly better than chance
- Standard documents offer little guidance in specific situations
- Patients still want proxy to make decisions

**New Ideas**
- Simpler educational and regulatory efforts:
  - No effect on DNR orders or discussions
  - Under evaluation:
    - Medical student training in communication
    - Values history incorporated into advance directive (POLST, Five Wishes, CAHCD, Your Life Your Choices)
Values History

- California Advance Health Care Directive
  - Low literacy with illustrations
  - English, Spanish, Chinese, Vietnamese
  - Online at iha4health.org

Your Life Your Choices

- Multiple worksheets including values history

Sudore R, SFDPH. http://iha4health.org/

California Advance Health Care Directive

Think about what makes your life worth living. Put an X next to all the sentences you most agree with:

- My life is only worth living if I can:
  - talk to family or friends
  - wake up from a coma
  - be free from pain
  - live without being hooked up to machines
  - I am not sure

- My life is always worth living no matter how sick I am
  - yes
  - no

If I am dying, it is important for me to be:

- at home
- in the hospital
- I am not sure

Is religion or spirituality important to you?

- yes
- no

Sudore R, SFDPH. http://iha4health.org/

It’s All About Communication

- Advance directives aren’t a one time event
- Establish proxy even for healthy elderly
- Discuss values early in disease
- Continue discussion as disease advances
- Effective communication prevents unnecessary hospitalization
- Continuity and trust

Your Life Your Choices

<table>
<thead>
<tr>
<th>What makes your life worth living?</th>
</tr>
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<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Life like this would be:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Difficult but still worthwhile</td>
</tr>
<tr>
<td>Uncomfortable, but still living</td>
</tr>
<tr>
<td>Can’t stand living, not living</td>
</tr>
<tr>
<td>can’t know now</td>
</tr>
</tbody>
</table>

Instructions: This exercise will help you think about and express what really matters to you. For each item, check one answer to express how you would feel if this fact describes you.

a. I can no longer walk but get around in a wheelchair.
b. I can no longer get outside—I spend all day at home.
c. I can no longer contribute to my family’s well-being.
d. I am in severe pain most of the time.
e. I have severe discomfort most of the time such as nausea, diarrhea, or shortness of breath.
f. I rely on a feeding tube to keep me alive.
g. I rely on a towel dialysis machine to keep me alive.
h. I rely on a breathing machine to keep me alive.
i. I need someone to help take care of me all of the time.

Sudore R, SFDPH. http://iha4health.org/
**Sally Brown – What I Didn’t Know**
- I gave her values history 4 years earlier
- Husband wouldn’t talk about it with her
- I asked her again at several visits
- Patient eventually completed values history with son on a sunny day in Dolores Park
- 4 years later family had values history to guide them

**Sally Brown – Values History**
- What are your biggest hopes?
- What are your biggest fears?
- What is important to you if you are dying?
- What would life mean if you couldn’t take care of yourself, recognize family, or talk and be understood by others?
- Is it wrong to forego treatment that could keep you alive?

**Sally Brown – What Happened**
- Family chose home hospice
- Progressively weaker
- Speech declined steadily
- Anger and distress gave way to grace and acceptance
- Died at home 3 months later

**Summary**
- State and local policies establish process for unilateral decisions without stating specific clinical determinants of futility
- Fear of restrictions in care may prevent early DNR orders, so goal-based discussions can achieve consensus
- Ongoing discussion about prognosis and values can influence end of life choices
References


Advance Directives: Ethical Dilemmas

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Dan is het altijd goed