END OF LIFE CARE: CASE STUDIES IN ETHICAL DECISION MAKING

GOALS:
- Use cases to discuss:
  - Models of decision making
  - Use/abuse of the term “futility”
  - Evidence of patient priorities at end of life
  - Evidence about surrogate decision processes
- Review some important recent literature
- Strategize ways of alleviating decision-making burdens for patients, families, care-givers
CASE #1

- Your patient is a 85 year old woman who has been your patient for many years. She has some hypertension, has easily controlled diabetes II, and lost her husband of 59 years last year. She lives alone, although they have 2 adult children with families in town.
- She comes in with some new R lateral chest pain and on chest Xray, there is a new R middle lobe mass that you suspect may be lung cancer. You suggest a lung biopsy, and she refuses. Her daughter is with her and wants her to listen to you.

What do you do?

How do you decide at times like this?

What is the physician’s responsibility – what about autonomy and who has it in this interaction?
THE PROBLEM

- Shift from Paternalism to autonomy-based decision-making.
- Patient-driven:
  - Physician and HC Team provide expert knowledge, make no recommendations.
- Shift to the middle with endorsement in past 8 years of “shared decision-making.”
  - Preferred by most patients & families
- What situations have you found where this runs into problems?
CONSIDERING COUNTER-MODELS

- Physician recommendation DM:
  - Present options
  - Make recommendations based on patient values.
  - "what would you do?"……
    - How do you respond to that?

- "Informed non-dissent"
  - Physician has major burden, guided by patient values
  - Patient may stand silent or veto.

- Physician-driven:
  - Used for value-neutral decisions (what size ET tube)
  - Pitfalls, even with simple decisions

- Can patient abdicate? Defer to physician?
- Can physician defer to patient?

HOW HAVE DNR FORMS AND ADVANCE DIRECTIVES CHANGED MEDICAL PRACTICE?
- POLST/MOST forms?
- CPR Directives?
- DNR forms?
- Advance Directives?
- Five Wishes?

Castillo (Ann IM 2011, VAH/Kaiser): negative unintended consequences of AD laws
  - Poor readability (>12th grade)
  - Marginalizes non-standard decision makers
  - Puts various restrictions on HC agents
  - 35 states don’t recognize oral ADs
  - 48 require witnesses, notaries

PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT
HTTP://WWW.OHSU.EDU/POLST/RESOURCES/INDEX.HTM
You get a call from the wife of a long-standing patient who was admitted to the hospital last week with an acute pneumonia. He was intubated in the ED, and is now at 6 ½ days on the ventilator. You last had last seen him in the office 3 weeks before, although you knew about this admission. At the last visit, you and he had discussed the result of a node biopsy from his L supraclavicular region that turned out to carry a diagnosis of lymphoma. You and he were planning to discuss what to do in terms of work-up at your next visit. His exam had otherwise been normal.
He is a 73 y.o. WWII veteran who had gone on to have a successful business career. He has 2 kids who don't live nearby. Since retirement a year ago (!), he has spent time with old friends playing active tennis, as well as traveling. He is a very organized person, and has completed advance directives indicating that he does not want to be intubated for more than 7 days if he was terminal.

His best friend from WWII is adamant that he get extubated, but his wife is anxious. His friend (a physician) says this is just the opportunity he would want to take to have a relatively gentle death, rather than the prolonged death from cancer he faces. She doesn’t want him to be angry with her if they delay extubation, but the CC physicians state they just need a couple of more days to be sure his pulmonary infections is sufficiently resolved.

She asks for your advice on what to do? Let him stay intubated a couple of extra days, or honor his written Advance Directives.
BEYOND INFORMATION: EXPLORING PATIENT PREFERENCES

CURRENT ASSUMPTIONS

- Patients base decisions on stable principles and values
  - Works with simple decisions, few consequences

- BUT.....these become unstable....

"...in complex or uncertain situations, with outcomes that have not been considered, or cannot be imagined."
Situations that are “rife with choiceless choices and inability to imagine the treatment ordeal despite being well informed.”
  - E.g. BMT, new cancer diagnosis
  - Failure of “informed consent.”
  - Preferences change as patients get sicker.

CLINICIANS MUST BE PART OF THE PREFERENCE CONSTRUCTION PROCESS

- Help patients imagine....
  - What are the pitfalls you’ve seen or “committed” in having these conversations?
  - Influence of affect – is the emotional side of this conversation good or bad? Avoidable?
“Current deliberations about preferences should go beyond paternalism (not considering the), naïve consumerism (giving patients what they initially ask for), and abandonment dressed as autonomy (“Go home, think about it, and let me know.”)

Epstein, JAMA 2009
You admit a 87 year old man from a nursing home. He has been there for 5 years with progressive dementia. The patient is sent in at the request of the family, since the nursing home suggested he get a gastrostomy tube. He can no longer feed himself and is losing weight.

Is this futile care?

How do you approach the family?

Do you have other examples of “futile care” issues in your practice?

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Recent attempts at defining futility:
- Physiologic
- Quantitative
- Qualitative
- As a generic descriptor

“The Rise and Fall of the Futility Movement” NEJM

A new approach: Goal futility vs. Value futility
- Mohindra, 2007
Some approaches:

- In the emergent situation:
  - Withdrawal may be ethically superior to withholding

- Non-invasive strategies

- We never “withdraw care”

- Conversation and negotiation

Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers.

If you sustained a severe spinal cord injury…..

- Glad to be alive:
  - 28% EM providers vs. 92% SC

- QOL average or better:
  - 17% EM providers vs. 86% SCI persons
You admit a 65 year old woman with advanced breast cancer and brain metastases to the hospital for a seizure. CT shows swelling and some hemorrhage into one of the brain metastases. She has designated her youngest daughter as her MDPOA, but two others daughters live in town. One is adamant that mom get surgery and aggressive treatment for this hemorrhage, and the daughter with the MDPOA is very reluctant to overrule her, even if she has always been “out of touch” and not a good caretaker or help during their mother’s 5 years of illness. The patient’s husband has early dementia and is frightened by the thought that he could lose his wife also.

- How do you approach this family?
- What is the physician role when the surrogate has been designated?
- How do surrogates make decisions?
SYSTEMATIC REVIEW: THE EFFECT ON SURROGATES OF MAKING TREATMENT DECISION FOR OTHERS

WHAT IS THE EFFECT OF MAKING TREATMENT DECISIONS ON SURROGATES?

- REVIEW OF LITERATURE
- 40 studies, 29 quant, 11 qualitative
- 2854 surrogates (half family members)
- Quantitative studies:
  - 1/3 of surrogates experienced “negative emotional burden”
  - One of most stressful experiences in life
- Qualitative studies:
  - Many or most surrogates experienced negative burden
  - Strain often substantial, lasting months to years in some cases.
    - Stress, guilt, doubt
    - One study: most with stress/anxiety mean of 3.3 years later
Beneficial effects: 9/40 studies
  ▪ Support for patient
  ▪ Feeling of satisfaction
  ▪ Most common when patient’s preferences known
    ▪ “…no regrets. I was carrying out her wishes.”

Some observations:
  ▪ Japanese study: decisions very difficult, but did not report emotional burden. (72% have ADs)

OBSERVATIONS

  ▪ Negative burdens can interfere with processing information and making complex decisions
  ▪ Represents a substantial harm
  ▪ Goes against patient wishes not to be a burden to loved ones.

  ▪ Need to ensure good communications, encourage ADs.
  ▪ Clinician role in mitigating against burdens, protect family and loved ones.
CAN WE IMPROVE TREATMENT DECISION-MAKING FOR INCAPACITATED PATIENTS?

SOME SURPRISES

- Closer relationships don’t necessarily make better decision-making
- Surrogates choose options that minimize their sense of responsibility (status quo bias)
- Surrogates no better that aggregate of what we know as HC providers about the “average” patient choices.

*Predictions of patient preferences should be based on their values, situation and other factors.*
-- “In a similar situation, some people....”
ONGOING QUESTIONS:

- How do preferences change over time and how do we account for that?
  - Would an algorithm work better than ADs?

  *This article talks about the “failures” of our current thinking. Where do YOU think we should go from here?*

SUMMARY

- Decision making is an important communication skill that requires relationship and needs to be longitudinal
- Non-beneficial care means the patient doesn’t value it, or it won’t achieve objectives
- Physicians need to help patients imagine the future in the face of serious illness
- Advance Directives – a starting place, not the “end all”?
- Surrogate burden can be heavy

  *....we have lots of work still to do to figure out how to do this as well as possible.....*
SIX ETHICAL GOALS

- Promote patient’s clinical interest
  - Clinician uncertainty about what is in the patient’s best interest
  - No method on horizon to resolve this
- Enable the patient to control treatment
  - AD guides, but only 25% have them
  - Often not pertinent to situation at hand or unclear
- Provide Tx consistent with patient preferences & values
  - Surrogates 68% accuracy
  - Stress and anxiety decrease surrogate accuracy
    - Difficulty processing information
    - Overconfidence
    - Assumption of similarity

- Respect patient preferences for how treatment decisions are made
  - Want family members to make decision
  - Patients assume family know preferences
- Respect and help patient’s family and loved ones
  - Burden evidence on surrogates/family
  - Desire not to be burden is pre-eminent for many patients
- Promote timely decision-making
  - Conflict in at least 1/3 of cases
  - Particularly true with uncertainty
### TABLE 3: MOST COMMONLY REPORTED STRESSORS AND POSSIBLE WAYS TO MITIGATE THEM

<table>
<thead>
<tr>
<th>Stressors</th>
<th>Possible Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsure of patient’s preferences</td>
<td>Encourage previous discussion and advance directives</td>
</tr>
<tr>
<td>Uncertain prognosis</td>
<td>Difficult to address</td>
</tr>
<tr>
<td>Discomfort with hospital environment</td>
<td>Help to familiarize and adjust to environment</td>
</tr>
<tr>
<td>Logistics of making decisions</td>
<td>Evaluate and address challenges to decision making</td>
</tr>
<tr>
<td>Poor communication by clinicians</td>
<td>Establish a contact person, hold consistent meetings, and use clear language</td>
</tr>
<tr>
<td>Insufficient time</td>
<td>Prepare surrogates and give time to decide</td>
</tr>
<tr>
<td>Conflict with clinicians and family</td>
<td>Identify and address sources of conflict</td>
</tr>
</tbody>
</table>

- A 78 year old long-time patient of yours has developed gradually increasing peripheral edema over the past 2 months. He is active, tends his own garden and yard, and is mentally alert. His initial work-up shows significant proteinuria, normal cardiac function, but no obvious cause. He has a 40# weight gain.
- You start him on furosemide, which works for a couple of weeks, but fluid accumulates. After renal consultation, you start high dose prednisone. Diagnosis still unclear.
- He presents to urgent care with HONK 2 weeks later, and progresses in the hospital to a fib with rate of 170. Renal consultation advises renal biopsy, consideration of cytoxan, cardiac cath.
- Patient says “no wires, no tubes, no ICU.”
- What do you do?
The patient’s wife catches you in the hall.....

- He has a Living Will. Why are you doing this to him??

You are called by the Emergency Department. A 56 year old woman who is your patient has presented with severe shortness of breath. She has Stage IV breast cancer, first diagnosed 10 years ago, with good response to initial treatment, but with recurrence over the past year. She has known brain and bone metastases, and new lung lesions, and the mets have failed to regress despite 2nd and 3rd rounds of chemotherapy.

- Last week you and she discussed Palliative Care options in the office, and she thought that hospice/PC might be the way to go.

- The ED says that she now has a fever, tachycardia, hypotension, a RR of 40, and they think that intubation and “early goal directed sepsis management” would be futile. The patient is poorly responsive, but the family wants the ED doc to “do everything.” They read your notes, and want to know what to do/
The family of one of your patients asks to talk to you. Their 82 year old father/husband is in a nursing home for progressive dementia. The family reluctantly placed him there 3 months ago because they were unable to care for him any more in their home. The nursing home called to notify them because he has had a fever for the past two nights. The weekend covering doctor tried some oral antibiotics and wants to send him to the hospital now. Most of them want him to go, but his daughter, who is a doctor in another state, says not to. This is his chance to exit. They are getting into a conflict about what to do. Can you help?

Table 2. Relationship between emergency care providers: Occupation and desired intervention following severe SCI

<table>
<thead>
<tr>
<th>EMTs (%)</th>
<th>Emergency Nurses (%)</th>
<th>Physicians (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No measures</td>
<td>31</td>
<td>27</td>
</tr>
<tr>
<td>Pain management only</td>
<td>16</td>
<td>26</td>
</tr>
<tr>
<td>Appropriate measures, but no intubation</td>
<td>24</td>
<td>33</td>
</tr>
<tr>
<td>Everything possible to ensure survival</td>
<td>29</td>
<td>14</td>
</tr>
</tbody>
</table>

\(P = .01\)

"If I had a 'fresh' SCI and respiratory distress, and intubation could increase my paralysis, I would still want to be intubated":

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<tbody>
<tr>
<td>No</td>
<td>68</td>
<td>77</td>
</tr>
<tr>
<td>Yes</td>
<td>32</td>
<td>23</td>
</tr>
</tbody>
</table>

\(P = .025\)