Capacity, Competency and Medical Decision-making at the end-of-life

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CASE SUMMARY - The Perezas

Mr. P 76 y/o man
- CAD, sp MI and CABG, negative stress test 3 yr ago;
- CVA 4 yr and 1 yr ago, no residual; DM-2, not controlled;
- HTN non-compliant;
- Gout;
- BPH;
- Multiple falls;
- "forgetful"

Mrs. P 73 y/o woman
- sp breast cancer & lumpectomy 6 yr prior;
- DM-2;
- early macular degeneration;
- osteoporosis,
- sp L Hip replacement post fall
- DVT and IVC filter;
- urinary incontinence;
- pale conjunctiva
NO ADVANCE DIRECTIVES
Your Life, Your Choices:
Planning for Future Medical Decisions

Well, he never fit in, so this is how he wanted to be remembered.
ATTITUDES TOWARD DYING AND DEATH

- Most frequent expressed fear about death was fear of being a burden to one’s family.
- 67% expressed the desire to make their own final choices about care if seriously ill; 28% wanted physician to decide.
- 9 out of 10 would prefer to be cared for at home if terminally ill with 6 mo or less to live; 70% would seek hospice care; 62% would still seek curative care.
- Younger people more willing to forego resuscitation/ventilator support than elderly.
- 1977 -96 , 77% supported euthanasia: highest among younger people (75% in 18-34 yr vs. 60% in 65+ yr of age.)
CULTURAL DIFFERENCES IN ATTITUDES TOWARD DEATH AND DYING

- Of non-terminally ill patients, there were cultural differences in views of family roles, information disclosure, expression of pain, and attitudes toward illness.

- In 800 elderly pts, there was less autonomy in Korean and Mexican vs black or white families. *deTrill, 1993*

- Immigrant families more likely to believe terminal diagnoses should be withheld from pts & families were considered proper decision-makers in EOL care. *Blackhall, 1995*

- Similar themes among Chinese and Latino-Americans with cancer. *Steinberg, 1996*
CULTURE

**ADVANCE DIRECTIVES**

- Non-hispanic whites more frequently knew about and accepted AD compared to African-Americans and Latinos. *Caralis, 1993*
- Study of 800 pts. found European Americans had significantly more knowledge and acceptance of AD compared to African, Korean and Mexican Americans. *Murphy, 1996*
- Lower rates of AD completion among non-whites. *Caralis 1993, Murphy 1996, Haiser 1997*

**REMOVING LIFE-PROLONGING RX**

- Non-hispanic whites are more likely to forego LP Rx than Latinos and African-Americans in various clinical scenarios. *Caralis 1993, Garrett 1993, Steinberg 1996*
- African, Chinese, Filipino, Iranian, Korean, Mexican Americans were more likely to agree with starting/stopping LP Rx under hopeless or terminal conditions than were European Americans. *Klessing 1992*
Suspicion of health care system and feelings of powerlessness negatively influenced Latinos’ and African-Americans’ attitudes about EOL decision-making and AD.

Whites were more likely to describe relationship with physician as collaborative and believe family could exert influence over health care decisions.

African-Americans and Latinos more often described role of spirituality and religion in patient’s prognosis and physician’s ability to cure.
How do we decide?

- ADVANCE DIRECTIVES
  - Living Wills
  - Durable power of Attorney for health care
  - State authorized Proxy decision-makers
Capacity
Competency is a legal term. Does the individual have the mental ability and cognitive capabilities required to execute a legally recognized act rationally.

The determination of incompetence is a judicial determination.

A person is presumed to be competent unless a court decides otherwise based on “clear and convincing evidence” standard.

Competence is usually task specific.
Capacity on the other hand is...

- Determined by a physician(s)
- Based on an assessment
- Can have a sliding scale determination based on risk/benefit of the treatment applied to the assessment.
For what?

Mental deficiency can leave a patient competent for one task but not for another.

For example:

- **Testamentary Capacity** - capacity to make a will—understand what a will is, know the extent of his/her estate (“bounty”) and know “the natural objects of their bounty” (living relatives).

- **Capacity to consent/refuse treatments** - intact ability to respond to a particular situation with appropriate appreciation and to act in one’s own self-interest.
1. Functional model which focuses on observable behavior in the real world.

2. Medical model based on identification of a disease.

3. Philosophic model - express desire, understanding, appreciation and reasoning.

Blum and Eth,
**ELEMENTS OF CAPACITY**

- **C** Communicates, consistent choices.
- **U** Understands the information given.
- **M** Manipulates the information in making the decision.
- **A** Appreciates the benefits/risks and applies them to their own situation.
Ability to Understand relevant information

- Have them rephrase or paraphrase information
Ability to Appreciate the situation and its likely Consequences

- Understand what having the illness means, including its course and likely outcomes
  - (Why have you been brought to the hospital?)
  - Tell me what your medical problem consists of?

- The probable consequences of treatment or its refusal.
  - What can happen if you don’t have the surgery?

- Likelihood of consequences from undergoing treatment versus forgoing treatment versus alternative treatments
  - Your doctor suggested some other options, can you tell me what they are and would you chose one of those?)
Ability to Manipulate Information Rationally

- Ability to employ logic or rational thought
A word about tests...

- Folstein Mini-Mental Status Exam
- Cognitive Capacity Screening Exam
- Short Portable Mental status Questionnaire

Formal tests may be influenced by education level, tangential thought, mood. They are best used as initial screens of probable cognitive impairment but are not determinative of capacity.
The Mini-Mental State Exam

Patient __________________________ Examining Practitioner ______________________ Date ____________

Maximum Score

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<th>Minimum</th>
<th>5</th>
<th>5</th>
<th>3</th>
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<tbody>
<tr>
<td>Orientation</td>
<td>What is the year (season) date? day? month?</td>
<td>Where are we (state) (country) (town) (hospital) (floor)?</td>
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<td>Registration</td>
<td>Name 3 objects; 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record. Trials _______</td>
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<td>Attention and Calculation</td>
<td>Serial 7s. 1 point for each correct answer. Stop after 3 answers. Alternatively spell “world” backward.</td>
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<td>Recall</td>
<td>Ask for the 3 objects repeated above. Give 1 point for each correct answer.</td>
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<td>Language</td>
<td>Name a pencil and watch.</td>
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<td>Repeat the following: “No ifs, ands, or buts”</td>
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<td>Follow a 3-stage command: “Take a piece of paper in your hand, fold it in half, and put it on the floor.”</td>
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<td>Read and obey the following: CLOSE YOUR EYES</td>
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<td>Write a sentence.</td>
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<td>Copy the design shown.</td>
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Total Score: ________________________

ASSESS level of consciousness along a continuum: Alert, Drowsy, Stupor, Coma.

Neuropsychological testing

- Assesses neuroanatomic domains, standardized Norm-referenced tests:
  - Appearance
  - Sensory Acuity
  - Motor Activity
  - Attention
  - Memory
  - Expressive Language
  - Understanding
  - Arithmetic skills
  - Reasoning
  - Visual-Spatial Reasoning
  - Executive functioning
  - Insight
Difficult Conversations

How to Discuss What Matters Most

Douglas Stone • Bruce Patton • Sheila Heen

Your Boss • Your Spouse • Your Friends
Your Kids • Your Clients

The NEW YORK TIMES Business Bestseller

With a foreword by Roger Fisher, coauthor of GETTING TO YES
Truth-Telling

- Patient-centered assessment of goals vs. Values/Requirements of health care professionals.

Central conflict is between the ethic of Truth-telling and the fear of causing the loss of hope.

*The miserable have no other medicine; But only hope.*

---William Shakespeare (1564-1616) Claudio, in Measure for Measure act3, sc.1.
Factors that often increase hope in the terminally ill include:

- feeling valued,
- meaningful relationships, reminiscence,
- humor,
- realistic goals, and
- pain and symptom relief.

Factors that often decrease hope include:

- feeling devalued,
- abandoned or isolated ("there is nothing more that can be done"),
- lack of direction and goals, and
- unrelieved pain and discomfort.
1. Ask the patient, *"Do you have long term hopes and dreams that have been threatened by this illness?"* Support the patient in recognizing and grieving the possible loss of these hopes.

2. Ask the person if there are particular upcoming events they wish to participate in--a wedding, birth, trip, etc.

3. Ask "What are your hopes for the future?" and "Do you have specific concerns or fears?"

4. Encourage the patient to make short, medium and long range goals with an understanding that the course of terminal illness is always unpredictable.
“Five Wishes” Aging with Dignity in Florida

www.agingwithdignity.org

American Hospital association

www.putitinwriting.org
"His last words were, 'Yes, Dear, those jeans make you look fat.'"
Should the physicians honor the proxy’s decisions or surrogate’s power of attorney?

- What are standards for proxy-decision making?

- Would it matter if pt. had a living will stating he/she didn’t wish to have life-prolonging treatments?
Standards for proxy decision-makers

- Willingness/availability to act
- Substituted judgment
- Best interest of patient
The Physician’s role in Surrogate Decision-Making: Helping patients find their way to “a good death”.

- Be clear, direct, authoritative, but not dictatorial
- Find out about the experiences of family and friends.
- Communicate with a single voice
- Ask specific questions
- Avoid jargon
- Don’t make promises you can’t keep.
“Do Everything”
PRACTICAL APPROACHES

• ESTABLISH TRUST

• OPEN COMMUNICATION
  – Focus on PRESENT EVENTS, PRESENT STATUS
  – Never ask permission to stop treatments.
  – Describe DX AND RX that are still planned.
  – Give family time to integrate information.
  – Prepare families by listing SIGNPOSTS FOR RECOVERY AND THOSE LEADING TO DEATH.
  – PREPARE CAREGIVERS to know when the point of futility has arrived.

• DEAL WITH DYSFUNCTION
  – Try to uncover WHY families have unrealistic expectations.
  – HELP THEM BALANCE aspects of care directed towards cure as well as coping with impending death.
  – HELP THEM gain ACCEPTANCE OF DEATH.
Are Advance Directives Final in decision making

- All AD are intended to be influential and binding.
- Disagreements and disputes are always possible.
  - Families /Surrogates can contest
  - Physicians are not compelled to act unethically or against their medical judgment.
Physician Orders for Life sustaining Treatment (POLST)

- POLST form is a standardized form designed to converse wishes for life-prolonging treatments into medical orders.

- POLST program was developed in Oregon but similar programs are used in W Virginia, Washington, Wisconsin, Pennsylvania, New York, Utah, New Mexico, Michigan, Georgia, Minnesota and Florida.

- POLST and Advance directives are complimentary.
Questions

- Are there specific life-prolonging devices/procedures that be considered for withdrawal and others that should not?

- Does withdrawal of devices unrelated to the terminal diagnosis constitute assisted suicide or euthanasia?
Should a feeding tube be placed?

Is this in accord with the patient’s desires?
- Insertion of a tube into a vein to provide IV hydration or into the stomach to provide tube feeding are medical procedures.

- Patients have the right to refuse any and all medical procedures that they consider invasive, burdensome, or undesirable for other reasons.

- Providing hydration to someone who is dying does not reverse the underlying disease that will result in the patient’s death.
There are two questions/answers involved:

1. **Clinically** - What can tube feeding do for the patient and are there any harms? Answer: medical.

2. **Ethically** - Whether a tube ought to be undertaken? Answer: based on patient’s own values and goals.
The state does not have an interest in keeping people alive against their advance directives.

Guardian / family can be sufficient evidence of desired wishes in the absence of specific advance directives.
A central goal of medicine is to relieve suffering by helping people die with comfort, support and meaning.