Effective advance care planning in under 5 minutes; now, what's the real work?

LINDA EMANUEL, MD, PHD
Outlines of our time together

1. Advance care planning in under 5 minutes
2. The real work
3. What is existential maturity
4. Clinical services
5. Discussion
Advance Care Planning: using thresholds

- 6 scenarios
- 6 goals
- Verify with Rx choices

Have the proxy present

SITUATION B

If I am near death and in a coma and, in the opinion of my physician and two consultants, have a small but uncertain chance of regaining higher mental functions, a somewhat greater chance of surviving with permanent mental and physical disability, and a much greater chance of not recovering at all, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only
☐ other (please specify): ____________________________
SITUATION F

If I am in my current state of health (describe briefly):

and then have an illness that, in the opinion of my physician and two consultants, is life threatening but reversible, and I am temporarily unable to make decisions, then my goals and specific wishes — if medically reasonable — would be:

☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only
☐ other (please specify):

I want treatment if no clear improvement, I am undecided, I do not want
**SITUATION D**
If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to think or have feelings, but I have no terminal illness, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (please specify): __________

**I want treatment tried. If no clear improvement, stop.**

<table>
<thead>
<tr>
<th>I want</th>
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<th>I do not want</th>
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**SITUATION E**
If I...
(describe a situation that is important to you and/or your doctor believes you should consider in view of your current medical situation):

- prolong life; treat everything
- attempt to cure, but reevaluate often
- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (please specify): __________

**I want treatment tried. If no clear improvement, stop.**

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Please check appropriate:

1. Cardiopulmonary resuscitation, drugs, electric shock aimed at reviving a person.
2. Major surgery (for example, removing a part of the bladder, heart, or lung).
3. Mechanical bowel cleansing through a tube in the stomach.
4. Dialysis (cleaning blood through a tube in the blood stream).
6. Artificial nutrition (feeding through a tube in a vein or into the stomach).
7. Simple diagnostic tests (for example, x-rays).
8. Antibiotics (drugs to fight infections).
9. Pain medication (for instance, for back pain or headaches).
### SITUATION D
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- other (please specify) ______________

### SITUATION E
If I...

(Describe a situation that is important to you and your doctor believes you should consider in view of your current medical situation.)

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- limit to less invasive and less burdensome interventions
- provide comfort care only
- other (please specify) ______________

---

**Please check appropriate boxes:**

1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying).
2. Major surgery (for example, removing the gallbladder or part of the colon).
3. Mechanical breathing (respiration by machine through a tube in the throat).
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly).
5. Blood transfusions or blood products.
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach).
7. Simple diagnostic tests (for example, blood test or x-ray).
8. Antibiotics (drugs used to fight infection).
9. Pain medications, even if they dull consciousness and indirectly shorten my life.
Do thresholds exist?

Box 1. Scenarios

1: You are in a coma with a small likelihood of recovering fully, a slightly larger likelihood of surviving with permanent brain damage, and much larger likelihood of dying.

2: You are in a coma/persistent vegetative state, with no hope of regaining awareness and higher mental functions no matter what is done.

3: You have brain damage or disease which cannot be reversed and makes you unable to recognize people or to speak understandably, and a terminal illness which will likely be the cause of your death.

4: You have brain damage or disease which cannot be reversed and makes you unable to recognize people or to speak understandably, without any other condition that is likely to cause your death, and you could live in your current condition for a long time.

Scenarios and interventions are from a previously-derived, validated advance care planning instrument, the Medical Directive. [JAMA 1989, 261:3288–3293]
## Psychological Thresholds

### Table 2: Responses by Scenario and by Intervention Intensity (N = 31)

<table>
<thead>
<tr>
<th>Scenario*</th>
<th>Response</th>
<th>No</th>
<th>Undecided</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>21.70%</td>
<td>8.50%</td>
<td>69.79%</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>67.74%</td>
<td>3.81%</td>
<td>28.45%</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>73.90%</td>
<td>6.16%</td>
<td>19.94%</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>70.67%</td>
<td>2.64%</td>
<td>26.69%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intervention Intensity*</th>
<th>Non-intensive</th>
<th>Minimally Intensive</th>
<th>Intensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>39.52%</td>
<td>55.85%</td>
<td>68.23%</td>
</tr>
<tr>
<td>Undecided</td>
<td>4.44%</td>
<td>3.85%</td>
<td>5.16%</td>
</tr>
<tr>
<td>Yes</td>
<td>56.05%</td>
<td>38.31%</td>
<td>26.61%</td>
</tr>
</tbody>
</table>

* *p*<0.0001 for distribution of Yes/No responses

Psychological Drivers

Winter L: Patient values and preferences for end of life treatments: are values better predictors than a living will?


“Providing better guidance than a living will in determining a patient's EOL treatment preferences are

1. knowledge about a patient's religiosity,
2. patient's wishes for longevity, and
3. patient's wishes for following family preferences.

Wishes for dignity and pain management and reluctance to burden others do not offer better guidance than a living will.”
Psychological Drivers...

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Wishes for dignity and pain management and reluctance to burden others do not offer better guidance than a living will.”

“It is known that goals of care selected by patients predict specific treatment choices well
[Fischer GS, Alpert HR, Stoeckle JD, Emanuel LL: Can goals of care be used to predict intervention preferences in an advance directive?. Arch Intern Med. 1997, 157 (7): 801-807]

The studies must still be done, but it is highly likely that characterization of the underlying drivers of individuals’ decisions would predict specific treatment choices even better.”
accurate predictions about treatment choices may be derived by using assessments that characterize the key drivers of individual’s decision making, thus relieving some of decision makers' burdens.

For instance, using Likert Scales of 5 units with 5 being most interventionist, a person inclined to save life of any state at all cost might have a threshold of ‘Prognosis 5, Disability 5, Burden 5’ which might be succinctly reported as: P5-D5-B5.

By contrast, a person inclined to emphasize quality of life over longevity might have a characterization of P1-D1-B1.

Or a person with a characterization of P1-D2-B5 would be someone inclined to try hard if the prognosis were good and if the likely disability were modest but otherwise to emphasize comfort.”
An Exercise

Consider this scenario:

You have metastatic adenocarcinoma of unknown origin with a prognosis of months to a year and you are bedbound and dependent on others for everything but can enjoy relationships with loved ones and care team members. Insurance covers most of your care but your family is paying out of pocket and taking time off work to manage.

Then you develop pneumonia and you are in a non-responsive state.

With full intervention, you have an small chance of recovery to your baseline but will more likely loose more function.
Guess what your neighbor would want

If medically relevant

a. Resuscitation
b. Mechanical ventilation
c. Chest tube
d. Antibiotics
e. Oxygen

Remember / note down your guesses.

Do NOT share your selections.
Find your ‘blink’ threshold

In case of an illness that no longer has hope of cure and has made me unable to make my own decisions, my proxy should speak for me based on these factors. If my best outcome involves:

**Prognosis of days to weeks**
chose treatments that are:
1. not ... 2. somewhat ... 3. average ... 4. very ... 5. very strongly
   *interventionist* (circle one)

**Severe Disability**
chose treatments that are:
1. not ... 2. somewhat ... 3. average ... 4. very ... 5. very strongly
   *interventionist* (circle one)

**Significant Burden to loved ones**
chose treatments that are:
1. not ... 2. somewhat ... 3. average ... 4. very ... 5. very strongly
   *interventionist* (circle one)
See if its useful to your ‘proxy’

Make a Note of your Thresholds
• P[x]-D[x]-B[x]

Trade with your neighbor to your right (or behind you)

Consider the same scenario

Predict what your neighbor would have wanted
Consider the same scenario:

You have metastatic adenocarcinoma of unknown origin with a prognosis of months to a year and you are bedbound and dependent on others for everything but can enjoy relationships with loved ones and care team members. Insurance covers most of your care but your family is paying out of pocket and taking time off work to manage.

Then you develop pneumonia and you are in a non-responsive state.

With full intervention, you have an small chance of recovery to your baseline but will more likely loose more function.
Now guess your neighbor’s wishes

If medically relevant

a. Resuscitation
b. Mechanical ventilation
c. Chest tube
d. Antibiotics
e. Oxygen

Tell your neighbor your before and after selections
How many:

Came closer to their neighbor’s wishes?
Got further afield?
Mixed?
No change?
Do these drivers change?

Personality is relatively stable
- With identifiable drivers, stability is better?
- An empirical question

Maturation does occur

What would maturity mean in this setting?
- Closer adherence to core drivers?
Outlines of our time together

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Existential Maturity

A state or stage of
Finitude acceptance (*Kohut*)
Generativity (*Erikson*)
With tasks and roles (*Richardson & Emanuel*)
Its own gratifications, type of loving
Ways of getting there (*Kubler Ross, Knight*)
Dying Role

Roles often life cycle connected
Roles guide us in unknown territory
Roles connect us to others
Roles have tasks/jobs
Is there a dying role?
Dying Role

Social science criteria:
Life cycle connected
Guides us in unknown territory
Connects us to others
Has tasks/jobs

Dying Role Tasks

Pass on
  ◦ Life roles
  ◦ Symbolic things
  ◦ Material things
  ◦ Narrative meaning

Blessing

Planning dying

Preparing loved ones for bereavement
Does Existential Maturity Help?

Quality of life
Quality of transgenerational life
Quality of culture
Goals of care
Stability of choices
How does one achieve existential maturity?

Cognitive acceptance
Empathic experience
Psychological development
= interwoven meaning related to mortality

Any age; any state of health
Developmental Process

infant
latency
adolescence
childhood
adult
Psychological Development

- Oscillation between aversive & conducive states; between fragmentation & integration
  - Confrontation, awe
  - Mourning, replacing
- In dialectic relationship
  - Holding
  - Idealizing attachment
  - ‘Play’
- Development of values, skills, ambitions
  - Active/intentional
  - Located/related
The Role of People

Someone to process with
Someone who has experience to help guide
Someone to explore possibilities with
Someone to be with
Someone to create the new realities with
How does one achieve existential maturity?

As other developmental stages are achieved
Not disavowal or repression; quite the opposite

Unique features?
◦ Place of awe
  ◦ ‘...there’s a transfer of life...’ ‘...the human cognition of that vastness, the awe and the wonder...’
  
  Yo-yo Ma NPR March 2016

◦ Death
  ◦ Earnest Becker on Death Anxiety
We have a greater purpose. We’re communing together and we want this moment to be really special for all of us. Because otherwise why bother. We need to be together.

...there’s a transfer of life...it’s the human cognition of that vastness, the awe and the wonder; something that’s in a way bigger than yourself.
Michelangelo’s Pieta

A patient, a loving wife, and a photographer
Should we think differently about hope?

Hope v. hopeless
  ◦ Ambitions v. depression

Value v. valueless
  ◦ Love, joy

Our ambition/clinical goal should be patient joy

Emanuel L J Pall Med 2015 The goals of medicine: Health? Joy? and lessons along the way
Fostering Existential Maturity

Psychodynamic psychotherapy

Sheldler J 2010 JAPA The Efficacy of Psychodynamic Psychotherapy

Division of Supportive Oncology NMH

- Psychodynamic services for caregivers, patients – 2015
- families, children – 2016/7
Interventions and Existential Maturity

Dignity Therapy - Chochinov
Meaning-centered Therapy - Breitbart
Advance Care Planning

Culture
  ◦ Movies
  ◦ Stories
  ◦ Personal experiences
  ◦ Music

Religious leaders
  ◦ Liturgy
  ◦ Ritual
  ◦ Chaplaincy training
Outlines of our time together

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NMH Psycho-oncology Service

Patient
- Counselling, CBT, Groups

Family

Psychodynamic therapy
- 2 – 4 x / week
- reclining chair
- analytic approach based on
  - identifying barriers to mourning, psychological growth and
  - facilitating development of existential maturity
Dignity Therapy: 10 questions

1. Tell me a little about your life history; particularly the parts that you either remember most, or think are the most important? When did you feel most alive?

2. Are there specific things that you would want your family to know and remember about you?

3. What are the most important roles you have played in life (family, vocational, community service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?

4. What are your most important accomplishments, and what do you feel most proud of?

5. What are your hopes and dreams for your loved ones?
10. In creating this permanent record, are there other things that you would like included?