Improving Use of Advance Directives

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the Clinical Research, Investigation, and Systems Modeling of Acute illness
Improving Advance Care Planning

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Goals

To examine the “EOL care orthodoxy” that the correct focus of advance care planning is in helping patients make treatment decisions in advance.
Advance Care Planning = Complete an Advance Directive

Traditional content of AD:
- Patients make treatment decisions in advance
- Patient designates surrogate decision maker
Problems with the Old Paradigm
Shortcomings of making decisions in advance

- Often document not available when needed.
- Infeasibility of anticipating all decisions.
- Deficiencies of affective forecasting

Affective Forecasting
Serious Problems Predicting Our Own Preferences about Future Health States

- People cannot predict what will have for dinner/buy

- Predictions do not reflect one’s current
  - Medical
  - Emotional
  - Social context

- Preferences change during:
  - Changing AND stable health, & end-of-life

If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.
LIVING WILL 3/20/05

I do not want to be kept on life support if I am in a vegetative state & the prevailing medical opinion is that I will not emerge from this state in the foreseeable future.

"Vegetative state" means that: (1) my communicative faculties are severely impaired such that my wishes can not be known; (2) I require artificial life support because I cannot feed or otherwise take care of myself; (3) I have a severely reduced state of consciousness. If there is any doubt about what I would want be sent to the following people who will vote on my fate. Simple majority wins:
Ted Ruel
Dog White
Seanne Strickland - 2 votes
Ross Rosen
Sill & Robert Rose
Eddie Gilmartin
My child (ren)
Terese Tafm
Renni Jensen

Also I would prefer a humane, assisted suicide (preferably by a physician) over a long and drawn out death, or even short and painful.

3/29/05

If any of the above are deceased or unavailable, the vote shall be counted by those available. Any person refusing to vote will be eliminated.

Jane L. Rosen

Refusal of life support would be made not less than 2 weeks after the incident causin a state of extreme suffering. The voting members by majority believe a lack of vote is in my interest. "Doubt" will be judged by the voting panel + 1/3 expressing doubt is sufficient to forward the fate determination to the panel.
Problems with the Old Paradigm
Shortcomings of Simply Designating a Surrogate

- Surrogates do not know they were chosen
- Unaided, they often do not make decisions the patient would make.
  - Use own hopes, desires and needs
- Stress, anxiety, PTSD

Fried TR, et. al., J Gen Intern Med. 2008; Sudore RL., JAMA, 2009
Benefits of ADs are Modest (At Best)

- Silveira M. NEJM 2010
- Teno J. JAGS 2007
- The SUPPORT Principal Investigators. JAMA. 1995
- Perkins HS. Ann Intern Med. 2007
- Fagerlin A. Hastings Cent Rep. 2004
New Objective of ACP

**PREPARE** surrogates to participate with clinicians in making the best possible in-the-moment decisions.

Sudore RL. & Fried TR. *Ann Intern Med*, 2010
New Objective: Prepare For In-The-Moment Decision Making

- Shifts focus away from asking pts to make premature treatment decisions

- Toward PREPARING surrogates through conversations with patient about values, goals, and leeway.

- Advance Directive is one tool in this ACP process.

Sudore RL. & Fried TR. Ann Intern Med, 2010
3 Key Preparatory Steps

1) Choosing AND engaging an appropriate surrogate decision maker

2) Clarifying patient’s values about outcomes of treatment over time

3) Establishing leeway in surrogate decision making

Sudore RL. & Fried TR. Ann Intern Med, 2010
Step 1: Choosing/Engaging a Surrogate

- **Ask the patient:**
  - “…is there anyone you trust…?”

- **Does surrogate know?**
  - “Does this person know you chose him/her for this role? What have you talked about?”

- **Ask the surrogate:**
  - “Are you willing to make medical decisions for him/her?”
Step 2: What Goals/Values Matters Most to the Patient?

- What matters most to patients is not the treatment BUT the **outcome of treatment**

- Not intubation or CPR, but how their life will be afterward

  - “What do you most hope for or fear?”

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Step 3: Establishing Leeway

- **Rationale:** “In-the-moment decisions” will often require some exercise of judgment → STRESSFUL FOR SURROGATES.

- **GOAL:** Mitigate stress by “getting buy-in” for LEEWAY.
  - “Will you give your loved one/s permission to work with your doctors to make the best decision they can for you even if it may differ from what you said you wanted in the past?”
  - “Are there certain decisions you would never want your loved ones to change?”

*Vig EK, et. al., J Gen Intern Med. 2007; Fried TR, et. al., J Gen Intern Med. 2008; Lo B, et. al., Arch Intern Med. 2004*
Is There Any Evidence this Model of ACP is Effective?

**Design:** single center RCT comparing facilitated ACP vs usual care among n=309 elderly inpatients w DM capacity

**Intervention:** In-person counseling of patient/surrogate by trained facilitator; values clarification, discussion of surrogate DM, documentation.

**Control:** Usual care (No ACP unless requested)

**Results:** Intervention resulted in:
- EOL wishes more often known and respected (86% vs 30%; p<.001)
- Improved quality of death (83% vs 48%; P=0.02)
- Less depression, anxiety, PTSD in bereaved relatives (p<0.001)

Detering K. BMJ. 2010
Comparative Effectiveness Question

Is “in-the-moment advance care planning” more effective than “traditional AD-focused ACP” in

- achieving value-concordant care and
- decreasing the psychological strain of decision making on surrogates?