Value-based End-of-Life Care: Patient Preferences and Resource Management

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Disclosures

- Employment – Colorado Permanente Medical Group
- Consultant ship – Life Quality Institute
On Value

“Achieving high value for patients must become the overarching goal of health care delivery, with value defined as the health outcomes achieved per dollar spent. This goal is what matters for patients and unites the interests of all actors in the system. If value improves, patients, payers, providers, and suppliers can all benefit while the economic sustainability of the health care system increases”.

Porter ME. NEJM, 2010
Objectives

1. Provide tips/resources for keeping people out of the hospital/ER using advance directives
2. Describe how to negotiate competing family dynamics at the end of life for hospitalists and PCPs
3. Explain time effective DNR counseling
4. State approaches to discussing marginal benefits/futility of care
Today’s Roadmap

- Advance Care Planning
- Family Dynamics and Conflict
- Discussing Preferences, DNR
- Demands for “Everything”
Advance Care Planning...
Basics: Advance Care Planning (ACP)

- **ACP = a process**
- **Advance Directives: tools to support ACP**
  1. Medical Durable Power of Attorney
  2. Living Will
  3. Colorado CPR Directive
  4. Medical Orders for Scope of Treatment (MOST)
- **ACP: grounded in informed consent**
- **Advance directives are only as good as the process by which they were created**
Why Advance Care Planning?

- To protect ourselves
- To support our loved ones
- To personalize care
- To strengthen relationships
- To spark public dialogue
- To support efforts to use medical resources more wisely
Truths about End-of-Life Discussions

○ EOL discussions associated with:
  ● **NO** increase in patient depression or worry
  ● Better patient *and* caregiver quality of life
  ● ↓ Ventilation, resuscitation, ICU admission; ↓ costs
  ● Earlier hospice admissions
  ● Less depression in bereaved caregivers

○ More aggressive therapies associated with:
  ● **NO** difference in mortality
  ● Worse patient QOL (*↑*Hospice LOS =*↑*QOL)

Directives Change Care Decisions

- Survey of 3746 proxies of decedent patients
- Nearly half (43%) required decision making:
  - 70% lacked capacity, 68% (of those) had ADs
- Those with ADs (either living will or MDPOA):
  - More likely to want limited care (93%) or comfort care (96.2%) vs. “all care possible” (1.9%)
  - Less likely to receive all care possible (AOR, 0.3)
  - Less likely to die in hospital (AOR=0.72) or receive “all care possible” (AOR=0.54)

Silveira MJ et al. NEJM, 2010
Ah, but the Challenge…

Nearly 8 in 10 Americans say that if seriously ill, they would want to speak with their doctor about end-of-life care, but fewer than 1 in 10 report having had a conversation, including just 13% of those age 65 or older.

Additionally, while 82% say that it is important to put their wishes in writing, less than one quarter have actually done so. More than half say they have not talked with a loved one about the kind of care they want at the end of life.

California HealthCare Foundation survey, Final Chapter: Californians' Attitudes and Experiences with Death and Dying, 2012
A Few Words on POLST in 2013

- Physician Orders for Life Sustaining Treatment (POLST) programs exist/ in development in 34 states: www.ohsu.edu/polst

- Recent POLST registry in Oregon showed:
  - Half of registrants with a DNR order wanted comfort measures only, but half wanted a higher level of treatment
  - Among persons with a POLST DNR order, a substantial proportion had orders for other life-sustaining treatments

Fromme EK et al. JAMA, 2012. www.ohsu.edu/polst/
Colorado Medical Orders for Scope of Treatment (MOST)

- Modeled on POLST (Physician Orders for Life Sustaining Treatments) in Oregon/ other states
- Who? → Seriously ill patients w/ frequent transfers
- Colorado MOST form: summarizes patient preferences for life-sustaining treatments: CPR, general scope of treatment, antibiotics, and artificial nutrition/ hydration
- 2010 legislation: a signed MOST form (by MD, DO, APN or PA) serves as a physician's order for EMS and/or a health care provider/ facility
- Statewide education and implementation ongoing
Reality Check

So, if advance care planning is such a good idea, why have we made so little progress?
Challenges to “Planning Ahead”

- Can we really know what we want a priori?
- “My family will make decisions when the time comes. They know what I want.”
- “Uninformed” consent: might we be bound by a promise not rooted in reality?
- System failures: not honoring ADs

The strength in “planning ahead” resides more with the process – reflecting upon and communicating personal beliefs and boundaries – than with the AD documents

Physicians Do Not Often Have End-of-Life Discussions: Why?

- “It will make people depressed” (Myth)
- “It will take away hope” (Myth)
- “Involvement of hospice or palliative care will reduce survival” (Myth)
- “We do not really know a patient’s prognosis” (Mostly Myth)
- “Talking about prognosis is not culturally appropriate” (Mostly Myth)
- **We do not like to have these discussions, and they are hard on us (Truth)**

Advance Care Planning System: What Would Success “Look Like”? 

Important elements:  
- Person-centered, respectful process  
  - Honors the diversity of our patients  
  - Attends to literacy, recognizes intimacy  
- Conducted by competent clinicians  
  - Doesn’t just assume that “anybody” can do this  
  - Assures dedicated time for trained individuals  
- Systematic approach  
  - Built into usual care processes, ongoing  
  - Standardized documentation, goals/values
Respecting Choices: The La Crosse Experience

- In 1991, La Crosse County, WI collaboration: tested systematic model of EOL decision making
- Unique approach: effective materials and training, [www.respectingchoices.org](http://www.respectingchoices.org)

- Now > 90% of persons who die have completed ADs; > 99.5% w/ ADs in one common record
- La Crosse Medicare patients: 13.5 days of hospital care in the last 2 years of life (vs. 20 d (regional) and 23.5 d (national) averages)

Matching the Care Delivered with Documented Preferences

- RCT of 309 older hospitalized patients
- Facilitated advance care planning (ACP, N=154) vs. usual care (N=155) using *Respecting Choices*

**Results:**
- Most (> 80%) in ACP Group expressed wishes or appointed a surrogate, or both.
- Of 56 patients who died by 6m, preferences more likely to be known/ followed w/ ACP group *(86% vs. 30%)*
- In ACP group, bereaved family members had less stress, anxiety, and depression (P≤0.02).
- Patient-family satisfaction greater in the ACP group.

Detering KM et al.  *BMJ*, 2010
Getting Help

“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Centers to Advance Palliative Care, 2011 Public Opinion Research on Palliative Care
Understanding Palliative Support

Old Approach

Integrated Approach

“Curative” Care  “Comfort” Care

Curative or restorative goals

Palliative support

Hospice

Medicare Hospice Benefit
- Life expectancy < 6 months
- Waive “curative” treatments
Not Just “Comfort Care”

- Randomized trial of 151 patients w/ stage IV lung CA
- Early integrated PC:
  - Higher QOL, less depression
  - Still with chemotherapy, but less IV chemo
  - Less resuscitation or ICU care, longer hospice stays (median 24 days vs. 9.5 days)
  - Longer survival (2.5 months)

PC Consultation is Associated with Lower Acute Care and Higher Hospice Utilization

- KP matched case-control study, 3380 hospitalized patients, IPC vs. usual care
- Results:
  - 40% less hospital readmissions (0.40 vs 0.67, $p < .0001$)
  - 56% less ICU readmissions (0.11 vs. 0.25, $p < .0001$)
  - 24% lower ER admissions (0.44 vs. 0.58, $p < .0001$)
  - 51% higher hospice admissions (0.44 vs. 0.29, $p < .0001$)
  - 55% higher mean hospice LOS (28 vs. 17, $p < .0001$)

When Things Get Complicated: Complex Family Dynamics

- Mrs. GF: an 83-year-old woman with DM, HTN, CVA, CAD, CHF, CKD, COPD, and biliary drain
- Documented conversation with PCP, DNR/DNI
  “I don’t want extended medical treatment or a breathing machine. My sister was on the machine. I don’t want any of that. … I do not want you to tell my daughters because they would not understand.”
- Presents septic to PCP → ED, with directives
- “Permission” for intubation asked for by ER MD, and granted by daughter despite ADs
- Died 22 days later in the ICU after LS withdrawal

More than a Piece of Paper…

“Albert Camus might suggest that physicians should warn patients and families that momentous, unforeseeable decisions lie ahead. Then, when the crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and, above all, should courageously see patients and families through the fearsome experience of dying.”

Perkins HS. *Annals Internal Med.*, 2007;147:51-57.
Daughters’ Reflections

Daughter E: “‘Emma, please don’t ever put me on a respirator, life support, anything. I don’t want none of that.’ I was just like, ‘OK, Mom.’ You never think that something like this would happen. ‘That’s OK, Mom, you’ll be OK.’”

Daughter P: “Few years ago, I went to her house and she had a DNR/DNI form on the refrigerator. I said, ‘Do you know what this is? If you have this on your refrigerator and someone walks in here, and you pass out and 911, the ambulance come in here and they see this form on the refrigerator, they are not going to try to bring you back if you are dying, you are just going to die because you got this form here and you already signed this form. This is what this form is. You do not need this.’ I took it off the refrigerator and tore it up.”

A family meeting is a procedure, and it requires no less skill than performing an operation.”

Susan Block, MD
When Perspectives Differ…

- Acknowledge the norm: patients/families have varied values and views
- Making decisions in isolation is risky!
- General tips for family meeting:
  - Elicit perspectives from all
  - Seek common ground
  - Expect (and attend to) emotion
  - “Empty chair” reminder
- Data shows patients most want to share values and grant “leeway” re: decisions

Talking with Seriously Ill Patients: A Framework to Support Transitions

1. Prepare yourself
2. Explore what they understand
3. Assess readiness to talk (what’s next?)
4. Explore values, goals, and hopes
5. Identify fears and concerns
6. Offer to make a recommendation
7. Propose a care plan
8. Ask for feedback about your proposal

Avoid temptation to skip!

From Back A et al, Mastering Communication with Seriously Ill Patients, 2009
Tips: Dealing with the “Difficult” Family

- Recognize that the expressed emotion (anger, apathy, etc…) is rarely, if ever, about you!
- Get curious, not furious
- Set limits – don’t work harder than they do
- Validate emotions – then look to refocus
- Be prepared to step back (to let family resolve)
- Be patient – “plant seeds”
When Directives Collide: Understanding the Law

- In Colorado, if no decision maker → Proxy Law: instruct family to gather interested parties

- If family conflict:
  - Make decisions w/ MDPOA/ selected proxy, BUT
  - Meet to understand perspectives, provide emotional support, and seek common ground or consensus

- If MDPOA disagrees with Living Will (LW):
  - First explore reasons/ rationale: grieving vs. other?
  - If LW addresses full situation, LW trumps MDPOA
  - Provide emotional support, consider time limited trial
Discussing Resuscitation: Meet Roger

A 81 y/o retired mailman with advanced CHF (EF 20%), CAD, DM and CKD (Cr = 3.0)

- Three admissions in 6 m, recent SNF stay
- Accepts hospitalization: “if that’s what it takes.”
- Growing weakness, mostly bed-bound
- Desires full resuscitation: “It’s saved my life once before… I’m not ready to just give up.”
- “Why d’ya keep asking…don’t y’all ever talk?”
Understanding Resuscitation

- Public perception shaped by TV and film
  - 1996 NEJM analysis of resuscitations on TV
  - 2006 study of elderly: 81% believed >50% chance of surviving inpatient CPR and leaving the hospital
- About 17%, or 1 in 6 patients, who undergo CPR in the hospital will survive to discharge
- Prognostic info. influences CPR preferences
- Specific co-morbidities reduce survival

Factors Predicting CPR Failure

- Factors which predict a *failure to survive to discharge* included:
  - Sepsis the day prior to the CPR event
  - Serum Cr >1.5 mg/dl
  - Metastatic cancer
  - Dementia
  - Dependent status

- In a 2006 meta-analysis, 6-7% of cancer patients survived CPR to discharge (less than 2% if a cancer patient in the ICU)

DNR Discussions: A Few Tips

- Conversation starts with goals/values!
- Know resuscitation outcomes data
- Avoid “partial code” discussions
- Beware of your own biases: LISTEN, LEARN, and LET GO
- Don’t be afraid to make a recommendation
- Attend to emotion
- Provide patients/families with time – most transition to DNR as losses accumulate
Video Support for DNR Discussions

“A picture is worth a thousand words”

www.acpdecisions.org
“Do Everything”: Meet Brenda and John

...an 82 y/o former librarian and her only son (and caregiver)

- Clinic visit following recent hospitalization 2\textsuperscript{nd} fall
- Progressive dementia, CAD, PVD, DM and frailty
- Marked decline in 6 months, weakness, not eating
- Two hospitalizations (CAP, urosepsis) in 4 months
- John “meticulous” w/ mom’s care at home, hired help
- Brenda: non-decisional with no advance directives
- Refuses PT (“no”), wheelchair bound, no ADLs
- Discussion re: goals: “she would want everything”
On Doing “Everything”: First Do No Harm

“Clinicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them. Denial of treatment should be justified by reliance on openly stated ethical principles and acceptable standards of care.”

What is “Doing Everything”?

Table 1. Different Treatment Philosophies Underlying Requests for “Everything”

<table>
<thead>
<tr>
<th>Philosophy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everything that might provide maximum relief of suffering, even if it might</td>
</tr>
<tr>
<td>unintentionally shorten life.</td>
</tr>
<tr>
<td>Everything that has a reasonable chance of prolonging life, but not if it</td>
</tr>
<tr>
<td>would increase the patient’s suffering.</td>
</tr>
<tr>
<td>Everything that has a reasonable chance of prolonging life, even if it may</td>
</tr>
<tr>
<td>cause a modest increase in suffering.</td>
</tr>
<tr>
<td>Everything that has a reasonable chance of prolonging life even a small</td>
</tr>
<tr>
<td>amount, regardless of its effect on the patient’s suffering.</td>
</tr>
<tr>
<td>Everything that has any possible potential to prolong life even a small</td>
</tr>
<tr>
<td>amount, regardless of its effect on the patient’s suffering.</td>
</tr>
</tbody>
</table>

# Words to Explore “Everything”

<table>
<thead>
<tr>
<th>Domain</th>
<th>Example Questions to Ask</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>“Tell me more about what you mean by ’everything.’”</td>
</tr>
<tr>
<td></td>
<td>“What is your understanding of your condition/prognosis?”</td>
</tr>
<tr>
<td>Affective</td>
<td>“What worries you the most?”</td>
</tr>
<tr>
<td></td>
<td>“What are you hoping for?”</td>
</tr>
<tr>
<td>Spiritual</td>
<td>“Does your religion (faith) provide any guidance in these matters?”</td>
</tr>
<tr>
<td>Family</td>
<td>“How is your family handling this?”</td>
</tr>
</tbody>
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Decreased Oral Intake is a *Normal* Part of the Dying Process

- Decreased oral intake ‘normal’ part of dying
- Studies show “hunger” or “thirst”, if present, easily manageable in palliative settings
- Often distressing for family and friends
- Little evidence to support parenteral (TPN) or enteral nutrition (PEG) for advanced illness
  - Does not improve mortality, muscle mass, function or quality of life in *advanced cancer* or *dementia*
  - Advanced. dementia: PEG w/ ↑ risk wounds
- Avoid dogma – seek to understand and support

Strategies for Limiting Therapies When Facing Unresolved Conflict

• Plant seeds: don’t demand urgent decisions
• If deemed harmful: obligation to NOT provide
• Consider recommendations (over coercion)
• If unsure: use *structured* “time limited trials”
  – Agree to reevaluate at a pre-defined future date
  – Clarify what “better” or “harm” would look like
  – STATE expectations: Tx will be stopped if harm
• Seek support via palliative care, ethics
• Hospital futility policies, transfer of care
A Final Word…

“For doctors, the primary purpose of a discussion about terminal illness is to determine what people want—whether they want chemo or not, whether they want to be resuscitated or not, whether they want hospice or not. They focus on laying out the facts and the options. But that’s a mistake…”

“A large part of the task is helping people negotiate the overwhelming anxiety—anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances. There are many worries and real terrors.”

Susan Block, MD
“You sit down. You make time. You’re not determining whether they want treatment X versus Y. You’re trying to learn what’s most important to them under the circumstances—so that you can provide information and advice on the approach that gives them the best chance of achieving it. This requires as much listening as talking. If you are talking more than half of the time, you’re talking too much.”

Susan Block, MD
That’s Enough!

Questions and Comments