End of Life Communication, MOLST, and Advance Directives
Maryland MOLST: A Six Month Check-Up

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Navigating Conversations:

- Atul Gwande’s video “How to Talk End-Of-Life Care with a Dying Patient”

www.youtube.com/watch?v=45b2QZxDd_o
4 Key Questions:

- Do they know their prognosis?
- What are their fears about what is to come?
- What are their goals (especially as time draws near) ?
- What are the trade-offs they are willing to make (threshold of suffering) ?
What is meant by Goals of Care?

Goals of Care = Patient Values

- Cure disease
- Avoid premature death
- Maintain or improve function
- Prolong life
- Avoid pain
- Avoid dependence
- Improve life quality
- Stay in control
- Support for families & loved ones support

Goals may change as illness evolves
What treatment would you want if:

- You could no longer talk or think clearly?
- You could no longer recognize or interact with your family?
- You couldn’t swallow safely and a feeding tube was suggested?
- You couldn’t breathe and needed a breathing machine indefinitely to keep you alive?
- You could no longer control your bowel or bladder?
- You lived in a nursing home?
- You had pain most of the time?
Additional Advance Care Planning Steps

• Besides hypothetical scenarios,
  ◦ Use past experiences
  ◦ Consider worst-case scenarios
  ◦ Focus on quality of life, defined by the individual patient
  ◦ Choose a surrogate who is willing to follow the patient’s wishes- family member may not be the best choice
Example of a living will that explores a patient’s values & goals

5 Wishes is valid in many states
Easy to read 1888-5-WISHES

www.agingwithdignity.org
Factors that Influence Care Goals Discussions
Communication: Do You Hear What I Hear?

• What do patients / families hear?
  ◦ “You are looking better today”.
    • Family hears “you are getting better, and will continue to improve each day”.
    • Mixed messages from various specialties

• What do we as staff hear?
  ◦ “Doc, have I bought the Farm?” (Am I dying?)
    • Is this patient delirious?
Communication: The Importance of Language

- Common Phrases that are confusing:
  - “Do you want us to do everything? (Yes, please)
  - “Should we withdraw care?” (and ignore my loved one?)
  - “Do you want us to restart your heart?” (can you replace it like a battery?)

- Clarifying language (examples):
  - “Allow natural death”
  - “How do you think we should focus our care with the time your loved one has left?”
Cultural and Spiritual Factors

- African Americans and Hispanics are twice as likely as white Protestants, Catholics, and people of no religious identity to insist that doctors do everything possible to stave off death, even in the face of incurable disease and great pain.

- “God is in control and his miracles are through the technology”. - family of Mrs. C.

- For African Americans, there may be a distrust in the healthcare system

Cultural and Spiritual Factors

• The role of spiritual leaders in the community for patients and families - may be very involved in patient/family discussions

• The role of suffering:
  ◦ “If Jesus suffered, so can I”
  ◦ May be defined differently by the patient/family – being in the hospital may not be viewed as suffering

  - www.huffingtonpost.com/2013/11/21/blacks-and-hispanics-end-of-life-care
Other Factors

• Generational
  ◦ “Why do we have to talk about things that haven’t happened yet?” – Dr. G, a 95 yo retired physician with CHF, CLL
  ◦ Paternalistic preferences in geriatric patients

• Cognitive Deficits
  ◦ Dementia, insight/capacity, higher levels of thinking & reasoning
  ◦ Delirium
Other Factors

- Family Dynamics
  - If patient was the matriarch/patriarch of the family, may be difficult for adult children to step in
  - Families in disagreement- with plan of care, patient wishes, etc
  - Patients who do not want to share their wishes in front of children/family to avoid disappointing them
Other Factors

- Health literacy
- Navigation of the healthcare system (acute care)
  - “who is my doctor?” - hospitalist movement, rotation of teams, etc.
  - Multiple specialists - lack of a global picture

“there was a bunch of people in white coats standing around my bed in a circle, staring at me. I don’t know what they were doing, but one of them did all the talking; he seemed to be their leader.” - Steve, a patient describing rounds
Other Factors

- Discomfort of patients / families to acknowledge poor prognosis, or talk about planning ahead

- Discomfort of staff to acknowledge poor prognosis
  - “my patients do not die”
Case Example: “Mrs. B”

- 92 yo female
  - Poor intake of nutrition/hydration, Failure to thrive
  - CHF (congestive heart failure)
  - Pneumonia
  - Dialysis had been started one week ago during a previous hospitalization (re-admitted 3 days after discharge).
  - Readmission due to the fact that she could not physically get out of bed for her next dialysis appointment in the outpatient dialysis center

“She loved dialysis and felt so much better afterwards!”
Case Example: “John Stevens”

- 89 yo male with:
  - CKD (chronic kidney disease)
  - Bladder cancer
  - Pneumonia (on day 4 of IV antibiotics)
  - COPD (chronic obstructive pulmonary disease)

Family: wife and daughter are nurses.

Plan: comfort care and transition to an inpatient hospice building. MOLST form was covered by medical resident, who was offering IV antibiotics, IV fluids, etc.- generally not offered in an inpatient hospice setting…

*(Consider the setting of care, and incorporate this into the MOLST discussion)*
In Summary:

- Effectiveness of the MOLST with Goals of Care Discussions
  - Most useful when patient values and goals are incorporated into the discussions
  - Advance Directives are useful tools in utilizing the MOLST form
  - Consideration of upcoming transitions for patients in new setting can also be a consideration (see Case Example John Stevens)
In Summary:

- The intent of the MOLST form is to ensure seamless transition and peace of mind not only for patients, but also for their families and caregivers.

“The DNR discussion took place again & I know we've had it numerous times. Who would I ask, Carla, to make sure that it's in their electronic records whenever another fall or anything occurs that the DNR is in place?” – M., daughter-in-law of a patient

“please do!! use me away!! it's the least I can do - and it's SO important. They both don't remember having the DNR discussion numerous times - but we have had them. As they don't remember them, it's very hard, but hard also on the kids & docs & SW'ers who have these discussions over & over when they've already been done before!! ” – M., daughter-in-law of a patient
References

- [www.abanet.org/aging/toolkit](http://www.abanet.org/aging/toolkit) (American Bar Association)


- McMahan, BS, BA, Ryan D., Knight, PhD, Sara J., Fried, MD, Terri R., and Sudore, MD, Rebecca L. *Advance Care Planning Beyond Advance Directives: Perspectives From Patients and Surrogates*. Journal of Pain and Symptom Management, V46, N3, Sept 2013
Thank You!