Ensuring Communication of Healthcare Wishes: Bridging the Gap between Medical Directives and End-of-Life Care

A Doctor’s Perspective

Tammie E. Quest, MD
Director, Emory Palliative Care Center
Associate Professor
Emory School of Medicine
The Problem

- Advance Directives Fail at the Bedside
  - Too vague
  - Unclear
  - Generic
- Family conflicts
- Physician conflicts
A Definition

Palliative Care...What is that?
Current Definition of Palliative Care

New Language:

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.
Practical Elements of Palliative Care

- Pain and symptom management
- **Advance care planning**
- Communication/goals of care
- Truth-telling
- Social support
- Spiritual support
- Psychological support
- Risk/burden assessment of treatments
Embrace the Transformational Model

Disease Progression

Diagnosis of serious illness

Death

Life Prolonging Care

Hospice Care

Palliative Care

Less Ideal/
Current

Ideal

Bereavement

Emory University
Figure 1. Trajectories of dying. Reproduced with permission of Blackwell Publishing (Lunney JR, Lynne J, Hogan C. Profiles of older Medicare decedents. JAGS. 2002;50:1108-1112).
How do we know they fail?

• SUPPORT STUDY
    • 688 directives
      – 66% were durable powers of attorney
      – 31% were standard living wills or other forms of written instructions (3%).
      – only 90 documents (13%) provided additional instructions for medical care beyond naming a proxy or stating the preferences of a standard living will
      – 36 contained specific instructions
      – 22 talked specifically about life sustaining treatments
Having an Advance Directive Made NO Impact

• NO IMPACT ON:
  – Earlier writing of DNR orders
  – Physicians knowledge of their patients' preferences for CPR
  – Number of days spent in an ICU before death
  – Patient reports of moderate or severe pain
  – Use of hospital resources
Are we doing any better?

• *Modest* improvements in the last 15 years
• What has helped?
  – Hospital and outpatient palliative care specialists at the bedside with patients and families
  – Greater awareness and acceptance of the PITFALLS of advance care planning
The Problem

• “If I am terminally ill, then I don't want the following treatment.....”
  – How do we define terminally ill?
  – Your surrogate, family, physicians, others may not agree on what “terminal illness”
The Problems

• Unclear understanding of what a “natural death” is:
  – Infection
  – Illness leads to not eating/drinking
    • Interpretation of dehydration as cruel, unusual
  – Lose sight that people die naturally from the complications of an illness
    • His heart is bad, but they say he has pneumonia
Family Conflicts

• “Well, he didn't really mean that, I don't think he understood what he was choosing.”
• “Mom is a fighter, she would want to fight.”
• “We can’t give up on him/her.”
• “I think we are acting too fast. We need to give him a chance.”
• “How to you know he is dying? Are you sure?”
• “I just can’t see starving him to death.”
High Risk for Family Conflicts

• Blended families
• Estranged families
• Parents or adult children with illness or abuse history (mental, physical, drugs)
• Standing conflict between families pre-illness
  – If they don’t talk before illness/end of life, it won’t get any better under stress
Feelings of the Surrogate

• Guilt
• Anticipatory Grief
• Don’t want to make the “final decision”
• Don’t want to “pull the plug”
• Afraid of conflict with survivors
  – I need to live with his/her/our children, I can’t go against them
• Don’t want to be wrong
• Rely on spiritual compass,
  – “God will tell me when it’s time”
Physician Conflict

- The patient and family has asked me to do “everything” to help Mr. Jones. Mr. Jones has advanced heart failure and is terminally ill. He is still getting around the house. Mr. Jones has elected a “natural death”.

  - What does “everything mean”?
  - If he collapses at home today with his heart stopping (natural death), what would be done?
  - When do we “invoke” his advance care plan?
  - I don’t want the family to think I am “failing them”
Drill Down - Challenge #1:

Lack of Understanding/Agreement on a “Natural Death”?
Death in the 1800’s..

• At home
• Died from
  – Injury
  – Infection
• Comfort with “natural dying”
  – Stop eating and drinking
  – Body begins to slip into ‘coma like state’
  – No IV’s, few medications
Death in 2013

20% of Americans die in the ICU
> 2 weeks with hospice care before death
What is “natural death”?

• What the body is doing, what we see...
  – The body weakens from underlying illness, injury
  – Usual measures to not help (rest, recovery, medical treatments)
    
    *Infection may ensue or progress*
  – The body loses the desire or ability to eat or drink
  – The body begins to shut down (kidneys, mentation)
  – The patient becomes sleepy, unconscious
  – The bodies chemicals make the heart stop and the body stop breathing

• End of life “event” could look “sudden”
Intervening in Natural Death

• Sometimes we should
  – IV’s, ventilators, antibiotics, dialysis, surgery

• When should be not?
  – Often a point of contention
  – Surrogates left to decide and speak to the doctors regarding interventions/treatments
The “Old Man’s Friend”

• Pneumonia
  – From overall weakness and inability to cough strongly
  – From saliva from the mouth that goes into the lungs because the body is weak (“aspiration”)
    • Not helped by feeding tubes, though commonly thought to be so
    • Can never eliminate saliva
    • 3/10 people will die from a single episode
Artificial Nutrition/Hydration

• No evidence that it improves comfort at end of life
• May cause life to be shortened
• May cause more symptoms
• May not meet goals
Drill Down - Challenge #2

Failure to Educate and Discuss the “Details” with the Surrogate

(and anyone else who will influence the surrogate)
Not Dinner Time Discussion

• I wanted to talk to you about the end of my life and just make sure that everyone understands... (doesn’t happen...)

![Image of people at a dinner table](image-url)
Healthcare Agent Choice

- "I'm married, I trust my wife or husband, so they will be my agent"
  - May not be the best choice...
  - Can they ensure your end of life plan to the bitter end?
    - Can they **stand firm with and against** all the concerned parties to protect your interests?
    - Can they stand to experience your natural death?
    - Could they allow you to die with pneumonia in advanced dementia?
Drive Down- Challenge #3

Failure to involve/inform your physician of your choices and support your physician NOT to be overly optimistic
Physician-Patient Miscommunication

• Physicians only know about AD’s 25% of the time when they exist

• When they exist, the physician needs to interpret and WRITE MEDICAL ORDERS
  – Physician needs to disclose that you are “terminal”
    • Extraordinary reluctance to say this until the “very end”
Fool Proofing....If Possible
Solution #1: Surrogate/Family Education

• Picture the end of your life and how you envision it
  – Dying at home vs. a hospital
• Discuss it with your surrogate
  – Are they uncomfortable, do they NOT want to talk about it?
• If you chose natural death, help your surrogate understand what a “natural death” looks like
• Ask your surrogate – “who would you want to agree with your decision when I am dying”
• Hold a “Home Family Meeting” to educate them
Solution #2: Be Proactive with your healthcare team!

• Electronic medical records don’t “talk”
  – Outpatient, emergency crew, inpatient don’t communicate

• The hospital may have it, but no one may immediately read it

• If the doctor doesn’t ask about it, bring it up
  – “Doctor X, I am not sure if you know that I have an AD. Is says...Please make sure that the team follows my wishes. I am willing to talk about them more even though you think I am going to get better.”
Solution #3 : Check to see if your doctor has the right ORDERS on the chart....

- Allow natural death to occur
  - Means “Do Not Resuscitate” (DNR)
- Have an explicit conversation
  - “I want you to know I have a directive and I would not want life sustaining therapy. This means if my heart dies, don’t bring me back”
- EMS and MD’s in a crisis do not look at AD, the look at ORDERS
Solution #4: *Keep talking* to your family and surrogate

- As illness gets worse, surrogates get more optimistic and more willing to hold onto the “slight chance”...

- Surrogates and families may feel that discussing your EOL wishes as you become ill translates into you believing they are “giving up the fight”
Solution #5: Bring your Spiritual Advisor in Early

• Share your AD with your spiritual advisor(s)
• Your spiritual advisor(s) can support surrogates and families under extreme conditions of stress
• Surrogates want to make sure they are making spiritually consistent choices
• Discuss this in a non-crisis atmosphere
Solution #6: Ask for Palliative Care

• Encourage your doctor to call us to help support the patient and family
• We specialize in supporting patient and family choice, ensuring understanding and “unraveling” and “untangling” difficult situations in communication between patients, families and healthcare providers
Questions