Respecting Patients Values when Goals Shift to Palliative Care

John G. Carney, MEd, President and CEO, Center for Practical Bioethics
September 12, 2022 (11:00 A)
Intercontinental Hotel, Kansas City, MO
Center for Practical Bioethics
Community based organization founded in 1984.

No conflicts of interest to report
Offer services and programs in advance care planning and ethics education and training to health systems and providers
All fees and honoraria inure to benefit of the organization
Return to mission

Declarations and COI Statement
For many older adults and their families...

Goals of care discussions don’t take place when they should.

Conversations about advancing chronic illness often only occur after a crisis.

Discussions often narrows to medical treatments rather than values, meaning, and purpose in life.

Most older people know they are mortal...
   Why do we not have these conversations when we should?
   How do we think about progressive chronic conditions?
   What exactly are Goals of Care?
What is language we should be using?

How can we make it not so intimidating/dreaded?

What cultural issues do we need to observe and respect?

What can Palliative Care teach us?

How do we use those tools to guide shared decision making?

Questions to ask ourselves
Upon completion of the session participants will be able to:

Distinguish between PC and curative measures for persons diagnosed with chronic conditions.

Engage with care providers using ACP resources that assist in clarifying values and preferences.

Describe how what is most important needs to be respected, honored and protected.
Tell me about your mother...
What do I need to know about what she needs to know?

Getting started
What do I need to know about what she wants to me know?

Getting started

DOWNLOAD THE WORKBOOK (ENGLISH)
DOWNLOAD THE WORKBOOK (CHINESE)
DOWNLOAD THE WORKBOOK (SPANISH)
Steps in the process

• Rationale for systematic approach to improving conversations about patient values and priorities in serious illness
• Understand functional trajectories and key variables to identify patients where these conversations become important
• Recognize benefit of using Serious Illness Conversation guides
• Describe supports needed to honor results of SICP
Most people want to be at home and prefer comfort-focused care at the end of life, but that is often not the reality.

- 86% Medicare beneficiaries want to spend final days at home (Barnato 2007)
- 25-39% die in an acute care hospital (Teno, JAMA 2013; Silveira NEJM 2010)
- 70% are hospitalized in the last 90 days (Teno JM JAMA 2013)
- 29% receive intensive care in the last 30 days (Teno JM JAMA 2013)
- Multiple care transitions & short hospice stays (Teno JM JAMA 2013)
Gap between what patients want and what they get

Patients with serious illness have priorities besides living longer.

• Symptom management and “quality of life”
• Sense of control and completion
• Strengthening relationships
  (Singer JAMA 1999; Steinhauser JAMA 2000; Heyland, Palliative Medicine 2015)
What do I call this?
When do I do it?

Advance Care Planning
Goals of Care Discussion
Medical Orders
What is Traditional ACP?

• For Healthy people
• Goal is educational and reflective, for them to ponder their values related to a potential future reality
• Provide resources for them to think through and discuss with their family
  • MyDirectives.com, Caring Conversations, 5 Wishes
• Potential outcomes:
  • Good family conversation only
  • DPOA-HC, Advance Directive
• This is something that people do on their own
Trajectories of Illness

- Trauma or Sudden Death
- Neoplasm/Advanced Cancer
- Heart Failure or Progressive Chronic
- Dementia/Neuro
Conversations too little, too late, and not great

• Studies show patients with serious illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life (Wright 2008, Dow 2010, Halpern 2011)

• Among patients with advanced cancer:
  • First EOL discussion occurred median 33 days before death (Mack AIM 2012)
  • 55% of initial EOL discussions occurred in the hospital
  • Only 25% of these discussions were conducted by the patient’s oncologist (Mack AIM 2012)

• Conversations fail to address key elements of quality discussion, especially prognosis
Aggressive care for patients with advanced illness can be harmful:

• For patients:
  • Lower quality of life
  • Greater physical and psychological distress
    (Wright, AA JAMA 2008; Mack JCO 2010)

• For caregivers:
  • More major depression
  • Lower satisfaction
    (Wright, AA JAMA 2008; Teno JM JAMA 2004)
Clinicians, medical system barriers to conversations and care planning

- Clinicians lack communication competencies, training and confidence  
  Baile Cancer 1999; Sullivan JGIM 2003; Buss Cancer 2011

- Culture of medicine does not value key elements of effective care:
  - Accepts late or non-existent conversations
    - Low priority
    - No accountability
  - Tolerates poor end-of-life care
  - Focuses on avoidance of emotions; these are inherently emotionally-intense discussions

- Clinicians feel they do not have enough time
It’s Time to Rename and Reframe

• Not about “End of Life” discussions. These conversations are...
  • About a priorities for how to LIVE
  • Intended to help prepare over a course of months, even a year or two
  • Not about people right now. Goals over time (last chapters not hours)
Earlier conversations about goals and priorities are associated with:

- Enhanced goal-concordant care
  Mack JCO 2010
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient/family satisfaction
  Detering BMJ 2010
- Less non-beneficial care & costs
  Wright 2008, Zhang 2009
Identifying Seriously Ill population

CAPC

Serious Illness Strategies for Health Plans and Accountable Care Organizations, 2017

FIGURE 9: Three Key Variables to Identify the Population in Need

**DIAGNOSIS**
- Cancer
- Advanced liver disease
- COPD with oxygen
- Heart failure
- Renal failure
- Advanced dementia
- Diabetes with complications
- ALS

**FUNCTIONAL IMPAIRMENT**
- Limitations in activities of daily living
  - eating
  - bathing
  - dressing
  - toileting
  - transferring
  - walking
- Significant memory loss
- DME-walkers, beds, home oxygen, etc.

**HIGH UTILIZATION**
- Hospital admissions, re-admissions, and length of stay
- Emergency Department visits
- Poly-pharmacy
- Skilled nursing/rehab stays
- Multiple home care episodes
Planning on trajectory:
What people need to know

If patients want to die at home, they and family need to know trajectory; make a plan for next “crash”

Requires system/provider to recognize trend and discuss it

Requires planning from hospital, provider’s office, NH and share

Requires support of community systems in a coordinated effort for preferences to be known across continuum of care (TPOPP/POLST)
How to bridge gap between what patients want and what they get?

FIRST and FOREMOST...

Ask patients about their values and priorities.

What is Most Important?
Rely on Guides, Decision Aids, Ask for PC consult
What do checklists or guides do?

• Bridge gap between evidence and “real world” implementation
• Assure adherence to key processes
• Achieve higher level of baseline performance
• Ensure completion of necessary tasks during complex, stressful situations
Perspectives of those using tool

- “Gives me actual words when I feel stuck”
- “Reminds me to cover elements of the conversation more systematically”
- “I have to remember this is a guide for our conversation, not a form to complete”
- “Gives me structure to conversation that naturally triggers meaningful responses from patient.”
Patients want truth about prognosis.

Patient won’t be harmed by talking about end-of-life issues. (Culturally sensitive)

Normalize anxiety for both patient and clinician

Explore patient’s goals and priorities beyond living longer

Give patients opportunity to express fears and worries. It can be therapeutic.
Practical Advice

Ask for honest prognosis
Explore time frames uncertainties and progression
Sit with silence
Acknowledge emotions (Sad is not always bad)
Focus on fears, and concerns, hopes and dreams
Differentiate between expectations and above
Have someone take notes
Avoid desire to make it all better
Focus solely on treatments. Be OK with Being.
Ideas to facilitate conversation

Ask patient’s using the 3 Vs: Wish (or Hope), Worry, and Wonder

Explore meanings behind each

Express empathy not sympathy
- Don’t rescue
Potential Outcomes of Serious Illness Conversations

No decision; conversation documented & archived

Needs to be EASILY accessible and vernacular

Creation of health directive &/or Agent appt.

Creation of actionable medical order set
Where do I find the tools and resources?

- Center for Practical Bioethics
  - Caring Conversations® & ...Continued
- Conversation Project
- Vital Talk
- Ariadne Labs - Serious Illness Care Planning
  - What Matters to Me Workbook (slide7)
- MyDirectives (A/D Vault)
- Get Palliative Care
- Prepare for Your Care (video tools)
- Five Wishes (many languages)
Thank you!

John G. Carney, MEd
President and CEO
816.979.1353
jcarney@practicalbioethics.org
www.practicalbioethics.org