Serious Illness Care planning: More, Better, Earlier Conversations and the Infrastructure to honor the Results

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Objectives

• Summarize the rationale for a systematic approach to improving conversations about patient values and priorities in serious illness

• Understand functional trajectories and use of the surprise question to identify patients with serious illness where these conversations become important

• Recognize the benefit of using the Serious Illness Conversation guide for such conversations

• Describe organizational infrastructure needed to honor the results of excellent serious illness care planning

Case Reflection

• Think about a time when communication about goals of care and treatment preferences had a positive or a negative impact on patient family experience

  • Positive experience
    • What made it good?

  • Negative experience
    • Why?
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

Gap between what patients want and what they get

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
– Many experience care transitions and short hospice stays Teno JM JAMA 2013
What patients *get* can harm them and their family

Aggressive care for patients with advanced illness is often 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

Conversations are too little, too late, and not great

- Multiple studies show patients with serious medical 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
Clinicians, the medical system are important 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

*Bottom line: Multiple factors make good conversations difficult.*

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It’s Time to Rename and Reframe

- Not about “End of Life” discussions
  - These conversations are about a person’s priorities for how they want to **LIVE**
  - These conversations are intended to help someone prepare over a course of months, even a year or two
  - This is not about people at the end of life (right now), it is about people living with serious illness
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
When is time to start Serious Illness Care Planning?

- Asking the “surprise question” can help
  - Would it **surprise** me if this person were to die in the next year? (answer of “no” means it’s time)
  - **NOTE:** **NOT** the same as saying someone has a prognosis of a year or less
  - **NOTE:** for cancer and renal patients, surprise question does a better job of predicting mortality than our current Medicare Hospice Certification criteria

- Recognizing functional trajectories can help

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**Functional Trajectories**

- A: Steep decline in function over time
- B: Steeper decline in function over time
- C: Steep decline in function over time
- D: Steeper decline in function over time
Identifying the Seriously Ill population

Planning on the trajectory: what people need to know

• If a person wants to die at home, not on machines, they, or their loved ones, need to know their trajectory and make a plan for the next “crash”

• Requires the system and the provider to recognize the trend and discuss it

• Requires planning from the hospital, the provider’s office, the nursing home

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

Ask patients about their values and priorities.

Conversations are Key

Earlier conversations about patient goals and priorities for living with serious illness are associated with:

- Enhanced goal-concordant care [Mack JCO 2010]
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient satisfaction [Detering BMJ 2010]
- Less non-beneficial care and costs [Wright 2008, Zhang 2009]
Subspecialty Palliative Care providers can’t provide this care to all patients with serious illness…nor should they!

- There are not have enough palliative care physicians to provide access to palliative care for all patients with serious illness
- Need to have scalable interventions targeted at generalist (non-palliative care) physicians and other clinicians to assure universal access to this key element of palliative care

Serious Illness Conversation Guide: Useful tool to improve conversations

- RCTs: Communication **skills** training programs work (Jenkins 2002, Fallowfield 2006, Szmulowicz 2010)
- Other studies demonstrate impact of training (Sullivan 2005, Back et al. 2007)
- Key elements:
  - cognitive input
  - modeling
  - skills practice with feedback
- Improvements are maintained for at least 6 months (Maguire 2002, Sullivan 2006)
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 the tool

- “Gives me the 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 the conversation that naturally triggers meaningful responses from the patient.”

Data- Dana Farber Cancer Institute

- Cluster-Randomized Controlled Trial of a Quality Improvement Intervention
  - Physicians randomized to intervention or usual care
  - Patients with same physician form a “cluster”
- Intervention: 2.5-hr training on Serious Illness Conversation Guide (SICG) for clinicians, follow-up coaching
- Identification of patients in last year of life through triggers
  - “Surprise” question
  - Disease-based
- Discussion by clinician using the Conversation Guide
- Patient provided with information on how to talk with their families
Dana Farber SICP Program Story

1. Pt identification
2. Clinician training
3. Trigger discussion
4. Prepare patient
5. Have conversation
6. Family Guide
7. Document in EMR

Do more, better, and earlier conversations change care and improve outcomes?

Dana Farber Summary

- Identifying appropriate patients.
- Training program viewed as effective by clinicians.
- Trigger system stimulates discussions in 90% of patients within 2 visits.
- Patients and clinicians find the intervention acceptable.
- Intervention results in more, better, and earlier conversations about serious illness care values and goals.
- Intervention results in more comprehensive and retrievable documentation in the EMR.
Principles of these conversations

- Patients want the truth about prognosis.
- You will not harm your patient by talking about end-of-life issues.
- Anxiety is normal for both patient and clinician during these discussions.
- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care.
- Giving patients an opportunity to express fears and worries is therapeutic.

Practical Advice

**Do:**
- Give a direct, honest prognosis
- Provide prognostic information as a range, acknowledging uncertainty
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient’s quality of life, fears, and concerns
- Make a recommendation (“Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend...”)
- Document conversation
Practical Advice

Dont’:

• Talk more than half the time
• Fear silence
• Give premature reassurance
• Provide facts in response to strong emotions
• Focus on medical procedures

More fun ideas to facilitate convo

1. 3 W’s: Wish (or Hope), Worry, and Wonder
   Patient: “Will I make it to my grand-daughters graduation in 2 years?”
   Clinician:
   ○ “I wish that things were different; I worry that that’s not likely.”
   ○ “I hope that you can, but I worry that it may not be possible.”
   ○ “I wonder if things you can do to prepare in the event you can’t be there.”

2. Explore
   ● “Tell me more”
   ● “Say more about what you mean by that.”

3. Responding to emotion
   ● “This seems to be very sad news for you.”
Potential Outcomes of Serious Illness Conversations

- No decision made; conversation documented in medical record
  - Needs to be in a place where it is EASILY accessed by other providers
  - Needs to be documented in a way that conveys that person's current goals and wishes
  - Can be billed for using ACP codes activated by CMS January 1, 2016
- Creation of POLST paradigm document (only if patient wants to have actionable orders in place at home)

Reimbursement

- Medicare will:
  - Reimburse Advanced Care Planning (ACP) Discussions as of January 1, 2016.
  - "Meat" of the ACP conversation must be present in the note.
  - Time must also be documented appropriately in the patient’s chart in order for it to be coded appropriately.
    - CPT Code 99497 – first 30 minutes of ACP (16-30 minute conversation)
    - CPT Code 99498 - each additional 30 minutes of ACP (you earn the next code if you talk for more than ½ of the code's timeframe)
System tools to help: examples--
University of Kansas Health System

• Unified inpatient and outpatient EMR header for one stop shopping for all ACP related items

• ACP report
  – Code status order history
  – Links to PDF’s of scanned AD, DPOA-HC, TPOPP/OHDNR forms
  – Links to Policies for TPOPP/resuscitation status
  – ACP notes for all Advance Care Planning/Resuscitation status conversations

• ACP note type in inpatient O2, ACP navigator in outpatient O2
  – ACP billing code pop up when APP or billing physician sign the note- All ACP codes are audited for billing compliance through THIS template

Unified inpatient/outpatient header

• ACP report accessible by clicking on “Code”, “Adv Dir filed”, or “OHDNR/TPOPP” icons

Advance Care Planning

• Code Status, Advance Directive, and OH DNR (Outside Hospital DNR) are present in both the Outpatient and Inpatient banners.
ACP Note Type and Note Template

Documenting Advance Care Planning

- To document Advance Care Planning, enter an “Advance Care Planning” note.
  - If you initiate the note from the navigator (shown above) the note type will be preselected.
  - If you choose to enter a note from the Notes activity you will have to select the note type ‘Advance Care Planning’.

- Complete the SmartText and sign your Advance Care Planning note.

Note template expanded

[Image of expanded note template]
Serious Illness Conversation

Serious Illness Conversation Smartphrase

SERIOUS ILLNESS CONVERSATION
(Please include dates when possible, if blank not yet addressed)
Illness understanding:
Desire for information:
Prognostic discussion:
Goals:
Worries:
Strength comes from:
Critical abilities you would not imagine being able to live without:
Trade offs he would be willing or not willing to make for the possibility of more time:
Family knowledge of the above:

Put Serious Illness Care Planning into action

• Develop institutional algorithms to identify seriously ill patients, where the surprise question is “no”.
• Develop workflows and training for providers to have more, better, earlier serious illness care planning conversations, using the Serious Illness Conversation Guide.
• Develop EMR tools that make outcomes of serious illness conversations as obvious as the allergies.
• For patients who wish their preferences for treatment to be translated into transportable physician/provider orders
  – build the tools and institutional/community infrastructure necessary to create and honor POLST paradigm (TPOPP) documents.
Discussion/Wrap Up

Join the Ariadne Labs Serious Illness Care Community of Practice!
www.ariadnelabs.com