

Patient Story:

John is a 87 yo man with h/o AF, DM, MCI who presented to the ED with worsening kidney function and dyspnea.

- Found to be in heart failure and kidney failure, both due new diagnosis of amyloidosis. Now on HD.
- Remains in the hospital 28 days later because we have been unable to find him in
 HD chair
- Now two-person assist, PT OT is recommending SNF (insistent on going home)
- Intradialytic hypotension, now down to only 2 days/week
- Nutritional intake declining, discussions re starting enteral feeding
- Family who are medical, asking about TP
- Multiple discussions about CODE STATUS but this time he would like to remain full code.



"Goals of Care"

- Ideally: Occurs earlier in illness, revisited throughout illness trajectory
- Often: Occurs urgently after recognition of acute change in condition
 - Patients and families often emotionally overwhelmed and have difficulty processing complex medical information



Best Approach to ACP Discussions

DON'T:



Focus on forms

Lead with treatment preferences

Present a menu of options

DO:



Use a systematic approach to elicit information about illness experience, values stakeholders (serious illness communication)



Serious Illness Conversation Framework

- 1. Prepare for the discussion
- 2. Introduce the purpose and set an agenda
- 3. Assess illness understanding, coping style, prognostic awareness
- 4. Deliver medical updates and prognostic Information
- 5. Expect and respond to emotion
- 6. Explore patients' values and preferences
- 7. Discuss treatment options and make a recommendation
- 8. Finalize the treatment plan



Preparation

- Thorough review of medical information
- Discussion with longitudinal providers
- Review prior documentation
- *Premeeting





Purpose and Agenda Setting

- Leader conveys purpose for the meeting
- Invite patient and family to share understanding of reason for discussion and any questions they would like to have addressed



Assessment of Patient/Family

- Elicit understanding of patient's medical condition
 - "What have you heard from your healthcare team about your illness?"
- Look for clues about prognostic awareness, coping styles, family dynamics
- Evaluate concerns
 - "what worries you most above the future when you think about your illness?
- Avoid the urge to correct any inaccuracies



Deliver Updates and Prognosis

- Summarize what has been heard
- Assess readiness to receive information
 - "How much information would you like about what lies ahead with your illness?"
 - "If I have information about specific time frames, would that be information you are interested in hearing?"
- Deliver serious news
 - Ask-tell-ask
 - Hope/worry statements



Expect and Respond to Emotion

- Attend to clues (i.e. body language) may suggest still processing and not yet ready to hear more
- Avoid false reassurance and backtracking
- Use silence or empathic statements
 - "NURSE Statement"

Statement	Example		
Naming	"It sounds like you are frustrated" VITAL talk		
Understanding	"This helps me understand what you are thinking"		
Respecting	"I can see you have really been trying to follow our instructions"		
Supporting	"I will do my best to make sure you have what you need"		
Exploring	"Could you say more about what you mean when you say that"		



Explore Values and Preferences

- Refrain from asking about specific treatment preferences
- Assess for acceptable quality of life and tradeoffs
 - "Have you experienced or observed anything you consider unacceptable?"
 - "If you become sicker, how much are you willing to go through in order to gain more time?"
- Be prepared for conflicting preferences



Discuss Treatment Options and Make a Recommendation

- Frame in contexts of benefits vs burdens, and likelihood of achieving outcome
- Tailor treatment options based on information gathered
- Check for understanding
- Remain engaged in deliberation
 - Decision tools (i.e. "best case, worst case")
- Offer Recommendation



Best/Case Worst Case

Best Case/Worst Case

"I have bad news. You have a serious problem that will change your life."

"We have a choice between 2 options"

"In the best case ..."

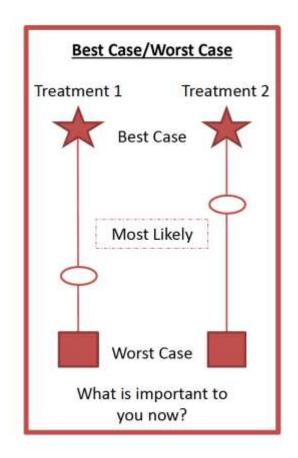
- Realistic best long-term treatment outcome: "I think your mom will eventually get home, but weaker and needing more assistance."
- Short-term implications: tell a story about what treatment & recovery entail, e.g. hospital course, SNF: "To get her there, we will need to do a big surgery, she will be in the ICU for 2-4 days, then in the hospital for another week, then rehab for 1-2 months."
- Orient into context of patient's overall health & prognosis "...still needs oxygen for her COPD."

"In the worst case ..."

Describe points 1-3. When death is possible, avoid euphemisms, e.g. "die" is preferred to "pass on".

"Based on what I know about you, what I think is most likely..."

- "How are you thinking about this?"
- "Based on what I'm hearing from you, would it be alright if I make a recommendation?"



Finalize the Treatment Plan

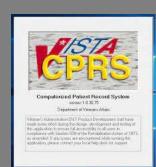
- Should leave with clear understanding of:
 - What treatments are being pursued
 - Timeframe for reevaluation
 - Any downstream treatments that may be considered



Follow Up

- Communicate outcome to all relevant team members
- Documentation
- Debriefing/Feedback









Communication Resources



Table 1 Select communication resources				
Communication Resource	Description	Audience	Tools	
Serious Illness Care Program https://www.ariadnelabs.org/ areas-of-work/serious-illness-care/	Intervention to facilitate more, better, and earlier conversations between clinicians and seriously ill patients	Clinicians Health Systems	Serious Illness Conversation Guide (available in multiple languages) Training, coaching, implementation, and reference materials for clinicians System for documenting conversation in the health record	
VitalTalk https://www.vitaltalk.org/	Resources and courses to strengthen clinicians' communication skills	Clinicians	In-person workshops Online courses Conversation guides and videos VitalTalk App	
Respecting Choices https:// respectingchoices.org/	Model for advance care planning geared toward creating a health care culture of patient-centered care	Clinicians Health Systems	Online communication curricula Design and implementation packages In-person certification courses	
PREPARE https://prepareforyourcare.org	Website that assists patients and families to have conversations with clinicians and make medical decisions regarding advance care planning	Patients and families	Question guides, videos and pamphlets to facilitate conversations Advance directives Toolkit for groups Resources in Spanish and English	
The Conversation Project https:// theconversationproject.org/	Public engagement initiative to help individuals speak to loved ones about their wishes regarding end- of-life care	Patients and families	Conversation starter and health care proxy kits Guide for beginning conversation with health care team Resources available in multiple languages	

Jain, N., & Bernacki, R. E. (2020). Goals of care conversations in serious illness: a practical guide. *Medical Clinics*, *104*(3), 375-389.

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want - is this okay?"

"What is your understanding now of where you are with your illness?"

"How much information about what is likely to be ahead with your illness." would you like from me?"

"I want to share with you my understanding of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."

Time: "I wish we were not in this situation, but I am worried that time may be as short (express as a range, e.g. days to weeks, weeks to months, months to a year)." OR

Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."

"What are your most important goals if your health situation worsens?"

"What are your biggest fears and worries about the future with your health?"

"What gives you strength as you think about the future with your illness?"

"What abilities are so critical to your life that you can't imagine living without them?"

"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"

"How much does your family know about your priorities and wishes?"

"I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we . This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

Serious Illn

CONVERSATION FL

Set up the conver

Introduce purpo Prepare for futu Ask permission

2. Assess understand

3. Share prognosis

Share prognosis Frame as a "wis Allow silence, ex

4. Explore key topics

Goals Fears and worris Sources of stren Critical abilities

Tradeoffs Family

Close the convers

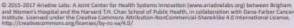
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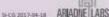
6. Document your co

7. Communicate wit





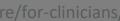














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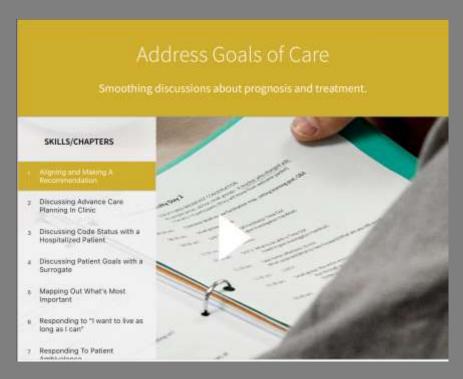
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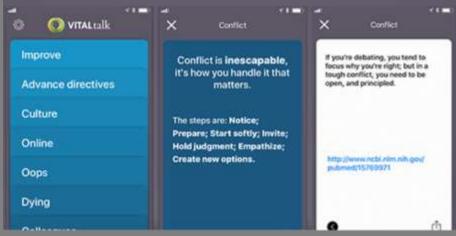
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VitalTalk





ww.vitaltalk.org



Back to John...

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Bottom Lines:

- Serious illness communication should happen early and often
- 2. Best to understand illness experience, values preferences and provide a recommendation
- 3. Using a systematic approach enhances quality and value of such conversations, try using tools like SICG or Vital Talk





"Yes, early palliative care is better...like, before it hits 4:30 on Friday afternoon!"



References

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www.vitaltalk.org

www.patientpreferences.org



Thank You!