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GoCARE: a performance improvement initiative for providers and clinicians about serious illness communication

The What/Why/How Guide to Serious Illness Conversations

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Disclosure and Acknowledgement

This presentation includes material adapted with permission from Ariadne Labs, Inc. in partnership with Optum.

Objectives

- Summarize the importance of a systematic approach to improving conversations about patient values and priorities in serious illness.
- Describe the components of the Serious Illness Communication Guide.
- Discuss observations related to demonstration of the Serious Illness Communication Guide.
- Identify opportunities for Optum/Compassus partnership and application of the technique within Compassus programs.

How do you currently have conversations about goals with patients who have a serious illness (or their surrogates)?

Conversations about Serious Illness – *What can go awry?*

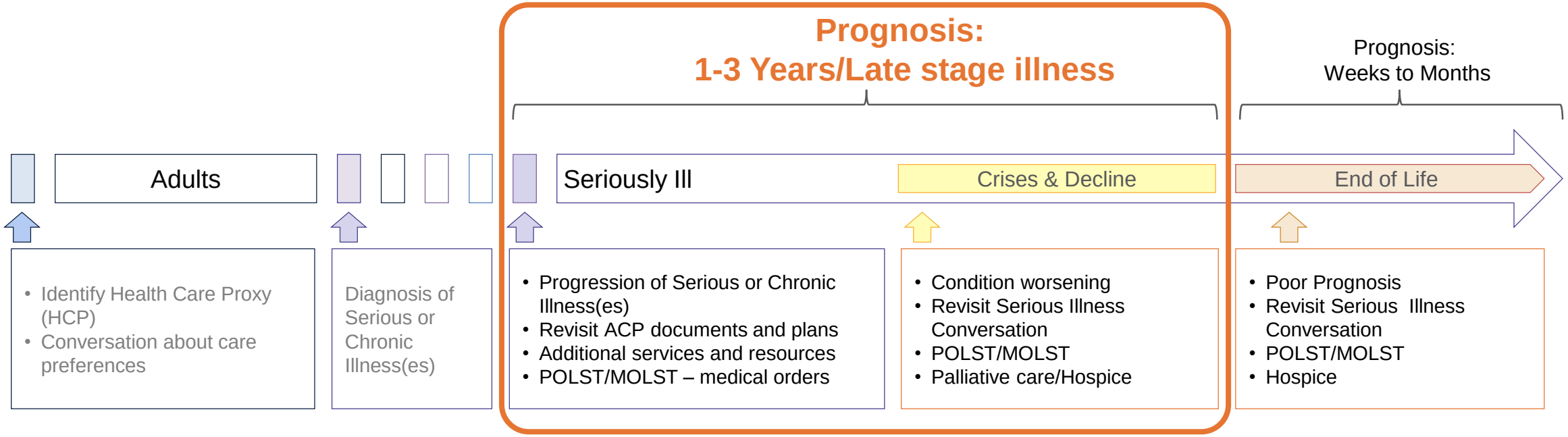
- Too many providers involved in decision-making with differing opinions
- Providers assume another provider has had the conversation already
- Transitions in care or care setting
- Magical thinking on the part of the provider and/or the patient/family
- Confusion around acute on chronic illness
- Clinicians and providers lack skill to facilitate quality conversations around goals of care
- Lack of accessibility to documentation of previous conversations

What makes a quality conversation?

- Relationship
- Mutual respect between all parties
- Assessment/confirmation of understanding
- Organized and goal-directed (not random)
- Outcome and next steps are clear and agreed upon
- **Active listening**
- **Attentiveness and response to emotion**

Communication is a process –
not a transaction!

The right conversation at the right time… helps ensure the right care at the right time



Advance Care Planning = Planning in Advance of Serious Illness

Serious Illness Care Conversation =
Planning in the context of progression of serious illness

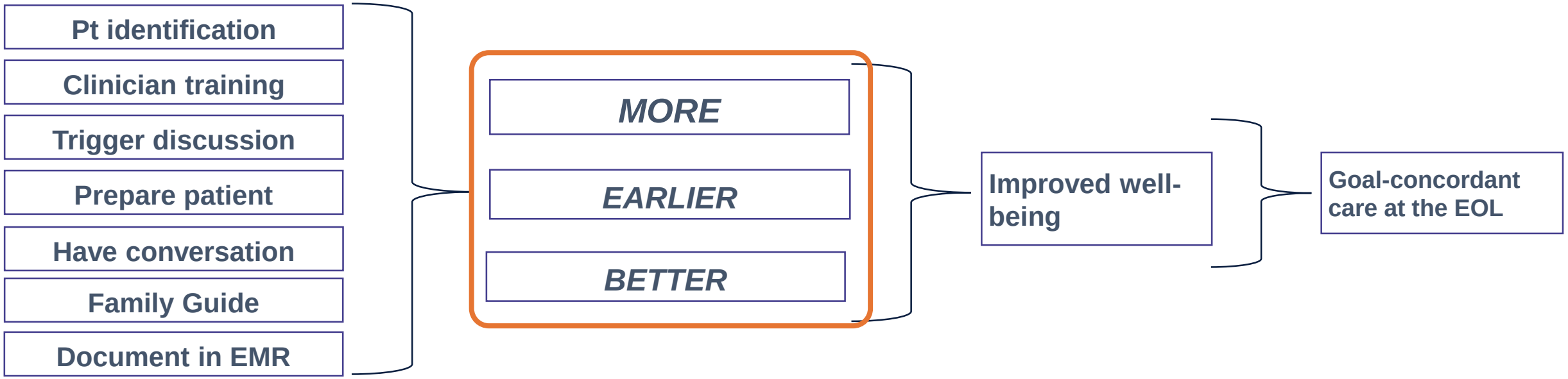
POLST/MOLST = Implementation of specific physician/medical orders

The Optum Serious Illness Communication Process Improvement Strategy

- In order to improve a process, you need to **define it**
- Expert consensus suggests that high quality serious illness conversations have a **best practice structure**
- A defined process can facilitate improved education, sustained improved organizational performance, and can improve communication between providers
- Behavioral science research suggests that learners best **incorporate new behaviors with role play and feedback**
- A checklist and specific language can **improve consistent high quality performance** during periods of stress/chaos
- Consistent improvement requires **ongoing practice and feedback**

see it – do it – get feedback – repeat!!

Future Perfect State



Patients with serious illness often receive care that can cause harm to the patient 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

Early conversations about patient goals and priorities in serious illness are associated with:

- Enhanced goal-concordant care
- Time to make informed decisions and fulfill personal goals
- Improved quality of life
- Higher patient satisfaction
- More and earlier hospice care
- Fewer hospitalizations
- Better patient and family coping
- Eased burden of decision-making for families
- Improved bereavement outcomes

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Deterring BMJ 2010; Zhang Annals 2009

Clinical Utilization and Outcomes

- **37%** of patients with advanced cancer reported having goals of care conversations
- First discussions occurred a 33 days before death
- 55% of initial discussions occurred in the hospital
- Conversations often fail to address key elements of quality discussions
- Clinical outcomes:
    - Lower rate of ventilation (1.6% vs. 11%)
    - Lower rate of CPR (0.8% vs. 6.7%)
    - ICU admission (4.1% vs. 12.4%)
    - Earlier hospice enrollment (66% vs. 45%)
    - Better quality of life and caregiver outcomes

Wright, AA, et al., Association between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008;300(14): 1665-1673. Heyland DK Open Med 2009; Mack AIM 2012

The Harvard - Ariadne Labs Experience with the Serious Illness Conversation Guide

- Research in an oncology clinic
  - Resulted in more, earlier and better conversations
  - 50% reduction in anxiety and depression
  - 86% of patients found the conversation worthwhile
- Primary care trial
  - Resulted in more, earlier and better conversations
  - Significantly increased referral rates to hospice
  - More than 30% reduction in costs in last three months of life

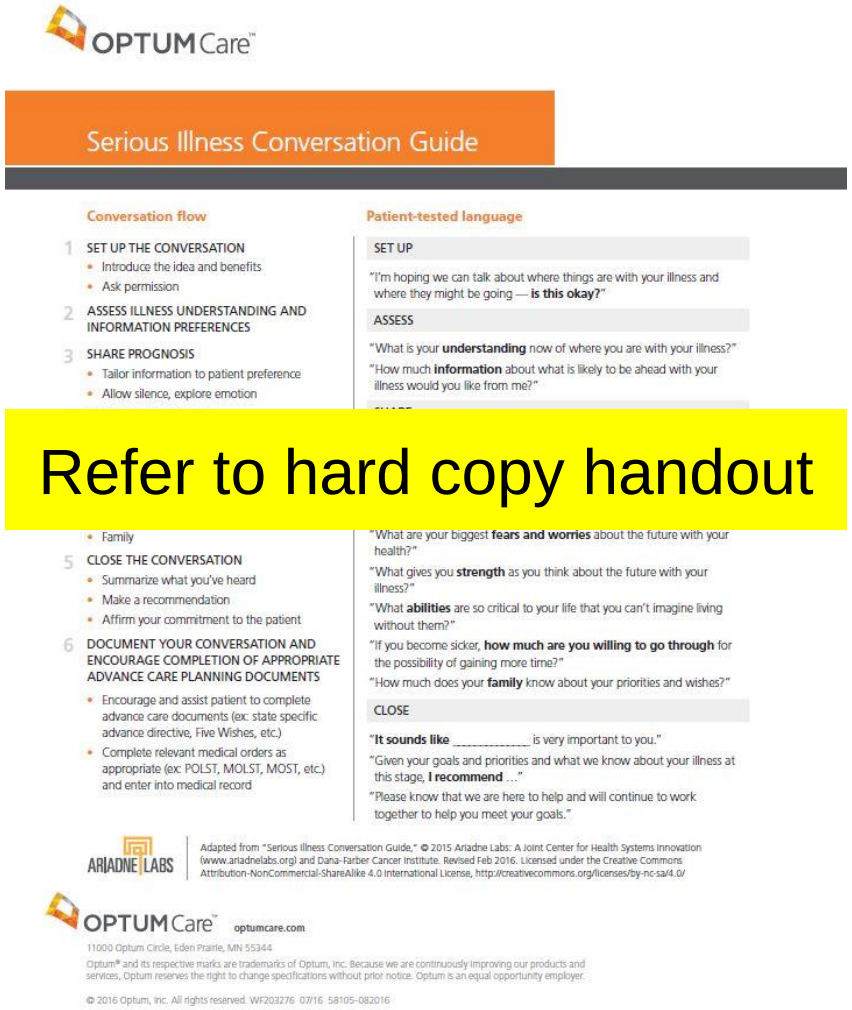
The Serious Illness Conversation Paradigm

- *Motivation* to ensure patient's care is goal concordant
- Start with *rapport and relationship*
- Share/Discuss *uncertainty and prognosis*
- Elicit and understand *patient values*
- Translate patient values into *specific recommendations*
  - Know risk, burdens, alternatives, end-of-life treatment choices as appropriate
    - Hospitalization, SNF/LTC preferences, CPR, mechanical ventilation, etc..
- *Document the discussion*, patient choices, complete orders, and confirm next steps

The Serious Illness Conversation Guide

Adapted by Optum to:

- *Emphasize the importance of responding to emotion*
- *Clarify documentation considerations*



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Serious Illness Conversation Guide

Conversation flow

1 SET UP THE CONVERSATION
- Introduce the idea and benefits
- Ask permission

2 ASSESS ILLNESS UNDERSTANDING AND INFORMATION PREFERENCES

3 SHARE PROGNOSIS
- Tailor information to patient preference
- Allow silence, explore emotion

- Family

5 CLOSE THE CONVERSATION
- Summarize what you've heard
- Make a recommendation
- Affirm your commitment to the patient

6 DOCUMENT YOUR CONVERSATION AND ENCOURAGE COMPLETION OF APPROPRIATE ADVANCE CARE PLANNING DOCUMENTS
- Encourage and assist patient to complete advance care documents (ex: state specific advance directive, Five Wishes, etc.)
- Complete relevant medical orders as appropriate (ex: POLST, MOLST, MOST, etc.) and enter into medical record

Patient-tested language

SET UP

"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay?**"

ASSESS

"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?"

"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?"

CLOSE

"**It sounds like** _____ is very important to you."

"Given your goals and priorities and what we know about your illness at this stage, **I recommend** ..."

"Please know that we are here to help and will continue to work together to help you meet your goals."

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Refer to hard copy handout

Why use a checklist or a guide?

- Reduce anxiety
- Ensure consistent content
- Ensure consistent structure
- Improve documentation
- Improve provider communication
- Increase evidence-based practice

Things to consider about the Serious Illness Conversation Guide:

- It is not necessarily designed to be completed in one visit
- The conversation can (and should be) ***team-based***
- It is not necessarily as linear as it looks – you may need to abort the conversation
  - Distressing symptoms (physical or emotional)
  - The patient does not wish to continue the conversation
  - Time does not permit the full conversation in one sitting
  - The patient needs more information (understanding, prognosis, etc.)

The components of the Serious Illness Conversation Guide

Set up the conversation

- Plan for the timing and setting
- Advise the health care team that the conversation will occur
- Eye level and eye contact
- Sit down
- Ask for permission

"I'm hoping we can talk about where things are with your illness and where they might be going. Is this ok?	Framing the conversation provides direction. Asking permission gives the patient more control and reduces anxiety.

ASSESS understanding

Clinician Conversation

- *"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 to have [from me]?"*

Conversation tips

- Try to find alignment with whatever the patient describes and gently clarify.
- Don't falsely reassure and misinform.
- Ask about what kind of information, and how much information, the patient wants.

SHARE: Transition from Understanding to Discussing Uncertainty around illness trajectory and prognosis

"It seems as though your kidney disease and heart failure are becoming more difficult to manage and I'm concerned. "	• Explore the emotion behind the question
"It sounds like you have a lot on your mind. Can you share more about what you are thinking?"	• Confirm that the patient <u>wants</u> more specific detail about prognosis
"It sounds like you'd really like more information about what to expect. Can I ask the doctors to talk with you about it?"	• Ask for permission to share their concerns with other providers when appropriate

SHARE: Expect and Respond to Emotion

- Naming emotions validates the patient's feelings and let's them know they've been heard
- Emotion is the vehicle for the brain to process threats or potential threats
- *Emotion typically precedes cognition* – "flight or fight" response
- *Clinicians tend to approach these conversations cognitively –NOT emotionally. It's the reverse for patients and families.*
- Clinicians may also experience emotion around the conversation and it is important to acknowledge these emotions, while not letting them get in the way of the patient/family experience

SHARE: Responding to Emotion

- I wish/I worry statements
  - *"I wish I had better news…I wish I could…."*
  - *"I'm worried that …"*
- Some/Other statements
  - "*Some people have very strong feelings about things like breathing machines and they know they wouldn't want that kind of care. Other people aren't so opposed to considering…."*
- NURSE statements:
  - Name the Emotion *("you seem angry, distraught, etc.")*
  - Understand *("I can't imagine how hard this might be to hear")*
  - Respond/Respect *("You've worked so hard and have done everything right")*
  - Support *("I'm here to help you and want to support you through whatever happens next")*
  - Explore – if appropriate *("Tell me more about… or "help me understand more about …")*

EXPLORE: key topics

GOALS	*"What are your most important goals if your health situation worsens?"*
FEARS AND WORRIES	*"What are your biggest fears and worries about the future with your health?"*
SOURCES OF STRENGTH	*"What gives you strength as you think about the future with your illness?"*

EXPLORE: key topics

CRITICAL ABILITIES	*"What abilities are so critical to your life that you can't imagine living with out them?"*
TRADEOFFS	*"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"*
FAMILY	*"How much does your family know about your priorities and wishes?"*

CLOSE: Summarize, Recommend and Connect

SUMMARIZE	*"It sounds like family and staying comfortable are very important to you."*
MAKE RECOMMENDATIONS	*"Given your goals and priorities, and what we know about your illness at this stage, I recommend _____."*
AFFIRM YOUR COMMITMENT TO THE PATIENT	*"Please know that we are here to help and will continue to work together to help you meet your goals."*

Making Recommendations

- ***Must be within scope (MD/CRNP/RN, etc.)***
- Clarify timelines and next steps
- Should be **specific** and **actionable**
  - *"Would it help if I called your pulmonologist and cardiologist and talk with them about our conversation, and then you and I can meet again to talk about options?"*
  - *"Given everything you've shared today, I recommend we talk with your oncologist about discontinuing chemotherapy."*
  - *"Based on our conversation today, and your goals, I'd like to talk with you about palliative (or hospice) care."*
  - *"Given your goals and your desire not be re-hospitalized or have us try to restart your heart or breathing if they would stop, I'd like to put an [order/POLST/MOLST"] on your chart. Is that ok?"*
  - *"It sounds like your pain and your breathing are not well managed. I'll talk with the team and we'll make the following changes…"*

The Serious Illness Conversation in Action

What did you notice?

Importance of debriefing

- These are difficult conversations for the patient/family, and for clinicians
- Take the time to debrief the content, the emotions, and the overall experience with colleagues and your team
- Build a system for routine observation of serious illness conversations for all team members

The Optum Experience and Lessons Learned

- Implementation in Care Delivery began August 2016
  - 6 markets
  - Generalist providers and clinicians, palliative care clinicians, social work, case management, and telephonic care management
  - Train-the-Trainer program implemented across WellMed, Nov 2016-Present
- Pilot Implementation in Complex Care Management, Sept 2016
  - Seattle, WA – ARPNs and leadership team
- Widespread Implementation across Complex Care Management, June 2017 – Present
  - 12 markets, APRNs and RNs, some Medical Directors
- Additional programs for telephonic care management with UHC and others
- Over 2000 clinicians trained since program inception!

The GoCARE Program

- 4 hours of in person training related to the Serious Illness Communication Guide and Communication Skills
- Materials include handbook of slide set, the Serious Illness Conversation Guide, sample cases for role play, guidelines for small group encounters, evidence supporting this method as best practice
- Includes:
  - 60-80 minutes of didactic introduction to the why and what of the program
  - 20 minute demonstration of the guide (patient, surrogate)
  - 90 minutes of small group simulated encounters\
  - 30 minutes of debriefing and discussion about documentation and next steps
  - A “Conversation Challenge”
  - Follow up email with additional resources, support and call for champions and mentors
  - Local market champion program (in progress)

- It all starts with leadership support, buy in, and financing
- Logistical support for the program and the faculty is key
- The training and support for faculty/facilitators is as important as the program content
- Measurement and success criteria should be agreed upon at the start
- Clinicians feel pressure to “cut to the chase” and get orders on the chart – metrics and targets can overwhelm them. The program demands some “unfreezing”. It’s important to connect the dots for participants.

- Formal partnership with Ariadne has been helpful
- The program works best when adapted for clinician audience, care setting, and patient population
- Face-to-face is great – and expensive and difficult to sustain
- Local champions and mentors are critical to the ongoing success of the program
- There will always be more clinicians to train, more clinicians to support, and more clinicians to celebrate – the training is the just beginning of the program of change.

Measurement and Sustainability Challenges

- It's not as easy as looking for a checkbox in the EMR
- Even if we document the conversation, ongoing surveillance and retrospective review must occur to assess provision of goal-concordant care
- Connecting this program with other programs and priorities is crucial for clinicians
- How is measurement of Advance Care Planning different/the same as Serious Illness Communication?
- Measures of individual success, team success, local market success, and organizational success
- Keeping up with the evidence-base is also key

Opportunities for the Optum/Compassus Partnership

- Education for Compassus clinicians and program leadership
- Scalability for Optum clinician and provider training in overlapping markets
- Shared training and education for Optum and Compassus clinicians as needed/appropriate
- Compassus consultation model to support Optum clinicians with additional palliative care or hospice education for families after serious illness conversations occur
- Measures of success – more/earlier hospice referrals, shared language related to goals of care

Considerations for community palliative and hospice care programs

- Allows for rich, values-based conversations around goals of care that are not so interventionally-focused
- Shared language across care settings and services will enhance patient/family satisfaction
- Supporting non-palliative care clinicians with conversation skills and resources promotes collaboration
- “More/Earlier/Better” conversations have been proven to increase # of hospice referrals and increase hospice LOS
- Clinicians who have “more/earlier/better” conversations also express improved job satisfaction

I had the opportunity to use the Conversation Guide today with a family (POA), of a relatively new patient to me. It was wonderful. I began the conversation with the tool and brought in the Disease Trajectory templates for both Parkinson's and dementia and ended up with a signed DNR, DNH. It really flowed well and the family member thanked me 3 times and even hugged me when we finished. It was awesome! - Barbara D.

Overall, I felt it was a good tool to start conversations, whether it be code status or simply long-term goals. My patient spent some time reflecting on her goals and I was able to make recommendations based on what she said. I will continue to use it and hopefully improve my comfort with it and the flow. – Ben H.

At the end of the conversation, …she said no one had ever asked those kinds of questions about their parents before, and thanked me for my time…. I felt like I had made a better connection than I had been able to make with families in a while. I have been able to set the stage for open communication and feel like the family and patients are going to have better outcomes as a result. – Alexandra W.

I had a serious illness conversation with one of my patients. Initially he wanted everything to be done (even "suffering") to prolong his life. During our conversation, he got tearful and asked for time to think. Later that day he asked to talk to a nurse, or to a provider. He has changed his mind to DNR. He is aware that his lung disease is getting worse and he does not want to "suffer" knowing that there is no "medicine" that will cure him. –Marina K.

Thoughts/questions?

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