Valuing “What Matters” Through Advanced Illness Conversations

Part 1: Kelly McCutcheon Adams, LICSW, IHI Director
“Unfortunately, the evidence demonstrates that even if one completes an advance directive or has a discussion on the subject with family and loved ones, it tends to be separated from the time of dying by months, years, or even decades. Most people envision their own death as a peaceful and an ideally rapid transition. But with the exception of accidents or trauma or of a few illnesses that almost invariably result in death weeks or months after diagnosis, death comes at the end of a chronic illness or the frailty accompanying old age. Few people really have the opportunity to know when their death will occur.”
Changing Culture

“The new hope is that we can change the culture to treat the patients as they wish to be treated rather than treating them because we can.”

-Billie Kester, Reid Hospital, Indiana, Conversation Ready Health Care Community Member
“And doctors, from the time we take organic chemistry forward, we don’t like to fail. But in a lot of ways, death is not the greatest failure. In a lot of ways, not giving patients the care they want is failure.”

-Dr. Ziad Obermeyer

https://www.bostonglobe.com/metro/2015/06/08/doctors-play-pivotal-role-determining-end-life-decisions-brigham-study-finds/vlkw2Cb5urAtgguvp7n7QL/story.html
The Conversation Project

A national public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are: Expressed and *Respected*. 
Five years ago on a trip to New York...
Conversation Ready Principles

Engage  Steward  Respect

Exemplify

Connect
Conversation Ready Principles

1. **Engage** with our patients and families to understand what matters most to them at the end of life
2. **Steward** this information as reliably as we do allergy information
3. **Respect** people’s wishes for care at the end of life by partnering to develop a patient-centered plan of care
4. **Exemplify** this work in our own lives so that we fully understand the benefits and challenges
5. **Connect** with patients and families in a culturally and individually respectful manner
Getting involved

“I see three choices: to run, to spectate, to commit.”
Movie: *City of Joy*, 1992
Goals of Care Conversation Education Program®

“What Really Matters to You”? 

Lori Ann Attivissimo, MD
Steven Walerstein, MD
M. Isabel Friedman, DNP
Experience with us a modified version of the Goals of Care Conversation Education Program® (GoCCEP™)
What is GoCCEP™

GoCCEP™ uses a blended learning, multimodal educational methodology consisting of:

• Online Pre-work - Institute for Healthcare Improvement’s “Conversation Project”
• Pre readings
• Instructor lead didactic session
• Two standardized patient encounters with feedback sessions
• Culminating with a group debrief
Objectives

- Provide structured guidance to increase the practitioner’s level of confidence engaging patients and their families in meaningful goals of care conversations
- Utilize different methodologies to conduct a successful Goals of Care Conversation
- Use simulation as a learning tool to enhance experiential learning
Background
## Available Tools

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<th>Ask-Tell-Ask</th>
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<td><strong>Set up and prepare for the meeting</strong></td>
<td>Prepare for Meeting</td>
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<td><strong>Patient’s Perception of</strong></td>
<td><strong>Ask</strong> – the patient to describe her current understanding of their illness**</td>
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<td>condition/seriousness</td>
<td><strong>AND how much information she wants</strong></td>
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<tr>
<td><strong>Invitation from patient to give</strong></td>
<td><strong>Tell</strong> – the patient in straightforward language what you need to communicate**</td>
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<td>information</td>
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<td><strong>Knowledge by giving medical facts</strong></td>
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<td><strong>Explore emotions and empathize as</strong></td>
<td><strong>Ask</strong> – the patient if she understood what was said.**</td>
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### SPIKE

**S**et up and prepare for the meeting

**P**atient’s **P**erception of condition/seriousness

**I**nvitation from patient to give information

**K**nowledge by giving medical facts

**E**xplore emotions and empathize as patient responds

**Str**ategy and summary

### Ask-Tell-Ask

**A**sk – the patient to describe her current understanding of their illness

**A**sk – the patient if she understood what was said.
Set-up

- Review medical history, diagnosis, treatment options and psychosocial information
- Collaborative with the primary care physician
- Review all advanced directive documents
- Coordinate and collaborate with the healthcare team
- Allow adequate time
- Determine who else the patient would like to be present
- Identify one clinician as the leader
- Plan what you are going to say
Language

• Avoid jargon, use everyday language

• Provide a certified medical language interpreter, if needed. Do not use family members as interpreters

• Be conscious of non-verbal communication – our presence, tone of voice and mannerisms.
Introductions

• Allow everyone to introduce themselves and their relationship to the patient

• Introduce the healthcare team

• Build relationship by asking non-medical questions about the patient
  • “Can you tell me about yourself?”
  • “Tell me about your father. What kind of person is he?”
Invitation to Receive Information

• Ask for permission to communicate information
  • “Would you like me to explain where you are with your current illness?”
  • “How much information would you like to receive?”

• Recognize patient preferences
  • Patients may choose to have information communicated to family members or surrogates rather than to themselves directly.

• People cope differently based on race, ethnicity, culture, religion, socioeconomic status, age and developmental level

• Asking permission allows the patient to be in control of the exchange of information
Assess Knowledge

• Most anxious part of the family meeting
• If the news is bad, let the patient/family know it is not good prior to giving any information
  • “I’m sorry I have to tell you this, Ms. Smith, but unfortunately the test results were not as I had hoped. The biopsy revealed a progression of your disease.”
• Name the disease
• Avoid medical jargon
• Pause frequently while speaking to assess their understanding
• Don’t minimize the severity of what you are saying
• Be empathetic
• Avoid vagueness and confusion
Utilize Silence

• Once the information is communicated – use silence

• Nothing will be heard at this point

• Invitational silence allows the patient/family time to process what they have just heard.

• Allows the patient to think and feel about what is happening.
# Explore and Empathize Emotions

- Allow patients and families to express their emotions. Give time for them to react.
- Telling them that the current plan is not working.
- Identify the emotion:
  - “It appears you are angry about this.”
- Range of emotions:

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<tbody>
<tr>
<td>Tears</td>
<td>Anger</td>
<td>Sadness</td>
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<tr>
<td>Anxiety</td>
<td>Relief</td>
<td>Denial</td>
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<tr>
<td>Blame</td>
<td>Guilt</td>
<td>Disbelief</td>
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<tr>
<td>Fear</td>
<td>Loss</td>
<td>Shame</td>
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Empathy

• Involves appreciation, understanding, & acceptance

• Most important relationship-building skill

• Helps to develop trust

• Used to assess and understand the meaning of the illness to the patient
Responding to Emotions

- Listen silently
- Encourage the patient/family to describe their feeling
- Use nonverbal communication
  - If you and they are comfortable with touch, hold the patient's hand
- Allows the patient to understand that the clinician acknowledges the emotions the patient/family is experiencing
- Emotions must be identified to develop realistic goals of care
- Acknowledgment allows you to move forward without causing additional anxiety or stress
Strategy and Summary

- Assess understanding - Ask the patient/family to repeat what they were told
- Use open ended questions
  - “What questions do you have for me?”
- Communicate prognosis
- False hope can deflect from establishing realistic goals of care
Goals of Care

• Begin with the patient's values
• Possible goals

<table>
<thead>
<tr>
<th>Improve functioning</th>
<th>Prolong life</th>
<th>Relief of suffering</th>
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<tbody>
<tr>
<td>See a family milestone</td>
<td>Return home</td>
<td>Staying in control</td>
</tr>
<tr>
<td>A good death</td>
<td>Family support</td>
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• Offer clear recommendations
• Make a plan including follow up
• Confirm your continued availability regardless of the plan developed
Closing the Conversation

• Assess the patient and/or family’s understanding. Ask the patient to state the ongoing plan
  • “If you were going to tell someone about your plan of care, what would you tell them?”

• Thank everyone for participating
  • “I want to thank you for helping to make these difficult decisions.”

• Provide contact information for the patient to use to reach you and a written summary of the plan

• End on a hopeful note, promising ongoing communication
After the Conversation

- Document the conversation in the medical record
- Record the patient’s goals and wishes
- Update the plan of care
UPCOMING SUNRISE CHANGE

DOCUMENTATION: Goals of Care Conversation - Personal Advanced Directives
August 16, 2016

WHO IS IMPACTED?
- Sites: All Sunrise-Live Hospitals
- Roles: Providers, Nursing, Social Workers, Chaplaincy, Child Life

WHAT YOU NEED TO KNOW:
- New structured note entitled “Goals of Care Conversation - Personal Advanced Directives” will serve to document conversations held between clinicians and patient/family in regards to the patient’s end of life care.
- The sections of the “Goals of Care Conversation-Personal Advanced Directives” note include:
  - Participants
    - Patients
    - Family
    - Staff
  - Advance Directives
    - Does patient have Advance Directive
      - Yes
      - No
    - Does Patient have a Surrogate
      - Yes
      - No
  - If Advance Directives is completed on the Patient Profile, all information will pull into this section, except for the question “Does Patient Have a Surrogate”, as this is not included on the Patient Profile.
  - The Nurse must update the Patient Profile if modifications are made to the Advance Directives section of the ‘Goals of Care Conversation – Personal Advanced Directives’ note.
    - An alert will advise the documenter to remind the RN to update the Advance Directives in the Patient Profile.
  - Conversation Discussion
    - Chaplaincy and Child Life Referrals can be placed by: Providers, Nursing, Social Workers
      - Note: Child Life Referral will only be available at NSUH & LU
    - Hospice and Palliative Care Referrals can be placed by: Providers only.
      - If an RN or SW selects the Hospice and/or Palliative Care referrals they will receive an alert to contact the provider to place the order.

WHAT MATTERS MOST TO PATIENT AND FAMILY

- Free text (e.g., emotional needs, spiritual preferences/concerns, etc.)

TREATMENT GUIDELINES

- “DNR Order” and “Comfort Measures Only” are to be placed by the provider.
  - If an RN or SW selects these orders they will receive an alert to contact the provider to place the order.

FUTURE HOSPITALIZATION/TRANSFER AND MOLST

- New Clinical Summary view entitled “Goals of Care Conversation” provides a summarized view of all “Goals of Care Conversation – Personal Advanced Directives” documentation made throughout the patient’s care.
  - Available tiles include: Documents, Participants, Advance Directive, Treatment Guidelines, MOLST, Conversation/Discussion, and What Matters Most to Patient and Family.
  - All tiles reflect the most recently updated information from the “Goals of Care Conversation-Personal Advanced Directives” note(s).

WHAT YOU NEED TO DO...

Review and become familiar with the new “Goals of Care Conversation – Personal Advanced Directives” Documentation before the August 16, 2016 Go Live.

If you have any questions, please contact your Site IT Leadership.
Real World Goal of Conversations

Mr. & Mrs. P

Personal Observations
Using Simulation to enhance Learning through experience and reflection
Debriefing

The act of reviewing a real or simulated event in which participants explain, analyze and synthesize information and emotional states to improve performance in similar situations.

**Major Strength of this methodology**
The voice of the Patient is heard utilizing Immediate Feedback.
Debriefing with Good Judgment

We do this by asking questions that invite the student to share their perspective.

- Avoid shame and blame; people “make mistakes”
- Strengthen our ability to talk about difficult topics
- Establish a context for learning and change
- Holds the belief that the participants are bright and caring...
- Use statements like: “help me understand”, “tell me what you were thinking”, “what went well”, “what can we improve on”? 
- Fosters reflection and experiential learning

Harvard University, The Institute for Medical Simulation, Cambridge, MA. 2008. Simulation as a Teaching Tool Instructor Training

Participant Survey Data: July 2015 – August 2016

% of Participants who responded Agree or Strongly Agree

1. GoCCEP™ met my learning needs 94.1%
2. I would recommend the GoCCEP™ program to a friend 95.8%
3. What I learned from GoCCEP™ will help me be more effective at work 93.3%
4. The Standardized Patient activities were helpful in my better understanding the subject matter 95.7%
5. As a result of GoCCEP™ I know more about this topic than I did before 92.2%

117/175 respondents
Challenges

• Unable to schedule enough classes to meet demand
• Expand cases in complexity
• Expand cases to be specialty specific
• Difficulty in giving clinicians time off to attend
• Use of Standardized Patients
Thank You!
Time for You to engage in Simulation
Instructions for the Simulation
Simulation

• Need 4 audience members to form an interprofessional Team (given a copy of the case)
• Team will Huddle
• Audience will be given a copy of the case and the communications skills checklist
• Team will have a Goals of Care Conversation with the patient
• Reminder: SP stays in character at all times
Team Debrief
followed by
Group Debrief
Thank You
Any Questions?
References


• © 2015 Ariadine Labs: A Joint Center for Health System Innovations, The Serious Illness Guide

References


