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PARTNERS HEALTHCARE

ARIADNE LABS 5 YEARS

BWH

Serious Illness Conversations

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Agenda

- Pre-Session Survey
- Power-point presentation
- Example Videos
- Watch/discuss a case simulation
- Post-Session Survey

Introduction

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Introduction

- Think of an instance when a conversation about goals of care had a positive impact on a patient, their family, and/or you
- Think of an instance when a conversation about goals of care had a negative impact on a patient, their family, and/or you

Introduction

- Mission: improve the lives of all people with serious illness by increasing meaningful conversations.
- Developed by physicians from Ariadne Labs (BWH/Harvard), Dana Farber Cancer Institute, Harvard, Johns Hopkins, and UCSF
- Objective: learn a structured, evidence-based, patient-centered approach for conversations with patients about their values, goals, and choices surrounding any life-limiting illness

Some Confusing Terms

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Confusing Terms

- **Serious Illness**
  - Any illness that is life-limiting
    - Advanced cancer, advanced COPD, Stage III/IV heart failure, dementia, CKD, cirrhosis or chronic liver disease, AIDS

- **Goals of care**
  - A patient's and/or a patient's family's expectation and priorities surrounding the end of life
  - Encompasses DNR, living will, power of attorney forms **BUT ALSO**
    - Treatment Expectations
    - Symptom Control
    - Curative Measures

Confusing Terms Cont'd

- **DNR- Do not resuscitate**
  - DNR automatically implies no CPR
  - Many times, DNRs are specified further, indicating whether a patient wants intubated, NIV, ICU admissions, and/or vasopressors (i.e. limited code)

- **MOLST- Medical orders for life sustaining treatment**
  - Also called POLST in some states
  - Similar to DNR
  - In some states, this is only physician order that is honored outside of hospital

Confusing Terms Cont'd

- **Living will**
  - Official state document outlining whether or not a patient wants artificial nutrition
    - Feeding tube/PEG and long-term ventilation (trach)
  - Can also indicate further wishes
    - Regarding dialysis, length of intubation, what to do if they will be unable to perform their ADL's or IADL's, etc.

- **Power of Attorney**
  - Multiple different POA's- the one applicable to us is Health Care Power of Attorney (HCPOA)
  - Form that allows patients to indicate <u>who they want to make decisions for them when they are unable to make them for themselves</u>

Confusing Terms Cont'd

- **Completing Living Will or HCPOA Forms require EITHER:**
  - Notarization
    - Stephanie Petersen (BHC in IMC), Elizabeth Dawson (SW in IMC), Lisa Geer (IMC Office Manager) or Valecia Pickett (Secretary in DOM)

OR

  - Signature of two witnesses (not a relative and not patient's attending physician)

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Confusing Terms Cont'd

- **Palliative Care**
  - "…an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1]

- **Hospice**
  - Palliative care focused in the last 6 months of life when curative measures have ceased

Why be trained?

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In the US…

- 2.8 million deaths annually[3]

- Heart disease
- Cancer
- Unintentional injuries
- Chronic lower respiratory diseases
- Stroke/cerebrovascular diseases
- Alzheimer Disease
- Diabetes
- Influenza and Pneumonia
- CKD

- Average life expectancy **78.7 years**

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Dying in America[4]

- **Of people who have discussed end of life issues with their families and/or physicians:**
  - Most choose to focus on alleviating pain/suffering

- **At the end of a peoples' lives:**
  - Most will NOT have the mental faculties present to make their own medical decisions
  - Most will be in an acute care setting, being taken care of by physicians who don't know them

- **Over 700,000 of the 2.4 million deaths recorded in 2010 occurred in a hospital[5]**

- Of Medicare beneficiaries, 70% hospitalized 90 days prior to death, and 29% received ICU care 30 days prior[6]

- "… most people, particularly younger, poorer, minority, and less-educated individuals have never had these conversations"

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Deficiencies in Serious Illness Communications

- **Patient factors**
  - Emotions[7]
  - Patients expect their providers to initiate discussions about goals of care[8,9]

- **Physician factors**
  - Feeling poorly prepared[7]
  - Emotions- both physician and patient[7, 10]
    - Worry it will take away hope, make people depressed, decrease survival, cultural appropriateness
  - Delaying conversations[7, 9]
  - Uncertainties about a patient's prognosis[7, 10]
  - Avoidance of discussing psychosocial factors[7, 9]

- **System factors[7]**
  - Default to life-sustaining treatment
  - Unclear responsibility when multiple sub-specialists are involved
  - Work flows and EHR inconsistencies

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Benefits of Serious Illness Conversations

- **Improved clinical outcomes[7]**
  - Multiple studies report *higher quality of life and better mood* when patients are referred to palliative care and hospice
  - Patient with lung cancer actually *live longer on hospice*[11]
  - Patients are *more likely to receive the care they wish* to at the end of life[7,9]

- **No increase in anxiety or depression[7]**
  - Exception being if physicians are not trained to conduct these conversations in a sensitive manner, there can be patient and surrogate distress

- **Reductions in cost[7]**

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Potential Triggers for Serious Illness Conversations[7]

- **Cancer**
  - Disease related
    - NSCLCa, pancreatic cancer, GBM
    - Patients >70 with AML
  - Third-line chemotherapy recipients

- **COPD**
  - No further treatment options
  - Functional decline
  - Symptom exacerbation/hospitalizations
  - Ongoing oxygen requirement

- **CHF**
  - Increased symptoms, reduced function, progressive increase of diuretics
  - Hospitalization
  - Hypotension or azotemia
  - Need for inotropic therapy or ICD shock(s)

Potential Triggers for Serious Illness Conversations[7]

- **ESRD**
  - Albumin <3.5 g/dL
  - Age
  - Dementia
  - PVD

- **General**
  - >80 and hospitalized
  - Prognosis-based criteria (http://www.eprognosis.org)

End of Life Curriculum in Residency

- Only 36% of IM residency programs have an established end of life curriculum[16]

- A study done at USF showed:
  - 88% of residency programs overall did not have a formal end of life curriculum, but
  - >50% of residents had >10 EOL conversations (which were mostly unsupervised)[17]

For our patients…

- We need to be trained and comfortable with end of life conversations
- More than a quarter of patients die in an acute care setting
  - Much less than that wish to
- Undergraduate and Graduate Medical Education are in dire need of increasing education on serious illness conversations
- A bad conversation can be extremely detrimental and hurt the patient and family
  - As can be NO conversation

Summary

- **Patients <u>WANT</u>**
  - Pain & symptom management
  - Increased quality of life
  - Sense of control[12]
  - Strengthened relationships[13]
  - The truth about their prognosis[8, 15]

- **As providers, we <u>must avoid</u>**
  - Making end of life conversations a low priority
  - Being uncomfortable with emotions
  - Poor end of life care
  - The “time crunch” (waiting until the last minute)

Serious Illness Care Program

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Overview of the Program

- Identify patients who benefit from having conversations about their GOC
- The Serious Illness Conversation Guide
- Training, coaching, and reference materials for clinicians on how to use the SIC Guide and implement the program
- Materials to help patients prepare for the discussion and help prepare them to discussion their care preferences with their loved ones

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Serious Illness Care Program

- Checklists help assure adherence to a process, achieve a higher level of performance, and ensure completion of complex tasks during stressful situations

- Checklists CANNOT help you establish a relationship/rapport and build trust
  - This must be done in the visits leading up to a difficult conversation

- Preliminary results show more patients in the intervention group (eg SIC) had conversations with their clinicians (and those conversations happened earlier and were better quality)
  - Also, lower levels of anxiety/depression

Examples

-Please click the link in the description: "Questionnaire for Simulated Cases."

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Patient 1

- 62 y/o male
- Married father of 3, one child still in school
- Pancreatic cancer with metastases
- Has failed several courses of treatment
- Worsening symptoms: abdominal pain, nausea, occasional vomiting, anorexia, fatigue

The goal for the office visit today is to begin to discuss his values and goals as he becomes sicker

https://www.youtube.com/watch?v=8TSniMxCU58&feature=youtu.be

Patient 1- Debriefing

Patient 2

- 57 y/o male
- Married, 1 daughter; wife of 35 years works as a waitress
- Disability due to HF and COPD (4L O2 NC continuously)
  - Adherent to maximal medical therapy
- Patient wants family to live “normal lives”
- Symptoms: DOE, multiple recent hospitalizations for respiratory failure

The goal for the office visit today is to begin to discuss his values and goals in case he declines further

https://www.youtube.com/watch?v=fhwa9f5O_U4&feature=youtu.be

Patient 2- Debriefing

Serious Illness Conversation Guide

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Serious Illness Conversation Guide

- **Organized as 2 parts: Conversation flow and language**
  - Conversation flow prompts the essential steps of the conversation and follows an intentional sequence
  - Language is patient tested

- **During the "set up" to the conversation, say things like:**
  - "We are thinking in advance"
  - "Is this okay?"
  - "We always hope for the best and prepare for the worst"
  - "It can be of benefit for you and your family"
  - "No decisions have to be made today"

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"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?**"
2. ***Assess understanding and preferences***	"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?"
3. ***Share prognosis*** · Share prognosis · Frame as a "wish...worry", "hope...worry" statement · Allow silence, explore emotion	"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." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(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."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"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?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"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."
6. ***Document your conversation*** 7. ***Communicate with key clinicians***	

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General principles

- **Patients want the truth about their prognosis**
  - Give a direct, honest prognosis as a range (hours to days, days to weeks, weeks to months, months to years), acknowledging uncertainty
  - You may need to evaluate prognosis and treatment options *prior* to talking with the patient[18]
    - Prognosis is about time as well as decline[18]
  - Ask/Tell/Ask
  - Do not give premature reassurance

- **You will NOT harm your patient by talking about end of life issues**

- **Anxiety is NORMAL both for the clinician and the patient during these discussions**

- **Giving patients an opportunity to express fears and worries is therapeutic**

- **ALLOW silence- you should talk LESS than half the time**

General principles

- **Acknowledge and explore emotions**
  - Do NOT give facts in response to a patient's strong emotions
    - Eg. **A patient asking medical information a lot of the times is an emotional question that warrants an empathetic response, not a discussion of medical jargon.**
  - Identify and name the patients emotions, "I sense you are feeling ____.", "This is ____", "You seem _____."

- **Focus on the patient's quality of life, fears, and concerns**

- **Make a recommendation**
  - Base the recommendation on the patients' priorities most compatible with the likely prognosis and available treatment options[18]

- **Document!**

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General Communication Tips

- Always start by asking what the patient and family understand of his/her illness
- ALWAYS sit down and ensure that there are enough chairs present so that everyone participating in the conversation can sit
- **Think of the 3 W's (wish, worry, and wonder)**
  - "Will I make it to my granddaughter's graduation in 2 years?"
    - "I wish that things were different; I worry that that's not likely."
    - "I hope that you can, and I worry that it may not be possible."
    - "I wonder if there are things you can do to prepare in the event you can't be there."
- "Hope for the best, prepare for the worst"
- It is always acceptable to say "Tell me more" or "Tell me what you mean by that"
- No specific goal, just getting patient up to speed, EXPLORING!, Don't need to get DNR

A Simulated Case…

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Simulated Case

- Janine is a 62 year-old homemaker who has a history of advanced COPD, generalized anxiety disorder, diabetes, and osteoarthritis. She's had multiple hospitalizations over the past year for COPD exacerbations, including two ICU admissions. With each admission, her functional status has worsened. She's missed several appointments with her PCP Dr. Brooks over the past few months due to increasing fatigue and difficulty managing tasks.

- Despite maximal therapy for her COPD, her functional status remains poor. She spends most days sitting in her recliner due to shortness of breath when she walks around and pain in her legs. She doesn't want to go to a nursing home, even though it's becoming more difficult for her to care for herself at home.

Simulated Case Cont'd

- Her spouse died two years ago from colon cancer. She has two younger sisters whom she talks with regularly, but they have their own health problems. She has two daughters but doesn't want to bother them with her issues as they are still mourning the loss of their father and have their own lives to worry about. Her dog is her only regular companion.

- While nothing has changed recently, her functional status is poor enough that she is a candidate for a discussion using the Serious Illness Conversation Guide. Dr. Brooks has her scheduled for a hospital follow-up appointment, but wants to ensure he begins to discuss her goals and wishes for the months ahead. He estimates her overall prognosis to be less than one year.

Survey and Evaluation

- Thank you ☺

- Special thanks to:
  - Dr. Jones
  - Mike Oravec
  - Lisa Geer
  - Rose Penix

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Resources

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Resources cont.

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Resources cont.

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