# Communication in Serious Illness

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## Objectives

- Define a population of patients with serious illness for whom improved communication holds many benefits
- Learn how to improve communication in patients with serious illness
- Apply a structured communication tool to facilitate and improve communication in patients with serious illness

# **Audience Participation**

Light travels faster than sound. This is why some people appear bright until you hear them speak.

# **Audience Participation**

You don't have the right to remain silent. Anything you say will be misquoted then used against you



"There's no easy way I can tell you this, so I'm sending you to someone who can."

## Communication in Serious Illness

WHY Should We?
WHY Don't We?
(have these conversations)

# Communication in Serious Illness: Principles

- Patients (most) want the truth about prognosis
- You will not harm patients
- Anxiety is normal
- Patients have goals and priorities besides living longer
- Giving patients opportunities to express fears and worries is therapeutic

# Conversations about Goals Improve Healthcare Value

In a prospective multicenter study of 332 cancer patients, family associated EOL conversation with:

- Better quality of care
- Less hospital/ICU, lower costs
- Lower risk complicated grief + bereavement among family caregivers

— Zhang et al. Arch Int Med 2009;169:480-8.— Wright et al. JAMA 2008;300:1665-73.



#### **Doctors Reluctant to Discuss EOL Care**



- Only 12% of providers had yearly discussions with HF pts as recommended by the AHA
- 1 in 3 report lack of confidence or know-how for EOL conversation

American Heart Association Meeting Abstract 352: 6/4/14; S Dunlay, MD, MS

## The Modern Death Ritual

- >95% of all health care spending is for the chronically ill
- **64**% of all Medicare spending goes to the 10% of beneficiaries with 5 or more chronic conditions
- 40% of Medicare dollars spent last 6 months of life
- 50% of decedents in ER in last month of life, 75% in last 6 months
- Despite high spending, evidence of poor quality of care
- Huge dissatisfiers for patients, families, and providers

## **Communication in Serious Illness**

WHO?

#### Patients with:

- Advanced organ failure:
  - HF
  - COPD
  - ESLD
  - CKD
  - ASCVD/PAD/CVA
- Advanced cancer
- Dementia/ Neurodegenerative
- Elderly with multiple chronic conditions
- "Surprise" question: Would I be surprised if this patient is not alive in ONE year?



People  $\geq$  65 20 -------35 ------70 million! 1965 2011 2030

#### Communication in Serious Illness

# WHEN?

# Trajectory of Advanced Illness



Phase I – healthy with "reversible illness"

Phase II – onset and progression of chronic symptoms

Phase III – frailty & functional decline

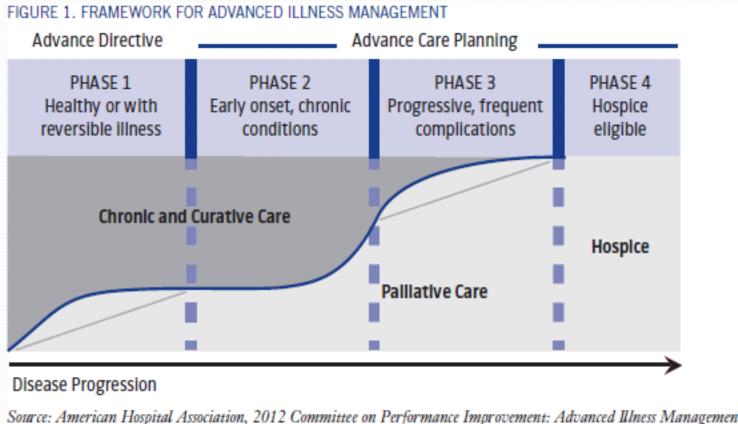
# The Challenge – Advance Illness Phase III



- Increasing:
  - burdens of disease
  - risks of interventions
  - frailty
- Declining
  - benefit of disease directed therapies
  - functional status
- Aware of frailty but unaware of approaching end of life (both clinicians & patients)

#### Advanced Illness Management

#### A New Paradigm



Source: American Hospital Association, 2012 Committee on Performance Improvement: Advanced Illness Management Strategies (in 2 parts). Chicago: American Hospital Association, 2012.

Primary palliative care



Specialty Palliative Care



# **PROGNOSTICATION**

# Prognostication Often Difficult

Biometric Models + Functional Status + Specific Biomedical Data + General Biologic Data

Equals

More Accurate, Useful, Compassionate and Professional Prognostication

# Biometric Models - Examples

- NYHA CHF
- Seattle heart CHF
- MELD Liver
- ECOG Cancer
- FAST Dementia

# Frailty: 3 of 5

- Loss of strength
- 2. Weight loss (unintended)
- 3. Low activity level/increased sleeping
- 4. Poor endurance or easily fatigued
- 5. Slowed performance/unsteady gait

# Patterns of Functional Decline Can Make Prognosticating Difficult



Patterns of Functional Decline; Lunney, J. R. et al. JAMA 2003;289:2387-2392

## **SURPRISE Question**

**Q:** Would I be surprised if this patient were not alive *ONE YEAR FROM NOW?* 

A: No

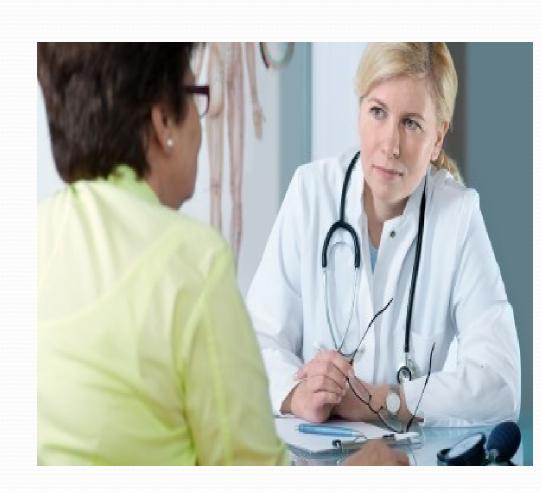
Plan: <u>SERIOUS ILLNESS CONVERSATION</u>

#### Communication in Serious Illness

# WHAT?

## Clinician's Role

- Inform patient that he/she has a progressive, ultimately fatal disease
- Learn about patient's values and goals
- Remember that family has to live with the memories



## Patient Priorities for Care

- Rank order what is most important
  - Independence! 76%
  - Pain management
  - Not to be a burden

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Staying alive as long as possible - LAST

#### Communication in Serious Illness

HOW?

# Communication in Serious Illness How?

- Serious Illness Communication Guide
- Structured Tool
  - Set Up Critical!
  - Seven Questions
  - Recommendations
  - Commitment/Follow Up

#### Dos

- Direct, honest prognosis
- Plain language
- Prognosis as a <u>range</u>
- Quality of life, fears and concerns
- Acknowledge/explore emotions
- Allow silence
- Make a recommendation: "based on XX medical situation, YY treatment options and ZZ goals and values, <u>I recommend....</u>"
- Document conversation, ensure follow up

#### Don'ts

- Talk more than half the time
- Use medical jargon
- Fear silence
- Give overly optimistic prognosis
- Provide facts in response to strong emotions
- Focus on medical procedures

Video Demo of Serious Illness Conversation

https://www.youtube.com/watch?feature=player\_embedded&v=RPQBukpyKAY

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#### ROLE PLAY

- APPLY Serious Illness Conversation Guide:
  - Ten minutes conversation
  - Groups of 3 clinician, patient & observer
    - #1 Set-up
    - #2 Understanding
    - #3 Information preferences
    - #4 PROGNOSIS: Use "Wish, Worry, Wonder"
- Five minute debriefing in small groups
- Collective debriefing

#### Dos and Don'ts

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