INTEGRATING PALLIATIVE CARE INTO THE PCMH/N MODEL

Serious Illness Conversations

Welcome

- Thank you for attending this event. Please ensure you sign in using link in chat box.

- Disclosure information can be found on this PowerPoint presentation.

- Please make sure you attend the entire session and complete the evaluation. Evaluation will be shared at the end of session and link will be included in a follow up email.

- You will receive your CME/CE Certificate after completing the evaluation.

- Deadline for evaluation is <u>10 business days after training.</u>

- We will be using Active Learning Strategies to support this assessment, such as break out sessions, polling during presentations and question and answer opportunities.

- It is important that you communicate with us that the content presented is clear, understandable and useful for you.

- Please ask questions and seek clarification whenever you have a concern.

- We need for you to share your wisdom and feedback with us.

Requirements for Completion

- Sign in and attend entire session.

- Complete evaluation. Evaluation will be shared at the end of session and link will be included in a follow up email.

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Social Work

This course is approved by the NASW-Michigan Social Work Continuing Education Collaborative Approval # 121621-01, # CE Hours approved: 2.5

Presenter

Mary Beth Billie, DNP, RN-BC, CCM

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Learning Objectives

- Identify factors in the US healthcare system that contribute to deficiencies in Serious Illness communication.

- Describe key SI communication concepts and strategies that can be undertaken to improve serious illness communication.

- Identify communication skills that have been demonstrated to be most applicable for Serious Illness Conversations.

- Define the components of an evidence-based Serious Illness Communication guide.

- Utilize serious illness communication skills and structured communication guide in role play.

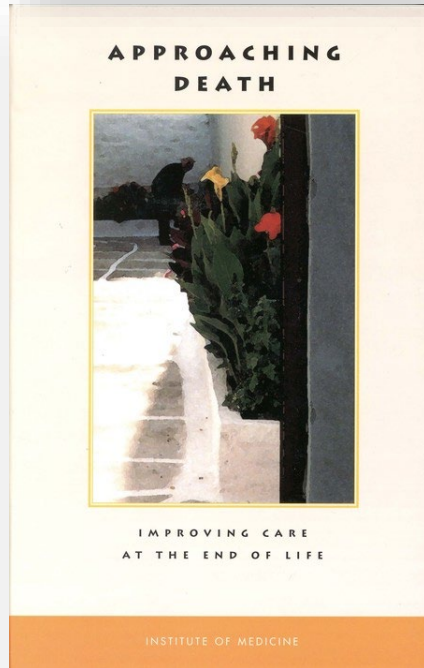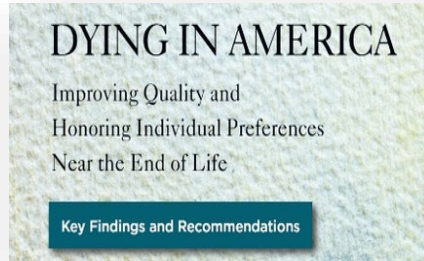**Erin Zimny, MD**
*Henry Ford
Health System*

In some respects, this century's scientific and medical advances have made **living easier and dying harder."**

Report from the Field
Approaching Death: Improving Care at the End of Life
-A Report of the Institute of Medicine (IOM, 1997)

Institute of Medicine Reports (1998, 2014)

- **System falls short of providing "humane" end-of-life care**
  - People dying while suffering from pain/distress that could have been relieved
  - Aggressive use of ineffectual or intrusive interventions

- **Education doesn't prepare clinicians with knowledge/skill for serious illness care and communication**
  - Fundamental failures in professional education

- **Significant research gaps about end-of-life care**
  - Insufficient knowledge to create EOL Evidence Based guidelines

Need for systematic improvements in clinician led serious illness conversations

Scalable interventions targeted at non-palliative care clinicians

The Way We are Dying is Changing

- Life expectancy in 1960 was 69 years old. Life expectancy in 2020 is 79 years old.

- Aged 65 and older, 69% will develop disabilities before they die and 35% will eventually enter a nursing home

- 9 of 10 older adults will live with one or more serious illnesses in the final year of their life.
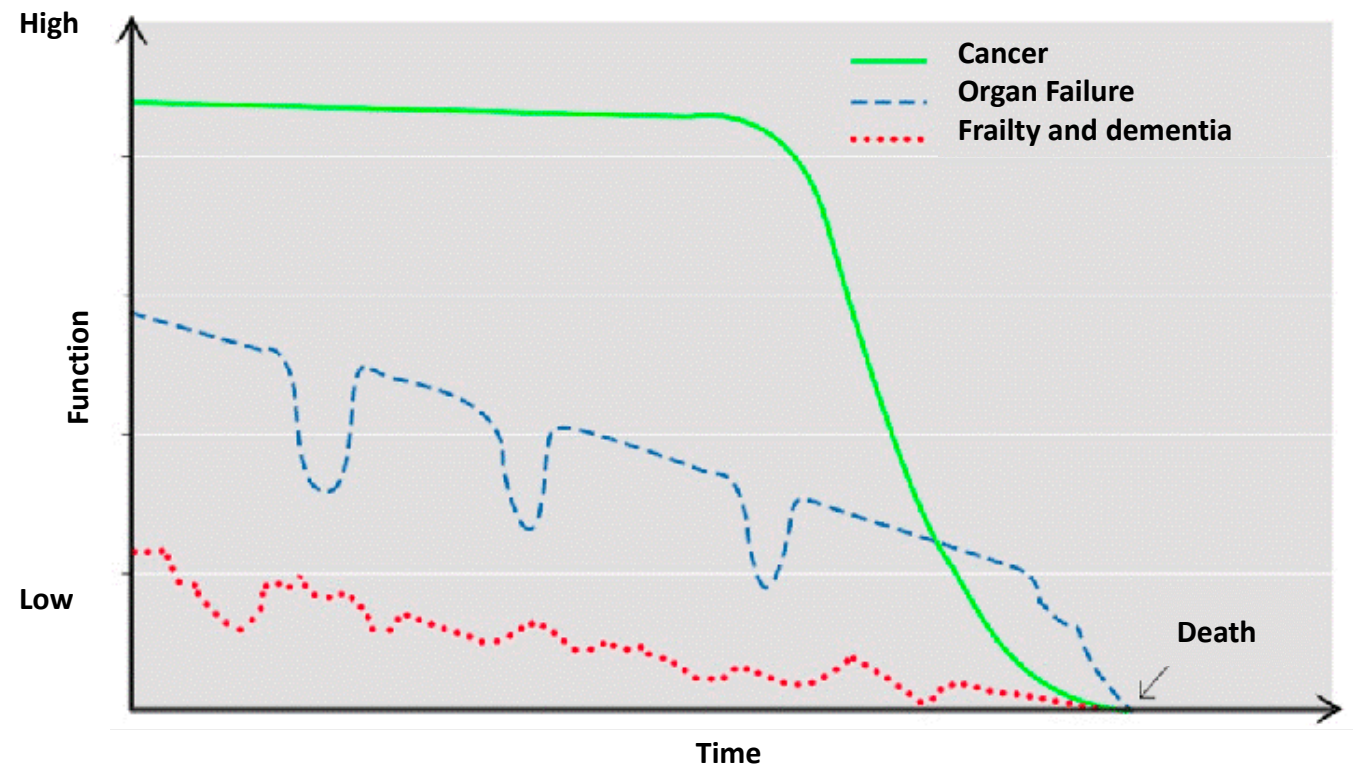
Lunney et al., 2002; Lynn & Adamson, 2003

Conversations are infrequent, late and limited

Infrequent	▪ Fewer than 1/3 of patients with end-stage diagnoses reported end-of-life (EOL) discussion with clinicians
Late	▪ First EOL discussion 33 days before death in patients with advanced cancer ▪ 55% of initial discussions occurred in hospitals
Limited	▪ Conversations often fail to address key elements of quality discussions ▪ When conversations take place, outcomes of discussions are often not documented, not documented accurately, or not easily retrievable in the EHR

(Heyland et al., 2009; Mack, et al., 2012 ;Wright et al., 2008)

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Current state

Dissonance between desired and actual end of life care

Desired: Almost **9 out of 10** Medicare patients prefer to spend their final days at home

Actual:

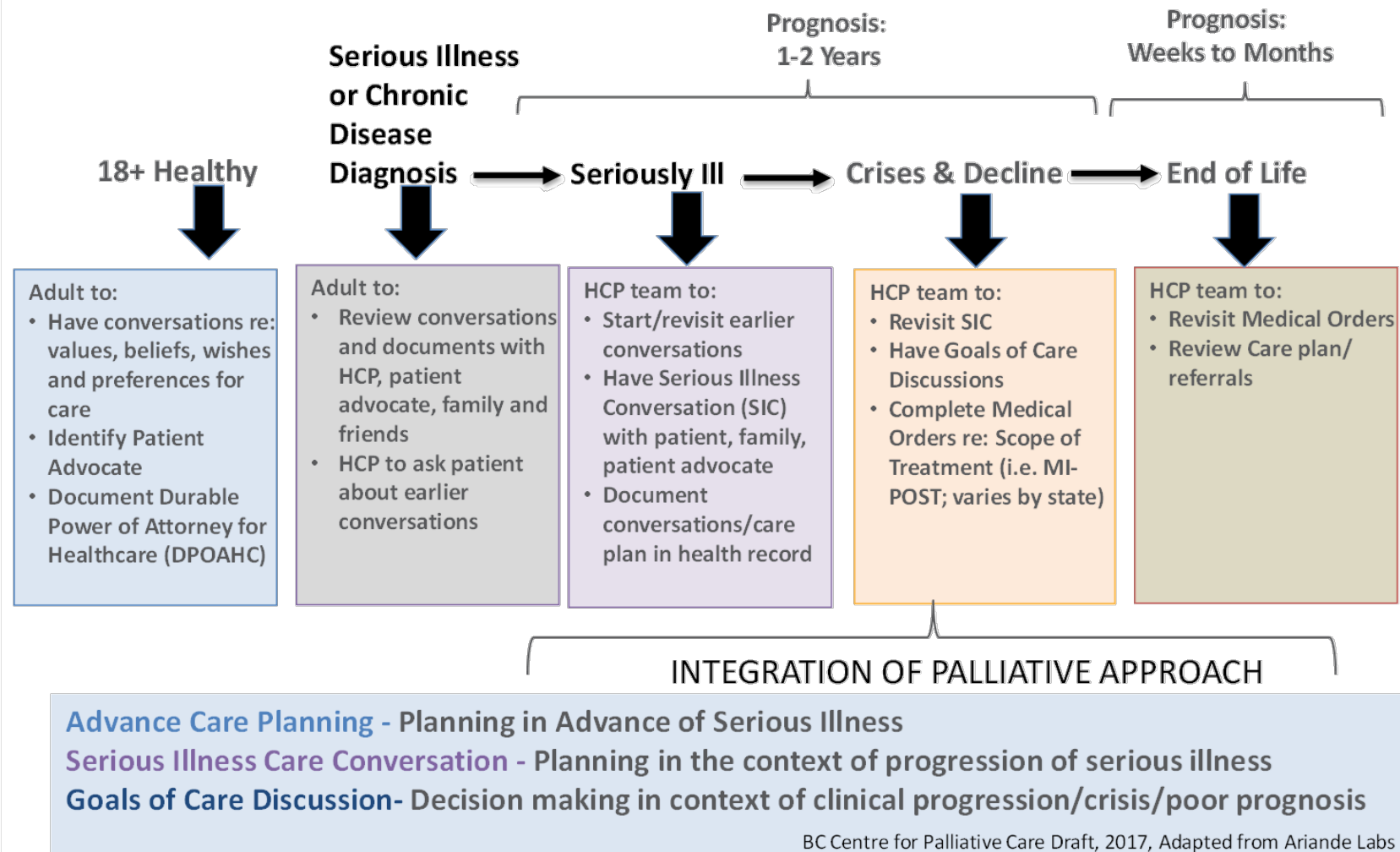| 70% are hospitalized in the last 90 days	29% receive intensive care in the last 90 days	25% to 39% die in acute care hospitals

Multifactorial

- Curriculum deficits regarding EOL care

- Lack of clinician communication skills training

- Lack of interprofessional collaboration

- Variance in chronic disease trajectories (i.e., CHF, COPD, ESRD)

- Major advances in technology and treatment options

- US healthcare system default is more care (medical model)

Serious Illness Communication

Concepts and Strategies

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Advance Care Planning Continuum

		Prognosis: 1-2 Years		Prognosis: Weeks to Months
18+ Healthy	**Serious Illness or Chronic Disease Diagnosis** →	**Seriously Ill** →	**Crises & Decline** →	**End of Life**

Adult to:
- Have conversations re: values, beliefs, wishes and preferences for care
- Identify Patient Advocate
- Document Durable Power of Attorney for Healthcare (DPOAHC)

Adult to:
- Review conversations and documents with HCP, patient advocate, family and friends
- HCP to ask patient about earlier conversations

HCP team to:
- Start/revisit earlier conversations
- Have Serious Illness Conversation (SIC) with patient, family, patient advocate
- Document conversations/care plan in health record

HCP team to:
- Revisit SIC
- Have Goals of Care Discussions
- Complete Medical Orders re: Scope of Treatment (i.e. MI-POST; varies by state)

HCP team to:
- Revisit Medical Orders
- Review Care plan/ referrals

INTEGRATION OF PALLIATIVE APPROACH

Advance Care Planning - Planning in Advance of Serious Illness

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

Goals of Care Discussion- Decision making in context of clinical progression/crisis/poor prognosis

BC Centre for Palliative Care Draft, 2017, Adapted from Ariande Labs

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Definitions

Conceptual Definition Serious Illness (SI)

"disease(s) that carry a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains the caregiver."

*(Kelley & Bollens-Lund, 2018)*

A Serious Illness Conversation **IS**	A Serious Illness Conversation **IS NOT**
A clinician facilitated conversation with individuals with a serious illness to determine goals, values and preferences that then inform the serious illness plan of care.	▪ Discussion of medical treatments
▪ Often a series of conversations	▪ Completing Advanced Directives Forms such as HCPOA and POLST forms
▪ Often involves patients and families	▪ CPR and DNR discussions
	▪ Referrals to Palliative Care or hospice (can be an outcome of SI conversation)

Let's Listen
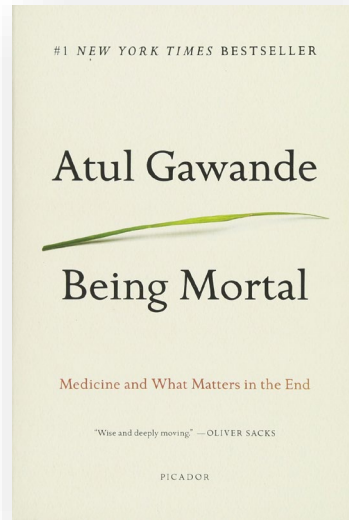
Atul Gawande, MD - Professor in the Department of Health Policy and Management at the Harvard T.H. Chan School of Public Health and the Samuel O. Their Professor of Surgery at the Harvard Medical School.
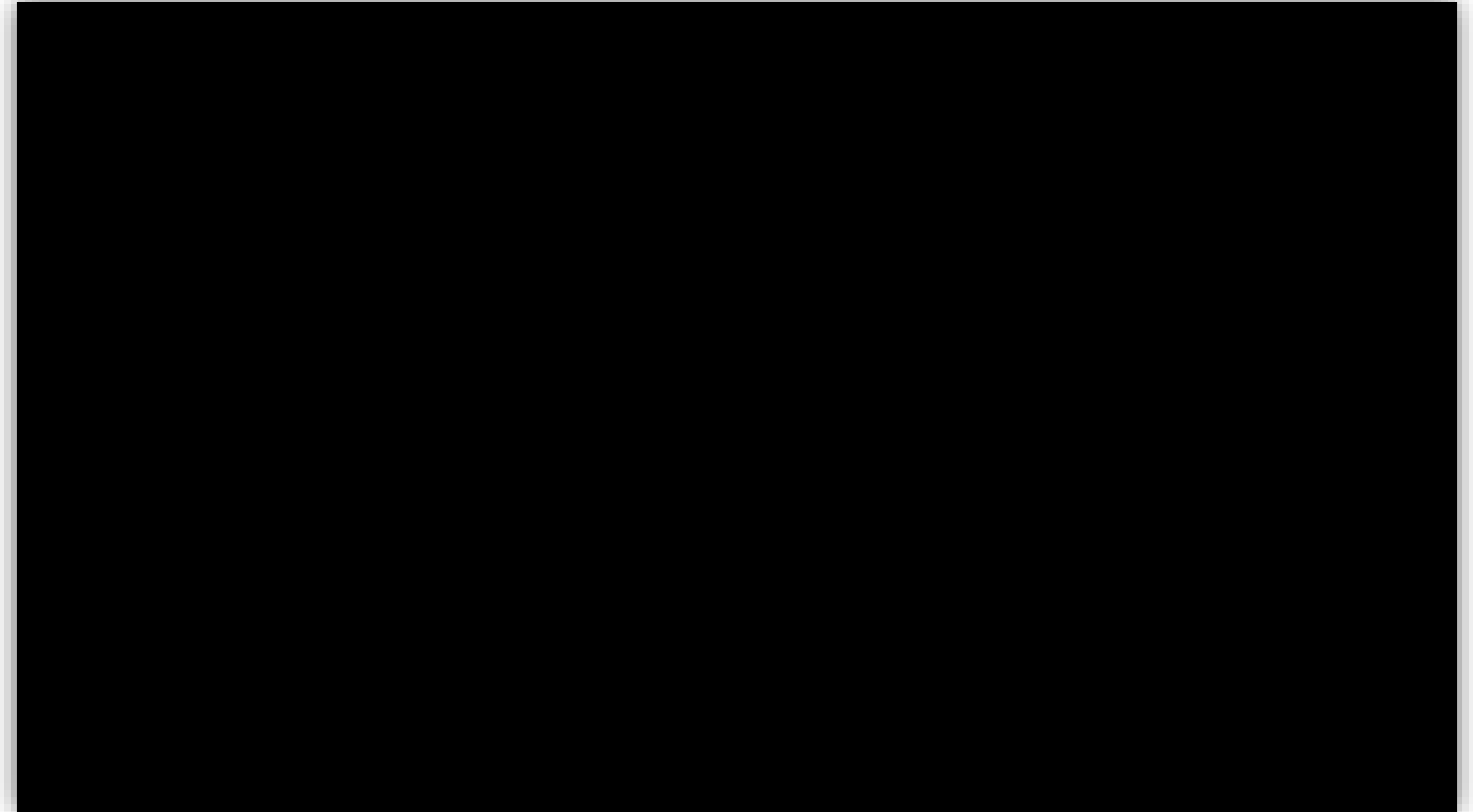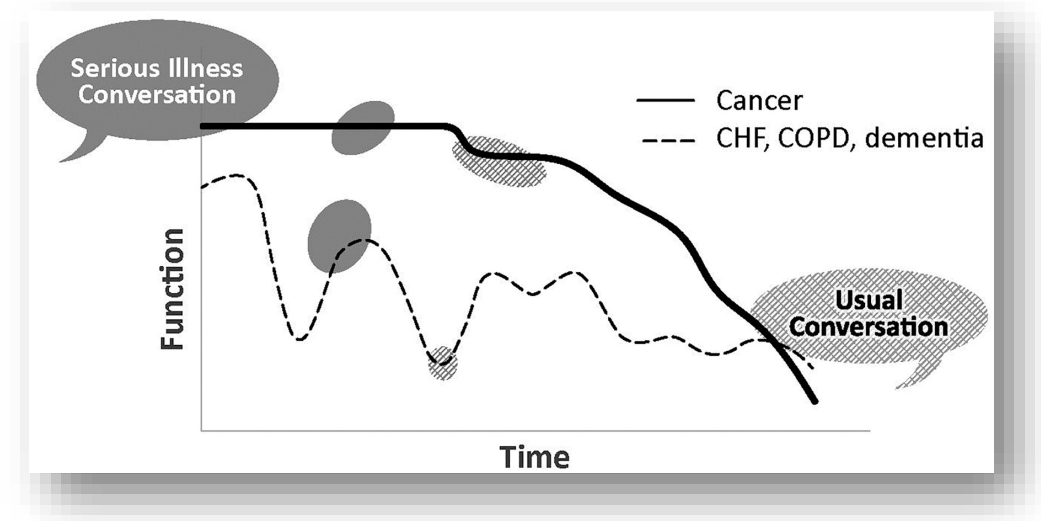
https://www.youtube.com/watch?time_continue=11&v=45b2QZxDd_o

Early Conversations

Early conversations about patient values and goals linked to better serious illness care

- Increased goal-concordant care
- Improved quality of life / patient well-being
- Fewer hospitalizations
- More and earlier hospice care
- Better patient and family coping

(Mack et al.,2010; Wright et al.,2008; Chiarchiaro et al., 2015; Detering et al.,2010; Zhang et al., 2009)

Failure to Recognize and honor patient's values and goals associated with harm

- Poor quality of life and unnecessary physical and emotional suffering for patients

- Increased family distress

- Poor alignment of medical care with patient wishes

- Prolonged, undesired hospitalizations and ICU stays

- Distress among clinical staff

- Harm of not getting benefits of conversations

- Harm of getting unwanted care

Wright et al., 2008; Wright et al., 2010, Teno et al., 2007, Teno et al., 2004, Wright et al., 2016

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The Knowing Doing Gap

Earlier conversations about patient goals and priorities are associated with **enhanced goal concordance, improved quality of life, reduced suffering, better patient and family coping, higher patient satisfaction and less non beneficial care and costs.**

(Mack, 2010; Detering, 2010; Wright, 2008; Zhang, 2009.)

If we know earlier conversations are associated with better outcomes, what changes are needed?

Evidence Based Intervention

Written for and Endorsed by the American College of Physician High Value Care Task Force **:**

A System Approach to Serious Illness Communication

Special Communication

Communication About Serious Illness Care Goals
A Review and Synthesis of Best Practices

Rachelle E. Bernacki, MD, MS; Susan D. Block, MD; for the American College of Physicians High Value Care Task Force

1. Mechanisms to **identify patients** who would benefit from a SI conversation

2. Prompts to **remind clinicians** to engage in SI conversations at the right time

3. Use of **structured communication guide**

4. Serious Illness (SI) **Communication Training**

5. Patient and family **education**

6. A system for **documenting personalized patient goals and priorities** in the electronic health record

SI Operational Definition

*"Disease(s) that carry **a high risk of mortality** and either **negatively impacts a person's daily function or quality of life,** or **excessively strains the caregiver.**"*

(Kelley & Bollens-Lund, 2018)

The Denominator Challenge

- **Diagnosis**
  - Dartmouth Atlas of Healthcare **9 serious chronic conditions accounts for 90% of death**
    - Modified above criteria to find most severely ill

- **Utilization**
  - Inpatient

- **Measures of Need Domains: high need if 2 or more of following are positive**
  - Functional dependence
  - Nutritional decline
  - Cognitive impairment
  - Pain limiting symptoms
  - Caregiver strain

1 Serious Medical Condition³ (18% of total FFS population)

Hospitalization in past 6 months (7% of total FFS pop)

Outcomes in 1 year			% of group that is:		
Total Medicare Costs, mean	Hospital Stay	Death	Top 10% costs	2+ needs screen	ADL Impairment
$30,489	53%	25%	37%	82%	67%

Adjusted C- statistic adjusted death within 1 year .78 (Bollens & Kelley Lund, 2018)

1 Serious Medical Condition³ (18% of total FFS population)

Hospitalization in past 6 months (7% of total FFS pop)

Dependent for 1 or more Activities of Daily Living (4% of total FFS pop)

Outcomes in 1 year			% of group that is:		
Total Medicare Costs, mean	Hospital Stay	Death	Top 10% costs	2+ needs screen	ADL Impairment
$34,425	58%	30%	42%	95%	100%

Adjusted C- statistic adjusted death within 1 year .77 (Bollens & Kelley Lund, 2018)

Serious Illness Criteria

Consider SI conversation if patient meets ANY of the following criteria:

Disease Based Criteria

Inpatient admission in last 6 months & one of the following:

- Chronic obstructive pulmonary disease or interstitial lung disease, only if using home oxygen or hospitalized for the condition
- End stage renal failure
- Congestive heart failure, only if hospitalized for the condition
- Advanced liver disease or cirrhosis
- Progressive metastatic cancer
- Diabetes with severe complications (ischemic heart disease, peripheral vascular disease and renal disease)
- Advancing dementia with evidence of advanced disease

Page 3
TRIGGERS FOR SERIOUS ILLNESS CONVERSATIONS

Disease-based/Condition-based criteria

- Chronic obstructive pulmonary disease or interstitial lung disease, only if using home oxygen or hospitalized for the condition
- End stage renal failure
- Congestive heart failure, only if hospitalized for the condition
- Advanced liver disease or cirrhosis
- Progressive metastatic cancer
- Advancing dementia
- Complex medical conditions resulting in frequent unplanned hospital or ED admissions

Additional criteria

- Two or more unplanned hospital admissions within past 6 months
- Resides in long term care facility
- Significant and rapid decline in ability to complete activities of daily living

Surprise question

- Would you be surprised if this patient died in the next 1-2 years?

# Roles and Responsibilities

RNs/SWs/Chaplains/MDs/APRNs/PAs	MDs/APRNs/PAs ONLY
▪ Introduce the goals of care conversations	▪ Deliver news about diagnosis and prognosis
▪ Discuss role of the surrogate	▪ Establish a Life Sustaining Treatment plan with patient (or surrogate)
▪ Elicit understanding of diagnosis and prognosis	▪ Complete Life Sustaining Treatment ST Progress Note and Orders
▪ Elicit patient's values, goals	
▪ Provide basic information about LSTs & services	
▪ Document the conversation	

Care Team Positioned to Initiate SI Conversations

- **Longitudinal relationships** with patients and families
- Ambulatory case managers – **ideal timing** – non urgent situation
- Ability to go **upstream** to help **inform** serious illness plan of care
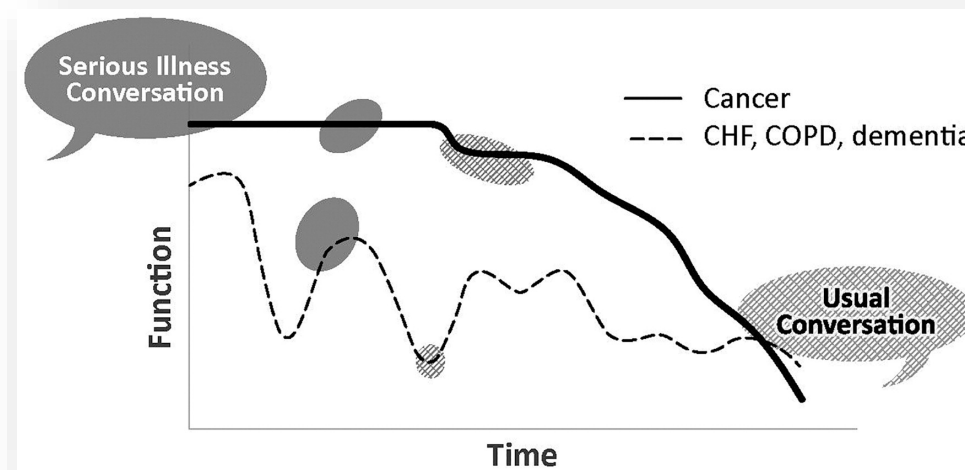
Communication Skills

"The single biggest problem in communication is the illusion that it has taken place."

- George Bernard Shaw

Take a Moment

- Think about an instance in which you cared for or interacted with a patient (or family member) with a serious life limiting illness.

- Reflect on how your communication skills had a positive or negative impact on the experience or outcome.

- Jot down a few key thoughts

Key Communication Skills

1. Open Ended Questions
2. Reflective listening
3. Exploring
4. Affirmations
5. "I wish" statements

Shift in Perspective

- Believe in the patient's ability to make difficult decisions

- Allow the patient to discover their own understanding

- View as a listening and learning conversation not a teaching conversation

https://www.vitaltalk.org/topics/establish-rapport/

32
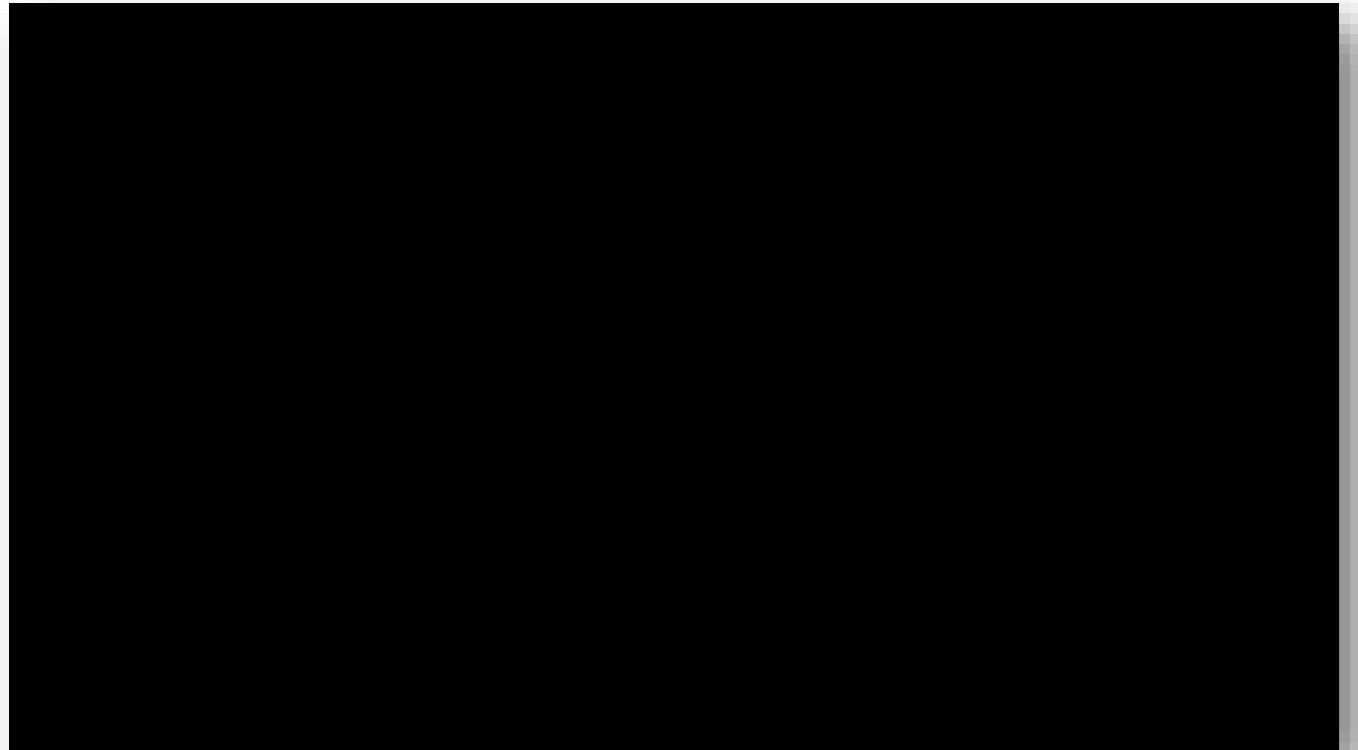
Questions Can Signal Emotion

- Watch for questions that are expressions of emotion:
  - "Isn't there something else they can do for the cancer?"
  - "Why is this happening to me?"

- Respond to the **emotion with empathy** rather than responding to the **question with facts**
  - "It must be so hard to be going through this."

https://www.ethics.va.gov/GoCC.asp

Recognizing Ambivalence

Ambivalence is having two conflicting desires

"I don't want to live like this. The treatment leaves me with no quality of life. "

" My husband is not ready to let me go so I can't stop treatment."
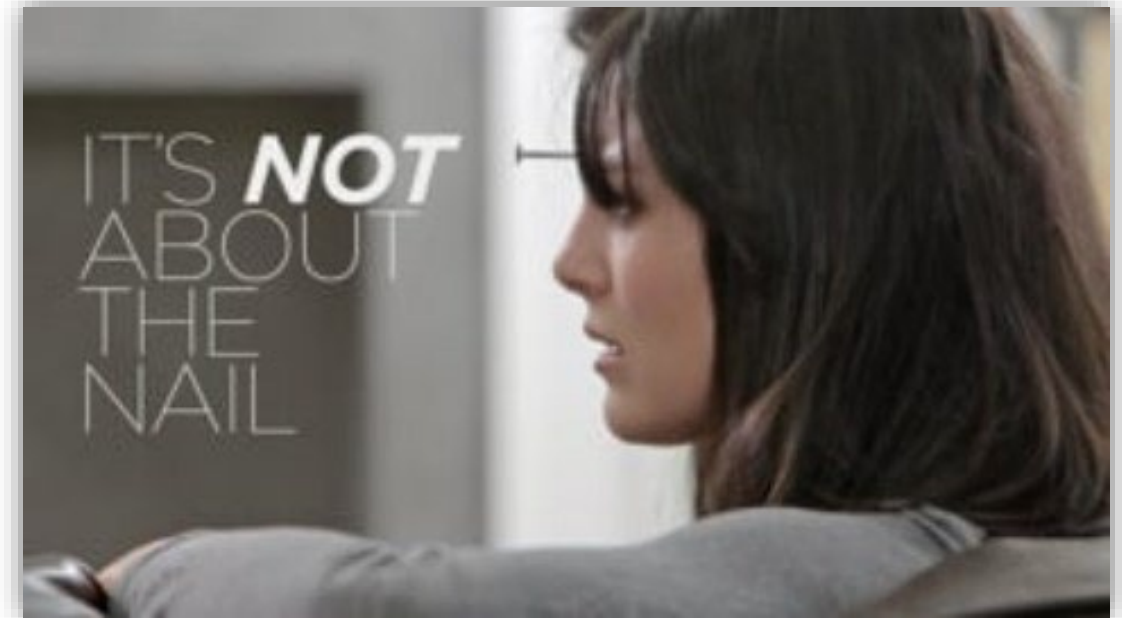
Open-Ended Questions

- Elicit the patient's own knowledge, language, understanding and/or feelings

- Elicit details rather than one-word answers

  - "How has your health affected your day-to-day life?"

  - "You mentioned you have heart failure; what is your understanding of that disease?"

https://youtu.be/fj5uUoNAtZU

https://www.ethics.va.gov/GoCC.asp

Reflective Listening

- The skill of listening carefully to another person and repeating back to the speaker the heard message to correct any inaccuracies or misunderstandings.

  - "It sounds like ….."
  - "It seems as if …."
  - "What I hear you saying …."
  - I get a sense that ….
  - "It feels as though…."
  - "Help me to understand. On the one hand you…. And, on the other hand…."

https://www.google.com/search?q=communication+the+nail&oq=communication+the+nail&aqs=chrome..69i57j0.3423j1j7&sourceid=chrome&ie=UTF-8

https://www.ethics.va.gov/GoCC.asp

Simple Reflections

Repeating or paraphrasing patient's statements

- Encourage continuation
- Confirm understanding
- Reinforce concepts or knowledge

PATIENT: "My breathing is bad – I can't walk as far as I used to, and I have to wear oxygen all the time now."

SIMPLE REFLECTION: "Your breathing has really been giving you a hard time."

DAUGHTER: "My mom was resuscitated and ended up on machines. I couldn't stand seeing her like that."

SIMPLE REFLECTION: "You have seen someone close to you need machines to stay alive."

Complex Reflections

- Interpret patient's statements
- Validate feelings
- Explore deeper meaning

PATIENT: "I don't want to come to the hospital anymore, but it makes my breathing feel a lot better."

Complex Reflection CLINICIAN: "You're feeling conflicted."

PATIENT: "My doctors keep telling me there is no way to know if my cancer treatments are working. They won't know anything until my next scan. Why do we have to wait so long?"

Complex Refection CLINICIAN: "It sounds like it's really hard to live with the uncertainty."

Exploring

Seeks more information

- Clarifies meaning

- Builds deeper understanding

  - "Tell me more…"

  - "What else?"

  - "What do you mean when you say 'live independently?

https://www.ethics.va.gov/GoCC.asp

https://www.vitaltalk.org/topics/establish-rapport/

Affirmations

- Recognize strengths & acknowledge positive behavior
- Build rapport & patient's confidence

PATIENT:

"I'm a fighter, I know I can beat this thing."

CLINICIAN:

"You've been so strong through so much."

CLINICIAN:

"You're saying this is difficult to talk about, and yet you came to today's appointment anyway."

"You have shown so much support for your dad."

"I Wish" Statements

- Recognize patient's hope
- Align with the patient
  - "I wish you didn't have to deal with these lung problems."
  - "I wish we had more effective treatments."
  - "I hope for a miracle, too."

  https://www.ethics.va.gov/GoCC.asp

https://youtu.be/gcJE2pK4Uyg

KEY SKILLS AND SAMPLE STATEMENTS

Affirmation Acknowledging patient's strengths and abilities	Reflection		Exploring Encouraging patient exploration	"I wish" Aligning with the patient's experience
	Simple Restate or rephrase what patient says	Complex Interpretation such as naming feelings		
You are such a (strong, committed, caring) person.	This is really important to you.	You can't imagine discussing this with your son, but at the same time you're worried about how this could affect him later.	What do you mean when you say I don't want to give up (be a vegetable/ a burden/ on life support)?	I, too, hope that _____ happens.
You (or your dad, mom, child, spouse) are such a strong person, and have been through so much.	You just aren't ready to discuss this yet.	One of the hardest things for you is all the uncertainty. On one hand,_____, and on the other,_____.	What else?	I wish things weren't so stressful for your family.
This is very difficult to think about, and yet you are still willing to talk to me about it.	So _____ has been the most difficult symptom for you to deal with.	This sounds frustrating (scary, overwhelming, difficult, challenging, hard).	Tell me more...	I wish the situation were different.
You have done so much to try to manage your illness (help your loved one with their illness).	Dealing with this illness has been such a big part of your life and has taken so much energy.	Other people in your situation have told me this feels very (name emotion).	Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you.	I hope for a miracle, too.

https://www.ethics.va.gov/GoCC.asp

SAMPLE RESPONSES TO CHALLENGING STATEMENTS/QUESTIONS

These statements are examples of empathic continuers. Patients may not immediately respond to your first empathic statement. It often takes multiple successive empathic responses to help patients work through strong emotion.

God's going to bring me a miracle. • I too hope that a miracle happens. (**Remember no buts!**) (**"I wish"**) • You have such a strong faith. (**affirmation**) • Having faith is very important to you. (**reflection**) • Can you share with me what a miracle might look like for you? (**exploring**)	**My dad is a fighter!** • He is. He is such a strong person and he has been through so much. (**affirmation**) • You care about your dad so much. (**affirmation**) • It must be so (**name emotion**) to see him so sick. (**reflection**) • Tell me more about your dad and what matters most to him. (**exploring**)	**Do you know something I don't know?** • Tell me more about what you are asking. (**exploring**) • You seem worried. (**reflection**) • You are wondering if there is something your doctors haven't told you. (**reflection**) • What is your understanding of where things are at with your health? (**open ended**) • This situation must be very (**name emotion**). (**reflection**)

Why are we talking about this now?
 	
• You seem worried/overwhelmed/scared. (**reflection**)
• Maybe you aren't ready to discuss this right now. (**reflection**)
• That's ok if you don't want to discuss this right now. (**affirmation**)
• You don't think this is a good time to discuss this. Tell me more about what the right time would look like. (**exploring**)
	Are you giving up on me?
	
	• It sounds like you might be feeling.... (**name emotion**)
	    ○ Alone
	    ○ Scared
	    ○ Etc.
	• We will go through this together. (**affirmation**)
	• No – I want to make sure we get you the best care possible to take care of what's going on for you now.
		Are you telling me my dad is dying?
		
		These responses will affirm the question empathically – so do not use them if the patient is not dying
		
		• I wish the situation were different. (**"I wish"**)
		• This must be such a shock for you. (**reflection**)
		• I can't even imagine how difficult this must be. (**reflection**)

https://www.ethics.va.gov/GoCC.asp

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Break Out Session (20 Minutes)

Break into teams of two. All participants will take turns **sharing their experience** (approximately 5 minutes per participant).

Each participant will provide a **brief summary of the situation** they identified at the beginning of this module.

The participant will identify **one communication skill** that could have been enhanced the discussion/outcome.   Provide your rationale for selecting that skill.

Serious Illness Communication

Structured Communication Reference Guide

What's challenging about talking to patients or families about serious illness and care near the end of life?

Dr. Susan D. Block is a Professor of Psychiatry, Chief of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute and the Co-Director of the Harvard Medical School Center for Palliative Care.

Why use a structured communication tool?

- Structure increases Confidence
- Assures adherence to key processes
- Achieve higher level of baseline performance
- Ensures completion of necessary tasks during a complex, stressful situation

From Novice

"Novices and advanced beginners can take in little of the situation-it is too new, too strange." Patricia Benner

Components of the Structured Guide

1. **Introduce** conversation and obtain permission

2. **Assess** understanding of health status

3. **Elicit** values and goals for care
   - If you were to get sicker, what would be most important to you?
   - What concerns or worries do you have?
   - How much are you willing to go through for the possibility of more time?

4. **Make a plan**
   - How much does your family, doctor know about your wishes?
   - What documents do you have in place?

5. **Summarize and close**

Eliciting Patient Goals, Values and Preferences for Serious Illness Care

And in stories, endings matter.

COMMUNICATION REFERENCE GUIDE

October 2020
Mary Elizabeth Billie, DNP, RN-BC, CCM
Maryebillie@gmail.com

(Bekelman et al., 2017)

Step 1: Introduce Conversation

- Purpose
- Orient the patient to the purpose of the discussion

- Create a safe environment for discussion of values, goals and preferences

- Obtain patient agreement to engage in the conversation.

STEP 1: INTRODUCE CONVERSATION

Sample Scripting: Mr./Mrs. XXX. Thank you for taking the time to speak with me today. I would like to discuss how we can provide care that lines up with what's most important to you. It would be beneficial to understand what your goals and preferences are for health care if you were to become sicker or at the end of your life and to help make a plan to make those things happen.

Alternative Scripting: Mr./Mrs. XXXX. Thank you for taking the time to speak with me today. I would like to discuss how I could make sure you have the best care possible. To do this it would be good to talk about what is happening with your health and what things are important to you. Is that okay?

If any resistance: _We know these conversations are hard, and you might not know all of the answers today but we at least want to start the conversation. Ideally, by the end of the time we work together we will have talked about and made a plan to help you make those things happen._

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Recognizing Resistance

Resistance occurs when we expect or push conversation content when the patient isn't ready

- *"I already wrote everything down 20 years ago in my advance directive."*

- *"I don't see why I need to talk about this right now."*

Strategies for Common Scenario's

Patient says: "I don't want to talk about it"
- *Help me understand the reasons you would prefer not to talk to talk about this?*
- *I'd like to understand what kind of thinking and planning you would find helpful as we think about what is ahead with your illness.*
- *I hear you saying you know it is important to do some planning and also that you worry this process will be too overwhelming.*

Patient says: "My daughter (family member) takes care of all of this for me."
Ask if patient has a POAHC for family member to make decisions.
- *"These are difficult discussions and should involve your family. Would you like to schedule time to talk together?"*

Patient says they are not ready to make any decisions
- *Reassure patient there is time to think things through. I brought up these issues early so you would have time to think about what's important you.*

Step 2: Assess Understanding of Health

- **Purpose**

  Understanding of condition or prognosis is necessary to make informed decisions about goals and treatments; assessing this helps identify & fill knowledge gaps

- **How**
  - Explore patient's understanding, any changes they have experienced to their health

  - **Do not provide information beyond your scope** - refer questions to appropriate practitioner

    "Tell me what you understand about your COPD."

STEP 2: ASSESS UNDERSTANDING OF HEALTH

What have you been told to expect in the future with your (insert their words for their illness)?

Alternative phrasing:
To make sure we are on the same page, can you tell me your understanding of what is happening with your health at the moment?

What changes have you noticed over the past 3 months?

What have your providers said you might expect in the future with your medical condition?"

Probes
- *"What do you think the future holds?"*
- *If applicable, "I am not raising this issue because we are worried you are getting sicker right now, it can be helpful to think about the future."*

IF INADEQUATE UNDERSTANDING OF MEDICAL CONDITION: "It may be helpful to talk with your provider more about your medical condition."

(Bekelman et al., 2017)

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Let's Listen

REFLECT · **QUESTION** · **OBSERVE**

Share

- How did the clinician deal with the patient's resistance?

- Other observations or comments?
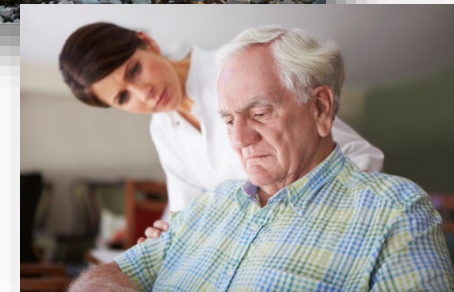
Step 3: Elicit Values & Goals of Care

- **Purpose**
  The patient's values and goals serve as the basis for the care plan

- **Values:** What matters to patient?

- **Goals of care:** What does the patient want their health care to help them accomplish or avoid?

- **Fears:** What is the patient worried about, with respect to their health?

Step 3: Eliciting, Exploring Values and Goals

- **Start with a broad question about values**
  - "What is important to you in your day to day life?"
  - "What else?"
  - Ask about goals
- **"What do you hope for with your medical care?"**

STEP 3: ELICIT VALUES AND GOALS OF CARE

If you were to get sicker, what would be most important to you?

Alternative phrasing
What matters most to you as you think about the future?
Is there anything that would be helpful for me to know about your religious or spiritual beliefs?

What do you hope for with your medical care?

Remember : Silence isn't empty- it's full of answers.

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(Bekelman et al., 2017)

Step 3: Eliciting, Exploring Values and Goals

- Ask about fears/concerns

  "Is there anything you're worried about as you think about the future with your illness?"

Concerns and Worries

As you think about the future with your health, what are you most worried about?

Listen for:

- Being a burden
- Being in pain or uncomfortable
- Prolongation of dying
- Not being in control or not being mentally aware
- Leaving loved one's behind

(Bekelman et al., 2017)

Step 3: Eliciting, Exploring Values and Goals

- **Explore trade off for more time**
  - Throughout, explore to fully understand:

  "You mentioned 'quality of life', tell me what "quality of life' means to you."

STEP 3. ELICIT VALUES AND GOALS OF CARE (cont.)

All of us at some point will reach the end of our lives and different people want different things at that time. Some people are at one end of the scale where they want to focus on comfort and quality of life, and other willing to have their lives be shortened to be more comfortable.

Other people are on the other end of the scale where they want to live longer no matter what treatments or procedures they would need?

When you think about the scale, where are you?

Alternative phrasing

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

(Bekelman et al., 2017)

Step 4: Make A Plan

- **How much does your family know about your wishes?**

- **How much does your doctor know about your wishes?**

- **What documents do you have in place about your priorities and wishes?**

(Bekelman et al., 2017)

STEP 4: MAKE A PLAN

How much does your family know about your priorities and wishes?
- *If family knows a lot, affirm benefits of good communication and ensure HCPOA set up*
- *If family doesn't know a lot, troubleshoot barriers and perhaps role model discussion with family members. Educate about HCPOA.*

How much does your doctor know about your priorities and wishes?
- *If doctor knows a lot, affirm benefits of good communication and ensure HCPOA set up*
- *If doctor doesn't know a lot, ask how much they would like their doctor to know. Educate about the importance of doctor being aware of wishes.*

What documents do you have in place about your priorities and wishes?
- *If they have document in place, ask if they are in their medical chart?*

Step 5: Summarize

- Summarize and check for accuracy
  - Patient's understanding of medical condition(s)
  - Goals
  - Concerns

STEP 5: SUMMARIZE

We want to make sure we heard you correctly so I'm going to summarize our plan.

- What is most important to you?
- Who do you need to talk to about what is important to you?
- What forms do you need to complete?

(Bekelman et al., 2017)

Step 5: Summarize

- Summarize and check for accuracy
  - Patient's understanding of medical condition(s)
  - Goals
  - Concerns

(Bekelman et al., 2017)

STEP 5: SUMMARIZE

We want to make sure we heard you correctly so I'm going to summarize our plan.

- What is most important to you?
- Who do you need to talk to about what is important to you?
- What forms do you need to complete?

Step 6: Close

- What are your thoughts about how this conversation went?

- We covered some important topics today and you might want to talk more. Please feel free to contact me.

(Bekelman et al., 2017)

STEP 6: CLOSE

What are your thoughts about how this conversation went?

Probes:
- How did this conversation make you feel?
- What were some of your thoughts about what we talked about today?
- Did our conversation bring up things for you to think about that were hard to talk about?

We covered some important topics today and you might start thinking about things later. If you do and would like to talk more, please feel free to contact us/me.

Step 7: Document Conversation

- **Discussion Date: MM/DD/YYYY**
    - Patient completed a(n) in-person/telephone interaction. (Chose one)
    - The patient spoke with the nurse/ social worker to discuss goals of care and advance care planning. *(Choose one)*

- **Patient stated understanding of Health Condition: (use "quotes" as much as possible):**

    i.e. I am getting sicker, I have been in the hospital more this last year, my doctors hasn't really said anything specific but I think I am getting worse

- **The following topics were discussed (*use "quotes" as much as possible*):**
    - Values/important goals if patient were to get sicker: *(from Care Goals worksheet for example, maximize function, not suffer, don't let family be present)*
    - Biggest concerns/worries: *(i.e., suffocating from COPD, being in high levels of pain, moving into a SNF)*

- **Optional if discussed**: End of life preferences were also discussed with the patient and s/he expressed the following

Putting It All Together

- Observe: What communication skills did you see the clinician use?

- Share other observations or reflections.

Role Play Exercise

all progress takes place outside the comfort zone.

Instructions: Break Out exercise

- Each group has a previously assigned facilitator

- There is one Serious Illness Conversation Scenario (20 minutes)

- Facilitator role plays the patient and stops at defined points to engage in the group in discussion

- Participants will take turns playing the clinician utilizing their guide. Participants will use a round robin to move through each of the following components
  1. Introduce
  2. Assess Understanding of health
  3. Elicit values and goals of care (priorities if they get sicker, worries, tradeoffs)
  4. Make a plan (physician, family)
  5. Summarize & close (establish next steps)

- Brief report out back to main group- what worked well?   What were the challenges?

Practice Case 1

SETTING: Clinic, one month after hospitalization for COPD exacerbation.

- Mr. Smith is a 68-year-old retired salesperson
- Chronic Obstructive Pulmonary Disease (COPD), on steroids and home oxygen; diabetes; chronic kidney disease; chronic hip pain
- Three hospitalizations this year (COPD exacerbations)
- Two ED visits (fall, med refill)
- Worsening shortness of breath, muscle weakness, fatigue
- Declining functional status at home, despite short stays in rehab after each hospitalization
- Spouse very involved, 28-year-old daughter lives locally

https://implementation.aria.ariadnelabs.net/aria2/resources/

Practice Case 1

- The goal of the discussion today is to use the Structured Communication Guide to explore Mr. Smith's values, goals and priorities for care in the setting of illness progression.

- As you prepare to speak with Mr. Smith, you consider the following:

  - Mr. Smith has COPD and multiple co-morbidities (diabetes, kidney disease, chronic hip pain)

  - Given the hospitalizations and declining functional status, you are worried that he will have a harder time managing at home and that something serious could happen quickly, so you want to begin a conversation.

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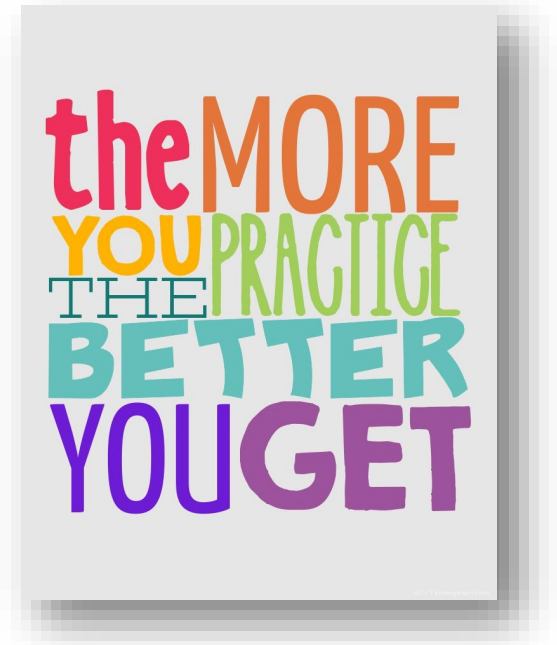
Closing Reflection

"If to be human is to be limited, then the role of caring professions and institutions—ought to be aiding people in their struggle with those limits. Sometimes we can offer a cure, sometimes only a salve, sometimes not even that.

But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it, the good we do can be breathtaking."
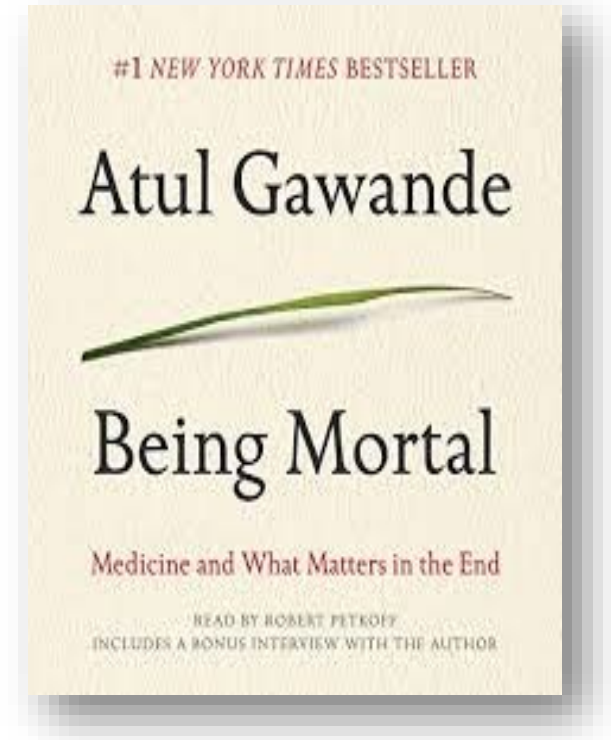
Atul Gawadne Being Mortal: Medicine and What Matters in the End.

Learning Objectives Recap

- Identify factors in the US healthcare system that contribute to deficiencies in Serious Illness communication.

- Describe key SI communication concepts and strategies that can be undertaken to improve serious illness communication.

- Identify communication skills that have been demonstrated to be most applicable for Serious Illness Conversations.

- Define the components of an evidence-based Serious Illness Communication guide.

- Utilize serious illness communication skills and structured communication guide in role play.

Additional Resources

Bekelman et al., 2017	Provides a Structured Goals of Care Communication Guide for nurses and social workers.	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5576094/
Ariadne labs, joint innovation of Brigham and Women's Hospital and Harvard T.H. Chan School of Public Health.	Provides comprehensive resources including a Serious Illness Conversation Guide, a Serious Illness Clinician Reference Guide, Serious Illness training program resources and patient and family resources.	https://www.ariadnelabs.org/areas-of-work/serious-illness-care/
US Department of Veterans Affairs, 2017 Life Sustaining Treatment Decision Initiative (LSTDI).	Includes comprehensive serious illness training materials and resources for patients, nurses, social workers, chaplains, physicians, advance practice professionals and physician assistants.	https://www.ethics.va.gov/goalsofcaretraining/Practitioner.asp

Questions?

Thank you

Acknowledgements

This presentation includes material adapted from and with permission from:

- Veteran's Administration Life Sustaining Treatment Decision Initiative (LSTDI)

- Serious Illness Conversation Program (SICP) Ariadne Labs

- Veterans Affairs Eastern Colorado Health Care System, Denver, Colorado

Acknowledgements

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Michigan Center for Clinical Systems Improvement

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- Sue Vos, BSN, CCN, RN – Program Director

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- Pauline Virro-Nic, MS, MBA, PMP – Project Manager

Practice Transformation Institute

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- Harmony Kinkle, BBA – Director of Operations

Sponsor

Blue Cross Blue Shield of Michigan

- Faris Ahmad, MD, MBA – Medical Director, Provider Engagement

- Sharon Kim, MPA – Health Care Manager, Value Partnerships

Acknowledgements

Special thanks to our content development partners

- Mary Beth Billie, DNP, RN-BC, CCM

- Ellen Fink-Samnick, MSW, LCSW, CCM, CCTP, CMHIMP, CRP, DBH-C

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- David Van Winkle, MD, MBA – Family Medicine

- Erin Zimny, MD – Emergency Medicine/Hospice and Palliative Care
  Henry Ford Health System

Acknowledgements

Special thanks to our video contributors:

Interview and roundtable discussion

- Faris Ahmad, MD, MBA
  Blue Cross Blue Shield of Michigan

- Kathryn D. Bartz
  Michigan Community Visiting Nurses Association

- Anthony Clarke, MD
  Health Centers Detroit

- Kim Farrow, MD
  Detroit Integrated Health

- Elizabeth Haberkorn, MSN, FNP, BC
  Judson Center Family Health Clinic

- Imam Kamau Ayubbi
  Michigan Medicine

- Charles Kibirige, MA, MDIV, BCC
  Henry Ford Health System

- Gregg Stefanek, DO
  Dow Family Health Center

- Lori Zeman, PhD, LP, ABPP
  Beaumont Family Medicine – Sterling Heights

- Erin Zimny, MD
  Henry Ford Health System

Video filming and producing

Bureau Detroit

- Julie Banovic

- Anthony Morrow

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