SERIOUS ILLNESS CONVERSATIONS

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Serious Illness (SI) Communication Program

- Developed and implemented at Loyola Health System part of DNP Program Loyola University (2019)
- Since trained over 300 case managers in multiple health systems and payer organizations

Industry interest and dissemination

- Professional Case Manager, July, 2020
- Hospital Case Manager (Relias, Inc., 2019)
- Poster presentations CAPC (2019); Chicago CMSA (2019, 2020)
- CMSA Chicago, Grand Rapids, Detroit and MiCCSI (2020)
- Integrated into Benedictine University BSN completion program (2020)
- Presented at National CMSA Conference (2020); AAACN annual conference (2021); American Case Management PA Chapter Conference, (2021); Chicago CMSA Conference (2021)

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.

VA | U.S. Department of Veterans Affairs
Veterans Health Administration
National Center for Ethics in Health Care

VA Eastern Colorado Health Care System

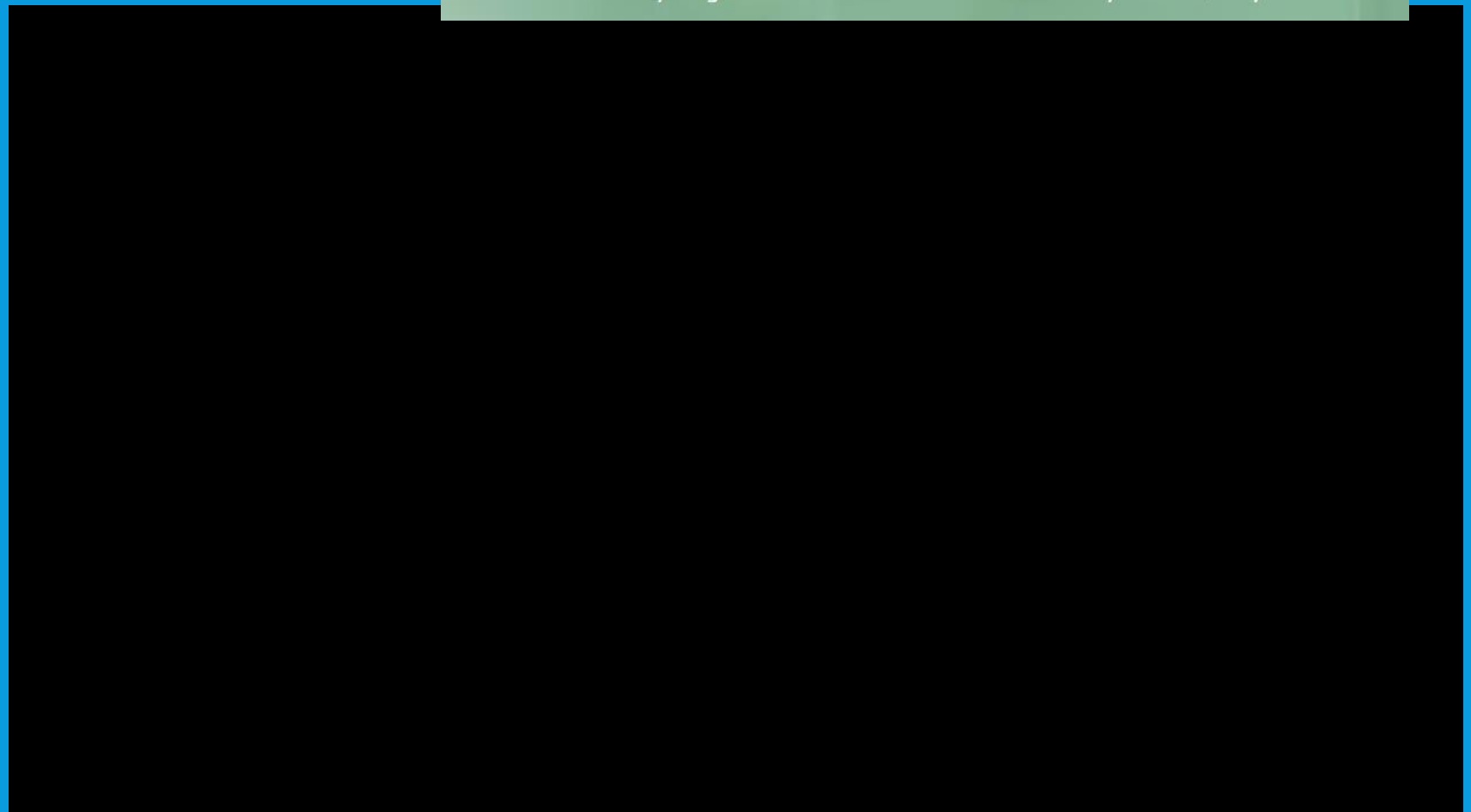
ARIADNE LABS
BRIGHAM AND WOMEN'S HOSPITAL | HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH

OBJECTIVES

1. Describe how Serious Illness (SI) Conversations relates to Case Management practice and aligns with ethical case management principles.
2. Define the six components of a Serious Illness Conversation.
3. Describe three key communication skills that are important for SI conversations.
4. Identify one action you can implement in your practice to support SI conversations.

LET'S BEGIN: MOUNT SINAI HOSPITAL, NEW YORK

FRONTLINE
"Facing Death" | Excerpt: "Mount Sinai ICU" | PBS



https://www.youtube.com/watch?v=N4objV7cLYg

"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)

MEDICAL ADVANCES CAN EXTEND LIFE BUT…..

End of life discussions occur too late in the course of illness

- Patients with metastatic lung and colorectal cancer (n=2155)
  - First conversation about end of life occurred an average of 33 days before death
  - 15% of hospice patients are referred in their last week of life

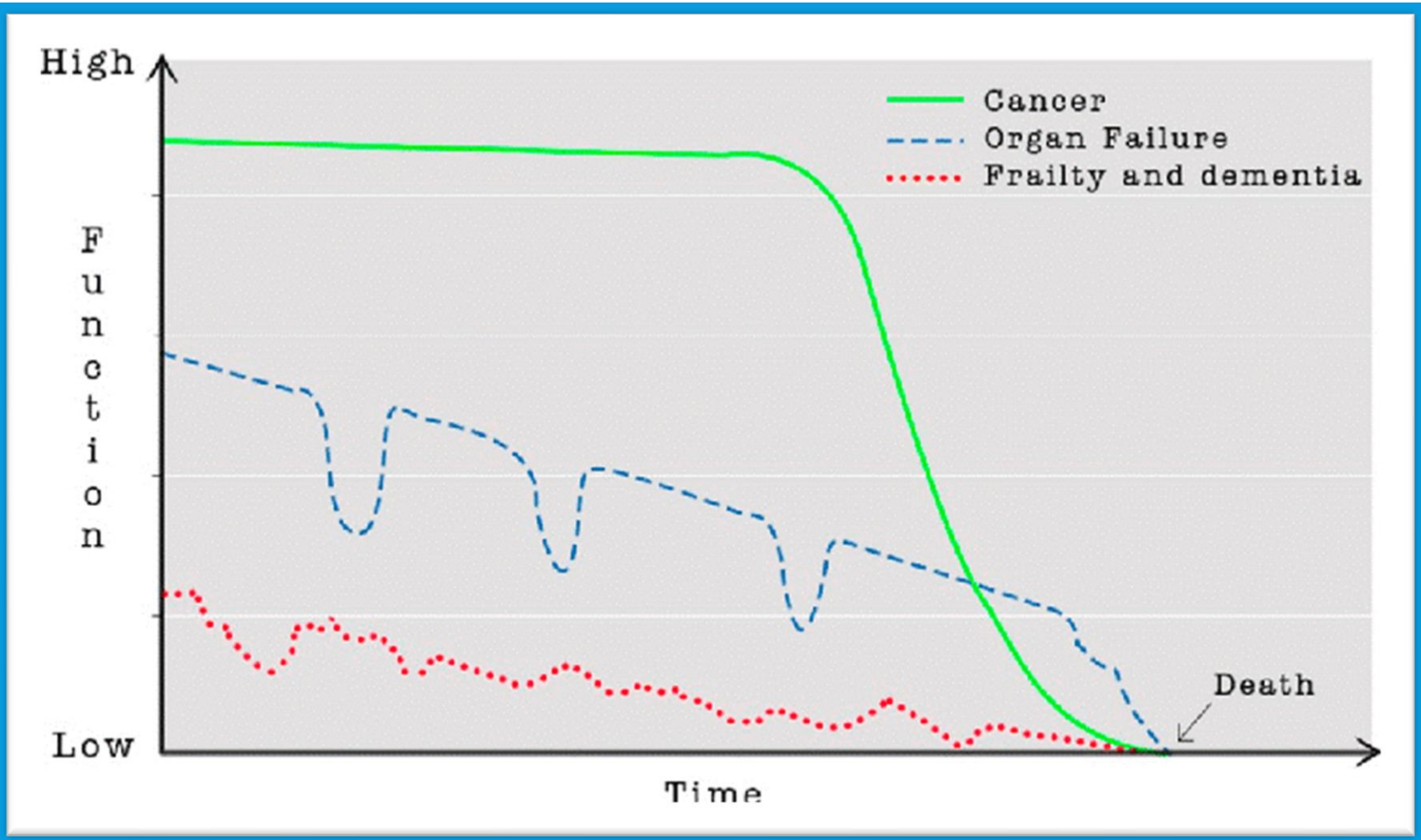
Patients (& families) often don't under the seriousness of their condition

- Patients receiving dialysis
  - 90% reported their physician hadn't discussed prognosis with them despite an annual mortality rate of 22%

More care can actually harm patients and caregivers

(Davidson, 2012; Mack et al., 2012; Teno et al., 2007, 2013; Sanoff et al., 2007)

THE WAY WE ARE DYING IS CHANGING



- Life expectancy in 1960 was 69 y.o
- Life expectancy in 2020 is 79 y.o.
- Aged 65 and older, 69% will develop disabilities before they die and 35% will eventually enter a nursing home

Lunney, Lynn, Foley, Lipson, & Guralnik, 2003

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

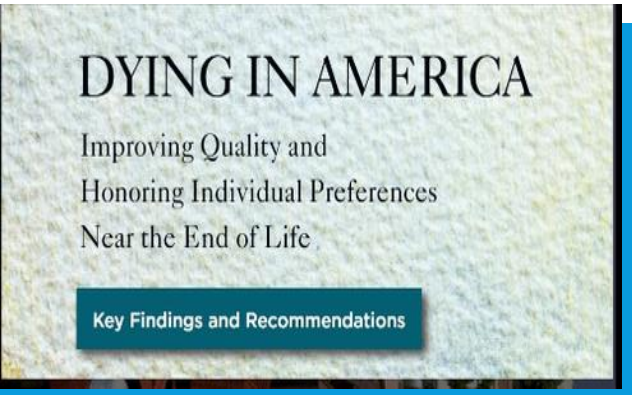
25% to 39% die in acute care hospitals

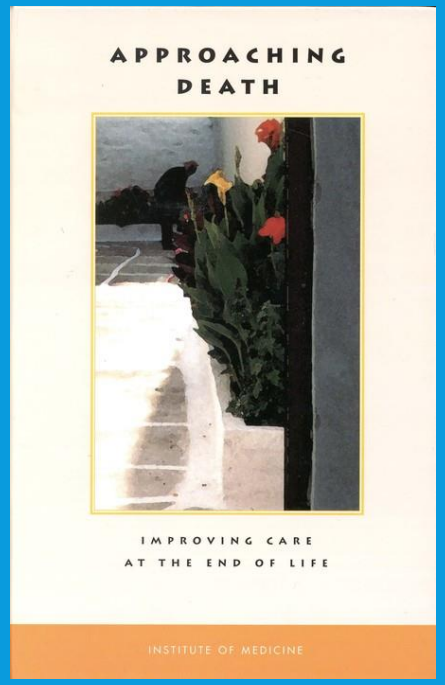
THE KNOWING DOING GAP

Evidence suggests **that *earlier conversations*** about patient goals and priorities for living with serious illness 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.)

Question: If we know earlier conversations are associated with better outcomes, what are the barriers?

INSTITUTE OF MEDICINE REPORTS (1998, 2014)



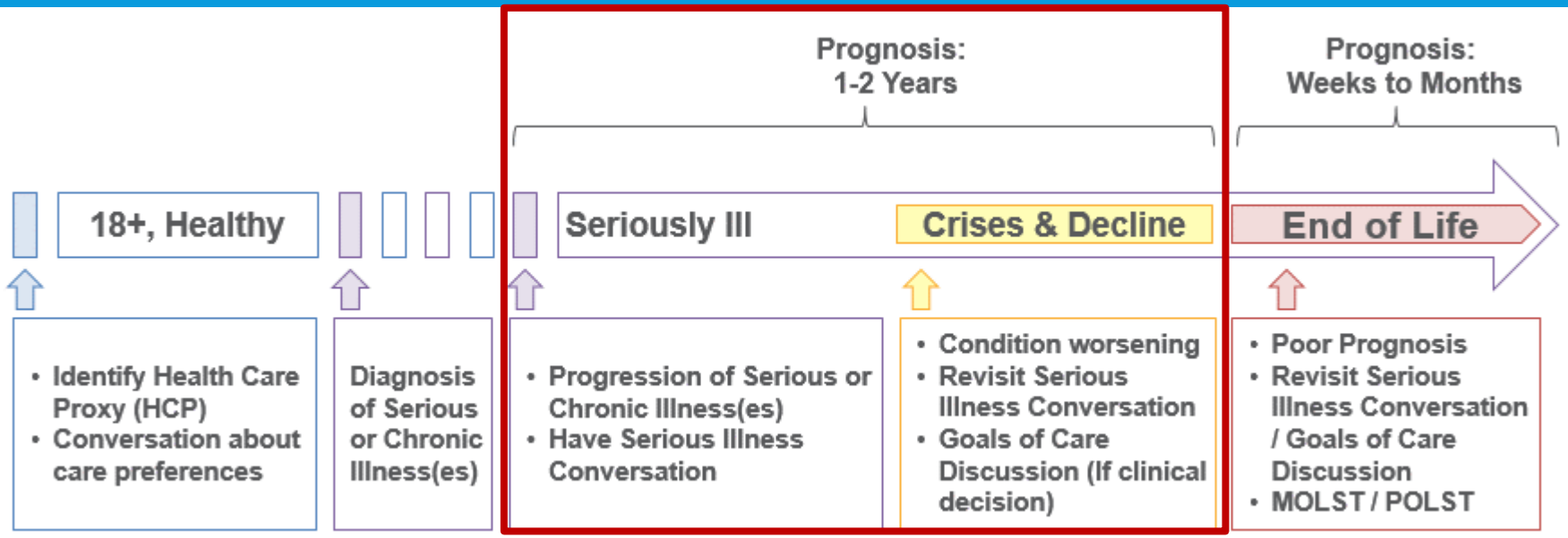


- System falls short of providing "humane" end-of-life care
  - People dying while suffering from pain/distress that could have been relieved
  - Aggressive use of ineffectual or intrusive interventions
- Education doesn't prepare clinicians with knowledge/skill for end-of- life care and communication
  - 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 conversations serious illness conversations

Scalable interventions targeted at non-palliative care clinicians

ACP TERMINOLOGY



Serious Illness - "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)

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

(Bernacki and Block, 2014)

SERIOUS ILLNESS CONVERSATION

WHAT IT IS

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.

- Often a series of conversations
- Involves patients and oftentimes families

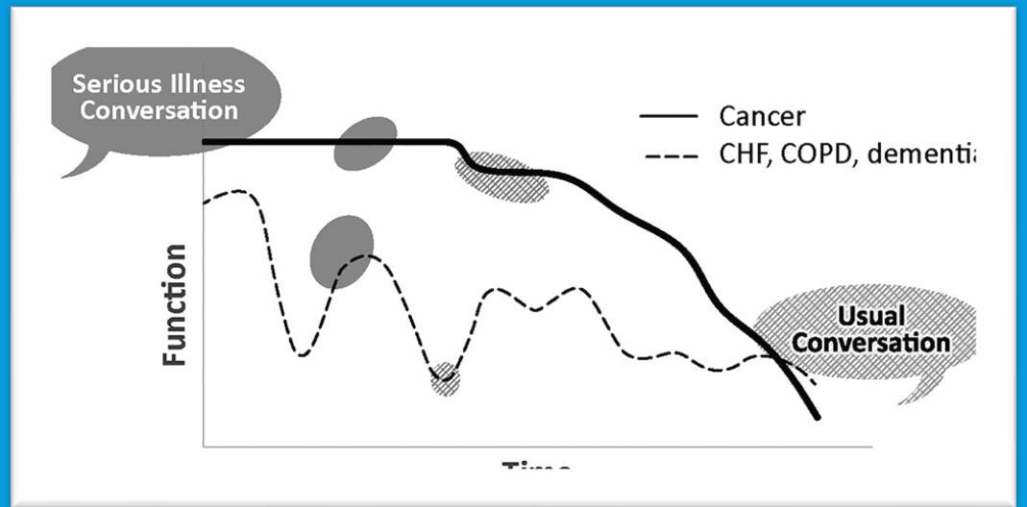
WHAT IT'S NOT

Discussion of medical treatments

Completing Advanced Directives Forms such as HCPOA and POLST forms

- CPR and DNR discussions

Referrals to Palliative Care or hospice (can be an outcome of SI conversation)



https://www.liebertpub.com/doi/full/10.1089/pmr.2020.0066

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_0

Excerpt from "How to Live When You Have to Die," featuring Atul Gawande.

ROLES AND RESPONSIBILITIES

RNs/SWs/Chaplains/MDs/APRNs/PAs

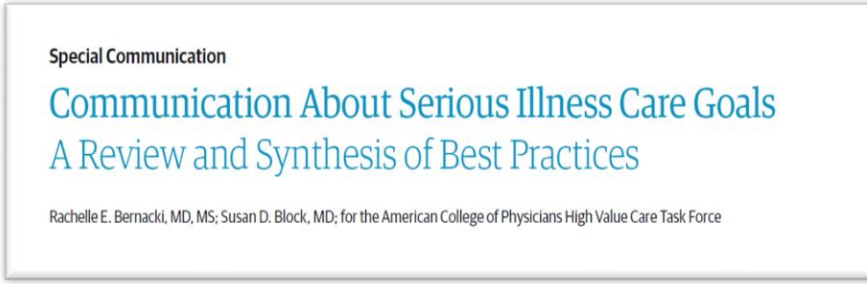
- Introduce the goals of care conversations
- Discuss role of the surrogate
- Elicit understanding of diagnosis and prognosis
- Elicit patient's values, goals
- Provide basic information about LSTs & services
- Document the conversation

MDs/APRNs/PAs ONLY

- Deliver news about diagnosis and prognosis
- Establish a Life Sustaining Treatment plan with patient (or surrogate)
- Complete Life Sustaining Treatment ST Progress Note and Orders

https://www.ethics.va.gov/goalsofcaretraining/team.asp. Updated January 24, 2018

EVIDENCE BASED INTERVENTION


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

Written for and Endorsed by the American College of Physician High Value Care Task Force :
A System Approach to Serious Illness Communication

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

(Bernacki and Block, 2014)

SI Trigger Criteria

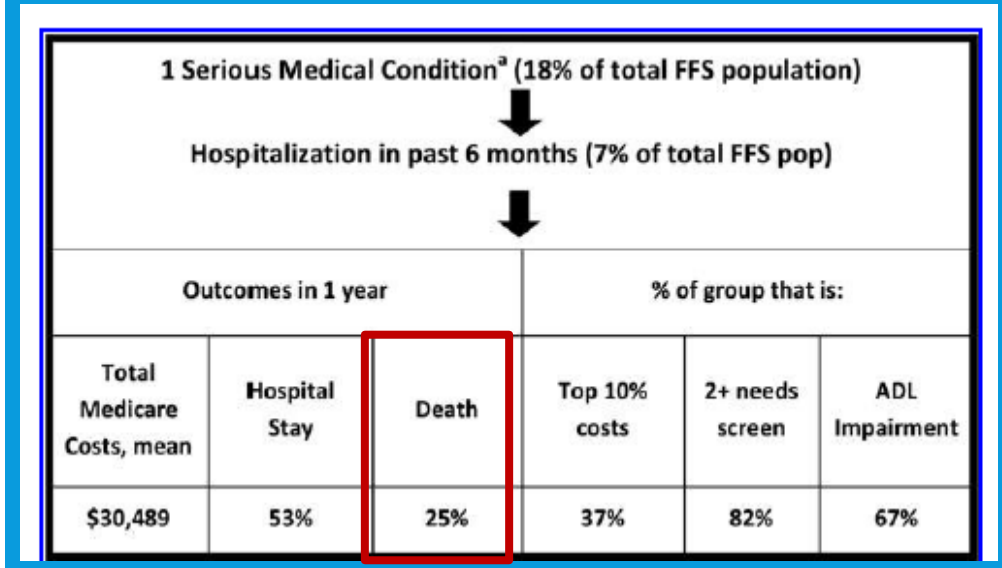
Consider SI conversation if patient meets ANY of the following criteria:

Disease Based Criteria

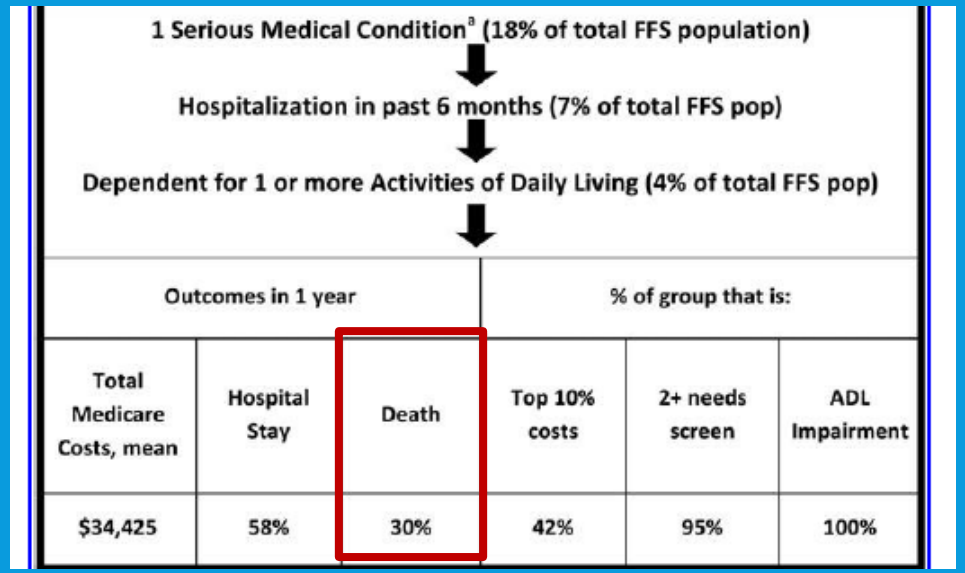
Inpatient admission in last 6 months AND one of the following:

- Cancer with poor prognosis, metastatic or hematologic
- 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
- Diabetes with severe complications (ischemic heart disease, peripheral vascular disease and renal disease)
- Advancing dementia with evidence of advanced disease

Kelley & Bollens-Lund, 2018



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



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

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.

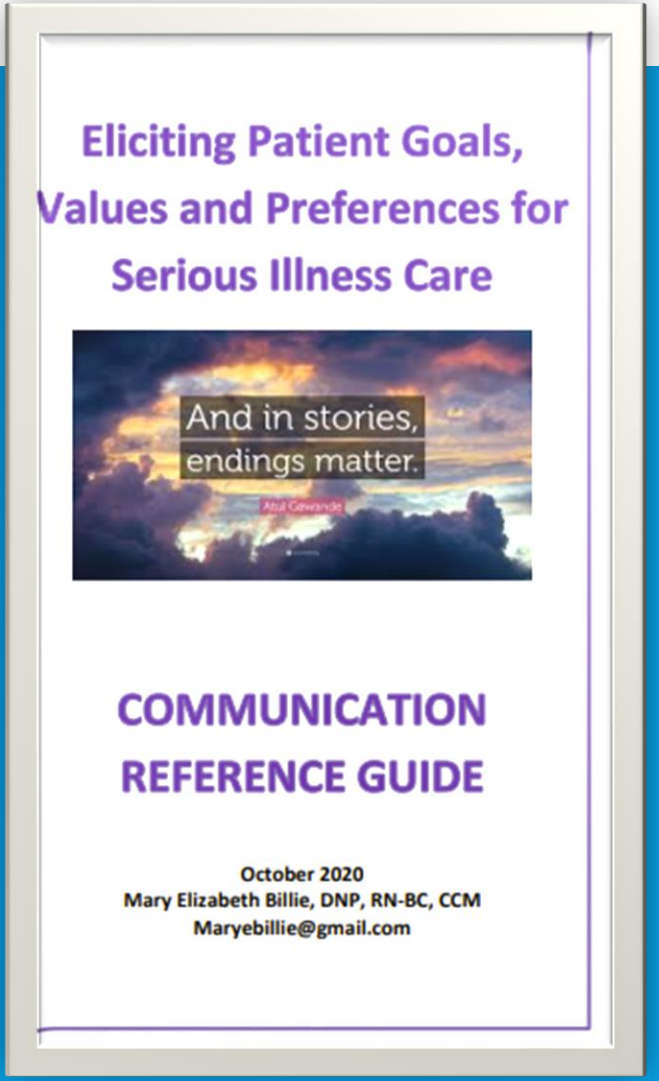
https://www.youtube.com/watch?v=mByh7f7F7a8

COMMUNICATION REFERENCE GUIDE

- Utilizes patient tested language from Ariadne and Veteran's SI communication guides
- Framework follows the six key components of a SI conversation

(Introduce, Elicit Knowledge of Condition, Elicit Preferences/Goals of Care, Plan, Summarize, & Close)

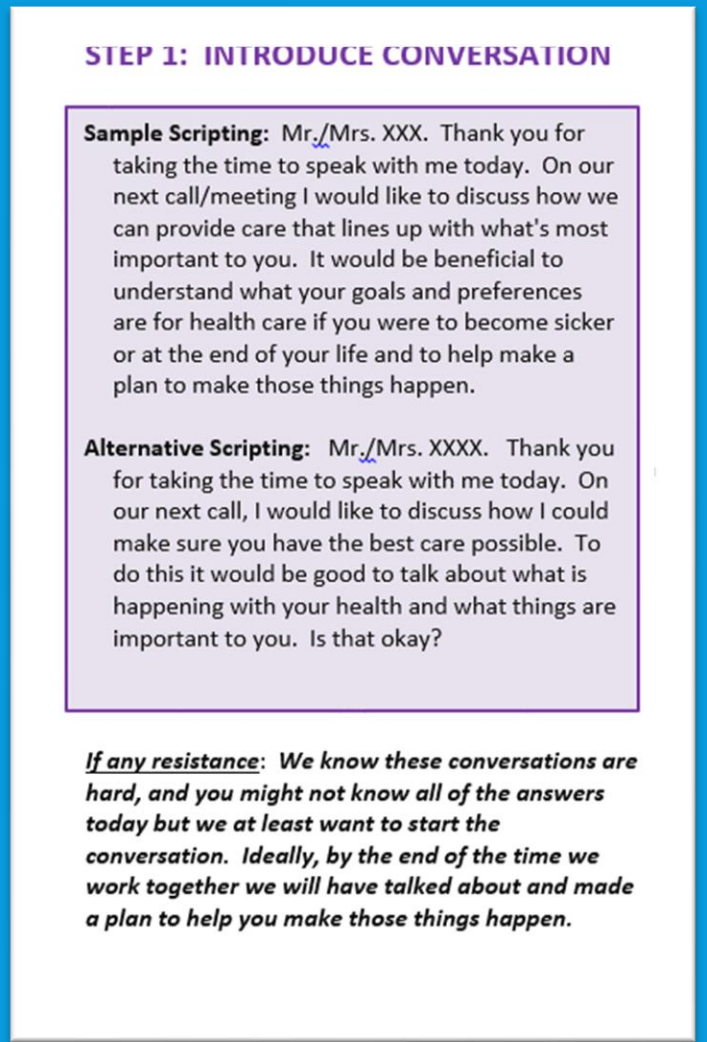
- Structured guide
  - increases confidence,
  - assures adherence to key processes,
  - achieves high level of baseline performance and
  - ensures completion of necessary tasks during a complex stressful situation



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. On our next call/meeting 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. On our next call, 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.**

STEP 2: ASSESS UNDERSTANDING OF HEALTH

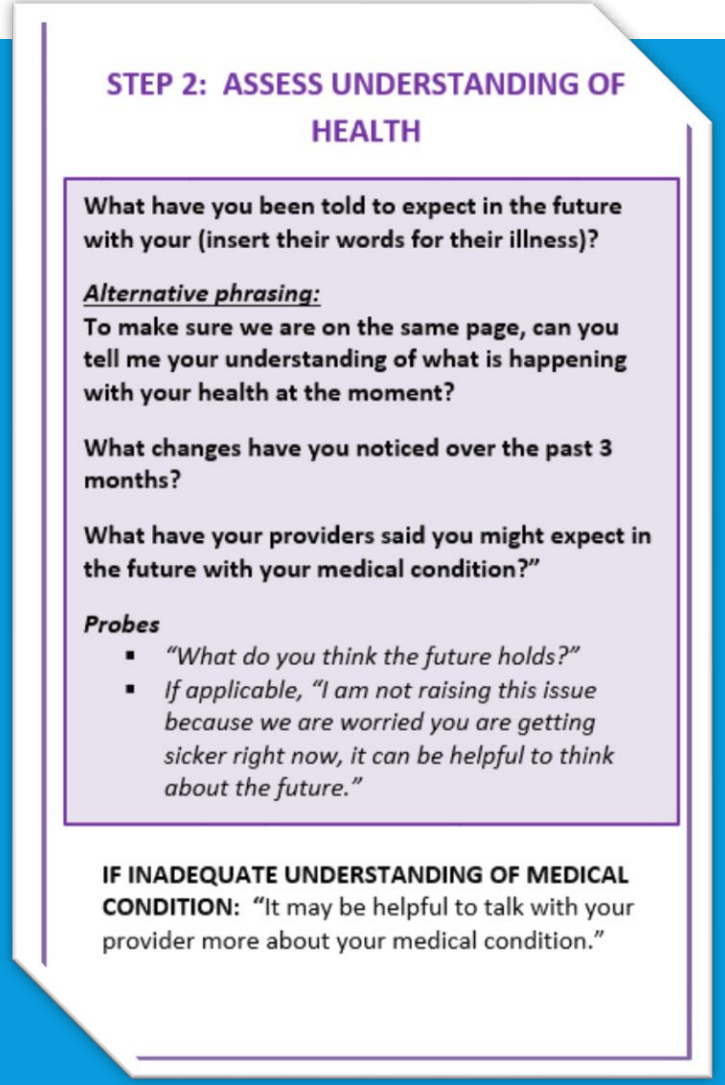
Purpose

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?"

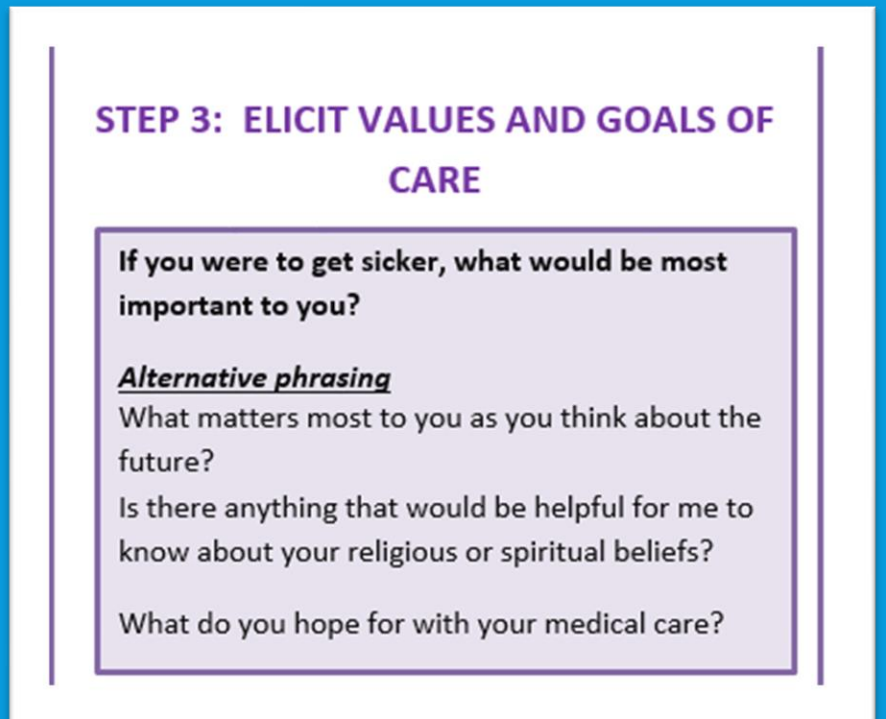
Probes

- *"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."

STEP 3: ELICIT & EXPLORE VALUES AND GOALS

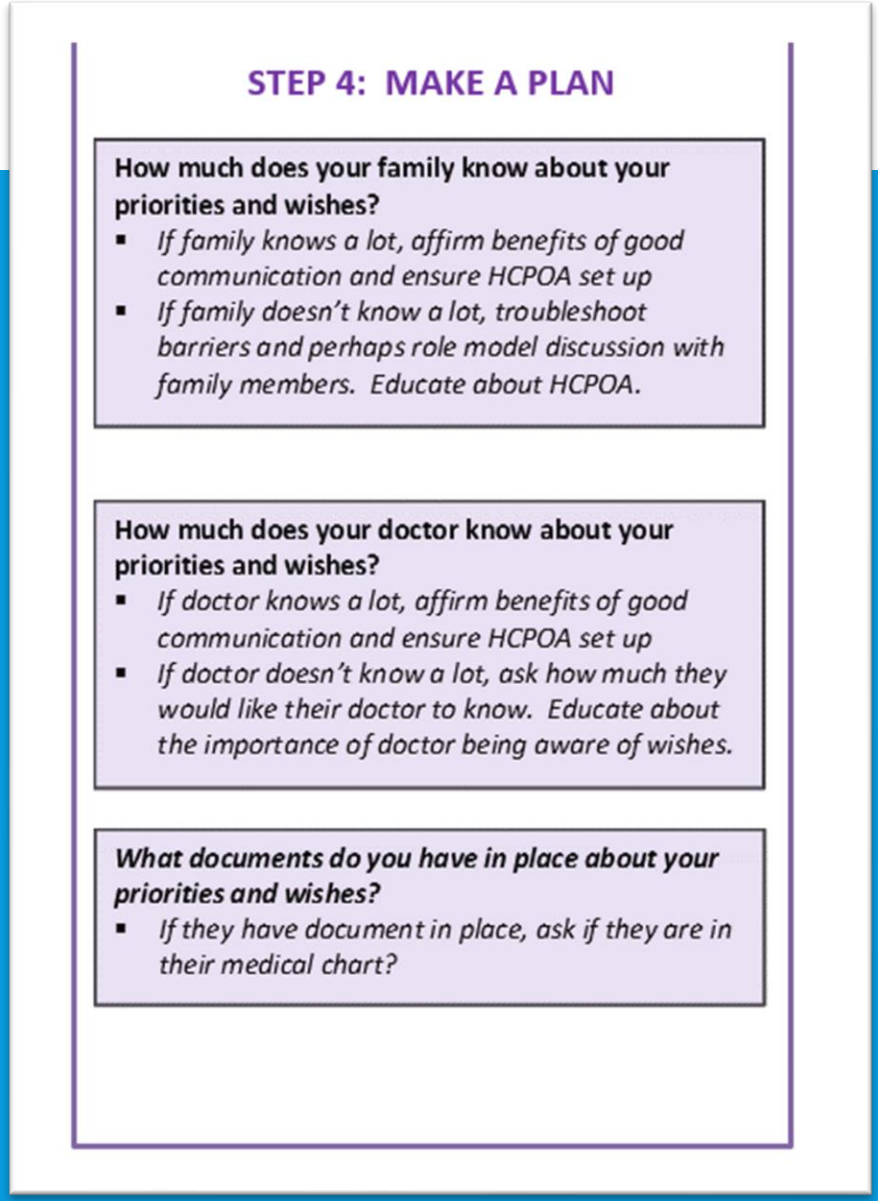
- Start with a broad question about values
  "What is important to you in your day to day life?"
- Ask about goals
  "What do you hope for with your medical care?"



- Ask about fears/concerns
  "Is there anything you're worried about as you think about the future with your illness?"
- Explore trade off for more time

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?
- Identify and facilitate what is needed to support the patient's plan (i.e. family meeting, physician visit) and create a plan to address needs.



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?

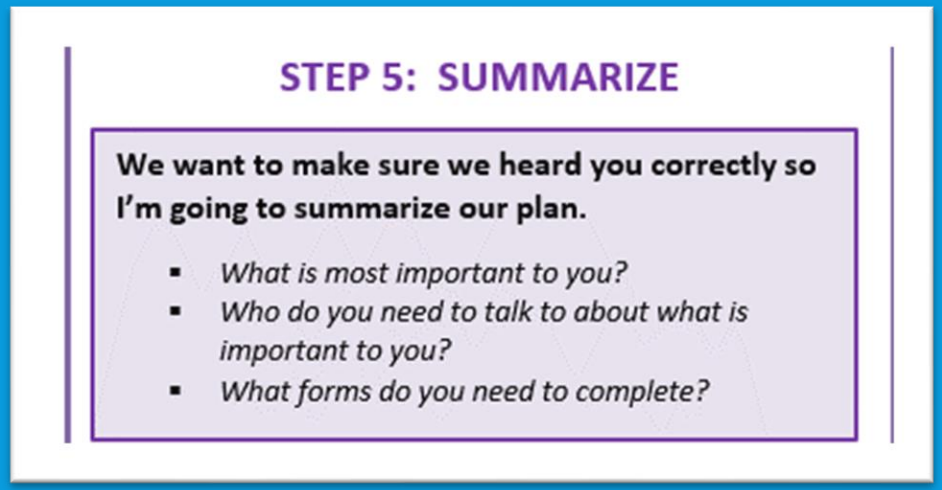
- *If doctor knows a lot, affirm benefits of good communication and ensure HCPOA set up*
- *If doctor doesn't know a lot, ask how much they would like their doctor to know. Educate about the importance of doctor being aware of wishes.*

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



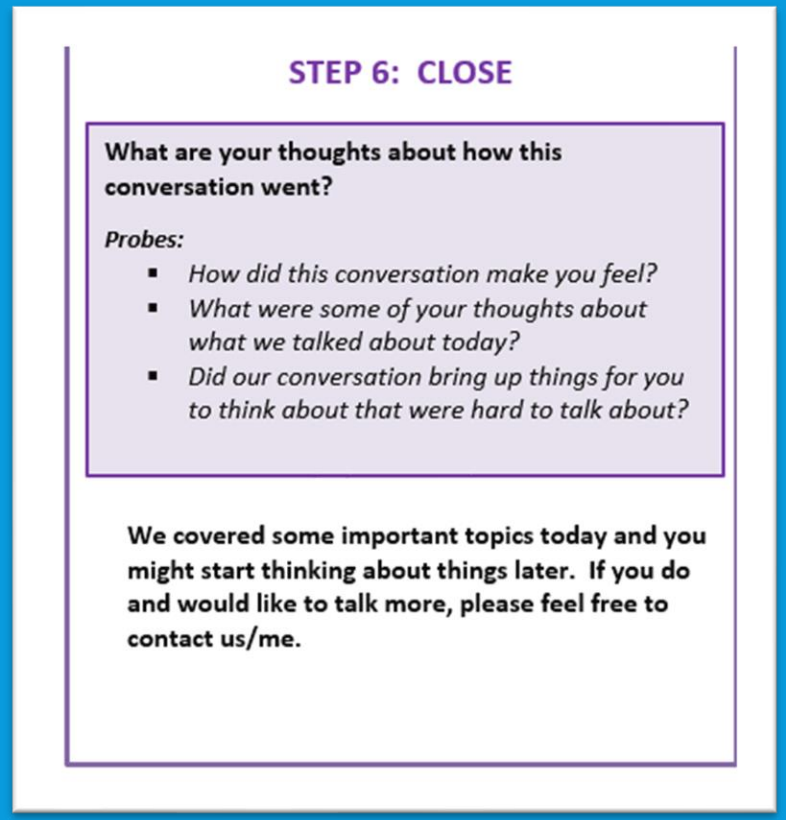
STEP 5: SUMMARIZE

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?*

Step 6: Close

- WHAT ARE YOUR THOUGHTS



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.

KEY COMMUNICATION SKILLS

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

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

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

Examples of Reflective Listening

- "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...."

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."

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."

https://www.ethics.va.gov/goalsofcaretraining/team.asp. Updated January 24, 2018.

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."

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/goalsofcaretraining/team.asp. Updated January 24, 2018

"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."

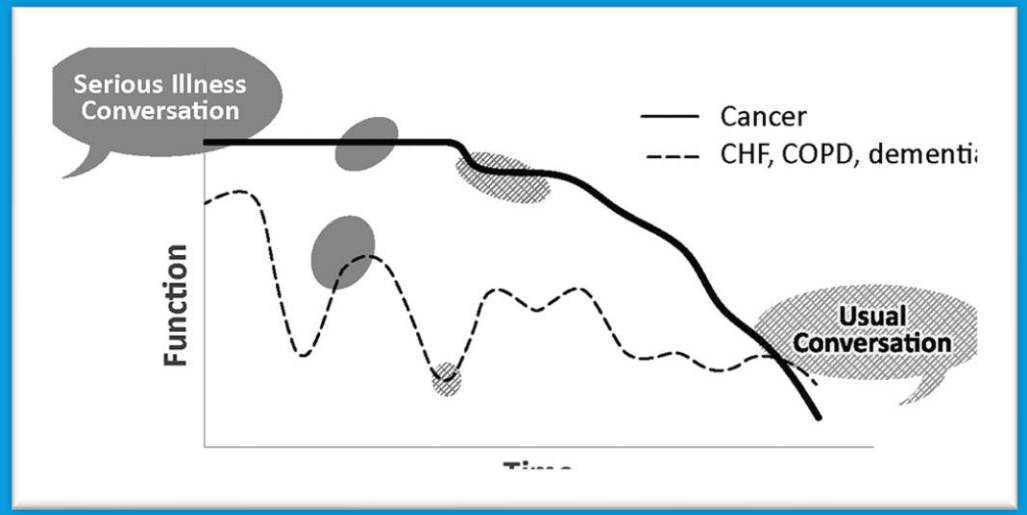
https://youtu.be/gcJE2pK4Uyg

https://www.ethics.va.gov/goalsofcaretraining/team.asp. Updated January 24, 2018

APPLICABILITY TO CASE MANAGEMENT

Case managers uniquely positioned to initiate SI conversations

- Longitudinal relationships with patients and families
- Ambulatory case managers - ideal position (non urgent situation)
- Initiate conversation upstream to help INFORM serious illness plan of care



Applicable Principles Code of Professional Conduct for Case Managers

Commission for Case Manager Certification

PRINCIPLE 2: Board-Certified Case Managers will respect the rights and inherent dignity of all of their clients.
PRINCIPLE 3: Board-Certified Case Managers will always maintain objectivity in their relationships with clients.
PRINCIPLE 4: Board-Certified Case Managers will act with integrity and fidelity with clients and others.
PRINCIPLE 5: Board-Certified Case Managers will maintain their competency at a level that ensures their clients will receive the highest quality of service.
PRINCIPLE 6: Board-Certified Case Managers will honor the integrity of the CCM designation and adhere to the requirements for its use.

Certified Disability Management Specialist

CDMS Ethics

The fundamental spirit of caring and respect with which the Code is written is based upon five principles of ethical behavior. These include autonomy, beneficence, nonmaleficence, justice, and fidelity.

CRCC Ethics

Section C: Advocacy and Accessibility
C.1. Advocacy

Section G: Assessment and Evaluation
G.1. Informed Consent

APPLICATION TO PRACTICE

Needs Assessment

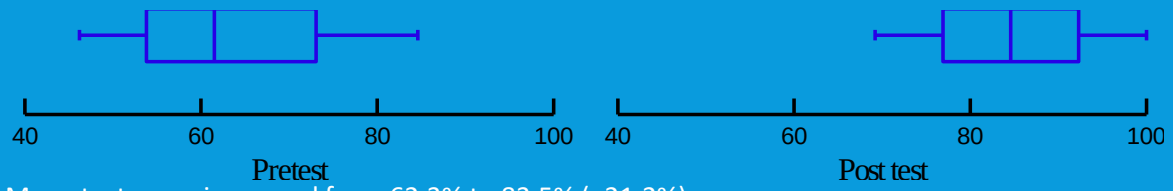
- No standard CM protocol to identify patients
- Case managers not formally trained in SI conversations
- Not consistently done as part of case management process
- Chart review indicated suboptimal use of palliative care and hospice services
- < 25% of sample of SI patients had HCPOA or POLST

Project Design

- Single sample non-randomized cohort
  - Care Coordinators: Nurses (n=14-16) and Social Workers (n=3) working in the Accountable Care Organization in large Academic Medical Center
- Serious Illness Conversation Education Program
  - 4 hour educational session
  - Pre and post launch case review sessions
- Serious Illness Conversation Protocol
  - Patients assigned to a primary care physician (n=100) located in one of fifteen ambulatory clinics
  - Age 18 and > meeting established SI criteria

PRIMARY PROJECT OUTCOMES

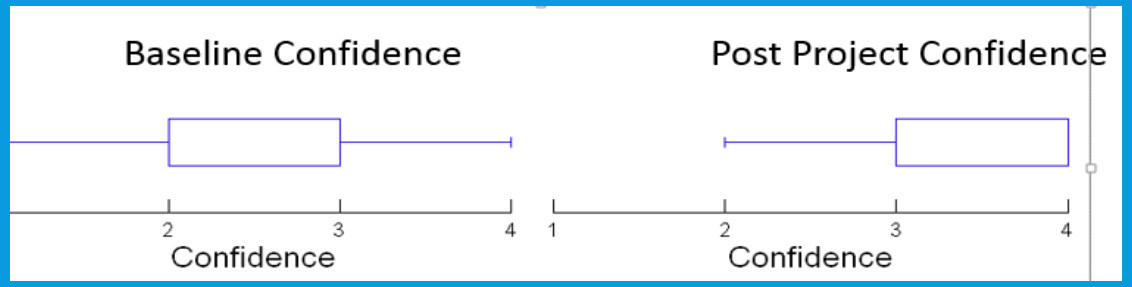
Increase in Case Manager Knowledge



Mean test score increased from 62.3% to 83.5% (+21.2%)
Paired sample t test statistically significant change (t -8.297, df 19, p value < .0001)

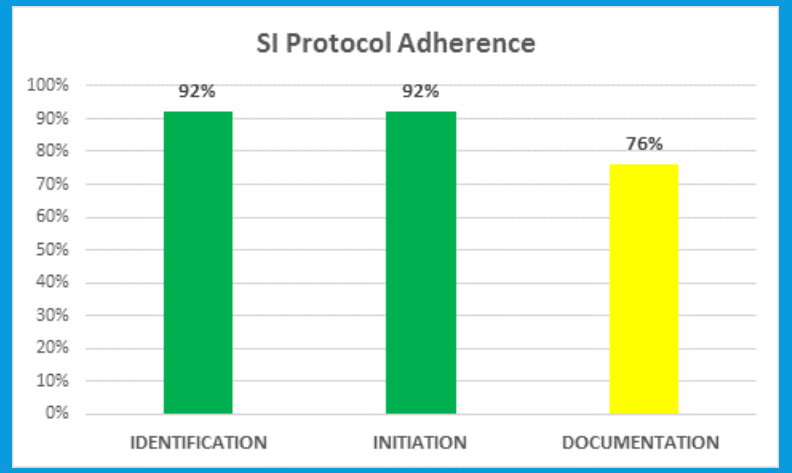
Increase in Case Manager Confidence

How confident do you feel, currently, engaging in Serious Illness conversations with patients to elicit their goals, values and preferences for their Serious Illness care?	☐ Not at all Confident 1	☐ Somewhat Confident 2	☐ Confident 3	☐ Very Confident 4



Mean confidence increased from 2.6 to 3.5 (+0.9) ; Paired sample t test statistically significant change (t-5.17, df 19, p value < .0001)

High Adherence to SI Protocol



- High adherence to identify and initiate components
- 24% of patients documentation missing patients values and goals only address ACP documents

SECONDARY PROJECT OUTCOMES

Increase in Palliative Care-Hospice Referrals

Program referrals	Pre SI	Post SI	Change
Palliative Care	0	7	7
Hospice	0	4	4

* 2 patients received both palliative care and hospice services

- 15% (9/59) of patients that engaged in SI conversations were referred to Palliative Care or Hospice

Increase in ACP Documents

ACP on File	Pre SI	Post SI	Change
HCPOA	25%	25%	0
POLST	5%	24%	11
% of population	31%	49%	18.6%

Qualitative Outcomes

"This is a lost part of nursing. I'm glad we have found this as our patient need this!"

"This has been a great experience as well as being much needed from our patients. I also believe our patients have gained and learned from addressing this topic. "

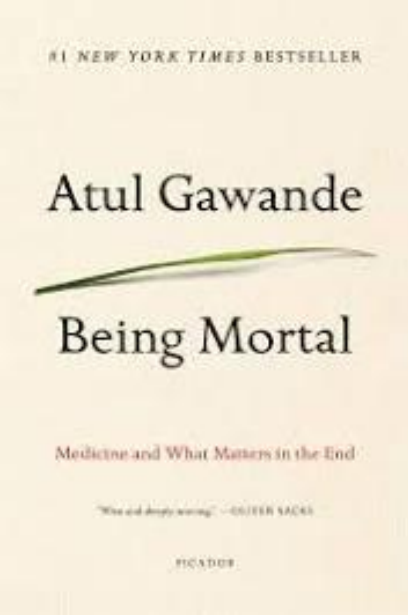
"I have become aware of more patients in need of the serious illness conversation."

A REAL LIFE EXAMPLE

Do you have the courage to ask an important question?

What are your goals for care- how can I help you?

CLOSING REFLECTION



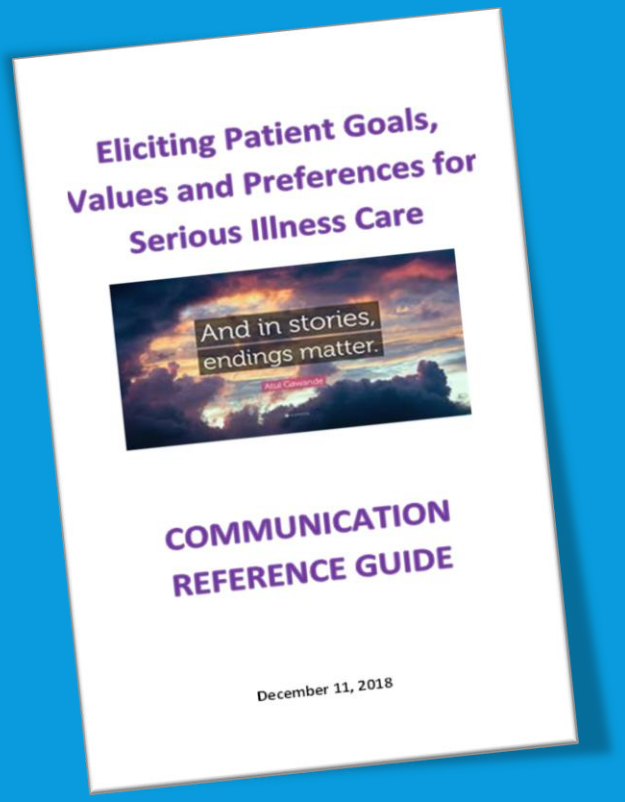
"If to be human is to be limited, then the role of caring professions and institutions—from surgeons to nursing homes—ought to be aiding people in their struggle with those limits. Sometimes we can offer a cure, sometimes only a salve, sometimes not even that.

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

ADDITIONAL RESOURCES

RESOURCE	DESCRIPTION	WEBSITE
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



To learn more about Serious Illness Education contact

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