SERIOUS ILLNESS CONVERSATIONS

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July, 2020

Program Overview

Session	Content
Pre-work	▪ Pretest and Confidence Assessment ▪ Assess baseline knowledge and confidence (aggregate reporting only)
Session 1	▪ Background & Overview of Serious Illness Communication ▪ Definitions ▪ Roles
Session 2	▪ Serious Illness Communication Skills ▪ Therapeutic communication ▪ Break out Session
Session 3	▪ Review Serious Illness Structured Communication Guide ▪ Review of SI protocol
Session 4	▪ Break Out Session- Putting it All Together ▪ Wrap up
Post work	▪ Optional Case Review Session ▪ Reassess knowledge and confidence (aggregate reporting only)

AT THE END OF THESE SESSIONS THE PARTICIPANTS WILL BE ABLE TO:

- Utilize trigger criteria to identify patients appropriate for a SI conversation
- Utilize the Structured Communication Guide to engage in a SI conversation
- Utilize communication skills to elicit a patient's goals, values and preferences to inform the SI plan of care

SESSION 1 OBJECTIVES

1. Describe the relationship between Serious Illness (SI) conversations and Case Management with respect to honoring the rights and inherent dignity of all clients.
2. Describe the differences between the medical model and the biopsychosocial model as it relates to SI Conversations.
3. Define two gaps related to Serious Illness (SI) care as identified by the Institute of Medicine.
4. Discuss how a Serious Illness Communication Program can benefit healthcare organizations and patients.

ACKNOWLEDGEMENTS

This presentation includes material adapted with permission from:

- Veteran's Administration Life Sustaining Treatment Decision Initiative (LSTDI)
- Serious Illness Conversation Program (SICP) Ariadne Labs
- Vital talk
- Veterans Affairs Eastern Colorado Health Care System, Denver, Colorado.

VA Eastern Colorado Health Care 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)

MEDICAL ADVANCES CAN EXTEND LIFE BUT.....

- **Dissonance between desired and actual end of life care**
  - 86% of Medicare beneficiaries want to spend final days at home
  - 25-39% die in acute care hospitals
  - 29% receive intensive care in last 30 days
- **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
  - Patients receiving dialysis
    - 90% reported their physician hadn't discussed prognosis with them despite an annual mortality rate of 22%
  - 15% of hospice patients are referred in their last week of life

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

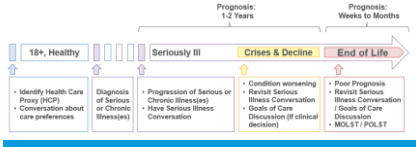
CARE SERIOUSLY ILL RECEIVE OFTEN MAY HARM THEM AND THEIR FAMILIES

Studies show aggressive care for patients with advanced illness is often harmful:

- For patients:
  - Lower quality of life
  - Greater physical and psychological distress
- For caregivers:
  - More major depression
  - Lower satisfaction

(Wright, 2008, Teno, 2004, Mack, 2010)

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

EARLY CONVERSATIONS ABOUT GOALS OF CARE BENEFIT PATIENTS AND FAMILIES

Early conversations about patient goals and priorities in serious illness are associated with:

- Enhanced goal-concordant care
- Time to make informed decisions and fulfill personal goals
- Improved quality of life
- Higher patient satisfaction
- More and earlier hospice care
- Fewer hospitalizations
- Better patient and family coping
- Eased burden of decision-making for families
- Improved bereavement outcomes

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009

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.)

- *If we know earlier conversations are associated with better outcomes, what are the barriers?*

MACRO LEVEL SYSTEM FACTORS

- **Approaching Death: Improving Care at End of Life** (IOM, 1997)
  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 EOL care and communication
  - Fundamental failures in professional education
  - Manage personal emotional reactions to death
- Significant research gaps about end of life care
  - Insufficient knowledge to create EOL Evidence Based guidelines

DYING IN AMERICA (IOM, 2014)

Some improvements due to Palliative Care Programs, however:

- Continued communication deficiencies with patients/families re: serious illness
- Need for systematic improvements in clinician led conversations about goals, values and care preferences for patients with serious and life threatening illness
  - Multiple poorly managed transitions between care settings
    - High rates of preventable readmissions
    - Significant burden on caregivers
  - Slow adoption of Palliative Care services among specialists

MICRO LEVEL- PROJECT INSTITUTIONAL GAPS

- There is no existing protocol in place at this institution to identify patients who are appropriate for a SI conversation
- Case Managers at this institution have not completed standardized education on how to conduct SI conversations
  - Case managers are not familiar with Structured Communication guides to elicit goals, preferences and values for care
- Conducting SI conversations has not been included in the role of Case Manager (although this is deemed appropriate)
- There is no standard documentation process for recording SI conversations

MICRO LEVEL- PROJECT INSTITUTIONAL GAPS

- Claims analysis of institution's Medicare ACO population – approximately 14,000 beneficiaries
  - 19.4% of beneficiaries triggered for palliative care evaluation
    - Significant end of life costs
    - High burden of illness including CHF, COPD, or ESRD
  - Despite high disease burden less than .5% of beneficiaries enrolled in hospice
- Chart review of 84 Medicare ACO patients discharged from the hospital in July 2018
  - 42% of the patients had serious medical condition with estimated 1 year mortality of 25-30%
  - Only 23% of patients with serious medical condition had advance directive or goals of care or POLST form on chart

EVIDENCE BASED INTERVENTION

WRITTEN FOR AND ENDORSED BY THE AMERICAN COLLEGE OF PHYSICIAN HIGH VALUE CARE TASK FORCE

Recommendation: 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 (Bernacki and Block, 2014)

SERIOUS ILLNESS CONVERSATION

WHAT IT IS	WHAT IT'S 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.* ▪ Often a series of conversations ▪ Involves patients and oftentimes families	▪ 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)

Serious illness (SI) Conversation(s) are synergistic with patient centered care and respect the inherent worth and dignity of individuals.

Patient centered care is "care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensures that patient values guide all clinical decision." (IOM)

CONVERSATIONS CREATE OPPORTUNITIES FOR INFORMED CHOICES

"Successful" SI Conversations

Mr. A., age 77, with progressive cardiovascular disease decides for continued treatment.

Multiple cardiac surgeries including coronary artery bypass, stenting and angioplasty

ICD pacemaker

Left ventricular assist device (LVAD)

Elected to receive a heart transplant

Mr. B, age 75, with progressive heart failure decides to forego LVAD and chooses hospice.

ICD pacemaker

Maxed out on medication therapy- only medical option is an implantable pump.

Fears becoming a burden as his heart gets worse.

"I have elected that if I get to that point," he said, "put me in a hospice and let me go."

A SHIFT IN CULTURE

During a health crisis	→	Earlier in the course of illness
Do you want us to do everything for you?	→	What do you hope for with your medical care?

Proactive, patient-driven care!

ROLES AND RESPONSIBILITIES

RNs/SWs/Cs/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

NURSING CODE OF ETHICS (ANA, 2015)

Provision 1. The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person.

Provision 2. The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population.

Provision 3. The nurse promotes, advocates for, and protects the rights, health, and safety of the patient.

Provision 4. The nurse has authority, accountability, and responsibility for nursing practice; makes decisions; and takes action consistent with the obligation to provide optimal patient care.

Provision 5. The nurse owes the same duties to self as to others, including the responsibility to promote health and safety, preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth.

Provision 6. The nurse, through individual and collective effort, establishes, maintains, and improves the ethical environment of the work setting and conditions of employment that are conducive to safe, quality health care.

Provision 7. The nurse, in all roles and settings, advances the profession through research and scholarly inquiry, professional standards development, and the generation of both nursing and health policy.

Provision 8. The nurse collaborates with other health professionals and the public to protect human rights, promote health diplomacy, and reduce health disparities.

Provision 9. The profession of nursing, collectively through its professional organization, must articulate nursing values, maintain the integrity of the profession, and integrate principles of social justice into nursing and health policy.

PRINCIPLES OF THE CODE OF PROFESSIONAL CONDUCT FOR CASE MANAGERS

CCMC Commission for Case Manager Certification

- PRINCIPLE 1: Board-Certified Case Managers will place the public interest above their own at all times.
- 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.
- PRINCIPLE 7: Board-Certified Case Managers will obey all laws and regulations.
- PRINCIPLE 8: Board-Certified Case Managers will help maintain the integrity of the Code, by responding to requests for public comments to review and revise the code, thus helping ensure its consistency with current practice.

CDMS Certified Disability Management Specialist

CRC Certification of Rehabilitation Counselors

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, as defined below:

Autonomy: To honor the right to make individual decisions.

Beneficence: To do good to others.

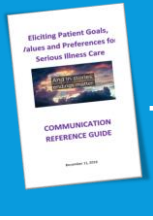
Nonmaleficence: To do no harm to others.

Justice: To act or treat justly or fairly.
Fidelity: To adhere to fact or detail.

Section C: Advocacy and Accessibility
- C.1. Advocacy
- C.2. Accessibility

Section G: Assessment and Evaluation
- G.1. Informed Consent
- G.2. Release of Assessment or Evaluation Information

QUALITY IMPROVEMENT PROGRAM



- Serious Illness Education Program
  - 4 hour face to face educational session included content from The Serious Illness Care Program (SICP, 2015), the Veteran's Administration (VA) Program for Life Sustaining Treatment Decision Initiative (LSTDI, 2017) and the Structured Goals of Care Communication Guide (Bekelman et al., 2017).
  - Pre-launch and post launch weekly practice and debrief sessions with case managers
- Serious Illness Conversation Protocol
  - ***Identify*** patients with SI using defined criteria
  - ***Initiate*** conversation by end of 3rd outreach
  - ***Document*** conversation on SI template

PROJECT DESIGN

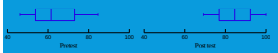
- Single sample non-randomized cohort nurse (n=16) and social workers (n=4) case managers embedded in primary care physician practices to coordinate care for high risk patients
  - High risk defined as individuals who utilize a disproportionate amount of health care resources
  - Uniquely positioned to initiate conversations with patients with SI
  - Access to TOC referrals and claims reports to identify patients with SI
- Serious Illness Conversation Protocol
  - Patients assigned to a primary care physician (n=100) located in one of fifteen ambulatory clinics
  - English speaking patients age 18 and older meeting established SI criteria
- ACO leader is committed to success of initiative and viewed as a physician leader

EVALUATION INSTRUMENTS

- Educational Session
  - Nursing demographic questionnaire, including question on confidence
  - Participant evaluation form re: educational program
  - Pre- and post measure of knowledge and confidence (baseline and post project)
- Serious Illness Protocol
  - Accuracy of patient identification utilizing SI criteria
  - SI conversation implemented within established timeframe in accordance with established communication guide
  - Use of SI documentation template including required components of SI conversation
- Secondary Outcome Measures Secondary data collected
  - Advance Directive or POLST completed during project timeframe

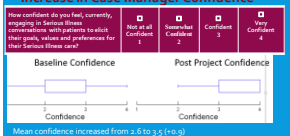
PRIMARY OUTCOMES

Increase in Case Manager Knowledge



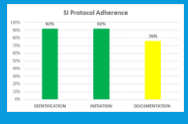
Mean test score increased from 62.3% to 83.5% (+21.2%)
Paired sample t test statistically significant change (t -8.297, df 19, p value < .0001)

Increase in Case Manager Confidence



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 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.*
- *It has become easier asking patients what their wishes are and how they see their lives going.*
- *The SI curriculum is straight forward and user friendly. It has been very enlightening to see the important changes that have happened from this common sense well thought out project.*

SUMMARY

- Gaps in clinician education coupled with the US Medical Model of care contribute to late or lack of SI conversations
- Earlier conversations 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.
- SI communication programs can result in earlier, better and more SI conversations
- Case Managers are uniquely positioned to initiate and engage in SI conversation

SERIOUS ILLNESS CONVERSATIONS

SESSION 2

COMMUNICATION SKILLS

Mary Beth Billie, DNP, RN-BC, CCM

July, 2020

OBJECTIVES

1. Describe the impact of communication on patient health outcomes.
2. Define five communication skills that enhance the Serious Illness conversation process.
3. Practice using communication skills in a therapeutic setting.

BENEFITS OF EFFECTIVE COMMUNICATION

- Profound effect on biological and functional health outcomes as well as patient satisfaction and experience of care.
- Increases patient's capacity to follow thru with medical recommendations, self manage a chronic medical condition and adopt preventive health behaviors.
- *"Extensive research has shown that no matter how knowledgeable a clinician might be, if he or she is not able to open good communication with the patient, he or she may be of no help."*

Stewart et al, 2000 Zachariae et al, 2003 Heisler et al., 2003, Wanzer et al., 2004

COMMUNICATION SKILLS ARE ESSENTIAL

- Clinicians serve the needs of human as a biopsychosocial and spiritual beings
  - Requires not only scientific knowledge, but also interpersonal, intellectual and technical abilities and skills.
  - Composition of knowledge, clinical work and interpersonal communication
- Patient centered care relies on core communication skills
  - Ability to respond to the unique needs, values and preference of individual patients

> *"The patient will never care how much you know, until they know how much you care."*
>
> *- Terry Canale*

THE SKILL GAP

- Health professionals lack adequate training in providing patient centered care
  - Underscores importance of communication training for clinicians and members of the healthcare team

Patient-centered care:
1. Care is based on continuous healing relationships
2. Care is customized to patient needs and values
3. The patient is the source of control
4. Knowledge is shared and information flows freely
5. Decision making is evidence-based
6. Safety is a system priority

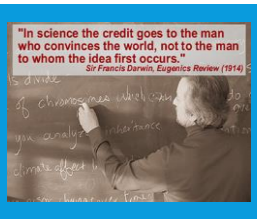
GUIDING PRINCIPLES

- 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/about-us/

KEY COMMUNICATION SKILLS

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



https://www.ethics.va.gov/patient-centered-communication.asp

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?"

EVIDENCE SUPPORTS OPEN ENDED QUESTIONS

RESULTS

One thousand and eighty-nine out of 1,220 students used the open-ended question (89.3%) during the medical interview.

A positive association was found between the use of the open-ended question during the medical interview and the amount of information obtained (Table 1).

Tamemoto, Y., Sakurai, Y., Yokoya, S., Ogiri, J., Matsuoka, T., Ban, N., Hirata, I., Mori, T. and Tetsu, T. *Open-Ended Questions: Are They Really Beneficial for Gathering Medical Information from Patients?* Tohoku J. Exp. Med., 2005, **206** (2), 151-154 —

On average, physicians tend to interrupt a patient within 16 seconds of asking an opening question.[7] Allowing patients to speak uninterrupted may take an average of just six seconds longer than redirecting them.[8] More significantly, allowing patients to speak reduces late-arising concerns. Because

7. Dyche L, Swiderski D. The effect of physician solicitation approaches on ability to identify patient concerns. *J Gen Intern Med*. 2005;20(3):267-270.
8. Marvel MK, Epstein RM, Flowers K, Beckman HB. Soliciting the patient's agenda: have we improved? *JAMA*. 1999;281(3):283-287.

OPEN-ENDED QUESTIONS EXAMPLE

CLINICIAN:

"Do you understand your health condition? "

CLINICIAN:
"Tell me your understanding of your health condition."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

Closed-ended questions begin with:

- Is /are
- Do / did
- Would / will
- Could / can
- Was / were
- Have / has
- Which
- Who
- When
- Where

THE IMPORTANCE OF A QUESTION


The Washington Post

A doctor discovers an important question patients should be asked

By Mitch Kaminski March 9

After 30 years of practice, I know that I can't possibly solve this man's medical conundrum. A cardiologist and a nephrologist haven't been able to help him, I reflect, so how can I? I'm a family doctor, not a magician…. I start mulling over the possibilities, knowing all the while that it's useless to try.

Then I remember a visiting palliative-care physician's words about caring for the fragile elderly: "We forget to ask patients what they want from their care. What are their goals?"

I pause, then look this frail, dignified man in the eye. "What are your goals for your care?" I ask. "How can I help you?"

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…."

https://www.ethics.va.gov/goalsofcaretraining/learn.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 any more, but it makes my breathing feel a lot better."

COMPLEX REFLECTION: "You're feeling conflicted."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

COMPLEX REFLECTIONS EXAMPLE

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?"

CLINICIAN:

"It sounds like it's really hard to live with the uncertainty."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

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/goalsofcaretraining/learn.asp

EXPLORING EXAMPLE

PATIENT:

"I've always told my kids… don't keep me alive if I'm a vegetable."

CLINICIAN:
"Tell me what you mean when you say 'vegetable'."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

"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."

"I WISH" EXAMPLES

PATIENT:

"My breathing has gotten so bad. Why can't they find a way to get rid of my COPD?"

CLINICIAN:
"I wish you didn't have to deal with these lung problems."

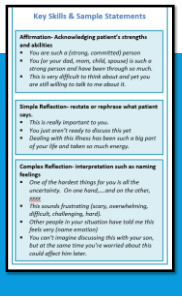
https://www.ethics.va.gov/goalsofcaretraining/learn.asp

AFFIRMATIONS

- Recognize strengths & acknowledge positive behavior
- Build rapport & patient's confidence
  - "You're saying this is difficult to talk about, and yet you came to today's appointment anyway."

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

CLINICIAN:
- "You've been so strong through so much."



Key Skills & Sample Statements

Affirmation- Acknowledging patient's strengths and abilities
- *You are such a (strong, committed) person*
- *You (or your dad, mom, child, spouse) is such a strong person and have been through so much.*
- *This is very difficult to think about and yet you are still willing to talk to me about it.*

Simple Reflection- restate or rephrase what patient says.
- *This is really important to you.*
- *You just aren't ready to discuss this yet*
- *Dealing with this illness has been such a big part of your life and taken so much energy.*

Complex Reflection- interpretation such as naming feelings
- *One of the hardest things for you is all the uncertainty. On one hand,…and on the other, xxxx*
- *This sounds frustrating (scary, overwhelming, difficult, challenging, hard).*
- *Other people in your situation have told me this feels very (name emotion)*
- *You can't imagine discussing this with your son, but at the same time you're worried about this could affect him later.*

RECOGNIZING AMBIVALENCE

Ambivalence: having two conflicting desires

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

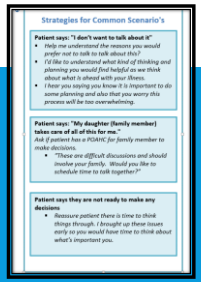
" My husband is not ready to let me go so I can't stop treatment."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

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.*

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

RECOGNIZING EMOTION

Manifests differently in different people
- Not usually tears!

Patient cues
- Shutting down/quiet
- Body language
- Intonation changes
- Ambivalence/resistance
- Questions - especially "why"

https://www.ethics.va.gov/palliativecaretraining/learn.asp

QUESTIONS CAN SIGNAL EMOTION

- Watch for questions that are actually 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/palliativecaretraining/learn.asp

RESPONDING TO EMOTION EXAMPLES


PATIENT:

"What do you mean CPR doesn't always work?"

CLINICIAN:
"This information seems really surprising."

https://www.ethics.va.gov/palliativecaretraining/learn.asp

RESPONDING TO EMOTION EXAMPLE

PATIENT:

"I just don't know how I'm going to talk to my kids about this. I want to talk to them so they know what to do, but they'll be so upset…"

CLINICIAN:

"You're worried about upsetting your kids, and at the same time you know it's important to talk to them about this."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

RESPONDING TO EMOTION EXAMPLE

PATIENT:

"My doctor says the cancer is in my lung and liver. Why can't they just cut the cancer out?"

CLINICIAN:

"I wish we could remove it, too."

https://www.ethics.va.gov/goalsofcaretraining/learn.asp

SESSION 3:

STRUCTURED COMMUNICATION GUIDE

Mary Beth Billie, DNP, RN-BC, CCM

July, 2020

OBJECTIVES SESSION 3

1. Describe three to five diagnoses/conditions that would make an individual appropriate for a Serious Illness conversation.
2. State two advantages of using a Structured Communication Guide.
3. Define three components of the Serious Illness Communication Guide.

SERIOUS ILLNESS TARGET POPULATION

CONSIDER SI CONVERSATION IF PATIENT MEETS ANY OF THE FOLLOWING CRITERIA:

Disease Based Criteria

Inpatient admission in last 6 months & 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
- Complex medical conditions resulting in frequent unplanned hospital or emergency room admissions

Functional Criteria

- Resides in long term care facility
- Significant and progressive decline in ability to complete activities of daily living

Surprise Question

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

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)

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

Better endings start #longbeforetheend

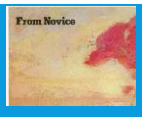
SERIOUS ILLNESS CONVERSATIONS

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=m8ghOfzPjs8

WHY USE A STRUCTURED COMMUNICATION TOOL?

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



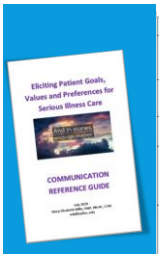
- Structure increases Confidence
- Assures adherence to key processes
- Achieve higher level of baseline performance
- Ensures completion of necessary tasks during a complex, stressful situation

STRUCTURED COMMUNICATION GUIDE


Development and Feasibility of a Structured Goals of Care Communication Guide

Tool developed specifically for Nurses and Social Workers

- Elicit knowledge of condition, preferences, and goals of care
  - What do you understand about your illness?
  - What are your priorities if you get sicker?
  - What are you most worried about?
  - What tradeoff's are you willing to make for more time?
- Plan for documenting wishes
  - State Specific Documents, Health Care Power of Attorney



SERIOUS ILLNESS COMMUNICATION GUIDE

CONVERSATION FLOW	PATIENT TESTED LANGUAGE
1. **Set up the conversation** • **Introduce purpose** • **Prepare for future decisions** • **Ask permission**	• Today we want to do two things: First we want to talk about your values and goals related to your health care if you were to become sicker or at the end of your life. Next we want to come up with a plan to help to make those things happen. • It is important to make sure we are providing care that lines up with what's most important to you. To do that, it helps to understand what you want to achieve throughout your health care, and what you want to avoid. • Is this a good time to begin talking about these things?
2. **Assess understanding of health**	• What have you been told to expect in the future with your (insert their words for their lung/heart) illness? • What is your understanding now of where you are with your illness? • What changes have you noticed over the past 3 months? ***If inadequate understanding of medical condition: It may be helpful to talk with your provider more about your medical condition.***
3. **Elicit Values and Goals of Care**	• If you were to get sicker, what would be most important to you? • As you think about the future with your health, what are you most worried about? • What concerns or worries do you have about your medical condition?
4. **Tradeoffs**	• 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 are willing to have their lives be shorted 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? • If you become sicker, how much are you willing to go through for the possibility of gaining more time?
5. **Summarize and determine next steps**	• I know you said xxx is important to you. We would like to make a plan so we can help make sure your wishes are followed! • How much does your family know about your priorities and wishes? • Who much does your doctor know about your priorities and wishes? What documentations to you have in place about your priorities and wishes? • Summarize the agreed upon plan and next steps. *Follow-up next steps may include: Healthcare POA, Meeting with PCP- would they like you to be present? POLST, Palliative care referral?*
6. **Wrap up**	• What are your thoughts about how this conversation went? • 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 me (us).
7. **Document your conversation**	Template
8. **Communicate with key clinicians**	As appropriate

Bollofman, et al, VA Life Sustaining Treatment, Aravedo Labs

BEFORE YOU TALK TO THE PATIENT, PREPARE

- Review medical record
  - Medical conditions & prognosis
    GOOD SOURCES: Hospital discharge summaries
  - Previously created advance directives, state authorized portable orders (SAPO) and Life Sustaining Treatment (LST) plans
    GOOD SOURCES: Medical Record
- If needed, ask practitioner or others about communications with the patient about diagnosis, prognosis, and goals

YOUR APPROACH MATTERS

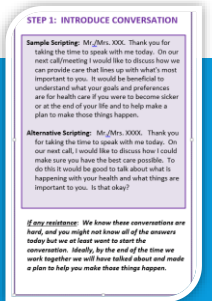
Build a partnership with the patient by…

- Creating an open, safe environment
- Believing in the patient's ability to make difficult decisions
- Allowing the patient to discover their own understanding

STEP 1: INTRODUCE CONVERSATION

Purpose

- Orients the patient to the purpose of the discussion
- Creates a safe environment for discussion of values, goals and preferences



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.***

TEP 2: ASSESS UNDERSTANDING OF HEALTH

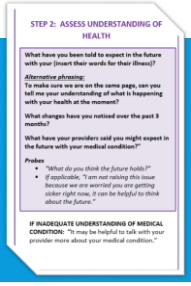
Purpose

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 VALUES & GOALS OF CARE

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?

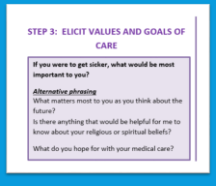
CULTURAL SENSITIVITY & PERSONAL PREFERENCE

"When individuals lose control over main aspects of their lives due to illness, their basic core beliefs & value systems are critical components of culture to which they can & often do hold." -- Norma Thomas, DSW

- **Family roles/relationships** (decision making)
- **Communication** (verbal/non-verbal, meanings of words/phrases)
- **Beliefs** (miracles, death, fate)
- **History** (access, discrimination)
- **Health Care** (technology, authority)

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?

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*

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 became sicker, how much are you willing to go through for the possibility of gaining 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?

STEP 4: MAKE A PLAN

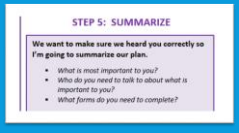
How much does your family know about your priorities and wishes?
- *If family knows a lot, affirm benefits of good communication and ensure HCPOA set up*
- *If family doesn't know a lot, troubleshoot barriers and perhaps role model discussion with family members. Educate about HCPOA.*

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 about how this conversation went?
- We covered some important topics today and you might want to talk more. Please feel free to contact me.


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. *(Chose 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*

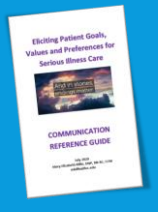
The following topics were discussed (*use "quotes" as much as possible*):

- 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:

ASSIGNMENT

- Identify patients on your panel that are appropriate for a SI conversation
- Practice the conversation using role playing with a peer



Reflect

- Did you adhere to the conversation guide?
- What worked well?
- What was challenging?

SESSION 4

PUTTING IT ALL TOGETHER

Mary Beth Billie, DNP, RN-BC, CCM

July, 2020

SESSION 4 OBJECTIVES

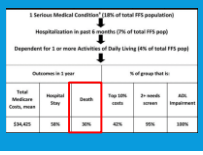
1. Utilizing role playing, apply communication skills and the SI structured guide to practice SI conversations.
2. Provide case managers with the knowledge, skills and confidence to engage in SI conversations.

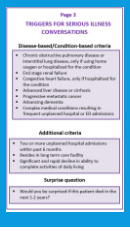
SERIOUS ILLNESS PROTOCOL

1. Identify patients appropriate for SI conversation using trigger list
2. Introduce conversation by the end of the 3rd completed contact
3. Initiate SI conversation using Structured SI guide
4. Document SI conversation utilizing SI template
5. Follow up with patient and clinicians as indicated

SERIOUS ILLNESS TRIGGERS

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)





PATIENT IDENTIFICATION SOURCES

- Transitional Case Management Referrals
- Claims Reports
- Physician Referrals

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. *(Chose 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:

PRACTICE INSTRUCTIONS

- Take out "Structured Communication Guide"
- Identify four volunteers (2 patients and 2 clinicians)
- Assign volunteers to practice case 1 or 2
- Decide who will be the clinician and who will be the patient
- Start with practice case 1- allow 20 minutes
- Move to practice case 2- allow 20 minutes
- Remainder of participants are observers- utilize competency checklist
- Quick group debrief

Refer to SI Guide

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

CASE DESCRIPTION

- **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.

PRACTICE CASE 2

- Mr. P. is a 63-year-old retired teacher whose prostate cancer has metastasized to his bones. Two years ago, doctors told him he had between 18 months and two years to live.
- He lives with his wife of 27 years, and is concerned about what will happen to her when he dies.
- He has no advanced directives on his chart.
- He is unsure about what he wants for his ongoing treatment plan.

CASE DESCRIPTION

- **The *goal* of the discussion today is to use the Structured Communication Guide to explore Mr. P's values, goals and priorities for care in the setting of illness progression.**
- **As you prepare to speak with Mr. P., you consider the following:**
  - He has terminal cancer
  - He is ambivalent about whether to continue palliative chemotherapy
  - He does not have a POA for health care or documented goals of care
  - You want to begin the conversation to elicit his values, goals and priorities

CLOSING REFLECTION

Better endings start #longbeforetheend

"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 Being Mortal: Medicine and What Matters in the End.

NEXT STEPS

Complete Evaluation

Complete Post Test

Register for Optional Mentoring Session

INFORMATION

To find out more about how Serious Illness Communication Education can assist your organization contact:

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

mbillie@luc.edu