

The Status of Serious Illness Care in the United States

Susan Block MD

Professor of Psychiatry and Medicine

Harvard Medical School

The Big Picture: Quality of End-of-Life Care in the US

- Overall Ranking = 9 (Economist Intelligence Unit)
- National policy embodied in Medicare Hospice Benefit
- 46% of decedents receive hospice care
- 70% of teaching hospitals have palliative care programs
- 1% of National Institute of Health budget goes to palliative care research
- PC is an ACGME- and ABMS- accredited sub-specialty of 11 co-sponsoring boards
- There is a large deficit (11,000 MDs) in trained PC professionals
- Standards for PC education in US medical schools are minimal

Focus of this presentation: Communication about serious illness care goals

- Why is communication important?
- What happens now?
- How can we make it better?
- What outcomes are achievable?

Why?

End-of-Life Experiences

	Cancer	COPD	CHF
Hospitalization	>50% last month	>60% last 6 months	>80% last 6 months
ICU admission	8%	33%	50%
Hospice care	65%		40%
ED visits	48%		
Invasive procedures in last month	40% chemo		20% CABG, dialysis, AICD, PM, Cath

Quality of end-of-life care (Teno 2004)

Families Reporting:	Hospital	Hospice
Inadequate contact or communication with MD	78	34
Inadequate help with emotions	52	35
Poor family support	38	21
Lack of respect	20	4
Excellent care	47	71

Cancer Patients and EOL Discussions

- Only 37% of cancer patients with average survival of 4 months reported having had discussion about EOL issues with physician (Wright 2008)
- Although 95% of hospitalized oncology patients believe it is important to have discussions about advance directives/EOL care, only 41% have them
 - Major barrier: Oncologists don't bring up issue (Dow 2010)
- 37% of cancer patients admitted to ICU had no HCP or living will (Halpern 2011)

Prognostication

- 90% of patients on dialysis (20-25% annual mortality rate) report they have not discussed prognosis (Davison et al. 2010)
- 75-90% of patients and caregivers (multiple diseases) say they want all the information about their disease , including prognosis (Jenkins 2001, Mack 2006; Janssen et al. 2012)

End-of-life discussions

- Discussions happen late, patients are unprepared, and are often at their worst
- Large prospective cohort study, lung and colorectal cancer
 - 87% of patients who died had EOL discussion reported or documented
 - 55% of first conversations took place in hospital
 - First conversation took place a median of 33 days before death
 - Only 27% were conducted by oncologists

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
- 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 Argument

- High-quality serious illness care planning improves outcomes for patients and families
- All patients with SI should have access conversations early in the illness trajectory to impact decisions and well-being
- Tools, training, and system changes are needed to support clinicians
- Clinicians who care for SI patients are best positioned to conduct these conversations for most patients
- Palliative care clinicians should focus effort on providing care for complex patients, on training other clinicians, and on creating systems for caring for SI patients

The goal: Better care for patients

Where we are now

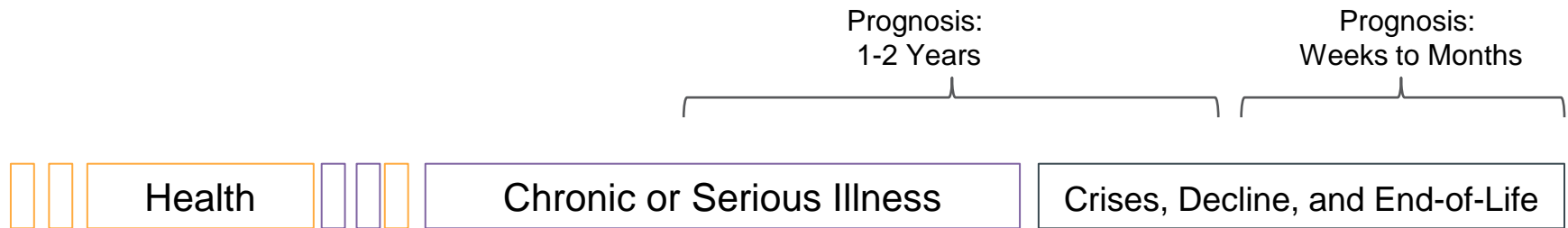
Doing some of the right things some of the time for some of our patients with serious illness



Where we want to be

Doing all the right things all of the time for all of our patients with serious illness

Conversation and Care Planning Framework



<p>Everyone age 18+</p> <ul style="list-style-type: none"> • Identify Health Care Proxy (HCP) • Conversation about care preferences with proxy and loved ones • ? Advance directive 	<p>Diagnosis of Chronic or Serious Illness</p> <ul style="list-style-type: none"> • Confirm HCP • Share natural history of illness • Assess decisional preferences 	<p>Progression of Serious Illness</p> <ul style="list-style-type: none"> • Have Serious Illness Conversation • Complete MOLST/POLST if patient ready 	<p>Condition worsening (e.g. hospitalization) or Very poor prognosis</p> <ul style="list-style-type: none"> • Revisit Serious Illness Conversation • Treatment and End-of-Life Decisions • MOLST / POLST
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Advance Care Planning = Planning in Advance of Serious Illness

Serious Illness Conversation(s) = Planning in the context of progression of serious illness, may or may not include clinical decisions, revisit when needed

Treatment and End-of-Life Decisions = Revisit serious illness conversation and make decisions in the context of clinical progression / crisis / poor prognosis

Where do we start?

Define the population of patients with serious illness

- Many strategies:
 - “No” to Surprise question: 59% sensitive, 90% specificity
 - Disease-related
 - Utilization-related
 - Functional decline
 - Combination (advanced disease, decline function, hospitalization)
 - Predictive modeling
 - Age, comorbidities
- No ideal model => **CHOOSE ONE TO GET STARTED**

A new role for palliative care: Improving quality and safety for all seriously ill patients

In addition to direct management of patients needing specialized PC services, PC team:

- Provides PC training to generalists and non-PC specialists
- Develops and manage systems improvements to improve PC system-wide
- Identifies appropriate population
- Shifts from measurement of outcomes of patients “touched” by PC, to measuring system-wide outcomes for all patients with serious illness
- Monitors and improves new processes

Why do we need systematic structures and processes for SI Conversations?

- Clinicians are not routinely trained to conduct high-quality conversations
- Even when training occurs, it has not been shown to improve patient outcomes
- Palliative care clinicians cannot fix this alone
- Responsibility for having conversations is unclear
- Normalizing the conversation may reduce anxiety of patients
- Clinicians are overburdened

Serious Illness Care Intervention is an approach to improving conversations and care



Tools



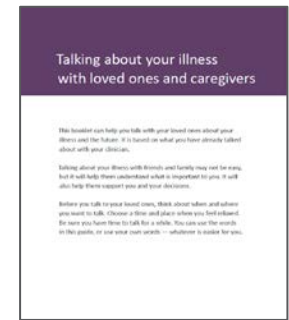
Serious Illness Conversation Guide



Clinician Reference Guide



Patient preparation materials



Family Comm. Guide



Education

Train Clinicians

2.5-hour clinician training sessions



Systems Change Change



Measurement and Improvement (QI)

Gentle Landings: What can checklists or guides do?



- Bridge gap between evidence and “real world” implementation
- Assure adherence to key processes
- Achieve higher level of baseline performance
- Ensure completion of necessary tasks during complex, stressful situations



Serious Illness Care Program

Mission: To improve the lives of all people with serious illness by increasing meaningful conversations with their clinicians about their values and priorities

Serious Illness Conversation Guide

Serious Illness Conversation Guide

CONVERSATION FLOW

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

2. Assess understanding and preferences

3. Share prognosis

- Share prognosis
- Frame as a “wish...worry”, “hope...worry” statement
- Allow silence, explore emotion

4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

6. Document your conversation

7. Communicate with key clinicians

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP “I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**”

ASSESS “What is **your understanding** now of where you are with your illness?”
“How much **information** about what is likely to be ahead with your illness would you like from me?”

SHARE “I want to share with you **my understanding** of where things are with your illness...”

Uncertain: “It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I’m **worried** that you could get sick quickly, and I think it is important to prepare for that possibility.”

OR

Time: “I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months to a year).”

OR

Function: “I **hope** that this is not the case, but I’m **worried** that this may be as strong as you will feel, and things are likely to get more difficult.”

EXPLORE “What are your most important **goals** if your health situation worsens?”

“What are your biggest **fears and worries** about the future with your health?”

“What gives you **strength** as you think about the future with your illness?”

“What **abilities** are so critical to your life that you can’t imagine living without them?”

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

“How much does your **family** know about your priorities and wishes?”

CLOSE “I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”



Research

Randomized Controlled Trial

- **Oncology (Dana-Farber Cancer Institute)**
- High-risk primary care (Atrius)

Implementation Trial

- **High-risk primary care Medicare patients**

Feasibility and Acceptability Pilots

- Chronic Critical Illness (Spaulding)
- Nephrology (BWH)
- African American patients (South Carolina)

DFCI Trial: Clinician and patient participants

Cluster- randomized controlled trial in outpatient oncology

- Clinicians

- 90 oncology clinicians (MDs, NPs, and PAs) volunteered and enrolled (72% participation rate)
- 46 of 47 enrolled intervention clinicians completed training
- Effectiveness of training: 4.3/5

Patients

- 11,000 patients screened
 - 278 patients with advanced cancer enrolled and randomized
 - 131 patients died

Outcome: Significant improvements in conversations

Of intervention and control patients who died (n= 131):

Conversation Outcomes

- More conversations (92.7% vs 74.7% p=0.006)
- Earlier conversations (147 days vs 62 days p=0.003)
- More accessible in EHR (59.4% vs 10.2% p=0.001)

Outcome: Significant improvement in quality and comprehensiveness of documentation

Significant increase in the intervention group in documentation about:

- Values and goals (85 vs 40%, $p=0.0001$)
- EOL care planning (85 vs. 55%, $p=0.009$)
- Prognosis (85% vs 30% $p=0.001$)

Outcome: Significant improvements in patient experience

Baseline

- No differences in moderate/severe anxiety (9.6% vs 9.0%, $p=0.85$) and depression (20.4% vs 19.3%, $p=0.84$) between intervention and control

Two weeks post conversation:

- Proportion of patients with **moderate/severe anxiety** in intervention group **half** that of control (4.8% vs 11%, $p=0.05$)
- Proportion of patients with **moderate/severe depression** in intervention group **half** that of control (10.9% vs. 21.8%, $p=0.03$)

Long term:

- Lower levels of anxiety persist for at least 4 months post conversation

86% of patients report conversation
was worthwhile

66% of intervention patients report positive behavior change

Practical planning	“Making changes to my will. Plan my funeral.”
Communication with family	“More realistic in my approach with family and friends about my prognosis.”
End-of-life care planning	“Made a complete list of all my last wishes, such as when I can no longer go to the bathroom myself I want hospice house care.”
Well-being	“I am doing the same stuff as before, just feeling less anxious about the future (hope for the best, prepare for the worst).”
Values, goals, and priorities	“I have started to think about what my priorities are in terms of quality of life.”
Therapeutic relationship	“Mostly the conversation brought us closer (Dr. X).”

Preliminary Qualitative Analysis

Primary Care Implementation Trial

887 high-risk primary care patients screened

- 212 identified with Surprise Question
- 130 conversations among identified patients
- Intervention group outcomes:
 - More conversations (63% vs 43%, $p=.002$)
 - More retrievable documentation (43% vs 3%, $p=.0001$)
 - More conversations about values and goals ($p=.03$)
 - 30% reduction in costs in the last 6 months of life

Summary: A feasible, acceptable, effective intervention that improves patient experience

- Intervention results in clinical practice change:
 - More and earlier serious illness conversations
 - More accessible documentation in the EHR
 - More patient-centered and comprehensive conversations
- Intervention significantly reduces moderate-severe anxiety and depression
 - Lower levels of anxiety persist for 4 months after the intervention
- Patients have a positive experience and report enacting concrete behavioral changes as a result of the serious illness conversation

Moving towards the Quadruple Aim

- Population Health
 - All the right things, all the time, for all patients with SI
 - Requires re-conceptualization of the role of Palliative Care
 - Development of QI systems to optimize care
 - Education of non-palliative care clinicians
- Better patient experience and outcomes
 - Reduced anxiety, depression
 - Increased well-being
- Lower costs
 - More, earlier and better
 - Increased hospice use
 - Reduced hospitalization
- Improved clinician satisfaction
 - To be determined