

Respecting Patients Values when Goals Shift to Palliative Care

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Show Me Summit on
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Center for Practical Bioethics

Community based organization founded in 1984.

No conflicts of interest to report

Offer services and programs in advance care planning and ethics education
and training to health systems and providers

All fees and honoraria inure to benefit of the organization

Return to mission

Declarations and COI Statement



For many older adults and their families...

Goals of care discussions don't take place when they should.

Conversations about advancing chronic illness often only occur after a crisis.

Discussions often narrow to medical treatments rather than values, meaning, and purpose in life.

Most older people know they are mortal...

Why do we not have these conversations when we should?

How do we think about progressive chronic conditions?

What exactly are Goals of Care?

What is language we should be using?

How can we make it not so intimidating/dreaded?

What cultural issues do we need to observe and respect?

What can Palliative Care teach us?

How do we use those tools to guide shared decision making?

Questions to ask ourselves

Upon completion of the session participants will be able to:

Distinguish between PC and curative measures for persons diagnosed with chronic conditions.

Engage with care providers using ACP resources that assist in clarifying values and preferences.

Describe how what is most important needs to be respected, honored and protected .

Objectives

Tell me about your mother...

Getting started



By Floyd J. Fowler Jr., Carrie A. Levin, and Karen R. Sepucha

Informing And Involving Patients To Improve The Quality Of Medical Decisions

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ABSTRACT Good-quality care requires that procedures, treatments, and tests be not only medically appropriate, but also desired by informed patients. Current evidence shows that most medical decisions are made by physicians with little input from patients. This article describes issues surrounding informed patient decision making and the steps necessary to improve the way decisions are made. Creating incentives for providers and health care organizations to inform patients and incorporate patients' goals into decisions is critical. Patient surveys are needed to monitor the quality of decision making. Health information technology can help by collecting information from patients about their symptoms, how well they understand their options, and what is important to them, and sharing that information with providers. We review public and private developments that could facilitate the development of tools and methods to improve patient-centered care.

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Good-quality care requires that procedures and tests be medically appropriate and executed safely—two criteria that have often been the primary focus of quality improvement efforts. However, appropriateness alone does not mean that the care is necessary or desired by the patient. High-quality medical care must go further and ensure that every procedure, treatment, and test ordered also meets patients' goals for care. High-quality medical decisions require that patients be fully informed and involved in the decision-making process.

The importance of involving patients in decision making was underscored as early as 1982 by the President's Commission for the Study of Ethical Problems in Medicine.¹ The proposition has since been reaffirmed and deepened, with subsequent publications and the support of organizations such as the Institute of Medicine,^{2,3} the National Quality Forum, and the American Medical Association.⁴

We address the questions of why shared decision making is so important to the quality of

health care and what steps need to be taken to ensure that patients routinely have a voice in the decisions about their care.

Shared Decision Making

Shared decision making recognizes that medical decisions require interaction between patients and their doctors; that decisions be informed by the best available clinical evidence; and that decisions reflect the individual patient's well-considered goals and concerns.^{5,6} Identifying the medical problem and laying out the reasonable options are primarily the responsibility of the physician. Patients have the primary responsibility for identifying and conveying their goals and concerns relevant to the decision they are facing. Patients and physicians each have important roles to play in the process and must be receptive to each other's input.

To help illustrate the issues and trade-offs that doctors and patients must consider in shared decision making, we use the example of taking a statin to reduce elevated low-density lipo-

By Karen R. Sepucha, Leigh H. Simmons, Michael J. Barry, Susan Edgman-Levitan, Adam M. Licurse, and Sreekanth K. Chaguturu

Ten Years, Forty Decision Aids, And Thousands Of Patient Uses: Shared Decision Making At Massachusetts General Hospital

What do I need to know about what she needs to know?

Getting started

What do I need to know about
what she wants to me know?



What Matters to Me

A Workbook for People with Serious Illness

[DOWNLOAD THE WORKBOOK \(ENGLISH\)](#)
[DOWNLOAD THE WORKBOOK \(CHINESE\)](#)
[DOWNLOAD THE WORKBOOK \(SPANISH\)](#)

Getting started

 CENTER FOR PRACTICAL
BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION

Steps in the process

- Rationale for systematic approach to improving conversations about patient values and priorities in serious illness
- Understand functional trajectories and key variables to identify patients where these conversations become important
- Recognize benefit of using Serious Illness Conversation guides
- Describe supports needed to honor results of SICP

Gap between
what
patients
want and
what they
get

Most people want to be at home and prefer comfort-focused care at the end of life, but that is often *not* the reality.

- 86% Medicare beneficiaries want to spend final days at home (Barnato 2007)
- 25-39% die in an acute care hospital (Teno, JAMA 2013; Silveira NEJM 2010)
- 70% are hospitalized in the last 90 days (Teno JM JAMA 2013)
- 29% receive intensive care in the last 30 days (Teno JM JAMA 2013)
- Multiple care transitions & short hospice stays (Teno JM JAMA 2013)

Gap between
what
patients
want and
what they
get

Patients with serious illness have priorities besides living longer.

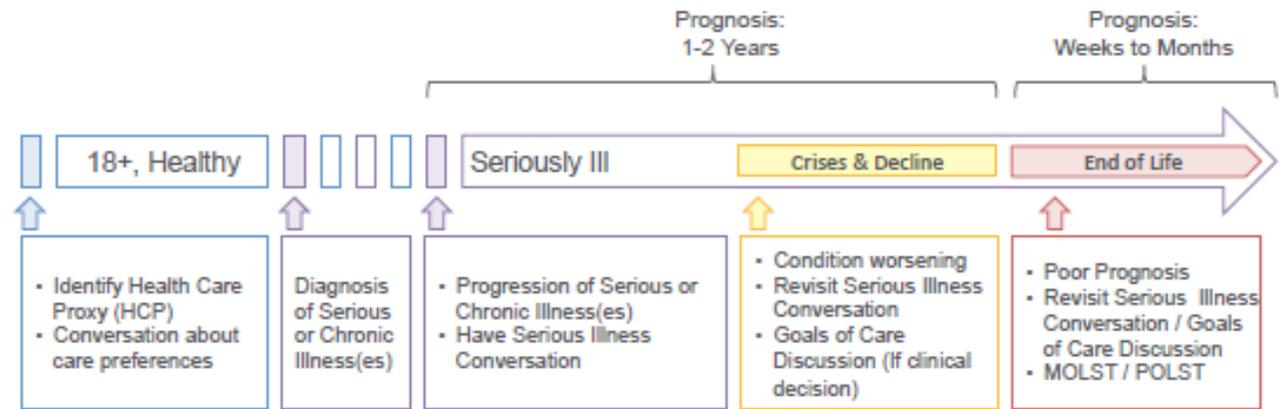
- Symptom management and “quality of life”
- Sense of control and completion
- Strengthening relationships

(Singer JAMA 1999; Steinhauser JAMA 2000; Heyland, Palliative Medicine 2015)

What do I call this?
When do I do it?

Advance Care Planning
Goals of Care Discussion
Medical Orders

Advance Care Planning Terminology



Advance Care Planning = Planning in Advance of Serious Illness

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

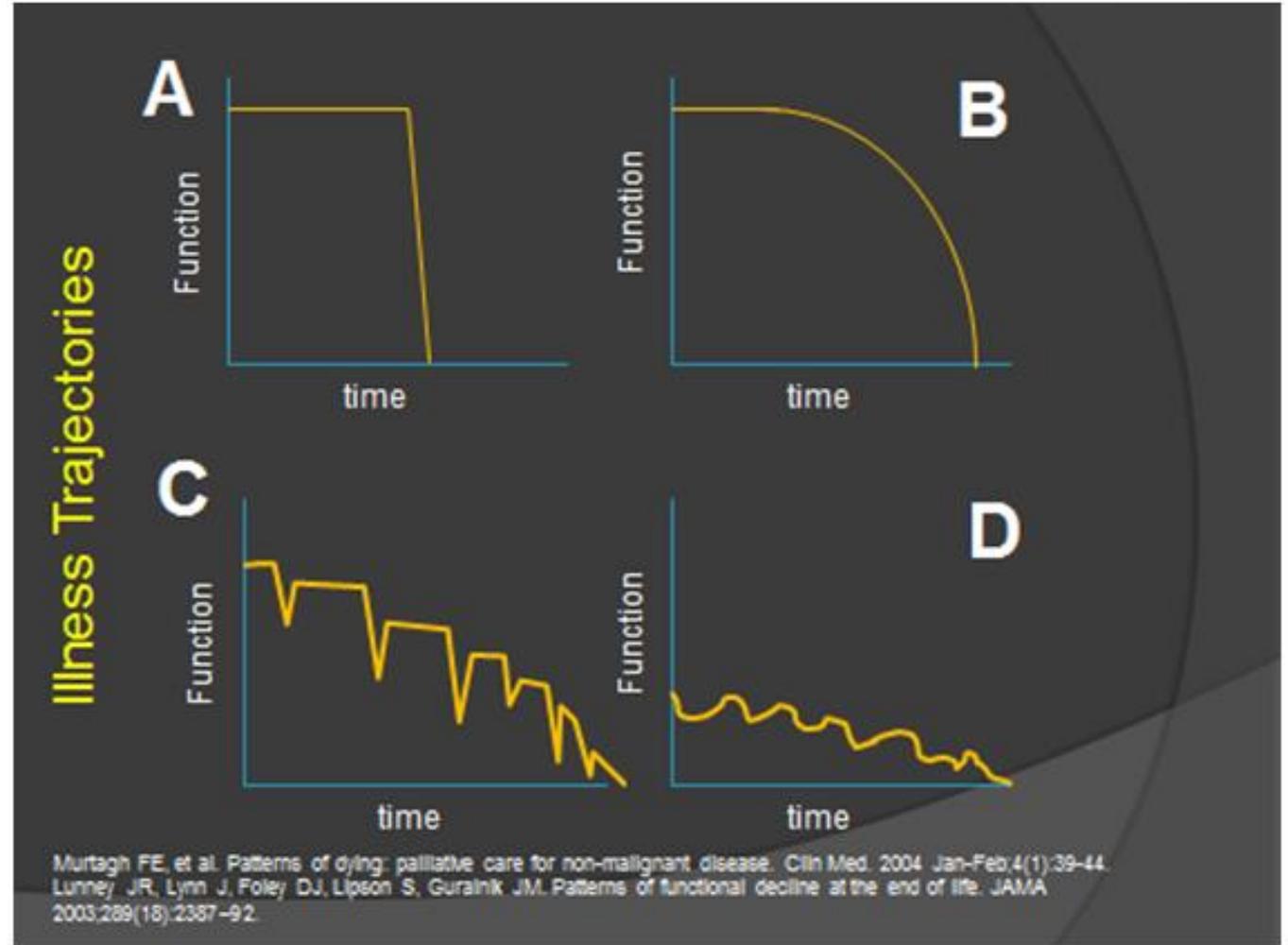
Goals of Care Discussion = Decision making in context of clinical progression / crisis / poor prognosis

What is Traditional ACP?

- For Healthy people
- Goal is educational and reflective, for them to ponder their values related to a potential future reality
- Provide resources for them to think through and discuss with their family
 - MyDirectives.com, Caring Conversations, 5 Wishes
- Potential outcomes:
 - Good family conversation only
 - DPOA-HC, Advance Directive
- This is something that people do on their own

Trajectories of Illness

- Trauma or Sudden Death
- Neoplasm/Advanced Cancer
- Heart Failure or Progressive Chronic
- Dementia/Neuro



Conversations too little, too late, and not great

- Studies show patients with serious illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life (Wright 2008, Dow 2010, Halpern 2011)
- Among patients with advanced cancer:
 - First EOL discussion occurred median 33 days before death (Mack AIM 2012)
 - 55% of initial EOL discussions occurred in the hospital
 - Only 25% of these discussions were conducted by the patient's oncologist (Mack AIM 2012)
- Conversations fail to address key elements of quality discussion, especially prognosis



What patients
get can harm
them and their
family

Aggressive care for patients with advanced illness can be harmful:

- For patients:
 - Lower quality of life
 - Greater physical and psychological distress
(Wright, AA JAMA 2008; Mack JCO 2010)
- For caregivers:
 - More major depression
 - Lower satisfaction
(Wright, AA JAMA 2008; Teno JM JAMA 2004)



Clinicians, medical system barriers to conversations and care planning

- Clinicians lack communication competencies, training and confidence Baile Cancer 1999; Sullivan JGIM 2003; Buss Cancer 2011
- Culture of medicine does not value key elements of effective care:
 - Accepts late or non-existent conversations
 - Low priority
 - No accountability
 - Tolerates poor end-of-life care
 - Focuses on avoidance of emotions; these are inherently emotionally-intense discussions
- Clinicians feel they do not have enough time

It's Time to Rename and Reframe

- Not about “End of Life” discussions. These conversations are...
 - About a priorities for how to LIVE
 - Intended to help prepare over a course of months, even a year or two
 - Not about people right now. Goals over time (last chapters not hours)

Conversations are Key

Earlier conversations about goals and priorities are associated with:

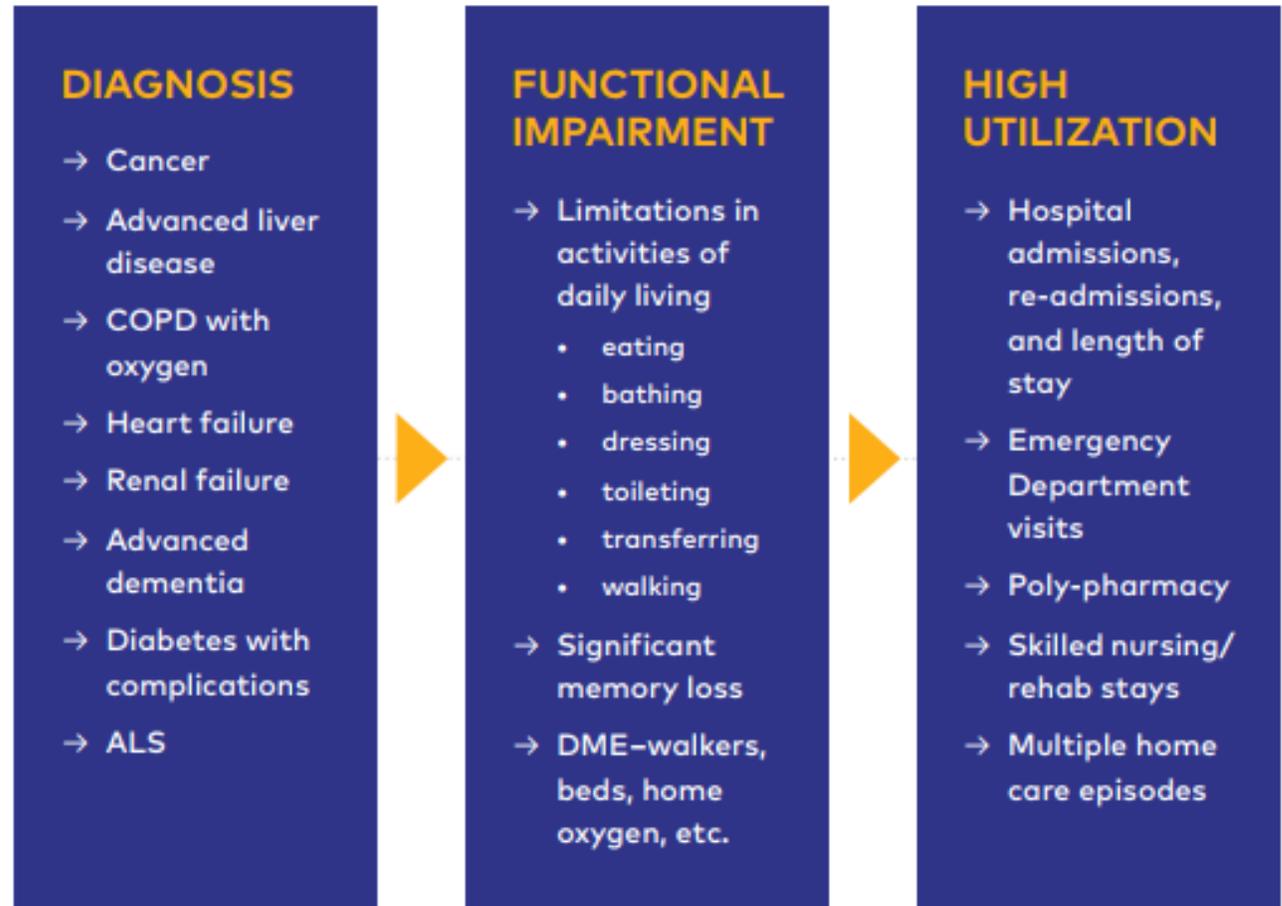
- Enhanced goal-concordant care
Mack JCO 2010
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient/family satisfaction Detering BMJ 2010
- Less non-beneficial care & costs
Wright 2008, Zhang 2009

Identifying Seriously Ill population

CAPC

Serious Illness Strategies for Health Plans and Accountable Care Organizations, 2017

FIGURE 9: Three Key Variables to Identify the Population in Need



Planning on trajectory: What people need to know

If patients want to die at home, they and family need to know trajectory; make a plan for next “crash”

Requires system/provider to recognize trend and discuss it

Requires planning from hospital, provider’s office, NH and share

Requires support of community systems in a coordinated effort for preferences to be known across continuum of care (TPOPP/POLST)

How to bridge
gap between
what patients
want and what
they *get*?

FIRST and FOREMOST...

Ask patients about their values and priorities.

What is Most Important?

Rely on Guides, Decision Aids, Ask for PC consult

Serious Illness Conversation Guide

CONVERSATION FLOW

1. Set up the conversation

Introduce the idea and benefits
Ask permission

2. Assess illness understanding and information preferences

3. Share prognosis

Tailor information to patient preference
Allow silence, explore emotion

4. Explore key topics

Goals
Fears and worries
Sources of strength
Critical abilities
Tradeoffs
Family

5. Close the conversation

Summarize what you've heard
Make a recommendation
Affirm your commitment to the patient

6. Document your conversation

PATIENT-TESTED LANGUAGE

SET UP

"I'm hoping we can talk about where things are with your illness and where they might be going — 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

Prognosis: "I'm worried that time may be short."
or "This may be as strong as you feel."

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

"It sounds like _____ is very important to you."

"Given your goals and priorities and what we know about your illness at this stage, I recommend..."

"We're in this together."

- 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

What do checklists or guides do?



Perspectives of those using tool

- “Gives me actual words when I feel stuck”
- “Reminds me to cover elements of the conversation more systematically”
- “I have to remember this is a guide for our conversation, not a form to complete”
- “Gives me structure to conversation that naturally triggers meaningful responses from patient.”

Principles of these conversations

Patients want truth about prognosis.

Patient won't be harmed by talking about end-of-life issues. (Culturally sensitive)

Normalize anxiety for both patient and clinician

Explore patient's goals and priorities beyond living longer

Give patients opportunity to express fears and worries. It can be therapeutic.

Practical Advice

Ask for honest prognosis

Explore time frames uncertainties and progression

Sit with silence

Acknowledge emotions (Sad is not always bad)

Focus on fears, and concerns, hopes and dreams

Differentiate between expectations and above

Have someone take notes

Avoid desire to make it all better

Focus solely on treatments. Be OK with Being.

Ideas to facilitate conversation

Ask patient ?s using the 3 Ws:
Wish (or Hope), Worry, and Wonder

Explore meanings behind each

Express empathy not sympathy

- Don't rescue

Potential Outcomes of Serious Illness Conversations

No decision; conversation documented & archived

Needs to be EASILY accessible and vernacular

Creation of health directive &/or Agent appt.

Creation of actionable medical order set

Where do I find
the tools and
resources?

[Center for Practical Bioethics](#)

[Caring Conversations® & ...Continued
Conversation Project](#)

[Vital Talk](#)

[Ariadne Labs - Serious Illness Care Planning](#)

[What Matters to Me Workbook \(slide7\)](#)

[MyDirectives \(A/D Vault\)](#)

[Get Palliative Care](#)

[Prepare for Your Care \(video tools\)](#)

[Five Wishes \(many languages\)](#)

Thank you!



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