Communication in Serious Illness: An Easier Way to Conduct Difficult Conversations

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Harvard Medical School
Cambridge Health Alliance
Figure 1

All deaths between 1930–2007

- Infectious diseases
- Cancer
- Cardiovascular disease
- Violence
- Other

Percentage of all deaths


The Lancet 2011; 377:1877-1889
Terms and Conditions
A small number of patients are responsible for a large portion of medical cost

Data from a large Massachusetts HMO--2000
Health care cost inflation in Saúde Suplementar

Custo médico-hospitalar bate recorde e cresce quase o dobro do IPCA

<table>
<thead>
<tr>
<th></th>
<th>Mar/2015</th>
<th>Jun/2015</th>
<th>Dez/2015</th>
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</thead>
<tbody>
<tr>
<td>IPCA</td>
<td>8,1%</td>
<td>8,9%</td>
<td>10,6%</td>
</tr>
<tr>
<td>VCMH</td>
<td>15,4%</td>
<td>17,1%</td>
<td>19,4%</td>
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Fonte: VCMH/IESS
Elaboração: IESS 17/05/2016
Variation in hospital use during last six months of life
• Ontario, Canada

• 10% of health care expenditures are incurred during the last year of life.

• Most of them in the last 2 months of life.

• Major expense driver is in-patient hospital use in final 120 days of life.
Welcome

• Agenda review
• Objectives
• What to expect today
Agenda

- Reflections on serious illness and on communication about the goals of care.
- Best practices & failures in conducting these conversations
- A systematic structured approach
- Video demonstration and debrief
- Review of the Serious Illness Conversation Guide
- Skills practice with feedback and debrief
- Next steps
Objectives

• Summarize the rationale for a systematic approach to improving conversations about patient values and priorities in serious illness
• Review the structured approach to conducting these conversations
• Engage in practice and skill building
• Plan next steps to implement these tools in day-to-day practice
Origins of this course

• The Checklist Manifesto

• Being Mortal

• A scientifically validated systematic approach to the problem

• Ariadne Labs at the Harvard T.H. Chan School of Public Health
Credits

The intellectual property in this presentation was developed by Ariadne Labs. Ariadne labs has not reviewed or approved this presentation.

Additional credit is given to Betsy Pollock, LICSW and the staff of the Mount Auburn Cambridge Independent Practice Association. A version of this course was developed in Cambridge by MACIPA.
Reflection
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

Most people want to be at home and prefer comfort-focused care at the end of life.

But that is often not the reality.

Singer  JAMA 1999; Steinhauser JAMA 2000; Heyland Palliative Medicine 2015
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 (elderly and disabled) want to spend final days at home \textit{Barnato 2007}

– 25-39% die in an acute care hospital \textit{Teno JAMA 2013; Silveira NEJM 2010}

– 70% are hospitalized in the last 90 days \textit{Teno JM JAMA 2013}

– 29% receive intensive care in the last 30 days \textit{Teno JM JAMA 2013}

– Many experience care transitions and very short hospice stays \textit{Teno JM JAMA 2013}
What patients get often harms them and their families

Aggressive care for patients with advanced illness is often harmful for patients and caregivers

• 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
Conversations are too little, too late, and not great

- Multiple studies show patients with serious medical illnesses do not discuss end-of-life preferences, or first discuss them only in the last days to month of life (Wright 2008, Dow 2010, Halpern 2011)
- Many conversations fail to address key elements of quality discussions, especially prognosis
- Clinicians and the medical system are important barriers to conversations and care planning
  - Time, under-valuing of cognitive services, lack of confidence on part of physicians
Clinicians and the medical system are important 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
    o Low priority
    o 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

Bottom line: Multiple factors make good conversations difficult.
Among patients with advanced cancer:

• First end-of-life discussion occurred median 33 days before death
• 55% of initial end-of-life discussions occurred in the hospital
• Only 25% of these discussions were conducted by the patient’s oncologist
How to bridge the gap between what patients want and what they get?

Ask patients about their values and priorities.
Palliative or symptom-management services have high value

• Improved quality of life, less use of aggressive interventions, lower costs, 25% longer survival!

• Conversation is a key component of good palliative care
  – When this occurs earlier in the course of illness: less suffering, more goal-concordant care, lower costs, better coping
What do checklists and 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

Materials

**Clinician**

- Conversation Guide (checklist)
- Reference Guide

**Conversation Guide (checklist)**

- **Introducing**
  - What is your understanding of what you face with your illness?
- **Learnt**
  - How much information about what is likely to be ahead do you think would help you?
- **Families**
  - How much does your family know about your illness and the possibility of getting worse?
- **Goals**
  - What is your biggest fear and what helps you face it?
- **What do you do in your life that you can't imagine living without?**
- **What do you do in your life that you can't imagine living without?**

**Reference Guide**

- **Key Influencers**
  - Assessing the world around you
  - Family and friends
  - Health care providers
  - Other resources

**Patient**

- Family Communication

**Family Communication Guide**

- Talking about your illness with loved ones and caregivers

- Guide patient-family conversation (mirrors clinician guide)
The story

1. Pt identification
2. Clinician training
3. Trigger discussion
4. Prepare patient
5. Have conversation
6. Family Guide
7. Document in EMR

More, better, and earlier conversations to change care and improve outcomes

Goal-concordant care at the end-of-life
Peacefulness at the end-of-life
Demonstrating the Skills

• Understanding the patient’s values and priorities
  – Does the patient know his prognosis?
  – What are his fears about what is to come?
  – What are his goals?
  – What trade-offs is he willing to accept, in terms of suffering and care, for the possibility of added time?
Demonstration and debriefing

**Patient is...**

- 67 year old man, lawyer
- Lung cancer, unresponsive to two lines of chemotherapy, metastatic. Renal failure.
- Several recent hospitalizations
- Married, has a 28 year old daughter
- Afraid of being weak and helpless and being a burden to family
- Experiencing weakness and increasing fatigue.

**Goal for today**
Begin to discuss values and goals in case he becomes sicker.
Debriefing

• Does the patient know his prognosis?
• What are his fears about what is to come?
• What are his goals?
• What trade-offs is he willing to accept, in terms of suffering and care, for the possibility of added time?
Serious Illness Conversation

Organized as 2 parts: Checklist + Language

LEFT SIDE

Clinician Steps

• Prompts essential steps
• Follow this intentional sequence
• CHECKLIST

<table>
<thead>
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<th>PATIENT-TESTED LANGUAGE</th>
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<tbody>
<tr>
<td>1. Set up the conversation</td>
<td>“I’m hoping we can talk about where things are with your illness and where they might be going — is this okay?”</td>
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<tr>
<td>Introduce the idea and benefits</td>
<td>“What is your understanding now of where you are with your illness?”</td>
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<td>Ask permission</td>
<td>“How much information about what is likely to be ahead with your illness would you like from me?”</td>
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<td>2. Assess illness understanding and information preferences</td>
<td>“Prognosis: “I’m worried that time may be short” or “This may be as strong as you feel.”</td>
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<td>3. Share prognosis</td>
<td>“What are your most important goals if your health situation worsens?”</td>
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<td>Tailor information to patient preference</td>
<td>“What are your biggest fears and worries about the future with your health?”</td>
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<td>Allow silence, explore emotion</td>
<td>“What gives you strength as you think about the future with your illness?”</td>
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<td>Explore key topics</td>
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<td>“How much does your family know about your priorities and wishes?”</td>
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<td>Sources of strength</td>
<td>“It sounds like __________ is very important to you.”</td>
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<td>Critical abilities</td>
<td>“Given your goals and priorities and what we know about your illness at this stage, I recommend...”</td>
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<td>“We’re in this together.”</td>
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5. Close the conversation

| Document your conversation | |

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Serious Illness Conversation

**Organized as 2 parts: Checklist + Language**

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### Serious Illness Conversation Guide

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Structure: Six Domains or Topics

• Set up the conversation
• Assess illness understanding and information preferences
• Share prognosis
• Explore key topics
• Close the conversations
• Document the conversation
Clinician Step: Set Up

CLINICIAN STEPS

☐ Set up

- Thinking in advance
- Is this okay?
- Hope for best, prepare for worst
- Benefit for patient/family
- No decisions necessary today

See page 5 of Reference Guide for suggested language...
Clinician Step: GUIDE

**Conversation Guide**

- Follow structured questions
- Use these words
- Omit questions not appropriate at this time
Clinician Step: ACT

Key actions to close

- Affirm commitment to care
- “I recommend…”
- Document in medical record
- Encourage patient to discuss with family

☐ Act
  - Affirm commitment
  - Make recommendations about next steps
    - Acknowledge medical realities
    - Summarize key goals/priorities
  - Describe treatment options that reflect both
  - Document conversation
  - Provide patient with Family Communication Guide

Talking about your illness with loved ones and caregivers

This booklet can help you talk with your loved ones about your illness and the future. It is based on what you have already talked about with your doctor.

Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions.

Before you talk to your loved ones, think about when and where you want to talk. Choose a time and place when you feel relaxed. Be sure you have time to talk for a while. You can use the words in this guide, or use your own words — whatever is easier for you.
Principles

• Patients want the truth about prognosis.

• You will not harm your patient by talking about end-of-life issues.

• Anxiety is normal for both patient and clinician during these discussions.

• Patients have goals and priorities besides living longer; learning about them empowers you to provide better care.

• Giving patients an opportunity to express fears and worries is therapeutic.
Practices

Do:

• Give a direct, honest prognosis
• Provide prognostic information as a range, acknowledging uncertainty
• Allow silence
• Acknowledge and explore emotions
• Focus on the patient’s quality of life, fears, and concerns
• Make a recommendation (“Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend...”)
• Document conversation
Practices

Don’t:

• Talk more than half the time
• Fear silence
• Give premature reassurance
• Provide facts in response to strong emotions
• Focus on medical procedures
General Communication

1. 3 W’s: Wish (or Hope), Worry, and Wonder
   Patient: “Will I make it to my grand-daughters graduation in 2 years?”
   Clinician:
   ○ “I wish that things were different; I worry that that’s not likely.”
   ○ “I hope that you can, but I worry that it may not be possible.”
   ○ “I wonder if things you can do to prepare in the event you can’t be there.”

2. Explore
   ● “Tell me more”
   ● “Say more about what you mean by that.”

3. Responding to emotion
   ● “This seems to be very sad news for you.”
Small Group Exercise
Understanding the Patient’s Values and Priorities

• Does the patient know her prognosis?
• What are her fears about what is to come?
• What are her goals?
• What trade-offs is she willing to accept, in terms of suffering and care, for the possibility of added time?
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