

Talking About What Matters:

A structured program to encourage serious illness conversations

Daniela Lamas, MD
Pulmonary and Critical Care Medicine
Brigham and Women's Hospital
Instructor in Medicine
Harvard Medical School
Associate Faculty, Ariadne Labs

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Presenter Disclosure Information

- No disclosures or conflict of interest to report

A little bit about me

- Critical care doctor
- Residency training, cared for many patients with serious illness, both in outpatient clinics and in the hospital
- Wanted to learn to do everything
- Never asked patients what was important to them, what they wanted out of their lives
- Struggled to begin these conversations

Many patients do not discuss their goals with clinicians

- Fewer than one third of patients with end-stage medical diagnoses discussed end-of-life (EOL) preferences with physicians
- Patients with idiopathic pulmonary fibrosis:
 - More than half of patients die in the hospital
 - Only 14% ever referred to palliative care, most of these referrals occurred in last month of life
- Conversations often fail to address key elements of quality discussions

Heyland DK Open Med 2009; Mack AIM 2012; Wright 2008

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



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

Care seriously ill receive often may harm them and their families

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, AA JAMA 2008; Mack JCO 2010

Wright, AA JAMA 2008; Teno JM JAMA 2004



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



Initiating conversations can be a challenge for clinicians

- Lack of clinician training
- Time constraints
- Varying attitudes about serious illness conversations
 - Uncertainty about timing; concerns about harming patients
- Prognostication challenges
- Ambiguity about who is responsible (multiple clinicians)
- No systematic way of identifying patients at high risk

Zhou G Oncology nursing forum 2010; Curtis JR Arch internal medicine 2000; Keating NL Cancer 2010; Sullivan AM Journal of general internal medicine 2003; Buss MK Cancer 2011; Lovell A Palliative medicine 2014; Clayton Support Care Cancer 2005; Back Arch Intern Med. 2009; Wilson J Palliat Med. 2013

Serious Illness Care Program

Multistep intervention includes:

- Conversation guide
- Clinician training
- Prompting clinicians to start the conversation at the right time
- Supporting patients and families as they discuss these issues
- Documenting conversations in the medical record and sharing information with the entire care team

Serious Illness Conversation Guide

Serious Illness Conversation Guide	
CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. <i>Set up the conversation</i> Introduce the idea and benefits Ask permission	SET UP "I'm hoping we can talk about where things are with your illness and where they might be going — is this okay? "
2. <i>Assess illness understanding and information preferences</i>	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?"
3. <i>Share prognosis</i> Tailor information to patient preference Allow silence, explore emotion	SHARE Prognosis: "I'm worried that time may be short." or "This may be as strong as you feel."
4. <i>Explore key topics</i> Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	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?"
5. <i>Close the conversation</i> Summarize what you've heard Make a recommendation Affirm your commitment to the patient	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."
6. <i>Document your conversation</i>	



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Results from study using the Serious Illness Conversation Guide

- Study included more than 70% of all adult outpatient oncology clinicians, over 90 patients
- Training in the guide led to more and earlier conversations, better and more accessible documentation
- Increase in documentation about values and goals
- More than two-thirds of patients reported positive experiences – the conversation helped them plan for the future, and improved their relationship with their clinicians
- No change in survival but it did lower anxiety and depression, and that effect lasted for months after having the conversation

Patients describe a range of positive experiences

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. Y).”

Preliminary Qualitative Analysis

Oncologist testimonial

“I have been using some of the questions when I speak with my other patients about continuing treatment versus hospice, who are not on study, and the one question that I use most frequently is ‘what are you willing to put up with’ I never thought that was a good question until I started to use it. Now, no one has ever told me what they will put up with specifically, but this question has allowed them to think of treatment in that way and it has been unbelievably useful for them to make decisions about stopping therapy.”

Patient testimonial

“This perfectly timed, sensitive, informative conversation brought on a cascade of good.

Immediately I felt gratitude for having a physician who could welcome me into conversation about this critical part of my medical care. This lead easily into the 'what ifs' if things did not proceed well, and the resources I have or do not have in place. I left with no sure answers except that Dr. X is an authentic part of the circle that is lifting me up and through this medical adventure.

Sharing this conversation, later, with my spouse and close family/friends allowed sharing my thoughts with others and, in turn, hearing new ideas and supportive words.”

What's next?

- Learning how to adapt conversation to different populations. Does the same approach and questions make sense for patients with interstitial lung disease?
- Developing partnerships to implement program more broadly
- Education locally, nationally and internationally
 - Healthcare workers
 - Patients/families

Goals

- Improve the lives of people with serious diagnoses, and their families, everywhere by increasing meaningful conversations about patients' goals, values and concerns
- Ensure that conversation outcomes shape the care that patients receive
 - Live as well as possible, for as long as possible
- Develop systems that support patients and clinicians in having these conversations

What can you do? Questions to consider and bring up with your doctor

- What would you like to know about your illness and what is likely to be ahead?
- What kind of information would help you make decisions about your future?
- What is most important for you to have a good quality of life?
- What are you afraid of about your illness?
- What kinds of medical care do you not want?
- If you haven't already identified a health care proxy, who would be able to fill that role?

What can you do? Questions to discuss with your family

Remember: Talking about illness with friends and family may not be easy, but it will help them understand what's important to you, and help them support you and your decisions

Talking with family: How do I begin?

TIPS:

Pick a time when you feel relaxed and have time to talk.

Choose a place where you are comfortable.

You can read the words in black out loud or use your own words — whatever feels best to you.

Start the conversation

I am doing OK right now, and even though there is no rush, my doctors think we need to begin talking about my future care.

They believe in being prepared and want to know my goals and wishes for medical care.

Since you are important to me, I'd also like you to be part of the conversation.

If at some point I can't speak for myself, I want you to be able to make decisions for me.

Talking with family: How to begin

Check in with your loved one

UNDERSTANDING

What is your understanding now of where I am with my illness?

INFORMATION

I know that it may not be easy, but I would like to share information about my illness with you. Is that okay?

How much information about what is likely to be ahead would you like from me?

My doctor and I talked about the outlook for my illness—can I share that with you?

Talking with family

GOALS & WISHES

I'd like to share some of my goals that might affect my healthcare decisions. Some things I'm looking forward to are...

EXAMPLES: Meet my new grandchild, celebrate my next birthday, etc.

FEARS & WORRIES

My biggest fears and worries about my future with this illness are...

EXAMPLES: Not being able to make decisions for myself, or having to ask others for help with basic needs.

ABILITIES

I can't imagine not being able to do certain things...

EXAMPLES: Not being able to recognize or interact with people, not being able to care for myself, etc.

TOUGH CHOICES

I know that we may have to choose between treatments that are hard to go through and more time.

EXAMPLES: Being in the hospital, having a feeding tube, living in a nursing home, being on a breathing machine, more chemotherapy, etc.

Here's how I think about those choices...

Plan to talk again

Do you have any questions about what we have discussed?

I would like to talk with you about my illness and medical care as my treatment continues. Is that okay?

I know this was probably not an easy conversation. How do you feel now that we have talked?

Are there other people we should talk with?

 Remember to talk again with your loved ones / caregivers as your situation or wishes change 

Thank you for your time

Questions?

Ariadne Labs Team

- Rachelle Bernacki, MD, MS
- Joanna Paladino, MD
- Daniela Lamas, MD
- Joshua Lakin, MD
- Bridget Neville, MPH
- Stu Lipsitz, ScD
- Atul Gawande, MD, MPH
- Susan Block, MD

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