

Coleman Supportive Oncology Initiative

Palliative Training Module

Topic: How to Communicate Prognosis

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and Betty Roggenkamp, BA

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Learning Objectives

By the end of this module you should be able to:

- 1. Prepare for a conversation about prognosis by identifying and addressing important steps**
- 2. Identify barriers in communication of prognosis to patients and families**
- 3. Describe how to best communicate a prognosis, responding to patients' emotions in an empathic and respectful manner, eliciting patients' understanding of their illness and identifying what is most important to them**

“Prognosis is a medical term for the expected pattern and outcome of a disease.”

National Comprehensive Cancer Network®, Patient and Caregiver Resources, Cancer Staging Guide,
<http://www.nccn.org/patients/resources/diagnosis/staging.aspx>

When patients have a better understanding of their prognosis and what to expect from their illness, they are better equipped to make decisions about their care that are consistent with their goals and preferences.

Adapted from Dr. Temel, Commentary, Palliative Care: A Primer for Oncologists, Lidia Schapira, MD; Jennifer Temel, MD, August 10, 2015, <http://www.medscape.com/viewarticle/849081>

“How To” Communication Tools

- **Assess preferences for communication**
 - When
 - With whom present
- **Make eye contact, offer a hand shake (if culturally appropriate) and use appropriate body language (e.g., sit close, facing the patient, with arms uncrossed)**

“How To” Communication Tools

- **Ask-tell-ask:**
 - “What do you know about....?”
 - Patients should not be interrupted while they are conveying their concerns or point of view.
 - Use active listening such as nodding or making noises of agreement and encouragement to indicate understanding and compassion.
 - “OK. Here is what the tests are showing us...”
 - “Does that make sense? Do you have questions about that?”
 - You can ask them to explain it back to you to check for understanding.
- **“I wish...”**
 - Enables you to ally with the patient while acknowledging the reality of the situation
 - Expresses empathy inherently

Common Barriers to Prognostic Communication:

- **Patients' or family members' difficulty:**
 - Accepting a poor prognosis
 - Understanding the limitations of cancer treatment
 - Understanding the limitations and complications of life-sustaining treatments
- **Providing information only upon a patient's explicit request or when no further treatment options are available**
- **Communicating overly optimistic survival estimates to patients**
- **Assuming:**
 - What information the patient/family knows or does not know
 - What information the patient/family wants to know or does not want to know
 - What is important to the patient and/or family
- **Feeling responsible for maintaining the patient's or family's hope**
- **Ignoring your own feelings, the patient and/or family**

Prior to a “Bad News” Prognosis Communication

- **If possible, ensure the patient has family or friends present, based on the patient’s preference**
- **Prepare yourself emotionally for how the patient may respond**
- **Be aware of the patient’s culture and background and how these may effect their response**
- **Make the physical space where the conversation will take place as private as possible, even if it is only closing a curtain**
- **Sit down whenever possible**
- **Turn off phones and pagers**
- **Be prepared with responses to common questions patients and family members often read about or researched themselves**
- **Provide the patient and family with contact information for a team member who is available around the clock**

How to Discuss Prognosis: **ADAPT** Mnemonic for Improved Communication

- **A**sk what the patient already knows, what they want to know
- **D**iscover what would be helpful information for the patient
- **A**nticipate ambivalence
- **P**rovide information in the form the patient wants
- **T**rack emotion

Remember, conversations should flow naturally.

This mnemonic and the accompanying information are to be used as signposts providing guidance on what to include in a prognosis conversation. The conversation must remain fluid to meet the needs of all participants. Over time this will come to feel very natural.

How to Discuss Prognosis (1 of 6)

- **Ask** what the patient already knows and what they want to know.
 - *“How do you think things are going with your cancer treatment?”*
 - *“What have you been told about your medical situation so far?”*
 - *“What is your understanding of the reasons we did this (test, procedure, etc)?”*

The goal is to better know your audience

- Can provide perception on how this news might be received
- May discover that some patients already suspect what is coming
- Can give insight on whether patient perceives their illness as serious or not
- May find that you only have to confirm bad news instead of having to break it

How to Discuss Prognosis (2 of 6)

- **Discover** what would be helpful information for the patient.
 - “What have you been told about your medical situation so far?”
 - “What are your current concerns?”
 - “What is your understanding of the reasons we did *this (test, procedure, etc)*?”

The goal is to help patients better plan how to move forward:

- Do not hurry the discussion
- Allow for ample emotional response
- Do not interrupt patients who are verbally conveying their concerns
- Be cognizant of how much the patient wants to know
- Give prognosis in relative terms, such as “days to weeks,” “weeks to months,” or “months to years,” rather than in absolute terms
- Avoid vague terms that can be misinterpreted, such as “poor” or “not good”

How to Discuss Prognosis (3 of 6)

- **Anticipate** ambivalence. Be patient & not falsely reassuring.
 - It is best only to proceed once you have the patient's explicit permission and buy-in as to why discussing this is helpful for THEM.
 - “Talking about this now will help you make the decisions for yourself that are most consistent with your personal beliefs.”

How to Discuss Prognosis (4 of 6)

- **Provide** information in the form the patient wants.
 - “Unfortunately I've got some bad news to tell you.”
 - “I'm sorry to tell you that _____”.

The goal is to be sure patients understand their disease course with or without treatment:

- Use language the patient will understand (e.g., say “spread” instead of “metastasized”).
- Give information in small amounts and check to see if the patient understands.
- Never say, “Nothing more can be done.” There is always something the care team can do for the patient, in terms of pain control, symptom relief, listening and providing answers or referring to palliative or hospice care.

How to Discuss Prognosis (5 of 6)

- Upon communication of prognosis, **Track** emotion.
 - *“I wish I had better news.”*
 - *“I know that this isn’t what you wanted to hear.”*
 - *“It takes a lot of courage to hear this, and to want to know what is coming.”*
 - *“I can only imagine how this feels to you.”*

The goal is to allow for patients to process and understand.

- After giving patients time to express themselves, reconnect with them by moving closer or placing a hand on them if appropriate.
- Use open-ended questions to be sure patients understand the disease course now, with or without treatment.
- Patients may not be able to hear much after prognosis is communicated and may need re-explanation.

How to Discuss Prognosis (6 of 6)

“When bad news is conveyed thoughtfully, honestly, and in a supportive manner, the patient feels less stress.”

Summary of Points Covered

- **Adequate preparation prior to a conversation of prognosis helps communicate empathy and can lessen the stress caused by difficult news. Communicating is a skill that providers should continue to improve upon throughout their practice.**
- **Recognizing and addressing barriers to empathic communication, providers can increase the likelihood that their patients will understand their prognosis. Patients will then be able to make decisions that are consistent with their goals and preferences.**
- **During a prognosis conversation, the best communications will include responding to patient emotions in an empathic and respectful manner, eliciting a patient's understanding of their illness and identifying what is most important to their future.**

Next Steps

For more detailed training on this topic, you can go to the following resources:

VITALtalk

- **VITALtalk: Training oncologists to be better communicators: honest, hopeful, empathic—online and f2f**
 - www.vitaltalk.org
 - www.vitaltalkconversations.com
- **[VITALtalk, Breaking Bad News Map: “SPIKES”](http://www.vitaltalk.org/sites/default/files/SPIKES_1pager_V1.0.pdf)**
http://www.vitaltalk.org/sites/default/files/SPIKES_1pager_V1.0.pdf
- **[VITALtalk, NURSE statements for articulating empathy](http://www.vitaltalk.org/sites/default/files/NURSEforVitaltalkV1.0.pdf)**
<http://www.vitaltalk.org/sites/default/files/NURSEforVitaltalkV1.0.pdf>

Education and Training for Health Professionals, EPEC-O

- **[EPEC](http://www.epec.net/example-EPEC-materials.php), Education in Palliative and End-of-Life Care**
<http://www.epec.net/example-EPEC-materials.php>
- **[EPEC™ -O-Self-Study](http://www.cancer.gov/resources-for/hp/education/epeco)**
<http://www.cancer.gov/resources-for/hp/education/epeco>

ASCO University

- **[ASCO University®](http://university.asco.org/communicating-prognosis), **[Communicating Prognosis](http://university.asco.org/communicating-prognosis)**
<http://university.asco.org/communicating-prognosis>**

Fast Facts

- **[Palliative Care Network of Wisconsin, Fast Fact and Concepts](http://www.mypcnow.org/#!/fast-facts/c6xb)**
<http://www.mypcnow.org/#!/fast-facts/c6xb>
 - **[Delivering Bad News – Part 1 #6](#)**
 - **[Delivering Bad News – Part 2 #11](#)**

Faculty Bio for Lauren Wiebe, MD

Dr. Lauren Wiebe attended medical school at the Columbia University College of Physicians and Surgeons, then she completed an Internal Medicine residency and fellowship in Medical Oncology, both at the University of Chicago. She completed additional fellowship training in Clinical Medical Ethics at the MacLean Center, and Hospice and Palliative Medicine at Northwestern University.

Dr. Wiebe joined the faculty practice at NorthShore University HealthSystem in January 2017 with dual appointments in Palliative Medicine and Gastrointestinal Medical Oncology. She specializes in the treatment of gastrointestinal cancers with a focus on improving quality of life.

For additional information:

<https://www.northshore.org/apps/findadoctor/physicians/lauren-a.-wiebe?qqs=doctor%3dwiebe>

<https://www.linkedin.com/in/lauren-wiebe-7b5aba2/>

Faculty Bio for Megan McMahon, Ph.D.

Dr. McMahon has a Ph.D. in Clinical Psychology with an emphasis in health and behavioral medicine. Her specialty is working with couples who are coping with chronic illness. In 2003 Dr. McMahon developed the program Partners Empowered™, a six-week structured intervention aimed at facilitating adjustment and softening the impact a cancer diagnosis has on a couple's relationship. In 2011, Dr. McMahon was named the Cancer Wellness Center Clinical Director.

For additional information:

<https://cancerwellness.org/about/our-staff/>

Faculty Bio for Betty Roggenkamp, BA

Ms. Roggenkamp has over 8 years of experience in cancer care improvement, through multiple projects in the Chicagoland area. Betty is a facilitator for the Coleman Supportive Oncology Initiative (CSOI) providing project coordination for the Palliative and Hospice design team. Ms. Roggenkamp has facilitated cancer survivor workshops and group discussions to generate areas of need in cancer care. She is also involved with several care initiation projects and cancer survivorship plan creation. Ms. Roggenkamp has Collaborative Institutional Training Initiative (CITI program) certification in human subjects research.

Betty consulted prior to 2010 as an architectural project coordinator for 10 years including planning, design and construction coordination. She also co-lead a team consisting of community, staff, elected officials and Chicago Public School (CPS) executives in an academic turn around of a CPS School that included an addition of a new building, doubled enrollment, increased test scores and improved community relations.

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