Nearing End of Life: Effective and Compassionate Communication Strategies

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Learning Objectives

1. Summarize the common communication **challenges** for clinicians caring for seriously ill patients and their families
2. Outline effective and compassionate communication **strategies** for difficult conversations at end-of-life
3. Describe how effective communication strategies may **benefit** patients and families as they experience illness, dying, and the grieving process.

What's hard about these conversations?

- Our reaction to the patient not doing well
  - Guilt, frustration, impotence
- The patient/family reaction to bad news
  - Emotional
  - What if they do not agree?

The Skills: Overview

- **The basics:**
  - Explore the patient's world: "tell me more"
  - Check expectations, then understanding: Ask-tell-ask
  - Demonstrate empathy: NURSE
- **Communicating bad news**
  - SPIKES
- **Discussing goals of care when things aren't going well**
  - Assessing goals and values, including spirituality and cultural issues
- **Forgoing life-sustaining treatments**
  - Making recommendations
  - Discussing the dying process

Benefits of Good Communication

- Skilled communication with patients and families about the patient's prognosis and plan of care is associated with
  - Improved family satisfaction and bereavement outcomes
  - EOL care consistent with patient preferences
  - Lower costs of care

Mack JW. *J Clin Onco* 2010
Wright AA. *JAMA* 2008
Zhang B. Arch Int Med2009

But how do I start using these skills?

- Deliberate practice:
  - How experts get good at what they do
  - Small bites – try one new skill at a time
  - Reflect back on how it went
  - Set a goal for next time – another skill to practice

VITAL talk

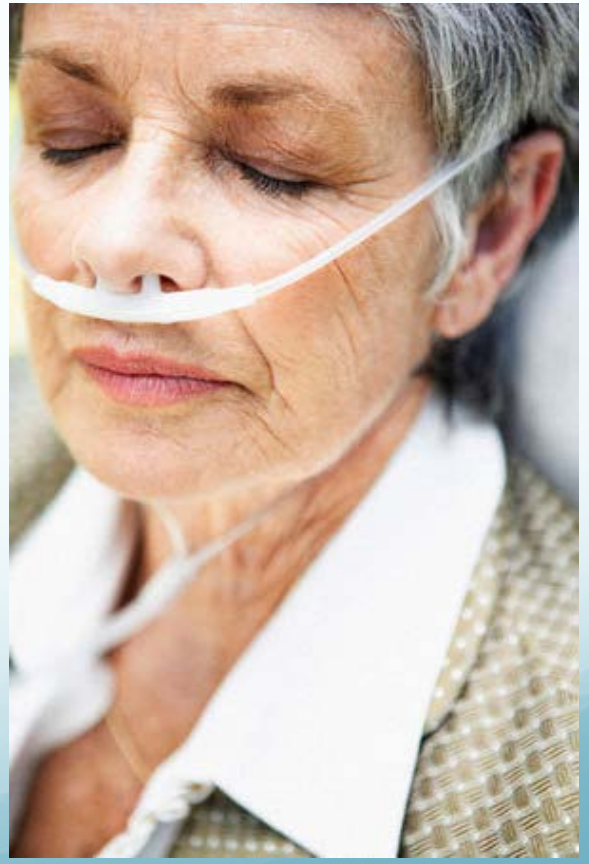
The Basics

The Basics

- Explore the patient's world: "tell me more"
- Ask-tell-ask
- Demonstrating empathy: NURSE
- Emotion vs. cognitive data

Case: Ms. Lopez

- 68 y.o. woman with advanced Idiopathic Pulmonary Fibrosis (IPF)
- Homebound due to dyspnea
- Recently enrolled in home-based care program
- Now hospitalized for pneumonia



Explore the patient's world ("Tell me more")

- Especially useful at the beginning of the encounter
- Helps to clarify their agenda/priorities

Check expectations, then understanding

- “Ask-tell-ask” involves
  - Checking patient expectations
  - Sharing information
  - Inquiring explicitly about the patient’s reaction

- Provides important data for you about comprehension, coping that helps you tailor what you say next

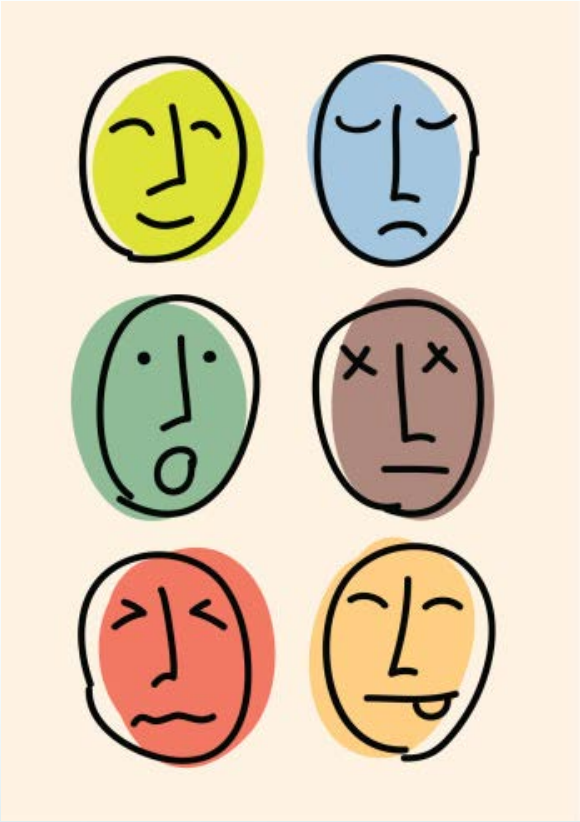
Back AL et al. *Cancer*. 2008

Case: Ms. Lopez visit with NP while in hospital

- NP: “Hi Ms. Lopez, how are things going?
- Patient (crying): “I don’t know how my mother is going to cope with all of this” (silence)
- NP: **“tell me more”**
- Patient: “She knows I am sick and she is praying all the time. I wish I could help her.”

Verbalize Empathy: skills for responding to emotion

- **N**aming
- **U**nderstanding
- **R**especting
- **S**upporting
- **E**xploring



Back AL et al. *Cancer*. 2008

Verbalize empathy

- **N**aming
  - You seem frustrated, worried, relieved...
- **U**nderstanding
  - It must be so hard to go through all of this, I can see how much the pain is affecting you, It must be so hard facing all these uncertainties...
- **R**especting
  - I am so impressed you have been here everyday to visit your mother, I have to tell you how strong you have been through all of these difficult treatments...
- **S**upporting
  - don't worry I will be back in a few hours to check on you, My team and I will be here to help you through this, Here's my card so you know exactly how to reach me if you ever need me...
- **E**xploring
  - Tell me more about how you felt, What do you mean when you said that...

Watch Out

Emotion Data vs. Cognitive Data

- Emotion data is independent of cognitive data
- Emotions can derail cognitive understanding
- Emotional data helps to
  - Judge how much information to cover
  - How much understanding has occurred
  - How fast you can proceed

Back AL AR, Tulsky J. *Mastering Communication with Seriously Ill Patients.* . New York, NY: Cambridge University Press; 2009.

Case: Ms. Lopez visit with NP while in hospital

- Patient: “She knows I am sick and she is praying all the time. I wish I could help her.”
- NP: “It sounds like you are pretty worried about her” (**naming** statement)
- Patient: “Yes, I feel terrible being a burden on my family. My sister works so hard, and my mother is just so sad about my being sick”
- NP: I can see how much this illness is affecting you and your family. It must feel overwhelming at times. (**understand** statement)

Communicating Bad News

Basic Communication Skills: SPIKES

S **Setting**

P **Patient's perception**

I **Invitation**

K **Knowledge (imparting)**

E **Empathetic response**

S **Strategy**

Baile WF et al. Oncologist 2000

Why is skilled communication of bad news important?

- Patients consider the supportive aspects of communicating bad news to be highly important [1]
- Skilled, high-quality communication, with prognostic disclosure, is associated with greater sense of hope among families of seriously ill patients [2]

[1] Parker PA et al. *J Clin Oncol.* 2001
[2] Mack JW et al. *J Clin Oncol*. 2007

Setting and Set-up

- What communication preferences?

“Some people want to know everything about their medical condition, and others do not. How much would you like to know? “

- Who will be present from the family? Who will be present from the medical team? Who’s the proxy?
- Private space, limit interruptions

Baile WF et al. Oncologist 2000

Patient's (or family's) Perception

- What does the patient know?
  - **Ask-tell-ask**
- Establish what the patient knows

  "Tell me what the doctors have told you ...."
- Sometimes patient gives/knows the bad news

Baile WF et al. Oncologist 2000

Invitation

- How much does the patient WANT to know?
  - *"Are you the type of person who wants information in detail or…"*

- "Is it ok if I give you the results of your CT scan?"

Baile WF et al. Oncologist 2000

Knowledge

- Give a warning shot: “unfortunately, I have bad news”
- Give news in small chunks
- **Avoid** phrases like, “there is nothing more we can do”
- **Instead**, focus on support and what you *can* do: “although we unfortunately we don’t have medicine to slow your disease, we will always be here to treat symptoms and help with concerns”

Baile WF et al. Oncologist 2000
Epstein A et al. JAMA Intern Med 2013

Empathy

- Remember NURSE statements
  - “I can tell you weren’t expecting to hear this”
  - “I know this is not good news for you”
  - “You said you are worried about ___. Tell me more”
- Potential Pitfalls
  - Trying to fix it / problem-solving
  - Answering feelings with facts
  - Moving on to strategy too quickly

Baile WF et al. *Oncologist 2000*

I wish…

- Communicates empathy and caring without fostering false hope
  - “I wish things were different”
  - “I wish had a better news for you”
  - “I wish we had stronger medicines to give”
- I wish statements do not need to be followed by a BUT… will negate the previous supportive statement

Quill TE et al. *Ann Intern Med*. 2001

Be sure to check in before moving on

- Problem: When one is emotional, cognition does not work

- Solution: Check-in before moving on

  - *I've given you a lot of information. Do you think it would be okay if we started talking about what happens next?*

  - If the answer is anything other than, "Yes," then you have to stay with the emotion.

Strategy and Summary

- Ask – Tell – **Ask**
- Examples of how to ask:
  - “We’ve talked about a lot of things today. Can you tell me what you will you go home and tell your daughter about our conversation”
- Summarize concrete next steps
- “What questions do you have for me?”

Ms. Lopez
meeting with pulmonologist

MD: “tell me what the doctors have told you about what is happening with your illness”

Ms. L: “I know it is serious. I don’t know if the CT showed anything new”

MD: “Is it ok if I give you the results?” (she nods yes)

MD: “**Unfortunately**, the results of the CT scan were not good (pause). There is worsening of the fibrosis.

Ms. L: “there must be some medicine that can help”

MD: “**I wish** we had something to slow down this disease” (pause)

Ms. L: (sighs) “I just want to feel stronger”

Discussing goals when things are not going well

Goals of Care

- What gives person's life meaning and what hopes s/he has
- Examples (may be multiple): life prolongation or cure, relief of suffering, maintaining functional independence, place of death
- We can support multiple goals:

"hope for the best and prepare for the worst"

Back A et al. Ann Int Med 2003

Eliciting Goals of Care

But first ……..

make certain the person has accurate understanding of disease:

- Ask-tell-ask
- SPIKES

Resistance to hearing the bad news

- Did they hear what you said?
  - Ask
- Is the resistance an emotional reaction?
  - NURSE
  - Wish statements

Eliciting Goals of Care: 3 Steps

	Tasks
1	Assess what gives life meaning
2	Identify hopes and concerns
3	Explore cultural and spiritual issues

Assess what gives life meaning

- What is your life like outside of the hospital/clinic?
- What do you enjoy when you are not in the hospital? How can we help you do more of this?

Elicit hopes and concerns

- What is most important to you if your time is limited?
- When you think about the future, what concerns you the most? What else?
- What's the hardest part of this for you and your family?

Supporting the Surrogate

The Approach	Things to Say
Bring the patient's "voice" into the decision-making process	What gave his life meaning? What things were most important to him as a person? If your husband were sitting here with us, what would he say?
Respond to emotion: "He's a fighter"	Yes, I can see that is a very strong person. He has fought very hard through this disease
"I want you to do everything!"	I can only imagine how hard this is for you. Could you tell me more about what you mean by 'everything'?[1]
Recognize the importance of time and support for surrogates	This is very difficult. Our team is here to support you and your whole family through this process

[1] Quill TE et al. *Ann Intern Med* 2009

Explore Cultural and Spiritual Issues

Cultural Values	Spiritual Needs*
Is there anything that would be helpful for me to know about how you and your family view serious illness? *Are there any cultural beliefs, practices, or preferences that effect you during illness?*	F – Faith and belief Do you consider yourself spiritual or religious? If yes, continue below I – Importance Have your beliefs influenced how you take care of yourself in your illness? C – Community Are you part of a spiritual or religious community? Is this of support to you? How? A – Address in Care How would you like me to address these issues in your health care?"

* FICA Spiritual History Tool. http://www.gwumc.edu/gwish/clinical/fica-spiritual/fica-spiritual-history/index.cfm.

Why addressing spirituality is important

- Most patients, physicians, and nurses believe it is important to address spirituality[1]
- Most patients with advanced cancer report never receiving spiritual care (SC); strongest predictor of provision of spiritual care is receipt of SC training by nurses and physicians[1]
- Among terminally ill patients who are religious, receiving spiritual support by medical teams is associated with increased hospice use, fewer aggressive interventions, and fewer ICU deaths [2]

[1] Balboni MJ et al. *J Clin Oncol*. 2013
[2] Balboni TA et al. *JAMA Intern Med* 2013

Pearls

- Invite the conversation - don’t force it
- Respond to emotion – NURSE
  - Acknowledge loss, reaffirm your support
- When there is conflict, consider:
  - “hope for the best and plan for the worst”
  - “time limited” trials
  - finding a common goal to work on

Dreaded Questions

- “How long do I have to live?”
  - “I’ll answer all of your questions. I wonder if it is frightening not knowing what will happen next, or when.”
- “Does this mean you’re giving up on him?”
  - “Absolutely not. Tell me, what do you mean by ‘giving up’?”
- “Are you telling me that I am going to die?”
  - “I wish that were not the case. I’m also asking, how would you want to spend the remaining time if it were limited?”

Case: PC team meets with Ms. L at home after discharge

- Recovers from pneumonia, now more weak and breathless, needs assistance with transfer
- Back home with sister Josephine (HCP)
- Pall care NP and chaplain meet with pt and sister at home to discuss GOC
- NP starts by asking patient her understanding of her condition now:

“I know I won’t get better. It’s a bad disease I have and it is getting worse. I’m just so relieved to be home. But I am so short of breath. ”

Case: Ms Lopez's GOC

Ms. L shares that her health decline has made her more dependent on others, and this has been difficult for her. She is most worried about her mother's well-being and how she will be able to cope when she dies. She also worries about being a burden on her sister. When asked about spirituality, she states she is Catholic and that her religion is extremely important for her and gives her strength. She believes her illness is part of God's plan, even though she does not fully understand.

She only remembers pieces of her past ICU admissions, but she remembers being in pain and so frustrated she could not communicate. She also recalls how distressing it was for her elderly mother. Ms. L hopes that when she dies she can be comfortable, not in the hospital. She knows she needs to tell her mother about her condition, but she can never find the words.

Forgoing Life-sustaining Treatments

Making a Recommendation

Task	Suggested Language (examples)
Restate the goal, confirm shared understanding	Thank you for sharing that with me. It sounds like the most important thing is to focus on your quality of life and support for you and your family
Ask permission to give recommendation	Given what you have told me, may I recommend some next steps?
Give a recommendation **focus on what you CAN do**	I recommend we treat your breathlessness and other symptoms aggressively to get you feeling better. Knowing that we can't change the underlying disease, if your condition gets worse we will focus on your comfort and allow you to die peacefully.
Confirm understanding and agreement	What questions do you have?, What else concerns you?

When death is near…

- Ask what they know about the dying process
- Ask what experiences they have had
- Emphasize non-abandonment
- Ask if they want to know what to expect in the dying process
- Acknowledge that death is uncertain and unpredictable

When they don’t know what to say:

- I love you
- I forgive you
- Forgive me
- Thank you
- Goodbye

Case: Ms. Lopez

With patient's permission, pall care NP, chaplain, and interpreter meet with patient, sister, and her mother to discuss her condition.

Mother expresses she has already "expected the worst" and that she feels some relief in having information. She holds her daughter's hand, expresses her love for her and tells her "I will be ok".

Patient begins receiving support of home hospice; opiates titrated up to improve dyspnea; and she dies peacefully at home 2 months later.

Communication: Take-home Points

- Skilled communication is key to improving patient and family outcomes at end of life
- The Skills
  - Respond to emotion: NURSE
  - Ask-tell-ask
  - SPIKES
  - Elicit goals of care and make recommendations to support goals
  - Support with guidance about the dying process
- Practice!