What to Say and Do: Communicating Well During Serious Illness

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“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
“The single biggest problem with communication is the illusion that it has taken place.”
George Bernard Shaw
1903

Learning Objectives

• Why it’s important for clinicians to learn to communicate
• How to communicate in a supportive way
• Review the steps guide for delivering bad news using two strategies: Ask Tell Ask and SPIKES 6 step protocol
• Conduct effective family meetings for understanding and clarifying goals of care
What are YOUR goals for this session?

What are some specific issues in communication or communicating bad news that YOU would like to address?

What is Bad News?

Bad news is any information that may negatively affect one’s life.

Examples:
- Diagnosis of HTN
- Diagnosis of dementia
- Disease progression despite maximal efforts
  - Disease recurrence
  - Treatment failure
  - No more disease treatment options
Communicating Bad News

Feared and difficult task for clinicians:
- We worry about anger, rejection, blame, intense emotion from patient and family
- We feel as if we are abandoning the patient by telling the truth
- Our unexamined feelings of failure, our own fear of death
- Time constraints

Why do clinicians avoid giving bad news?
Why do clinicians avoid giving bad news?

• One of the most difficult tasks a clinician has to do
• Not reason for entering healthcare
  – We want to help patients feel good, not bad
• Upsetting confrontation with limits and mortality
• Wish to protect patients from distress
• Fear of patient/family reaction
• Lack of training

Why is it important to learn?

• Most patients (>90%) want to know diagnosis and prognosis
• Strengthens clinician-patient relationship
  – do not turf to specialist if you are a primary care clinician
• Fosters trust- they already know.
• Permits patients/families to plan and cope
Strategies to Improve Skills
(in reverse order of effectiveness)

• Lecture
• Role play
• Standardized patient
• Role modeling, practice, feedback, debriefing
• See @vitalktalk or vitaltalk.org for superb just in time training resources, download app on iTunes

Conversations are a procedure and require training and practice like any other procedure.
Buckman’s 6-step guide
S.P.I.K.E.S.

S etting, listening S kills
P atient’s P erception, P ermission
I nvite patient to share I nformation
K nowledge transmission
E xplore E motions and E mphatize
S ummarize & S trategize

Adapted from Robert Buckman

Step 1: Setting, listening Skills

• Plan what you will say
  – Confirm medical facts; do your homework
  – Don’t delegate
  – Read about prognosis of disease and treatment options, pros and cons
• Determine who else the patient would like present
• Allot adequate time
  – prevent interruptions; silence beeper
Step 1: Setting, listening Skills

• Create a conducive environment
  – Privacy
  – Chairs in a circle, water, tissues

– **Body Language**
  • Seated
  • Eye-to-eye level
  • Open body posture- uncross your arms and legs, make eye contact

Step 1: Setting, listening Skills

• Start with introductions:
  – “My name is...I am from the oncology team. We are meeting to talk about how (patient) is doing. It would be great if everyone here would introduce themselves and say what your relationship is to the patient.
  – Establish ground rules: We have about 45 minutes to talk now. We can always set up another time later if we need it. I want to make sure everyone has a chance to talk and ask questions, so let’s not interrupt each other. I am going to begin by asking you a few questions.”
Ask Tell Ask

• ASK: “What is your understanding of the current medical situation? What have the other doctors told you?” LISTEN

Step 2: Patient’s Perception

• This establishes what the patient/family know already
  – Listen. Then ask if other family members have similar or different understandings.
• Assesses ability to comprehend medical issues, literacy, language, cultural beliefs
Step 3: Invite patient/family to share information

- People handle information differently
  - culture, religion, primary language, literacy, capacity, socioeconomic status
  - age and developmental level
- Autonomy
  - Right to know AND right to refuse information
- Recognize and support patient preferences
  - patient may not want the information
  - patient may designate someone else
  - patient may only want general rather than detailed information

Step 3: Invite patient to share information

- “Some of my patients like to know all the details about their condition, but others of my patients prefer a more general outline— or would prefer I speak with someone else about the situation. Which kind of person are you?”
- What does this question accomplish?
Step 3: Invite patient/family to give their permission

- Ask patient/family’s permission to give information: “Would it be okay if I tell you about the latest scan results?”
- What does this question accomplish?

Step 4: Knowledge transmission

- WARNING SHOT
  - “I’m worried” because the CT scan didn’t turn out quite as well as we had hoped. . . .”
  - What does saying “I’m worried.” accomplish?
- Say it (the news “your cancer has progressed and the treatment is not working.”), then STOP TALKING
  - avoid monologue, jargon, euphemisms
  - pause frequently, check for understanding
- Don’t say “I’m sorry.” Say “I wish it were different.”
Ask Tell Ask

• TELL: “I am worried because the CT scan showed that the cancer is growing.” STOP TALKING, ALLOW SILENCE, ALLOW EMOTION

Step 5: Explore Emotions and Empathize

Prepare for a wide range of responses

• Emotion
  – Tears, anger, sadness, love, anxiety, relief at knowing what they already suspected

• Intellectualized response
  – Denial, blame, disbelief

• Basic psycho-physiologic responses
  – Fight-flight, leave the room, agitation
Step 5: Explore Emotions and Empathize

- Give time to react, it’s a lot to deal with
- Be the calm center who models non abandonment, presence, support, and being able to tolerate strong emotion
- Offer tissues and water
- Listen quietly and attentively
- Encourage descriptions of feelings
  - “Can you tell me a little about what you are feeling right now?”

Ask Tell Ask, cont’d.

- ASK: “Sometimes I use a lot of medical language and I want to be sure I was clear. Can you tell me back what you understood from what I just said?” ASSESS UNDERSTANDING
- ASK: “I know this is a lot to take in. Would you like to talk about next steps?” GET PERMISSION
Developing the plan of care

• Clinicians should take the lead in constructing and recommending the plan, based on the goals developed earlier
  – Avoids “a la carte” medicine, presenting a list of options and asking the patient/family to choose.
  – Appropriate assumption of clinical responsibility, guidance.
  – Check for understanding/agreement

Ask Tell Ask

• LISTEN for: “What’s the next step, Doc?”
• TELL: “At this point in your disease, I’m afraid that the cancer treatment is not working. I want to try other strategies to improve your life and get you as much time as possible at home with your family.”
• TELL: “Your father is dying.” STOP TALKING. LISTEN. (Remember, they already know).
• ASK: “Would you like to talk about what to expect?”
Establishing goals of care

- Consider asking, “If your father were able to get out of that bed and sit here with us, listening to what we’ve discussed so far, what might he say?”
- Refocuses attention on patient’s values/beliefs rather than family wishes

Ask Tell Ask

- **TELL**: “In my professional judgment it is time to focus maximizing your quality of life and having good quality time at home. More chemo won’t help the cancer and may even be harmful. I am going to ask the hospice nurse to talk to you about the support we can arrange at home. *I will continue to be your doctor* and I will work directly with your hospice team. I will be in touch with you by phone and see you in the office when needed.”

**NON ABANDONMENT**

- How does this differ from offering a menu of options?
Step 6: Summarize & Strategize. . .

- Allow for questions
  - “We’ve talked about a lot of things; do you have any questions for me?”

- Summarize
  - “Just to be sure I’ve been clear, I’d like to ask you to tell me in your own words, what your understanding is of what we discussed?”

- Plan for the next steps
  - Additional information, tests, referrals
  - Treat symptoms
  - Next meeting
  - Write it down and hand to patient or family

Step 6: Summarize & Strategize. . .

- Give contact information, set next appointment- write it down

- Before leaving, assess
  - Safety of the patient
  - Adequacy of supports at home
  - If patient is home, call the next day to check in (what does this signal?)
  - If in-patient, come back the next day to check in
Post-Conference

• Communicating the results of the family conference
  – Chart note- who was present, issues discussed, major decisions
  – Discuss relevant issues with members of health-care team not present at meeting

• Debriefing
  – Time to teach
  – Time to reflect

Pearls and pitfalls

• Presence of relevant specialists can be critical to effective meetings
• Families will want to know: what happened, what is happening now, and what will happen next?
• Comfort in the face of strong emotion (the calm in the eye of the storm)
What not to say. . .

Language with unintended consequences

• “Do you want us to do everything possible?”
• “Will you agree to discontinue care?”
• “He’s suffering from our treatments.”
• “It’s time we talk about pulling back on all this”
• “I think we should stop aggressive therapy”
• “I’m going to make it so he won’t suffer”
• “There’s nothing more that we can do”
• “We need to talk about withdrawing care”
• What do these common phrases imply?
What to say. . .

Language to describe the goals of care . . .

- “I will give you the best care possible until the day you die”
- “I will concentrate on improving the quality of your husband’s life”
- “I know this is a lot to take in. I am going to give you some time to talk it over, then we’ll get together again tomorrow.”
Language to describe the goals of care . . .

• “Given what you have told me about what matters most to (patient), I’ll do everything I can to help get him home/maintain his independence/control the pain.”

. . . Language to describe the goals of care

• “Let’s talk about all the things we can do to make the next days and weeks the best they can be.”

• What does this statement signal?
How long do I have doc?

Communicating prognosis…

• Inquire about reasons for asking
  – “Why do you ask?”
  – “What are you thinking will happen?”
  – “How specific do you want me to be?”
  – “Are there things you need to take care of before you die?”
  – “What experiences have you had with:
  • others with same illness?”
  • others who have died?”

• Asses what patient is really asking
  – Some patients want to plan
  – Others are seeking reassurance
  – If they want to know, tell them.
Communicating prognosis

• **Offer a range or average for life expectancy**
  – “On average a person with your illness at this stage lives about 2 months. That’s an average so some people will live longer and other have less time. We will do everything we can to put you on the longer end of that number.”
  – hours to days … months to years
  – can’t predict surprises, get affairs in order now “Hope for the best, plan for the worst.”

• Helps patient / family cope, plan
  – increase access to hospice, other services

Am I dying?

• TELL: “Yes.” STOP TALKING, ALLOW SILENCE AND EMOTION.

• ASK: “Would you like to talk about what to expect in the next few months/weeks?”

• TELL: “The normal dying process involves getting weaker and sleepier over the next months. Eventually it will be harder to get out of bed. At the end, most people sink into a peaceful coma for a few days before they actually die.”
Take Home Points

• How you communicate is important and long remembered by patients and families.
• Communication skills can be learned and improve with practice.
• Use vitaltalk resources

Questions?