

EPEEC-O

Education in Palliative and End-of-life Care - Oncology

Participant's Handbook

Module 7

Communicating Effectively

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Abstract

Communicating information, whether it is good or bad news, is an essential skill for oncologists. This module presents a 6-step approach to structuring communication. The steps include getting started, finding out what the patient knows, finding out how much the patient wants to know, sharing information, responding to feelings, and planning/follow-up. Approaches for handling the family who says ‘don’t tell’ the patient and for using a translator when language is a barrier are advocated.

Key words

Bad news, communication skills, information sharing, language barriers, planning, responding to emotion, translators

Objectives

After studying this module, oncologists and other members of the cancer care team will be able to:

- Explain why the communication of information is a core clinical skill for oncologists.
- Use a 6-step protocol to deliver bad news.
- Use a translator effectively when language is a barrier.

Clinical case on trigger tape

This is an earlier point in time in H.G.’s condition, who presented in Module 2.

H.G. is a 67-year-old mechanic who immigrated to the United States from Mexico 10 years ago. Dr. O’Brien has cared for his family for three years. One week ago H.G. presented to Dr. O’Brien with a chief complaint of weakness. On physical exam, he had occult blood in his stool. Laboratory testing revealed iron-deficiency anemia. H.G. underwent colonoscopy, which demonstrated a mass in the descending colon. The biopsy confirmed the diagnosis of adenocarcinoma. The video shows a scene in which Dr. O’Brien gives him the news of his colon cancer.

Introduction

Communicating information, whether it is good or bad news, is an essential skill for oncologists. Many find it challenging to communicate effectively, especially when this involves a cancer where there is a chance the patient may eventually die. Some feel inadequately prepared or inexperienced. Others fear the news will be so distressing as to adversely affect the patient, family, therapeutic relationship, or the course of the business day.

However, the vast majority of Americans want to know if they have a life-threatening illness.¹ Studies in other cultures yield surprisingly similar data.^{2,3} Although legitimate cultural variations are important, communicating in a direct and compassionate manner improves the patient's and family's ability to plan and cope, encourages realistic goals and autonomy, supports the patient emotionally, strengthens the physician-patient relationship, and fosters collaboration among the patient, family, physicians, and other professionals.

6-steps for communicating effectively

Although this module is designed as a guide to the communication effectively of both 'bad' and 'good' news to patients, the protocol may be viewed more generally as **a model for communicating any important information** to patients and families, or within the cancer care team.

The recommended 6-step protocol has been adapted from *How to Break Bad News: A Guide for Health Care Professionals* by Robert Buckman.^{4,5} He and colleagues have subsequently developed a mnemonic, SPIKES, that helps physicians remember it.⁶ Others have reported similar approaches.^{7,8}

SPIKES

6-step protocol to communicate effectively

Setting. Getting started.

1. Set the stage

Perception. What does the patient know?

2. What does the patient know?

Invitation. How much does the patient want to know?

3. How much does the patient want to know?

Knowledge. Sharing the information.

4. Share the information.

Emotion. Responding to feelings.

5. Respond to feelings.

Subsequent. Planning and follow-up.

6. Plan next steps and follow-up.

During the first 3 steps, prepare to share the information. Start by gathering the facts. Then sit down comfortably and assess the patient's understanding. Inquire what the patient knows, and what s/he would like to know.

Some of these first 3 steps can be completed before the session at which the physician actually discusses the news.

During the last 3 steps, manage the information carefully. Deliver the news clearly, succinctly and without using jargon. Once the facts have been stated, stop talking. Give time for the patient's reactions and respond to them. Once the patient is settled, plan for follow-up.

Don't consider this protocol to be a script to be followed rigorously. Use it as a tool to guide important aspects of an interaction in which difficult information is shared.

Step 1: Set the stage

Before starting to communicate any news, plan what will be discussed. Confirm the medical facts of the case. Ensure that all the needed information is available. If this is an unfamiliar task, rehearse what you will say. Don't delegate the task. If several team members will be present, it may be helpful for the team to meet to plan the communication in advance.

Create an environment conducive to effective communication. Ensure privacy and adequate seating. Ensure that a box of facial tissues is handy and a glass of water.

Allot adequate time for the discussion. Do not slip this into a short interval between other critical tasks. Prevent interruptions. Arrange to hold telephone calls and pages or give them to someone else.

Determine who else the patient would like to have present for the discussion. This might include family, significant others, surrogate decision makers, and/or key members of the interdisciplinary team, eg, nurse, social worker, chaplain, etc.

Step 2: What does the patient know?

Start the discussion by establishing what the patient and family know about the patient's health. With this information, ascertain if the patient and family will be able to comprehend the information.

Questions might include:

- What do you understand about your illness?
- How would you describe your medical situation?
- Have you been worried about your illness or symptoms?
- What did other doctors tell you about your condition or procedures that you have had?
- When you first had symptom X, what did you think it might be?
- What did Doctor X tell you when he sent you here?
- Did you think something serious was going on when...?

Occasionally a patient will fall silent and seem completely unprepared or unable to respond. To ease the situation and stimulate discussion, try to clarify what the patient understands about his or her medical history and recent investigations. Identify absent family members or others on whom the patient relies. If this is ineffective and the patient remains silent, or if it appears the patient requires more support, it may be better to reschedule the meeting for another time.

Step 3: How much does the patient want to know?

Next, establish what and how much each patient wants to know.

People handle information differently, depending on their race, ethnicity and culture, religion, and socioeconomic class. Each person has the right to voluntarily decline to receive any information and may designate someone else to communicate on his or her behalf. Ask the patient and family how they would like to receive information. If the patient prefers not to receive critical information, establish who to give information to.

Possible questions include:

- If this condition turns out to be something serious, do you want to know?
- Are you the kind of person who likes to know all the facts?
- Would you like me to tell you the full details of your condition? If not, is there somebody else you would like me to talk to?
- Some people really do not want to be told what is wrong with them, but would rather their families be told instead. What do you prefer?
- Do you want me to go over the test results now, and explain exactly what I think is wrong?
- Who would you like me to talk to about these issues?

The way the patient answers the questions will give clues as her/his educational level, verbal fluency and family dynamics. Listen carefully and observe everyone's responses to your questions. Use this experience to influence how you deliver your news.

Advance preparation

All of the discussion to this point is about preparation to give the diagnosis and prognosis. Some of that preparation might best occur well before the information is actually given. The initial assessment, and subsequent discussions that prepare the patient for critical tests, all provide opportunities to determine what the patient already knows and how he or she would like to have information handled.

Provide periodic information and caution that the news might not always be good. With this incremental approach and periodic 'warning shots,' the patient and family may be better prepared for 'bad' news.

When the family says ‘don’t tell’

Many times, family members will ask the physician not to tell the patient the diagnosis or other important information. While it is the physician’s legal obligation to obtain informed consent from the patient, an effective therapeutic relationship requires a congenial alliance with the family.

Rather than confronting their request with, ‘I have to tell the patient,’ inquire why they are concerned. Possible questions include:

- Why don’t you want me to tell the patient?
- What is it that you are afraid I will say?
- Tell me about your past experience with cancer?
- Is there a personal, cultural, or religious context that you want me to know about?

Suggest that you go to the patient together to ask how much s/he wants to know about her/his health and what questions there might be. Share anecdotes, talk about the pain of secrecy and the opportunities that come with open communication.

These situations may require significant negotiation. In particularly difficult cases, support from the institutional ethics committee may be very helpful. Ultimately, it may be decided, after discussion with the patient, that details of diagnosis and prognosis and treatment decisions will be discussed only with the family. However, unless the patient has previously indicated that s/he wants no information, hiding the diagnosis or important information about prognosis or treatment from the patient is neither ethical nor legally acceptable.

Physicians do not need to feel constrained to practice in a way that compromises care or feels unethical. If the physician and the family cannot come to agreement, the physician may choose to withdraw from the case and transfer care to another physician.

There are ethnic and cultural differences in the preferred handling of information. While knowledge of such differences is useful as a background, global conclusions about them rarely help with decision making for an individual. Ask a patient about general preferences for handling of medical information and decision making early in the clinical relationship before significant information needs to be shared. This will help the clinician to avoid making a misstep.

Step 4: Share the information

Deliver the information in a sensitive but straightforward manner.

Start by letting the patient know that you have bad news, then share the facts. Say it, then stop. Avoid delivering all of the information in a single, steady monologue. Use simple language that is easy to understand. Avoid technical jargon or euphemisms. Pause frequently. Check for understanding. Use silence and body language as tools to facilitate the discussion.⁹

Do not minimize the severity of the situation. Well-intentioned efforts to ‘soften the blow’ may lead to vagueness and confusion.

You might choose to break the ‘bad’ news by using language like:

- I feel badly to have to tell you this, but the growth turned out to be cancer.
- I’m afraid the news is not good. The biopsy showed that you have colon cancer.
- Unfortunately, there’s no question about the test results: it is cancer.
- The report is back, and it’s not as we had hoped. It showed that there is cancer in your colon.
- I’m afraid I have bad news. The bone marrow biopsy shows that you have leukemia.

I’m Sorry

The phrase “I’m sorry” may be interpreted by the patient or the family to imply that the physician is responsible for the situation. It may also be misinterpreted as pity or aloofness. If you use the phrase, adjust it to show empathy. For example, instead of saying, “I’m sorry to have to tell you this,” the phrase, “I wish things were different,” may be equally effective at communicating empathy without conveying responsibility for the condition.¹⁰

Step 5: Respond to feelings

Patients and families respond to bad news in a variety of ways. Some respond emotionally with tears, anger, sadness, love, anxiety, relief, or other strong emotions. Others experience denial, blame, guilt, disbelief, fear, or a sense of loss or shame, or may even intellectualize why the situation is happening. A few may demonstrate reflexive psychophysiologic responses such as ‘fight or flight’ and may even try to bolt from the room or totally withdraw into themselves.

Outbursts of strong emotion make many oncologists and other physicians uncomfortable.¹¹ Give the patient and family time to react. Be prepared to support them through a broad range of reactions.

Listen quietly and attentively. Acknowledge their emotions. Ask them to describe their feelings:

- I imagine this is difficult news...
- You appear to be angry. Can you tell me what you are feeling?
- Does this news frighten you?
- Tell me more about how you are feeling about what I just said.
- What worries you most?
- What does this news mean to you?
- I wish the news were different.
- I'll try to help you.
- Is there anyone you would like for me to call?
- I'll help you tell your son.
- Your Mom and Dad are sad now. They'll feel better when you get better.

Remind them that their responses are normal. Make a box of facial tissue available. Nonverbal communication may also be very helpful. Consider touching the patient in an appropriate, reassuring manner. Offer a drink of water, a cup of tea, or something else that might be soothing.

Allow time for the patient and family to express all of their immediate feelings. Don't rush them. Once the emotion is 'spent,' most people will be able to move on. This usually last only a few minutes. The most frequent physician error is to talk.¹² Yet, this is counter-productive. A shared understanding of the news and its meaning enhances the physician-patient relationship and facilitates future decision making and planning.

Step 6: Plan next steps and follow-up

Establish a plan for the next steps. This may include gathering additional information or performing further tests. Treat current symptoms. It may include helping parents to tell their child about their illness and what treatment will be like for them. Arrange for appropriate referrals. Explain plans for additional treatment. Discuss potential sources of emotional and practical support, eg, family, significant others, friends, social worker, spiritual counselor, peer support group, professional therapist, hospice, home health agency, etc.

Reassure the patient and family that they are not being abandoned and that the physician will be actively engaged in an ongoing plan to help. Indicate how the patient and family can reach the physician to answer additional questions. Establish a time for a follow-up appointment.

Ensure that the patient will be safe when he or she leaves. Is the patient able to drive home alone? Is the patient distraught, feeling desperate, or suicidal? Is there someone at home to provide support?

At future visits, elements of this protocol may need to be revisited. Many patients and families require repetition of the news to gain a complete understanding of their situation.

When language is a barrier

This same 6-step protocol for communicating information effectively can be used when the patient and physician do not speak the same language. The assistance of an experienced translator who understands medical terminology and is comfortable translating bad news is required. There are several services in North America that offer translation by telephone if there is no one directly available. Brief translators before the interview and reassure them their role is only to translate. Verify that they will be comfortable translating the news you about to give.

If possible, avoid using family members as primary translators. It confuses their roles in the family unit and may raise issues of confidentiality. Additionally, family members may not know how to translate the medical concepts the oncologist is trying to convey, and/or they may modify the news to protect the patient. Instead, when family members are present who do speak both languages, ask them to supplement the primary translation and support the patient and other members of the family.

When working with a translator, sit in a triangular arrangement so that you can face and speak directly to the patient, yet still turn to look at the translator. Speak in short segments, then give the translator time to convey the information. Verify the patient's and family's understanding and check for an emotional response.

Summary

This 6-step protocol for delivering information offers guidelines and practical suggestions on how to communicate any medical information effectively and compassionately, and respond to a patient's and family's feelings and needs. Approaches for handling the family who says "don't tell" the patient, the use of a translator, and the communication of prognosis are also discussed. Tips are provided for when language is a barrier.

The protocol is a framework for approaching this essential task for physicians and all other members of the interdisciplinary team. It is not meant to be a rigid set of rules that must be followed in all cases. Once you have learned the basic steps, learn to customize it to your day-to-day practice patterns, ie, just as you learned to drive a car, etc.

When provided effectively, clear communication can only strengthen the physician-patient relationship.

Key take-home points

1. The vast majority of Americans (>90%) want to know about it if they have a life-threatening illness.
2. Use the 6-step approach, particularly when learning this skill.

Step 1: Getting started

3. Create an environment conducive to effective communication.
4. Ensure that the right people are present.

Step 2: Finding out what the patient knows

5. Start by establishing what the patient and family know about the patient's health.

Step 3: Finding out how much the patient wants to know

6. People handle information differently.
7. Each person has the right to voluntarily decline to receive any information and may designate someone else to communicate on his or her behalf. Find out how the patient would like to receive information.
8. Rather than confronting family members' request not to tell with "I have to tell the patient," explore why they do not want you to tell the patient. Suggest going to the bedside together to find out what the patient wants to know.

Step 4: Sharing the information

9. Deliver the information in a sensitive but straightforward manner.

Step 5: Responding to patient and family feelings

10. Outbursts of strong emotion are an expected component of information sharing. Learn how to cope with this.

Step 6: Planning, follow-up

11. Establish a plan for next steps.

When language is a barrier

12. Verify that translators will be comfortable and sufficiently skilled in translating the news you are about to give.
13. Avoid using family members as primary translators. It confuses their role, frequently compromises the therapeutic quality of the interview, and may compromise some patients' desires for confidentiality.

Pearls

1. The shorter the expected survival, the more accurate physician predictions tend to be.

2. Jargon confuses the message, check for patient/family understanding.
3. The 6-step protocol for communicating effectively provides tools for communication in difficult situations; for families that say “don’t tell,” for defining treatment goals, etc.
4. Don’t use jargon. Patients don’t always understand that, ‘lesion,’ ‘tumor,’ ‘growth,’ ‘nodule,’ and ‘cancer’ may all be the same thing. Use the C (cancer) word. Be clear.
5. If you are feeling overwhelmed by the patients and family’s emotional response, name that emotion, “I can see that you are feeling overwhelmed.” Whatever you are feeling is usually a reflection of the patient’s emotions.

Pitfalls

1. If a patient/family conversation is making you feel anxious, recognize that the family and patient are likely feeling anxious.
2. Stay away from exact predictions of survival. Instead of saying, “Your survival is 6 months,” try, “Your survival is months; how you do over the next month or so will help us better determine what to expect.”
3. Listen, don’t talk too much.
4. Ask the patient what he or she knows about the illness. Nothing is worse than jumping into a discussion of the treatment of advanced cancer only to discover that the patient doesn’t know the diagnosis.
5. Be kind, but don’t try to ‘soften the blow’ by being falsely hopeful.

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