Palliative Care Communication Issues

Joshua Hauser

ABSTRACT

Difficult conversations for patients and families can be challenging for physicians and other healthcare providers as well. Optimal preparation for conversations about bad news, prognosis, goals of care, and hospice can make them more effective and less of a burden. The SPIKES strategy can assist in preparing and implementing these difficult conversations with patients and families. Effective communication can be made a priority by addressing issues proactively with colleagues.

Key Words: Goals of care; Conversation; Prognosis; Hospice; SPIKES strategy; Communication

Ms. A is a previously healthy 50-year-old schoolteacher who initially presented a seizure. A CT scan showed an enhancing mass and she was referred to a neurosurgeon for a biopsy.

CONSIDER

1. How should a clinician prepare to break bad news to patients and families?
2. How does one help patients or families determine the goals of care?
3. What are some ways colleagues communicate with each other about patients near the end of life?
2. KEY POINTS

- Difficult conversations for patients and families can be challenging for physicians and other healthcare providers as well.
- Optimal preparation for conversations about bad news, prognosis, goals of care, and hospice can make them more effective and less burden.
- The SPIKES strategy can assist in preparing and implementing conversations with patients and families.
- When getting a test with potential bad news, make a follow-up appointment to discuss the results so the patient does not need to wait for a phone call.
- Avoid superficially reassuring phrases such as “don’t worry.”
- Have certain phrases in mind before beginning this conversation; do not use these as a script, but consider them preparation.

SCENARIO 1: BREAKING BAD NEWS

Ms. A’s biopsy showed a high-grade glioblastoma multiforme and she has now returned for follow-up.

While it may be seen as a prototype for the act of “breaking bad news,” a new malignancy is not the only type of bad news. Episodes of potentially difficult news include: the first discovery of a diagnosis, subsequent test results, changes in physical or cognitive condition, a transition of care from home to a nursing home, the lack of availability of further disease-modifying treatments, and the transition to hospice care. A strategy to deliver difficult news such as these examples is a skill commonly underdeveloped and therefore a situation often avoided by physicians and other health care professionals. This may be because of lack of comfort, lack of time, or lack of competence. Recognizing its importance and having a framework has been shown to help overcome these barriers.

SPIKES six-step protocol

1. Setting
2. Perception
3. Invitation
4. Knowledge
5. Empathy
6. Summary

One paradigm, developed by Robert Buckman, for breaking bad news is the “SPIKES” strategy. There are six steps in the preparation, discussion, and conclusion. In this framework, Setting describes the physical and temporal context in which one is delivering the news. Perception characterizes the patient’s current understanding of the medical condition, treatment options, and prognosis. Perception can be addressed with an open-ended question such as “What have others told you about what is going on?” Invitation empowers the patient to define the amount of detail she prefers; for example, “Are you the kind of person who prefers to know all the facts about your illness or a more general description?” “How much
information would you like me to give you about your diagnosis and treatment?” “Who else in your family is important for me to talk with?” Knowledge covers the aspect of communicating the difficult information. Most commentators suggest some kind of “warning shot” about news that is about to come: “Unfortunately, I’ve got some bad news to tell you, Mr. James.” “Mrs. Haskin, I’m sorry to have to tell you....” After this introduction, the diagnosis or other piece of news should be delivered clearly, plainly and with a pause at the end of delivery. Empathy is the act of trying to connect with a patient on an emotional level, it may be mistaken for reassurance, but it is a much harder act since it involves understanding the patient without presuming to know exactly how she feels, “How does that make you feel?” “I imagine this must be difficult…” While empathy is considered the fifth step in Buckman’s sequence, it is clearly an important bearing at each communication step. Finally, Summary refers to making clear follow-up plans regarding goals, treatments, and accessing resources.

SCENARIO 2:
GOALS OF CARE

Ms. A’s glioblastoma was treated with surgical resection and a course of radiation therapy. She went home and comes in for a routine follow-up visit. She would like to return to work as a teacher and get back to normal. You realize the value of discussing the goals of care while she is feeling well, but are not sure how to start.

The idea of patients having dichotomous goals of cure at one point and comfort at another is outdated. In reality, most patients balance a mixture of these two goals throughout their illness. There is diversity in patient’s goals of care and these goals are dynamic in nature depending on new medical results, social context, and evolving patient preferences. Therefore, it is never too early to discuss goals of care.

One of the foundational elements of palliative care is that aggressive life-prolonging and aggressive comfort treatments can occur concurrently. Patients may want both concurrently in order to achieve a specific personal goal, such as reaching a certain event or spending more time with a spouse. All members of the interdisciplinary team should strive to elicit patient’s goals, understand and clarify them and advise patients about how to achieve them. One challenge is that the concept of “goals” may seem overly abstract. Therefore, when inquiring about goals of care, consider more concrete questions such as:

- “What is most important for you at this point in your care? What about if things should change?”
- “Are there specific things you want to do or accomplish?”

When asking this, physicians should both acknowledge uncertainty and help patients to think about the future. While “getting rid of the tumor” and “being cured” may be commonly hoped for treatment goals, you may need to insert the possibility of this not occurring. Even in the setting of a partial remission of a tumor, this can be done by using a phrase such as “I hope a cure might be possible, but I also want to help you think about if that doesn’t happen....” You may also want to suggest more specific goals: being at home, going on a certain trip, seeing certain friends or family, finishing a specific project....
“From our talks before and from my sense of you from your daughter, it seems like something important to you at this stage is...”

Other pointers for these discussions include:

– Having ready examples of potential goals of care.
– Beginning with more open-ended questions, and following up with more specific questions.
– Acknowledging uncertainty and changing goals.
– Asking for specific goals and tasks.

**SCENARIO 3: DISCUSSING HOSPICE**

Several months later, Ms. A has become increasingly tired and has lost 20 pounds. She subsequently has a seizure and is admitted to the hospital. A head CT shows tumor recurrence. Her oncologist believes her current performance status makes her a poor candidate for further disease-modifying therapy. You agree that her prognosis is less than 6 months. You visit her in the hospital to discuss next steps.

For many patients and families, hospice may be seen as another piece of bad news. As such, it is important to go back through the SPIKES protocol. As part of this, a crucial element is prior experiences with hospice for themselves, family members, or friends. For some, hospice is associated with giving up and abandonment; for others, it may be associated with emotional and practical support. These associations may not be an abstraction. Since more than 1/3 of deaths are currently cared for by a hospice at some point in their course, increasing numbers of patients and families will have experience with hospice and hearing about their experience is vital for physicians. A patient with a relative who died comfortably and peacefully with hospice care will have a very different association with the idea than one who felt abandoned and “left to die” because her doctors did not know what to do.

In the SPIKES framework, this is part of the Perception step. This can be done simply and straight-forwardly: for example, “A lot of people have had experiences with hospice. Have you? What were they like?” You may even want to be more specific and ask something like, “Were there things about hospice that were particularly helpful? What were they? Were there things about hospice you found less helpful? What were they?” These phrases both allow you to connect with the patient and also get a concrete sense of experiences and expectations of hospice.

Before even introducing hospice, however, establishing a context is important: this includes review of the goals of care, the medical facts, including the lack of available disease-modifying treatments or the recommendation that further treatment for the cancer is likely to be ineffective. The goals of care may help to integrate prior conversations with a change in treatment goals. “I know we’ve discussed what’s important for you. I think hospice may be one way to achieve these things.” Know general outlines of the services that hospice can provide and be prepared to discuss how you will integrate and coordinate with the hospice team.
SCENARIO 4:  
PROGNOSIS

At the end of your conversation about hospice, Ms. A asks, “How long do you think I have to live?” How do you answer her?

For more than a decade, there have been data to suggest that not only are physicians poor at formulating a prognosis, but they are also poor at discussing prognosis. Patients want our accuracy, our candor, and an acknowledgment of uncertainty. A phrase such as “I have no idea, I’m not God,” is not a helpful one since it gives no overall idea of prognosis and actually underplays the amount we do know. At the other extreme, a phrase such as “2 months” or “6 months” can be overly exact almost ensuring the inaccuracy of the statement. Presenting the percentages is also of limited value.

Some clinicians prefer using ranges of time that are based on populations of similar patients. There are various prognostic scales, such as the “Palliative Prognostic Index” for patients with cancer that can give overall estimates for populations of patients based on disease and performance status and comorbidities.

In conversations where a new diagnosis or a change in status is presented, patients may want to know prognosis but be afraid to bring it up: A helpful phrase is “Some patients want to know about their prognosis (or ‘life expectancy’). Is that something that would be helpful to you?” By asking this, a physician can give the patient the option of not hearing about it. If the answer is yes, presenting your best estimation using ranges, such as hours to days, days to weeks, weeks to months, months to years, is most helpful. If the prognosis changes, make sure to review the updated prognosis and the underlying reasons for the change to help patients and families appreciate the dynamic quality of prognostication.

Aside from the exact information, the nature of the request is important. The question of prognosis can be motivated by issues that are financial, physical, emotional, legal, or existential. If a physician only presents numbers, then the real question may not be answered.

SCENARIO 5:  
TEAM COMMUNICATION

Ms. A is being cared for at home with hospice. However, in the last several days, she has become increasingly agitation. Because of concern that this was due to increasing edema around her tumor, the dexamethasone was increased but the agitation continued. Haldol and lorazepam were both added with minimal improvement.

After extensive discussion with her family, a decision was made to admit her to inpatient level of care with the treatment goal of tapering of her steroids and symptomatically treating her agitation, with an understanding that she might die during the admission. Her hospice nurse discussed this with the admitting physician. He signed out to the physician covering for the night that “there’s a hospice patient who is coming in for agitation.”
That night, the covering physician found Ms. A to be agitated with right-sided hemiparesis and an expressive aphasia such that she could not effectively communicate. Given her known glioblastoma, an additional 20 mg of IV dexamethasone was given and the patient’s condition began to improve such that she was more alert and less agitated.

The next morning, her family appeared and said, “I thought that she was dying and now and now she’s more alert. This wasn’t what we wanted and wasn’t what she would have wanted.”

What Happened and How Can We Communicate Better as a Team?

Clinician–patient communication is classically regarded as a core competency in medical care of every sort. Less attention is often paid to communication between team members. This communication must be efficient and thorough if complex care is to be delivered safely and effectively. In this case, communication went from hospice nurse to the inpatient physician. There was a dropped hand-off between the two physicians resulting in a medical error (giving dexamethasone) in the treatment that this patient received.

Specific clinicians may have preferred ways of communicating and different disciplines may have different styles. Nurses, for example, may prefer to sign-out or “hand-off” by voicemail or tape-recorder, while physicians may prefer to be paged. Some clinicians are most comfortable face-to-face, while others prefer email messages. When “hand-offs” do occur, it must be clear who the recipient is and the type of information is conveyed in a compatible style.

Physicians tend to hand-off medical data in bullet points. Nurses may convey more varied information in full sentence format. Rarely do physicians include the goals or intent of the treatment in sign-out unless it relates to future treatments. Developing clear protocols around team communication is vital because missed information, especially about patient preferences and goals of care, can change treatments as it did in this case. This may be especially true in end-of-life care as the treatment goals for symptom management are frequently not congruent with acute care, disease-modifying goals. Since goals may be less obvious and more nuanced, a communication tool that includes goals of care as well as more traditional treatments is vital. Also in the hospice and palliative care setting, there is interdisciplinary hand-off which highlights the need for efficient communication between providers. Therefore, it is helpful to have clear protocols for hand-offs that include both medical details and goals of care.

FURTHER READING

Palliative Care
A Case-based Guide
Loitman, J.E.; Sinclair, C.T.; Fisch, M.J. (Eds.)
2010, IV, 83 p. 2 illus., Softcover
ISBN: 978-1-60761-589-7
A product of Humana Press