Communication: What Do Patients Want and Need?

Oncologists face special challenges when it comes to communicating with patients. The treatment options and adverse effects are complex. Patients are at a time of crisis in their lives. Often, communication involves giving patients bad news. In the midst of these complex aspects of care, dealing with patients' emotions is critical. The good news is that specific communication techniques can help oncologists to improve patient interactions, and training makes a difference, according to communication experts.

Establish Rapport and Lay the Groundwork for Partnership

Lidia Schapira, MD

Oncologist Lidia Schapira, MD, notes that at the outset oncologists often face patient cynicism and mistrust. "There are numerous reasons that a patient might have initial mistrust. They might have had a bad experience with other doctors. They might have been given incorrect information about you or about the cancer center. Many patients don't trust established medicine in general. I've had many patients who talk to me as though there's a kind of conspiracy, such as pushing drugs for profit or personal motives. They sometimes distrust the pharmaceutical industry." Schapira practices at the Gillette Center for Breast Oncology at the Massachusetts General Hospital (Boston, MA) and publishes on oncology communication issues.

To gain patients' trust, Schapira offers these practical suggestions: "The most important thing is a genuine, caring presence. Show interest in the person. Let the patient know that you have reviewed the records, that you understand the diagnosis and pathology. Set the agenda to work collaboratively with the patient, aligning your expectations with those of the patient. Only then discuss the treatment options."

Debbie, a patient from Virginia with stage 4 melanoma, corroborates this approach. She sings the praises of her current oncologist: "He's always prepared when he comes in. He's not afraid to make physical contact—he puts his hand on my shoulder or back when he listens to my lungs. He makes eye contact. He never rushes me."

Listening actively is critical for establishing patient rapport. Let the patient tell his or her story. Do not interrupt or break in with your conclusion or even your questions. If you need to write something in the record, explain that you need a moment to jot down some notes. These behaviors help convey attentiveness.

James Tulsky, MD

The trust and rapport established in early patient encounters lay the groundwork for effective communication later on, when more difficult conversations regarding end of life care or disease progression may be needed. In addition, says James Tulsky, MD, "Patient concerns early in their illness affect later anxieties and depression. So if we are better at resolving those concerns early, we can decrease future anxiety and depression." Tulsky is director of the Center for Palliative Care at Duke University (Durham, NC) and on the faculty of "OncoTalk," a communication skills educational program for oncologists.

Devote Time to Explanations

Before explaining treatment options and your recommendations, tell the patient that you realize he or she is probably anxious, that anxiety is quite normal, and that it may result in the patient's not remembering everything. Acknowledging their anxiety helps puts patients at ease.

Patients often bring a family member or friend to oncology visits. If they do not, consider encouraging them to do so, not only for the social support it provides, but also so that another person is hearing your explanation and recommendations, to help the patient recall them later.

Listen attentively to patient questions. This is how Shirley, who lives in Ohio and has stage 3C melanoma, describes her dream oncologist: "The first thing, he would be willing to sit there and answer my questions. The most important thing is to have my questions answered." Shirley had experiences with two oncologists who failed to do so. "The only time my surgical oncologist answered my questions was at the initial visit. From then on it was 'one hand on the door.' I felt brushed off." Later, her medical oncologist was not forthcoming with information. "He was kind but I had to push for everything. I finally got fed up and switched to another cancer center."

Schapira notes, "If the patient is unable to ask a single question, that's a red flag. In the absence of questions, invite the patient to tell you what they've understood. Use very clear language and speak with pauses."

Debbie, the patient from Virginia, put it this way: "Doctors need to explain in lay terms what is going on and what they can do for patients."

Multiple modes of communication are helpful. In addition to your oral explanation, use drawings and diagrams with the patient. Provide a written record of what is recommended, along with suggested reading and a referral to a Web site with trusted information. "Don't put pressure on the patient to make a decision at that time, but encourage him or her to take time to make a truly informed decision," Schapira says.

Tulsky suggests using the "ask-tell-ask" approach to provide explanations to patients. "Start with asking the patient what their understanding of the illness is. Ask 'What have the other doctors told you is going on?' Their understanding of things is incredibly important. Then, after you've heard, tell. Tell them new information you want to add to what they already know. Finally, ask what they understand that you have told them."

One Size Does Not Fit All

Some patients want more information or need a different kind of explanation about their treatment options and prognosis. Be sensitive to cultural values and personal experience that may affect what they want to hear. For example, some people consider talking about death as unwise, unlucky, or a violation of their spiritual beliefs.[1] Do not assume what patients want to know; before initiating explanations, ask questions to ascertain the level of information wanted or needed.

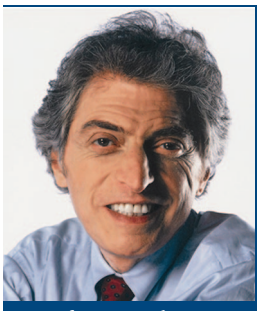
For patients with low health literacy, detailed factual information is often not relevant or useful. All patients, but especially those with low health literacy, are interested in information that helps them address their immediate health problems. Consequently, you should be clear about what patients need to do, when they should do it, and why doing it will be beneficial for them. Keep in mind also that patients with limited health literacy tend to ask fewer questions than do others.[2]

Decision-making preferences are also highly variable. Schapira points out that some patients favor a "more collaborative style whereas some want a clear, simple recommendation that is more directive."

Debbie is a registered nurse with 33 years of experience, and in determining treatment for her stage 4 melanoma, she definitely wanted a strong voice. Her cancer is now in remission after interleukin-2 treatment. "It's very important that patients are allowed to assume ownership of their treatment," she says. She left the care of an oncologist who "wouldn't listen to me. He would interrupt me, cut me off. I never felt we were on the same team—it always felt adversarial." She greatly appreciates her current oncologist, who "affirmed that I knew what I was talking about and validated that I was the captain of my team. I could call the shots."

In contrast, Judy, the mother of a patient with stage 4 cancer in California, wishes the oncologist were more directive. "If he suggests a certain treatment and my son or his wife balks in any way, he will back down. This is absolutely a communication issue. My son does no research and is somewhat in denial. He really doesn't seem to realize the urgency of this situation, and the oncologist doesn't push the issue. There have been times when I want to ask a question but am terrified of what the answer might be, so I let it go. I think the oncologist needs to address all possibilities of treatment and consequences. We need that in order to make informed decisions. Our fear of answers should be addressed."

Addressing Emotion Is Key



Robert Buckman, MD

Toronto oncologist Robert Buckman, MD, who has taught and published in the field of physician-patient communication for more than 20 years, confirms that patients' not asking questions because of fear of the answer is common. "It could be the patient is completely quiet, or maybe they've raised their eyebrows. The important thing is to realize your patient is in the grip of fear," he says. He suggests offering a simple statement such as "this is a bit scary," or "you seem frightened" to open the door to the patient.

Buckman states emphatically that dealing with emotions is the most important aspect of communicating with patients. "If a patient is deeply distressed or panicked, we need to be able to acknowledge that. It should be an essential part of our skill set, but we haven't been trained in how to deal with emotions in interviews. If you can do that, you can do almost anything—break bad news, tell about recurrence, or make the transition to palliative care."

The first step in responding empathically, Buckman says, is to identify the emotion the patient is experiencing. "Give it a name in your mind—fear, panic, disappointment, anger, despair. There may be a dozen emotions. Pick a lead one, and think about what caused it. Then, respond in a way that shows you have made the connection between the emotion and its cause. You might say 'This outcome is very disappointing' or 'This is obviously a terrible shock to you." Buckman says that this response does two things: It tells the patient "you are allowed to feel this" and it also says "you and I are allowed to discuss your feelings."

Barriers to Addressing Emotion

Kathryn Pollak, PhD

Duke social psychologist Kathryn Pollak, PhD, points to a number of barriers oncologists face in addressing patients' emotions. "Physicians are trained to be medically oriented, not psychologically oriented, and patients often express their emotions very indirectly," she says. "The patient may say 'the tumor is getting bigger,' which represents an opportunity for the doctor to acknowledge the emotion that the patient must be feeling. Instead, the physician responds from his medical perspective: 'Yes, it was 4 millimeters and now it is 6 millimeters.'

Shirley, the patient from Ohio, recalls how she felt after an interchange that demonstrates this mismatch between desire for emotional support and the doctor's medically oriented response: "When I asked about my five-year survival rate, he told me I had a 24% chance of being here in five years. That was it. No pep talk! No telling me, 'Oh, you're a fighter—you'll make it.' Just a cold slap in the face. I looked at my husband after the doctor left and said 'I'm going to fight like hell to beat this thing just so I can prove him wrong.'"

Another communication barrier oncologists have is dealing with their own emotions. Pollak comments, "Oncologists are trained to cure, but their patients don't do well, and many times their patients die. For a doctor, trained to be a healer, it is really hard to suffer loss after loss. They start to distance themselves because it hurts."

Communication Barriers

Patients might not ask questions because they:

- Fear the answer
- Want to avoid feeling stupid
- Consider their uncertainties trivial
- Feel rushed
- Were previously brushed off by the doctor

Patients might not disclose problems because they:

- Do not want to seem negative or ungrateful
- Want to be strong
- Think their concerns are not legitimate
- Do not want to add to the doctor's burdens
- Believe nothing can be done

Physicians block communication when they:

- Give cues that they feel time pressure
- Allow distractions
- Do not acknowledge the patient's emotions
- Address physical aspects only
- Offer reassurance before the main problems have been identified

Skills Can Be Learned

Training in communication skills can help physicians effectively address patient emotions. "There's a growing awareness that these skills can be modeled and evaluated," Schapira notes. Indeed, all the communications experts consulted for this article stressed that communication skills can be learned and that additional training is needed.

An educational program developed by Tulsky, Pollak, and others at Duke teaches the use of a "continuer statement" when an opportunity for an empathic response occurs in a patient encounter.[3] Such a statement offers empathy and allows patients to continue expressing emotions. The Duke team uses the mnemonic "NURSE" to label five types of continuer statements:

Name: State the patient's emotion

Understand: Empathize with and legitimize the emotion

Respect: Praise the patient for strength

Support: Show support

Explore: Ask the patient to elaborate on the emotion

Using the example of the patient's comment that the tumor is getting bigger, Pollak says the doctor could use any of several of these continuers, such as showing respect with a statement such as, "You've been so strong." With this comment, she says, "The patient feels heard and can then go on. When the doctor goes right past it, the patient feels a sense of unrest and anxiety."

Address Social Support, Too

Schapira reminds us that in addition to directly acknowledging emotion, oncologists need to "ask patients about distress—an umbrella term that encompasses social, physical, and financial worries, whether that is transportation, who is going to mind the children, or the fear of dying. They need a way of opening up the conversation so that patients will disclose concerns." If the oncologist can't do it, then he or she needs to be sure that another member of the staff does it.

Shirley expresses an example of such concerns. "My husband had no one to talk with. He didn't want to say certain things to me to make me worry more. He was like a lost puppy with no one to turn to. It would have been nice if some sort of support was offered to the spouses and family members. After all, they are a crucial part of our recovery process."

She reports that her emotional and social needs and those of her family were never addressed at the first cancer center she went to. "No one said, 'How do you feel? Are you OK? Would you like to get into a support group?'"

Techniques to Improve Physician-Patient Communication

- Sit at eye level with the patient
- Be focused on the patient during the visit
- Make eye contact
- Speak in short sentences
- Use simple language and pause frequently
- Use drawings and pictures to explain a procedure or a condition
- Ask the patient to describe his or her understanding of your explanation
- Give a written summary of recommendations
- Acknowledge the patient's feelings
- Determine how involved the patient wants to be in decision making
- Find out about the social and financial concerns of the patient and family
- Fight the urge to interrupt the patient
- Allow silence during the conversation
- Hide any cues that you feel time pressure
- Avoid asking simply, "Do you understand?"

Breaking Bad News

Every oncologist dreads telling the patient that no additional treatment will be helpful. Schapira offers the following advice for this patient communication: "The first place to start is to anchor the conversation in the shared history between the physician and the patient. I often remind the patient of the journey we have traveled together, how perhaps we both wished for more successful treatment. If the patient is able and willing to hear more, explain what lies ahead. If there's no good anticancer treatment, put it out there as clearly and honestly and empathetically as possible. Help the patient sort through this news, explaining that more cancer treatment is not likely to produce a good benefit, and that's why you are recommending no more treatment. Then, turn the page, basically, and talk about how you are committed to the well being of the patient, paying particular attention to relieving symptoms."

Often, Schapira notes, the patient expects this at this point in treatment. She suggests scheduling a follow-up meeting for a few days later. "The kindest thing to do is to talk in installments over time." Give the patient the opportunity to process the information and ask questions.

The instinct for physicians to be protective may lead them to withhold information, Schapira says, but "this ends up not being good." In other words, as hard as it is, be honest with the patient. A study on communicating with dying patients found the need for physicians to be honest and candid was the top priority of patients, family members, and health care workers.[4] The researchers concluded, "Maintaining an element of hope is important to many patients. If cure is not an option, then hope may be oriented toward maximizing quality of life and making the patient comfortable. Any hope offered must be realistic and relevant."

Tulsky suggests incorporating the instinct to help into a "wish statement." When the patient asks, "Doctor, isn't there another treatment I could try?" Respond with, "I wish there were another chemo[therapy] treatment to help you."

Tulsky explains that the wish statement is powerful because "you are aligning yourself with the patient, saying 'I want the same thing that you want.' You are also implicitly acknowledging that it's not going to happen."

A response that Tulsky calls the "converse to the wish statement" should be avoided. In this scenario, when the patient asks, "Isn't there something that we could do?" The physician should not answer, "I suppose there is. We've never used it in your illness, but we can try." The physician knows that this treatment will not make any difference, but responds in this way out of the instinctive desire to meet the patient's needs and lessen the patient's distress and feelings of hopelessness. But, Tulsky cautions, this approach is ultimately deleterious because it does not allow the patient to make the transition to new goals. Making the transition from the primary goal of curing the illness to other goals such as peace and dignity in dying is an essential element of palliative and end-of life-care. Offering false hope to the patient delays this transition and is not helpful for the patient or the patient's family.

In breaking bad news to patients, Buckman suggests using SPIKES, a six-step protocol taught in communications skills workshops developed at the M. D. Anderson Cancer Center (Houston, TX).[5] Like the NURSE mnemonic, SPIKES is an acronym that you can use as an aid in implementing a complex and stressful task.

The SPIKES protocol calls for these six steps:

S—Set up the interview: Plan ahead for details such as being sure that you are in a private, comfortable setting, that significant others are involved (if the patient wants that), and that your pager is silenced.

P—Assess the patient's perception: As described earlier, before you begin an explanation, ask the patient open-ended questions to find out how he or she perceives the medical situation. In this way you can correct any misunderstanding the patient has and tailor the news to the patient's understanding and expectations.

I—Obtain the patient's invitation: Find out how much detailed information the patient wants regarding diagnosis and prognosis.

K—Give knowledge and information to the patient: Communicate in ways that help the patient process the information. For example, preface your remarks with a phrase

such as, "I'm sorry to tell you that . . ." or "Unfortunately I have some bad news to tell you." Use plain language and avoid medical jargon: use the word "spread" instead of "metastasized," for instance. Provide information in small amounts, use short sentences, and check periodically for understanding.

E—Address the patient's emotions with empathic responses: As described earlier, identify the patient's primary emotion and express that you recognize that what the patient is feeling is a result of the information received. This is the place to use continuer statements such as "I can imagine how scary this must be for you."

S—Strategy and summary: Present treatment or palliative care options, being sure to align your information with what you ascertained (during the assessment of the patient's perceptions) to be the patient's knowledge, expectations, and hopes. Providing a clear strategy will lessen the patient's anxiety and uncertainty.

Research on patient preferences for communication regarding bad news confirms that using a protocol such as SPIKES is likely to meet patient expectations regarding the content, the setting, and the emotional support for this conversation.[6]

Benefits of Improving Communication Skills

The focus here has been on the benefits of good communications for patients. Numerous studies as well as anecdotal reports make clear that improved communication improves patient satisfaction, promotes adherence to treatment, and reduces anxiety.

Training that includes modeling of effective interactions and evaluation of how the learned behavior is incorporated is available. Acquiring key communication skills will help you identify your patients' problems more accurately and give you greater job satisfaction and less work-related stress.

Additional Resources

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