

It's Never Easy

DELIVERING BAD NEWS TO PATIENTS

BY DIANE TOROIAN KEAGGY, M.A.

There are two things oncologist Robert Quadro never forgets when he is about to tell a patient bad news — Kleenex and his watch. “When I give bad news I try to say nothing for two to three minutes so the patient can process the information, and I just try to be present with them,” said Quadro of Mercy San Juan Medical Center in Carmichael, Calif. “I actually watch my watch because it’s going to seem like an eternity. So often a doctor will give bad news and instantly jump in and say, ‘We can do this, we can do that.’ There’s just too much talking.”

Medical school taught Quadro how to treat cancer, but not how to talk to patients when treatment failed. But today, physicians and caregivers are taking special care to deliver bad news in ways that are humane, yet honest.

“We are finding that language is everything,” said Satya Jaech, regional coordinator for palliative and end-of-life care at the Providence Center for Health Care Ethics in Portland, Ore. The center developed a language guide to help clinicians hold difficult conversations. “Language can invite people to talk more; language can calm people’s fears.

“In our hospitals we are absolutely committed to the fact that dying is a sacred event,” Jaech said. Using language that eases the fear and confusion of patients and their families can reduce emotional turmoil and free people to focus on the quality of the patient’s life and death.

Medical schools offer courses on the topic of delivering bad news, researchers are studying how patients absorb these conversations and hospitals are providing caregivers training to help patients grapple with the

spiritual implications of their medical conditions.

Quadro lectures on the subject. The first thing he tells students is that it’s never easy — not for the patient, not for the doctor. One patient slammed Quadro against the wall when he learned he had AIDS, another tried to choke him. And then there was the 92-year-old woman who could not fathom her cancer returning.

“She said to me, ‘I just never saw this coming,’” recalled Quadro.

“And I felt like saying, ‘Really?’ But it reminded me no one is prepared. It’s always an emotional experience.”

When it comes to delivering bad news, most doctors agree on a common set of dos and don’ts: Do make enough time to answer a patient’s questions; don’t use technical jargon. Do find a private space to talk; don’t expect a patient to remember most of the conversation. Do prepare; don’t get flustered when those preparations unravel.

“No matter how hard you try to set the time and place, sometimes the patient will take that out of your hands and ask you a question at the most inopportune moment, in the hallway, in the

elevator,” said Quadro. “I’ve learned that patients will force your hand, and they do so on purpose. Many times I’ve had a patient say while leaving the room, ‘I’m going to beat this cancer, right doc?’ and what they are trying

to do subconsciously is to get you to say everything is going to be fine. If that happens, I’ll say, ‘Let’s go back in the room and sit down and talk because this is too important a conversation to have in the hallway.’”

‘DEAD IN A YEAR’

Like Quadro, Jean Keck trains physicians as well as volunteers to speak to the dying. She also is suffering from Stage 3 lung cancer. Her primary care doctor could barely tell her the news.

“It was so hard for her,” recalled Keck, a 57-year-old bereavement therapist for the Visiting Nurse Association & Hospice of Erie County, Pa. “I said to her, ‘First of all sit down’ and then I held her hand. She was simply overwhelmed by her compassion. I was the one who said, ‘It’s lung cancer, right?’”

The next doctor, a specialist, had more experience with life-threatening illnesses, but was no better talking to patients. When Keck asked about surgery, he looked at her incredulously.

“He said, ‘Oh no, you are going to be dead in a year,’” said Keck. “I had that deer in the headlights look. I couldn’t believe he just said that. He asked if I had any more questions, and I said no.

I knew there was no way this man was going to be my doctor. I'm not unrealistic, I work for hospice."

Keck's experiences have reinforced her belief that doctors do not undermine their mandate to be honest by demonstrating hope and compassion.

"Many physicians have received pitifully little education in this area," said Keck. "It takes courage to listen to someone's fears and end-of-life issues. I think doctors who invite people to talk about their feelings and express their needs serve their patients best."

THE GIFT OF HOPE

As a family physician and medical director at Hospice of the Gorge in Hood River, Ore., Dr. Tina Castañares has delivered every imaginable diagnosis — autism, cancer, heart disease. Still, she calls bad news a misnomer.

"That's the term, it appears everywhere," said Castañares. "But sometimes it's a great relief to hear a name given to the condition they've been suffering symptoms from and to have a real nuts-and-bolts discussion. Or sometimes it's a great relief to get away from the medical discussion and to now look at something that is not so medical — a discussion about death and dying and preparing for it."

Dr. P. Terrence O'Rourke, chief clinical officer at Trinity Health in Novi, Mich., agrees doctors should not presume to know what a diagnosis means to a patient. When he treated seriously ill patients, he often invited families to return at the end of the day to talk about a diagnosis. Their responses and questions provided O'Rourke valuable clues about their medical literacy and personal priorities.

"Never say, 'There's nothing we can do.' There's always something that can be done, like controlling pain for instance. We can almost always control pain. So clarifying what is the greatest concern and what they really want to talk about is very important," said O'Rourke. "It requires time and requires that you really stop and listen to what patients have to say. If you're going to

take care of these kinds of patients, you have to take time. It would be immoral to tell a woman she has breast cancer and not be prepared to talk an hour plus about what that means."

WHY ME?

But doctors often are stumped when the conversation moves from "how long" to "why me?" Castañares turns to her faith for these talks.

"I don't believe it's God's punishment, but it doesn't matter what I believe. When I was younger I might have said that, but all that does is distance me from the patient," said Castañares. "When you respect people's spiritual lives as much as their physical lives, you can help make this a very uplifting passage, a time for reconciliation with this earth and the people on it, a time for preparation. The spiritual questions give me an opening to remind them I'm going to stand with them."

Highly trained chaplains also help patients work through the tough questions, said Mary O'Neill, vice president of mission and ministry at Maryhaven Center of Hope, a long-term care facility in Port Jefferson Station, N.Y. At many Catholic facilities, chaplains are a central part of a patient's team.

Experience has taught O'Neill that how bad news is delivered has both

medical and spiritual repercussions.

"Patients and families will forever remember that moment when bad news is given," said O'Neill. "They will remember where they were, what was said, how the doctor said it. That can have a real impact on how the patient copes, and how a patient copes with an illness has an impact on the illness."

"Even if [patients] are moving towards death, they can have meaningful good-byes, meaningful relationships with family, they can have meaningful grieving," said O'Neill.

This holistic approach has long been at the core of Catholic health care. In addition, studies show that patients with a strong faith tend to greet death with less anxiety and anger.

Castañares said it is an honor for a doctor to be able to care for a patient in the throes of a terminal illness. "It scares us, but it's a privilege. When it comes to looking back at our professional lives, I think many of us will wish we engaged more. We'll wish that we held that person's hand, we'll wish we hadn't turned and walked out the door" after delivering a bad prognosis.

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PROVIDENCE HELPS PROVIDERS CHOOSE WORDS WITH CARE

Words can soothe like a mother's lullaby or hit with the force of a loaded weapon. The power of words is particularly important in conversations in which a physician must broach the subject of a patient's mortality.

To help clinicians choose their words carefully in these situations, the Providence Center for Health Care Ethics developed and distributes a guide to doctors and nurses that includes conversation-inducing words and phrases, as well as tips on conducting family meetings. The guide is based on a semantic tool used at the University of California, San Francisco.

These are examples of useful language for conversations with sick patients:

- Can you tell me what your understanding is about your illness?
- When you think about the future, what do you hope for?
- We will never give up on you; we are just shifting our care from curing to healing.
- Do you have any spiritual beliefs or practices that are important to you?

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