

What to Say

WHEN TREATMENT FAILS

by Mary Sawyers



third underestimated the extent of their disease, and one-fifth mistook the goal of treatment as curative rather than palliative.² Their doctors were rarely aware of this misunderstanding.

It's not just the patients who recognize this disparity in understanding. Twenty percent of oncologists surveyed said they lacked the skills needed to communicate with patients at the transition to palliative care. And those are just the doctors who admit to the problem, says Karen Stanley, R.N., M.S.N., AOCN®, F.A.A.N., a clinical nurse specialist who helped design the survey. Stanley has spent 20 years as a palliative care nurse. "My unofficial title was the 'Death Nurse.' It was never spoken, but the doctors often relied on me to give the bad news. It's remarkable to me that these folks knew when they got into this that their patients were

going to die, and many don't have the skills to handle it."

Stanley was one of 15 oncology clinicians attending a training session at the Bayer Institute for Healthcare Communication. The participants spend five days learning to teach a course entitled "Care Not Cure: Dialogues at the Transition." This four-hour workshop is designed to give practitioners the skills they need to communicate with patients about treatment failures and palliative care. The participants return to their home institutions ready to teach the workshop to fellow oncologists and their support teams, including nurses, social workers, and psychotherapists.

"The whole idea is that they'll develop a more effective method of relating to patients in transition to palliative care," says course instructor Gordon. "There's a big difference in prescribing treatment protocols for patients and talking to them about what's meaningful and enjoyable in their life. Both are important, but we tend to emphasize one over the other in training and practice."

The workshop draws on cancer communication literature published during the last 10 years. The workshop alternates short, evidence-based descriptions of key skills with hands-on, small-group exercises to practice the skills using videotaped and workbook cases.

One of the videotapes shows an office visit between

What do you say when a young lung cancer patient has exhausted all her treatments and she tells you that dying is not an option? She has two small children at home and her husband doesn't even know how to dress them for school. What do you say when a patient with advanced colon cancer asks if you believe in God and if you will pray for him?

Cancer clinicians face these kinds of scenarios on a regular basis, but few of them know how to respond, says Geoff Gordon, M.D., F.A.C.P., a general internist and associate director at the not-for-profit Bayer Institute for Health Care Communication in West Haven, Conn. "The problem is that physicians, patients, and families take on high-risk, high-burden treatment hoping it will cure or control the disease. When it doesn't, it's hard for everyone to acknowledge the situation and shift towards setting more realistic goals. Patients look to doctors for hope, and I think it's our responsibility to learn the appropriate communication skills."

This breakdown of communication is well documented in the literature. In one survey, 80 percent of breast cancer patients said they had trouble communicating with their physicians.¹ Another survey of lung cancer patients found that, compared with their physicians, one-

Katie Johnson, a 45-year-old mother of two, and her doctor. Johnson has lung cancer that has spread to her liver. Even after extensive treatment, the lesions in her liver are still growing. When her doctor tells her more treatment won't slow the growth of her cancer, Katie breaks down, sobbing. The doctor listens to her concerns and suggests that she bring her husband in for the next appointment, but he doesn't respond easily to her distress and stands up to leave as he asks her if she needs anything else.

Workshop participants are asked to write down what they liked about the doctor's communication skills, and what they would do differently. "He said all the right things, but his body language didn't match what he was saying," comments Cecile Carson, M.D., an internist from Rochester, N.Y. Al Brady, M.D., an oncologist from Pontiac, Mich., says he would have been a lot more physical with the patient, assuming such contact was appropriate and acceptable. "I just think touching is so important in this whole relationship with people who are critically ill, so I would absolutely be touching the patient or holding her hand."

"The average medical oncologist sees between 100 and 200 patients die every year," says Cathy Harvey, R.N., Dr.P.H., an advanced practice nurse attending the course. "You have to walk a fine line between distancing yourself so your heart is not broken every time someone dies and relating to the patient on a personal basis."

The workshop uses a conceptual model to help clinicians understand and recall key communication skills at the transition to palliative care. The model describes the "4R's" of Relate, Review, Revise, and Reflect that roughly parallel the components of care.

According to the model, clinicians can better "relate" to patients by sitting next to them instead of across the desk, making eye contact, listening to patients' ideas and values without interrupting, responding to their feelings with empathic statements, and asking about their preferences for receiving information and making decisions.

Physicians can individualize care when they "review" treatment histories with patients, helping them recall the goals of treatment and understand the results. Clinicians are offered sample scripts to help them tell patients that treatment has failed. For example, a doctor might say, "We've done all the appropriate treatments. I wish we had better ones," or "the cancer hasn't responded like we hoped, we won't be able to remove it or cure it." If the doctor says, "There's nothing more I can do for you," the patient also gives up hope, says Gordon. Giving up chemotherapy or radiation is not giving up on the patient.

Since patients are likely to feel abandoned at this point, practitioners should work with them to "revise" the goals of care. New goals might include minimizing physical pain, doing a special activity, reconciling with loved ones, or simply reviewing one's life and legacy. By engaging in an ongoing dialogue, doctors, patients, and families can learn about each other's goals, share treatment decisions, and plan treatment to achieve those goals.

Finally, health care providers should "reflect" on how their roles and relationships with patients change at the transition to palliative care. Physicians who are accustomed to certainty, control, and emotional distance from patients may find themselves drawing on different resources to do this work. The rewards they experience

will now have more to do with tailoring care to specific patient goals than curing or controlling disease.

Many physicians report that talking to patients at this transition time is the least satisfying part of their profession. It doesn't have to be that way, says Karen Stanley, R.N., the palliative care nurse. "You don't do this unless there's some reward at the end of the day. No matter how sad you might be, if you feel like you made this a little easier for this person, my God, what a reward."

At the end of the workshop, participants are asked to choose two specific techniques from the 4 R's of patient care. They are then asked to concentrate on those techniques in their own practice

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Peeter Poldre, M.D., a hematologist and faculty member at the Bayer Institute, recently had a chance to practice his skills in a Toronto hospital. Poldre was covering for another doctor during the Christmas holidays. A patient, who Poldre had never met before, was receiving his latest round of chemotherapy to shrink a tumor on his spinal cord. The chemotherapy didn't work, and he was expected to live only a few days.

"I didn't have the benefit of any kind of background with this patient. I had no relationship with the patient at all," said Poldre. "In that short period of time, I had to establish a rapport, had to develop empathy, and had to break some very horrible news to him and his family."

Poldre first introduced himself, and then asked the patient to introduce himself and to recount the history of his illness and his treatment. The patient ended by saying he was expecting to hear good news about the chemotherapy. That gave the doctor an opportunity to use a phrase he'd learned at the Bayer Institute, "I wish I had better news for you, but the chemotherapy didn't work, and in fact the tumor has grown." Poldre then told the patient that there was no other therapy that would prolong his life. Then he asked him how he wanted to spend the time he had left. The patient said he wanted to leave the Toronto hospital and return to his home two hours away. Poldre was able to arrange a combination of home care and short stays at a hospital near the patient's home. The patient died peacefully two weeks later. 📖

Mary Sawyers is a medical writer living in Orange, Conn. Learn more about the Care Not Cure workshop at www.bayerinstitute.org.

References

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²Quirt CF, Mackillop WJ, Ginsburg AD, et al. Do doctors know when their patients don't? A survey of doctor-patient communication in lung cancer. *Lung Cancer*. 1997;18:1-20.