

The Most-Avoided Conversation in Medicine

By Pauline W. Chen

J. R. was an auto mechanic of French Canadian descent with a perfectly square gap between his two front teeth and the slightly off-kilter face of a retired boxer. Soon after I met him on the surgical ward, after he had been found to have cancer, he developed a habit of planting himself in front of me whenever I got within 100 feet of his room, to spin stories about his life, wax poetic about his girlfriend, and offer free auto-repair advice.

I thought we had caught the tumor in J. R.'s colon early, but in the operating room we found that the cancer had grown into his pelvic sidewalls. After surgery, when I began to tell him that some of his cancer remained, he stopped me. "Hey, Doc," he said. "I know I'm going to be fine because you did my surgery."

Pauline W. Chen is the author of the forthcoming "Final Exam: A Surgeon's Reflections on Mortality."

BOSTON

J. R. sent me a Christmas card that year, but I could not bring myself to write back. I told myself that I was too busy, when in fact I was afraid to acknowledge that J. R. was dying. Patient deaths, for many doctors, represent a kind of failure, and so without really thinking, we look the other way.

I am not the only doctor who has had difficulty dealing with dying patients. Researchers who in the mid-1990s observed more than 9,000 seriously ill patients in five American teaching hospitals found substantial shortcomings in the care of the dying. More than a third spent at least 10 of their last days in intensive care. Among patients who remained conscious until death, half suffered moderate to severe pain. And fewer than half of their physicians knew whether or not their patients wanted to avoid cardiopulmonary resuscitation.

The researchers then made a multi-million-dollar effort to improve communication between patients and doctors on end-of-life care. They generated frequent reports to physicians on patients' expected survival and hired specially trained nurses to talk with patients, families, physicians and hospital staff about prognoses, pain con-

trol and advance care planning.

Yet after two years, the problems they had identified were undiminished. The changes in practice had done nothing to get physicians to better communicate with dying patients. As the investigators wrote, the doc-

Doctors must get better at caring for the dying.

tors "did not wish to directly confront problems or face choices."

This study — called the Support trial — was a wake-up call for the medical profession. Physician leaders responded by creating specialized curriculums in end-of-life care, and licensing boards widened their competency requirements to include this expertise. Professional organizations issued mandates to improve standards of care for the terminally ill, while hospitals began offering more pallia-

tive care consultation services. Interest in end-of-life care surged; by early 2005, the American Academy of Hospice and Palliative Medicine grew to more than 2,000 members, from only 250 in 1988.

Still, many of us remain unwilling to talk with patients about death.

In a recent Harvard survey, nearly half of attending physicians at teaching hospitals refused to participate in a 25-minute telephone interview to discuss end-of-life care education. The most cited reason? They were not interested in the study. Other reasons included being too busy, refusing to participate without payment, or believing that end-of-life care had no relevance to their work.

J. R. continued writing to me every Christmas for three years longer than I would have expected, given the extent of his tumor. Then one year there was no card, and none the next year or the one after. After four years, I found the courage to write to him, and a month later, his girlfriend replied. J. R. had died but had managed to marry her first and to send me that last Christmas card.

And I was left wondering how I, and all doctors, could ever do better by our

dying patients.

I think there is a simple way to change. We could add one question to every discussion we have about patients with terminal illnesses: "How good is this patient's end-of-life care?"

The forums for posing this question are plentiful in medicine. Every morning and late afternoon, physicians in hospitals "round" on their patients, discussing their decisions in small groups or writing progress notes on patients' charts. Doctors hold "grand rounds" (lectures before their colleagues) monthly or weekly, and in academic centers, physicians hold regular teaching conferences.

If in these settings we could bring ourselves to ask about each patient's end-of-life care, we could influence one another in a more personal way than the Support study did. And while we might not get all the details right at first, we would grow more familiar with advance directives and pain treatment and learn to manage our patients' resuscitation wishes.

We also might find ourselves — as I have found myself with patients since J. R. — one step closer to being the compassionate doctors we have always dreamed of becoming. □