

Talking Frankly at the End of Life

By *Pauline W Chen, M.D. nytimes.com*

I've spent a lot of time over the last few years thinking, writing and speaking about end-of-life care, but this issue recently became quite personal for me. My mother-in-law died two weeks ago.

A ringer in her youth for Donna Reed, with Rita Hayworth legs, my mother-in-law possessed a dazzling memory and a designer's flair, and she loved to surround herself with family and friends ("where the *action* is," she used to say). She spent most of her 86 years following her husband across the country, teaching art in the schools where he taught. But wherever they landed, she managed always to make new friends. Lots of friends. When one of her sons passed away, she and my father-in-law received more than six hundred letters of condolence.

But by the time my mother-in-law died 14 days ago, her social circle had shrunk considerably. She had been battling rheumatoid arthritis for almost 50 years, a series of debilitating strokes for 10, and the ulcers on her legs that would not heal would, in the final year of her life, necessitate an above-the-knee amputation. **Over the last few months, unable to hold a pen to write and too weak to speak into a phone, my mother-in-law saw her social life wither away. Her once expansive world was reduced to the square footage accessible by wheelchair and amenable to the trappings of all the medical equipment she needed.**

In the days since her death, I have often thought about the many conversations my mother-in-law and the family had with the doctors and nurses about the dying process. There was the initial discussion over two months ago that she was likely to die soon and would benefit from hospice, and then there were also the many daily conversations about her comfort, about what she wanted and what she did not.

While I have become over the last few years a voice in the movement to improve end-of-life care in this country, these kinds of conversations with patients and their families still hit hard. As a close friend of mine once said, **"One of the scariest things in the world is to look someone in the eye and tell them they are dying."** But in my practice I do try to tell patients they are dying because I believe in my heart that it is worse when clinicians don't.

Nonetheless, every doctor comes to these conversations with some anxiety. It is hard not to feel as if you have failed your patients and their families, to wonder if taking out an inch more of bowel when removing the colon cancer, starting with a different antibiotic, or ordering a different diagnostic test might have somehow changed the course of events.

And then there is the conversation itself. "Death" and "dying" are words that can echo in a room long after they are said. Hopes can be shattered in an instant. Patients and families may feel abandoned.

It is hard as a doctor not to wonder: Am I doing more harm than good?

One particular study came back to me during these last few weeks, a study that attempted to answer just this question. Published last fall in *The Journal of the American Medical Association*, **the study examined how end-of-life care discussions with terminal patients affected their quality of life and that of their caregivers.**

Over the course of almost six years, Professor Holly Prigerson, director of the Center for Psycho-oncology and Palliative Care Research at the Dana-Farber Cancer Institute in Boston, and her colleagues **interviewed more than 300 terminal patients, asking them if their doctors had ever discussed care at the end of life. After these patients died, the investigators analyzed the type of medical care received prior to death, then interviewed the patients' caregivers six months later to assess how they were adjusting to their loss.**

What Dr. Prigerson and her co-investigators found was that those patients who had had discussions with their physicians were more likely to have better quality of life at the end of their lives. These patients were not more depressed or more worried as a result of these discussions, and they tended to receive less aggressive medical care and earlier hospice referrals. Moreover, their caregivers fared better and suffered from significantly less depression six months after the patient's death than caregivers whose loved ones had received more aggressive care.

I spoke to the lead author of the study and one of the investigators, Dr. Alexi Wright, a medical oncologist at Dana-Farber.

"There is almost an assumption *a priori* that these end-of-life discussions will cause harm, so doctors are afraid to have them," Dr. Wright said. "Patients then fail to realize that their time is limited, and they don't make the kind of choices they would if they did know."

I asked Dr. Wright if telling patients that they were dying might take away hope. "In trying to emphasize only the positive, we can end up with a misguided sense of hope," Dr. Wright responded. "I think it's really important to define hope more broadly. Hope is in the life we live, in our families. When I meet patients with incurable cancer, I hope they live as long as they can and with the best quality of life they can have. But I know from the outset that they will die from their disease, so hope is helping them to live as long as and the best that they can."

Dr. Wright also emphasized the need to have several discussions about end-of-life care choices. "These conversations are not a one shot deal, but often need to happen repeatedly, as patient preferences about end-of-life care change and their disease states can change," she explained. "It's possible, too, that a patient might be in denial or may not be ready to hear such news and wouldn't remember a discussion. But at the end of the day what's important is what the patient remembers"

Individuals can differ markedly in the amount of information they want to know, and conversations should be tailored accordingly. "About 20 percent of patients don't want to know prognostic information," Dr. Wright said. "But if patients have feelings about the kind of care they want, they should bring it up with their physicians. You want to be treated by a physician who you feel really understands and respects your values."

That sense of understanding can have a cascading benefit for survivors. "As doctors we tend to focus on the patient, the person sitting before us. We need to think about the legacy of our treatments and the potential to help families cope with inevitable loss."

The loss of my mother-in-law hangs heavy in our house. There are moments when my husband is silent and I know that he, like me, is thinking about her life and her last days.

Those last days were not always perfect. There was the clinician whose well-meaning but overly enthusiastic pronouncements that my mother-in-law was "actively dying" left all of us more exasperated than comforted. And she suffered for a few days from a side effect of morphine. But in the end, the ongoing discussion and interactions with the doctors and nurses about her desires and her dislikes gave my mother-in-law not only comfort but also a sense of still being part of the conversation, part of "the action," part of life.

And those discussions also gave my husband and his sister opportunities. They sat with their mother and read to her. They fed her when she was hungry and put cool towels to her face when she was hot. My sister-in-law even organized one last social event, a "Spring Fling," for her mother. The children, grandchildren and two great-grandchildren from across the country filled the room with the kind of lively conversation and laughter my mother-in-law had always loved.

I remember that she glowed that day. Her cheeks, once pale, were flushed pink, and her voice, usually barely audible, rang clear. She smiled, she laughed and she kissed all of us as we leaned over her bed.

After all the festivities had come to an end, my husband and sister-in-law left the room to escort everyone out. I saw my mother-in-law look up toward the sky after they left, opening her mouth as if to speak. I walked closer and heard her say softly to herself, "I am so happy."