



The art of medicine at the end of life:

The challenges ahead

by Pauline W. Chen, MD, FACS

I accepted an invitation to be the keynote speaker at the Art of Medicine at the End of Life symposium, organized by the Cunniff-Dixon Foundation, because I found the foundation's mission—"to educate individual physicians and inspire them to provide the kind of care at the end of life that we all wish for ourselves and our loved ones"—particularly compelling. I think most other physicians would feel similarly, as the mission resonates with the very reason we chose this profession in the first place: We want to help others.

For surgeons, I think there is something even deeper. The Cunniff-Dixon Foundation's mission (see page 15) evokes a deep sense of responsibility to patients, a sense that I believe lies at the very heart of how surgeons define themselves.

Surgeons routinely push the limits of endurance in order to do the best they can by their patients. I think some of the most moving examples of empathy in medicine exist among surgeons. When a surgeon opens up a patient and finds tumor so diffusely studded in the abdomen that a curative operation is impossible, the silence in the operating room (OR) is profound. When a patient becomes critically unstable, a surgeon will hover close by, spending the night at the patient's bedside or in the hospital office. Putting patients' needs above your own is part of the ethos of surgery.

When I was a junior resident, I remember watching a fellow resident learn the meaning of surgical responsibility from the late C. Elton Cahow, MD, FACS, the gifted and highly respected elder statesman at Yale University at the time. The resident was eager to leave the hospital one afternoon, even as one of the patients under his watch became unstable. Dr. Cahow stepped in front of the resident, literally blocking his path

out of the hospital, and pointed back at the patient's room. "Son," he said in the sternest voice I had ever heard him use, "once you lay your hands on a patient, that patient is yours." The resident ended up staying at the hospital late into the night, and I don't think he, or I, ever forgot that lesson.

To me, that sense of responsibility fits seamlessly with the goals of palliative care. But it also poses a particular challenge for surgeons.

Death is difficult for all of us, but it is made all that much harder for surgeons because of our highly refined sense of responsibility. Moreover, we use our hands to effect therapy; it's hard not to leave the OR feeling a kind of shared identity with that patient on the table.

Although the strong connection with patients inspires some pretty heroic caregiving on a surgeon's part, it can also be problematic when we interpret therapeutic "failure" as a personal failure. It *is* devastating for surgeons when patients are dying, because it's hard not to wonder if the outcome is, in some way, our fault. Moreover, like so many other challenges in our clinical work, these deaths end up becoming something we face alone in a health care environment that barely gives us enough time to get the job done, let alone reflect on it. Helping our dying patients die well thus puts our professional ethos to one of its toughest tests.

Here is where the work by the Cunniff-Dixon Foundation is invaluable. Through its educational work, the Foundation gives individual clinicians the opportunity to discuss the challenges of caring for the dying, to share their experiences, and to place those experiences within the larger palliative care framework.

At the recent symposium, for example, there were roughly 100 attendees. (Of note, there was a

sizeable surgical presence among the attendees, and two exemplary surgeons—Edward M. Cope-land III, MD, FACS, Immediate Past-President of the College, and Thomas Herman, MD, FACS, one of the conference’s chief organizers—were involved in the symposium’s planning.) There were lectures by leading experts in end-of-life care that covered a wide range of topics relevant to any clinician.

But what was most remarkable were the questions, comments, and even challenges from the audience after each lecture. The lively and spontaneous discourse reflected a void in health care. There are few opportunities for clinicians to reflect openly with one another on the challenges of practicing quality end-of-life care, to discuss ways we can provide dying patients with the kind of care “we all wish for ourselves and our loved ones.”

The Cunniff-Dixon Foundation symposium was one of those rare opportunities. And, fortunately for all of us, the Foundation is planning on sponsoring more symposia in the future.

The draw to palliative medicine

I think I have always been at least curious about palliative medicine. A resident sees, on average, 28 deaths a year, so it’s hard not to go through residency without reflecting at some point on *how* our patients die.

Unfortunately, what many of us end up taking away from these reflections is that death should be depersonalized. Medical sociologists have written about the “informal curriculum” of medical training—the language and the subtle gestures and responses that form the professional culture of medicine. Through the informal curriculum, young doctors learn the values of our professional culture and come to believe that these values, such as distancing ourselves from the terminally ill, will somehow make them better doctors. I, for one, certainly embraced the informal curriculum during my training.

What made me begin to question these values were two things. First, I had the good fortune of training with some exceptional individuals—surgeons and other health care professionals, patients, and their families. Second, I began writing.

I did not write much in residency, but after my training was done, I found myself writing stories in notebooks, on my computer, and on loose papers in my white coat pocket. It was as if some pot inside had finally boiled over and I had to scramble to catch the contents that kept spilling out. Most of the pieces I wrote back then were fictional, and nearly all of them had some medical theme.

After a few months, I signed up for two writing courses at the University of California—Los Angeles, where I was an attending surgeon in the division of liver transplantation. Midway through the second course, the instructor asked to meet with me privately. I was convinced that she was going to ask me to tone down the graphic clinical details of my stories or to repeat the course since I had missed several classes because of transplants. Instead, she said simply, “Pauline, you *have* to write these stories.” She and my other writing instructor recognized my short stories as thinly veiled personal narratives, and her comment gave me the kind of permission I needed to write what I really wanted to write about—that is, my experiences with patients.

I began then to write in a more organized fashion, and as I collected the stories, I saw that a fair number of them had to do with grief—grief over patient complications, grief over deaths, and grief over the kind of care I had provided over the years. But some stories were also hopeful; they involved surgical colleagues and teachers or other health care professionals who had pushed me to think or to act a little differently. Unbeknownst to me at the time, they were teaching me about palliative care. They were showing me that there was much more we doctors could do for our patients than simply cure.

In retrospect, I think that writing the stories gave me an opportunity not only to reflect on the past but also to consider ways in which I might improve my work in the future. As I wrote these stories, I was, in fact, experiencing narrative medicine, a field that uses writing, reading, narratives, and the approaches used in literary critique as a way for physicians to improve themselves. And what was emerging for me from this experience was a greater understanding of and appreciation for the power of palliative care.

Skills for end-of-life care

In terms of end-of-life care and the skills necessary, there is a terrific canon of research out there, including the excellent series of articles by Geoffrey Dunn, MD, FACS, and others that were published a few years ago in the *Journal of the American College of Surgeons*.

I think that, given our strong sense of responsibility toward patients, we surgeons are uniquely qualified to provide effective care to patients at the end of life. In fact, some of the most moving caregiving testimony I have heard since my book came out has been from surgeons, particularly from some of the more senior members of our specialty. A retired general surgeon told me with pride that some of the most rewarding moments of his career were those times he had helped his breast cancer patients die with dignity. An older thoracic surgeon told me about the lessons of his mentor: that part of being a good surgeon was knowing when one could do no more and being honest with patients and their families.

Probably the most moving story I heard was from the adult daughter of a surgeon who had practiced in the Midwest from the 1950s until his death from pancreatic cancer in the mid-1980s. Her father had been head of surgery at a couple of local hospitals and had had a terrifically busy practice. One day, as a teenager, she went to look for her father at one of his hospitals. She found him in a patient's room. He was sitting at the bedside reading the Bible aloud.

The daughter became annoyed. Her father was so busy clinically that he was always running late for the OR, for the clinic, and especially for family occasions like dinner at home. Why, she asked herself, was he now just sitting there reading by his patient's bedside?

When her father finally came out of the room, the daughter confronted him. Her father looked surprised for a moment, then quietly told her that the patient had asked him to read a Bible passage aloud. "She is dying," he explained. "When I realized that there was nothing more I could do for her medically, I did what I could."

I'm not sure we can change that unpleasant aspect of death for our patients and their families, but I do think we make the experience much worse for all, including ourselves, by deny-

ing death's very existence. We doctors are in a unique position; we are often the guardians of the last days of life. We can talk with our patients and their families, we can provide guidance and support, and we can be present.

And in the end, I think that being present may be the most important thing all of us can do, surgeon or not. □

Dr. Chen is a surgeon and author of the New York Times best-seller, *Final Exam: A Surgeon's Reflections on Mortality*. She lives outside of Boston, MA.

