THE REST OF YOUR LIFE

Bringing Grace to Patients at the End of Life

Death is not often discussed among physicians, but after Dr. Pauline W. Chen's critically acclaimed book "Final Exam: A Surgeon's Reflections on Mortality" (New York: Knopf, 2007) hit bookstores, many physicians approached her, eager to share their own stories about caring for patients at the end of life.

"I feel the same way," they'd tell her, said Dr. Chen, a transplant surgeon who lives near Boston. "They don't feel so alone in some of their emotions."

The book chronicles Dr. Chen's transformation from a medical student taught to depersonalize death to a transplant surgeon who must be emotionally present for patients and their families during the end of life. "I don't pretend to be an end-of-life care expert," she said. "I'm certainly not perfect, and I continue to struggle to do the best for those I care for; but this is my experience. I hope that being open about my experience helps their efforts."

JOANNE CHAN

After the death of her aunt, Dr. Pauline W. Chen began contemplating the importance of end-of-life care.

In one chapter she recalls the challenges of her Aunt Grace's kidney failure. On the one hand, she knew what to expect and was a key person for relatives who wondered, "What happens next? What really happens when someone dies?"

But Dr. Chen became preoccupied with her aunt's physical status and transplant candidacy, and forgot about her as a whole person. Aunt Grace realized this, and 3 weeks before she died, she called her niece on the phone. Part of the conversation involved Dr. Chen's request to include her aunt's story in an article she was writing about organ donation. Aunt Grace granted permission but insisted the article mention the care and support that Dr. Chen's uncle and cousin had provided her. "They have been here for me always; they have listened to me always," Aunt Grace told her. "Your uncle has taken such good care of me, and your cousin has helped him. They have sacrificed so much. . . . I owe everything to them." That brief conversation reminded Dr. Chen of the importance of caring for the person beyond the symptoms and illness.

Despite the growing popularity of palliative medicine and hospice care, Dr. Chen said that some physicians equate patients' deaths with failure.

"The metaphor for a surgeon is that you've actually got your hand in there affecting the cure, so you really feel tied in with them and personally responsible," she said. "When those deaths occur, it can be devastating for doctors, not only on the relationship level—because you form relationships with your patients—but also, personally, you feel like you failed them and you failed your profession in a way." That sense of responsibility "can hamper our future ability to care for people and to care for ourselves," she said. "I think we only worsen the situation by not doing the small little bit that we can, which is discussing [end-of-life care] with our patients and among ourselves. By talking about it—by being present for our patients—we can fulfill those ideals that brought us to medicine in the first place."

No One Is Immune

When two patients of Dr. Robert S. McKelvey committed suicide during his psychiatry residency in the 1970s, he was so devastated that he considered leaving the field. "I took it as an accusation against me that I wasn't doing a good enough job or that I wasn't cut out to be a psychiatrist," recalled Dr. McKelvey, now director of the division of child and adolescent psychiatry at Oregon Health and Science University, Portland. "I've practiced for many years now, so I realize that's part of the profession: you're going to have people die from time to time if you work with severely disturbed patients. But then I was brand new."

Physicians' reactions to death vary, said Dr. McKelvey, author of "When a Child Dies: How Pediatric Physicians and Nurses Cope" (Seattle: University of Washington Press, 2007). Patient deaths tend to affect residents and early-career physicians the most, but no physician is immune. "No matter how experienced you are, there are going to be situations that are really going to affect you, especially if you get a little too attached to a patient or to a patient's family," said Dr. McKelvey, who interviewed about 35 pediatricians, pediatric residents, and pediatric nurses for his book.

In interviewing pediatricians, he discovered many coped with a dying child by focusing their energies on trying to keep the child "comfortable on the one hand and on the other hand trying to make the dying process as good as it can be for the family by explaining what's going on and trying to provide support—being emotionally present for them," Dr. McKelvey said. "Not everybody can do that. One of the things about physicians is that there is a certain self-selection; many tend to compartmentalize things. They may be less likely to be open with their feelings than others." One strategy he recommends is to share your feelings about death with someone you can confide in. That's easier said than done, because people not in the medical field "don't want to hear about the death of a child," he said. "Physicians usually find either someone within their own field to talk to, or a professional listener like a psychiatrist or psychologist, or their spouse—if their spouse is able to bear the pain of hearing about those kinds of losses."

Dr. McKelvey met with a psychiatrist for more than a year to discuss his feelings about the suicides. "Another thing that's helpful is to continue to do the job and get some more experience under your belt. Gradually, you realize that there is only a limited amount of control you have over what patients do and what happens to them."

He thinks hospitals should provide pediatric residents with free, confidential counseling. "A lot of physicians are afraid to go see a psychiatrist because they somehow feel that it's going to appear on their record and the medical board will wonder about them," Dr. McKelvey explained.

One of the physicians interviewed by Dr. McKelvey said that ultimately, patients' deaths are not about physicians. "He told me, 'Our goal is to support the patient and his or her family through this. It's important for us to get our own support, but we have to put their needs first and remember whose suffering it really is.' I thought that was a good comment," Dr. McKelvey said. "On the other hand if you neglect your own needs, you become less available to patients and families and to the other people in your life. You kind of walk a tightrope."

Overwhelmed by Gratitude

When San Diego–area physicians feel isolated due to a patient's death, many speak with Dr. Charles F. von Gunten, a consultant in hospice and palliative medicine.

"For most doctors, caring for a dying patient feels very lonely, because all the other consultants go away," said Dr. von Gunten, medical director of the Center for Palliative Studies at San Diego Hospice and Palliative Care. "If I have been involved in the case or am asked to consult and agree that they have done everything that can be done and that they are doing a good job, hearing that from me helps them cope."

Such support marks one benefit of expanding palliative care and hospice programs, but medicine has yet to devote adequate training to coping with death, said Dr. von Gunten, who also is editor in chief of the Journal of Palliative Medicine. "The loud message from the medical culture is, 'You should have no feelings about death; you move on to the next case who needs your help,' " he said. "Your personal feelings are not germane. The culture of medical training teaches that doctors are not supposed to be upset by this."

As an oncology fellow, Dr. von Gunten was rattled when his first patient died. He remembered what he'd learned: Send a sympathy note and attend the funeral of patients with whom you are close, "to help you grieve, move on, and be emotionally available to other patients." When Dr. von Gunten arrived at the funeral, the man's family expressed unexpected gratitude. "He'd had a difficult course with difficult symptoms that I hadn't controlled very well, and I couldn't make sense of how grateful the family was. It was only with more maturity that I realized that they were expressing gratitude for the sense that I had cared as a doctor; cared enough to look after him, even though the cancer didn't get better; cared enough to stick with him, even though I didn't get his symptoms under better control; and cared enough to go to the funeral."

In notes to families of patients that die, he expresses condolences and offers to meet with them. This helps families cope, he said, "because there are frequently questions that come up that the doctor can easily answer."

ANN STURLEY

Unfortunately, "the loud message ... is, 'You should have no feelings about death,' " said Dr. Charles F. von Gunten.

It's also plain good care. "If you're interested in family satisfaction with care, they want to know some expression that the doctor cared about the patient as a person," Dr. von Gunten said. "The chief complaint from patients about their doctors and about their hospitals is, 'as soon as the patient died, all communication stopped. It was as if he was just a case: wasn't an important person.' "

Recently, a retired physician Dr. von Gunten had been caring for died. He sent a note to the man's daughters, who asked him to be a pallbearer. "This was a well-respected man with many friends in the community," said Dr. von Gunten, who accepted. "I felt not unlike I did when I was at my first funeral of a patient: What am I doing? Why am I here? But it was their way of saying, 'You were important to him. You're an important part of our family in the doctor role, and it's a place of honor.' It reaffirmed why I wanted to be a doctor." ■

By Doug Brunk, San Diego Bureau

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Please send an e-mail to column writer Doug Brunk at d.brunk@elsevier.com.