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# Bringing Doctors to the Dying Patient's Bedside

By PAULINE W. CHEN, M.D.

When D., a woman in her mid-30s, learned that she was dying from complications of AIDS, she fully expected that her life would end in much the same way it had been lived: homeless, alone and among strangers.

If it hadn't been for Dr. Jason K. Alexander, a medical student at the time, she might have been right.

Two years earlier Dr. Alexander, along with four other classmates, had created a project that paired medical students with patients who were dying alone. "We wanted to reach out to patients who had been shunned, the people others didn't want to deal with," Dr. Alexander recently recalled.

The program, which also helps family members who are struggling with terminally ill loved ones, was part of an innovative new center for humanism at the University of Medicine and Dentistry of New Jersey-New Jersey Medical School in Newark. The center offers four-year scholarships for students with outstanding academic and community service records.

D. was one of the program's first patients, a woman who years earlier had been rejected by her own family. "She was angry at first," Dr. Alexander said, recounting his initial visit with her. "She was dying, but she took the opportunity to attack me, a medical student who had walked into her room and said that he was just there for her to talk."

Dr. Alexander was about to leave when he remembered the advice of his faculty adviser: let the patient guide the conversation. "I surrendered to her anger and told her that we didn't have to talk, that I would just sit in the room with her." After several minutes of trying "to embrace the deafening silence," Dr. Alexander heard a noise coming from where D. was sitting. "I saw tears rolling down her eyes," he said remembering the moment. "She began sobbing that she was scared and had no one."

That visit would be the first of nearly daily conversations between Dr. Alexander and D., meetings that would continue several months until her death.

The school's initiative, started with a \$3.2 million grant from the Healthcare Foundation of New Jersey, is part of what many believe is an expanding movement in medical education: a growing emphasis on the human side of medical care. Leaders of this "humanism movement" have come from both the general public and within the ranks of medical education. And although they have focused on issues like patient-centered care, physician professionalism, clinics for the uninsured and disaster relief, nearly all have agreed on one thing: the importance of supporting what they believe are the natural, but often suppressed, ideals and inclinations of those who chose to pursue a career in medicine.

"I believe there is a yearning among physicians to practice this way," said Sandra O. Gold, president and chief executive of the Arnold P. Gold Foundation. The nonprofit organization has financed the bulk of the movement's initiatives in the last two decades, with more than \$15 million in grants for research, lectures and conferences. "But everything that is happening to doctors dissuades them from these humanistic ideals," she said.

Most notably, the foundation initiated and continues to support two national programs: the Gold Humanism Honors Society, which inducts physician members based on both their clinical acumen and bedside manner, and the white coat ceremony, now carried out at most medical schools across the country. During the formal event, first-year medical students take the Hippocratic Oath, pledge to provide compassionate care, hear from prominent figures in the humanism movement and receive their first white coats.

"With programs like these," said Lester Z. Lieberman, founding chairman of the Healthcare Foundation of New Jersey, "we are hoping to gain some leverage with these young doctors, so that they go out and practice and treat their patients as human beings and press their colleagues to do the same."

Critics assert that the benefits of such programs are transient at best, pointing to failed efforts of generations past. They maintain that once young doctors are exposed to the dehumanizing forces of internship and training and to the financial exigencies of practice, they will lose even their most cherished ideals.

But those who have researched the impact of the newer initiatives disagree. They counter that over the last two decades the "science" of humanism has made tremendous inroads, many of which are helping current efforts to succeed where past ones have failed.

“What makes a difference is that we now have ways to measure professional behavior,” said Dr. David T. Stern, vice chair of professionalism at Mount Sinai School of Medicine in New York and a Gold Humanism Honor Society member. While identifying professionalism, compassion and patient-centered behavior was once an “I-know-it-when-I-see-it endeavor,” he said, “deans and faculty can now weigh actual indicators of humanism on evaluations.” Such measurements allow teachers to model, recognize and reward behavior more effectively. “Students now know that it isn’t just a couple of geeky, crunchy granola types who are talking about it.”

The ubiquitous nature of events like the white coat ceremony as well as the growing popularity of programs like those that bring medical students to dying patients’ bedsides help keep the ideas of humanism front and center in the conversations and thoughts of students and more experienced physicians. “We’ve been able to create an environment where people feel safe and comfortable expressing some of those inner thoughts that weren’t so readily expressed maybe 15 years ago,” said Dr. Dorian Wilson, associate professor of surgery and director of the humanism center at UMDNJ-New Jersey Medical School. “Administrators, faculty and students, all of us are definitely more conscious of it than we’ve ever been.”

That consciousness in turn helps the students follow through on their aspirations. For example, over the last two years the project created by Dr. Alexander and his fellow students has helped nearly 20 patients and several families; at the UMDNJ-University Hospital, where their project is based, it is now rare for patients to die alone. And although the five co-founders, including Dr. Alexander, just graduated this past week, their work will continue, thanks to faculty and administrative support and nine current medical students, some of whom are among the school’s newest humanism scholars.

“What the Gold Foundation and others have done is brought the language of humanism into the light of the hospital day,” Dr. Stern said. “It is O.K. to talk about compassion and respect. And that, I think, has made a difference for doctors and for patients.”

On what would be her last Christmas Eve, D. insisted to the nurse assigned to her for the night that Dr. Alexander would visit. But the nurse gently reminded D. that it was winter break for the medical school and, like the other students, Dr. Alexander had gone home for vacation.

But just before midnight, Dr. Alexander appeared at her door, carrying a Christmas card he had bought for her. D. looked at him, then her nurse, and together all three began to cry.

She was no longer alone.

*Join the discussion on the Well blog, "Making Sure Patients Don't Die Alone."*