



BECOMING A PHYSICIAN

Learning from the Dying

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“ I thought I would find out what death actually is. I thought I would learn the proper words to speak. . . . I thought I would leave with answers to my questions about the end of life and how peo-

ple cope with dying. . . . I hoped there would be a protocol to follow when a patient dies that would protect me from the suffering and grief. My experiences throughout this course have proven to me that to have answers to these questions would make me nonhuman.”

— Mauro Zappaterra, Harvard Medical School, Class of 2007

Teaching about end-of-life care was virtually nonexistent when we attended medical school and trained in residencies more than 20 years ago. We cared for many dying patients, but both the formal curriculum — what was overtly taught in the classroom

and in structured settings on the wards — and the informal or “hidden” curriculum¹ — the implicit values and attitudes of our peers and teachers, as expressed in their behavior — conveyed a distinct sense that end-of-life care held no great clinical interest and required no special expertise. Occasionally, we became uneasy about the way in which we were caring for these patients. What was the effect on us, as persons and as physicians, of the model of detachment that we saw around us in dealing with this profound human event?

In the ensuing decades, following the publication of the works

of Elisabeth Kübler-Ross² and others, academic health centers began to explore new approaches to caring for terminally ill patients and their families and to teaching about such care. These approaches have the potential to help us become better caregivers for the dying and to provide us with the kind of physicians we hope to have at our bedsides as we approach the end of life.

The experience described by Mauro Zappaterra with his patient, Judit Komaromi, who has breast cancer, took place in a preclinical course for medical students called “Living with a Life-Threatening Illness,” which we have directed for the past 10 years. A popular feature of the Harvard Medical School curriculum, the course annually engages 20 to 30 percent of the first-year students. Most of them, like Zappaterra, develop



strong and deeply affecting relationships with the volunteer patients, all with life-threatening illnesses, who serve as teachers in the course, teaching the medical students important lessons about the power of listening and bearing with suffering. He wrote:

Initially I was really eager and anxious. At our first visit, I remember being so amazed and shocked that this woman would share so much of her personal life with me — that she would tell me these intimate stories. It awed me. I thought I was the luckiest person in the world. I didn't expect to get so emotional . . . or so attached.

The course begins with a large-group discussion with a dying patient. Through homework and small-group exercises, students reflect on and share personal experiences of death and dying, focusing on how different families handle such matters as truth telling, decision making, and after-death rituals.

Over a period of four months, in a series of one-on-one interviews, often conducted in the pa-

tient's home, students learn from "their" patients about living and dying with a terminal disease: about the fears and uncertainties that accompany a serious illness; efforts to make sense of one's life and death; the kinds of support that help patients to manage physical, emotional, and existential crises; the nature of suffering and hope; and the ways in which crucial medical decisions are made. Students meet weekly with a small group of peers and faculty members to share what they have discovered, to learn from one another's narratives, and to reflect on implications for their future practice.

Interspersed throughout the course are model interviews, brief readings, and large-group discussions that touch on central issues in end-of-life care, such as pain management, depression, the adaptive and maladaptive qualities of denial, spirituality, hastening death, hospice care, bereavement, and self-care for health care professionals. In Zappaterra's words,

I felt that Judit was grateful that I was there and that I was listening. . . . By my

coming, she had a chance for some relief from things she'd kept inside. . . . My questions were innocent, curious questions because I was interested in her path and her life; her seeing that made her open up more.

The patient-teachers vary in terms of age and disease. They come from a spectrum of socioeconomic, religious, and cultural backgrounds and have widely varied coping styles. Similarly, the students represent a great diversity of backgrounds and life experiences, including dissimilar personal histories of loss.

Inevitably, several patients die during the semester, bringing forth stories of wakes, funerals, and grief. Students learn how to write a condolence note, and they often remain involved with family members after the patient's death. Zappaterra described what he learned in this way:

I'll always remember her as an amazing teacher — a gift to me in terms of my life. Since I know that she is ready [to die] and has found acceptance and completion, it makes it easier for me to

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accept. When I first met her, she asked, “How can it be that I won’t be here to watch the waves crash on the shore?” Now she says, “Isn’t it great that the waves will still crash on the shore even after I am gone?” And I believe that she means it.

How does the course prepare students for providing end-of-life care? Foremost, their tendency to avoid the sadness, hopelessness, and helplessness they had associated with dying persons is replaced by a sense of the approachability of the dying, an interest in the medical, psychosocial, and spiritual aspects of “the case,” and a belief in the possibility of doing good work through such encounters. Students learn to elicit and value the patient’s perspective and come to understand that each person’s approach to dealing with illness is unique — a fundamental tenet of a patient-centered approach to doctoring.³ As Zapatera reflected:

I didn’t want to be the kind of physician who keeps his distance in order to keep his professionalism. The course

gave me a template for how to talk about intimate things with patients and gave me permission to do it.

Students experience the slow deepening of interpersonal connections that happens over time when conversations are open to deeply personal and meaningful issues that would otherwise be treated, in usual history taking, as irrelevant “noise” that obscures the tale of the body. They reflect on the best way to calibrate closeness, avoiding overinvolvement as well as excessive distancing. Students begin to understand how they can be healers, even in the face of a terminal illness. And they have an opportunity to understand how their backgrounds both inform and obscure their appreciation of others and to reflect on, and modify, their own values and beliefs about life, death, and dying.

This course is designed for the preclinical years. But students and physicians, throughout their years of training, need appropriate learning opportunities and practice to address death, dying, and the human experience of medical practice. Unfortunately, the

“hidden curriculum” of contemporary medicine — especially the hurried, disease-centered, impersonal, high-throughput clinical years — still tends to undermine the best intentions of students and faculty members and the best interests of patients and families. Medical schools, residencies, and continuing medical education programs can help learners and their patients by investing in expanded training in palliative care and by hiring and training faculty members who, at all stages of medical training, can model and teach these fundamental skills.

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2. Kübler-Ross E. On death and dying. New York: Macmillan, 1969.
3. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL, eds. Through the patient’s eyes: understanding and promoting patient-centered care. San Francisco: Jossey-Bass, 1993.