My first patient who died was a middle-aged man diagnosed with disseminated oat cell carcinoma. Mr. Mathorn (not his real name) lived in the neighborhood around the medical school. He had a devoted family but no insurance and few resources. Mr. Mathorn understood that he had a kind of cancer that would kill him. He also understood that experimental chemotherapy would not benefit him. Still, he signed up for the Phase 2 trial just after Thanksgiving, believing and hoping that it was his best chance of making it to his 11-year-old son’s middle school graduation in May.

Snow still on the ground and no sign of spring on the South Side of Chicago, Mr. Mathorn died in early January.

In the years since medical school, I have carried thoughts of Mr. Mathorn with me. He was a brave and memorable person. He was dealt a bad hand, so to speak, and participating in the clinical trial made matters worse. Caring for him in the last terrible weeks of his life and grappling with the difficult circumstances of his death greatly influenced who I would become as a physician. Mr. Mathorn’s trauma was knotted into my heart, and Mr. Mathorn’s story became intertwined with my own.

I honor Mr. Mathorn as my great teacher. He taught me about terminal illnesses, with their ruthless, impersonal brutality. He instructed me on the differences between understanding, believing, and hoping, and why the distinctions matter in making health care decisions. Mr. Mathorn taught me about vulnerability and dignity, stoicism and solace at the end of life. He taught me about good deaths and hard deaths. His was a hard death.

As I have grown older, the story of Mr. Mathorn continues to teach me. Our braided narrative imparts existential, brutality. He instructed me on the differences between understanding, believing, and hoping, and why the distinctions matter in making health care decisions. Mr. Mathorn taught me about vulnerability and dignity, stoicism and solace at the end of life. He taught me about good deaths and hard deaths. His was a hard death.

Thoughts of Mr. Mathorn help me to recall the significance of not turning away from suffering, even as it reminds us of our own inexperience and inadequacy. Over time, I have come to understand more about the social determinants of Mr. Mathorn’s overall health and the societal context in which he had few alternatives but to turn to a local academic medical center for care through a clinical trial—lessons that resonate with findings and observations underscored by many authors in this issue of Academic Medicine. Mr. Mathorn’s death still shows me how much we need the discoveries of science to help us defeat disease, as well as the very dear price paid by ill and vulnerable people for such advances.

Our Patients as Co-Creators and Partners in Academic Medicine

The intentional engagement of patients both as formal teachers of medicine and also as co-creators of health professions education has received some—but fairly limited—attention in the literature. A few authors have suggested that the unilateral “provision” of medical education is not appropriate or tenable and that full engagement of all stakeholders, including those with lived experience of illness, is essential to curriculum development and implementation.

Patients serve in a number of crucial roles in academic medicine, including acting as standardized or volunteer patients, helping to teach and assess learners, sharing personal experiences of illness, and contributing to learning resources. Patients also act as local stakeholders who provide partnership and feedback to health systems and research institutions—for example, by participating on student admissions committees, serving on institutional research review boards, defining philanthropic priorities, and offering guidance on advisory committees.

Proponents, including myself, of acknowledging more fully the role of patients as teachers emphasize how the elevation of our patients’ authentic, often underrepresented voices is invaluable to our work as health advocates in society. Academic medicine does not yet sufficiently acknowledge, venerate, or uplift the essential contributions of patients from our institutions’ local communities as co-creators and partners in health professions education and biomedical sciences, but is increasingly recognizing this obligation to our neighbors and community stakeholders. Academic health systems are stepping forward to more fully address health disparities contributing to poor health outcomes for individuals who belong to underserved and vulnerable populations—disparities that have grown and taken a grave toll during the coronavirus pandemic.

Our Patients as Our Teachers

On the path to becoming clinicians, learning to listen attentively and accurately to our patients brings greater awareness of others’ experiences and values that are vital to empathic and effective care practices. Furthermore, making meaning of our encounters with our patients—individuals who may be ill and suffering and for whom we have responsibility—is an important element in arriving at our identities as caring health professionals.

Our patients teach us medicine. They become our unexpected companions throughout our professional lives. Our experiences in caring for our patients define our work, instantiate our values, and shape our identities as clinicians, educators, scientists, and agents of change in medicine.

Mr. Mathorn inspired me as a physician; he motivated me to study end-of-life care, ethical dimensions of clinical research, and health disparities. And, yet, Mr. Mathorn did not wish to be a teacher of medicine—he wanted to see his son graduate from middle school. The Phase 2 trial for his fatal cancer did not deliver on that misplaced hope. And the asymmetry of how much he has given me and how little I was able to do for him still weighs on me. He joins the many patients whom I am honored to carry forward with me—all my teachers to whom I owe an immense debt.
References