Gain of Function: Empathy for the Uncertain Patient With Cancer

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The news came from the embassy. Chest x-rays were performed on all immigrants to screen for tuberculosis, and my father’s was markedly abnormal. A theologian with a masterful command of language, he would later write of “a tumorous excrescence of considerable magnitude and menace.”1(p403) But he described it to me, in terms comprehensible to his 8-year-old child, as a pineapple-sized cancer occupying much of his right lung. I never saw the chest x-ray, but its opacity cast a long, unwelcome shadow over my family’s new life in the sunny American South. We were unsettled in every sense, inhabiting a sparsely furnished house while we awaited my father’s curative-intent resection. Like his unseen metastases, our belongings were still in transit.

The discovery of a lung tumor in a lifelong nonsmoker (indeed, a teetotaler) elicited the expected gaps of surprise from his peers and, from his son, misplaced moral outrage. It was simply “unfair” that a devout, clean-living man of God could develop cancer, especially a type so causally linked to smoking. To his credit, my father never asked “Why me?” but rather “Why not me?” Amid all the accidents and disasters that gave no premonition of impending death, why was he permitted the luxury of a warning? He used his time—the time between initial diagnosis and recurrence, between surgery and palliative chemotherapy—wisely. He died after finishing his life’s work, relishing his retirement.

But questions of cause and effect lingered in my mind. It would be dishonest to say that my own faith was not profoundly shaken by my father’s disease, all the more so when my clumsy prayers for an explanation received no discernible reply. Even while he was still alive, I searched for answers in science. My first literature search involved desperately rifling through encyclopedias in the school library, hoping to find some crucial fact that his doctors gave no over- looking. Such an epiphany was not to be found in the Britannica’s elementary account of cancer.

The analogy between medicine and detective work resonated strongly with me as I assembled the facts of a clinical presentation to identify the culprit illness. In my own private investigation, I had no access to my father’s discarded records, but I accrued details of his case from my mother’s recollections. I learned that he had been inexplicably hypercalcemic throughout adulthood. I discovered that the histology of his lung tumor had not been adenocarcinoma but atypical bronchial carcinoid. And then my paternal uncle died from complications of a pituitary macroadenoma, another cruel twist of fate that I could not rationalize.

At the beginning of medical school, I succumbed to the same temptations of hypochondria as every other student awoken suddenly to the frightening vast- ness of human pathology. While joking with my friends that every nosebleed presaged some exotic hemorrhagic fever, it never occurred to me that the explanation for my father’s disease would arrive through a process so prone to folly as self-diagnosis.

The answer first appeared not in front of my nose, but on it. During residency, small fleshy papules erupted on my face, which a wise dermatologist diagnosed as angiofibromata. These red spots remained merely an affront to my vanity until the day before I started oncology fellowship, when I awoke with right lower quadrant pain so severe I was convinced I had appendicitis. In fact, there was no surgical emergency, and a subsequent visit to the internist revealed that I too was hypercalcemic. Suddenly, the hereditary connection became clear to me. I beseeched my internist to order the necessary tests and consultations to confirm my suspicion. Adenomas were found in every parathyroid gland, islet cell tumors were seen on endoscopic ultrasound of my pancreas, and I had a frameshift mutation in chromosome 11q13. Multiple endocrine neoplasia type 1 explained everything.

My interest in oncology long predates my diagnosis with a familial tumor syndrome. I had been drawn to the field ever since watching my father’s doctors tend to him. Neutrophil counts rebounded as if by magic when they administered filgrastim. My other student awoken suddenly to the frightening vastness of human pathology. While joking with my friends that every nosebleed presaged some exotic hemorrhagic fever, it never occurred to me that the explanation for my father’s disease would arrive through a process so prone to folly as self-diagnosis.

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table—was vanquished when they dispensed ondansetron. Fleeting but mercifully, morphine banished the agony of spinal metastases. Although his oncologists could not provide a cure, their supportive measures seemed to work wonders.

Having never heard the clarion call to join the clergy, I knew I could not authentically follow my parents’ footsteps into the ministry. But I was struck by the similarity between effective pastoral care and the healing presence of his physicians. Bearing witness to a mutual compassion for the suffering, I recognized a similarity between the church’s sacraments for the sick and medicine’s secular acts of palliation. Occupying this common ground would allow me to continue a tradition of providing solace without misrepresenting the strength of my beliefs.

Time and education have not diminished my fascination with the treatment of cancer, even if its mechanics are gradually becoming less mysterious. As I train to practice oncology myself, I am grateful for insight into my own condition and hopeful that self-awareness will improve my ability to empathize with patients. That said, I pray I will never be presumptuous enough to tell a patient, “I know exactly how you feel.” When I see a newlywed twenty-something ravaged by acute leukemia refractory to induction, consolidation, and allogeneic transplantation, I cannot possibly identify with the depth of their loss. Such tragedies lie beyond my frame of reference. It would be an unconscionable farce to pretend otherwise.

Instead, my experience with multiple endocrine neoplasia type I has, so far, been an exercise in measured uncertainty. I cannot predict if or when my islet cell tumors will metastasize to the liver. I could yet develop the bronchial carcinoid that heralded my father’s sickness. But what I have lost in menin, I have more than gained in perspective.

In assessing the newfound threat of my disease, I became attuned to the military metaphors that abound in oncology. On a large scale, today’s research efforts perpetuate the war on cancer declared while combat still raged in Vietnam. On a personal level, patients are praised—and rightly so—for their valor as they willingly incur toxicity to “fight” their malignancies. I can claim no such courage, as I have not yet taken any risky action against my own tumors. Meanwhile, in preparation for battle, I am hardly defenseless. I have already found a calming power in awareness.

My diagnosis alerted me to the potential for insurrection within my own body and finally gave a name to the source of my unease, labeling my family curse. Such self-knowledge can provide comfort even when it does not alter the inexorable march of advanced disease. Patients with incurable metastases at the time of presentation may still be vanquished when they dispense ondansetron. Fleetingly and prednisone. They are thankful for their clinical improvement but untrusting of its durability. I understand their apprehension when they return to my office: Will the intelligence gathering of scans, laboratories, and physical examination bring word of a resurgent adversary? Each re-evaluation could announce the end of a fragile ceasefire.

Adopting the rhetoric of war during active treatment is perilous. We may imply cowardice whenever the most aggressive intervention is not chosen, and we may also undercut peace of mind during recovery. After the rhythmic assault of regimented cycles of chemotherapy, surveillance could feel more like surrender, and watchfulness could mutate to worry about inaction.

Without resorting to glib dismissal of their anxiety, I counsel patients under observation to enjoy life—always finite even in the best of circumstances—to the fullest. I can give this advice without artifice because I try to follow it myself. I am aware that my words might ring hollow, given that my condition may never require any treatment at all. But whether my disease remains indolent or progresses, I know that undue nervousness will not have determined the outcome. I will not allow the dark possibilities of the future to cloud the present, and I do not want my patients to have battled their own cancers in vain. A hard-fought remission that ushers in constant fear is a Pyrrhic victory.

I first sought a career in oncology in the hopes of providing sympathy and providentially discovered a wellspring of empathy. It is, of course, not necessary to have cancer to treat cancer empathetically. A shared diagnosis is only one locus at which our patients’ lives might intersect identifiably with our own, and the acknowledgment of uncertainty can itself serve as the common bond. Oncologists are often asked to peer into a crystal ball and speak knowingly about what the future holds, as if we alone can see through the haziness of mortality. We should admit, first to ourselves and then to our patients, the limitations of our gaze. In fact, in confessing our lack of prescience, we can begin to understand our patients’ own precarious state. The best prognostic models available to us are still vulnerable to stochastic events. When we critically assess the evidence that guides our management, we apply the rigor of statistics and discard underpowered studies as insufficiently robust, but each individual patient with cancer partakes in an ongoing, irreproducible experiment where n = 1. A median overall survival measured in years does not preclude an unfortunate outlier from dying within weeks, and it is impossible to foresee each person’s point on the probabilistic curve. But no matter how much time remains, and whether the goal of care is cure, control, or comfort, we can tell our patients with absolute certainty that we will not abandon them to the unknown.

**AUTHOR’S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

The author(s) indicated no potential conflicts of interest.

**REFERENCE**