REFLECTION

Seeking the Proper Tense

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This used to be a story about the past. Good story, happy ending, finished. Non-medical friends found it interesting. Doctors nodded sagely, secretly wondering if they would have recognized my pathognomonic symptom and made the diagnosis.

The year was 1965. I was 18, a college freshman. Over the course of a few weeks, I experienced several self-limiting episodes of severe chest pain.

I found a common denominator: a glass of wine, or a can of beer, produced very uncomfortable chest pain. I went to student health and told my story. Years later, as a resident working at that same student health services, I retrieved my records. The physician's notes were clear, emphasized by exclamation points—"pains in chest on ingestion of alcohol; lymphoma?!!!" A chest X-ray and a hospital admission followed, with a cervical mediastinal exploration and lymph node biopsy.

I sat in a room with my parents, the attending hematologist, and my intern. "You have Hodgkin's disease. This is a cancer of the lymph system. People used to die with this, but you are lucky. Now we can treat you and you will be fine." I would be among the first generation to be cured. I was told to ignore people who looked at me with pity. I had no reason, or interest, to disbelieve. I went home for the summer, had radiation therapy that gave me the worst sore throat of my life, and went back to school in the fall. In my senior year of college, I wrote a term paper "on surviving a fatal illness."

After 5 years, I stopped getting chest X-rays. I no longer had an oncologist. I went to medical school. Not only was I a Hodgkin's cure, but I had escaped chemotherapy and splenectomy, both of which would have been my fate several years later. I shared the story with friends. As a primary care doctor, I shared parts of the story with patients when I thought it would be therapeutic. Parents of young people with newly diagnosed cancer found hope in my story. Cured, a story in the past tense, I told them.

In my 30s, I developed bouts of tachycardia and felt short of breath with exercise. I searched the medical literature and found reports of radiation-induced constrictive pericarditis. I sought an opinion from a noted researcher. "You're fine," he told me, "no constrictive pericarditis." He suggested that as a doctor I was more aware of my heartbeat than the average person. "You're just out of shape."

At 41, a life insurance company technician came to my house. A new right bundle branch block came spooling off the EKG machine. The company turned me down. Anxious, I saw a new cardiologist. I now had two murmurs (I hadn't listened to

my own heart since medical school), but my echo was basically fine, just a little diastolic dysfunction, not to worry. I probably had "a little radiation damage" to my heart. Or that's how I remember it.

I let the reassurance message trump the damage message. My oncology colleagues helped by reassuring me that my breast cancer risk, 30 years after radiation, had returned to the average risk for a woman my age. At 56, I walked 200 miles across Wales, proud of my achievement. I thought of my irradiated heart as having a kind of scar that gave me minor limitations. Scars are finished, not evolving. The story was over, only now with a subtly different final chapter.

I turned 60, feeling incredibly strong and healthy. My internist asked if I had noted the enormous thyroid nodule she had just found. Before you could say "risk following radiation," I had fine-needle aspirations and a total thyroidectomy.

Pathologists found a small focus of thyroid cancer.

Frightened, I recognized that the anti-nuclear activists are correct: radiation is forever. I suddenly felt very vulnerable.

I asked a radiation oncologist colleague to explain the difference in dosage terminology between my 1965 records and current literature. He confirmed I had received large doses of radiation and thoughtfully sent me an article detailing all the solid tumors for which I was at increased risk.

With remarkable timing, that same week the New England Journal of Medicine published an article recommending that Hodgkin's survivors who received mantle radiation should have an annual breast MRI. After I adjusted to this reality, I had to convince my health insurer to do the same.

My shortness of breath, resting tachycardia with occasional atrial arrhythmias, right bundle branch block, and heart murmurs were not only classic for radiation-related heart disease, but markers for possible progressive cardiac disease. I have never tried to be my own doctor, but I was the only one putting it all together. I found guidelines for survivors of childhood cancer¹ and asked my internist to order pulmonary function tests. I wasn't surprised to see a moderate decrease in diffusing capacity.

In 2008, hiking from 5,000 to 8,000 feet in Big Bend National Park, I got scared. Nothing physically happened, but the exertion, the scenery, the fellow hikers passing me by—I thought how beautiful the country, and how terrible a place to have a heart attack. My self image as a totally healthy person collided with the realization that totally healthy women don't have yearly breast MRIs, cardiac echos, and thyroid cancer monitoring. My dreams of Machu Picchu or the Canadian Rockies might require readjustment. I came home and had a stress test.

When I first consulted a cardiologist in 1980, I was ahead of my time. It took awhile for the medical world, and its literature, to catch up and adequately describe what happened to me, and others who lived to tell the tale. From his perspective, the

hematologist who gave me my diagnosis was correct—mine would be the first generation to be cured. But as another cancer survivor, Dr. Fitzhugh Mullan, wrote, what we really have is not cure but “permanent survival,” with substantial emotional and practical aftermath.²

So is this still a story about the past? Clearly, not in the same way I once thought. My past medical history is not just an interesting case story, but also an integral part of my history of present illness. That means that I have a present illness, a reality I am just beginning to accept. As I see it, I’m the last one up the hill on a hike, but so far I make it to the top.

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