Shrinking From What We Don’t Understand: A Memoir of Ambiguity in Medicine

Program in Bioethics and Humanities
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Submission
03/09/2023

I cannot tell you my story without telling you someone else’s.

Before I went to medical school, I spent 10 years teaching high school English, much of that time in a program for at-risk youth. These students consumed my every waking moment. An average day would see students dealing with homelessness, abuse, gender dysphoria, student refugees from Sudan and South Africa who did not yet speak English, unplanned pregnancy, and mental health conditions.

One of my favorite students was named Tom. Tom was a straight-A student with schizophrenia and autism spectrum disorder. I spent countless hours with Tom, analyzing great works of literature and writing essays. He even joined the after-school theater program I had started, helping to paint sets and working the light board. I went to his graduation party and hugged him at his commencement ceremony.

But on a chilly spring night shortly after graduation, while his mother made supper in the kitchen, he sat on the living room couch and carefully cleaned his handgun that he liked to use for target practice. He brought it to his forehead and pulled the trigger.

An after-school theater program wasn’t enough for Tom.

Later on in medical school, an attending I worked with in Addiction Medicine made a comment that will forever resonate with me: “When a patient with schizophrenia presents to urgent care or an outpatient clinic, most are triaged according to their mental illness. The patient's concerns and complaints are all chalked up to his/her illness and many providers never stop to think that this is a patient with schizophrenia who may also have hyponatremia or hyperlipidemia or an ischemic stroke. They are labeled as schizophrenic and shuffled out of the way. No further understanding of the situation is pursued.”

This was exactly what had happened to Tom. He had been shuffled out of the way more times than he could count, and he just couldn't take it anymore.

In his book *Hidden Valley Road: Inside the Mind of an American Family,* Robert Kolker describes the evolution of our understanding of schizophrenia. As recently as 50 years ago, it was believed that schizophrenia was the result of "cold, demanding mothers". When twin studies began to make it clear that there was a genetic component (twins separated at birth and raised by different mothers were still more likely to develop schizophrenia if the other did), scientists got to work trying to identify what that genetic component was. Although differences have been found in the genetics and subsequent expression of proteins in the schizophrenic brain, treating those differences at the source has not been as successful as hoped.[1]

Today, scientists believe there are genetic components that can be catalyzed by environmental components. In other words, it's nature AND nurture, and the best way to treat it continues to be treating the symptoms with 2nd generation antipsychotics rather than treating the pathophysiology at its source.

This is part of the reason patients like Tom suffer so much. When society at large, and even medical professionals, understand a pathophysiology, when there is an obvious and visible cause (such as in the case of trauma) or an identified genetic variation that manifests predictably and does not depend on unknown outside factors (such as trisomy 21), most people are able to separate the person from the pathology, and they are comfortable interacting with this person.

But, as I've witnessed throughout medical school, when the pathology becomes murky, everyone gets uncomfortable.

We shrink away from what we don't understand.

This became clear in my first year of medical school when we had our first rheumatology unit. Many classmates, who were normally extremely calm and agreeable became skeptical, irritated, even pugnacious. I saw fellow students argue with professors about the diagnosis and genetic components of these diseases, I saw friends roll their eyes and even share their frustrations in the form of silly memes about rheumatology being “the worst specialty” or a “non-specialty” because it was so poorly understood. I was not offended or surprised by this.

But it did confirm that I had done well to keep my secret.

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I don't remember how many appointments I'd had at the University of Iowa Children's Hospital when the medical students came to observe me, but I do remember them crowding into the examining room in their white coats, clutching their clipboards, smiling earnestly.

The attending physician proceeded to explain to them that I was a six-year-old female, had contracted some sort of virus months before but had never recovered from the chronic fevers, and was now unable to walk. I was a medical marvel and was flattered at their interest but wasn't sure I liked the implications.

Especially because I had thought it pretty evident that I was female!

A virus had indeed made the rounds through my family, causing neck stiffness and back pain in my father and myself. My stiffness, however, never resolved and progressed to my knees, hips, hands, and ankles. An appointment at the Children’s Hospital in Iowa City two hours away from our home was finally made when the retired sheriff who lived across the street from my elementary school called my parents to tell them he had rushed out to help me after school because I was crawling across the street.

In the lobby of the Children's Hospital was a huge 12-room dollhouse. It could be viewed through a protective glass case, not to be touched by sticky little fingers. Each room was intricately planned and appointed. Tiny apples in a bowl on the kitchen counter were never eaten and tiny beds were never unmade.

Over the course of my illness, I must have stared at that perfect dollhouse for hours. Absolute control and predictability were comforting concepts during that tumultuous time, because we can control and predict what we understand.

But I was just beginning to learn that true beauty is not necessarily found in complete understanding.

I was eventually diagnosed with Juvenile Rheumatoid Arthritis, and I proved to have an especially stubborn case. Far from going into remission as I aged, the disease seemed to grow more fierce and doctors were never able to halt disease progression. Over the years, I would get a firsthand experience of the history of RA management and pharmacotherapy between 1990 and the present. I was put on huge doses of prednisone, hydroxychloroquine, meloxicam, celecoxib, methotrexate, and perhaps most memorably, monthly gold compound injections. All I remember about them is that they hurt horribly.

Specialists in Iowa City and Omaha were never able to halt disease progression, and at the age of 20 I had bilateral hip arthroplasties, with the promise that my shoulders and knees were next.

I did not let this interfere with my life, however. I did well in school, had lots of friends, and was involved in music, theater, and student leadership, since most sports were impossible for my body to handle. When I got married, we knew from the beginning that we wanted to have children.

This would be my first taste of medical professionals trying to put me in an easy category so I could be more easily and quickly evaluated and treated. Everyone advised that I not have children. When I asked “Why? Would it be dangerous?” they hesitated. “Well, no, not dangerous, but most people with your level of disease activity elect not to have children. If you do, it will very likely be a long, hard road.”

My response was that I would at least try.

It turned out that it was not a long and difficult road at all. And over the next 8 years, I would give birth to 4 healthy children. One third to one half of women with autoimmune disorders who become pregnant will experience remission during the pregnancy.[2]

I experienced remission for all of my pregnancies and was able to be off medications during each pregnancy and for about 2 months after. Then, I would flare again and would add back drugs that were safe for breastfeeding, and at about 6 months postpartum, stop breastfeeding and resume my other medications. My rule was, when my hands, elbows, and shoulders were so stiff and painful that I couldn’t easily pick up my baby, it was time to stop breastfeeding.

I would come to find great joy in nurturing others. I have never been so happy as when I sacrificed my sleep, my finances, my emotions, my physical wellbeing for these little humans in need. It didn’t matter that I often didn’t understand why they were crying. I was simply glad to be of comfort when they were.

This discovery would lead me to teach at-risk high school students, and later, to apply to medical school.

When I made my first application to medical school, it never occurred to me that I should keep my children a secret. I talked about them freely in the interview, which was with two male doctors. This particular school would give feedback after interviews were over, and my feedback was “It seems the applicant does not understand the time commitment involved in medical school.”

I was so confused because we had never talked about time management or time commitment in the interview. But I had talked about my children.

I did not achieve admission.

Over the next 5 interviews, I decided to try out my theory. In 3 total interviews (including the first), I mentioned my children, in 3 total interviews, I took off my wedding ring and pretended my children didn’t exist. I got into three medical schools. Guess which ones they were?

When I first started on the interview trail, I didn’t know if I should mention my lifelong battle with a chronic disease. I look perfectly healthy on the outside, so no one would guess if I didn’t offer the information.

When I realized that interviewers would rather I didn’t mention my children, however, I concluded that mentioning a poorly understood disease would be even worse. And so, as I stashed my wedding ring in my pocket yet again, I tried my best to fit into their understanding of what a medical student should be:

If she can’t be male, at least she can be completely healthy and childless.

Never mind that the opposite of these two characteristics were what motivated me to become a physician in the first place.

And now that I have been in medical school for a few years, people are still shocked when I tell them I have four children. So, I leave out the part about having a poorly understood chronic disease. I feign ignorance during rheumatology clinic and masquerade as innocent when I scrub into a hip arthroplasty.

People shrink away from what they don’t understand, and I don’t want them to shrink away from me.

When will we as physicians be self-reflective enough to understand that we don’t understand? At least not everything. And when will we learn to be content when there is only ambiguity and gray?

I get it. We became physicians because we like answers. We like to diagnose and prescribe.

But maybe the art of medicine lies in suspending judgement. In approaching each human as completely unique. A beautiful tangle of genetics, circumstances, experiences, perceptions, and abilities. Who are we to say that a woman with RA shouldn’t have children? Who are we to say that a mom with a chronic disease can’t be a doctor? And who are we to say that a person with schizophrenia can’t live a full and meaningful life?

So, I will approach each person with a new mind, not listening to the same old story, but hearing everything for the first time. Even when I don’t understand.

Especially when I don’t understand.

My life is covered in sticky little fingerprints, the beds are unmade, and the apple bowl fell off the counter. I wouldn't have it any other way.

Because, in the end, we all have a choice. We can put a glass case around our lives, doing our best to protect ourselves from the confusion, the unpredictability, the mess of this world. Or, we can get involved. We can run towards that which we don’t understand, instead of shrinking away. It will not be easy, but nothing worth doing ever is.

I am suspending judgement, forgetting the script, content in ambiguity, living in the gray.

I will not shrink.

Will you join me?

References

1. Kolker, Robert. *Hidden Valley Road: Inside the Mind of an American Family*. Penguin Random House; 2020.
2. Smeele HT, Röder E, Wintjes HM, et al. Modern treatment approach results in low disease activity in 90% of pregnant rheumatoid arthritis patients: the PreCARA study. Annals of the Rheumatic Diseases 2021;80:859-864.