

I hope to spend my career conducting and applying research to improve doctor-patient relationships and communication. The seeds of my passion for research were planted when I was about 9 years old, when my dad, a search engine developer, taught me that, with Boolean search techniques and critical thinking skills, I could find answers to almost any question that puzzled me. Now, what ultimately drew me to healthcare as my research field? Like for most, the answer is personal.

I was born with a rare genetic condition. For the first 12 years of my life, the signs and symptoms were relatively mild and didn't raise major red flags. But then, following a growth spurt, things started to go downhill quickly.

My diagnostic odyssey began with a series of visits to my pediatrician. Blood tests were run and the results appeared normal. When my pediatrician ran out of ideas, she referred me out for specialty consult.

Over the next 4 years, as my condition worsened, I was passed from one specialty to the next, to no avail. The message I got from many of these providers was that I must be imagining, exaggerating, or even making up my symptoms. Eventually, my parents started to believe this, too. Despite my persistent attempts to do all the "right" things, my body continued to fall apart, and I was blamed and punished for it. Slowly but surely, this bright, bubbly, cheerful girl faded away into a shell of a person, empty all but for a mass of internalized shame and confusion.

Finally, at age 16 I was referred to a geneticist who quickly put the pieces together, and my connective tissue disorder was diagnosed. But by then, I'd already experienced 4 years of unnecessary harm, not only to my physical health, but also my psychological health, emotional development, trust, self-esteem, identity, and relationships with family and peers. It's taken years of work to repair this damage, and some of it is irreversible.

A couple of years ago, while reviewing my medical records, I discovered a handwritten-chart note from my pediatrician that accompanied my chart and made the rounds with me to every specialist I saw. In large print, all in caps and underlined, it read: "PATIENT WAS LOOKING UP SYMPTOMS ON INTERNET!!" with two exclamation points for added measure.

What if my pediatrician, who had always told me to "be my own advocate", had welcomed my attempts to do just that?

What if the doctors I saw during those four years had listened to, and considered, the things I said about my experiences and symptoms, rather than dismissing them because I was "just" the patient?

What if my doctors had understood the harm they were causing me when they implied that I was the problem, and had instead admitted that they were simply unable to attach a label to my collection of symptoms?