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Chronic Illness and Disability in Medical Providers: Finding Space to Exist

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The first time I read my own medical records, I cried. It was August of 2013, and I was 19 years old. I had been sick for over six months. Initially, my illness had seemed minor: sore throat, swollen lymph nodes, low-grade fever. But within a few weeks, I found myself nearly bed-ridden. I was so fatigued that I could easily sleep 20+ hours per day. In my waking moments, I began to lose cognitive skills/abilities and developed anterograde amnesia. I suffered from periods of extreme weakness and partial paralysis down my left side.

My illness devastated me. Yet my chart, which I would not see until years later, described me in a way that made me feel like a monster: “she argued,” it said when I inquired about a test. “She balked,” “she is grasping at straws,” and worse: “she is unwilling to accept that nothing is wrong.”

It was hard to believe that the words in my medical records, the way my story would be told, was what the physician had gleaned from our one-time encounter. We spoke for only 11 minutes. He drew no labs; he conducted no scans; he ran no tests. This was the first doctor I had visited, despite being desperately ill for months. It was then that I heard what would grow into a pattern of words I never expected: “You know, college is hard, and it’s not for everyone. We need to deal with this mood issue.”

Even as I reflect on my experience five years later, I still vividly feel my heart sink in my chest. I feel the heaviness of the air around me as my breath was momentarily plucked out from within me. It had taken me so long to even realize that I was sick, and then to find an internist who could see a new patient without multiple months of

waiting. I was so confident that this visit would be the end of the pain. I trusted that my doctor would listen to me, believe me, and know what was wrong. I figured he would give me some kind of treatment, and things would get better.

Instead, I felt shattered and violated as I limped out of the office that day. For years, as a college and then medical student, I seemed like the sickest person around. I felt like the anomaly, the case so rare that it was not worth time trying to solve anymore. I started to internalize the sentiments of the physicians who told me that because my basic lab results were normal, I was not sick at all; the problem was just me. I simply couldn’t handle school, and I couldn’t be a physician.

So I was determined to prove them all wrong. I would not be limited by whatever was happening, by this “internal flaw.” In the process, I inadvertently tried to erase my own story: I wasn’t sick. I couldn’t be sick. I wanted to be a doctor, after all. These comments from my physicians and my peers convinced me that my identity, my reality, could not exist. I could not be both a doctor and a patient. I could not be disabled and still pursue my dreams.

It wasn’t until much later, after seeing nearly a dozen more physicians, that we began to understand what had happened. It may indeed have started out as a common virus. But within months, by the time I visited the physician, the virus had traveled to my brain and caused encephalitis, a swelling that went undetected. Years later, my condition morphed into the poorly understood myalgic encephalomyelitis (M.E.), an illness that leaves over 75 percent of its patients homebound.

It wasn't until much later, after I began medical school myself, that this information set me free. I discovered a community of students with similar experiences. I started to own my illness and my disability. I shared my story without shame, without feeling as though I was defective or a burden to academia. I sought out younger students who, like me, began to doubt whether their health would allow them to become a physician. I helped counsel them as we were all questioned by our superiors: "Have you really thought about what you're getting into?"

How do you expect to keep up? How will you handle residency?" Now, as a student-doctor, I can raise my voice and I can be proud. Yes, my disability comes with its disadvantages. Yes, I may need to study differently than some of my peers or take the elevator rather than the stairs on occasion. However, I now realize that my chronic illness does not preclude me from the medical profession. Instead, it is perhaps my greatest asset. Because, quite simply, I have been on the other side of that patient bed. I have been told that "it is all in [my] head." I have been denied testing that could have provided me medical help years ago, when this may have been treatable.

Thus, I will understand in ways that my peers may not. I know that there will be other times when our medical tests fall short, and that this does not negate the existence of my patient's story. I am determined to ensure that under my watch, no other patient, no other human, leaves my office in more pain than when they entered. I will listen, I will believe, and I will advocate.

Because the first time I read my own medical records, I cried. It took me years to realize that the physicians' comments on my personal character during my attempts to seek help did not define me. Their words did not limit me. But they could have, and they nearly broke me. To my colleagues in the medical community: we must never make any human feel as though they do not belong in their own shoes, or even in our own profession. We must do better.