

## Education

### Disabilities and Medicine: From Stairs to Stares

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#### Abstract

##### Description

The current state of medicine has done little to correct the imbalance of underrepresented groups in the physician workforce. In this editorial, a psychiatric resident physician retells his experience as an individual who is completing his medical training while being affected by a neuromuscular disorder and how it impacts his daily life. The primary goal of this paper is to elucidate the need for greater representation and understanding of the disabled physician workforce.

##### Keywords

physicians; training; disabilities; underrepresented; medical school; resident; medical disorders; barriers; neuromuscular disorder; discrimination

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How would the field of medicine change if the individuals who are weak, disabled, or possess chronic disorders were the physicians? Furthermore, would they be perceived by their peers to be robust practitioners? We live in a time where we hear buzzwords like “diversity and inclusion,” yet there is little to show for this amalgamation. The history of medicine highlights the care of those who are often seen as weak, uneducated, and poor in comparison to the stalwart physician. Just speaking the word “Physician,” connotes an individual who is extremely intelligent, has an almost impervious character, and is a superhuman physical specimen.

Long has the model of grandfatherly wisdom, “Do as I say” pervaded our culture of authoritarianism by doctors. That attitude has continued throughout medicine’s long history with little break from tradition. To speak of a weakness would be akin to saying that you are, in fact, in need of something. In practice, doctors do not speak of needing anything and are often believed to have the answers to everything. The tenets of medicine assume that all physicians are performing miracles, overachieving, constantly working in the face of persistent

stress, and able to manage difficult people and situations, all while being in perfect health and without personal issues. Let’s not forget the time paradox; it is not uncommon for doctors to work with little to no sleep, sometimes eating only snacks or depriving themselves of regular nutrition while running from one emergency to another, all the while making complex medical decisions. It is in this tension of the existing hierarchy that many physicians, residents, and medical students find themselves. We are supposed to be superhuman, and yet many of us feel inferior to our colleagues due to these draconian ideologies. This begs the question, “Are physicians with disabilities and other health conditions provided the necessary resources to excel?”

I was born with a neuromuscular condition, Charcot Marie Tooth, or CMT for short. It is caused by a mutation in the mitochondria (mitofusin), which leads to peripheral weakness and sensory loss. It is one of the main reasons I decided to pursue a career in medicine. I inherited it from my mother, who was, when I was born, confined to a wheelchair and continued to be throughout my life. She lost the function of her hands and legs and was completely reli-

ant on me and other caregivers for daily tasks. Because she was unable to work, we were very poor. I have a mild form, although as I age I can feel the tendrils of the disorder creeping through my body.

For the most part, I have lived a very active life. In my teenage years, I was on the swim team and was an avid cyclist. My best friend and I would ride our bikes 40 miles to the beach on the weekend and boogie board at the beach. Other than having a limp, CMT didn't really impact my life to any significant degree except perhaps my pride and popularity as a teenager.

I decided to pursue a career in medicine in my late 20s and was at a crossroads: Do I choose the physician assistant route or the physician route? I had to take my age, skills, and medical condition into consideration. Thanks to the encouragement of some great friends in my men's group at church, I decided to go all in and attend medical school. It took me several years to complete my classes because I was my mother's main caregiver. After completing my classes, I kept getting emails from a medical school on an island in the Caribbean: Trinity School of Medicine. After some serious soul-searching, I applied and was accepted. The caveat, the entire island was a series of steep mountains and hills on a volcanic landscape. I spent the better part of my first year confined to my apartment. My legs had begun to get weaker over the course of a year, and I was taking falls at home. Prior to leaving for the island, I was fitted with a pair of plastic ankle-foot orthosis (AFOs) by an orthotics graduate student that I knew. Within several weeks, they lost their shape and cracked at the ankle joint. I was completely stuck at that point. I had to accept the fact that I needed help, and I researched alternative options. There was an orthotist in Las Vegas who designed carbon fiber AFOs and who had impressive online videos of patients with CMT. I fundraised \$5,000 and put \$8,000 more on credit cards. On a break between semesters, my wife and I flew out to Las Vegas and I was fitted with a Helios brace. It revolutionized my life. I went from being mostly confined to a stationary life to enjoying a moderate level of freedom. I completed my training on the island and returned home for year 3 of medical school clerkships.

My wife and I lived in Baltimore, MD, for the entirety of my formal clerkships. The days were long, the weather was cold, and the logistics were a nightmare. For most able-bodied individuals, living in the city is exciting and new. However, if you have mobility issues, it is one headache after another. I had to add time to every part of my daily routine because it takes me longer than my classmates and coworkers to complete tasks. My fingers move slower; they have difficulty performing fine motor tasks, such as buttoning a shirt or writing. I also take more time walking because I have to constantly survey my surroundings for hazards and how to react to them. In order to be functional, facilities need to have several things: ramps with handrails, no stairs, and flat surfaces with no slick or wet surfaces. Most of the clinical rotations were downtown, so I had to park on the street and in parking garages, which meant I had to navigate city blocks, up and down curbs with no ramps, and often in the snow. Handicap parking spaces, while nice, are often occupied, or some able-bodied individual has parked in the spot.

During the time of my training, I had an attending physician tell me that no one gets any handouts, and if I couldn't handle it I should consider quitting. Other physicians were very understanding, often meeting me on a specific floor of the hospital rather than making me take the stairs, as is the current practice for moving between floors. While some of my supervisors made concessions for me, there were many times I deferred so I would not appear to be the weak one in our group. Rather than feeling as if I was excelling in medical school, every day was akin to treading water to stay alive. While I had several friends who supported me and who I could confide in, being in this culture was, and is, very difficult for me. The expectations are extreme: Go until you are exhausted, and then keep going and don't show weakness. All the while, we give lectures on physician wellness with subsequent suicide rates being exponentially higher in the field of medicine. With little physical and emotional reserves, I ultimately finished my medical school clerkships and began residency.

During my intern year, I was in a Transitional Year program. It was a blessing in disguise. I was able to rotate through each general med-

icine service with an elective peppered in for good measure. If you asked me what I wanted to specialize in during med school, I would have said it was Emergency Medicine, without hesitation. However, as I rotated through the Emergency Department, I discovered that I did not enjoy it anymore. What I did enjoy was talking to patients and finding out what brought them to this place in their lives. I found myself talking to homeless individuals, the disabled, and others with mental illnesses. I believe that my past experience as a patient gave me a unique insight into my patients' lives and a currency that I might not otherwise have, which led me to choose psychiatry.

While the rigors of medical school are gone, life as a fourth-year psychiatry resident has presented a new and unique set of challenges. Hospital systems are large, with interconnected buildings and separate clinics, and sometimes antiquated facilities. In my current institution, the elevators are out of service with regular frequency. This might be inconsequential to most, but to me, it means walking an extra path while expending energy I do not have the fortune of exerting. Everywhere I go, I can feel the gaze of others watching me walk. When I meet their gaze they quickly avert their eyes. Oftentimes, there are large ramps with steep inclines and no handrail to assist your efforts. My day largely consists of planning how to navigate from point A to point B while expending the least amount of energy and getting the most amount of work done. As residents, we see a large number of patients each day in different areas of the hospital. This requires placing orders, writing notes, and prescribing medications by using a computer. Repetitive use of my hands will often lead to contractures and the need to wait for their release. In addition, the task of walking is core to any physician. Due to my chronic fatigue, I need frequent periods of sitting, after which I can resume my work.

Residents are encouraged to take part in wellness programs, which often have discriminatory undertones. For example, a hospital may offer a health assessment screening or questionnaire and the employee will inadvertently reveal a disability or disorder in their answer choices, which may impact their career or other health benefits. In addition, disabled employ-

ees may feel discriminated against when they are unable to achieve the expected "normal" program goals of BMI, fitness steps, or weight loss. Should residents come forward and express their need for help, or will they endure criticism, discrimination, or retaliation from coworkers or supervisors? We live in a culture where HIPPA reigns over everything we do, yet, as medical providers, it is often impossible to keep our health information private.

I can recount many times when I was singled out in a group of medical professionals. With almost regular frequency, I will have someone at work ask, "Why are you walking like that?" One day, during an orientation as an intern, there was a large group of medical students and other residents who were on a tour with us. I emailed the resident in charge of the tour prior to the date, requesting that the group use the elevators for the tour. At the time of our meeting, the resident greeted all of us and asked "Who is the one with the leg braces?" At that moment, I couldn't think of a more humiliating way to be singled out for my medical condition.

On another occasion, I was on a rotation that turned out to be the worst experience of my professional career thus far. On the second day, I was in the attending physician's office, waiting to see our first patient. I thought this was a perfect opportunity to ask this seasoned physician if there are any treatments for my condition. After asking my question, he was silent for a moment, and smirked at me, saying, "After this whole residency thing, no one is going to hire you." I didn't show it, but on the inside, I was crushed. I felt like getting in my car and never returning. I responded to him by mentioning that there are residents and attending physicians with prosthetic legs and others in wheelchairs who are successful in their careers. He made the insult even worse by stating, "Those individuals have static conditions, while yours will get worse, which is grounds for companies not to hire you." I had to endure 3 more weeks with the physician because I was afraid of reporting him for fear of retaliation or jeopardizing my chances of matching into the programs of my choice. Needless to say, he used this hierarchy to insult me throughout the rest of the rotation.

Often, in sharing my experiences with other residents I have inadvertently given them permission to broach the subject of their own disability or health condition. By having this evolving discussion, we can elevate others who have lived in the shadows. Rather than creating a culture of exclusivity, we should break from tradition and focus on acceptance of our peers who are different from “the norm.” Perhaps we should measure each other not by standardized scores or by achievements, but rather by our interconnectedness or uniqueness. In a culture pressing for everyone to be the same, we should stand for something that is not the same. How would this impact our practice of medicine and the subsequent shaping of our treatments? To be able to see and treat our patients, we must first be able to see and treat ourselves and speak kindly to those around us. Empathy can and must be at the heart of medicine, but it must start with us.

### **Conflicts of Interest**

The author declares he has no conflicts of interest.

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