

A PIECE OF MY MIND

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Losing Vision and Gaining Perspective

“Lead with your science, not your disability.” Hearing this from a colleague left me stunned. While well intentioned, this advice reflects disability stigma and the common belief that disability makes individuals unable, instead of differently abled.

I was diagnosed with a degenerative retinal disease when I was 26 years old. My initial vision loss was unexpected and life changing. I began to have retinal hemorrhages just weeks after submitting applications to master of public health (MPH) programs. As permanency of my vision impairment sank in, I became convinced that my research career was over before it even began. The timing seemed impossibly cruel. I couldn't imagine or visualize pursuing a research career as a person with a disability, as I didn't know another researcher who had paved this path.

After a period of depression and a yearlong deferment, I challenged myself to make it through just 1 term of graduate school. Fearful that other students and faculty would consider me less competent or incapable due to my visual impairment, I hid my disability. I pretended to see things that I could not in an effort to avoid conversations about my vision. This also meant that I didn't ask for accommodations, missed important

prised, “If you can't talk about your disability then, how can I?” I was speechless. The patient was right. This tough conversation forced me to challenge my own behavior and question how I could be both afraid to reveal my disability status yet dedicate my career to helping others like me. I think about this patient often, especially when I feel defeated, vulnerable, or stigmatized, and it reminds me of my valuable dual role as a patient and researcher.

I briefly believed that outing myself as a person with a disability was enough, but quickly realized that the barriers for faculty members with disabilities surpass personal acceptance. As an academic researcher, I am responsible for developing my own research ideas and obtaining funding for myself, staff, and collaborators to achieve these goals. Productivity is crucial. Promotion, invited talks, and committee membership hinge on your colleagues' judgment of your abilities. Although all academics are chasing these goals, scientific success is often more difficult for persons with disabilities. We must not only work to meet the sensory, physical, mental, or cognitive challenges that come with being differently abled but also combat the stigma associated with disability.

I have worked to meet the demands of an academic career by developing elaborate compensatory strategies. My vision loss makes reading difficult and inefficient, even with the use of technology. I now rely on others to summarize literature to help me determine

which papers I need to read fully. Attending lectures with visual presentation of data requires creative strategies that range from listening techniques, asking other attendees for help, and requesting electronic copies of the presentation. I have difficulty identifying people's faces and instead use an algorithm of features, including height, style of clothing, hair color, and walking cadence, to identify colleagues—but this calculation can fail in environments with too much glare or dim lighting. These occasional miscalculations in identity have resulted in unnoticeable mistakes as well as more offensive social faux pas. However, these strategies are likely not permanent solutions for me. My eye disease is degenerative, and I could wake up tomorrow with another retinal hemorrhage and worse vision as a result. With each decline in my vision, I must recalibrate these strategies, adding complexity to meeting academic demands.

Even with the most ideal strategies, misconceptions about disability continually challenge my career. My disability is not obvious. Most people have no idea that I am visually impaired when they meet me. I usually disclose my disability early on to collaborators because I don't want to hide my disability. Thankfully,

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learning opportunities, and skipped many graduate school-related social gatherings. The work of hiding my vision loss was exhausting.

Despite the challenges, I completed my MPH program. I attribute this success to finding supportive mentors who didn't see my disability as a limitation. Instead, viewing my visual impairment as a unique perspective that could bring a truly patient-centered approach to my research. Most importantly, my mentors never viewed me as less able. That support was critical to my academic achievement and helped start a cathartic transition to accepting my new identity as a person with a disability. By helping me focus my career on research that could improve the lives of others who were visually impaired, my mentors changed the trajectory of my life.

However, it took an interaction with a patient for me to be truly open about my disability status. During a conversation with a participant in a research study, I admitted that I was also visually impaired. Feeling vulnerable, I quickly changed the subject, but the patient pressed me to find out more about my vision status. I hesitated, and admitted that I didn't normally discuss my visual impairment. The patient was sur-

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most of my colleagues respond respectfully. Only rarely has news of my disability status led to outright questioning of my ability as a scientist. Instead, the misconception I experience most often is exclusion, when collaborators retrospectively inform me that a task or project was “too much” for me to handle because of my vision loss. I encourage others to ask me questions about my disability in an effort to normalize those who are differently abled and to have open discussions about allowing me to decide the extent of my physical limitations.

When I transitioned from a postdoctoral fellow to a faculty member, I was prepared to take on the challenges due to my vision loss, but I did not anticipate the institutional barriers to success. While many academic and research institutions promote the inclusion of persons with disabilities through diversity initiatives, this subset of the academic population is sometimes excluded from inclusion initiatives and practices that go beyond the Americans with Disabilities Act are absent. For example, at my institution, there are limited data on the number of faculty members with disabilities, which is necessary to justify and monitor the allocation of resources to enhance the representation of this population. Additionally, funding for disability accommodations is complicated, and

departments or divisions must cover the costs, a policy that impacts the hiring unit's bottom line and has the potential to influence hiring practices. These issues are not limited to my institution, but without individuals willing to take on these inequities, change will not occur and there remain limits on the potential for many scientists and clinicians with disabilities.

Despite some barriers to academic success, I don't want to suggest a bleak outlook. My department has been exceptionally supportive. Being a researcher who is visually impaired in an ophthalmology department has many advantages; I am surrounded by mentors, colleagues, trainees, and staff who have dedicated their lives to helping patients like me. My disability has given me some advantages in my field because my personal experience is a constant source of research ideas and is a renewable source of motivation.

My career has helped me grieve my lost vision and accept my identity as a person with a disability. I also recognize that my academic position enables me to help others with disabilities. This includes advocating for other scientists and clinicians with disabilities because we have a valuable perspective that is often missing in research and medical settings. This perspective drives innovation and provides an opportunity to better care and advocate for others.

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