

Bent, Not Broken: Overcoming Spinal Deformity

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The ripping sound of Velcro brings back the memories. Hearing it, I'm in eighth grade again, when I would stand in front of my mother each morning at six o'clock, my back toward her as she pulled on the straps of my Boston brace to tighten its grip around my torso. The sun had not yet risen, but the worst part of my day was already complete—the three large curvatures in my spine once again locked into a position suffocating them from every direction, altogether forming the straight vertebral line my body did not find natural.

I was diagnosed with juvenile idiopathic scoliosis at five years old, with a severity meriting the wearing of a constrictive Boston brace for 23 hours per day, seven days per week. Within months, this phase of my life culminated in brain surgery for a Chiari malformation, a condition in which brain tissue extends into the spinal cord. This operation corrected my spinal curvatures, and wearing the brace became a distant memory. I was so thrilled that I announced I was going to become a physician, and poured over a human body atlas daily. Checkups with my orthopedist were uneventful for seven years, until a shocking day in which my mother and I learned that my curvatures had more than doubled in severity. A new Boston brace was needed, with an invasive spinal fusion surgery on the horizon.

No number of subsequent trips with my mother to the local mall for clothes to fit over my brace could soothe my anxiety about peers noticing it when I started eighth grade that fall. Despite full days spent in fitting rooms trying on hundreds of clothes, we struggled to find anything that could conceal the brace with normalcy. Withdrawing to the refuge of my family's home at all times, I could not find a way to feel like myself again; the bubbly, confident student-athlete was gone.

The school year surpassed my worst expectations, and I arrived each morning not wanting to leave the safety of my father's car. My classmates would hit my brace and look at my body with obvious disapproval, my silhouette noticeably larg-

er with my brace in tow. Once a student who fearlessly participated in class, I was suddenly too nervous to raise my hand, not wanting to draw attention to my appearance. The worst moment came during English class, when I was tripped by a student whose friends found humor in how my rigid brace inhibited my ability to get up from the floor. I called my mother from the school bathroom afterward, my silence on the phone an indication that I was holding back tears and needed to come home.

This was the moment when the seeds of resentment my brace had planted began to bloom. In addition to resenting the visible asymmetry in my shoulders and ribs, I resented my physician for prescribing my brace, and for his failure to prepare me for the emotional turmoil it would cause. In his nonchalant tone of voice when discussing my prognosis, I could tell that he had no understanding of the brace's impact on my life. Gone were my aspirations to become a physician; I could not stomach the idea of making a patient feel the way that I did.

Concerned by the impact of my scoliosis on my mental health, my mother devoted herself to finding an alternative solution and came across a physician who was pioneering a minimally invasive surgery called vertebral body tethering (VBT).¹ At the time of my initial consultation with this physician, only nine of these procedures had been performed. Eager for a future in which bracing was a part of my past, I expressed my desire for VBT, and on March 14, 2012, became the sixteenth patient ever to undergo the procedure, which is now performed across the world.

It is impossible to overstate my surgery's success and subsequent positive impact on my mental health and self-esteem. No longer wearing a brace, I spread my wings; once an insecure girl always hiding in the back of the room, I transformed into a young woman giving speeches on the weekends advocating for scoliosis patients. My desire to become a physician returned, and VBT's roots in innovation inspired me to obtain my undergraduate degree in biomedical engineering. While I still have some noticeable asymmetry in my ribs, I have grown to sincerely love it, and regard it as one of the things that makes me who I am. Now a medical student, I use my scoliosis experience as the prism through which I see patients. I take great measures to learn not just the pathophysiology of their disease, but also how care plans will manifest in their lives.

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There is a phrase shared among the scoliosis patient community about the strength we hold within ourselves—that we are “bent, but not broken.” I often speak to adolescents undergoing scoliosis treatment and tell them that this phrase is rooted in truth. However, for them to believe it, they need similar messaging from their care team and recognition of their everyday struggles and insecurities. As physicians, we have the critical power to shape how patients view and live through their illnesses. We must hear their stories and recognize patients as our greatest teachers.

Medicine can bring so much hope and joy, but also so much pain. While bracing was medicine for my physical health, it ultimately left me feeling more abandoned than ever. I was not heard during my initial treatment, and this contributed to the disappearance of my confidence, friends, hobbies, and career ambitions. To provide the best form of healing, we must ask patients to share what challenges them the most each day, their preferences regarding connections to peers with shared experiences, and their goals and fears regarding care. Above all else, however, we must find out from them where we have failed, and create an opportunity to begin again once more.

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