

## THE CANARY'S WARNING: LESSONS FROM PATIENTS WITH SPINA BIFIDA

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A child with spina bifida has been described as the canary in the coal mine.<sup>1</sup> Much as the canary signals impending disaster when there is decreased oxygen in the mine, these children, with their chronic, multidisciplinary medical needs, signal inherent weaknesses in the medical system. As a patient with a form of spina bifida (lipomyelomeningocele), and as a physician, I have come to understand this analogy all too well.

If my medical problem list could talk, it would say, 'I am lucky'. I have a wonderful family, a great career, and a healthy body. I am fortunate indeed. But I have worked very hard to earn these successes, harder than many. Growing up with a neurogenic bladder and bowel, tethered cord syndrome, and a large lipoma, my goal was to be 'normal'. To run, to ski, to do all of the things my siblings and peers did. Dreams were not altered to accommodate, rather extra effort was made to make them attainable. I did not want my medical list to define me, but really, I wanted to out-do it, to get as far away from it as I could.

Recently, the opportunity to be the physician in the Spina Bifida Program presented itself and I seized the opportunity, completely unaware of the challenges it would present. I never realized how challenging it would be to see children struggling, not quite disabled and not quite normal, or those children more severely affected and for whom the system was failing them already. Not quite disabled but not quite normal, I silently identified with these patients but chose not to share my personal history with the patients and their families. I wanted to prove myself to the team, and to the families, and not be defined by this condition. I also did not want to be identified as weak, less capable, or disabled in any way. Years

of hearing disparaging comments made by my peers in medicine echoed in my head and I did not want to be identified as a "bif brain". Having sat in on conferences debating the quality of life (or lack thereof) of individuals with challenges to continence and sexuality, I did not want to be placed under similar scrutiny.

I have finally learned, however, that there is no escaping this condition. Prior attempts at doing so have inevitably resulted in my failure because I have deviated from my own internal compass. Through these patients, I have learned that the thing I most wanted to outrun is the very feature that has guided me in most decisions and helped me to stay true to myself as an individual and physician. I have learned that there is a fine line between privacy and shame. I learned that somewhere along the way, I had let my desire for equipoise and privacy drift into a sense of shame demonstrated by my silence.

In righting my compass, I hope this essay can acknowledge that there should be no shame in the issues these patients and I suffer from. These are medical conditions, nothing more and nothing less. My own feelings about my condition certainly vary day to day and if asked by a parent or patient to describe the impact, my answer would be ambiguous. The essential aspect, however, is that ambiguity cannot be mistaken for shame. Nor should these conditions define us as individuals. They are facets to our lives that are unique and at times, isolating.

In speaking out, I hoped I could provide better care for my patients and be true to myself. Discreet conversations about continence or sexuality with an adolescent became much more meaningful when the patient realized I spoke from an experience quite similar to theirs. Finally, years

of wisdom, not taught in medical school, could be put to use and shared. I hope, with increasing openness on my part, that I can continue to share my wisdom, and continue to learn from the wisdom of my patients.

As the canary in the coalmine, these patients alerted me to my self-failure and have helped to right my compass. In observing and experiencing the shame and stigma that they perceive, I have an opportunity. The opportunity is to be true to myself and not let the stigma I too perceive infect me. Rather, I have the opportunity to alter perceptions of these conditions. There is an opportunity to demonstrate that while these conditions may mark an individual as not quite normal, we have faces and share similar goals and aspirations to those without them. I hope by acknowledging that I have spina bifida, my patients can see that there should not be shame, that one can exist with dignity. Perhaps, not quite normal may be just normal enough.

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#### REFERENCE

<sup>1</sup>Liptak GS. Health Care and spina bifida: the canary in the coal mine. In: The Future is Now: First World Congress on Spina Bifida Research and Care, 2009 World Congress on Spina Bifida Research and Care (Post Meeting Edition). 2009;109-114.

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