

Medical Humanities, Ethics, and Disability

One Fellow's Confession and Transformation

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In *Confessions of a Knife*, Richard Selzer gives a candid account of his life as a surgeon, divulging mistakes, regrets, impressions, and emotions in beautiful, metaphorical prose.¹ I too have a confession to make about my experience as a neophyte physician, albeit less gracefully. When starting my fellowship in neuromuscular medicine several months ago, I thought I was ready to take on the challenges of the diseased and disabled, well practiced in my professional abilities after eight years of medical school and residency training. I was well poised in my skills of empathy. I was a listener. I knew how to think openly about my patients. I gave excellent quality care. Or, so I thought.

Now I will be candid. I met a patient on my first day of fellowship, and I saw my best of intentions thwarted. She was a 36-year-old woman with facioscapulothoracic dystrophy (FSHD), a disease with a characteristically normal life expectancy and a relatively more benign course compared to its other muscular dystrophy counterparts. Pleasant and eloquent, she told me that she loved to dance as a child, her narrative proudly

affirmed by her similarly afflicted mother. However, in her late teens she began progressively weakening, and her abilities gradually declined. She was left with a slight waddle in her gait, an inability to raise her arms above her head, and the wasting away of various face, back, arm, and leg muscles. But this did not stop her. She graduated from college with a degree in art history and landed a dream job as a cultural critic for a well-regarded magazine.²

As I reflect back on our first encounter, I am sure the confounded look on my face did not instill much confidence in my new patient. I thought, *she seems so confident, so self-reliant, but look at her! She is so atrophied and weak, rising precariously from her seat unassisted.* And yet there she was, proud of contributing to her family and refusing disability support, which would have been wholly justified. At the time it seemed incongruent. She was so different from all of my other patients, who came through our doors focused on how much they could not accomplish. Instead, she emphasized what she had and “ran” with it, attaining the type of success that eludes even the strongest and healthiest of individuals. I reflected, this lady is pretty singular.

But I was soon proven wrong after reading about a patent lawyer with amyotrophic lateral sclerosis (also known as Lou Gehrig’s disease) by the name of Robert Paulson. He too was remarkable.

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As his voice weakened, he mastered the use of an eye-controlled computer, one of many types of devices allowing the voiceless to be heard. He was able to write a book entitled *Not in Kansas Anymore* and work for many years after diagnosis. He did so despite much physical and professional adversity: "Though I'd been a partner at the [law firm] for thirty years, I now felt like a pariah. . . . Since I was in a wheelchair, it seemed *ipso facto* my worth to the firm had diminished. Yet each year an examination of the records showed that I was still among the six or seven highest-billing partners." He attributes much of his ability to continue working to his preserved cognitive abilities and his eye-controlled computer: "I can send email messages; I can prepare, edit, save and retrieve documents; and I can conduct research on the Internet as though I were in a library. As a result, I have been able to pursue projects that are intellectually challenging and allow me to function as a professional."³

Mr. Paulson's story also amazed me. Why did he have the will to keep working? With this rapidly progressive and incurable disease, why didn't he give up, like so many other people with ALS had, retiring to their homes and awaiting the arrival of death at their doorsteps?

Hearing about this successful lawyer with ALS opened my mind. I realized that he and the patient with FSHD were not such anomalies after all. Soon after, I met another successful ALS patient, then one with chronic inflammatory demyelinating polyneuropathy, and yet another with multifocal motor neuropathy. *They were coming out of the woodwork.*

With so many of these people emerging into my consciousness, I thought, why was I so surprised about this concept of disability and success occurring simultaneously? Had I ignored this co-existence all along? Were there other examples of such people in my past that I simply glossed over? I thought back to

a seminar I attended given by Rosemarie Garland-Thompson, an English professor who presented her work on the ethics of disability. Standing behind the podium, she appeared like any other distinguished professor. She spoke of the exploitation of the disabled in the media, especially when they are asked to pose for "freak show" posters, billboards, and magazine articles.⁴ Then it happened: as she lifted her arms to talk with her hands, I saw that one of her arms was *deformed*. Ashamedly, I could not hold in my instinct to quietly gasp. Before me was an intelligent woman presenting an enthralling talk; then suddenly, as her limbs rose, my valuation of her changed. For that split second, I saw the beauty of her talk and the deformity of her limb. *This did not add up.*

Although not incisive enough at the time to realize what was happening, eventually I saw her presentation itself as an illustration of Dr. Garland-Thompson's success despite disability, counter to others' expectations, including my own. Intended or not, it was itself a social experiment designed to make a point, and I was the subject. Brilliant. My respect for her was so much greater and my personal embarrassment so much deeper.

Reflections about this gifted academic and my new patients brought me to a disturbing conclusion: I had a very real, deeply-rooted bias against the disabled, truly a problem for any physician and especially one training to become a specialist in neuromuscular medicine, a field comprised largely of disabled patients. Somewhere along the way, I had mistakenly decided that success and disability were incongruent.

My shame over this newly recognized bias grew. How did I allow myself to develop such prejudices? I should have known better. After all, there are many well-worn examples of courageous and talented individuals with disability who

achieve greatness. Like most neurologists, I had read *The Diving Bell and the Butterfly* by Jean-Dominique Bauby with great admiration. The “locked-in” author and magazine editor “wrote” his autobiographical volume painstakingly through many hours of eye blinks.⁵ And then there is Stephen Hawking, the well-known theoretical physicist, who has ALS. There were plentiful examples of severely disabled persons who employed various tools and technologies to communicate with the world.

And yet, somehow, I had developed a fixed false presumption about these patients. Why had this become apparent only now, so many years down my professional path? How could I reconcile my defeatist attitude toward my patients and still be their advocate, much less their doctor? Some might view my response as an overreaction, but I felt a personal standard undermined, and it wounded my very core.

To rectify this lapse in judgment, I needed to understand the source of my bias. I thought back. Maybe society molded me to develop this view. Even the word “disabled” suggests the notion that a dis-abled person is an un-able person, one who cannot do; one who cannot accomplish. The phrase “my successful disabled patient” is itself conceptually oxymoronic.

But such rhetoric seemed to evade moral responsibility for what I had come to believe. So how did I become this way? Truthfully, I could not blame the conservative leanings of my family, my neighbors, my schooling, or my church in middle-of-nowhere Texas. I had often seen frail little old ladies in town clinging to their walkers on their way to the grocery store. My past had shown me plenty examples of resilient “disabled” folk, and back then I found it rather unremarkable that they managed. I realized then that my bias had not always existed.

Instead, I believe I accumulated these perceptions in the early stages of my professionalization: medical school, residency, and within the confinement of hospital walls. At the time, my professors taught my classmates and me to classify our patients diagnostically based on pathology and dysfunction. Implicit in this approach was that there was something wrong with the patient, which made them unable to function normally. Normalcy and its absence became something like two competing camps of us versus them. Confronted as students with an ever-increasing torrent of illness, it was necessary to distinguish those who were ill from those (of us) who provided care.

As trainees, our lives were about making countless divisions and categorizations, figuratively distinguishing healthy and functional “doctors” from the unhealthy and malfunctioning “ill,” making the chasm between them and us even wider. Immature as it may have been, it was all a psychological defense. We were young Aristotelians cataloging the world of illness for our professors in the service of our emerging professionalism. This outlook taught us our craft but also shielded us from the ever-present threat of hypochondriasis. We were protected by dispensing a hefty dose of pity, which we mistook for care or empathy. Given the primacy placed on diagnostic parcelation—and the differences between our patients and us—how could I ever see any similarity or find any common human bond between them and my healthy cohort of twenty-somethings? Their fragilities—the foot drop, the tremor—became diagnostic clues to solve, not infirmities to overcome or people with whom to engage.

I feel great guilt for having allowed myself to be vulnerable to this parcelated perception of the ill patient that, in a real sense, dehumanized them in my mind. As descendants of Hippocrates,

my fellow doctors and I sought to think of and see our patients through an intensely focused diagnostic lens. We found ourselves isolated from the outside world, as often happens when one spends countless long hours working in hospitals and clinics. Perhaps because of this seclusion, I saw my handicapped patients as static beings doing little else in their lives other than playing the sick role in my antiseptic clinical home. I neither traversed their non-sterile thresholds with them nor saw them interact with their families and friends. I did not watch them survive and achieve quotidian successes. Biology, not empathy, was the focus of our interactions, and despite the fact that I routinely laid hands on my patients to examine them, over the years I soon lost touch with them.

Unfortunately my journey has not been a solitary one. I am not alone in my distorted perception of disability. A survey conducted by Tervo and colleagues demonstrated that medical students in both the United States and Canada are less comfortable with and held negative attitudes toward disabled patients, especially compared to those with a background in caring for the disabled.⁶ When UK medical students were asked to write about what came to mind when they heard the word “disability,” 74 percent ascribed negative personal attributes to and felt nervous about those with disability.⁷

However, trainee naiveté cannot be solely to blame for the perpetuation of such attitudes. When surveyed, resident and attending physicians were more uncomfortable completing disability assessments than other potentially uncomfortable tasks, such as performing a code, assessing domestic abuse, or discussing end-of-life issues,⁸ underscoring the potential bias toward disabled persons compared to other patients.

These influences in our medical education system are pervasive, but I have been fortunate. Not only am I a Fellow in neuromuscular medicine, but concurrently I work as a Fellow in medical ethics in a joint training program. This opportunity has allowed me to take a step back after meeting my patients with FSHD and ALS and reflect on them through the prism of the medical humanities. For the modern physician-trainee, the opportunity for reflection is rare but essential.

Reflecting on these cases through my exposure to medical ethics gave me the opportunity to delve into the works of others who have written about physician biases toward the disabled. I was thus introduced to the work of S. Kay Toombs, a phenomenological philosopher who herself is disabled from multiple sclerosis. She helped me appreciate how I had become acculturated by my training, recounting how physicians develop “habits of mind” that view a patient as an object categorized into a certain diagnosis and that reduce them to symptoms, signs, and laboratory values, disregarding how illness will affect patients’ lives.⁹

Toombs’s view is notable for its patient-centered vantage point, written from the perspective of a patient. Her observation that “a clinical diagnosis may be regarded as ‘terrible’ by one patient and as merely inconvenient by another”¹⁰ differs from that of the physician who does not view illness as a mere inconvenience or nuisance; illness is an ill. After all, it is the abolition of illness that motivates physicians to do the work we do, and even for the most ethically motivated and principled of physicians, the concept of beneficence fundamentally assumes that there is “badness” on which “goodness” must be affected. My initial reaction toward my disabled—yet accomplished—patients was of surprise, because I perceived a festering infirmity. It was as if

they had a devastating or even life-ending disease and little hope of resuming a “normal” life. The patients, however, were with Ms. Toombs. They did not wallow invariably in devastation—some of them just saw an inconvenience, and they preserved hope of achieving the goal of normalcy.

Moreover, according to a recent article in *The Lancet* by Shakespeare, Iezzoni, and Groce, disabled persons may not even perceive their disability as a problem, especially if the source of disability is congenital or long term, and they may feel that “having a disability is not incompatible with being healthy.”¹¹ In fact, many patients with disabilities do not necessarily abandon their lifestyles, goals, or sense of self. Toombs refers to the great neurologist-humanist Oliver Sacks, who echoes this sentiment:

A disease is never a mere loss or excess . . . there is always a reaction, on the part of the affected organism or individual, to restore, to replace, to compensate for, and to preserve its identity, however strange the means may be: and to study or influence these means, no less than the primary insult to the nervous system, is an essential part of our role as physicians.¹²

Disabled individuals may use any means available to remain as close to their elemental selves as possible. Here, both physician (Sacks) and patient (Toombs) point to one’s core personal identity as that which transcends the limitations created by disability. Sacks urges his fellow practitioners to help patients through the process of regaining identity from the moment illness sets in. Toombs echoes these sentiments because of the following concern: “In the event that illness is chronic or life-threatening this experience of disability relates not only to one’s immediate engagement in the world but portends the ‘inability to’ carry out future projects or to complete anticipated

goals.”¹³ Both Toombs and Sacks agree that illness forces a patient to adapt to the changes brought forth by illness. Any sense of threat to the pursuit of future goals must be overcome to reclaim that future and to succeed.

As I move from confession to pedagogical redemption, I hope to help bridge these conceptual gaps between physician and patient and overcome any lingering negative biases and stereotypes that can undermine care and sabotage the doctor-patient relationship. Disabled patients are not to be existentially categorized distinctly from other patients or doctors, and thus consideration and treatment should also not be disparate.

Without the benefit of my second fellowship in ethics, I wonder if I would have recognized and developed more insight into my “habits of mind.” I was lucky, but what of my colleagues who do not have the benefit of a similar immersion in ethics and the humanities?

Short of an ethics fellowship, there are several practical responses to the biases described. Shakespeare, Iezzoni, and Groce suggest the avoidance of negative assumptions and attitudes, the development of communication skills, the monitoring of discourse, and the respect of privacy and individuality. They recommend changing medical curricula to include peer groups and home visits to reduce negative stereotypes. Perhaps most critically, they suggest the following: “Education in disability should range from clinical information about specific conditions, practical issues about medical procedures, through to exploration of the human rights approach to disability.”¹⁴

The picture is not all grim. Educational innovation has resulted in increased use of standardized patients with disabilities to improve attitudes and funds of knowledge.¹⁵ Dedicated training programs for physical medicine and rehabilitation

residents resulted in long-term improvements in attitudes toward patients.¹⁶ Clinical immersion with disabled persons resulted in language of enablement and positive descriptors of patients.¹⁷

These studies suggest that, through education and appropriate mentoring, attitudes toward disabled persons can be ameliorated. From my vantage point, improvement in attitudes and practices can be meaningfully enhanced through a robust exposure to medical ethics and humanities. These disciplines become fonts for self-reflection and professional growth. If my experience is illustrative, and even illuminating, it is because I had the opportunity for deep and sustained mentored study of my clinical work via the humanities, in a way that neither science nor empiricism can offer.¹⁸ I learned to ask bigger questions and came to appreciate that sometimes the answers were embedded in the very place of mentored inquiry, a process reminiscent of the training obtained routinely by psychiatry residents to understand their own biases and countertransference. This is something we should think about incorporating into clinical training for all those who deal with the disabled, if not with all patients.

I believe that without adequate and appropriate reflection, we will never be able to provide our patients with the quality of care that they truly need, or to willfully integrate into our practice an understanding of our patients' feelings and the human condition as easily as we would order a laboratory test or prescribe a medication. Medical science and medical humanities can complement each other, but to do so, the humanities must be better integrated into the culture of medicine itself. They must be more than an ancillary subject. They must be at medicine's core, providing a counterpoint or harmonic to clinical experience.

We have much to do to provide more humane care to our patients, but it is an

attainable goal. As Shakespeare, Iezzoni, and Groce remind us: "Disabled people have great insight into their own condition and this can ideally make their relationships with health professionals more of a partnership, where each can learn from the other and where disabled people and their health-care choices are respected."¹⁹

An enhanced partnership between the humanities and the sciences can make our relationships with our patients flourish. As our successful disabled patients show us, anything is possible with drive and the right frame of mind. We should follow their example, laying aside those biases that indeed disable us as health-care professionals and hinder the provision of quality care. Let us instead work toward a goal that enables all of our "disabled" patients to reach their fullest potential and achieve the success they deserve.

Notes

1. Selzer R. *Confessions of a Knife*. East Lansing, MI: Michigan State University Press; 2001.
2. Certain elements of the patient's story have been changed to protect the patient's privacy. None of these changes are inconsistent with the patient's actual narrative experience.
3. Paulson R. *Not in Kansas Anymore: A Memoir of the Farm, New York City, and Life with ALS*. Winnipeg: Gemma B Publishing; 2009, 207–208, 235.
4. Garland-Thompson R. Seminar. *Disability as Human Variation, Cultural Construction, and Bioethical Issue*. Kennedy Institute of Ethics Intensive Bioethics Course. Washington, DC, June 4, 2009.
5. Bauby J. *The Diving Bell and the Butterfly*. New York: Vintage Books; 1998.
6. Tervo RC, Azuma S, Palmer G, Redinius P. Medical students' attitudes toward persons with disability: A comparative study. *Archives of Physical Medicine and Rehabilitation* 2002; 83(11):1537–42.
7. Byron M, Cockshott Z, Brownnett H, Ramkalawan T. What does "disability" mean for medical students? An exploration of the

- words medical students associate with the term “disability.” *Medical Education* 2005;39(2): 176–83.
8. O’Fallon E, Hillson S. Brief report: Physician discomfort and variability with disability assessments. *Journal of General Internal Medicine* 2005;20(9):852–4.
 9. Toombs SK. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. Boston: Springer; 1992.
 10. See note 9, Toombs 1992:11, 17.
 11. Shakespeare T, Iezzoni LI, Groce NE. Disability and the training of health professionals. *Lancet* 2009;374(9704):1815–6, at 1815.
 12. Sacks O. *The Man Who Mistook His Wife for a Hat: And Other Clinical Tales*. New York: Touchstone; 1985:6.
 13. See note 9, Toombs 1992:63.
 14. See note 11, Shakespeare et al. 2009:1816.
 15. Duggan A, Bradshaw YS, Carroll SE, Rattigan SH, Altman W. What can I learn from this interaction? A qualitative analysis of medical student self-reflection and learning in a standardized patient exercise about disability. *Journal of Health Communication* 2009;14(8):797–811.
 16. Moroz A, Gonzalez-Ramos G, Festinger T, Langer K, Zefferino S, Kalet A. Immediate and follow-up effects of a brief disability curriculum on disability knowledge and attitudes of PM&R residents: A comparison group trial. *Medical Teacher* 2010;32(8):e360–4.
 17. See note 7, Byron et al. 2005.
 18. Fins JJ. The humanities and the future of bioethics education. *Cambridge Quarterly of Healthcare Ethics* 2010;19(4):518–21.
 19. See note 11, Shakespeare et al. 2009:1816.