

Words Matter

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I write and teach that words are powerful.¹ I invite my students into a metanoia, a complete change of mind, to see words as generative. We say maxims such as “sticks and stones...,” “those are nothing but words,” “talk is cheap,” and “actions speak louder than words.” I teach that words are a form of action. The sticks and stones expression gives tacit permission to use the same hurtful words in retaliation, which is the opposite of what we intend. Many doctors do not understand what their words are doing, so they use them carelessly.^{2,3}

We conceived our twins via in vitro fertilization and were told that having multiples was the best possible outcome (“hopefully, a boy and girl—instant family,” as one doctor said). We were not informed of the high rate of disability in multiples. I teach that words create worlds. The thought of having twins never occurred to us before the doctor spoke this into being. I take partial responsibility for the outcome because I did not do my homework. The risks associated with multiples have been known since the 1990s. Recently, I have heard doctors speak about the risks, and they blame the parents. They say it is a practice driven by what parents want.

I chose to stay with in vitro fertilization doctors, despite their words, because I thought that the doctor had something that I needed. I, and they, focused on the end product. This framework led me to stay with doctors who objectified me. I had one doctor say: “Just do not say that I raped you” when I told him that he could examine me without a nurse present. I had another doctor tell me that he had multiple planes ready to take off from LaGuardia Airport and that he needed to create a holding pattern to even out the workload. I was the

plane and the workload. I teach that metaphors are figures of speech and also figures of thought. His words spoke of my body as an object. We both thought that, through in vitro fertilization, my body could be bent to will.

I have a child with multiple disabilities; he is both nonverbal and not ambulatory. I have learned in the last 20 years that doctors see my child as less than neurotypical kids.

Andreas was diagnosed with cerebral palsy at age 1. For a long time, I searched for an alternative diagnosis because my son does not present as someone with cerebral palsy, and he did not have the precondition of deprivation of oxygen either in utero (I was sent for many sonograms) or at birth (both babies had high Apgar scores). My son had multiple MRIs, each of which revealed no abnormality. I was confused by how my son could be diagnosed with cerebral palsy without the test results reflecting an alignment with that disorder.

I traveled from doctor to doctor in search of someone interested in a more exact diagnosis. I had researched and discounted disorders that mimic cerebral palsy; Andreas tested negative for all of them. We took him to several pediatric neurologists. One neurologist never looked at him during the examination. She said that he was autistic (something that no one else had said); she wanted to test for pyruvate dehydrogenase deficiency. I spent 5 hours researching pyruvate dehydrogenase deficiency; when I called with questions, she was incredulous. I told her that this diagnosis was discounted by the NICU doctors. I invited her to read the medical chart; she said, “No.” She recommended a spinal tap, artery blood sample, and a skin graph. I said, “No.” When I questioned the reasoning behind her autism diagnosis, she offered a tautology: “Because I think he is autistic.” Her lack of eye contact, lack of intellectual curiosity, and lack of reason told me that this was an expensive waste of time. I was represented on the report as “mother refuses.”

Several years ago, my son began to have cluster seizures and needed to be hospitalized. Many interactions within the hospital made the suffering worse. Entering the hospital was like entering another world. Part of that world seemed idiotic (from the Greek *idios* meaning

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one's own): cold, prejudiced, and, in some cases, cruel. I had a doctor speak of my son during rounds as a "12-year-old patient with mental retardation." No one had ever used that language, and this doctor had no prior interaction with him, had never seen him awake, but still labeled him mentally retarded. The doctor equated being nonverbal with being mentally retarded. Her prejudice was documented in his medical record. It took 2 years to have the language expunged. I know that my son's medical history follows him and shapes the perceptions of future doctors.

My son used to have excruciating stomach pain, and I could not find a doctor who took his pain seriously. One head of pediatric gastroenterology said: "Kids like these always have stomach issues." The doctor offered nothing; when I said I was experimenting with a change of diet, he ridiculed me. He dismissed the pain as something of no consequence because it happens to all kids with disabilities. I knew that, once again, I was dealing with someone who did not see us. He told me to give my son Frosted Flakes (Kellogg's) and castor oil. For obvious reasons, I did neither.

I tried to figure out what was going on with my son, so I started researching the gut as the second brain. I had kept a log of his seizure activity, and I noticed that, when he had typical seizures, he did not have stomach pain. When he had stomach pain, he was not having typical seizures. I found the condition of abdominal seizures within the medical literature; in all cases, the patient's

condition improved with antiseizure medication. I asked our pediatrician and the neurology nurse practitioner if we could increase his dosage of antiseizure medications. Thankfully, they listened and agreed to give it a try. It worked.

At the same time that we increased the medication dosage, we changed his diet. It created an immediate impact; his entire system began to function better by eliminating wheat, grains, rice, and flour. He has been on this diet now for 8 years, and I am delighted to report that he is healthy and pain free.

I have written about medical culture as paternalistic because my son and I are not seen as individuals. We are both seen as generic constructs reduced to the ubiquitous language of "mom" and "kids like these." The word respect means to see again, and I believe that medicine has the potential to change if the patient (and his mother) is seen.

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