

# I'd Rather Be Dead

K. Hope Wilkinson, MD

**W**hen my daughter was born, something was clearly wrong. She was just shy of term, but she weighed only 3.5 pounds. Her initial Apgar score was 0, and she was coded, intubated, and resuscitated. On her fifth day, the neonatologist did brain magnetic resonance imaging (MRI) “for prognosis.” Specialists pointed out to us everything that was wrong: the way she flapped her hands, the tilt of her ears, the size of her chin, the crease of her palm. They constantly reminded us what most babies do: smile, lift their heads, not just be little lumps. Eventually they diagnosed her with a rare chromosomal disorder, one that is barely described in a few publications. The kind pediatrician told us we would sing to her, we would read her stories, and she would go to school because we do those things for all children, but they didn't know what else her future held. After 12 weeks she came home from the neonatal intensive care unit weighing an additional 5 pounds and further burdened with home oxygen, a feeding tube, continuous pulse oximetry, and oh so many therapy exercises. I went back to work.

My first clinical rotation after returning from maternity leave was as a fourth-year medical student in the adult intensive care unit. We had a patient with an extensive polysubstance abuse history who had relapsed and overdosed on heroin. He was intubated and not showing any signs of recovery. The team constantly reminded his family that most patients usually start to wake up, squeeze hands, or try to remove their breathing tubes. We ordered a brain MRI for prognosis, and the radiologist's interpretation was eerily similar to another brain MRI I had read. The senior resident said, “I'd rather be dead than be dependent on others for the rest of my life,” to which the junior resident said, “The family should just let him die.” I said nothing; meanwhile, at home waiting for me was my daughter, distinctly not dead.

In my darkest moments, I wondered if they were right. My daughter's early days were not free from suffering. Like all babies, most of her time was spent sleeping, eating, and spitting up, but her reflux was relentless, leading to violent vomiting and mournful crying. The e-mails I had signed up for during pregnancy constantly reminded me that even the

simplest milestones, making eye contact, holding a toy, smiling, were passing us by.

I was relying on the wisdom and experience of the residents and attendings to guide the care for our patients and to guide and educate me. I was learning to place lines, interpret chest x-rays, and manage ventilators. I was also learning how we talk about our patients when they can't hear us, how we value people differently based on the circumstances of their illness, and the self-inflicted damage of preventable chronic medical conditions versus the tragic lightning strikes. And I was hearing over and over that people with lower intellectual abilities are less valuable.

During my intern year, my daughter was living and thriving; she enjoyed Norah Jones but not Phil Collins. She preferred feeling her stuffed dog to her stuffed giraffe. By then, I knew her specialists and my ICU colleagues were wrong. Her ears are perfect, her chin is perfect, and no one should let her die. One month my senior resident used the word “retarded” frequently and with derision, but most often to describe herself. One time, when a resident described themselves as “retarded” for missing a question on rounds, I found the courage to gently suggest, “Please find another word.” The rest of the team objected, saying, “No, she's using that word correctly.” I shook my head, but said nothing. I suspect that, for many of my colleagues, the idea of being “retarded” is a fate worse than death.

We jump through unimaginable hoops to become physicians. We go to school for 2 decades. Our experience has taught us that we are valued for our ability to do well on exams, to remember the obscure diagnoses, and to never forget a single detail. Every day we wonder if we're smart enough to make it through residency. We were each at the top of our class with high scores on the ACT, MCAT, shelf, and STEP exams. But, the process of becoming a physician, and then being one, has consumed most of our lives and identities. When I hear my coresident say, “I'd rather be dead,” what I tell myself they are saying is, “I can't imagine who I would be if I couldn't do this job and couldn't think like I do.” This makes me wonder how they can value their patients' lives if they would not know how to value their own, if they were differently abled.

This year in the ICU we had a patient with a traumatic brain injury and ventilator-associated

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pneumonia. He was otherwise young and healthy, and the inpatient rehab team was excited for the progress they thought he would make once he was off the ventilator. The team stood at the bedside making ventilator adjustments. To me he was just another ICU patient, just another set of fevers and cultures to follow, another ventilator to adjust, and a family to update, but as we stood there my staff said, “I hate brain-injured patients.” I said, “I don’t think you mean that.” He sighed and said, “You’re right; I hate taking care of brain injured patients.” I worry that people feel the same way about taking care of my daughter.

Now, my daughter goes to school. She recognizes my sadness. She gives me hugs and kisses. I know without a doubt that her life and value to society are equal to everyone else’s. Before I was her mom I laughed and smiled when grand rounds lecturers

bragged about their kids going to state in a sport or being valedictorian. Now I hope their children know they are loved for more than their accomplishments, and I hope they love themselves for more than their accomplishments. I long for a culture where I would hear as much enthusiasm for someone’s child being kind or doing a good deed. Let us teach our children, students, and residents that they are more than their brains, abilities, and accomplishments—to value themselves for more than their intelligence and to please value my daughter for more than hers.



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