

Quality of Life

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I entered residency having completed not 1, but 2 ethics courses during medical school. The first course was theoretical in nature, offered during the first year. We reviewed Beauchamp and Childress's *Principles of Bio-medical Ethics*¹ and discussed the principles of justice, autonomy, beneficence, and nonmaleficence, with the thought that this training would allow us to approach our clinical years with a moral and ethical compass. Toward the end of medical school, we revisited the principles, this time with a touted case-based approach and with 2 years of clinical experience under our belts.

Although beneficial, my medical school courses have done little to mitigate the relative impotence that I often feel as a resident faced with children and families in crisis. One of the most difficult scenarios that I faced was as the primary intern for a 7-month-old child with a progressive neurodegenerative disorder who had, in addition, suffered from anoxic brain injury secondary to cardiac arrest a few months prior to my caring for him. He had a tracheostomy tube and a feeding tube, had been on a ventilator since the cardiac arrest, and his long hospital course had been complicated by repeated and life-threatening infections. His prognostic evaluation by neurology was dismal.

Most days on rounds, I would begin by discussing the number of sympathetic storms he had experienced in the prior 24 hours, many of which I witnessed. During a storm, his heart rate and blood pressure would rise to nerve-racking levels, and he would sweat profusely. We had some medications to relieve the symptoms, but our orders were to give them only when a storm did not break spontaneously after 20 minutes. I would report whether or not he withdrew to pain on my exam; this fluctuated daily. We would occasionally discuss the fact that this child, whose only signs of neurological activity were his intermittent withdrawal from pain, some nonpurposeful eye movements, and those terrible sympathetic storms, was a full code at the request of his parents.

Where did the principles of biomedical ethics fit into my experience with this child? I thought back to the concept of justice as fairness in resource allocation. It did not support my role as a caregiver. Was anyone considering the cost of maintaining the child's ventilator, the frequent imaging and lab draws, his need for vigilant and constant nursing care? Was anyone considering the big picture, the health care system, or for that matter, global health? My background in public health keeps these issues on my mind, even as I dedicate myself to the immediate needs of my patient. The level of resources that we allocate to patients with a dismal prognosis seems inappropriate—even morally wrong—when one takes into account the fact that adults and children around the world die of simple and treatable diseases because they lack access to basic health care, sanitation, and the adequate nourishment to weather physical stress. Daily, I am forced to confront this imbalance. But what does that mean when I approach this patient or his parents at the bedside?

The hospital is probably not the place to reconcile and resolve these feelings, particularly not a tertiary care center such as our own. Even in asking the questions, I sense my inexperience and personal limits. My tendency to question the cost of this patient's care brings up the question of how much I value the individual life that I am dealing with. As an outsider, can I possibly appreciate the unique value of this life? Can I appreciate the attachment that the parents have to the child? I sometimes find it hard to view patients like this as more than sources of intense stress and pain to parents, and I tend to imagine the parents being "better off" without living their lives in the hospital, watching their child become more and more uncomfortable, infected and reinfected. It is hard for me to understand their desire to prolong their child's life.

I think about another patient I knew with a significant neurological and medical compromise and a similarly poor long-term prognosis. I was deeply moved by the joy that the child brought to his family in the small gestures that he was able to make: waving, grunting, slightly smiling. Those glimpses gave me second thoughts about the futility of his treatment and the exorbitant cost of keeping him alive. I consider accounts I have read by and about people with illnesses that seem horrific, yet the ill person is able to offer reflection and contribute greatly—not only to the lives of their families and friends, but to society. I am reminded in particular of Jean-Dominique Bauby's²

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autobiographical account of his experience as a patient with locked-in syndrome. Able only to move his eyes, he used a blinking system to write 100 beautiful and unforgettable pages about his life with that neurologically devastating condition. I question why my sense of justice seems to minimize the value of the medically compromised life.

Justice is not the only principle I struggle with here. Autonomy is always a difficult issue to address with the pediatric patient, who is not himself or herself autonomous. It is an even more difficult issue with the nonverbal child, who cannot express feelings to parents or health care providers. In the case of this patient, we respected the autonomy of the parents and their wishes that we do what we could to keep their child alive. Each time I witnessed a sympathetic storm, however, I found myself wondering how much the child was suffering for his parents' right to autonomy. Is keeping the patient alive in this case actually doing harm to the patient? Is it violating the principle of nonmaleficence? As a pediatrician, is it ethical to address the needs of the parents if doing so increases the pain of the nonautonomous patient? Whose interests am I bound to protect?

There may be no real way to solve the question of whether we are harming the patient who is unable to communicate, or how much harm is tolerable. At the very least, however, we need to understand the parents' perspective. What is it about their child that brings them joy? How do they feel when their child has a sympathetic storm, a painful procedure, a lab draw, or has vital signs taken in the middle of the night? What is their understanding of their child's prognosis? The answer to these questions, I have found,

can really only come from frequent, gradual, and unrushed conversations with the parents, which, amidst pages about critical events, panic laboratory values, admissions and discharges, is virtually unheard of for an intern. In the case of my patient, the answers to these questions were even more complicated by the fact that the parents only came at night when parking at the hospital was free and by their reputed distrust of our efforts because of past experiences in our hospital.

As is usually the case, I switched residency rotations while the child was still in the hospital, and these theories and questions became reality for another intern the following month. But the issues brought up in this case have resurfaced in the stories of many other patients. Although we witness and manage the day in and day out events in the lives of extraordinarily frail children, it is often the attendings who have the kinds of conversations with families that allow them to understand and weigh ethical principles in their decision making. And I believe this is as it should be. For all of my training and education, I do not feel professionally qualified to decide the relative value of all the conflicting aspects of these cases. I wonder, however, at what point I will be qualified and how I will get there.

REFERENCES

1. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 4th Edition. New York, NY: Oxford University Press; 1994.
2. Bauby J. *The Diving Bell and the Butterfly: A Memoir of Life in Death*. New York, NY: Vintage Books; 1997.