

The Sound of Silence

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The sound is the same as I enter the room for the first time in 5 months. The oscillator's constant humming is like white noise that drowns all the other beeps and alarms that are the moment-to-moment life in the neonatal intensive care unit. He is only a few bed spots from where I left him. He has grown to an impressive 4 kg—having been only the size of a Coke can when we earlier worked so hard to save his life. His skin is much thicker now. It has changed from the gelatinous red goo that came off in my hands when we placed umbilical lines. Now it has a yellow hue from liver failure, and areas of necrosis from prolonged anasarca. His head is grossly swollen in proportion to his puffy body. I still have a hard time seeing him as wholly human. He has multisystem organ failure: a thin ring of cortex after grade IV intraventricular hemorrhage, severe chronic lung disease complicated by multiple chest tubes, contractile heart failure requiring dopamine, end-stage liver failure, and bowel perforation. He has never tolerated feeds and remains on total parenteral nutrition. Recently, his kidneys have failed, and peaked T-waves are apparent even on the bedside monitor. As the list of problems repeats in my head, tragedy plays in my heart.

I am asking so many of the same questions that I asked myself months before. Why do we continue to keep this child alive? Will there come a time when we should stop pushing the limits of viability? Has our technology outpaced our capacity to make ethical decisions about life and death? What is in the best interest for the child? For the family? What is our responsibility in these decisions? Should a family with unrealistic expectations for survival and recovery be allowed to make medical decisions? Is there a point at which their decision making should be limited? How can we justify millions of dollars of care spent on one child's survival when so many others go without basic health care?

I have often felt this way in the neonatal intensive care unit—concerned, perplexed, and bothered by the daily reflex decisions that are made that determine life or death. I have been to prenatal counseling sessions when parents are

told the often-tragic outcomes for extremely premature infants. How, in that one rushed, petrifying moment can they truly understand the implications of their decisions? How can they look 10 years down the road to understand the possibility of life with a neurologically devastated child? Are they asking for a miracle when they ask me to “do everything” to save their child?

It is in this microcosm of the larger hospital where I feel most ethically challenged and most alone. Caught up in the intensity of the never-ending barrage of this place and the challenge of learning the basics of neonatal medicine, there seems little time to step back and raise these larger questions. Each day I stand beside the attendings and fellows who have dedicated themselves to neonatal care—presenting on rounds and doing procedures on children whose situations are seemingly hopeless—yet I do not share my concerns. As I watch them provide consults and make life and death decisions, I wonder about their concerns.

When this baby was born, we spoke with his parents at length about the likelihood of death, and if he did survive, the lifetime of difficulties he would experience, yet they continued to ask us to do all we could to keep him alive. I spoke with them one night on the phone when we were inserting the second chest tube in less than 4 hours and having difficulty ventilating him. I explained to them the severity of the situation. They continued to ask us to take all measures to prolong his life. Talking with the many other interns who took care of him during his 5 months of life, it is apparent that this conversation repeated itself over and over. The family consistently refused to consider withdrawal of care or limits on interventions employed.

We call the family one more time to stress the magnitude of the situation. His serum potassium has climbed to 10, and he is requiring resuscitation drugs to keep him alive. His small chest continues to jiggle with each oscillation of the ventilator. The constant morphine given to keep him comfortable is hardly enough to keep him still. Only then, 5 months, thousands of hours of heartache, and hundreds of thousands of dollars later, having reached the end of our measures, are his parents finally able to allow us to silence the oscillator. As this baby boy, deformed from our “heroics,” quietly dies in his mother's arms, the futility of all our efforts should seem crystal clear.

I look outside the room. Just a few feet away, a nurse holds his sleeping healthy twin; none of us had given him any hope of survival either.

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