Lucky

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The author declares that he has no conflict of interest.
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LUCKY DID NOT have an easy start to life. He was born breech at home without a birth attendant, and his umbilical cord was wrapped tightly around his neck. His brain was severely injured by the prolonged lack of oxygenated blood. Paramedics rushed to the house and resuscitated him before bringing him to the county hospital's newborn intensive care unit.

During that first week, the attending neonatologist asked me to come and meet Lucky's family. His parents were refugees who had only recently come to the United States. While they were still getting used to a radically different lifestyle in America, Lucky had burst into their lives. I had a clinical interest in the care of immigrant children and had established a primary care clinic for recent arrivals that provided both primary and specialty care. Through this clinic, I had seen many refugee children and had developed a small reputation. Also, though I wasn't fluent, I spoke the family's native language.

When I arrived at the hospital, the attending physician told me that the anoxia had been extreme. Computed tomographic (CT) scans revealed severe swelling of his brain. Lucky was ventilator dependent, and he was not expected to survive. I left the hospital that day unsure how long Lucky would last. But Lucky's heart kept pumping.

Repeated head imaging showed that the swelling in his brain had led to severe atrophy. By 2 months of age, he had just a small rim of cortical tissue remaining. Although the imaging looked bad, his body would not quit. To everyone's amazement, Lucky was extubated at 3 months of age. Though this was no small victory, he had many stumbles left in his journey.

After extubation, he developed a series of aspiration pneumonias. Lucky's traumatic birth had also injured his brain stem, impairing his ability to suck, swallow, and cough. Without a cough reflex, he could not prevent food or secretions from trickling down his airway and into his lungs. However, his family's faith was strong. They believed that Lucky would get better and that they would take him home one day.

That day came when Lucky was 6 months old. His parents called to tell me that he was indeed going home, and they asked me to be his primary care pediatrician. The first months at home were difficult for this fragile infant. His parents did not seem to fully appreciate the seriousness of his condition. Initially, he and his parents seemed to encounter setback after setback. Then, slowly but steadily, he started to reach certain developmental milestones: improved head control, rolling over, reaching for objects. Considering the small ribbon of cortex that remained on the CT scans, his progress astonished those involved with his care.

Over the next several months, there were a number of hospitalizations, but Lucky always seemed to bounce back. He overcame recurrent bouts of pneumonia and other serious infections despite the cards stacked against him. Eventually, I recommended the placement of a gastrostomy tube to minimize the pneumonias and to optimize his nutritional status. The family was initially opposed to surgery; the idea of enteral feedings through a gastrostomy ran counter to their cultural beliefs. They thought that a child had to "eat to survive" and that the gastrostomy somehow bypassed this vital human need. However, after a few more hospitalizations, the family eventually agreed. After the procedure, he began to gain weight and was able to spend more time away from the hospital.

Things were better, but they were not perfect. Lucky's parents needed a lot of help. He required a home health aide to assist with the G-tube feedings, oxygen administration, and nebulization treatments every few hours. Also, he needed early intervention services to help him learn to sit up and stand with support. With the extra help, Lucky slowly continued to reach milestones. By 18 months, Lucky was scooting around on his bottom, exploring his surroundings. He became increasingly interactive and social, actively engaging his environment through play. Though he had not developed speech, we provided an augmentative communication device that enhanced his communication. He continued to surprise me over the years with his accomplishments. When he turned 5, we planned for him to attend a kindergarten program designed for those with developmental disabilities. This time, it was not to be.

As I was driving home one day during a summer rainstorm, I received the message. Lucky had died. He had

been playing outside with his siblings and cousins. One of the children gave him a grape. He put it in his mouth and tried to swallow, but it lodged in his trachea. Lucky died the same way he entered this world, struggling for air.

As I drove, I thought about Lucky and the past 5 years that he had spent in my life. The first image that came to me was his smile—beautiful and joyful, yet mischievous. Second, I recalled his vital personality and strong will that seemed to prove everyone wrong. I remembered Lucky as a loving young child who, despite his inability to speak, still had a voice. Through expressions, gestures, and powerful tenacity, he made his desires and wishes known. I recalled how he had navigated his surroundings, sometimes with difficulty but always with intention. I remembered him scooting about on his bottom, pulling his IV pole in one hand and his nebulizer tubing in the other.

After his death, some in the hospital spoke of the waste of limited medical resources, the time and effort expended, and the apparently inevitable poor outcome. Others spoke of the irony of his name, Lucky. Throughout his life, there had been ongoing discussions and questions among the hospital, department, providers, and ancillary services staff members about whether it was appropriate to allocate so many resources for the benefit and care of a single child. Many expressed frustration that the family never put in place an advanced directive. However, to me, Lucky's life was not a waste of resources. Despite his delays and challenges, he lived a life full of love for 5 years. With every day he was alive, he grew, developed, and thrived far more than his health care team had expected.

Thirty years later, I still feel fortunate to have known Lucky. In such a short life, he touched my life and the lives of the many others who knew and cared for him. In many ways, Lucky made me into a much better pediatrician. Through my interactions with his family, I realized that the translation of intercultural awareness into culturally competent care means more than simply providing interpreter services and multilingual staff. It requires a deeper understanding of the gaps between a family's wishes and a provider's recommendations, each emanating from their respective lives and cultures. To be successful in the many challenging discussions with his family, we had to seek common understanding and create a shared approach to difficult medical choices. In addition, Lucky gave me a much greater appreciation of the challenges faced by children with severe chronic illness and developmental disabilities. At the same time, Lucky showed me how resilient even our most fragile patients can be and how they can repeatedly surpass our expectations. Biologic and social risk factors may suggest future challenges, but they can never totally predict a particular child's life course. Finally, Lucky reminded me that we are only here for a finite time. Lucky's time was shorter than most, but it was still filled with great meaning, for him and for those who loved him. I will forever be grateful for a young boy named Lucky who changed my life and my approach to caring for children.

POSTSCRIPT

The clinical case described above occurred several decades ago. Multiple attempts were made to locate the family and seek their permission before publication. Unfortunately, as a result of the passage of time, this effort was not successful. However, every effort has been made to deidentify the patient and family in the narrative above.