NARRATIVE
ESSAYS

Elvis Presley, New Technology, and Dying in the PICU

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I've been watching children die in the pediatric intensive care unit for almost 10 years now. Some die quickly from conditions just too voracious to be stopped despite the medicines and technologies we have at our disposal: severe traumatic brain injuries progressing to brain death, overwhelming sepsis leading to irreparable multiorgan failure, or insidious myocarditis precipitating a fatal arrhythmia. Most die over the course of minutes to hours after a family makes what has to be the most excruciating decision they've never expected to have to make, to withdraw life-sustaining therapies and let their child go.

Even with a fair amount of experience providing direct care while a child dies, my patients and their families can still surprise me. Some children whom I've expected to linger after support has been withdrawn die in minutes, never requiring additional medications to assure that they sleep through the removal of their breathing tubes, or to treat any pain precipitated by the process of dying. Other children have persisted despite my gut feeling they would die quickly after I nod to the respiratory therapist, signaling that it's time to pull the tube. It should go without saying that all of my dying patients' families are sad. Some families are silent, their tears falling on what have become their children's silent chests. Some want to hear the monitors continue to chirp as the child's heart slows to a stop. Some families pray, some sing lullabies. None of these things surprise me anymore. And I hadn't been surprised for a long time when I had the opportunity to care for Sophia.

Sophia was a beautiful 2-week-old infant admitted to our unit with acute respiratory failure secondary to altered mental status of unclear etiology. In the workup that ensued, it was discovered that she had disseminated herpes simplex virus. She required multiple antiepileptic medications to control her seizure activity and many transfusions of blood products to correct the significant coagulopathy associated with her developing liver failure. Given her overall poor prognosis, it was clear that she would not be eligible for liver transplant. As her neurologic exam continued to decline and evidence on MRI showed that Sophia's neurologic injuries associated with the virus had been severe, her parents tearfully made the decision to withdraw life-sustaining therapy. Family from across the country was called to come meet her for the first time and, in the same visit, say goodbye. I watched from outside the room as memories were made: perfect feet with ten perfect toes dipped in pink paint to decorate mementos, pictures taken with the blankets in the bed arranged just so, so that the breathing tube in the image could be easily overlooked and the focus would be only on the little girl laying in her all-shades-of-pink onesie. And then, with her dad and mom, both sets of grandparents, two uncles and an aunt, it was time to remove the breathing tube.

Her neurologic exam had declined to the point that she had lost her cough and gag and was only initiating her own breaths while remaining completely reliant on the breathing machine. Given this, I thought she would likely die relatively quickly after her tube was removed. But she didn't. After the tube was removed, she never opened her eyes, but her breathing ticked along like a metronome. I stood a couple of feet behind the rocking chair where Sophia was being held in her mom's arms. Finally, after about 15 minutes, her breathing slowed and became punctuated by agonal breaths. We administered her first postextubation dose of narcotics to treat air hunger. I couldn't hear what her mom whispered to her grandma, but I watched as she fumbled with her purse to get her smartphone in response.

As I watched Sophia's grandma, I started to reflect. When I began my fellowship, the children I cared for

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seemed to die in quiet rooms, the silence punctuated by the beeping of monitors, agonal breaths, or the sound of a parent's grief. In my short time working exclusively in an intensive care unit, the sounds in the room of a dying patient had changed. They had become more varied, more difficult to anticipate, acknowledged and subsequently disregarded much less easily. In observing these changes, I'd become quite annoyed with smartphones. I've seen parents torn between watching their child take her possible last breath and checking the buzz of a new text coming from their pockets. I've watched older siblings updating their Facebook statuses in between sobs, learning how to deal with a loved one's death on the fly, but doing so with the remote support system of social media, a forum rarely able to be kept as private as the user (or parents) would hope. I could never be sure how long a child's dying process would take, and some parents holding their dying children would begin looking to where their phones were housed after some arbitrary threshold of "too long" had come to pass. Once the acute grief of the inevitable had dissipated in the minutes after extubation, a waiting game began in which the reflex of reaching for a smartphone could not be suppressed.

I cringed when Sophia's grandma found her phone. The endearing impression I'd had of the family began to crumble as I started to picture texts being sent from the dying child's bedside. She scrolled until she found what Sophia's mom had asked for, and a lovely instrumental lullaby began to play. I found myself impressed with how the music filled the room despite the small device from which it came. As the song ended and we were again met with the sound of Sophia's slow breathing, her grandpa looked at his wife.

"Got any 'How Great Thou Art' on there?" he asked.

Sophia's grandma scrolled. "Will Carrie Underwood's version work?"

Every person in the room allowed themselves a small laugh. Sophia's mom assured her Carrie Underwood's version would be just fine.

Though Sophia's breathing had stopped, her heart continued to beat. Sophia's grandma's job was now that of DJ, finding one comforting song after another as we waited. Soon after we had listened to a batch of gospel by Elvis Presley—absolutely "The King," Sophia's mom and grandpa agreed—her heart stopped. Taking my cue, I approached Sophia in her mom's arms. I listened for the heartbeat I knew I wouldn't hear. I felt for the pulse I knew wouldn't be there. With tears in my eyes, I pronounced her dead.

I'm not sure how I'll feel the next time I hear the buzz of a text message coming from a pocket during a child's death. I'll probably still feel irritated when I see somebody updating a Facebook status. Maybe now though, the next time I hear that telltale new-message buzz, I'll remember a little girl dying surrounded by her loved ones while listening to Elvis Presley.

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