The Sounds of Grief

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NEVAEH'S* SWOLLEN, SEPTIC body shone like a stone—the dome of her abdomen turgid, her obsidian skin smooth and clammy. At 10 months of age, she was already a chronically ill child who breathed and was fed through tubes, and that day, the unremitting river of illness finally eroded her. Within minutes of our initial assessment in the emergency department, she vomited a thick, tarry sediment of blood, the stress of which stopped her burdened heart.

After Nevaeh's abrupt decompensation, her grandmother and uncle arrived and remained near her bedside for the subsequent prolonged resuscitation. They were guided in and out of the cacophony, alternating between holding the child's hands and talking with members of our multidisciplinary resuscitation team. I was a senior fellow at the time and co-led the resuscitation with my attending, Dr L.* To better oversee our team's efforts in one of the smaller patient examination rooms of our emergency department, I perched myself, somewhat precariously at 8 months' pregnant, on a stepstool. Nevaeh's sudden arrest hadn't left time to move to the trauma bay. Parents are en route, I was told.

We performed rounds of cardiopulmonary resuscitation (CPR), inserted intravenous and interosseous lines, drew labs, and administered fluids, medications, and blood products. The corridor outside of her examination room was cordoned off for privacy, and providers lined that hallway, ready to rotate in for chest compressions. When the resident whose 2 fingers were stationed on Nevaeh's groin exclaimed, "I have a pulse!" the room swelled with a collective inhale of quixotic anticipation, many eyes and ears on the monitor as it produced its monotonous bleat. . . bleat. . . bleat.

Exhales.

Whispers of relief. For while we, in pediatric emergency medicine, are accustomed to resuscitations, a sudden death remains relatively rare. Those who do die in the emergency department often arrive in irreversible arrest, and I convinced myself that Nevaeh—despite arriving in severe shock—would not die, not on my watch.

I caught the gaze of her hopeful relatives, her parents still absent. As we transitioned to postresuscitation care, Nevaeh lost her pulses again, and we dutifully restarted our efforts. With x-rays demonstrating pneumatosis intestinalis and diffuse free air, I thought, improbably, if only we can stabilize enough to get to the operating room. After another teasing visit of her heartbeat, I locked eyes with the surgeon, half-heartedly mouthing "ECMO?" and he, characteristically laconic, answered, "The patient is not an ECMO candidate."

In that still point of organized chaos, I knew the answer, as much as one can know these things. For a total of nearly 40 pulseless minutes, I had been hoping against hope, invested. Parents are in the parking garage, I heard. Forty minutes. We had to decide whether to continue or cease our resuscitation.

I, like many colleagues, feel wed to selectively hopeful aspects of the literature regarding pediatric resuscitations, continually balancing ethical principles of respect for autonomy, beneficence, and nonmaleficence. In pediatrics, we tend to engage in lengthy resuscitations, recognizing that few criteria can accurately predict the futility of CPR, and citing studies—and personal experiences—of intact survival after unusually prolonged resuscitations.[1,2]

These considerations are particularly nuanced in a child such as Nevaeh, whose neurologic and developmental statuses were severely impaired at baseline. However, we must guard against making value judgments about another's present or future quality of life. Moreover, when it comes time to terminate a resuscitation in the pediatric emergency department, it is almost always in partnership with the child's parents or surrogate decision makers. We know that parental presence in the resuscitation room provides comfort to patients and families in parting moments, helps the family's adjustment to death, and may ease some of the depression and anxiety associated with grief.[2,3]

**All names (patients and colleague) and pertinent identifiers have been changed for privacy.*

In considering our ethical duties to Nevaeh, Dr L and I found ourselves weighing the maleficence of continued CPR—how harmful would another two, or five, or seven, minutes be? —against the beneficence not only to the patient but also to her parents. Our "best interest test" was not just, "What would Nevaeh choose for herself, if she were competent?" but "Would a competent patient prolong CPR to benefit the grieving process of her family?"

Of course, in real time, these were not strictly academic deliberations; they were imprecise shadows of our thoughts, tainted by my more immediate, selfish desire to show her parents the sweat, hope, and love we put into bringing their baby back, for them to know we didn't just give up on her without a fight. The moral ambiguity of our situation was reflected in the ranks of our resuscitation team, with some members ready—and others unwilling—to cease CPR. I was still on the stepstool and felt heavily the great burden and privilege of my position.

We kept going.

I imagine that just as Nevaeh's heart restarted its sullen rhythm, again, for the third time, her parents must have been hurriedly turning off the ignition of their parked car. Dr L and I agreed on a time limit for the resuscitation, should there be another round. Our team had just enough time to clean Nevaeh's room, adjust her lines, tubes, and drips, and place her small, cleaned body peacefully at the center of the large bed, waiting. Waiting for her parents, for transport to the pediatric intensive care unit, for the body's final decision of life versus death. It was all very serene.

Until it wasn't.

What is the sound the parent of a dying child makes?

It is a sound I know too well and should have expected. But didn't. It is not a sound, exactly, but a primitive, soulful emission, simultaneously high-pitched and guttural, originating from the deep and recessed forests of the limbic cortex. It is a sound that sometimes reverberates in my skull at night, keeping me from sleep, as I blink away invasive thoughts of being on the other side of the trauma bay doors, being the parent; hearing those sliding doors creak open and closed, open and closed.

What sound would I make? What would I do? Would I collapse to the floor in suicidal agony, like the father of Aiden,* the 8-year-old patient with terminal brain cancer who was receiving hospice care but came in because his family could not manage his suffering at home? A father, who, just 3 months before, had lost his wife to the same pernicious disease, and in front of our trauma bay doors—open and closed, open and closed—lost his will to live?

Would I freeze in catatonic shock, waxy and dull, like a marionette, my impenetrable grief building up to puppeteer me in the aftermath? Like the mother of Taylor,* a 17-year-old patient who was, inexplicably, shot in the chest while waiting in line at a movie theater?

As for Nevaeh's parents, they stormed into the emergency department, howling.

"My baby! What did they do to my baby??! Is she dead?" screamed her father—all 6'6" and 300 pounds of him—as he tore along down the hallways, pushing over the makeshift barricades and punching the walls. To say I wasn't afraid would be a lie. But I was also ashamed of my fear in the face of parental grief. When he entered Nevaeh's room, he hurled a chair against the sink, which skidded a few feet from me. "They are killing my baby. Mother f***kers, she's just a baby, my baby, my baby! No. No. No. What happened to my baby?!"

Nevaeh's mother, a few feet behind her towering husband, made The Sound. And then collapsed to the ground, unconscious.

Our security guards ushered me out of the room, Dr L and the nurses tended to Nevaeh's stirring mother, and the small body at the center of it all kept holding on, bleat... bleat... bleat... When I tried to re-enter, the security guards insisted that my gravid state made me more vulnerable around a potentially violent parent, and Dr L took over communications. After juice and a few minutes of sitting, I placed my hands on my swollen abdomen and felt the reassuring flutter of small limbs, a life preparing its entry. The irony was not lost on me.

The team was in the room—guards an arm's reach away—with the challenging task of explaining that Nevaeh was not yet dead, but that her heart had already stopped 3 times, and we didn't expect it to continue beating much longer, even with all the medications. I couldn't discern Dr L's exact words from the door but heard the unmistakable tone—earnest, kind, forlorn—of her explanation. When it was met with more anger and screams, our guards—veritable psychologists of their own right—walked the father to a private section of the emergency department, where he could bellow and swat freely, releasing his rage.

Nevaeh's mother stayed in the room, looking alienated as she awaited the inevitable. When Nevaeh's heart stopped again, we were prepared. We resumed our positions like actors on a stage—places, everyone!—and went through the rehearsed round of motions—compressions, medications, pulse check. Her mother and father howled in the room, begging us to do what we could. After a while, I overheard Nevaeh's grandmother talking to her own daughter, "Baby, they've been doing this all night. They've worked so hard, and brought her back so many times. Her poor body is tired of fighting." Her uncle nodded in agreement. For the first time, Nevaeh's parents were quiet. Dr L was at their side, holding mom's shoulders—"all we can do," "too sick," "so sorry"—pieces of the conversation floated up to my ears like flotsam from the ocean below. The parents nodded. Dr L gave me the cue, and we called it.

Ultrasound.

Time of death.

Silence. Nevaeh's parents held her body, wrapped in the white hospital sheet, for a long time. They sat in the corner chairs of the room, side-by-side, cradling her—mother holding top half, father holding bottom, like a family crowded in an airplane row, heading elsewhere, anywhere—while we went through all the steps that come after. They were silent the entire time.

After a long while, as I was filling out Nevaeh's death certificate, her father unexpectedly roared for a physician. I stood up, and the guard—still tending duty—put up a cautious hand. He peeked in, and we both knew, from timing and timbre, that this was not a violent cry, but a desperate one.

"Doc! Doc! She is still alive! She is moving! What are you all doing? I'm telling you, I felt something! She is alive!" He was frantic, unhinged, wild-eyed.

I sat down next to Nevaeh's mother, who had not altered her posture at all, a marble Pietà.

"Please, tell me what you are feeling?" I asked. He pointed to her right shoulder.

"Right there," he said, voice now trembling, 2 fingers mimicking the resident's pulse-check, "I felt her heart!" I placed my own 2 fingers on her right shoulder, where he indicated, waiting. Rigor mortis is what I felt.

"I don't feel anything here," I offered. "It really is not possible for her to be alive, but describe to me what you felt?"

"It was like… like a flutter," he said, unconvinced by my certainty. I took out my stethoscope, and carefully, deliberately, placed it on the left side of Nevaeh's chest. "Her heart," I said, "is here. Let's take a listen." After a minute, I kept the diaphragm against her stiff body, and took off the earpiece, offering it to her father, the way we do for medical students. He placed the stethoscope in his ears.

And listened.

And listened.

A wave of recognition crashed onto the shores of his face, briefly erasing all animation, flattening and then contorting his expression into what I now recall only as amorphous heartbreak. "Doc," he whispered almost imperceptibly.

"I don't hear anything."

"Then what was I feeling?" he pleaded. I scoured my thoughts for a suitable response.

"Sometimes." I exhaled. "We can feel the blood coursing through our own fingertips, and that can trick us into feeling a pulse. Or sometimes, as the body dies, its muscles twitch with leftover energy." He was silent, taking it in. "And sometimes, when we want something very badly, our mind can play tricks on us, too."

I will never know what Nevaeh's parents' grief reaction might have been had we called her death earlier, had we not waited for their walk from the parking garage; but I believe that brief time with their daughter, heart still beating, helped quell their anger and forge a therapeutic alliance. Nor will I know the true probability of alternate outcomes, ones I discounted and that may be worse, even, than death—persistent vegetative state, brain death, months in an intensive care unit tethered to ventilators—and whether we made a too-risky gamble. We make our decisions in real time, fraught with ethical strife and saddled with the emotions of our own humanity.

He looked up at me, and then at his wife, wounded, beseeching.

"You see? I'm not crazy. I just needed…. to understand." On this final word, his voice cracked and his shoulders heaved with hard-earned, unbridled sobs. His wife, who remained ceremoniously bowed, nodded her head and sighed ever so slightly, unloosening a lone teardrop that rolled off her right cheek onto the sheet, consecrating her daughter's makeshift shroud.

REFERENCES

1. Parra DA, Totapally BR, Zahn E, et al. Outcome of cardiopulmonary resuscitation in a pediatric cardiac intensive care unit. *Crit Care Med*. 2000;28:3296–3300.
2. American Heart Association. Ethical and legal aspects of CPR in children. 2006. Available at https://co.grand.co.us/DocumentCenter/Home/View/606. Accessed June 10, 2018.
3. Boudreaux ED, Francis JL, Loyacano T. Family presence during invasive procedures and resuscitations in the emergency department: a critical review and suggestions for future research. *Ann Emerg Med*. 2002;40:193–205.