Care of Extremely Small Premature Infants in the Neonatal Intensive Care Unit

A Parent's Perspective

Kelley Benham French, MJ, BA, BS

KEYWORDS

- Extremely small premature infant • Neonatal intensive care unit
- Life-and-death decisions

KEY POINTS

- Parents and doctors look at a baby from fundamentally different perspectives.
- Every prognosis expands or contracts a universe for a doctor or a parent.
- When the clinician and the parent come together to make a life-and-death decision, language matters.

My daughter was born twiggy and translucent as a baby bird; her eyes fused shut, mouth agape. Through her chest, we could see her flickering heart.

She arrived at 23 weeks and 6 days: the threshold between viability and futility, between everything and nothing. For me, after 5 years of infertility, she came at the trembling membrane between motherhood and despair. The doctors made it clear that no matter what they did, she would probably end up broken or dead.

Juniper French spent 196 days in the neonatal intensive care unit (NICU) at All Children's Hospital (now Johns Hopkins All Children's Hospital) in St. Petersburg, Florida. In that time, my husband and I were reborn, too, morphing into entirely new people with new perspectives and new roles to play. Part of what shaped us were the dozens of conversations we had with the doctors and nurses who led, prodded, encouraged, guided, and steered us along.

Each of those conversations shifted the tectonic plates beneath our lives. Some had the power to salvage our family or destroy it. We saw the doctors and nurses studying our faces, trying to determine what we could handle. How much science? How much hope?

Disclosure: K.B. French is the author of the book, *Juniper: The Girl Who Was Born Too Soon*, published by Little, Brown.

The Media School, Indiana University, 601 E Kirkwood Avenue, Bloomington, IN 47405, USA
E-mail address: kbfrench@indiana.edu

Clin Perinatol ■ (2017) ■–■
http://dx.doi.org/10.1016/j.clp.2017.01.008 perinatology.theclinics.com

We studied their faces, too, noting the lines of their worry and the weight of their responsibility, as we tried to figure out what they were hiding. Our primary nurse, Tracy, had a habit of wearing a mask when she didn't want us to know how scared she was.

One cardiologist, explaining a clot in our daughter's heart, drew a square, divided it into 4, and said, "This is a heart." I realized he probably had to talk to parents every day who truly did not know what a heart looks like or what it does.

Doctors have impossible conversations every day, I realized. But the skills that make someone a good doctor are not the same as those that make a good teacher, counselor, interpreter, or therapist. We needed all of those things. Training in communication skills can be inadequate in neonatal fellowship programs.[1] Even in the unit, the conversations tend to be heavy on medical information but skirt the harder stuff: long-term outcomes, right and wrong, quality of life.[2] It's hard to imagine, given the complexity of the task and the stakes of the job, that any training could ever be enough.

Many times, before our daughter's birth and after, her life hung on how a conversation unfolded. How unsettling, then, to discover later that the tone, content, and style of those talks varied so wildly depending on which member of the medical team showed up.

I'd like to describe some of the conversations that rerouted our lives. Each is worth revisiting, for they all held such staggering and beautiful power.

THE DECISION

The first took place a day before our daughter was born. I had been in and out of the hospital since the 20th week of pregnancy, when I'd begun to bleed. I was wired to monitors and haunted by the lullabies that played over the intercom in the labor and delivery unit. Every time a healthy, squawking newborn entered the world, those lullabies reminded me mine would likely be born only to die.

I was cramping and bleeding, inverted in the bed. Magnesium sulfate pumped through my veins, making me feel like I was scalding from the inside out. A neonatologist visited my husband and me to explain the odds. I had never seen a neonatologist, even on TV. He was professional and compassionate, and I could see that the conversation was not easy for him.

He dutifully plodded through the relevant acronyms: IVH, PVH, NEC, ROP, CLD, RDS. A head-to-toe litany of disability. He appeared to be following a standard, if unofficial script, covering all bases. Our daughter could be damaged to any degree in any corner of her body or mind. He worked his way from the brain to the heart and lungs and gut, from cerebral palsy to nearsightedness.

Looking back, it reminds me of the absurd humor of a Cialis commercial. How immediate is the threat of the 8-hour erection, and is now the best time to consider it?

While my daughter is about to be pulled into the bright cold air and made to breathe, is asthma something I should be thinking about, or should we focus on the odds she'll spend her life on a ventilator? The information was a fire hose of calamity.

He delivered the numbers: 53% chance of death no matter what; 80% chance of death or moderate to severe disability. He talked a lot about morbidity.

He said more, but when he left, what remained in my head was that figure: *Eighty percent*.

I saw an 80% chance that she would die or live in misery. That she would look at me with stoned eyes that asked: Why did you do this to me? I saw an 80% chance that my marriage would collapse, that medical debt would destroy us, that any hope for future children would dissolve.

I saw a pistol with 5 chambers, 4 bullets. Russian roulette for my daughter's life. Would I gamble on 20%?