



INSIGHTS

When a neonatologist become the father of a NICU baby: How do I feel and how did I change?

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It was a cheerful sunny Easter Sunday when my wife and I chose to undergo an elective induction at 39 weeks gestation based on our obstetrician's (OB's) recommendation, a recommendation that was based on a recent NEJM (*New England Journal of Medicine*) study named the ARRIVE trial (A Randomized Trial of Induction Versus Expectant Management). Joy was in the air! The moment we have all been waiting for is finally here. We had high spirits and we were eagerly waiting to welcome our first child, the first grandchild in my wife's family. The induction process went smoothly in the first 24 h, and with every hour passing, I was getting closer to holding my daughter. However, my wife developed high fevers (39–40 °C) and rigors. My heart sank as my wife was diagnosed with chorioamnionitis or Triple-I, a diagnosis that every OB and neonatologist fears.

A decision was made by the OB team to continue the induction process, up to hopefully a vaginal delivery based on reassuring fetal heart rates. But the fevers did not relent. My wife, despite antipyretics and antibiotics, continued to spike high fevers. As I continued to watch my wife struggle with labor, I grew more and more anxious. After 2 days of induction, because of arrest of descent, a cesarean section (CS) was performed.

Our beautiful daughter shined our world across the CS drape. Nevertheless, the minute I saw her, as a neonatologist I felt something was wrong. She opened her eyes but was not breathing and looked dusky. Torn between my agony as a father and my urge to resuscitate my baby, I sat there helpless. Our daughter was quickly rushed to the radiant warmer where my colleagues began to actively resuscitate her.

I could see the looks on my colleagues' faces while the resuscitation process continued. Every minute felt like a year going by. Questions about everything that was done, every decision taken, and above all the safety of my family struck me hard. I felt the stress grow by the minute in the room. My colleague trying to hide her concerns, congratulated us and informed us of the need to transfer our daughter to the neonatal intensive care unit (NICU).

I am now the parent of a NICU baby, experiencing feelings that are hard to conceptualize. Trying to reassure my wife, hide my concerns, and preserve my professional picture in front of my colleagues, fellows, nurses, and residents were my biggest challenges. As neonatologists, we understand the pain of a parent of a sick child, but we can never truly understand the mass of emotions they feel. For the first time, I can genuinely say "I understand". Within 2 hours, my fears became a reality; our daughter was apneic, and needed to be intubated. I started running my list of differential diagnosis of apnea in the first 24 h of

life. Could it be sepsis, a metabolic disorder that is incurable, a seizure disorder that is difficult to manage, a structural brain anomaly, or a fatal genetic syndrome? Within 4 hours, our daughter was diagnosed with seizures and placed on electroencephalogram (EEG). And now, I had to put on my neonatology hat to educate my family members on my daughter's diagnosis. That night, I was treated as a neonatologist not as a heartbroken father.

As I thought my worst nightmare could not get any worse, it did. A magnetic resonance imaging (MRI) brain revealed a diagnosis that struck our whole family and tore our hearts. Our beautiful daughter suffered an extensive left-sided brain stroke. A devastating diagnosis that left me speechless and in a world of sadness.

As physicians, when we become patients or parents of patients, we sometimes face a situation where medical providers either tend to minimize our concerns relying on a belief that we are probably exaggerating or tend to over react to our concerns subjecting ourselves or relatives to unnecessary laboratory work or radiation. Another major struggle that we encounter is the reliance of the primary team on our medical background as an open invitation for medical discussions or deferred medical decisions. This practice should strongly be avoided as with emotions being high, decision making is usually in vain and clinical judgment is clouded. Primary care teams are encouraged to take full ownership for these cases allowing their colleagues to just be parents.

As neonatologists when we become parents of NICU babies, our knowledge serves as a double-edged sword and becomes means for more suffering and anxiety. We struggle to avoid conflicting opinions with the caring teams, trying not to bias their management. We have the urging feeling to take control rather than wait for results. We are treated by our families as physicians rather than parents and our colleagues have high expectations for tolerance from us. We walk this tight rope of maintaining a professional relationship, even if decisions being made are not what we expect or desire, while being a safe haven for those who need our support the most. In the most stressful times, we are called to be the most contained individuals in the room. One of the other challenges is our access to multiple medical providers, with all it carries of conflicting expert opinions that could occasionally hinder care provided. With all the benefit that those opinions carry, they can also bring confusion and distractions to the primary care team.

This experience has changed a lot in my perspective of what NICU parents go through. There is this hidden fear at discharge of

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being the solo providers and in charge of these sick and vulnerable babies at home. It opened my eyes to a new busy, hard to organize world of appointments and home visits (physical therapy, occupational therapy, nutrition, etc.). Who to choose to be in charge of this life-defining task of home therapies, how to judge who is the best, and how to overcome this anxiety of waiting to see what the future would carry of outcomes for those babies? Although our patients are our responsibilities, this profession demands us to care for their parents as well. It is, without a doubt, imperative that we as providers continue to prioritize the families' needs and emotions as part of our overall plan of care. NICU parents are the true champions and heroes, whose burden of care and feelings intensifies more and more when they leave the NICU, a feeling we tend to forego as we discharge them.

Perinatal stroke, as defined by National Institutes of Health workshop, is "a group of heterogeneous conditions in which there is a focal disruption of cerebral blood flow secondary to arterial or cerebral venous thrombosis or embolization, between 20 weeks of fetal life through the 28th postnatal day confirmed by neuroimaging or neuropathologic studies." The incidence of perinatal arterial ischemic stroke (PAIS) is 17.8 per 100,000 live birth/year. Numerous significant sequelae such as hemiparesis (cerebral palsy), epilepsy syndromes, language, and behavioral challenges are part of a large spectrum of expected short- and long-term outcomes affecting the development of these babies. Early

intervention services are critical in defining the functional level and productivity of these neonates as they grow. Perinatal stroke is a disease with lifelong lasting burden not only on the affected neonates but their families too. The annual cost of managing a pediatric arterial ischemic stroke range from \$15,000 to \$140,000 in the first year of life. Ongoing clinical trials are underway to evaluate the use recombinant human erythropoietin (EPO) in neonates with PAIS. EPO is believed to reduce the hypoxia-ischemia-induced free radical formation and pro-inflammatory and apoptotic activity in brain cells, promoting a regenerative capacity for these neurons. These trials are very promising and provide a glimpse of hope to all of us that one day we might be able to ameliorate the consequences of this disease.

Neonatology is one of the rigorously developing branches of medicine, with a lot of discoveries in the field of pathophysiology and novel therapies still being unearthed. However, neonates have resilience and an amazing regenerative power that surprisingly enough we still rely on.

While medicine relies on research studies to define its future, we should always remember and appreciate those scientists who spend hours and hours with frustrations trying to explore and find new therapies for our precious babies. In the midst of all this, we should always engulf the concept that medicine is an art, an art of balancing the guidelines and the presenting clinical scenarios. Every patient we meet is different.