

Stronger and more vulnerable: Impact of the NICU experience on parents

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For parents, the experience of having a baby in the Neonatal Intensive Care Unit (NICU) is often psychologically traumatic. No parent can be fully prepared for the extreme stress and range of emotions of caring for a critically ill newborn. Many studies document the anxiety, depression, insomnia, grief, and post-traumatic stress symptoms that parents experience.¹ These studies are important as they help us to understand, to empathize, and maybe even to discover ways to improve families' experiences. However, such studies are also incomplete and tell only part of the story. They are mostly conducted in the first months or years after the NICU hospitalization, when the babies and their parents are still fragile. They generally do not report how parents' feelings, perceptions, and coping mechanisms change over the years.

A different set of studies, from other domains of medicine and pediatrics, has investigated the longer-term impacts of a critical illness. These studies show that positive transformations often follow traumatic life-altering events. In the medical literature, these changes are referred to as post-traumatic growth.² They have been reported most frequently in adults: cancer survivors, trauma victims, HIV-infected individuals, and those with spinal-cord injuries. But recent investigations have demonstrated that post-traumatic growth also occurs for children and families after the serious illness of a child.³ Many factors are associated with resilience: socio-economic status, the nature and permanence of the health condition, patient/parent psychological state and family/social/societal support. Unfortunately, investigations relating to positive family transformations after neonatal hospitalizations are scarce. They have been described for parents of children with Down syndrome, trisomy 18, trisomy 13 and cerebral palsy.^{4,5,6} However, positive impacts of the NICU experience can be found in abundance outside of the medical literature, from first-person reports in books, memoirs and parental blogs.^{7,8,9} Clinicians and researchers must be mindful that the negative impacts of the NICU-experience are only one side of the story.

As health care providers familiar with the NICU, we thought that we understood the impact of the NICU on parents. But we were not prepared to see the children in our own families as NICU patients. We were not ready for the ways in which the medical jargon

could be alienating to us when used to describe our babies.⁹ We were not ready for the lack of control that accompanies a typical NICU stay. Even if we are highly rational and organized individuals as providers, as parents we often gave consent for interventions with our hearts, not our heads.¹⁰ We had trouble when health care professionals attempted to be honest with us and to help us develop realistic expectations about the future. Neonatal intensive care providers were often perceived as negative and pessimistic, especially at times when we needed hope. We came to a new appreciation for the delicate balance that health care providers must seek between honesty and compassion, between realism and optimism.

The experience of having a baby in the NICU altered both our professional and our personal lives in profound and permanent ways. We had to slowly reinvent ourselves to be a new parent with a fragile baby, instead of the healthy baby that we had hoped for and dreamed about.

Here are some of the lessons our NICU experience has taught us. We offer them in the hope of helping health professionals consider a balanced view of the NICU's impact on families. Despite sharing similar experiences in our professional lives, our NICU experiences were very different. We all rewrote our life stories to include parts we were not prepared for: some of us had to write a chapter about being the parent of a dead child, others about being the parents of children with lifelong disabilities. Our children are now between one and 32 years old. We are not the same people nor the same providers we were before being parents in the NICU. For many, these are a series of small transformations. All of us had to rebuild ourselves after our challenging NICU experiences that, to some degree, destroyed who we were. We share our perspective of a life-transformation rather than a "post-traumatic growth." We did not grow. We are stronger and yet more vulnerable. Families' reports of positive transformations outside of the medical literature resonate with our experiences. All families have unique and different experiences, but many will learn similar lessons.

GRATITUDE: Gratitude for the gift of life, for simple and important things in life. Gratitude for our families and friends, for skilled professionals, for the kindnesses of strangers. We understand every day, with our hearts, that we have much to be grateful for.

PERSPECTIVE: Learning to not sweat the small stuff and to recognize what is truly precious. We now pay less attention to things that are not worth fussing over and fight like hell for the things that are. We now see that perfection is in many places where we could not see it before. Perfection does not necessarily equate with percentages, excellence, performance, high grades, beauty, speed, or quantity.

LACK OF CONTROL: One of the most difficult things for a parent to recognize is that many things are beyond our control. We now focus on controlling the things that we can, but recognize when there are things that we cannot. We no longer plan and predict what may happen with every possible decision. Often, life doesn't follow our predictions.

DECIDING WITH THE HEART. We have experienced the limitations of informed consent, statistics, probabilities and predictions. We know that being informed repeatedly that something bad may happen to X% of babies doesn't help much: parents do not have 100 babies. We have gained a new appreciation of uncertainty, of the role of emotions in decision-making. We know that vulnerability and emotions are sources of strength. They allow us to connect with our passion and purpose, to become happier, more compassionate and more hopeful as human beings and as providers.

CONNECTEDNESS: In whole new ways, we have come to understand the importance of family and relationships and the need to nurture precious connections. In the most difficult moments in life, some people held us while others disappeared. The NICU experience reminds us how important it is to be there for those who matter in our lives.

RESILIENCE: We learned we are stronger than we think. We now know it is possible to see our hopes, dreams, and plans totally destroyed and then to rewrite our story with a new plot line. We can adapt. We can experience a "freedom from fear" when dealing

with life challenges or with the imperfections of the healthcare system. We rarely look backwards and regret.

HUMILITY: We are more humble about the powers of science. As providers, we had thought about what we would do as parents if tragic things happened to our children. We were convinced we knew what we would do. Yet, faced with reality, we often did not act in ways we thought we would: more important thoughts came through our heads, more important values we did not predict. We now have a much greater respect for how to act in unexpected scenarios, in situations of uncertainty. We are more flexible.

FORGIVENESS: Having a sick baby is often associated with parental guilt or grief. The ability to “move on” not only takes time, but requires forgiveness. Forgiveness to ourselves, for what we perhaps could have, should have done/been. For those of us whose child dies, we must forgive ourselves when in time we realize that life goes on. Forgiveness for those who disappeared when we needed them, for real and perceived human failings of our families or friends or providers. We have learned that forgiveness is a journey and apply that understanding to other spheres of our lives.

DEDICATION: We are more dedicated to excellence in clinical care. We witnessed the pure beauty of bedside clinical excellence, which we sometimes found in unexpected places and with all types of healthcare providers. We learned the power of small gestures, the deep impact of an extra effort, a genuine smile, or a kind word. We also met some less competent people. We are now intolerant of mediocrity and uncompromising with regards to patient care.

RECOMMENDATIONS TO CLINICIANS AND RESEARCHERS

1. Be aware that parents experience both negative and positive impacts after an NICU-experience. Researchers examining these outcomes should investigate both sides of the story. Communications with parents should be balanced.
2. Remain humble. Avoid sentences such as: “Parents don’t understand” or “If I were in their situation, I would not....” Too often, it is providers who don’t understand.

3. Tell parents that they did not choose the misfortunes that are happening to their baby, that there is nothing they could have done to prevent this. Remind them often that their baby is lucky to have parents who love him.
4. Parents should know that positive transformations are possible.
5. Temper discussions about risks with words about something good happening, resilience, love and the chances of healing.
6. Help parents prioritize their energy and learn to know what they can and cannot control. Encourage them to let go where they can.
7. Inform parents that life will not always be like this, that the roller coaster will become a train with a known destination. That one day, it will be better. That they are stronger than they think. That they have to believe it.
8. We can be there for parents at tough moments or avoid them. Be there.

These lessons do not in any way attempt to sugar-coat or diminish the difficult and bitter reality of having a baby in the NICU. However, parental NICU experiences may be improved by balancing the cold, hard facts, bleak outcomes and psychological toll with the insights we offer. Most parents are resilient. They advocate for their child in ways they cannot or would not advocate for themselves. The realization of their own strength and resilience will lead to “life-transformations” that allow the world to make sense again and their families to rebuild themselves and write a new story.

More on the POST group authors (in alphabetical order) and their “NICU children”

Judy Aschner (neonatologist) is the mother of Nadav, who was born at 31 weeks after rupture of membranes at 21 weeks’ gestational age (GA).

Beau Batton (neonatologist) is the father, and Daniel Batton (neonatologist) is the grandfather of Charlie who was born with a univentricular heart.

Siri F Berg (anesthesiologist) and Odd G Paulsen (anesthesiologist and emergency physician) are the parents of Evy Kristine who was born with trisomy 18 and died of cardiac failure.

Deborah Campbell (neonatologist) is the mother of Courtney Alexis, born at 27 weeks during a pregnancy complicated by preeclampsia and massive abruption. Courtney died at 28 days of age.

Brian Carter (neonatologist, palliative care physician and clinical ethicist) is the father of Sean who was born at 34 weeks’ GA.

Felicia Cohn (clinical ethicist) is the mother of Amanda who was born with transposition of the great vessels.

Dan Ellsbury (neonatologist) is the father of Codey, Kyle and Hope. Codey and Kyle were born at 28 weeks’ GA. Kyle died of complications of prematurity and Beckwith-Wiedemann syndrome. Hope was born with hypoplastic left heart syndrome.

Jonathan Fanaroff (neonatologist and bioethicist) and Kristy Fanaroff (neonatal nurse practitioner) are the parents of Mason, who was born at 32 weeks’ GA. Avroy Fanaroff (neonatologist) is the grandfather of Mason and the father of Jonathan, who was critically ill at birth with meconium aspiration syndrome.

Sophie Gravel (chief NICU nurse) is the mother of Roxanne, who was born with in utero volvulus at 29 weeks.

Marlyse Haward (neonatologist, bioethicist) is the mother of Charlie diagnosed in utero with multi-organ congenital anomalies who is now doing well.

Annie Janvier (neonatologist and clinical ethicist) and Keith Barrington (neonatologist) are the parents of Violette who was born at 24 weeks’ GA.

Stefan Kutzsche (neonatologist and anesthesiologist) is the grandfather of Jakob and Vegard, twins who were born at 25 weeks of GA.

John Lantos (pediatrician and clinical ethicist) and Martha Montello (clinical ethicist) are the grand parents of Sam and Will who were born at 23 weeks of GA. Sam died of complications of prematurity.

Anne Drapkin Lyerly (obstetrician and bioethicist) is the mother of Will who was born at term with an intra-abdominal mass.

Nathalie Maitre (neonatologist, follow-up physician and researcher) is the mother of Leo, who was born at 27 weeks of GA.

Neil Marlow (neonatologist) is the father of Tom and Simon who were born at 30 weeks' GA.

Joshua T Morris (pediatric hospital chaplain) is the father of Isaac who was born at 28 weeks of GA.

Trisha Prentice (neonatologist, PhD cand) is the mother of Jordain, who was born at 28 weeks of GA.

Alan Spitzer (neonatologist, researcher) is the grand father of Jacob, Matthew, Alexandra, Shaun, born at 29 and 36, 35 and 35 weeks of GA.

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