Parenting in the NICU is an intense journey. Parents struggle to build intimacy with their child amid complex emotions and medical uncertainties. They need to rapidly adapt their vision of parenthood to the realities of intensive care. The psychological impact of this journey can have important effects on their psychological health. For parents of sick older children, “good parent” beliefs have been shown to foster positive growth. This concept is also essential for parents of infants in the NICU, although their path is complex.

We write as clinicians who were also families in the NICU. We suggest parents need to hear and internalize 3 important messages that overlap but are each important: you are a parent, you are not a bad parent, and you are a good parent. We offer practical suggestions to NICU clinicians that we believe will help NICU parents cope while their infant is in the NICU and afterward.

The very fact that you worry about being a good mom means that you are already one.

Jodi Picoult (House Rules)†

The NICU can be a place of fear and uncertainty. Some infants are very sick. The technology is frightening and dehumanizing. Nobody can tell parents with any certainty what the outcome will be. Other infants are healthier, but all are attached to wires and monitors. Friends don’t know what to say. Many different clinicians weigh in, and each gives a slightly different message. These features of the NICU often take a psychological toll. Many parents who have had children in the NICU suffer from posttraumatic stress disorder, anxiety, depression, and prolonged grief,²⁴ whereas others develop resilience, adapting constructively to traumatic experiences.⁵

It is difficult for parents who have an infant in the NICU to figure out what it means to be a good parent in those circumstances. Beliefs about what it means to be a “good parent” will inevitably influence how they navigate the emotional turmoil and medical uncertainty.⁶⁻⁹ Is it better to show one’s emotions or to hide them? If you see something unusual, should you say something? Parent’s beliefs (and actions based on those beliefs) have an impact on their psychological outcomes.

A rich legacy exploring “good parent” beliefs exists in the pediatric literature for parents of older children. Parental narratives have concurrently defined what it means to be a good parent in the context of a critically ill child and demonstrated how these beliefs help guide parenting and decision-making.⁶,⁷ Researchers have developed tools to help clinicians uncover and support a diversity of good parenting beliefs with broad applicability across ethnicities and illness trajectories.⁶⁻⁸ Support of good parent beliefs subsequently becomes beneficial for parents as well, helping them to cope with their child’s clinical condition.⁷,¹⁰

However, in each of these circumstances, parents of older children already know what it means to
be a parent. Parenting styles are already established. This may not always be the case for NICU parents. They find themselves two steps behind in the development and acceptance of good parent beliefs. Not only must they learn what it feels like to be a parent, they must also often liberate themselves from “bad parent” feelings.

Some NICU parents have it tougher than others. If you are in prison and have an infant in the NICU, it is tougher. If you have preexisting serious mental health conditions, it is tougher. In this article, we do not cover these tragic situations. By contrast, our own experiences were mostly best-case scenarios: we had health insurance, psychosocial support, and knowledge, spoke the language, and were treated with respect. We also had the advantage of being health care professionals with baseline knowledge of how the NICU functioned and were known by our peers. It was still tough. On the basis of our experiences, we have suggestions for how clinicians might better support parents in the NICU.

Parents need to hear and internalize 3 important messages: “You are a parent,” “you are not a bad parent,” and “you are a good parent.”

**MESSAGE 1: YOU ARE A PARENT**

Parents of infants in the NICU need to feel like real parents. They may feel conflicted about whether to invest emotionally in an infant who could die, who could have future health problems, or simply looks too fragile. These feelings can be reinforced by medical language when doctors call an extremely preterm infant nonviable or peri-viable or say that certain congenital anomalies are incompatible with life.11 Pregnant women whose fetus has a congenital anomaly or may be born prematurely may not feel they will ever become parents. They may remain ambivalent toward the pregnancy and their infant.12–14

It is difficult to bond with an infant in the NICU. Separation after birth is upsetting. Premature infants look different from term infants. Infants born with dysmorphisms may also look strange. The medical accoutrements of NICU treatment, such as breathing tubes, monitor leads, or medication side effects alter the infant’s appearance and inhibit bonding.13–15 All of these phenomena make the parenting experience different from what parents were expecting or what seems natural.

Parents deal with their emotional distress and sense of inadequacy in different ways. Some become hyperrational information gatherers, learning about machines and numbers, trying to find certainty in uncertainty, or attempting to control the uncontrollable. Desperate to hold strong emotions at bay, they have little time or space for considering the meaning of parenthood. Other parents find the emotional stress of trying to be with their infant in the NICU too difficult and they stop visiting16,17 or, when they are there, they become emotionally numb.13,14,17

**MESSAGE 2: YOU ARE NOT A BAD PARENT**

Parents of infants in the NICU often experience powerful emotions of inadequacy and guilt.18–20 It is common for parents to blame themselves for the infant’s illness and to think of things they might have done (or not done) differently. This internal sense of guilt is magnified and reinforced by medical labels such as “incompetent cervix” or “placental insufficiency.” Some mothers must wait to meet their newborn because of their own medical fragility after delivery. During this waiting period, they may feel that they are not being good mothers. Fathers, too, may feel culpability.21 Did they help out enough during the pregnancy? If not, did that cause the preterm birth? With genetic diseases, either parent may feel guilty because they carried bad genes.22

People surrounding the family (both professionals and nonprofessionals) can further augment parental anguish by searching for reasons. They may unintentionally ask too many questions that suggest blame, such as whether the mother was working too hard or spending too much time near wireless radiation. These speculations are generally without scientific basis but are common and frequently cause people to feel like bad parents.

On other occasions, the clinical team implies to parents that their decisions are not the same as the ones the clinical team would make for their own children. This external judgment coupled with the parent’s own internal struggle can deepen feelings of inadequacy.

**MESSAGE 3: YOU ARE A GOOD PARENT**

Many parents need to imagine a new way of being a parent: a way that allows them to parent their NICU infant. To get there, their previously held parenthood beliefs, expectations, and hopes often undergo transformations. New parenthood models can be built on the rewarding feelings that come from being able to love and comfort one’s infant and being emotionally present for the infant and learning ways to be a “good” NICU parent.

It is not always easy for a parent to comfort an infant who is critically ill in the NICU. Because of the critical condition of many NICU infants, parents must often ask permission to perform the most basic parenting tasks: changing diapers or feeding, talking to, or even touching and holding their child.13,14,16,17,23 Parents may also need help understanding how to care for their other children and themselves while
being NICU parents. There is no one-size-fits-all solution to these challenges, but, at the very least, providers can help parents to acknowledge that these are real problems and can facilitate access to resources that may address them.

**PRACTICAL SUGGESTIONS**

It is important to remember that all NICU parents are different. Not all NICU parents experience these feelings, and, among those who do, they don’t necessarily arise in a predictable order. Each parent defines parenthood differently, travels the journey at a different speed, and holds a different idea of what it means to be a good or bad parent. The reality of the situation, the space, the people, and the interactions that parents experience with clinicians and their child conflict with previous beliefs about or experiences with early phases of parenthood. This juxtaposition of past beliefs and current circumstances creates a profound cognitive dissonance. They may ask themselves how they can be parents because parents are not supposed to feel what they are experiencing nor do what they are doing. Every parent experience is different. Many are characterized by feelings of confusion and alienation.

Health care providers should remind themselves that NICU parents can be as fragile as they are strong. Even a small, unintentional comment by a professional can harm parents, causing them to suffer silently and acutely. Such comments can leave lasting scars.

The opposite is also true. Health care providers can help facilitate posttraumatic transformation by fostering good parenting beliefs. Many of us recall the varied ways clinicians helped us face our challenges. Here are 5 lessons our NICU experiences on the other side of treatment have taught us.

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**Parents Have Conflicting Emotions: Validate Them (Including Guilt)**

Remind us, as NICU parents, that it is normal to rapidly oscillate between conflicting emotions: excitement after first seeing our infant, terror of being in the NICU, and grief at the thought of losing our precious child. This journey is not rational. Just by acknowledging this, you can normalize it for us and reassure us that we are not crazy.

Consider telling us something like this to alleviate guilt: “When our children are sick, it is not rare to wonder what we could have done differently. Many parents here feel this way. But there is nothing you could have done to prevent what happened. It is not your fault. Just by asking us why this happened, you show how much you care.” For mothers who give birth after prolonged rupture of membranes who may feel guilty that we couldn’t carry the infant to term, try saying, “You did an amazing job carrying the pregnancy as far as you did. That helped your infant tremendously.”

**All Parents Are Different: Allow Flexible Care Models**

Do not assume we all enjoy strategies you have to promote bonding. Avoid saying "parents like...,” “fathers want...” or "mothers enjoy...,” but rather use “some parents...” For example, when you tell mothers they will love skin-to-skin contact, you can unintentionally harm those who only find it stressful. We may not immediately gush with love or find our infants beautiful. Some of us were asked to present our infants on rounds or insert feeding tubes. We may not, even as physicians who are experts at such actions, find this helpful in our journey as parents. This does not mean we are bad parents. Help parents understand that their responses are acceptable by saying things like, “Some parents love the positive feelings that they get from doing kangaroo care. Others feel stressed and do not enjoy it for a while. We want to find ways for you to help your child that are comfortable for you.”

Ask us how we want to receive information about our infant. You could say, “Some parents want a lot of information, which helps them understand and feel in control. Other parents prefer the big picture, because too much information can be stressful. Please tell us what is most helpful for you.” Recognize that we may change our preferences on the basis of our infant’s changing condition or as we, ourselves, change.

Remind us not to compare ourselves and our infants with others in the unit. There is always a mom who pumped more, a dad who did more kangaroo care, parents who seemed stable emotionally, and well-dressed parents who were not wearing the same jogging outfits every day. They have their problems too.

Within reason, try not to limit who can come and visit us; we need to be surrounded by those who can support us. Try not to delegate care duties to us without understanding our preferences. We need personalized care models so that family integrated care does not feel like “family imposed care.”

**Words Matter**

Please choose your words carefully. We will quote you for decades. We prefer that you describe our children as a fragile group of infants rather than objectified as “the hypoplast” or “perivable micropreemie.” Be mindful of your tone of voice and nonverbal communication.

We want hope, but we also want the truth. It is a fine line to walk. Try to share balanced information compassionately with honesty and clarity. Tell us what isn’t going well and what is, what is malformed and what isn’t, and what you fear and what you hope for.
Empower Us

Ask us if we have chosen a name for our child. Using our infant’s name can help us feel like the infant is our infant. Reinforce and remind us that we are stronger than we think. Find concrete examples such as “Thank you for your milk” or “Thank you for pointing this out. You know your infant so well.” Consider sentences such as “The most important thing for Jason is to have parents who love and support him. In my time getting to know you, I can tell you will find ways to help him in life.”

For most infants and parents, there is a lot of downtime in the NICU. Give us suggestions for how we can create and personalize memories during this difficult period. For example, suggest we keep a journal, take pictures, listen to music together, read, record our voices for our infants, or create a blog or a Facebook page. Consider saying, “Other parents have chosen some of these activities as a way of adjusting to this new and stressful reality. Different parents find different ways to do this.”

Support Us; Don’t Judge Us

Recognize we each have an individualized approach to stress and bring different levels of knowledge to the situation. Give us every opportunity to share our concerns. Embrace those of us who question as much as those of us who don’t. Some of us are nervous wrecks, others are distant, and others speak loudly or too much. Encourage and validate our plight by saying, “There are no silly questions when your child is in the hospital.”

Many kinds of support can help us. Refer us to a social worker, psychologist, or spiritual adviser; ideally, these individuals should be available in the unit or during outpatient visits. Less formal sources of support, such as veteran resource parents, who have had a NICU experience, can validate our feelings and concerns in your unit through an organization, on the phone, or through the Internet.28,29

Uniquely complicated circumstances exist for parents whose infants die. If the infant’s suffering appears intense or decisions feel uncertain, moments surrounding death can become burdensome memories to carry. Clinicians can help parents redefine their parenthood during and beyond death. If our infant dies, take opportunities to remind us that our infant will always hold a special place in your heart. Let us know you are grieving too. Remind us of ways that our son or daughter was loved in this world. Help us find meaning during this period of grieving.

Conclusions

Our goal in this article is to offer insight based on the unique experiences of health professionals who were also parents of infants in the NICU. The experience of each member of this group was different. Our coping mechanisms were different. Still, we learned similar things that have influenced and improved the ways in which we care for families in the NICU. We know that these strategies cannot fully negate the impact of trauma and stressful experiences in the short-term. However, we believe that all providers can learn from our experiences in ways that will allow them to better help parents to feel like good parents. This, in turn, will promote resilience, empower parents, and help them and their families heal.

MORE ON THE PARENTS ON THE OTHER SIDE OF TREATMENT (POST) GROUP AUTHORS AND THEIR “NICU CHILDREN”

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

Marin Arnolds, MD (neonatologist and clinical ethicist) is the mother of Annie, who was born at 31 weeks’ GA.

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

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

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

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

Dan Ellsbury, MD (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, MD, JD (neonatologist and bioethicist) and Kristy Fanaroff, MSN, NNP (neonatal nurse practitioner) are the parents of Mason, who was born at 32 weeks’ GA.

Avroy Fanaroff, MD (neonatologist) is the grandfather of Mason and the father of Jonathan Fanaroff, who was critically ill at birth with meconium aspiration syndrome.

Amaryllis Ferrand, MD (neonatologist and bioethics doctoral candidate) is the mother of Ludwik, who had hypoxic-ischemic encephalopathy and was in septic shock at birth.

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

Marlyse Haward, MD (neonatologist and bioethicist) is the mother of Charlie, diagnosed in utero with congenital anomalies.

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

John Lantos, MD (pediatrician and clinical ethicist) and Martha Montello, PhD (clinical ethicist) are the grandparents of Sam and Will, who were born at 23 weeks’ GA. Sam died of complications of prematurity.

Anne Drapkin Lyerly, MD, MA (obstetrician and bioethicist) is the mother of Will, who was born at term with an intraabdominal mass.

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

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

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

Matthew Rysavy, MD, PhD (neonatal fellow and epidemiologist) and Mary Rysavy, MD (obstetrician and gynecologist) are the parents of Samuel, who was born with a congenital diaphragmatic hernia diagnosed after birth. He died after several days in the NICU.

Alan Spitzer, MD (neonatologist and researcher) is the grandfather of Jacob, Matthew, Alexandra, and Shaun, born at 29, 36, 35, and 35 weeks’ GA, respectively.

Christiane Theda, MD, PhD (neonatologist and medical geneticist) is the mother of Thomas and Michael, twins born at 31 weeks’ gestation after a complicated pregnancy. Michael had intraventricular hemorrhages and a large subdural hematoma with acute hydrocephalus requiring emergency surgery and, later in his course, had necrotizing enterocolitis.

APPENDIX

The POST Group is composed of health care providers who all experienced the NICU as providers and as parents or grandparents for children in their family. The group authors are listed below in alphabetical order.

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ABBREVIATION

GA: gestational age

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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Helping Parents Cope in the NICU
Marlyse F. Haward, John Lantos, Annie Janvier and for the POST Group
Pediatrics 2020;145;
DOI: 10.1542/peds.2019-3567 originally published online May 29, 2020;

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