When parents voice their dissatisfaction with the neonatal intensive care unit (NICU), it is often not because they think their baby has not received good medical care. Instead, it is often because their needs have not been addressed. Policy statements and pedagogy alike urge health care professionals to be empathetic, compassionate, honest, and caring. However, these theoretical concepts are generally endorsed without practical suggestions on how to achieve these goals. Negative encounters for parents are generally not about the caregivers’ technical expertise or knowledge and often reflect a failure in a different domain. Simple rules of etiquette are not always applied in a busy NICU or in the hospital at large. The investigators of the POST (Parents from the Other Side of Treatment) group are health care professionals who regularly communicate with parents of sick children and who were also “NICU parents.” We have developed an etiquette-based systematic approach to communication with families in the NICU. These specific and practical recommendations may help parents feel well treated and respected as they go through a challenging NICU stay.

A special communication about ethics and etiquette in neonatal intensive care.

M any of the ethical controversies in neonatology reflect problems in communication between health care professionals and parents. Policy statements and pedagogy alike urge health care professionals to be empathetic, compassionate, honest, and caring. However, these theoretical concepts are generally endorsed without practical suggestions on how to achieve these goals. Empathy, compassion, and caring are hard to fake.

All of the authors of this article are health care professionals who regularly communicate with parents of sick children and who have had a sick child or grandchild of their own in the neonatal intensive care unit (NICU).1-6 Some have experienced the death of their child. Our collective experience gives us insight into what it is like to be on the other side of these interactions.

Having a critically ill child is always a challenging experience. Being a parent in the NICU presents unique challenges. Parents are grieving the loss of their hope for a healthy pregnancy, delivery, and term newborn. The sickness of their child is preceded immediately by pregnancy and the major impact that a high-risk delivery entails. Parents are often still trying to understand what it feels like to be a parent and to process the responsibility of that role as they establish an intimate relationship with this new life. Furthermore, most of the babies in the NICU depend on life-sustaining interventions, making bonding more complex. This bonding may be complicated by the fact that many parents do not know how much time they will have with their child, whether minutes, days, weeks, or years. When a newborn survives, the acute crisis of the first days is followed by many “ups and downs” and a seeming normalcy through a NICU experience. These are useful exercises. But what we most need is a rapid way to teach health care professionals how to interact with families in a uniformly empathetic, helpful way.

In an article on etiquette-based medicine, Kahn7(p1988) suggested that physicians can learn simple behaviors that convey empathy and respect. Even when they are unable to fully understand patients’ suffering, he writes, they “can nevertheless behave in certain specified ways that will result in [their] feeling well treated.” He provides a checklist of behaviors that are easily taught and practiced and efficiently evaluated. The checklist is a guideline for good manners. Kahn stresses that the checklist “does not address the way the doctor feels, only how he or she behaves; it provides guidance for [those]...whose bedside skills need the most improvement.” From Kahn’s valuable guidelines, we have developed a more robust etiquette-based approach to communication with families in the NICU.

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We hope these specific and practical recommendations will help physicians help parents as they go through a challenging NICU stay. They may even prevent some ethical dilemmas from arising.

Here are 10 essentials of etiquette-based neonatal care from the parents’ perspective:

1. Say my baby’s name, regardless of how odd or misspelled it may be to you. Know my baby’s sex.
2. Don’t label my baby. My baby is not a diagnosis. She is not the “T-18,” the “23-weeker,” the “tiny critter,” or the “horrible BPDer in room 8.”
3. Say your name. Tell us who you are, what your profession is, and why you are here. Don’t assume we know and don’t assume we remember.
4. Listen to me. When you enter my baby’s bedside, acknowledge my presence. Sit down if you can. Ask me how I think my baby is doing. Embrace silence. Expect us to be upset. Don’t take it personally.
5. Speak my language. Every parent is different. Some of us want numbers, predictions, and statistics. Others don’t. We generally want to know whether our baby’s course is comparable with other babies with similar conditions or gestational age. Adapt your language to fit our needs.
6. Speak with one voice. We are overwhelmed with health care team members—nurses, students, residents, advanced practice nurses, respiratory therapists, and more. Limit the number of providers attending deliveries, difficult conversations, and code situations. Limit the number of people who examine my baby. Communicate with us in a consistent way.
7. Know my baby. We expect you to know everything about our baby. Take ownership and be responsible. Give us the results that are important to us the same day. Know the facts. Never tell us, “I’m just covering for today.”
8. Acknowledge my role. I contribute to my baby’s care too. I spend hours at the bedside; I pump my breast milk. I may be juggling a job or other children, operating on little sleep, and exercising continuous worry. Please understand and acknowledge this. Your acknowledgment of me in the role of a caring parent strengthens my resolve to be that good parent.
9. Don’t label me. Remember you are meeting me under the worst of circumstances. What is routine to you may be the greatest stress I’ve encountered in my life. Avoid the expression “difficult parents.” Instead, talk about “parents in a difficult situation.” If you feel the need to complain about a family, do so in privacy.
10. Know how important you are to me. I am placing my child’s life in your hands. Do not underestimate how important you are to our family.

Conclusions

Although these guidelines may seem like common sense, simple rules of etiquette are not always applied in a busy NICU or in the hospital at large. A physician who can remember a patient’s hemoglobin level can remember a patient’s name. These guidelines do not require the system to change; they require us to change.

ARTICLE INFORMATION

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Additional Information: More on the POST investigators (in alphabetical order) and their “NICU children:” Dr Judy Aschner (neonatologist) is the mother of Nadav, who was born at 31 weeks after rupture of membranes at 21 weeks’ gestational age (GA). Dr Beau Batton (neonatologist) is the father and Dr Daniel Batton (neonatologist) is the grandfather of Charlie, who was born with a univentricular heart. Dr Siri F. Berg (anesthesiologist) and Dr Odd G. Paulsen (anesthesiologist and emergency room physician) are the parents of Evy Kristine, who was born with trisomy 18 and died of cardiac failure. Dr Brian Carter (neonatologist, palliative care physician, and clinical ethicist) is the father of Sean, who was born at 34 weeks’ GA. Dr Felicia Cohn (clinical ethicist) is the mother of Amanda, who was born with transposition of the great vessels. Dr Dan Eilssby (neonatologist) is the father of Codey, Kylle, 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. Dr Jonathan Fanaroff (neonatologist and bioethicist) and Kristy Fanaroff (neonatal nurse practitioner) are the parents of Mason, who was born at 32 weeks’ GA. Dr Avroy Fanaroff (neonatologist) is the grandfather of Mason. Sophie Gravel (chief NICU nurse) is the mother of Roxanne, who was born with in utero volvulus at 29 weeks. Dr Annie Janvier (neonatologist and clinical ethicist) and Dr Keith Harrington (neonatologist) are the parents of Violette, who was born at 24 weeks’ GA. Dr Stefan Kutzsche (neonatologist and anesthesiologist) is the grandfather of Jakob and Vegard, twins who were born at 25 weeks’ GA. Dr John Lantos (pediatrician and clinical ethicist) and Dr Martha Montello (clinical ethicist) are the grandparents of Sam and Will, who were born at 23 weeks’ GA. Sam died of complications of prematurity. Dr Anne Drapkin Lyerly (obstetrician and bioethicist) is the mother of Will, who was born at term with an intra-abdominal mass. Dr Neil Marlow (neonatologist) is the father of Tom and Simon, who were born at 30 weeks’ GA.

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