

HELPING PARENTS SURVIVE THE EMOTIONAL ROLLER COASTER RIDE IN THE NEWBORN INTENSIVE CARE NURSERY

JOURNAL OF PERINATOLOGY VOL. XIV, NO. 2, 1994

By **Dianne I. Maroney**

During my 11 years as a nurse in the newborn intensive care unit (NICU), I witnessed my share of tragedy, joy, and suffering. I worked in state hospitals, private hospitals, and teaching hospitals. My patients ranged from wealthy to poor. These experiences provided me with an objective view of what families endure when a baby is premature. Then my own worst nightmare happened; I delivered a 26 week and 1 day, 790 gm baby girl.

Suddenly I felt the anguish I had only seen in others, and I began to understand the depth of pain and the length of struggle parents live through. It was difficult to comprehend the overwhelming nature of this crisis until I lived it. By sharing my journey, my joy, and my pain I hope to give other nurses better insight in helping parents survive their emotional "roller coaster ride" in the NICU.

MACKENZIE'S HOSPITALIZATION

I began having contractions and bleeding in my twenty-third week. I was an hour and a half from home, it was midnight, and my regular obstetrician-gynecologist was out of town for a month. I went to the emergency department in the small town where I was vacationing; they stabilized my contractions and wanted to send me home. Uncomfortable with the obstetrician-gynecologist on-call, I insisted they call a well-known perinatologist in Denver. To my immense relief he assumed my care, placing me on bed rest and oral terbutaline. I was reasonably stable at home for 6 days. My diagnosis was chronic abruption placentae with questionable premature rupture of membranes.

At almost 24 weeks I began bleeding, my contractions worsened, and I had to be hospitalized. My physician administered steroids and thyrotropin-releasing hormone, hoping I would make it to 28 weeks. By ultrasonography the baby was 25 weeks, 2 days. This was hard for me to believe, because I had been taking my temperature to increase the odds of pregnancy and thought my dates were accurate.

My husband and I then had to face the heart-breaking choice of whether my dates were correct and whether we would consider not resuscitating our baby. After many years of watching these tiny babies suffer, I always told myself I would not resuscitate my own 24 or 25 week baby. (Believe me, objectivity changes when it's your baby.) We chose not to resuscitate at 24 weeks and no heroic measures at 25 weeks.

By now there were six neonatologists involved, and we had to discuss our decision with each of them (each was on call on a different night). Some agreed, but others had difficulty relinquishing their control. Speaking with them was painful and emotionally draining. The choice was difficult enough, but having to justify our decision to each doctor, and in essence override their control, was overwhelming.

A miracle happened. Mackenzie was born the day she turned 26 weeks, and control was no longer an issue. Full resuscitation was in order, and we prayed the need would never arise again.

Mackenzie made exceptional progress for her prematurity and size. She had minimal lung disease and was placed on nasal continuous positive airway pressure for the first three weeks of life. Then sepsis resulted in intubation for two weeks. Her condition improved and she graduated to nasal continuous positive airway pressure for one week, then to a hood, and

eventually to a nasal cannula. Indomethacin successfully treated a patent ductus arteriosus at 10 day of age. She had a significant weight loss in the first six days of life, dropping from 790 grams to 600 grams. Her weight gain remained poor throughout her hospitalization. My biggest fear was necrotizing enterocolitis (NEC). The physicians were very conservative with her feedings and there were no NEC scares. At 34 weeks, when Mackenzie was ready to come off continuous feedings, she was found with her nasogastric tube partially out; she had aspirated. This caused a significant insult to her lungs, and her lung disease progressed to moderate bronchopulmonary dysplasia. Because of her tachypnea and high oxygen requirement, she had difficulty nipple, which improved after a five day course of steroids. At 34 weeks, grade I and II retinopathy of prematurity developed. She was discharged at 41 weeks on 0.25 L of oxygen, showing a good weight gain.

REFLECTIONS OF MY EXPERIENCE

For years I had been telling parents, “Having a baby in the NICU is a roller coaster ride.” Although accurate, the analogy pales beside the reality. The range of emotions is beyond imagining. There is the moment of joy when she opens her eyes peacefully, followed by panic at the slightest hint of trouble.

My anticipation of seeing Mackenzie for the first time bordered on dread. I knew what to expect, but I couldn’t help fearing the worst. When I entered the nursery and saw her on her tummy, swaddled and peaceful, it meant the world to me. Keeping her swaddled, positioned well, and comfortable became essential. It provided that one picture of her that looked “normal.”

Before Mackenzie’s birth I hadn’t realized the magnitude of grief parents experienced surrounding the loss of a “normal baby.” When Mackenzie was born, we hadn’t been through the normal parent bonding that occurs during pregnancy. I had just begun to feel her kick. Nothing was prepared at home. We lost the joy of holding, talking to, and taking care of our precious baby girl. The mourning for our “normal baby” was unbelievably painful.

Lack of control was one of the most powerful and frustrating issues I felt. All parents feel a lack of control; it’s a vital issue while helplessly watching their children suffer. To help understand how I felt, remember the first baby you became very attached to. Imagine coming to visit him everyday, not as a nurse, but as a mom. During your time with him you wanted nothing more than to help him through the difficult periods, hold him, dress him, change his diaper; but you were powerless. Every single thing that happened to him mattered! It mattered not only for the moment but for the future: his eyesight, his lung disease, his ability to walk. There may have been brief moments where you were helpful, but the baby’s life was truly in the hands of others. This lack of control is very intimidating to parents and is often interpreted as failure.

Although I often felt powerless, it helped that I was an NICU nurse. Mackenzie had wonderful primary nurses who allowed me to have input and thus a sense of control. The days her primary nurses were not there were difficult days; relationships varied, and so did my control. I now know from experience that primary nursing is crucial.

Attitudes of the nurses made the difference in the day. Mackenzie knew who was taking care of her and did better if her nurse cared and took that extra step to show her. Their friendly, trusting, and caring attitudes relieved my stress. When they looked at me with empathetic, understanding eyes and shared words of support, it helped more than they realized during those unstable moments of fear and depression.

NURSING INTERVENTIONS

Firsthand experience is the most effective teacher. I learned from both positive and negative experiences during Mackenzie’s journey. Here are some suggestions that might help you deal with the emotional issues of parents in the NICU.

(1) Keep babies comfortable and as “normal” looking as possible. Give parents a few moments of feeling they have their

own little baby, not a sick “preemie”. This will help them through the grieving process of losing their “normal” infant. Swaddling, noise reduction, soft music, dressing them, or even a small bow in their hair can mean the world to parents. If sedation is available, use it. It will help keep babies comfortable and able to cope with their noxious surroundings.

(2) Show parents that you’re trying to understand their struggle by recognizing their feelings. Nurses can only do so much, but often just asking how they feel and validating their feelings is enough. Remember that, although you may perceive the baby as doing well on a particular day (and it may help parents to hear that), it may not be how the parents are feeling. Explore how they are feeling first. Avoid using the words “at least”. “At least you have the girl you wanted”; “At least you have two other kids at home”. “At least statements are not empathetic statements; they do not validate and may trigger anger.

(3) Let parents have as much control as possible. You are working with a family, not just an infant. There are a number of family dynamics that you probably won’t know. Educate families, give them choices, and involve them in the baby’s care. The more you educate, the more you can enable parents to feel control. This can range from taking temperatures, to feeding schedules, to whether to do surgery on a patent ductus arteriosus. Make parents feel they are part of the team taking care of their baby. Mackenzie’s nurses sometimes provided this feeling for me by calling me at home to update me on the baby’s condition. This made me feel that what I said and felt really mattered.

(4) Be accountable for your actions, right or wrong. If there is a problem, whether big or small, your fault or not, let the parents know what is being done. When Mackenzie aspirated I was angry. The anger was present regardless of the fact that I knew, better than the average parent, that these incidents happen. The nurse may or may not have been at fault. A simple, empathetic “I’m sorry” would have helped heal my anger. Because of Mackenzie’s long-term problems resulting from the aspiration, I frequently go over this incident and feel anger.

Keeping parents naïve does not prevent lawsuits; it creates fear, suspicion, and anger. Prompt explanations and apologies are the best healers.

(5) Do extensive teaching and encourage home care. I cannot imagine surviving Mackenzie’s homecoming without my nursing knowledge. Because of Mackenzie’s problems with significant reflux, we received approximately 12 hours of respite care per week. Home care was a lifesaver for us and should be offered to all parents whenever possible.

(6) Most important, recognize that the baby you are taking care of is a child of a parent or parents in a family with a distinct set of dynamics. Remember that the NICU is a very intimidating place. (There were moments my husband was so intimidated he had to push himself to walk through the door.) Help parents to overcome intimidation so they can be a part of their child’s life. Don’t forget to speak to the father as well as the mother. Often fathers feel left out because medical people tend to address only the mothers.

Many parents feel similar emotions, but each family expresses them differently. Recognize those differences and be their advocate. If there are no parents, then you are the baby’s advocate.

CONCLUSION

I believe being an NICU nurse was (for the most part) a benefit. I didn’t fear the things that most parents fear (monitors, intravenous injections), but I was aware of things that most parents aren’t (NEC, retinopathy of prematurity, intraventricular hemorrhage). I used my nursing coping mechanism by separating myself from the situation emotionally when the pain was too much to bear. This may not have been healthy, but it was something I already had that gave me an advantage over other parents. I had worked in Mackenzie’s unit just 1 year before her birth, so it was easier to establish trusting relationships with the staff. I knew when to be Mackenzie’s advocate sooner than other parents might. However, it took a great deal of patience and diplomacy to simply observe Mackenzie’s care.

At 6 months Mackenzie weighs 10 pounds 8 ounces. Five weeks after coming home she had a Nissen fundoplication with a button placement. She nipples approximately one third of her feedings and is fed the rest through her gastric tube. She is

on 0.25 L of oxygen and continues to progress with her occupational therapy. She smiles and is beautiful. I am so grateful she was born in 1993 and was able to receive the best care possible.

Reprint permission granted by Stockton Press, a division of Nature America Inc. Users may download a single copy each, but any multiple copying or downloading requires permission from Stockton Press, the copyright holders.

Stockton Press 345 Park Avenue South, 10th floor New York, NY 10010-1701 (212) 726-9200