

REALITIES OF A PREMATURE INFANT'S FIRST YEAR: HELPING PARENTS COPE

By Dianne I. Maroney

“Just make it through the first year and everything will become much easier.” How many health professionals have said this to parents of premature infants as they prepare to leave the neonatal intensive care unit (NICU)? In my 12 years of experience working as an NICU nurse, I said it to many parents. Yet it wasn't until I delivered my premature daughter, weighing 790 gm at 26 weeks, that I began to understand the reality of the crisis that parents endure in the first year of their premature infant's life.¹

There is a wonderful illusion presented by the medical staff and believed by parents: When a premature infant is discharged home, family life will settle in, calm down, and become somewhat “normal”. However, the crisis that begins in the NICU often continues after discharge, as a result of the overwhelming medical needs of the infant, and the recurring grief and emotional devastation that the family of a chronically ill child must cope with.

This “continuing crisis” is frequently unrecognized by professionals. It is essential that medical professionals, both during the NICU course and later in the follow-up setting, appreciate the intricacies of a premature infant's first year of life so that they are better able to educate parents, facilitate an easier transition to home, and prepare them for the possible difficulties ahead.

Although our daughter Mackenzie's first year of life was unique to her, other premature infants certainly share many experiences and have similar needs. I would like to share with you some of my family's experiences and suggest ways health professional can better assist parents during these overwhelming first 12 months.

Transitioning To Home

As I reflect over my daughter's first year of life, I am struck by the life we have lived. Even though Mackenzie was very premature, she had a fairly stable hospital course. The hospital staff, my husband, and I shared in the typical illusion that things would progress and Mackenzie would do well once she came home. However, the crisis that began in the NICU continued and in some ways intensified. Our lives remained in turmoil.

Although Mackenzie was discharged with only a nasal cannula for oxygen, she was still a child with special needs. She was sensitive to stimulation, had increased calorie needs, was developmentally delayed, and her respiratory status was very unstable. After 3 1/2 months of around-the-clock NICU care, my husband and I were suddenly left to ourselves to assume the roles of nurses, doctors, and parents.

Mackenzie's first night home was quiet and uneventful, but she soon began crying constantly and stopped eating. Over the course of 5 long weeks, during which she received orogastric and nasogastric feedings, she failed at numerous attempts to improve nipping, received a variety of medical managements, and was seen in consultation with medical specialists. Finally her care was transferred to a graduate preemie specialty clinic. She underwent a Nissen fundoplication (and button placement) that relieved her esophageal pain and improved her ability to receive more calories. This time at home was as stressful as the 14 weeks in the hospital.

Transitioning to Pediatrician

Graduates from the NICU can present a tremendous challenge to health care professionals.³ Many general pediatricians or family practitioners may not feel comfortable with nor realize the complexity of these infants with multiple medical needs. Our initial visits with Mackenzie's first pediatrician were extremely frustrating because I did not feel he saw Mackenzie

as a child with continuing problems. He did not listen to my observations and was not supportive of my concerns. It wasn't until we began taking Mackenzie to the multidisciplinary, graduate preemie clinic that the management of her care was assumed by the proper medical professionals. The staff at the clinic listened to me and dealt with my concerns and Mackenzie's needs.

In discussing our frustrations with other parents and the staff at the clinic, we quickly realized that a frequent complaint from parents of premature infants is poor communication and lack of support when transitioning to their pediatrician (even pediatricians with the best reputations). A large majority of physicians are not educated during their training about the multidisciplinary needs that families with special-needs children require. Many have not had the opportunity in their practice to further their education in this evolving area. For those physicians who are educated, it is frequently difficult to manage these complex patients because of the time required and the cost of care. As a result, families frequently feel lost and are unable to receive the care they need.

Coping with the Emotions

Beyond Mackenzie's suffering, the most difficult part of the first year was coping with our grief. Days and nights were filled with fear, depression, anger, frustration, sadness, guilt, disappointment, self-doubt, joy, and triumph. As another parent wrote, discharge did not stop the well-noted roller coaster ride, it only made it lonelier.⁴

In our lives, fear surfaced in a variety of settings. It surfaced when development evaluations were performed and the question of how Mackenzie would progress (Will she have cerebral palsy?) became apparent. There was the fear and depression that occurred during the isolation of the winter respiratory virus season. There was anger that could surface at any moment and be directed at anyone within our emotional environment (spouse, children, or healthcare provider). There was the frustration of Mackenzie's oral aversion and lack of desire to eat and the few solutions to her problems. There was sadness and self-doubt when decisions had to be made for surgery or more tests and invasive procedures. There were the common questions we asked ourselves over and over: "Why me?" "Why our baby?" Many parents continually struggle to find meaning and answers to these questions.

Guilt surfaced when I asked myself, "Could I have done something different to prevent this?" I was shocked when I was told that Mackenzie could have died had she not had her monthly intravenous infusions of an experimental drug, when she was simultaneously culture positive for respiratory virus and in uenza A. We were exhausted and fatigued when our nights were filled with the alarms of the apnea monitor and the unnatural feeling of having strangers in our home watching Mackenzie as we slept. I was disappointed when Mackenzie wouldn't wean down on her oxygen requirement (or when her needs would increase). There was a knot in my stomach when I would finally venture out into public, only to be stared at by strangers.

I continue to grieve the loss of my "normal" baby and child; this is a major cause of grief in parents with chronically ill children.² I have never fed my daughter a full bottle while she was in my arms; I rarely am able to hold her and feed her. She lies on her side when she eats because of her inability to organize herself and handle stress. I continually need to be aware of her inability to handle stress when I am holding or interacting with her. There are many limitations on daily routines that result from being attached to 50 feet of oxygen tubing. Many of these routines were taken for granted with our other term, healthy children.

Parents often stay in the "survival mode" while their pre-term baby is hospitalized and even for the period of time that their baby continues to require more care at home. Often when the baby finally does come home or the baby's health improves, the reality of the seemingly avoided crisis sets in. Parents let down their guard, begin to feel hidden emotions, and often feel overwhelmed. They may feel emotionally spent and exhausted. The coping and grieving process can be incredibly difficult and can be burdensome to individuals and marriages. At the recent Parent Care conference in Salt Lake City, I was amazed by the number of parents of premature infants (born 2 to 19 years ago, some with disabilities, some without) who continue to grieve.

Daily Management

Managing a premature infant's daily medical needs can be overwhelming. Although Mackenzie stabilized after her fundoplication and her needs became more "typical", her care continued to be demanding and exhausting. I spent many hours on the telephone dealing with insurance issues, scheduling weekly doctor visits, coordinating nursing visits, arranging occupational and physical therapy visits, and requesting oxygen and medical supply deliveries. I averaged seven phone calls per day just dealing with Mackenzie's medical needs. Between phone calls, office visits, treatments, tube feedings, occupational therapy (OT) and physical therapy (PT) visits (and daily exercises), and managing a home with two other children, there was very little time to just hold and spend time with Mackenzie. I will always miss this part of relating to her that I never had.

Impact of Family and Friends

The impact that a special-needs child has on a family is enormous. Most of the energy parents have is taken by the needs of the child or children. There is little energy left to keep parental relationships healthy. Although the effect of chronic illness on divorce rates can be debated, it is safe to assume that marital stress increases in families with chronically ill children.⁷ Admitting the impact of this stress on a marriage or relationship is crucial. Through counseling and a great deal of work together, we have kept our marriage alive.

Having other children can add a great deal to the intense stress of daily life. Often there is very little energy left to handle the day-to-day needs of siblings, let alone meet their need to understand and cope with an ill brother or sister. Just at the moment when there is nothing left to give to them, they are demanding something from you, and they cannot understand why there is so little left for them. I frequently asked myself if I had enough energy to cope with our 4- and 6-year-old sons' needs and whether there would be problems that stem from this in the future. My husband and I often feel that we missed a very important year in each of our sons' lives.

Talking with other parents of premature infants, I found that the dynamics of the relationships between parents and extended family and friends often become problematic. Already dysfunctional relationships can become even more dysfunctional and therefore more painful. Many people have a hard time hearing about a life that is constantly overwhelming for a long period of time. They often will just stay away out of their inability to absorb it all or because of feelings of inadequacy about not knowing how to respond.

Beyond the difficult relationships, there are very special new relationships that form out of an incredibly compassionate understanding between two people who share similar circumstances.

Rehospitalization

One of the most distressing incidents that happens in the first year is rehospitalization. Premature infants are rehospitalized at a rate of four times that of a "normal" term infant.^{5,6} Mackenzie was rehospitalized three times in her first year of life. When she recently came down with viral pneumonia and we began thinking she might need to be admitted, I was overwhelmed with panic. I was completely a parent at that point! Although I have worked in hospitals for 12 years, I was overcome with fear; Fear of death, fear of reintubation, and fear of her suffering. I began feeling very guilty and thought, "Was there something I did wrong?" The loss of control had returned, and every emotion I had felt when Mackenzie was in the NICU came boiling to the surface.

Financial Concerns

Mackenzie's medical costs in the first year of life were in excess of \$400,000. Fortunately, we had "good" insurance and she qualified for Medicaid because of her size. Many people are unaware of the "hidden costs" in premature care. Often insurance companies do not pay for occupational or speech therapy, breast pump rentals, premie diapers, or special formulas. After a recent hospitalization for viral pneumonia, Mackenzie needed home nursing care for approximately 6

weeks (in lieu of hospitalization). We just received notice that our insurance refused to pay the \$7000 claim because they determined that it wasn't medically necessary. We are now having to appeal the claim, which requires a great deal of time and energy, and is an obvious financial strain. I also know of a mother of 20-month-old twins, born at 28 weeks, who spends \$450 per month on special formulas alone. This may seem extreme but even small amounts of extra costs can be burdensome to already financially stressed families.

Working parents have to deal with the difficulty of finding suitable child care. Because most pediatricians recommend that at-risk children avoid contact with large groups of other children (to reduce the risk of respiratory illness), many parents seek (expensive) child care within their homes. Just finding suitable child care for a child with special needs can be extremely difficult. There are few resources in the community to help with this time-consuming process. Having Mackenzie has forced me to stay home and only work one 12-hour night shift per month. Having to quit a job in a dual-income home can be financially devastating.

How Professionals Can Help

Giving birth to a critically ill infant is an emotionally painful as coping with the death of a loved one or learning you have a long-term illness. Medical professionals should remember that this emotional pain happens to parents of 24-weekers, 34-weekers, or a term baby who requires extended hospitalization for a sepsis evaluation.⁷ The intensity may be greater for the smaller or sicker child but the emotions are similar. By preparing parents in the NICU for possible difficulties after discharge and identifying prospective sources of support, professionals can give parents an advantage in coping during the first year. Below are my recommendations on preparing families for discharge and the first months at home.

(1) Begin by helping parents identify feelings. Talk about what many parents of critically ill infants feel, such as anger, fear, guilt, and so on. Tell parents that when the crisis is over they may begin to feel overwhelmed with emotion. Encourage them to seek help through counseling or with other parents who have been through a similar experience. Parents may want to contact the national organization for families of critically ill infants, Parent Care Inc. (Parent Care, Inc., 9041 Colgate St., Indianapolis, IN 46268-1210; (317) 872-9913). This organization refers parents to related organizations and offers a variety of pre-term infant-related literature.

(2) Maintain frequent communication with the family's pediatrician or other health care provider throughout the baby's hospitalization to make the transition to outpatient care easier. Provide a complete summary of medical and nursing care (including OT and PT observations) to the pediatrician's office when the baby is discharged. If the baby needs extensive follow-up care, refer the family to a multidisciplinary clinic whenever possible where they can have the benefit of complete and managed care from various professionals.^{3,4,8}

(3) Be sure the NICU patient-care coordinator or social worker knows the resources in your community, including where to refer parents for services, such as child-care providers who will take children with special needs, organizations that will help pay for therapy, programs for developmentally disabled children, breastfeeding support groups, and so on.⁹ Connect parents with these programs early in the infant's hospitalization. Many NICU babies qualify for assistance from the Part H section of the Individuals with Disabilities Education Act. Part H refers to supports and services for children <3 years old and many NICU graduates qualify for these services. Refer parents to their county's Child Find Service Coordinator to initiate the programs. If it appears that the baby will be chronically disabled, the Katy Beckett Waiver for Medically Fragile Children gives Medicaid to parents who make more than \$24,000 per year. This is a federally funded program that is state regulated. It is important that parents sign up for this program as soon as possible because there is often a long waiting list. Remember that in most counties, parents with children on home oxygen will qualify for a handicap sticker for their car. Whatever you can do to make life easier and lessen the stress on parents will be greatly appreciated.

(4) Encourage parents to take care of themselves, including rest, nutrition, exercise, and a balanced routine. Explain that they won't be able to care for their baby if they are not healthy themselves. Find out about insurance or community-based respite care programs. Encourage parents to find time to work on their relationships; they may need counseling or they may just need an occasional date together. Give parents a list of area counselors qualified in counseling parents in crisis situations.

(5) Be sure that parents feel ready and are realistic about taking their baby home. Give them as much education and information as possible without overwhelming them. Let them know that they can call the NICU at any time with questions and concerns. Periodic calls from the primary nurses after discharge can be very helpful and comforting, even if their only purpose is emotional support. Connect them with parent support groups.

(6) Practice family-centered care in your nurseries.¹⁰ Begin to empower parents during their baby's hospitalization. Give them praise and positive feedback. Let them be involved in the discharge planning. Teach parents to be their baby's advocate before discharge so they will be more comfortable speaking up for their baby in future potentially intimidating situations. Educate parents about their responsibility in the coordination of their child's care and their responsibilities with their pediatrician.

(7) Physicians and practitioners should educate themselves through literature or seminars regarding managing a family with a special-needs child using family-centered care. Contact other physicians that understand this management, as resources, when you have questions or concerns about patients. If time and cost are issues, work with insurance companies to reimburse for coordination of care.

Conclusion

Not all premature infants and their families experience the difficulties that our family experienced; unfortunately some may experience even more. Medical professionals rely on statistics from follow-up studies to predict how infants will progress in the first year, yet there are children who do the unexpected: the 25-weeker who has minimal sequela and the 30-weeker who has severe cerebral palsy. All parents should be educated by an empathetic hospital staff about what the first year at home may bring. In addition, concrete suggestions, support, and understanding from the care provider are essential in helping parents cope with the hidden complexities of the first year of their child's life.

For Mackenzie's first birthday we had a huge celebration. We needed to put a closure on 12 very difficult months. Through all the pain, there have been life's lessons of love, commitment, and the will to live. I am constantly amazed at my daughter's strength and I feel tremendous joy in her smile. We celebrate each of her milestones and take nothing for granted. We continue to deal with issues surrounding chronic lung disease and her oral aversion. Developmentally she has had her struggles but we are encouraged by her progress. We are hopeful that someday she will be able to function normally in society and that no one will be aware of her incredible struggle.

If reading this article makes you feel overwhelmed with information, imagine living it on a daily basis. I have learned a great deal from our journey both as a nurse and as a parent. I hope that by sharing our experiences, other health professionals will be better informed in helping parents cope with the realities of the first year of a premature infant's life.

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