

## The Role of the Primary Care Pediatrician in the Care of the NICU Graduate

William Sessions\*, Elizabeth Waldrop, Ayo Olanrewaju, Sumesh Parat and Mubariz Naqvi

Department of Pediatrics, School of Medicine, Texas Tech University Health Sciences Center, Amarillo, Texas, USA

\*Corresponding author: William Sessions, Department of Pediatrics, School of Medicine, Texas Tech University Health Sciences Center, Amarillo, Texas, USA, Tel: +1-214-733-2323; Fax: +1-214-733-2323; E-mail: William.S.Sessions@ttuhsc.edu

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### Abstract

A 33 year old female diagnosed with twin gestation, received adequate prenatal care and all prenatal screens were negative. She took synthroid and prenatal vitamins, denied smoking, drinking alcohol, or using illicit drugs. Spontaneous preterm premature rupture of membranes for Twin A at 19 weeks, admitted to the hospital at 24 weeks. Received dexamethasone, ampicillin, and erythromycin; for the preterm premature rupture of membranes. Twin A's umbilical cord prolapsed at 24 2/7 weeks; emergency cesarean section was performed to deliver both babies. Twin A, expired shortly after birth secondary to respiratory distress. Twin B developed multiple clinical problems in the NICU, many of which required intervention. Twin B's parents were very supportive and understanding and were constantly involved in the child's care during NICU stay. The mother and father participated in the discharge planning education course and roomed-in with their baby for 2 days. Twin B lost weight initially and regained birth weight by the 7-8th day of life and remained above the 10th percentile for weight on the growth curve. Twin B was discharged from the NICU on day 109 at post conception age 39 weeks, weighed 2834 grams (10th percentile for corrected age), measured 49 cm length (50th percentile for corrected age), fronto-occipital circumference 34 cm (50th percentile for corrected age). The patient's care was transferred to the primary care pediatrician. As for our patient, he was dismissed from the NICU 9 years ago and was followed by the high-risk clinic associated with Texas Tech Pediatrics in Amarillo for 2 years after NICU dismissal. He continues to gain weight and is progressing well. His ophthalmologist follows his visual status as he has to wear glasses for visual acuity. His broncho pulmonary dysplasia has resolved. He continues to follow up with his primary care pediatrician.

**Keywords:** Premature; NICU follow-up; Complications of prematurity; Role of primary care Pediatrician

### Introduction

Approximately 4 million babies are born in the United States per year. Roughly 1 in 10 of those babies is premature, defined as birth before 37 weeks gestational age. Prematurity potentiates complications in the neonate spanning most organ systems, with the most severe effects on the respiratory, gastrointestinal, metabolic, neurological, and immunologic systems. A classification of premature neonates is by weight, dividing the infant into birth weight categories of low birth weight (less than 2.5 kg), very low birth weight (less than 1.5 kg), and extremely low birth weight (less than 1 kg) [1]. The lower the gestational age and the lower the birth weight, the more potential for complications the neonate faces and the more likely the neonate is to be admitted into the NICU. Once the premature infant is discharged from the NICU, it is the responsibility of the primary care pediatrician to assume care of the infant and provide follow-up care for the collective complications of prematurity that may have transpired.

### Case Presentation

The mother of our patient was a 33 year old G2P3003 female who received adequate prenatal care. All of her prenatal screens were negative. She was diagnosed with twin gestation. She took synthroid and prenatal vitamins but no other medications during pregnancy, and denied use of other medications, smoking, drinking alcohol, or using illicit drugs. She had spontaneous preterm premature

rupture of membranes for Twin A at 19 weeks gestational age and was admitted to the hospital at 24 weeks gestational age and received dexamethasone, ampicillin, and erythromycin for the preterm premature rupture of membranes. Twin A's umbilical cord prolapsed at 24 2/7 weeks and at that time; an emergency cesarean section was performed to deliver both babies with the NICU team in attendance (Figure 1).



**Figure 1:** Baby JM at 24 2/7 weeks gestation in the NICU.

Twin A weighed 640 grams and assigned Apgar scores of 3/7 at 1 and 5 minutes. Twin B weighed 690 grams and received Apgar scores of 2/7 at 1 and 5 minutes. NRP guidelines were assigned and both infants were transferred to the NICU. Twin A developed respiratory distress shortly after birth, which progressed to respiratory failure secondary to severe lung hypoplasia and preterm premature prolonged rupture of membranes. He expired at 12 hours of age in the NICU. He was found to have multiple restrictive deformations secondary to

oligohydramnios. Twin B developed multiple clinical problems in the NICU, many of which required intervention: pulmonary interstitial emphysema and pulmonary hemorrhage requiring oxygen supplementation and diagnosis of bronchopulmonary dysplasia, hyperbilirubinemia requiring phototherapy, electrolyte abnormalities including hyponatremia and hyperkalemia, late-onset sepsis due to Staphylococcal epidermidis, persistent ductus arteriosus requiring ligation, total parenteral nutrition, osteopenia of prematurity, inguinal hernia requiring repair, iatrogenic neonatal abstinence syndrome secondary to prolonged opioid and benzodiazepine therapy requiring methadone for detoxification, anemia and thrombocytopenia requiring blood and platelet transfusions, and intraventricular hemorrhage, periventricular leukomalacia, and non-hemorrhagic ventriculomegaly.

During the NICU stay, Twin B's parents were very supportive and understanding and were constantly involved in the child's care. His parents lived in a trailer parked in the hospital parking lot and made it their home for 3 months despite living permanently out of town. The mother provided breast milk for the baby. The mother and father participated in the discharge planning education course and roomed-in with their baby for 2 days. The patient lost weight initially and regained birth weight by the 7-8th day of life and remained above the 10th percentile for weight on the growth curve. Twin B was discharged from the NICU on day 109 at post conception age 39 weeks. He weighed 2834 grams (10th percentile for corrected age), measured 49 cm length (50th percentile for corrected age), fronto-occipital circumference 34 cm (50th percentile for corrected age), his hearing screen was normal, and his retinopathy of prematurity screen was stage 2, zone 2 at time of dismissal.

After dismissal, the patient's care was transferred to the primary care pediatrician. The patient received all 2 month immunizations as recommended as well as Synagis prophylaxis. He was being fed expressed breast milk every 3 hours for 15-20 minutes. His medications include PolyViSol with iron, calcitriol, home oxygen therapy, home apnea monitor, and breathing treatments.

## Discussion

Premature birth is defined as the birth of an infant prior to 37 weeks gestational age. Prematurity can be further differentiated into late preterm, born between 34 and 36 weeks of pregnancy, moderately preterm, born between 32 and 34 weeks of pregnancy, very preterm, born less than 32 weeks of pregnancy, and extremely preterm, born at or before 25 weeks of pregnancy. Most preterm births occur during the late preterm stage. The specific cause of premature birth is not always defined, however there are known risk factors associated with preterm labor and delivery. These include previous premature birth, multigestational pregnancy, interval of less than 6 months between pregnancies, conception through *in vitro* fertilization, anatomical problems of the uterus, cervix, or placenta, cigarette smoking, infections of the amniotic fluid, maternal hypertension and diabetes, history of multiple miscarriages or abortions, and physical injury or trauma. In addition, women of African descent are more likely to experience premature birth, however the reason is still unknown [2].

The complications of prematurity can be broadly classified as short-term and long-term complications. In the first few weeks of life, a preterm infant can develop breathing problems secondary to an immature respiratory system. Without ample time to develop surfactant, the substance that allows the lung to expand, the infant may

develop respiratory distress syndrome due to inability of the alveoli to participate in gas exchange for appropriate oxygenation. The infant may also present with cardiovascular problems, commonly associated with patent ductus arteriosus. The neurological system is also affected--the earlier the baby is born, the higher the risk of developing intraventricular hemorrhage that has the potential to cause permanent brain injury [3]. A newly born premature infant may have difficulty controlling temperature due to decreased stored body fat, which inhibits the neonate's ability to generate heat to counteract what is lost through evaporation off the surface of their bodies. Hypothermia can result in breathing problems and hypoglycemia, as the infant uses all energy gained from feedings to regulate a body temperature compatible with life. A serious complication of an immature gastrointestinal system is necrotizing enterocolitis, in which the cells lining the bowel wall are injured and can lead to necrosis of the bowel resulting in a potentially life-threatening condition for the infant. Premature infants are also at an increased risk of hematologic problems, including anemia, newborn jaundice and thrombocytopenia, and immune system immaturity resulting in the infant being more susceptible to contracting infections leading to neonatal sepsis [3]. Long term complications of prematurity are manifested at differing times throughout childhood and adolescence. Preterm infants are at an increased risk of developing cerebral palsy due to an immature newborn brain, impaired learning, vision problems secondary to retinopathy of prematurity, hearing and dental problems, behavioral and psychological problems, developmental delays, and chronic health issues such as infections, asthma, and feeding problems. In addition, premature infants are at an increased risk of sudden infant death syndrome than term infants [4].

Not all preterm babies experience complications but decreased gestational age is associated with short-term and long-term health problems. Generally, the earlier the baby is born the higher the risk of complications and typically the lower the gestational age, the lower the birth weight of the neonate. Therefore, the lower the birth weight of the infant, the more likely complications of prematurity will manifest in the neonate.

Extremely low birth weight neonates, infants born with a weight of less than 1 kg, have high potential to develop complications associated with prematurity. The majority of these infants are transferred to the NICU immediately after birth to address emergent concerns such as respiratory distress and inability to regulate temperature and hydration. Close surveillance of these low birth weight babies in the intensive unit is prudent to minimize morbidity and anticipatory guidance for parents is essential in eliciting good outcomes for the infant.

In order for an infant to be discharged from the NICU, AAP guidelines require a sustained pattern of weight gain, adequate maintenance of normal body temperature in an open crib, competence in breast and bottle feeding, physiological stability of cardiovascular and respiratory status, appropriate immunization, completed metabolic, hearing, and vision screenings, and stable hematological status. The family and environment must be prepared and ready in order for the infant to be discharged home. Two committed family members must attend the discharge planning and demonstrate independent care for the infant through rooming in and psychological assessment. The parents must also exhibit competence in feeding, basic infant care, bathing, cord and genital care, as well as CPR training and ability to detect early signs and symptoms of illness. If the infant is to be discharged home on medications, the caretaker must show

understanding of safety and maintenance of equipment and attached devices as well as how to administer medications [5].

A premature infant discharged from the NICU requires special considerations when care is transferred to the primary care pediatrician. These points of importance can be divided into biological factors including extreme prematurity, neonatal infections, bronchopulmonary dysplasia, severe growth restriction, intraventricular hemorrhage and neurological sequelae, interventional factors such as resuscitation, postnatal steroids, prolonged ventilation and oxygen therapy, prolonged IV nutrition, blood transfusions, and surgical interventions, social and environmental factors for the infant including parental education and socioeconomic status, stressors in the household, and insurance for the ability to follow up care, parent-infant bonding, and infant growth and nutrition [5]. Communication of the NICU team at discharge to the primary care pediatrician is essential in minimizing poor outcomes resulting from non-disclosure of critical information regarding the infant's hospital course. Some of the most essential information that should be expressed to the pediatrician include laboratory information such as highest bilirubin level, most recent hemoglobin and reticulocyte count, and newborn screening, diagnostic imaging performed during the hospital course, medications given to the infant, hearing and vision status, immunizations, and feeding and nutrition. The pediatrician should also be made aware of the discharge physical exam and growth chart, equipment sent home with the infant at dismissal, and family dynamics of the infant that may influence care [6]. For parents, the NICU may be a terrifying experience, far from their hopes and dreams attached to a normal birth experience. This stressful situation triggers a grieving response, creating a major strain on family dynamics and relationships [7].

The role of the primary care pediatrician once information has been transferred and open communication with the NICU team has been established may require more attention and consideration than a typical patient. Ideally, the pediatrician would visit the infant and infant's family in the NICU and become acquainted with the neonatal providers that have established care over the new patient. They should review the discharge summary and schedule an office visit one week after the infant's NICU dismissal to address status and lingering concerns. The pediatrician should examine and analyze the infant's medical conditions and serve as the medical home during the coordination of care between subspecialists that the infant may require [8]. It is particularly important to monitor the growth of these infants until 24-30 months corrected age and assess their nutritional status as their needs differ from the term neonate, typically requiring specially prepared formulas with additional protein, calcium, phosphorus, and vitamins until 9-12 months corrected age [9]. An augmented diet has been shown to promote catch up growth, increase bone mass, and result in better neurological outcomes compared to an ordinary diet for term neonates [10]. In surveillance of these infants, the pediatrician should plot the infant's length, weight, and head circumference on the growth chart, monitor for neurodevelopment problems using corrected age, screen for anemia at 2, 6, and 12 months of corrected age, and provide close and frequent follow up appointments. Neurodevelopmental issues such as cognitive delay, IQ impairments, Autism spectrum disorders, attention deficit disorders, and interpersonal connection problems should be monitored as they have been shown to have increased incidence in preterm infants [11]. However, these neurodevelopmental deficits manifest at differing ages and therefore must be assessed throughout childhood and adolescence

[12]. Beyond assessing the needs of the infant to grow and develop, another crucial component of care is support of the parents including discussion of parental concerns, education with anticipatory guidance, and potential referral to Early Childhood Intervention, Women Infants and Children, and support groups such as Parents of Preterm Infants.

As for our patient, he was dismissed from the NICU 9 years ago and was followed by the high-risk clinic associated with Texas Tech Pediatrics in Amarillo for 2 years after NICU dismissal. He continues to gain weight and is progressing well. His ophthalmologist follows his visual status as he has to wear glasses for visual acuity. His bronchopulmonary dysplasia has resolved. He is currently in the 2nd grade and is very interactive with his peers despite having a motor disability. He continues to follow up with his primary care pediatrician.

## Conclusion

Although emergent medical concerns have been addressed and stabilized by the NICU team, some complications of prematurity in preterm infants linger after discharge, into childhood and further, into adulthood. The care of the premature infant after discharge from the NICU by the primary care pediatrician is essential in ensuring optimal health for the infant in the forms of close monitoring of the infant, acting as the medical home for subspecialist information, and providing support to the infant's parents.

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