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The NICU Graduate: Implications for Pediatric Primary Care

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ABSTRACT

Mortality rates of extremely preterm infants continue to decline as neonatal technology and care improve. Following graduation from the Neonatal Intensive Care Unit, preterm infants will transition to pediatric primary care offices for continued care and treatment. These infants often have complex health care needs that present inherent challenges to the pediatric health care providers who will provide that ongoing care. Implications for primary care providers include knowledge and treatment modalities of the common complications of the preterm infant. These complications typically include chronic lung disease; catch up growth and additional nutritional needs, neurodevelopmental monitoring, feeding challenges, retinopathy of prematurity and apnea of prematurity. Each patient–parent dyad will need a customized approach to primary care, coordinating care with physical, occupational, and speech therapy as well as other specialist in order to accomplish the best long term outcomes. Strategies for success in meeting the health care needs of infants and families following transition from the Neonatal Intensive Care Unit to primary care are provided.

According to the March of Dimes,[1] 9.6% of infants are born prematurely (before 37 weeks gestation) worldwide and in the United States the annual statistic is 12.3% (over 430,000 infants). The most common reasons for preterm births in the United States are preterm labor, preeclampsia, maternal infection and other adverse events.[2] Preterm birth continues to be the leading cause of neonatal mortality and morbidity. Although significant improvement in our rates of premature births has not been gained; dramatic advances in our neonatal mortality rates for infants born less than 1000 grams are clearly evident. Those infants born at 24 weeks gestation now have a reported 80% survival rate compared to less than 50% survival just 15 years ago.[3] The survival of the extremely premature infant has been linked to increased morbidity which translates into more complex long term medical and developmental care needs. This has significant implications for primary health care providers (PCP) who care for these infants after discharge from the Neonatal Intensive Care Units (NICU). The aim of this article is to highlight both the health care and developmental concerns related to preterm birth and provide strategies for primary health care providers to meet the complex health care demands of these specialized infants and their families.

Primary Care

Primary care according to the Institute of Medicine is defined as "the provision of integrated, accessible health care services by clinicians who are accountable for addressing the personal health care needs, developing a sustained partnership with patients and practice in the context of family and community."[4] Specifically pediatric primary care includes the following elements: 1) contact care which refers to the intermittent health care needs of the child; 2) comprehensive care which refers to the approach to the patients care that encompasses all aspects of development and other health care issues; 3) coordinated or integrated care entails the health care providers ability to provide continuity of information within the primary care practice as well as arrange and coordinate specialized services according to health care requirements and finally; 4) longitudinal care refers to the care delivered over time regardless of presentation of additional health care concerns.[5] Primary care providers are the constant force; to not simply provide care but support all additional required health care delivered intermittently by specialist.

There are some examples of specialized primary care facilities for the preterm infant throughout the country, like the Tiny TOTs program at Baylor University Health system in Dallas.[6] This specialized clinic provides an intermediate link between the NICU and graduation to traditional primary care at the age of 2 years for high risk infants. The clinic is supported financially by the hospital and is staffed by neonatal specialists; both neonatal nurse practitioners (NNP) and neonatologist who provide continued excellent care to this high risk population. This type of specialized primary care for the NICU graduate is the exception rather than the rule, with most

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preterm infants mainstreamed into the care of area pediatric offices following discharge from the hospital.

Discharge Readiness

The American Academy of Pediatrics (AAP) statement on readiness for discharge of the high risk neonate from the NICU describes a standardized measure to determine patient and family readiness for discharge. The AAP policy statement provides professionals within the NICU clear recommendations with regards to the critical timing of patient transfer from inpatient to primary care. These recommendations (see Table 1) are categorized to include specific parameters of infant, family and home as well as community health care readiness of infant discharge.[7]

Although it is standard of care that discharge begins at hospital admission; the reality that is discharge readiness is the last priority when providing acute life saving care to an extremely preterm infant. Once the child has stabilized the parents are encouraged to participate and learn specifics of infant care. This bedside education has been reported to contribute to families' confidence in caring for their preterm infants following discharge.[8] Parents of NICU patients agree that discharge teaching becomes a focus close to discussions around "going home".[9] Parents of term infants were tested on their perceived discharge preparedness and those who had felt ill prepared on discharge have been statistically linked to increased parental physical and psychosocial problems and inappropriate infant care behaviors putting both infant and parents at risk.[10] Although not as well studied in the preterm population, NICU parents of high-risk preterm infants describe the increased teaching that occurs around the time of discharge as overwhelming. Poor discharge planning and implementation can have significant negative ramifications on discharge success and readiness for transition to primary care.[11]

Obviously every attempt to employ early and effective discharge planning strategies to prepare families for the transition to home is a goal in the NICU. Using the AAP guidelines as a standard for assessing discharge readiness can facilitate successful outcomes through the assurance that each high risk neonate eligible for discharge is "ready" for the transition to home.[7] Evidence that we could do better with this high risk group is well documented. These infants are significantly higher users of health care resources as demonstrated through increased number of primary health care visits, emergency room visits and additional pharmacy cost. They are also at a significantly higher risk for hospital readmission following discharge.[12] Improved NICU discharge planning and parent teaching to promote discharge readiness as well as the successful transition to primary care have implications to reduce this level of health care utilization and expense.

To summarize, the AAP supports discharge from the NICU based on specific readiness guidelines. NICU health care providers are encouraged to provide parental support and education through the discharge process to ensure both competence and confidence to care for this high risk neonate at home. The next link in the chain, to best meet the complex needs of this specialized population is the pediatric health care provider. To accurately describe the specific health care concerns related to this specialized population, a topical review will be included below. Each section will describe specific pathophysiological concerns related to the premature infant and those strategies that could be employed by the primary care provider to address many neurodevelopmental and physical issues.

Table 1
Policy Statement on Discharge Readiness for the High Risk Neonate (AAP).

Infant Readiness (physiological stability):
- Pattern of sufficient weight gain established. No predetermined minimum weight was published by the AAP in the policy statement.
- Normothermic in open bed.
- Established competent feeding pattern at breast or bottle.
- Stable cardio-respiratory stability without bradycardia, apnea or desaturation events for a sufficient duration (specific time-frame was not delineated by the policy statement.
- Up to date immunizations administered.
- Metabolic screening completed with established follow up plan in place when required.

Family and Home Environmental Readiness:
- Environmental safety (safe supply of water, electricity, adequate heating, available phone access).
- Review of family's resources to include; parenting strengths and risks, financial resources and support, additional family or friends available to assist during care giving activities.
- Parents and caregivers are required to demonstrate adequate capacity to care for the child. These skills include; feeding and formula preparation, basic infant care, temperature measurement, infant safety precautions including infant CPR, medication administration and correct assessment of infant's status and changes in condition.
- For child discharged with special needs or additional technology; the parents or caregivers should demonstrate adequate safety precautions and use of this equipment.

Community and Health Care System Readiness:
- A primary care health provider has accepted responsibility to care for the infant.
- Neurodevelopmental referrals including follow-up specialty clinic where available is scheduled.
- Follow-up care has been arranged with pediatric medical and surgical specialist where appropriate.
- Home care assistance has been arranged to include; nursing visits, parental support with an established home-care plan.
- Lactation counseling and support is offered to breastfeeding mothers.

Adapted from the AAP policy statement 2008 (revision from original statement 1998; Committee on Fetus and Newborn; Hospital Discharge of the High-Risk Neonate, Pediatrics 122 (5) 1119–1126).

Transition to Primary Care: Pearls for Practice

As the NICU graduate transitions into primary care, there are many considerations and specific details of care for the primary care provider (PCP) to focus upon. The universal starting point is to carefully review the discharge summary; preferably prior to the first visit. A comprehensive summary for a typical 24 week gestation infant who graduates contains four to six months of hospital records. Key consideration when reviewing the discharge summary includes, but is not limited to, maternal history and delivery, clinical course including health maintenance, admission diagnosis and treatment received in the NICU. Finally, a major focus on unresolved discharge diagnoses, current growth and feeding regimens, current medications, immunization status of patient and family (to include siblings/caregivers), car seat status, and all other current familial history and living situations must be noted and addressed by the PCP for successful transition of care.

After careful review of the discharge summary the PCP must then consider both the chronological age and corrected age for the NICU graduate. This information is critical for assessing development and delivering ongoing care. The chronological age is used to schedule routine well-child visits and must also be used to administer the required immunizations.[13] The use of corrected age remains the recommended method for proper growth and developmental assessment and anticipatory guidance regarding nutritional changes/introduction and supplementation as discussed in later sections.[13,14]

Immunizations

Special immunization considerations for the NICU graduate can vary from a normal immunization schedule to an intricately planned catch-up schedule. Special considerations should include possible previous or current steroid therapy, previous blood transfusions or infant weight at the time of immunization; all pertinent to the infant's ability to produce a successful immunologic response to the vaccine(s). Each of these considerations for proper immunizations of the NICU graduate must be assessed and planned for on an