

Neonatal Follow-up Programs



CARRIE-ELLEN FLANAGAN, BSN, RN
2ND YEAR PHD STUDENT IN NURSING
LEND FELLOW

Background



- **Infants born prematurely are at greater risk for healthcare challenges**
 - Neurodevelopmental delay, sensory impairment, hearing and vision loss
- **Follow-up programs provide early identification and intervention**

More Background



- Follow-up programs are designed for former Neonatal Intensive Care Unit (NICU) patients and the providers understand the challenges these children face relative to their illnesses, and time in the hospital
- Recent literature has shown that late premature infants (Between 34 and 37 weeks gestation) are at increased risk for neurological delay compared to full-term infants

American Academy of Pediatrics: Recommendations



- **Follow-up programs should be multidisciplinary and focus on evaluating for developmental milestones**
- **NICU patients should receive care from a healthcare professional who is experienced with high-risk infants**
- **Referral criteria have been suggested, but have not been accepted universal**

The Problem



- Recommendations have been made about what referral criteria should be, but no formal guidelines have been developed
- Programs determine their own referral criteria
- This may leave some children not receiving support if they were born at a one hospital versus another

Purpose



- This study aims to understand current practices of Neonatal Follow-up Programs within New England states and compare how they relate to current recommendations of best practice.
- Neonatal follow-up programs were surveyed to assess each program's referral criteria, the duration of services provided, and coordination of care between families and other healthcare or early intervention service providers.

Research Question



- **What differences are there among Neonatal Follow-up programs in New England?**
 - Programs were evaluated to assess what types of supports are in place for families who have children with an increased risk of experiencing developmental delays.
 - Comparisons were made to understand similarities and differences among referral criteria and were evaluated by looking at current literature and best practice guidelines.

Sample



- **Neurodevelopmental Follow-up programs identified in New England**
 - Connecticut (2)
 - Rhode Island (1)
 - Massachusetts (2)
 - New Hampshire (1)
 - Vermont (1)
 - Maine (1)
- **Directors of these programs were the target participants**

Design



- A survey was designed and then reviewed with professionals in the field on Neonatal Follow-up (not professionals eligible to take the survey)
- The survey was internet-based on SurveyMonkey
- Once IRB approval was obtained, emails were sent to the Directors with a link to the survey
- A follow-up email was sent about a week after initial email invitation

Results - Demographics



- **4 Programs Responded (50% Response Rate)**
- **Each response was from a different state which made the state representation 4 out of 6 states in New England**
- **All of the responding programs were directly affiliated with a neonatal intensive care unit that is classified as at least a Level III center**

Results – Referral Criteria



- **There were differences among referral criteria for gestational age at birth:**
 - 1 Program – Refers <33 weeks
 - 1 Program – Refers <32 weeks
 - 1 Program – Refers <30 weeks
 - 1 Program – Refers <27 weeks
- **All of the programs have updated their referral criteria in the past three years, which may indicate that all of these programs are following current recommendations and making changes based on new research and findings in neonatal outcomes.**

Results - Overview of Neonatal Follow-up Program



- 3 out of 4 programs have someone who meets with families prior to discharge to discuss the purpose of the follow up program and the logistics of a typical visit
- At least half of the responding programs had the following disciplines in their follow-up programs:
 - Pediatricians, Developmental Pediatricians, Nurses, Occupational and Physical Therapists, Nutritionists, Neurologists, Social Workers, and Psychologists

Results - Duration of Care



- Once follow-up services are no longer provided to former NICU patients, all of the programs refer their patients to other resources
- Half of the programs refer to the child's local school district for early intervention services
- At least one program refers to either a Developmental Pediatrician, Birth to Three, and/or Head Start.

Systems Change



- Funding is a concern for many programs and is likely the barrier for more consistent referral criteria
 - This gap in care means that there may be an inequality among the services that children receive in different parts of states and regions
- Funding issues may not be changed in the near future, so former NICU patients must be able to receive appropriate care from a pediatrician who is experienced in the care of premature infants.
- Families should be aware that their premature infant is at an increased risk of developmental delays and should have assistance in selecting an appropriate pediatrician.

References



- American Academy of Pediatrics, Committee on Fetus and Newborn (2008). Hospital discharge of the high-risk neonate. *Pediatrics*.122: 1119–1126.
- Fanaroff AA, Stoll BJ, Wright LL, et al; NICHD Neonatal Research Network (2007). Trends in neonatal morbidity and mortality for very low birthweight infants. *American Journal of Obstetrics & Gynecology*, 196:147.e1-147.e8.
- Kalia, J. L., Visintainer, P., Brumberg, H. L., Pici, M., & Kase, J. (2009). Comparison of enrollment in interventional therapies between late-preterm and very preterm Infants at 12 months' corrected age. *Pediatrics*, 123, 804-809.
- Kumar, P., Sankar, M. J., Sapra, S., Agarwal, R., Deorari, A. K., & Paul, V. K. (2008). Follow-up of high risk neonates. *Indian Journal of Pediatrics*, 75, 479-487.
- Labree, W., Foets, M., & Weisglas-Kuperas, N. (2010). Continuity and coordination of care during and after neonatal intensive care. *Journal Child Health Care*, 14(3), 239-249.
- March of Dimes. (2010). *Peristats*. Retrieved September 25, 2010, from www.marchofdimes.com/peristats
- O'Shea, T. M., Nageswaran, S., Hiatt, D. C., Legault, C., Moore, M. L., Naughton, M., Goldstein, D. J., & Dillard, R.G. (2007). Follow-up care for infants with chronic lung disease: a randomized comparison of community-and-center-based models. *Pediatrics*, 119(4), 947-957.
- Vohr, B. R., Wright, L. L., & Dusick, A. M., et al; NICHD Neonatal Research Network (2000). Neurodevelopmental and functional outcomes of extremely low birth weight infants in the national institute of child health and human development neonatal research network. *Pediatrics*, 105(6), 1216-1226.
- Vohr, B., Wright, L. L., Hack, M., Aylward, G., & Hirtz, D. (2004). Follow-up care of high risk infants. *Pediatrics*, 114(5), 1377-1397.
- Vohr, B., Stephens, B., & Tucker, R. (2010). 35 years of neonatal follow-up in Rhode Island. *Medicine and Health Rhode Island*, 93(5), 151-153.
- Wang, C. J., McGlynn, E. A., Brook, R. H., Leonard, C. H., Picuch, R. E., Hsueh, S. I., & Schuster, M. A. Quality-of-care indicators for the neurodevelopmental follow-up of very low birth weight children: results of an expert panel process. *Pediatrics*, 117(6), 2080-2092.