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Families' perspectives on monitoring infants' health and development after discharge from NICUs

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Abstract

Based on a survey of families of very preterm infants, Seppanen et al report that: 1) parents rated post-discharge (post-NICU) care as poor or fair for 14.2% of children; 2) parents of one-third of children with health or developmental disorders rated their child's post-hospital care as poor or fair, as compared to 12–13% of parents of typically developing and healthy children; and 3) parents' suggestions for ways to improve post-hospital care focused primarily on better communication between the health care team and parents and better coordination of the child's care. These findings point to a large opportunity for improving post-NICU services for infants born very preterm, especially for children with health or developmental disorders. In addition to gathering more information about families' perspectives, vigorous quality improvement methods should be applied to improve the effectiveness of post-NICU clinics and the health and development outcomes of the infants and families served by these clinics.

Tremendous progress in perinatal care has increased survival rates of very preterm infants to greater than 80% in developed countries,¹ but the risk of chronic health disorders and neurodevelopmental impairments continues to exceed that of children born at term, with risk ratios of about 2 for ADHD, to at least 50 for cerebral palsy.² Evidence-based approaches to improving health and neurodevelopment of very preterm infants include medications administered prenatally to mothers^{3,4}, medications and therapies administered to neonates in neonatal intensive care units (NICU),^{5,6} rehabilitative/educational interventions,⁷ and comprehensive coordinated care after infants are discharged home from NICUs.^{8–14} Of particular relevance to the study of Steppanen is that multiple studies, including the findings from two large randomized trials^{8–13} indicate that providing families with a continuous relationship with a single point of contact, who integrates the resources from neonatal intensive care, post-NICU follow up, and community services, can improve patient outcomes and reduce health care cost.

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Post-NICU care for very preterm infants is the aspect of health services on which Seppanen et al focus in their paper titled "Parents' ratings of post-discharge healthcare for their children born very preterm and their suggestions for improvement: a European cohort study".¹⁵ This study is an important step towards the goal of incorporating families' perspective into efforts to improve post-NICU care for very preterm infants and other high-risk groups of infants. Seppanen et al surveyed families of very preterm infants about their overall rating of the quality of post-hospital care for their very preterm infants. In addition, families were asked to suggest how post-hospital care could be improved. Parent perspectives were obtained from a large sample (n=3635) of parents of infants born prior to 32 weeks of gestation from 19 regions in 11 European countries. In addition to geographic diversity, the sample was reasonably diverse with regard to maternal education and age. The most important findings by Seppanen et al are: 1) parents rated post-discharge (post-NICU) care as poor or fair for 14.2% of children; 2) parents of one-third of children with health or developmental disorders rated their child's post-hospital care as poor or fair, as compared to 12–13% of parents of typically developing and healthy children; and 3) parents' suggestions for ways to improve post-hospital care focused primarily on better communication between the health care team and parents and better coordination of the child's care. Based on these findings there is a large opportunity for improving post-NICU services for infants born very preterm, especially for children with health or developmental disorders.

The most compelling rationale for focused efforts to improve post-NICU care important is that the services provided in NICU follow up clinics, such as care coordination, developmental surveillance, and support for families are evidence-based interventions that improve outcomes^{8,10,11,16} and, at least in some cases, reduce costs.^{11,12} NICU follow up clinics also offer an opportunity for health care providers and developmental specialists to provide recommendations and support to families over an longer interval of time as compared to the duration of a typical NICU hospitalization. These benefits accrue, however, only if the family returns for scheduled visits, and it is reasonable to assume to families' satisfaction with the care provided in NICU follow up clinics influences their likelihood of continuing to return for scheduled visits. With their survey of families, Seppanen et al point to communication and coordination as aspects of NICU follow up care that families value highly.

Prior studies of families' perspectives on NICU follow up care have either evaluated factors associated with compliance with follow up (returning for scheduled clinic visits) or have interviewed families and/or health care providers to obtain their perspectives about barriers and facilitators to compliance with clinic visits for post-NICU care. Lakshmanan et al interviewed a sample of 21 families, comprised primarily of under-represented minorities, about their experiences when transitioning home from the NICU and afterwards. Resources that were cited by families as being of value during their transition home from the NICU were supports for caregiver mental health, and information, support systems, and financial assistance for families.¹⁷ Similarly, Ballantye et al interviewed 12 families and 20 health care providers about barriers and facilitators and concluded that the primary barriers to attendance were limited support, capacity and resources for mothers.^{18,19} Harmon et al found that families who were non-compliant with follow up cited distance from the hospital and travel expense as the most important reasons for noncompliance.²⁰ In two studies in

which large datasets were analyzed to identify factors associated with non-compliance with NICU follow up, indicators of lower socioeconomic status, such as less maternal education, unmarried mothers, public insurance, and more people in the household were associated with noncompliance.^{21,22} These same factors have been associated with less optimal outcomes among very preterm infants.^{23–25} Focused efforts to partner with families in overcoming barriers to follow up should be a priority of efforts to improve post-NICU follow up care, thereby increasing family engagement, effectiveness of care, and outcomes for infants and families.

What are the clinical and research implications of the research reviewed above? One is the importance of continuing efforts to learn from families how health care practices, programs, and policies can best support them after their infants' discharge from neonatal intensive care. This information be used to improve compliance with scheduled clinic (or virtual) visits as well as enhance engagement and confidence of the family. The family is a primary driver of health and developmental outcomes for individuals born very preterm,²⁶ and some evidence suggests that benefit of developmental interventions is enhanced by greater involvement of parents²⁷ and greater breadth and intensity of services, both of which depend on a high level of family engagement.²⁸ Families who are more satisfied with post-NICU care are probably more likely to bring their child to scheduled developmental and health surveillance encounters (clinic or virtual visits) and more likely to comply with physicians' and therapists' recommendations, implying that family satisfaction with post-NICU care influences the effectiveness of that care and, in turn, child health outcomes.

A second lesson from the work by Seppanen et al, and the others whose research is reviewed here, is that there is a large opportunity for increasing families' satisfaction with post-NICU care. The rigorous methods that have been applied successfully to improve the care of critically ill neonates during neonatal intensive care^{29–33} have not, to date, been frequently applied to the goal of improving post-NICU care. To the extent that very preterm infants' health and developmental outcomes are shaped not only by perinatal interventions during maternal and neonatal hospitalizations, but also by care and experiences during early childhood, extension of quality improvement methods to post-NICU care holds great promise for weakening associations between very preterm birth and adverse health and developmental outcomes later in life.

One of the earliest systematic approaches to evaluating the quality of post-NICU care was described by Wang et al who in 2003, convened an expert panel to develop a list of quality of care indicators for neurodevelopmental follow up of very low birth weight infants. Their intent was to provide a tool for assessing and monitoring the quality of follow-up care and thus for improving the quality of care for this high-risk group.³⁴ It appears that the authors did not ask families for direct input on the quality indicators, but the expert panel did recommend that for “families with social risk(s), a specific intervention (re-evaluation, primary care management, referral to a specialist, or referral to a specific intervention program) should be started within 1 month of the psychosocial assessment”. A more recent example of the application of quality improvement methods to post-NICU care is the successful initiative led by the California Perinatal Quality Care Collaborative to increase

referral of very low birth weight infants to high risk infant follow up care after discharge from NICUs.³⁵

The findings of Seppanen et al provide an initial “needs assessment”, but much work is needed to further understand the range of health care and developmental surveillance activities that families value, so that health care systems can improve experiences for families in NICU follow up clinics. Simultaneously, rigorous quality improvement initiatives are needed to assure that best practices are used after NICU discharge to strengthen supports and resources for families, including care coordination, and to improve communication between families and developmental and health care providers and among developmental and health care providers.

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