



ORIGINAL ARTICLE

Examining disparities in the long term follow-up of Neonatal Intensive Care Unit graduates in Nebraska, U.S.A.

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KEYWORDS

Disparities;
 NICU;
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Abstract *Purpose:* To determine contributing factors related to rates of completion in a NICU follow-up clinic in Nebraska, U.S.A.

Methods: The sample included 5856 children. All participants were eligible for a statewide follow-up program of infants from the major newborn intensive care units (NICUs) in Nebraska, U.S.A.

Results: Using binary logistic regression, several variables made significant contributions to the prediction of completion of follow-up services with payment type (Medicaid vs. private), minority status (minority vs. White), and health risk (low and high risk) producing the largest odds ratios. Specifically, those with Medicaid, of low health risk, and of minority status were less likely to complete follow-up services.

Conclusions: Insurance type and minority status emerged as the strongest predictors of completed follow-up. Additional findings revealed that infants characterized as moderate risk, male, and had lower birth weight, lower gestational age, and lived in a rural areas were most likely to attend all follow up visits.

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Introduction

Of the four million children born in the United States each year, about 12% will be admitted to a Neonatal Intensive Care Unit (NICU) to address critical newborn health problems (Health Resources and Services Administration, 2013). Following discharge, these NICU graduates are at higher risk for developmental problems that may require monitoring and early intervention (Darlow et al., 2009; Newnam and Parrott, 2013). Research shows that NICU graduates are at risk for a variety of suboptimal developmental outcomes relative to their healthy peers (Kessenich, 2003). Delayed cognition, vision, speech and language, mobility, behavior, and poorer health status are notable among this population in the first few years of life relative to healthy babies (Klassen et al., 2004).

Regional NICU follow-up clinics offer the expertise of a multidisciplinary team that provides screening, assessment, and referral specifically for these at-risk children (Newnam and Parrott, 2013; Jackson and Needelman, 2007). NICU graduates who are followed by a regional follow-up clinic can receive repeated developmental and medical screenings across the critical periods of development. Professionals with expertise in developmental medicine, psychology, and early intervention are able to identify areas of concern and provide a direct link to services for children at risk for delays. The benefits of this approach are born out in research which suggests that families who receive developmental monitoring and assistance with care coordination through a NICU follow-up clinic are more likely to access early intervention services for their children (Pritchard et al., 2013; Tien et al., 2002).

NICU follow-up clinics offer the advantage of monitoring specific indicators at timely intervals across early development. The value of follow-up screening is highlighted in findings from Jackson and Needelman (2007), who documented that the proportion of children who failed standardized developmental screening tools increases with age. Specifically, among NICU graduates with medical histories considered low- and moderate-risk, the proportion of children showing indications of developmental delays increased and peaked between the ages of 16 and 24 months. As such, repeated screenings in NICU follow-up programs serve a critical role in early identification of delays, as well as referral to appropriate services. To illustrate, the same study found that 94% of children referred to early intervention qualified to

receive services. Thus, assessment in NICU follow-up clinics functions as a valuable link connecting young children with targeted early intervention services.

Unfortunately, evidence suggests that NICU follow-up attendance tends to decline over time, with the greatest attrition occurring immediately following discharge from the NICU itself (Ballantyne et al., 2012). As such, there are a substantial number of NICU graduates whose developmental outcomes are unknown. Given the importance of early identification and intervention for children with developmental delays and disabilities, it is important to understand the factors that prevent parents from accessing NICU follow-up services. Addressing these factors may help to ensure that a maximum number of NICU graduates have access to high quality screening and referral.

Factors associated with attendance at NICU follow-up clinic

Available data suggest that a majority of families, between 55% and 82%, attend at least one appointment at their designated NICU follow-up clinic (Ballantyne et al., 2012; Harmon et al., 2013; Nehra et al., 2008; Perenyi et al., 2010; Ballantyne et al., 2013). A variety of factors have been identified as being associated with attendance. One variable of interest is the health of the infant. Some data indicate that infants who experience more neonatal complications are more compliant with their appointments than healthier NICU graduates (Harmon et al., 2013; Perenyi et al., 2010). For example, Harmon and her colleagues (Harmon et al., 2013) found that factors such as chronic lung disease, a longer stay in the NICU, and more days on oxygen after discharge predicted stronger attendance at the follow-up clinic. It would seem that medically complex children attend clinic more consistently in order to meet their greater health needs. However, studies have also found that some infant health variables are not associated with attendance. Nehra and her colleagues (Nehra et al., 2008) for example, found that respiratory distress syndrome, hyperbilirubinemia, surgery in the newborn period, and length of stay were not associated with attendance at the follow-up clinic. Furthermore, it has been found that other indicators of morbidity, such as gestational age and birth weight, are not associated with follow-up clinic attendance (Harmon et al., 2013; Ballantyne et al., 2013). The literature remains equivocal regarding the influence of

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