



Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes

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ARTICLE INFO

Keywords:

Neonatal intensive care unit
Preterm
Parent engagement
Participation
Development
Holding
Skin-to-skin care
Presence
Visitation
Outcomes
Environment
Attachment

ABSTRACT

Objective: To 1) define predictors of parent presence, any holding, holding in arms, and skin-to-skin care in the NICU and 2) investigate the relationships between parent participation and a) early neurobehavior and b) developmental outcomes at age 4 to 5 years among preterm infants.

Methods: Eighty-one preterm infants born ≤ 32 weeks estimated gestational age were prospectively enrolled within one week of life in a level III–IV NICU. Parent (maternal and paternal) presence and holding (including holding in arms and skin-to-skin care) were tracked throughout NICU hospitalization. Neurobehavior at term equivalent age and development at 4 to 5 years were determined using standardized assessments.

Results: The median number of days per week parents were documented to be present over NICU hospitalization was 4.0 (IQR = 2.4–5.8) days; days held per week 2.8 (IQR = 1.4–4.3) days [holding in arms days per week was 2.2 (IQR = 1.2–3.2) days and parent skin-to-skin care days per week was 0.2 (IQR = 0.0–0.7) days]. More parent presence was observed among mothers who were Caucasian, married, older, or employed and among those who had fewer children, familial support and provided breast milk ($p < 0.05$). More holding was observed in infants with fewer medical interventions ($p < 0.05$) and among those who were Caucasian, had a father who was employed, had fewer children and family support ($p < 0.05$). More parent holding in the NICU was related to better reflex development at term age ($p = 0.02$). More parent skin-to-skin care was related to better infant reflexes ($p = 0.03$) and less asymmetry ($p = 0.04$) at term and better gross motor development ($p = 0.02$) at 4–5 years.

Discussion: Social and medical factors appear to impact parent presence, holding, and skin-to-skin care in the NICU. Parent holding is related to better developmental outcomes, which highlights the importance of engaging families in the NICU.

1. Introduction

It is well-understood that preterm infants have high rates of developmental problems, including cognitive delays, language impairments, and behavioral problems [1–3]. The rate of developmental delay, however, cannot be fully explained by medical complications or cerebral injury alone. Early experiences in the neonatal intensive care unit (NICU) can also alter developmental trajectories [4–7].

The NICU environment can be stressful for the preterm infant. Infants may be exposed to loud noises and bright lights that interrupt sleep and occur during a vulnerable period of brain development [7]. Further, infants are often exposed to repetitive and painful, but necessary, medical interventions while in the NICU [5]. Environmental

stressors can cause physiologic changes, such as increased heart rate, blood pressure, and respiratory rate, as well as decreased oxygen saturation levels [8,9]. The increased energy expenditure to overcome these changes can alter physiological function, slow healing, and negatively impact the organization of the central nervous system [9].

The NICU environment can also be overwhelming for parents. The role of the primary caregiver can be altered by the infant's need for advanced care provided by NICU personnel [10]. This can result in high levels of stress, depression, and anxiety in parents of NICU infants [11,12], which can negatively impact the way in which they engage with the infant [13]. In addition, many parents are challenged by needing to balance daily activities with parenting an infant outside the home, needing to return to work sooner in order to save time to stay

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with the baby at NICU discharge, and/or having other children to care for at home. Barriers to parenting a high-risk infant in the NICU can negatively influence parent engagement with the preterm infant during the months of NICU hospitalization, resulting in shorter, less frequent visitation [14–16]. However, parent engagement in the NICU is vital.

The relationship between parent-child attachment and developmental outcomes is well understood [17,18]. For the very preterm infant, the parent-child relationship begins in the NICU. The relationship is established and developed when the parent is present in the NICU, holds the infant, and learns how to identify and respond to the needs of the infant [19–21]. In addition, parent presence and infant holding in the NICU is related to improved neurobehavioral outcome at term equivalent age, observed prior to discharge from the NICU [22]. Although the importance of parenting is well-established, there are few studies that have investigated the impact of early parenting in the NICU on outcomes in early childhood.

Parent participation in the NICU, which includes parent presence and infant holding, can promote feelings of usefulness and can improve attachment. Parents can also help to improve the ability of the infant to cope with NICU stressors [23–26] and provide appropriate, meaningful sensory stimuli and human contact. While the effect of being held has not been a focus of current research, there is a growing body of evidence related to the effects of skin-to-skin care. Skin-to-skin care, which involves placing the unclothed infant directly on the parent's bare chest, is related to decreased acute pain responses, improved weight gain, improved infant growth and development, reduced hypothermia, earlier discharge, better cognitive outcomes in childhood, and enhanced nurturing and parent-child interactions [23,25–31]. Additionally, high maternal involvement in the NICU has been related to superior cognitive and language outcomes in early childhood [32]. Despite efforts in implementing family-centered care and engaging parents in the NICU, suboptimal rates of parent presence and engagement have been reported in the United States [22].

While parenting in the NICU can be challenging, there is a paucity of research that has identified factors that impact parent participation and whether parent participation in the NICU is related to short and long-term outcomes. The aims of this study were to 1) define predictors of parent presence and holding (including holding in arms and skin-to-skin care) in the NICU and 2) investigate the relationships between parent participation in the NICU and early neurobehavior as well as developmental outcome at age 4 to 5 years.

2. Methods

This study consisted of 81 preterm infants born ≤ 32 weeks estimated gestational age who were prospectively enrolled in the year 2011 as part of an overarching study investigating the effects of neonatal positioning [4]. Infants were enrolled within the first week of life. Infants with a known congenital anomaly and those who were not expected to live were excluded. This study was approved by the Human Research Protection Office of Washington University in St. Louis, and parents signed informed consent. During hospitalization, parent presence and holding (including holding in arms and skin-to-skin care) were tracked. At term age, infants received neurobehavioral testing in the NICU, using the NICU Network Neurobehavioral Scale (NNNS) and Dubowitz Optimality Scale. At 4 to 5 years of age, parents completed a parent-report measure of child developmental outcome, the Ages and Stages Questionnaires-third edition (ASQ-3).

Participants were recruited from the NICU at St. Louis Children's Hospital, a 75-bed level III–IV NICU. At the study site, parents could be present 24 h per day while the infant was in the NICU. Holding the infant was supported, provided the infant could maintain physiological stability during handling. Parents were encouraged to hold infants on mechanical ventilation, but holding was not encouraged during times when the infant was on oscillatory ventilation and/or when chest tubes were in place. However, practices varied based on the comfort level of

nurses, the medical team, and the parents. Nurses fostered parent participation through instruction on caregiving and developmentally appropriate interactions, and documentation in the medical record included when a parent visited and whether the infant was held in arms or held skin-to-skin. Documentation was routinely done at each care time, which typically occurred every 3 h, or was completed after each 12 h shift.

2.1. Parent participation

For the purposes of this study, parent participation was defined as parents being present and/or engaging in holding (including holding in arms or performing skin-to-skin care) in the NICU. Parent presence, infant holding, and infant skin-to-skin care were captured from documentation in the electronic medical record. From this documentation, the average number of days per week a parent was present as well as the average number of days per week a parent held the infant, 'any holding', were calculated. In addition, the average number of days per week the infant was held in arms and average number of days per week the infant was held skin-to-skin were calculated separately from 'any holding'. Separate tabulations were done for mothers and fathers, as well as combined to represent total days per week a parent was present and/or held the infant.

Medical and socio-demographic factors were collected for descriptive purposes, to identify factors that relate to parent participation, and to enable control for social and medical risk when investigating relationships between parent participation and outcomes.

2.2. Medical factors

Infant medical factors collected included: sex, delivery type (Caesarean vs. vaginal), whether the infant was a multiple, estimated gestational age (EGA) at birth, Apgar scores at 1 min and 5 min, days of oxygen therapy [which included days of ventilation, days of continuous positive airway pressure (CPAP), and days of delivery of oxygen via nasal cannula], presence of necrotizing enterocolitis (NEC; all stages), confirmed sepsis, and cerebral injury (defined as Grade III–IV intraventricular hemorrhage or cystic periventricular leukomalacia on cranial ultrasound), length of stay, postmenstrual age at discharge, whether breast milk was received by the infant at discharge, and assigned room type (private room vs. open ward). Room type was investigated due to previous findings related to more parent visitation among infants in private rooms [33]. From these descriptives, high medical risk was defined as having EGA < 28 weeks or cerebral injury.

2.3. Socio-demographic factors

Socio-demographic factors that were collected included race (Caucasian or non-Caucasian), marital status (single or married), maternal age, insurance type (public vs. private), maternal and paternal employment status, number of siblings in the home, distance traveled to the hospital, and familial support (documentation of extended family visiting an average of one or more days per week). From these descriptives, social risk was defined as maternal age < 21 years or having public insurance.

2.4. Neurobehavioral outcome

Neurobehavior was assessed at 35 weeks postmenstrual age or when medically stable, whichever occurred last, using the NNNS and Dubowitz Optimality Scale. A single trained and certified examiner (author, RP) completed the NNNS and Dubowitz Optimality Scale assessments. The NNNS is a 115 item test with 13 summary scores: Habituation, Orientation, Hypertonicity, Hypotonicity, Arousal, Lethargy, Asymmetry, Sub-optimal Reflexes, Excitability, Tolerance of Handling, Stress, Quality of Movement, and Self-Regulation [34].

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